



REGIONAL GERIATRIC PROGRAM OF TORONTO

Affiliated with the University of Toronto

A Report on the Dementia Network Community Consultation Process

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The Dementia Network of Toronto was convened for the purpose of better understanding and improving the system of dementia care provided by the complex network of communities, institutions and associations across the city of Toronto. Towards this end the network steering committee has undertaken two initiatives. The first, in response to an often identified knowledge gap is the development of a web based compilation of city wide services for dementia care, their contact information, range of services and general information. The web-based resource is now available to the community at: <http://www.dementiatoronto.org>.

The second initiative of the network was to invite the participation of key stakeholders in dementia care across the city in order to focus on the system of care and to identify system gaps that will provide future direction to planners, educators and service developers. Two key groups of stakeholders were identified – service providing organizations and consumers themselves.

The purpose of the present report is to describe the results of a citywide consultation with the organizations that provide services to people with a dementing illness.

The consultation was organized around an innovation in problem-based learning called the build-a-case method (Ryan et al, 2004). In the present context, service providers were invited to a series of regional meetings where, in small groups, they used the build-a-case method to construct cases “typical” of dementia care in their region. After constructing cases, participants were asked to develop real intervention plans that could presently be provided and ideal plans that could be provided in an ideal world. Gaps were identified by asking participants to reflect on the differences between these real and ideal intervention plans. The gaps were then sorted into the categories of Service, Knowledge and Communication. The list of gaps that were identified across the city were compiled and sent back to participants who were asked to rate the importance of each gap in their region of the city in order to identify regional differences.

The anticipated outcomes of the community consultation process were the development of a set of illustrative case studies on dementia care, a listing of gaps in the system of care for people with dementia, the identification of any regional differences in these areas, and the transfer of knowledge to participants.

The Community Consultation Process

Participants

A list of agency was constructed for each region of the city using several databases: dementiatoronto.org database, MOHLTC and the Regional Geriatric Program of Toronto. Once compiled the list of agencies was circulated to the PRConsultants for review. Finally the Dementia Network Steering Committee reviewed the lists.

Letters were distributed by mail and email (see appendix 2) explaining the meetings and inviting each agency to send a representative. Agencies were encouraged to nominate representatives with good knowledge of the realities of dementia care. Two hundred agencies were invited to participate, 170 (93%) registered and 158 people from 92 (54%) agencies participated in the community consultation process across the city. The participants were distributed as indicated in Table 1.

Table 1 - Participants in the Community Consultation Process		
Region 1 Scarborough North 1. Number invited 25 2. Number represented 22 3. Participation rate = 88% Number of build-a-case groups 4 Participants: Managers, DOCs, coordinators, SWs, RNs	Altamont LTCF Carefirst Services Circle of Care COTA Ehatare LTCF Preferred HC Rockcliffe	Saint Elizabeth HC Scarborough CCAC Seven Oaks HFA St. Paul's Lamoureux The Scarborough Hospital VHA Yee Hong Centre
Region 2 Toronto Central/West 1. Number invited 35 2. Number represented 22 3. Participation rate = 63% Number of build-a-case groups 4 Participants: Managers, DOCs, coordinators, SWs, therapists, RNs	AST Barton Place Castlevew- Wychwood Elm Grove Grace Carman Hellenic Care Lincoln Place	Meighan Manor New Horizon Towers Norwood O'Neill Centre Second Mile Club Spencer House Toronto CCAC
Region 3 North York 1. Number invited 50 2. Number represented 40 3. Participation rate = 80% Number of build-a-case groups 5 Participants: Managers, DOCs, coordinators, SWs, therapists, educators, RNs, PSWs	Carefree Lodge CPL – Wm. Morgan CPL – Queen's Drive Cheltenham NH COTA Cumber Lodge Donway Place Extencicare – Bayview Extencicare – North York	North York CCAC NYSHC – ADP NYSHC – LTC 921 Millwood Reh'ma Foundation SPRINT – ADP & H.S. St. Elizabeth HC VHA Village Park
Region 4 Etobicoke 1. Number invited 30 2. Number represented 25 3. Participation rate = 83% Number of build-a-case groups 5 Participants: Managers, DOCs, coordinators, SWs, educators, PSWs, RNs	CAMH – Pace West CANES CPL COTA ESS Etobicoke/York CCAC Golden Days	Highbourne Lodge Home Instead Care Kipling Acres HFA Lakeshore Lodge Leisureworld UCC Trillium HC
Region 5 Scarborough South 1. Number invited 30 2. Number represented 24 3. Participation rate = 80% Number of build-a-case groups 5 Participants: Managers, DOCs, RNs, coordinators, SWs, educators, PSWs	Bendale Acres Birchmount Residence Centre D'aqueil Heritage COTA Extencicare Scarborough Friendly Visitors Home Instead Care	Lasalle Manor Providence ADP Senior Link Shephere Lodge Tendercare West Hill CS
Region 6 Toronto East/East York/York 1. Number invited 30 2. Number represented 25 3. Participation rate = 83% Number of build-a-case groups 4 Participants: Managers, DOCs, coordinators, SWs, educators, PSWs, RNs	Baker Centre Belmont House CCEY and EYAC Chester Village COPA and COTA Fudger House George Syme Centre Good Neighbors Club Heritage House	Ina Grafton Gage Leisureworld – O'Connor Crt Lincoln Place Mid-Toronto C.S. Nisbet Lodge Seaton House St. Clair West Services St. Hilda's Towers Woodgreen CS

The consultation process

The 6 community consultations were held in the city's Metro Homes for the Aged amphitheatres as shown in table 2.

