

# ***LEARNING FROM EACH OTHER***

Proceedings from the

**Ontario Dementia Network Conference**

**October 20, 2003**

**Toronto**

**Local Dementia Networks' Experiences**

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## **Comments from Morning Small Group Discussions**

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### **Theme A - *Fostering interagency/intra agency cooperation/partnerships***

- What are the perceived process, benefits and challenges of interagency cooperation/partnerships?
- How did your network initiate involvement/buy-in?

#### Process:

- shared information
- contacted those agencies that were known to provide services – by invitation
- Alzheimer Society and PRC initiated Dementia Care Network
- created a membership Work Group to ensure personal invitations to relevant people/organizations – produced a core group
- making sure there is common interest
- brought together stakeholders – Asked them to identify who should be part of DN.
- Palliative Care Network served as an excellent model for a network
- build on existing groups
- invited many agencies for membership in DN
- look at all of the committees/network in the area – find representation from that group to join at DN
- using video conference/ teleconference to overcome distances.
- focus on inventory of services – useful
- building on DHC –CCAC “Caregivers Guide”
- involved consumers through CCACs, Alzheimer Society, Council on Aging

#### Benefits:

- people recognize benefits of sharing and collaboration.
- partnerships a survival necessity in North – it’s not an option – meets obvious need
- involvement of family caregivers required – to foster/provide incentive.
- need to market related to needs of person with dementia
- keeping focus on person with ADRD helps services put aside vested interests
- DN – essential to enhance quality of care.
- know roles of other organizations – clears up overlaps; clears up misunderstandings; lets front-line staff manage – look at how can work together and eliminate duplications, collaborate together
- able to identify key service needs – contribute to DHC multi-year planning

#### Challenges:

- agencies want information but can’t make the commitment
- involve MDs - varied success in involvement
- challenge to keep people at table by having a common interest/issue (e.g., to develop Dem. Network) or common project
- need to get local health agencies to buy-in – It’s a challenge because don’t see it as part of their mandate
- huge geographic area – same people sit on different groups therefore have positioned it as Geriatric Services Network (broader mandate)
- Vested interests – lines drawn through hospital restructuring
- don’t have representation - need to look at duplication on networks
- city/rural split
- distances
- many other groups in community focused on dementia
- keeping info accurate, complete, current

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How did you network initiate involvement/buy-in?

- at each meeting have an agency profiled, to share info between agencies.
- need to develop a common vision statement
- needs assessment
- letter of interest to come to workshop – share all available resources (brought Ken to speak)
- need tangible action plans – quick hits
- need strategy of 'bottoms-up' – people to identify needs in local area – report back to SC – up to CCAC council . Use a standard questionnaire.
- a common website – CCAC funded it initially but now agencies contribute to it.
- need involvement of people in DN who can make decisions.
- a lot of initial enthusiasm - brainstormed themes – agreed to sign up for Work Groups – identified Work Group leads but then groups challenged by work load - refocused to avoid overlap, keep primary goal.
- keep focus manageable, meaningful work for groups
- don't want to bite off too much - develop work plan for Work Groups.
- pooling resources
- structure – align with other advisory groups e.g., CCACs, Regional Geriatric Advisory Committee
- have used case scenarios from all members in network, each responsible for bringing a case helped to identify new agencies and look at standard approaches to referrals – will follow model for kids' services
- attend family MD meeting in the local hospital
- involving caregivers/consumers; tap into Alzheimer Society
- PRCs – went with assumption they were part of network.
- pushed goals- common goal
- used MAREP report

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### **Theme B - Integration with the broader health care system**

- How do Dementia Networks link with other system reforms/strategies/networks in your region? (e.g., LTC, Palliative Care, Mental Health, Elder Abuse, etc.) - Associated processes, benefits and challenges?

#### Processes:

- joint DHC and ASO with local CCAC
- built on existing LTC Mental Health-LTC groups/networks
- other strategies/networks e.g. Elder Abuse, oncology, RGP, palliative care, Stroke Strategy
- members also attend other networks (i.e. Mental Health, Palliative Care)
- determine if other working groups are duplicating tasks of DN
- First Link – physician referral to Alzheimer Society for dementia assessment and education and advice. Pilot in London.
- video conferencing/ teleconferencing
- use of drug companies to host info dinners
- include nurse practitioners where physicians are not available
- developing a table (focus) for all service providers
- have an education person from local college (Dementia Studies) at table
- one network, to address this, has updates from other networks/groups as standing items on agenda
- one region looking at establishing a Senior Leaders group that includes decision-makers to take and implement issues - members to include reps from the various networks and advisory groups in the region
- another region has a Seniors Advisory Group that includes reps from 35 groups – includes decision makers - responsible to share info with each other about each group
- need to have the decision makers in the loop – otherwise action can't move forward.
- example of Connect Ontario – to help agencies be networked to each other
- Alzheimer Society of Ont. – perhaps needs to reach out to other societies

#### Benefits:

- clients and caregivers should see better linkage with services across systems
- at the point of the person, these strategies have to be integrated
- information sharing about other services/agencies (i.e. LTCFs, CSS agencies, acute care)
- identify gaps, barriers and opportunities to service provisions –identify solutions -use of case studies to illustrate barriers and solutions.
- having physicians is very beneficial – (even if they don't attend, provide minutes for input)
- can't plan in isolation of the other issues/needs that clients face.
- many providers involved; clients often have multiple conditions.

