

Dementia Network Evaluation Report – Phase 1

**Initiative #9A, Ontario's Strategy for Alzheimer Disease
& Related Dementias**

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Highlights from Phase I Evaluation Report

- A telephone survey was undertaken with communities across the province to determine what activities they had undertaken toward the development of dementia networks in their local areas.
- A total of 36 communities were surveyed.
- 44% of networks were at Stage 3 in their development (i.e., there was reference to a network; the network structure had been developed and/or was evolving; their goal was to finalize their structure/vision; projects may have been underway in order to have something concrete to work towards).
- Almost 80% of the respondents indicated that their network had an established structure. However, the type of structure varied across the province.
- Seventy-five percent of respondents reported that their network was a newly formed group and 85% indicated that the group formed after the Alzheimer Strategy was announced.
- Over 40% of respondents indicated that their networks included subcommittees and over 55% reported that their networks were undertaking some type of special project or initiative.
- When asked about the benefits that had been realized (or were anticipated to occur during the following 6 months), the benefits identified included: impact on services or service delivery; increased awareness and communication among providers and organizations; solidification of network structure and membership; and increased information sharing.
- The challenges faced by the networks included: time, costs and competing demands; the logistics involved in trying to involve smaller communities in the network; and physician involvement.
- When asked about what steps the networks planned to undertake in the near future, the following activities were identified: further network development/refinement; service-related activities; special projects or initiatives; and strengthening relationships.

The results from the first phase of the evaluation indicate that there is more than one way to conceive of a network and that communities must develop in a way that makes sense to their own strengths, needs and resources. The results also indicate that there has been considerable progress made across the province toward the development of dementia networks.

A second survey of the dementia networks is planned for fall 2003. The goal of this survey will be to assess where the networks are at in terms of their development and to gather other information related to their activities.

Introduction

As part of the evaluation of Initiative #9A - Dementia Networks, Ontario's Strategy for Alzheimer Disease and Related Dementias, a survey of communities across the province was conducted. The purpose of the survey was to gather baseline data on the activities communities had undertaken toward the development of a dementia network in their local areas.

A survey that was to be administered via telephone was developed in conjunction with the Initiative #9A Dementia Network Work Group. The survey was designed such that communities would only have to respond to questions that were relevant to the stage of their network's development.

An initial list of network representatives within each region was provided by the LTC Program Consultants with the Ministry of Health and Long-Term Care. An information letter outlining the purpose of the survey and what the representatives were being asked to do was sent out along with a copy of the survey questions. Each representative was then contacted by phone and asked if they would be willing to participate in the survey. In the introductory letter and during the first telephone contact, the representatives were encouraged to involve other members of the network in the completion of the survey. For those communities that were willing to participate, a time to complete the telephone survey was scheduled.

The following definition of a dementia network was used during the survey:

A dementia network is a vehicle to facilitate people and resources coming together locally, regionally and provincially to improve the system of care (including service delivery, education, research and planning) for persons with dementia, their families and caregivers. Dementia networks formalize, improve and build on existing relationships/linkages and provide a means to achieve what autonomous organizations cannot do on their own.

(Dementia Network Resource Guide, 2002)

Response Rates

Initially, there were 35 communities identified by the LTC Program Consultants as possibly developing a new (or supporting an existing) dementia network. When these communities were contacted, one community reported that it had divided itself into 2 areas and that a dementia network would be formed in each area. Thus, there were a total of 36 possible networks across the province. All 36 communities agreed to participate in the survey.

Network Stages

It was realized that communities across the province would be at different stages in terms of the development of their networks. In creating the survey instrument, we decided to use a staged approach and look at how the networks evolve over the course of the evaluation.

An initial set of stages was identified prior to administering the survey. However, after the survey data were analyzed, we realized that the stage of development that many of the networks were at was not accurately reflected in the results. Therefore, the stages were modified and the stage at which each network was at was reassessed. The following provides an overview of the stages used in the current report:

- Stage 1:** Pre-contemplation (i.e., no activity to date, perhaps considering the idea of a network or how a dementia network might fit within existing structures)
- Stage 2:** Discussion, communication and/or actively working towards the development of a network, working on determining a structure, may have a vision about how the network may work or what it may look like
- Stage 3:** A “network” has developed (i.e., there is reference to a network), the structure has been developed and/or is evolving, the goal is to finalize their structure/vision, projects may be underway in order to have something concrete to work towards.
- Stage 4:** The network is somewhat established and is undertaking initial projects to sustain the network, strengthen the network and/or establish linkages.
- Stage 5:** The network is established and network is undertaking projects and activities that relate to the goals of the network. The established network may also be re-examining its goals and/or structure.

Responses to the survey questions, together with the use of an algorithm, determined which stage communities were at. Of the 36 networks that were identified, most (44%) were at Stage 3. Thirty-four networks were beyond Stage 1, that is, they were either in an active network development process or had an existing network.

Table 1: Stage of the Dementia Care Networks

Stage	Percentage (Number) of Networks (N=36)
1	5.6% (2)
2	16.7% (6)
3	44.4% (16)
4	25.0% (9)
5	5.6% (2)

Development and Structure of the Network

Participants were asked if the group had identified how they would be structured in order to perform the functions of a network. The majority (78.8%) of the networks identified how they were structured.

Table 2: Identification of Network Structure

Identified Structure	Percentage (Number) of Networks (N=36)
Yes	78.8% (26)
No	21.2% (7)

In examining the responses related to the structure and organization of the networks, there was considerable variability. Definitions for the terms “steering committee” and “network” were provided at the beginning of the survey; however, the communities did not always follow these definitions. For example, in some cases, planning groups were considered to be the steering committees. As well, “subcommittees” were defined in different ways. For some, subcommittees represented a permanent part of the network structure, while for others it included short-term planning groups, coordinating committees, communication strategy committees, work groups, and/or task groups. In addition, the memberships of some steering committees and/or networks were not fixed (although this may have been a reflection of their stage of development).