Table 2 - Dates, locations and regions of the consultation process

- 1) Tuesday, September 23rd at Seven Oaks, Scarborough North
- 2) Tuesday, October 14th at Castlerview-Wychwood, Toronto Central/West
- 3) Tuesday, October 28th at Cummer Lodge, North York
- 4) Thursday, November 13th at Kipling Acres, Etobicoke
- 5) Tuesday, November 25th at Bendale Acres, Scarborough South
- 6) Tuesday, December 9th at Fudger House, Toronto East/East York/York

Participants were greeted at a registration desk and were given a brochure containing information on the dementia network, the websites of the Alzheimer's Society, the dementia services repository, the RGP, a notepad, evaluation form and name tag.

Each participant was directed to a pre-assigned case building group. Tea and muffins were available throughout the morning. Two facilitators staffed each group comprising 5-8 participants. Facilitators included the city's PRConsultants and an educator from the Alzheimer Society of Toronto.

Each consultation ran from 9.30 to noon and the process steps are as outlined in Table 3. Adjustments to the process of introducing participants were made after the initial consultation and subsequent consultations varied only in terms of the clinical content presented and discussed in the case and gaps processing stage.

Table 3 - An outline of the consultation process

1. Introduction by the regions - PRConsultants
2. Welcome from the Homes for Aged Educator or Administrator
3. Introductions of participants
4. Overview of the Dementia Network, the Community Consultation Steering Group, the provincial Alzheimer's Strategies and the Morning's objectives by the regions - PRConsultants
5. Overview of the morning's activities by Dr. Ryan.
6. Case building session facilitated by build-a-case facilitators
 - a) Case profile
 - b) Real intervention plan
 - c) Ideal intervention plan
 - d) Gaps identification
7. Group sharing and discussion of constructed case profiles
Facilitated by Dr. Ryan
8. Sharing and discussion of identified gaps facilitated by Dr. Ryan
9. Wrap-up, "next steps" and evaluation facilitated by Dr. Ryan

Prior to the onset of the consultation process, a faculty development workshop was held to increase faculty skill in use of the build-a-case method and the consultation process.

Cases built using the build-a-case process

Participants constructed a total of 27 cases.
Examples of the cases are found in table Tables 4 & 5

Table 4	
Scarborough South	Elizabeth 82 years old
Personal, social and cultural status	<p>A retired nurse, (was a charge nurse) Born in England, moved to Canada many years ago Lives along in community, in a seniors' apartment bldg Has 1 daughter who lives ~ 40 minutes away, daughter has Power of Attorney for finances & personal care Elizabeth has a family doctor who knows her well, she has been seeing him for a long time She attends an Alzheimer Day Program twice/week. In the program, she tries to run things, is quite bossy, and believes nothing is wrong with her, that she is a volunteer. She speaks very convincingly. Other risks include: not eating regularly (tea & toast); eats +++ at the Day Program Has spoiled food in fridge (program staff must often go in to help Elizabeth get ready and get on bus, so they have noticed things in the home). Her personal hygiene is not good. Day Program staff have told daughter of their concerns. They are also noticing that Elizabeth also has poor attention, increasing agitation, making frequency bathroom breaks, more accusatory, increasing confusion. Thinks people are taking her things, cannot find her coat, etc</p>
Health Status	<p>Diagnosed with Alzheimer's Disease and has taken Reminyl for 6 months without noticeable effect. Has hypertension taking anti-hypertensive medication Periods of agitation are being treated with Risperidol Day Program staff have noticed some motor changes Is ambulatory with walker. Suspected non compliance with medications</p>
Reason for referral	For the management of agitation and home safety
Real world intervention plan	<p>Day program staff will talk to daughter – suggest that she take her mum for a physical assessment due to increased confusion, irritability, etc (possible UTI?) Home support to more closely monitor medication Senior Link day program can provide a community worker to go into the home at least once per week. Arrange MOW Contact CCAC for home assessment and personal support worker Increase Day Program visits and if evening or nights are needed, involve the program at Providence.</p>

	<p>An RGP assessment through the Elders Clinic at Providence Day Program services will be increased almost immediately. The CCAC referral can take from 1-2 days (if an onsite CCAC coordinator is used) to one week to process (if they go through Scarborough CCAC)</p> <p>If Elizabeth refuses “there’s nothing wrong with me” and “I’m not paying for this”, things might take a little bit longer. In that case, the team will use the GP, who Elizabeth trusts, the daughter, and any of the Day Program staff that Elizabeth trusts, to help get these services implemented. A social worker through CCAC or the Day Program, or the RGP, may also be helpful here.</p>
In an ideal world	<p>All family physicians would know about Day Programs and other support services and would encourage and initiate service use for client.</p> <p>Timely Geriatric services would be available to residents of LTC</p> <p>Service details would be well known by all agencies and a phone call away.</p> <p>Public education – starting with the younger generation to address the stigma attached to dementia.</p> <p>Shared resources between agencies instead of competing for dollars</p> <p>Transportation for medical appointments would be more available/accessible</p> <p>Transportation for all frail elderly for other appointments at no cost</p> <p>Respite would be available outside LTCs for people with behavior problems</p> <p>Respite beds would be used appropriately – not just as holding pattern while awaiting placement in LTC</p> <p>More psychogeriatric assessment units in GTA</p> <p>More information in public domain (TV, news, etc) re dementia care supports that are available</p>

