

**Summary**  
**Specialized Services for People with**  
**Alzheimer's Disease: Literature Review**

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# Summary

## Specialized Services for People with Alzheimer's Disease: Literature Review

### Introduction

#### Background

Alzheimer's disease and related dementias are affecting more and more people in Canada. The estimated number of affected people was around 540,000 in 2011. These disorders are the most significant causes of disability in older people and cost Canadian society billions of dollars per year. In Québec, these disorders affected an estimated 100,000 people aged 65 years and older in 2009, and this figure is expected to climb to 120,000 by 2015 and to 160,000 by 2030; the number of affected people younger than 65 years is projected to be 2250.

Alzheimer's is a progressive, degenerative disorder that leads to major disabilities and even incapacity. It is a disease that necessarily involves families and relatives by placing them in the role of primary caregiver. This role may become a major source of physical, psychological and social exhaustion leading to significant repercussions on their health and financial situations.

In Québec as elsewhere, efforts are being made to improve care and to meet as best as possible the needs of affected people and their caregivers in order to enable them to have a better quality of life. Achieving these objectives depends on having accessible, well-organized quality services.

The Alzheimer Society of Canada has proposed meaningful actions and interventions to make a difference in this area and to reduce the consequences of Alzheimer's disease: delaying the onset of dementia; supporting and training caregivers by developing their ability to adjust to patient behaviour and by building their skills; and introducing the case management approach. It is up to each province to implement appropriate strategies and measures responding to the needs of affected people and their families.

In December 2007, Québec's Ministère de la Santé et des Services sociaux (MSSS) entrusted an expert committee with the responsibility of developing a ministry action plan on Alzheimer's disease and related disorders that would encompass all aspects of this issue (from prevention to end-of-life care), including research. In 2009, the committee tabled its report, which included a proposed action plan composed of seven priority actions and an implementation strategy. An urgent need for action emerged from the many gaps found in the services offered to people with Alzheimer's disease in Québec in terms of specialized resources, service accessibility, continuity and quality, and the use of professional, material and financial resources earmarked for this clientele. Moreover, the report pointed to the growing prevalence of Alzheimer's disease, which would increasingly burden the health system unless immediate actions were taken.

#### Assessment Request

To implement the measures required to promote access to specialized services and continuity of care and to improve the quality of interventions, the MSSS's Direction générale des services sociaux and Direction générale des services de santé et de la médecine universitaire asked the Institut national d'excellence en santé et en services sociaux (INESSS) to contribute to providing operational definitions for the structural entities that would need to be involved in offering the services to be deployed, namely, Alzheimer support centres, memory clinics, and teams specializing in behavioural and psychological symptoms of dementia (BPSD).

## Objectives

The assessment questions covered the necessary criteria and parameters for the service offerings: the target clientele or critical masses, the nature and modalities of service delivery, human or professional resources, and the clinical processes for:

- memory clinics;
- Alzheimer support centres;
- BPSD teams.

Note that these three specialized services may be part of broader services such as mental health services or geriatric services, but they may also be fully independent structures within these services.

These three structures offer services adapted to the evolving needs of people with Alzheimer's disease and of their caregivers and also regularly collaborate with primary care services involved in screening, treatment, psycho-educational interventions, psychotherapy and respite services for these people. **Memory clinics** diagnose and treat more complex cases; **Alzheimer support centres** facilitate access to information and local resource; and **BPSD teams** intervene to assess, diagnose and develop intervention plans when the symptoms are too complex or persistent. It must nevertheless be acknowledged that it is sometimes difficult to distinguish between primary care services and specialized services (e.g., the definitions or functions attributed to these services are not always clearly specified).

## Methods

We performed an exhaustive, critical descriptive review of relevant documents on the three service structures mentioned above. We focused on the specialized services offered in several countries (or in their state territories), in particular, Australia, France, the United Kingdom (U.K.), and Canada, because they met the following criteria: clear existence of a specialized program for people with Alzheimer's disease; services provided to all people with Alzheimer's disease in the country or state territory concerned; and availability of a sufficient amount of information on their respective programs. Some information available in Québec is also presented. Note that an exhaustive review of Québec's service offerings exceeded the scope of this mandate; this report focuses more on what is being done outside this province.

## Organizational Aspects

### General overview of different countries' strategies and measures

In **Australia**, the federal government began to show interest in the needs of people with dementia and of their caregivers by developing a strategy to reform the care for older people. Some states and territories followed suit by developing policies, plans and recommendations. One of the major initiatives that emerged was the creation of memory clinics in each of the regions of the State of Victoria. In 2005, Australia's Department of Health and Ageing made dementia a national health priority, and the State of Victoria has recently proposed a new service model to improve the care and support for people with Alzheimer's disease and for their families and caregivers.

In 2000, **France's** Ministry of Employment and Solidarity granted a mandate to analyze and offer proposals concerning Alzheimer's disease and its effects. This work culminated in 12 proposals that led to the development of an action plan the following year. This plan aimed to make up

for shortcomings in the fields of diagnosis, management, support and assistance for caregivers. An Alzheimer plan followed in 2004, and these initiatives resulted in the implementation and strengthening of memory clinics, among other actions. The last Alzheimer plan, developed in 2008, emphasized the need to organize comprehensive care management for affected people and their caregivers.

In 2005, the **U.K.** introduced a policy specifically on older people with cognitive disorders and made dementia a national priority. Eight major recommendations, a national strategy and a memory services national accreditation program (the first in the world) were released in 2007, 2009 and 2010 respectively. An audit tool was proposed by England in 2011.