While the variability in network structures provided some challenges in trying to categorize the structures, it indicated that there was more than one way to think about a network, and that each community must develop in a way that is most appropriate for that community. The following table provides a breakdown of the ways that networks were structured.

Table 3: Structure of Network

Structure	Percentage (Number) of Networks (N=36)
[Steering Committee <i>same as</i> Network]	25.0% (9)
[Steering Committee] <i>and</i> [Network] <i>and</i> [Others]	22.2% (8)
[Steering Committee <i>same as</i> Network] <i>and</i> [Others]	16.7% (6)
No Formal Structure	16.7% (6)
[Steering Committee] <i>and</i> [Network]	5.6% (2)
Other	5.6% (2)
Network (network structure) not yet established	5.6% (2)

Participants were asked whether their dementia network had evolved from another group or whether they were a newly developed network. The majority (75%) indicated that their network was a newly formed group.

Table 4: Formation of Network

	Percentage (Number) of Networks (N=36)
Newly formed group	75.0% (24)
Evolved from another group	25.0% (8)

Participants were also asked when their network developed relative to the announcement of the Alzheimer Strategy (i.e., before or after the strategy was announced). The majority (86%) of the networks developed after the announcement of the Alzheimer Strategy.

Table 5: Development of Network Relative to the Announcement of the Alzheimer Strategy

	Percentage (Number) of Networks (N=36)
Pre-Strategy	14.3% (4)
After Strategy	85.7% (24)

Participants were then asked about the types of organizations and agencies that were represented on the network. Table 6 provides a summary of their responses.

Table 6: Types of Organizations and Agencies Represented

Organizations and Agencies	Percentages (number) of Networks (N=36)
Alzheimer Society	86.1% (31)
Community-based Services	83.3% (30)
Psychogeriatric Resource Consultant(s)	77.8% (28)
Planning Bodies (e.g. DHC)	75.0% (27)
LTC Facilities – non-P.I.E.C.E.S. trained staff	72.2% (26)
Specialized Geriatric Psychiatry Services	66.7% (24)
Acute-care Services	63.9% (23)
MOHLTC	58.3% (21)
Specialized Geriatric Medicine Services	58.3% (21)
Caregivers	47.2% (17)
LTC Facilities – PIECES Trained Staff	41.7% (15)
Primary Care (i.e. physicians)	30.6% (11)
Person with dementia	11.1% (4)
Other Government Representations	8.3% (3)
Others *	47.2% (17)

* “Other” includes: community colleges, universities, police, clergy, retirement homes, substance abuse specialists.

Many networks (41.9%) had subcommittees as part of their network structure. Almost all networks indicated that the development of a subcommittee was part of their plan. A number of networks indicated that project committees had been developed and would continue to be developed as needed (i.e., for special projects and initiatives).

Examples of subcommittees:

- Assessment
- Client Services (can include delivery, access issues)
- Public Awareness (can include early diagnosis)
- Advocacy
- Education
- Ethical Issues
- Research

Benefits and Challenges of a Dementia Care Network

Participants were asked about the benefits of establishing a dementia network and the benefits that are anticipated in the next 6 months. They were also asked about the challenges they faced in trying to establish a network in their community. A summary of their responses is provided below.

Benefits realized or anticipated:

- impact on services or service delivery
 - improving care, mapping services, identifying service gaps, coordinated support system, development of a resource guide
- increased awareness, communication, networking among providers & organizations
 - collaboration, process for communicating, increased knowledge of providers
- network structure / membership
 - terms of reference, objectives, increase membership
- information sharing
 - among providers, with other networks

Challenges faced:

- time / costs / competing demands
- logistics
 - geography - distance; differences in needs across different geographic areas
 - lack of services / specialized services
- including the right people
 - lack of physician involvement
 - inclusion of smaller and rural communities

Activities of the Network

Networks were asked whether they had taken on any special projects or initiatives. Over 50% indicated that they had. Examples of the types of projects undertaken are provided after Table 7.

Table 7: Special Projects or Initiatives

Special Projects or Initiatives	Number (Percentage) of Networks (N=36)
Yes	56.7% (17)
No	43.3% (13)

Examples of Projects/Initiatives:

- community mapping / service inventory
- establish “First Link”
- profile of needs among persons with dementia and their caregivers in local community
- physician newsletter
- development of a website
- development of decision trees for providers
- meeting of dementia networks in the region
- establishment of a database
- gap analysis / identification of gaps in services
- coordination of educational presentations
 - public
 - service providers
 - physicians
- development of educational materials
 - public
 - service providers
 - physicians
- development of care maps / tool guides

Communication with other Networks

Most networks (91.2%) identified that they had had opportunities to communicate/liaise with other dementia networks in their MOHLTC region or with networks from other regions in the province.

Table 8: Communication with other Networks

Communication with other Networks	Percentage (Number) of Networks (N=36)
Yes	91.2% (31)
No	8.8% (3)

Next Steps

The networks were asked to indicate the steps their network planned to undertake next. The following provides a summary of their responses.

- Further network development/refinement (e.g., finalizing vision, establish priorities, set work groups, formalize commitment, formalize steering committee, develop terms of reference, establish goals of network, develop subcommittees, define roles and responsibilities)
- Undertake service-related activities (e.g., community mapping, gap analysis)
- Undertake special projects or initiatives (see above for examples)
- Work on establishing / strengthening relationships (within the community / between communities)

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