Table 5	
Scarborough North	Sarah 82 years of age
Personal, social and cultural status	<p>Widow for past 5 years</p> <p>Living in own home, alone, with cat and dog</p> <p>Still manages own finances</p> <p>English is second language</p> <p>1 daughter – lives in city – visits once a week</p> <p>2 sons – one in city, one out of town</p> <p>Daughter is getting concerned about forgetfulness</p> <p>Unpaid bills, not eating much, not taking medications, can’t remember when daughter last spoke with her, personal hygiene slipping, house not as neat as before</p> <p>Recently Sarah fired cleaning lady because she didn’t recognize the latter</p>
Health Status	<p>Alzheimer disease (early to middle)</p> <p>Osteoporosis</p> <p>Depression (mild)</p> <p>Left hip replacement 3 years ago, now walks with cane, (had home set up with equipment with occupational therapist after discharge)</p> <p>multiple medications</p>

Reason for referral	Daughter has contacted mum's GP about concerns
Real world intervention plan	<p>GP will see Sarah</p> <p>Does informal cognitive screen (asking questions)</p> <p>Physical work up</p> <p>Referral to Geriatrician or neurologist but there is a 1-2 month wait list</p> <p>Home care referral</p> <p>Home care coordinator will do initial ax (between 2 days – 2 weeks after referral picked up)</p> <p>Homemaker/PSW will be sent in ASAP after coordinator does ax</p> <p>PSW in 3 x/wk for 1 hr – assist with bathing, personal hygiene, light meal preparation. Extra hour possible once / wk for light housekeeping</p> <p>Social work may be involved for MMSE ax and long term planning</p> <p>Friendly visiting, security check also available</p> <p>Family education available through local community service agency</p> <p>Attempt will be made to get as much cultural information on Sarah as possible, so culturally appropriate care can be provided</p> <p>Sarah may be able to attend an Alzheimer Day Program for socialization, recreation</p> <p>Daughter will be asked to visit at least once a week to help monitor meds</p> <p>If Sarah becomes incontinent, this will likely trigger a placement application</p>
In an ideal world	<p>Single access number for Alzheimer care</p> <p>Provide general info and link to resources</p> <p>CCAC needs to act faster (i.e., 2 days to start services)</p> <p>Family would be linked to Alzheimer Society every time</p> <p>Sarah would be linked to recreation program</p> <p>Alzheimer Day Program would be used more often</p> <p>Social work more consistently involved to assist with family stress and future planning</p> <p>RPN available for regular visits (1x/wk) to monitor meds & nutrition</p> <p>Long term planning would start sooner (link to Alzheimer Wandering Persons registry and consideration of long term care application)</p> <p>In home help – minimum 2 hrs/day</p> <p>In home help available in a.m. to help Sarah get ready for Day Program</p> <p>Multidisciplinary geriatric clinic available to assess and organize all needed services including assessment of home safety, capacity, risk, mental health</p> <p>Report to GP and monitoring of GP's follow up</p> <p>Plan for continuing care in clinic by fully staffed clinic team</p> <p>Items in red would be top priority</p>

Among the notable features of the 27 cases was the frequency with which participants constructed cases of seniors whose first language was not English (17/27 or 63%). Languages included Gujarati, Italian, Macedonian, French, Ukrainian, Russian and Polish.

While all the constructed cases had dementia as the primary medical problem, 20 additional diagnoses were also in evidence. These additional diagnoses/functional problems included diabetes (17), behavioral problems (16) depression (11), rheumatoid and osteo-arthritis (11), vision difficulties such as macular degeneration (8) , hypertension (8), mobility difficulties (5), osteoporosis (5), hearing problems (4), heart disease (4), alcohol related problems (3),

delirium/confusion (3), continence problems (3), skin ulcers (2), falls (2), paranoia/hallucinations (2), stroke (2), CHF, sleep disturbance and anemia.

On average each constructed case was given 4 additional health related problems in addition to their dementia. The most frequent additional problem being diabetes (17/27) and behavioral problems (16/27).

The most frequent source of referral for the cases was a family member (11). Other sources of referral included emergency departments (7), friends and neighbors (2), Physicians (2), Day Program staff (2), the police (1), retirement home staff (1) and a CCAC. Twenty-five of the referrals were to CCACs. One referral came from a CCAC to a physician while another was initiated by a CCAC for medical assistance.

None of these characteristics - language/culture, kind and frequency of other diagnoses, sources and recipients of referrals - appeared different across the city regions.

The gaps identified during the consultation process

In addition to developing a series of case studies, the identification of gaps in the framework of services for people suffering from a dementing illness was an important goal of the consultation process. Gaps were identified in two ways. First, in the context of the case building exercises, participants were able to identify gaps in service arising from a comparison of the real and ideal intervention plans for the cases that were constructed. Second, on the evaluation form, participants were asked to give their personal opinions regarding the most serious gaps in their community's in meeting the mental health needs of seniors in their communities.

Gaps identified during case building

During the case building exercises, participants were asked to identify the gaps revealed by their cases. These case based gaps were organized in three areas - knowledge, service and communication. These case based gaps were subsequently examined by the consultation process coordinators to remove redundancies, blend and clarify the meaning of recorded items. As a result of this process 21 Knowledge Gaps, 30 Service Gaps and 19 Communications Gaps. These Gaps are listed in Tables 1, 2, and 3 below.