In 1999, **Ontario** established a strategy for Alzheimer's disease and related disorders that led to the implementation of a dementia network. Actions have since been taken to ensure the continuity of this strategy. Specialized services for people with BPSD are currently being developed: local networks are working on developing and implementing the Behavioural Support System Project to meet the needs of these clients.

**Québec** has also shown interest in improving care and services for people with Alzheimer's disease and their informal caregivers by developing proposals for action plans on this disease and by passing the Act to Establish a Caregiver Support Fund. Some information is available on memory clinics in Québec.

## **Results of the Analysis**

Currently, there is very little information on the organizational structures for specialized services for people with Alzheimer's disease, and the information available focuses mostly on major program components. The relevant information collected derives from government documents and descriptive studies. No assessment data or audit data are currently available; however, an audit tool has been developed in the U.K. The results provided below are presented by type of structure.

### **Memory Clinics**

The information on memory clinics is relatively the most abundant and detailed compared with that on the other two types of services. Two studies on memory clinics were located, one from the Netherlands and the other from the U.K. The objectives of the first study were to develop and validate quality indicators for memory clinics. To do so, the researchers performed a Delphi survey and used data from clinical medical records in the Netherlands. Fourteen indicators on structures, processes and care outcomes were developed. The second was a descriptive study addressing memory clinic organization, structures and processes.

Policy documents and descriptive studies are also available in Australia, the U.K., France and Québec. In Australia's State of Victoria, memory clinics are specialist clinics that are part of the ambulatory services of the Sub-acute Care Services System. In France, these clinics are housed within university hospital centres and are either independent structures or part of another department (e.g., neurology or geriatrics). In the U.K., memory clinics are mental health services for older people in the National Health Service. In Québec, according to the association for geriatric short-term care units and hospitals (*Regroupement des unités de courte durée gériatriques et des services hospitaliers de gériatrie du Québec – RUSHGQ*), memory clinics are organized as part of highly specialized outpatient geriatric consultations.

According to currently available information, **memory clinics** should have the following characteristics:

- Be composed of qualified teams bringing together multiple disciplines: specialist practice, neuropsychology, nursing care, and social work.
- Respond to individuals presenting with cognitive disorders, such as dementia.
- Be primarily geared to cognitive disorder assessment and diagnosis, and clinical patient follow-up.
- Have access to specialized diagnostic imaging equipment.

### **Alzheimer Support Centres**

Alzheimer support centres exist in Australia, the U.K., Ontario, and Québec. In Australia, the Commonwealth Respite and Carelink Centres are national organizations located across the country. In the U.K., The Princess Royal Trust for Carers is a charity service network. This network is a company limited by guarantee regulated by statutes, governed by a board of trustees and administered by a management team. In Ontario, the Alzheimer Knowledge Exchange network is an initiative partially funded by the provincial government; its resource centre is housed within the Alzheimer Society of Ontario and is partnered with an Ontario network concerned with older people. In Québec, the centres are not-for-profit organizations, which have received funding from the Québec government and a trust company.

These services are often offered to caregivers by primary care services. It was difficult to highlight any areas of consensus on Alzheimer support centres, given the lack of detailed information on their organization.

Only one point of consensus on **Alzheimer support centres** was found:

- They facilitate access to quality information and provide advice to caregivers.

### **BPSD Teams**

Two different models of teams specializing in BPSD were found, one in Australia and the other in Ontario. In the first case, more particularly in New South Wales, this service has existed since 2007 and consists of specialized mental health service teams that intervene with people who have complex BPSDs. In Ontario, this service has also been recently created. This system is governed regionally under the Local Health Integration Networks (LHIN). It is organized like a steering committee, exercises its authority under the guidance of inter-agency protocols and is accountable for its outcomes to the LHINs and to the Ministry of Health and Long-Term Care. The Program Level Coordinated Network (Operations Committee) is responsible for the services offered by mobile interdisciplinary seniors behavioural support outreach teams.

The key elements of the organizational structure of **BPSD teams** are:

- Multidisciplinary teams composed of professionals qualified to carry out assessments and specialized interventions with older people who have complex, persistent symptoms associated with dementia.
- Role of support, information and counselling on dementia and on BPSDs with caregivers.
- Collaboration with a network of partners, including patients, their families and caregivers, primary care services and health institutions.
- Short-term management of complex, difficult cases and brief interventions.

## Conclusion

An exhaustive, descriptive review of the literature and of government documents revealed that there is little information on the organizational structures of specialized services offered to people with Alzheimer's disease and to their caregivers.

Some relevant information is nevertheless available from policy documents and descriptive studies of the health systems in Australia, France, the U.K., and Canada (Ontario and Québec). In this literature, certain aspects meet with consensus and could guide the development of programs for people with Alzheimer's disease in Québec. The U.K. manual of standards and England's audit tool are also documents likely to be useful in organizing memory clinics.

Considering the magnitude of Alzheimer's disease and the paucity of the literature on the organizational structures of specialized services for people with this disease and their caregivers, high-quality research on the organization of specialized services is needed in order to develop integrated care models meeting the needs of this clientele.

A disease as complex and prevalent as Alzheimer's must be considered a priority in Québec's health system, as it is in other countries such as Australia, France and the U.K., which have implemented public policies on this disease. These policies recognize the importance of funding research, supporting caregivers, developing professional care providers' competencies, and improving the care delivered to affected people, among other issues.

In Québec, services are already being offered to these people within existing structures. It would be desirable to maintain and enhance Québec's current resources or to create new ones, according to the different regions' needs, by integrating them into the current health service architecture, while respecting their hierarchy. Specific policies, guides and practice tools, based on the local and international experiences presented in this report, must be developed to ensure that standardized services are delivered in continuity in order to offer the best care to patients and caregivers and to meet the challenge raised by Alzheimer's disease.