

Outcomes from a
two-day workshop held
October 3 & 4, 2012
in Toronto

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Assessing the impact of the First Link® program

Forging a nationwide partnership



Building on existing relationships with researchers and policy makers

First Link® is an innovative referral program designed for people newly diagnosed with Alzheimer's disease and other dementias and their families. The purpose of this planning initiative was to evaluate this program, building on the strong relationships that Alzheimer Societies across the country have established with researchers and policy makers. Participants identified and prioritized areas for research that would support the further development of First Link across Canada, influence related government policy, and contribute to knowledge on health system integration, dementia care, and program evaluation.

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Workshop purpose

To create a formal nationwide partnership to focus on research that will inform the further development of First Link® across Canada, influence related government policy, and contribute to knowledge on health system integration, dementia care, and program evaluation.

Workshop participants

RESEARCHERS

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Institute for Clinical and
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First Link® was founded in Ontario ten years ago.

The program has expanded across Canada and is now offered in six additional provinces: British Columbia, Alberta, Saskatchewan, Manitoba, Prince Edward Island and Newfoundland.

Building on prior program evaluations

Program evaluations conducted in British Columbia, Saskatchewan, and Ontario have shown that First Link has been successful at connecting individuals diagnosed with dementia and their caregivers to services and education programs sooner than would have otherwise been the case. The British Columbia evaluation and a current study in south central Ontario analyzed program costs. An evaluation of the *First Link learning series* is currently being conducted in Ontario (see references on page 4).

However, several questions remain unanswered:

- How are the different needs of individuals with dementia, spousal caregivers, and adult children caregivers best met?
- To what extent does First Link increase the knowledge and understanding of their needs?
- To what extent does the program help each of these groups better cope and plan for the future?
- Does First Link have a demonstrable impact on quality of life?
- Does it help to reduce stress and prevent crises?
- Provincial ministries of health and regional health authorities are keenly interested in understanding what impact, if any, First Link has on health care service utilization (such as reduced emergency department visits, decreased alternative level of care days in acute care, or delays in admission to long-term care homes).
- A better understanding is also needed of the influence the program has on the use of primary care and various community services, such as adult day centres.



Dr. Samir Sinha, Provincial Lead for Ontario's Seniors Strategy, recognized First Link as a "vital program and service for older adults and unpaid caregivers affected by dementia."

Source: Living Longer, Living Well: Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on recommendations to inform a Seniors Strategy for Ontario

Workshop participants (cont'd)

POLICY WORKERS

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Marg Eisner

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ALZHEIMER SOCIETY REPRESENTATIVES

Barbara Lindsay

Alzheimer Society of British Columbia

Kathy Kennedy

Alzheimer Society of British Columbia

David Harvey

Alzheimer Society of Ontario

Selecting research questions

Workshop participants agreed to use the following **criteria** to rank potential research questions:

- Magnitude (addresses important question/area with relevance to large population)
- Relevance to the work and mandate of the Alzheimer Society
- Relevance to clients and families
- Relevance to government
- Potential impact (addresses knowledge and/or practice gap; likely positive impact on persons with dementia and/or care partners)
- Potential for knowledge transfer
- Innovation (question/topic addresses something unique/innovative)
- Addresses barriers to access of care, health system integration or capacity
- Does not impede client engagement
- Manageable impact on program staff

Highest-ranked research questions

- a) Impact on caregiver stress/distress, including a quality of life perspective that considers both the caregiver and person with dementia
- b) Impact on acute care, institutionalization, emergency departments as well as referrals to specialists and community services
- c) Cost-benefit analysis of transferring the burden of care to caregivers (weighed against hospital utilization)

Workshop participants (cont'd)

ALZHEIMER SOCIETY REPRESENTATIVES (cont'd)

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Alzheimer Society of British Columbia

Norma Kirby

Alzheimer Society of Manitoba

Corrine Hendricken-Eldershaw

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Joanne Michael

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Philip Caffery

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Jennifer Bethnell

Alzheimer Society of Canada

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Moving forward with the partnership

Commitments were made to confirm **core components of the partnership**:

1. Institute for Clinical Evaluative Sciences (ICES) to advise on data resources and use of data across jurisdictions.
2. Researchers to work together with the support of the Alzheimer Societies of Ontario (ASO) and British Columbia (ASBC).
3. Government, regional health authorities, local health integration networks to be consulted regarding priority research questions.

Taking the next steps

- ASO and ASBC will assess readiness for research by Spring 2013.
- Carrie McAiney and Craig Mitton will lead researchers in Ontario and British Columbia and will pursue funding with CIHR research programs, Alzheimer Society Canada (ASC) and other organizations.
- ASO and ASBC will continue to analyze methods and procedures of data collection.
- ASBC will organize a future workshop with provincial Alzheimer Societies.

Go to [Full Summary](#) for more details from this workshop.

McAiney CA, Harvey D, Schulz ME. (2008). First Link: strengthening primary care partnerships for dementia support. Canadian Journal of Community Mental Health, 27: 117-127.

McAiney CA, Hillier LM et al. (2012). Throwing a lifeline: the role of First Link in enhancing support for individuals with dementia and their caregivers. Neurodegenerative Disease Management, 2: 623-638.

Links to prior evaluations of First Link®

Alzheimer Society British Columbia. (2009). Quality Assurance Evaluation Report: The First Link Dementia Network & the Dementia Transition Project

McAiney C, Hillier L, Stolee P. (2011). First Link Saskatchewan Demonstration Project: Final Evaluation Report

McAiney C, Hillier L, Stolee P. (2010). First Link Demonstration Project: Final Evaluation Report