In order to better understand perceived regional differences in the structure of gaps in knowledge, service and communications regarding care of people with dementia, the refined list of gaps has now been circulated to all participants. The format for this circulation is a rating scale in which each participant is asked to first indicate their CCAC region and then rate the importance of each of the 60 identified gaps on a four point scale representing their perception of whether the gap is present or absent in their community. A total of 37 responses were received.

In the following tables the ratings of degree of each gap are presented for the city as a whole.

Table 6 - Knowledge gaps identified in the citywide consultation process and their ratings (where 1 = not a gap in our community and 4 = a very big gap)	
1. Family and general public knowledge of dementia services	3.4
2. Knowledge of how to plan to avoid crisis situations	3.3
3. General knowledge of how the system works	2.9
4. Public education on aging, stigmatization and dementia	2.9
5. Understanding of problems mixing young, old and demented people	2.9
6. MOH doesn't understand the reality of care	2.9
7. Limited education on aging for younger people	2.8
8. Professional awareness of all services available in the community	2.7
9. Volunteer training	2.7
10. Family physician knowledge of resources/medications/dementia/delirium	2.7
11. Knowledge of what services require extra payment	2.7
12. Knowledge of the role of case managers	2.7
13. Lack of emphasis on aging in the training of health professionals	2.6
14. Awareness of boundaries/catchment areas	2.6
15. Awareness of value of alcohol treatment programs.	2.6
16. Methods for the resolution of family conflict	2.5
17. Information systems sometimes encourage disability not health	2.4
18. Support and Education for the PSW/home support workers	2.2
19. Some organizations are not committed to developing their staff	2.0
20. Misuse/misunderstanding of the purpose of respite beds	2.0
21. Lack of information about the client for PSW and home support workers	1.9

Table 7 - Service gaps identified in the citywide consultation process and their ratings (where 1 = not a gap in our community and 4 = a very big gap)	
1. Services for people with behavioral problems	3.6
2. Affordable, readily available and flexible transportation services	3.4
3. Provision for “adult care leave “	3.2
4. Staffing levels are insufficient	3.2
5. The salary gap between community and facility/hospital staff	3.2
6. Translation services 7 days a week, 24 hours a day	3.1
7. Psycho-geriatrician house calls	3.1
8. Geriatrician house calls	3.1
9. Wait lists for specialized services	3.1
10. Lack of hospital beds prompts discharge to early	3.0
11. Inconsistent services across agencies	2.9
12. Individuals don't have power to make decisions or individualize services	2.7
13. Sharing of clinical data across agencies	3.1
14. Insufficient numbers of nurse practitioners with geriatric expertise	3.1
15. Payment schedules to encourage doctors work with seniors	2.9
16.No standard of care or management protocols for people with dementia	2.9
17. Geriatric Assessments in the emergency room	2.9
18. Funding to renovate facilities	2.9
19. Insufficient focus on prevention and health promotion	2.9
20 Access to day programs that can adjust to changing functional levels	2.9
21. Cultural and linguistically sensitive services and programs	2.9
22. Extended hours for programs and services.	2.8
23. Telephone assistance services for dementia	2.8
24. No continuum of housing services	2.7
25. Services just for meal preparation, housekeeping and socialization	2.7
26. Bedside coaching and mentoring services for PSWs	2.7
27. Availability of respite services	2.3
28. Services for sponsored immigrants	2.3
29. Family physicians who do house calls	2.3
30. Not enough case coordinators	2.2

Table 8 - Communication gaps identified in the citywide consultation process and their ratings (where 1 = not a gap in our community and 4 = a very big gap)

1. Communication between doctors and community agencies	3.1
2. Better marketing of services	3.1
3. Communications that would help physicians make referrals to other services	3.0
4. Inter-agency case conferences for common goal setting/evaluation.	3.0
5. Need for a single source information database	3.0
6. Insufficient involvement of mass and local media in aging issues	2.9
7. Communication between family doctors and Emergency Departments .	2.9
8. Legal/ethical gaps re: sharing information about clients i.e. confidentiality	2.9
9. Sharing information between community, acute care and LTC	2.8
10. Ability to communicate with involved social groups e.g. churches.	2.7
11. Services to help seniors communicate with family members.	2.7
12. Communication between family, physicians and client	2.7
13. Communication between all staff on all shifts and all disciplines	2.6
14. Timeliness of interagency communication	2.6
15. Need for information in plain language	2.4
16. Lack of communication between regulated and unregulated staff	2.4
17. Insufficient information on service applications forms	2.4
18. No one who seems to push “the agenda” or advocate for individual clients	2.3
19. Communication between care providers and care coordinating agencies	2.3

Not only were there more service gaps identified than knowledge or communication gaps, but a comparison of the weighted mean gap size ratings for each category of gap indicates that respondents viewed service gaps (mean rating = 2.89) as being more frequent but also slightly though significantly larger than knowledge (mean rating= 2.63) and communication gaps (mean rating = 2.71) ($t = 2.88, df = 30, p < .05$ and $t = 2.38, df = 30, p < .05$ respectively).

Similarities and Differences across Regions and Services

One-way analyses of variance across regions and services revealed no statistically significant differences in the rated size of gaps.

Table 9 - Communications gaps rated higher than 3 for each service sector	
CCAC	
Communication between family doctors and emergency departments	3.0
Better marketing of services	3.0
Community service agencies	
Communication between physicians and community agencies	3.6
Communications that would help physicians make referrals	3.3
Better marketing of services	3.3
Need for single source information database	3.2
Inter-agency case conferences for common goal setting/evaluation	3.1
Sharing information between community, acute and LTC	3.0
Long Term Care	
Better marketing of services	3.1
Insufficient involvement of mass and local media in aging issues	3.1
Need for a single source of information database	3.1
Services to help seniors communicate with family	3.0
Legal/ethical gaps sharing information confidentially	3.0
Communications that would help physicians make referrals	3.0
Inter-agency case conferences	3.0

Table 9 suggests that “better marketing of services” is a priority for CCACs, Community Service Agencies and Long-Term Care Facilities. Each service sector also identified communications with physicians as being a priority though the elements of physician communication might be different in the three sectors.

With CCACs identifying a priority in emergency/family physician communication, CSAs perceived a gap between themselves and physicians as well as communications to assist the referral process an issue that they share with the LTC sector. The absence of inter-agency case conferences was perceived as an important gap by CSA and LTC sectors, less so for CCACs.

Table 10 - Communications gaps rated higher than 3 for each region	
Etobicoke	
Ability to communicate with involved social groups, e.g. churches	3.7
Communication between physicians and community agencies	3.3
Communication between family doctors and emergency departments	3.3
Better marketing of services	3.3
Insufficient involvement of mass and local media in aging issues	3.3
North York	
Communication between physicians and community agencies	3.3
Sharing information between community, acute and LTC	3.3
Legal/ethical gaps sharing information confidentially	3.2
Need for single source information database	3.2
Communication between family doctors and emergency departments	3.2
Communications that would help physicians make referrals to services	3.0
Need for information in plain language	3.0
Better marketing of services	3.0
Insufficient involvement of mass and local media in aging issues	3.0
Scarborough	
Inter-agency case conferences	3.3
Need for single source information database	3.3
Timeliness of interagency communication	3.1
Legal/ethical gaps sharing information confidentially	3.1
Communication between physicians and community agencies	3.1
Communications that would help physicians make referrals to services	3.0
Better marketing of services	3.0
Toronto	
Better marketing of services	3.3
Communications that would help physicians make referrals to services	3.1
Insufficient involvement of mass and local media in aging issues	3.0

Table 11 - Knowledge gaps rated higher than 3 for each service sector		
CCAC		
Knowledge of how to plan to avoid crisis situations	Family and	3.6
general public knowledge of dementia services		3.3
Family physician knowledge of resources/meds/dementia/delirium		3.3
Knowledge of the role of case managers		3.3
Organizational commitment to staff development		3.0
Knowledge of what services require extra payment		3.0
Community Service Agencies		
Family Physician Knowledge of resources/meds/dementia		3.7
General knowledge of how the system works		3.3
Awareness of boundaries/catchment areas		3.2
Family and general public knowledge of dementia services		3.2
Limited education on aging for younger people		3.0
Public education on aging, stigmatization and dementia		3.0
Long Term Care		
Family and general public awareness of dementia services		3.5
MOH doesn't understand the reality of care		3.4
Understanding of problems mixing young, old and demented people		3.3
Knowledge of how to plan to avoid crisis situations		3.3

Table 12 - Knowledge gaps rated higher than 3 for each region	
Etobicoke	
Family and general public knowledge of dementia services	3.3
Knowledge of how to plan to avoid crisis situations	3.3
Public education on aging, stigmatization and dementia	3.0
Family physician knowledge of resources/meds/dementia/delirium	3.0
General knowledge of how the system works	3.0
Knowledge of what services require extra payment	3.0
Limited education on aging for younger people	3.0
Awareness of alcohol treatment programs	3.0
North York	
Family and general public knowledge of dementia services	3.8
Knowledge of how to plan to avoid crisis situations	3.7
Public education on aging, stigmatization and dementia	3.3
Family physician knowledge of resources/meds/dementia/delirium	3.2
Understanding of problems mixing young, old and demented people	3.2
Limited education on aging for younger people	3.0
Lack of emphasis on aging in the training of health professionals	3.0
Scarborough	
Knowledge of how to plan to avoid crisis situations	3.4
Family and general public knowledge of dementia services	3.3
General knowledge of how the system works	3.3
Understanding of problems mixing young, old and demented people	3.0
Information systems sometimes encourage disability not health	3.0
Toronto	
Family and general public knowledge of dementia services	3.3
Knowledge of how to plan to avoid crisis situations	3.3
MOH doesn't understand the reality of care	3.3

Table 13 suggests that all sectors perceive a knowledge gap amongst the general public. CCACs and CSAs perceive that there is a gap in physician knowledge of resources and practice. CCAC and LTC respondents perceived a gap in “knowledge of how to plan to avoid crisis situations was”.

Table 13	
CCAC	
No standard of care or management protocols for people with dementia	3.7
Geriatric Assessments in the emergency room	3.7
Psycho-geriatrician house calls	3.7
Geriatrician house calls	3.7
Services for people with behavioral problems	3.3
Wait lists for specialized services	3.3
Affordable, readily available and flexible transportation services	3.3
No continuum of housing services	3.3
Provision for “adult care leave “	3.0
Sharing of clinical data across agencies	3.0
Access to day programs that can adjust to changing functional levels	3.0
Insufficient numbers of nurse practitioners with geriatric expertise	3.0
Services just for meal preparation, housekeeping and socialization	3.0
The salary gap between community and facility/hospital staff	3.0
Family physicians who do house calls	3.0
Lack of hospital beds prompts discharge to early	3.0
Not enough case coordinators	3.0
Insufficient focus on prevention and health promotion	3.0
Payment schedules to encourage doctors work with seniors	3.0
Community Service Agencies	
The salary gap between community and facility/hospital staff	3.5
Payment schedules to encourage doctors to work with seniors	3.3
Family physicians who do house calls	3.3
Psycho-geriatrician house calls	3.3
Geriatrician house calls	3.3
Translation services 7 days a week, 24 hours a day	3.3
Services for people with behavioral problems	3.3
Affordable, readily available and flexible transportation services Inconsistent services across agencies	3.2
Access to day programs that can adjust to changing functional levels	3.1
Extended hours for programs and services	3.0
Staffing levels are insufficient	3.0
Geriatric Assessments in the emergency room	3.0
Lack of hospital beds prompts discharge to early	3.0
Insufficient focus on prevention and health promotion	3.0

Long Term Care	
Services for people with behavioral problems	3.8
Affordable, readily available and flexible transportation services	3.5
Provision for “adult care leave “	3.5
Staffing levels are insufficient	3.4
Funding to renovate facilities	3.4
Insufficient numbers of nurse practitioners with geriatric expertise	3.2
Translation services 7 days a week, 24 hours a day	3.2
The salary gap between community and facility/hospital staff	3.1
Lack of hospital beds prompts discharge to early	3.0

Gaps identified on the consultation evaluation form

Table 14 Service Gaps rated higher than 3 for each service sector

Several of the highest rated gaps emerging from the build a case exercises outlined above are also evident in the list of gaps provided on participant evaluation forms as seen in table 7.

Table 15 - Service gaps rated higher than 3 for each region	
Etobicoke	
Geriatrician house calls	4.0
Psycho-geriatrician house calls	3.7
Services for people with behavioral problems	3.7
Wait lists for specialized services	3.3
Inconsistent services across agencies	3.3
More rehabilitation programs	3.3
Services just for meal preparation, housekeeping and socialization	3.3
Extended hours for programs and services	3.3
Geriatric assessments in the emergency room	3.3
Family physicians who do house calls	3.3
Insufficient focus on prevention and health promotion	3.3
No standard of care or management protocols for people with dementia	3.0
Individuals don't have power to make decisions or individualize services	3.0
Affordable, readily available and flexible transportation services	3.0
Cultural and linguistically sensitive services and programs	3.0
Insufficient number of nurse practitioners with geriatric expertise	3.0
Funding to renovate facilities	3.0
Telephone assistance services for dementia	3.0
Translation services 7 days a week, 24 hours a day	3.0
North York	
Services for people with behavioral problems	3.8
More rehabilitation programs	3.3
The salary gap between community and facility/hospital staff	3.3
Funding to renovate facilities	3.3
Access to day programs that can adjust to changing functional levels	3.2
Insufficient numbers of nurse practitioners with geriatric expertise	3.2
Staffing levels are insufficient	3.2
Bedside coaching and mentoring services for PSWs	3.2
Insufficient focus on prevention and health promotion	3.2
Sharing of clinical data across agencies	3.0
Cultural and linguistically sensitive services and programs	3.0
Geriatric assessments in the emergency room	3.0
Translation services 7 days a week, 24 hours a day	3.0

Table 16 - Service gaps rated higher than 3 for each region - Continued	
Scarborough	
Services for people with behavioral problems	3.6
No standard of care or management protocols for people with dementia	3.6
More rehabilitation programs	3.5
Geriatrician house calls	3.5
Psycho-geriatrician house calls	3.5
Affordable, readily available and flexible transportation services	3.4
Lack of hospital beds prompts discharge too early	3.4
Wait lists for specialized services	3.3
Inconsistent services across agencies	3.3
The salary gap between community and facility/hospital staff	3.3
Staffing levels are insufficient	3.3
Translation services 7 days a week, 24 hours a day	3.3
Family physicians who do house calls	3.3
Extended hours for programs and services	3.2
Insufficient numbers of nurse practitioners with geriatric expertise	3.2
Sharing of clinical data across agencies	3.1
Geriatric assessments in the emergency room	3.0
Toronto	
Affordable, readily available and flexible transportation services	3.8
Staffing levels are insufficient	3.4
Services for people with behavioral problems	3.3
The salary gap between community and facility/hospital staff	3.3
Access to day programs that can adjust to changing functional levels	3.2
Sharing of clinical data across agencies	3.1
Payment schedules to encourage doctors to work with seniors	3.1
More rehabilitation programs	3.0
Cultural and linguistically sensitive services and programs	3.0
No continuum of housing services	3.0
Insufficient numbers of nurse practitioners with geriatric expertise	3.0
Funding to renovate facilities	3.0
Translation services 7 days a week, 24 hours a day	3.0
Lack of hospital beds prompts discharge too early	3.0

Table 17 - “Serious Gaps” and their frequencies identified on individual consultation evaluation forms							
Self identified gaps	Etob (19)	NY (28)	Scarb N (23)	Scarb S (20)	To C/W (18)	TO E/ York/ East York (25)	TOTALS
Funding	1	11	14	6	10	14	56
Communication between health care providers/agencies	6	11	6	14	7	5	49
Public awareness	4	11	14	7	7	5	48
Information on service availability	1	12	6	2	7	3	31
Waiting lists prevent timely care	0	12	1	5	4	5	27
Continuity of care	0	7	6	0	2	3	18
Community resources for ethno-specific groups	2	5	1	2	4	2	16
GP involvement with patient care plan and services	2	4	0	2	3	2	13
Transportation to day programs and appointments	1	1	1	1	4	0	8
Day programs for seniors with dementia	0	0	0	2	3	2	7
GPs to do in-home visits to assess patients	1	0	3	1	0	2	7
More educated and better prepared staff needed	0	0	0	0	0	5	5
Specialized services, e.g. geriatricians, etc	1	0	3	0	0	0	4
A streamlined referral process for services and placement	1	0	1	0	0	2	4
Supportive housing	0	0	0	0	2	1	3
Balance between the rights of the client and the caregiver	0	1	0	0	2	0	3
Family involvement with care planning and services	0	0	0	0	2	1	3
Limitation of CCAC hours	0	0	1	2	0	0	3
Universal Consent Form	0	3	0	0	0	0	3
Centralized database of patient/client information	0	3	0	0	0	0	3

Consultation Process Participant Evaluations

Table 18 - The results of three ratings of consultation process effectiveness (In each cell the number indicates the number of respondents and the corresponding percentage of respondents is in parentheses)					
Rating scale	1	2	3	4	5
	(where 1 = very much so and 5 = not at all)				
Productive and informative	79 (59%)	40 (30%)	8 (6%)	5 (4%)	1 (1%)
Well organized	91 (68%)	32 (24)	5 (4%)	4 (3%)	1 (1%)
Influence practice	51 (37%)	44 (33%)	25 (22%)	7 (6%)	2 (2%)

Feedback from 133 of the 158 participants who completed the meeting evaluation are very positive as shown in Table 18. Participants felt that the sessions were productive, informative and well organized. Seventy percent of participants indicated that the sessions helped them to learn things that would influence their practice. Given that the sessions were not designed to focus on teaching, this result indicates an added value of the community consultation process.

The positive tone of evaluations gathered from the rating scales were mirrored in the following collection of comments that participants provided in a section of the evaluation labeled “other comments”.

1. A very valuable session
2. Interesting morning
3. Very informative and I discovered that by listening to others the main focus is the client and we need to improve the communication in all areas.
4. A very good session and helped increase my knowledge
5. Love the format of build-a-case
6. Enjoyed the session and learned from it
7. Very informative and enlightening. This session needs to be presented across the health care system.
8. Great information sharing, dynamic
9. It was helpful to have an opportunity to voice concerns, ideas and to brainstorm solutions in long term care. It can sometimes feel like no one is listening outside of our facility. These events help me to remain excited about my work and the service I provide.
10. I really learned a lot from this course.
11. Thank you – A very informative session and a positive environment to share information. Good Job!
12. Informative, interesting and well organized.
13. Interesting session! I liked the diversity of the group members. I would have liked more opportunity for information sharing and tips we can take away as front line workers for those with dementia. Great to hear what other agencies do and learn about their role.

14. This is a very informative networking session. It would be ideal to include hospitals, more LTC facilities and CAMH staff.
15. Extremely well done! I am glad you will be sending out summaries of gaps identified.
16. Would be good to do introductions of the whole, large group for networking purposes. We really only met people at our table.
17. Your program today was very informative and a real eye opener to what we need to plan for.
18. It was a good informative session to coordinate ideas from groups coming from different areas and facilities.
19. It was a pleasant experience to work with other people in the field. It was educational to provide information to other colleagues and residents.
20. Need to develop a community directory, i.e. yellow pages for all services available.
21. Ensure staff have same module of learning and use same approach, interventions. Ensure we all speak the same language with dementia.
22. Need of educational material for direct staff with updated information and approaches.
23. Enjoyed this workshop – it was great to network and develop what will hopefully be valuable “case studies” for others to learn from.
24. Good medium to help professionals look outside the narrowness of specific disciplines.
25. Thanks a lot!
26. I work with volunteers (students) who have no idea of dementia and I would like information sessions offered to schools, enabling young people to have an idea.
27. Good Morning!
28. Well done! Very Interactive!
29. Really liked the caring/sharing/discussions. Would like to know the outcome of these sessions – Will services improve? Will knowledge be increased as the population ages? What are the alternatives?
30. Interesting, valid and a good use of time.
31. Very interesting experience.
32. We need more funding to develop culturally sensitive programs and sensitive health workers to cultural needs.
33. Too long of monologue unrelated to the cases built by each group impacting on decreased group discussion time.
34. The chat and education in between was perhaps interesting but reduced the time spent on the cases. Large areas were not touched on
35. Great session! Really enjoyed it!
36. Excellent! Provided a venue to discuss issues, concerns, gaps, etc...
Excellent Program! Stimulating and educational!
37. David Ryan was fantastic. I learned so much from his comments.

Identifying next steps: A review of ongoing initiatives and a menu of possible action items

Following the consultation process the steering committee reviewed the collected data in order to identify those gaps that ongoing Alzheimer Strategy initiatives were expected to close. As well the group identified a set of suggested action items arising from the consultation process that the dementia network might consider over the forthcoming year.

Current initiatives expected to meet needs identified in the community consultation process.

Physician education initiative
Geriatric emergency management program
Psycho-geriatric Clinical Care Committee (Dr. Corinne Fischer)
Management of dementia in primary care webcast archive
Dementiatoronto.org

Suggested foci for future dementia network activities

1. Community consultation phase 2
 - a) Initiate a consultation process focused on family care-givers recruited from the:
Support groups listed on dementiatoronto.org
Use the case studies developed in phase 1 to focus discussion.
Expected outcomes include:
Refinement of the currently available and ideal service framework
Clarification of the needs of family caregivers
Networking support groups
 - b) Understanding dementia from a cultural perspective
Identify leaders within each cultural group
Train trainers from each community
Trainer/PRCP run culturally specific focus groups
2. Inter-agency collaboration and a cross-sectoral standard of care
 - a) Convene an inter-sectoral task force to develop consensus on a standard of community based care for people with dementia.
 - b) Develop and promote an Intersectoral workshop on the opportunities and obstacles (e.g. privacy legislation) to interagency collaboration.
3. Advocacy issues suggested by the community consultation process
 - a) Expanded cadre for Public Education Consultants in Toronto
 - b) Continuum of housing services
 - c) A program of Adult Care Leave
 - d) Training and Recruitment of Geriatricians and Psycho-geriatricians
 - e) The business bottom line on the impact of employees giving care to family members with a dementing illness.

Community Consultation Process Phase 2: A family caregiver focus group

In order to guide dementia network steering committee in its selection of a next step, a family caregiver consultation process was initiated.

A letter of invitation for family caregivers to circulate to convenors of all family support groups and CCAC home care managers in the city. The invitation explained the work of the dementia network and convenor and manager to nominate two members of their community to participate in a family care-giver meeting, in which participants would be given a brief lecture on current initiatives in dementia care and the work of the dementia network before joining in a focus group to better understand their valuing of key services and identify their needs.

Dr. Ryan, Director of Education for the Regional Geriatric Program of Toronto along with Sylvia Davidson and Lynda Perry from the Psychogeriatric Resource Consultation Program in Toronto provided meeting facilitation. Eventually 24 family caregivers convened at Sunnybrook & Women's College Health Sciences Centre on December 4, 2004. There for four hours over tea and coffee with muffins, a lively discussion ensued the key elements of which are outlined below.

- Living with dementia is a career – a marathon not a sprint.
- Control is lost and bureaucracy often doesn't help us to manage depression and anger.
- Questions about accountability for health dollars
 - Public wants to know how much money and where it goes
 - How much has been spent for restructuring consultants over the years?
 - What will the accountability process be for LHINs?
- Adult care leave and respite care were valued but participants are frustrated by the need for advanced scheduling and recommend more "impromptu" service Hospital staff need to know more about managing patients with dementia and helping those who are not easy to engage verbally
- Support groups are very helpful but many seniors who might benefit don't know about them or how they can be useful
 - Support groups vary in their ability to meet the blend of emotional and informational needs and are not for everyone.
 - Family services of Toronto workshops and counseling and Providence Centre Satellite Program were recommended.
- Participants thought that the family councils could be helpful, wanted to help, and asked about terms of reference
- The MOHLTC long-term care public reporting utility <http://www.ltcfacilities.net/publicreporting> was considered very useful but hard to find by those who did know about it. Dementiatoront.org was recommended by several participants
- Participants expressed frustration that they don't know what to expect from all the service providers and don't think that they talk with each other
 - Families need to know exactly what best practices to expect from each hospital/community/ltc provider and who does the best job.
 - Participants offered their help as key informants at interagency meetings to discuss expectations for standards of care.

Next steps revisited: The Family Focused Intersectoral Guideline Initiative

Following the family caregiver consultation process the dementia network steering committee revisited the list of action items arising from its earlier community consultation process. As a result, the network agreed to focus its attention on finding ways to enhance inter-agency collaboration and meet family caregiver needs through the identification of cultural and life style sensitive, standards that reach across the spectrum of dementia care.

To develop this initiative a network task force was struck comprised of Dr. Ryan, Rhona Phillips and Amanda Falotico and what follows are the notes arising from the preparation for this work that will be supported by staffing provided by the Regional Geriatric Program of Toronto.

The task force identified several values to guide the work:

1. Avoid unnecessary redundancy while preserving essential diversity
2. Ensure that any materials developed through the initiative be usable “working” documents that inform the entire “circle of care”
3. The work should build on other similar initiatives such as the OCSA standards for day care and Alzheimer Society Standard etc.
4. Participants in the consultation process should be involved
5. Cultural sensitivity should be reflected in all outcomes
6. Applications of any standards should be achievable within present resources

The outcomes of this anticipated work were seen as:

1. Ensuring that the dementia network is seen to be active in the community
2. Ensuring that the dementia networks actions is seen as building on what has gone before and is meeting needs identified by the community
3. Ensuring that the dementia network add value to the transformation agenda by focusing on inter-sectoral integration
4. Learning about the challenges and opportunities in developing inter-sectoral collaboration
5. A compilation of standards developed within specific sectors, that would of help to health professionals across the spectrum of care
6. The consolidation of information resources to meet the needs of the lay “circle of care”. These might include:
 - a) The translation of key standards and guidelines into non-professional language that is senior friendly?
 - b) Clarification of service components and reasonable expectations of service across the spectrum of care
 - c) The development of a “Five Key Facts” FAQ to meet the common queries of lay caregivers across the spectrum of care

The steering committee has approved this direction and recruitment of staff to assist the task force has been initiated by the RGP.

References

Ryan, D. & Marlowe, B. (2004) Build-A-Case: A Brand New CME Technique that is Peculiarly Familiar, *Journal of Continuing Education in the Health Professions*, (24), 112-118.