#### Challenges:

- how to get front-line service providers involvement. How to link with them?
- knowing what everyone in region is doing? Need more integration in other networks
- need framework to integrate with Mental Health.
- physicians need incentive
- privacy is an issue
- keeping people at the table.
- agencies are protective of their services but there may be duplication, however, instead of integrating, agencies are protective

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### **Theme D - *Inter-regional relationships Rural perspective:***

- What are the perceived process, benefits and challenges of inter-regional relationships?

#### **Process:**

- primarily by e-mail contact to interested members
- use of video conference through North Network -works better than audio conference
- meeting in person –rotating sites
- 2 regional conferences Spring 03 and Fall 03; annual DN day is useful to learn from each other
- try to incorporate educational component in meetings
- emphasize benefits of meetings improves attendance
- agencies have funded members' travel costs; coordinate meetings to take advantage of travel efficiencies
- include other networks
- meeting quarterly face-to-face
- caregiver input has been significant
- have developed a resource guide
- completing inventory of services
- funding from Pharmaceutical Companies
- electronic minutes of meeting to all DN members
- do not try to duplicate/replicate already existing resources – Piggy-back on existing resources when possible. Ask to be added to existing info/resources.
- people want to come together to work on a project not just to meet for the sake of meeting
- identify priorities and move along the list of priorities
- financial incentives for physicians to attend DN committees
- DHC may take a lead in getting local network together by chairing/co-chairing regional meetings
- MOHLTC regional offices need to identify DHC support as necessary for the development of DN – as a regional Planning Priority
- develop DN Binders for all DN members – to give history, minutes, etc. to all members – this provides good orientation to new members - \$ from DN supports the \$ for binders and is coordinated by DHC
- three times per year if someone (i.e. ASO) could take the lead of what is new and disseminate this information to all DNs in the province (i.e. research, new resources)
- develop a vehicle to flag and identify Key issues and Knowledge and Public Advocacy and Public Direction, i.e. a Coordinator to take the lead to ensure things move forward.
- link with politicians to impress on them the importance of DNs

#### **Challenges:**

- cost not substantial if agencies cover travel
- time to attend in person is also major consideration
- difficult to get Physicians on DNs
- remote (travel time and distance) – isolation
- trying to accommodate all players at a central location where everyone is comfortable
- how to link local networks within regional level
- how to ensure local DNs are not duplicating work
- staff changes = loss of momentum and continuity in work
- winter months (travel, cancellations)
- technology not available in all communities
- DHCs have not been given consistent messaging about priority of DNs across the province

#### **Benefits:**

- empowerment of front-line staff to gather info from other networks.
- sharing resources and common goal
- get to see challenges of other areas

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### **Theme E - *Evolution from a Steering Committee to a broader network***

- What are the perceived process, benefits and challenges of evolving from a steering committee to a network?

#### Process:

- one started as group at large – became unwieldy – now core group of 8-10 that meets quarterly (people dropped off) –how to pull back in wider group to become a network?
- subgroups that some share members with Steering Committee
- could use a coordinating body which recruits and communicates to address issues identified by broader networks (with larger membership)
- getting info out – effectiveness of newsletters
- Toronto built website that was e-mail addresses for 300 agencies involved in dementia care – considering sending out regular briefings re what's going on with the network – keeping people informed even if they don't want to directly become involved
- buy-in depends upon what Steering Committee does (e.g. specific projects)
- some have shifted to work groups (roll up sleeves)
- representation from CEOs rather than managers (able to commit resources)
- each member of Steering Committee makes phone contact with one other person
- involve other community members (outside health and Dementia network) in education of the work of DN, then seek their active involvement, i.e. general public members – police, church/clergy, education, financial sector, etc.
- special project development may be used as launch of DN
- ask for more \$ from Regional office? Carry over original seed funding to June 30, 2004
- piggy-back on existing structures in community, i.e. Mental Health Implementation Task Force and DN to develop DN or maintain DN, or extend meetings by an hour to include DN activity
- 'Telehealth' DN to allow members to attend Video network for meetings or Teleconferencing.
- technology – Videoconferencing/Teleconferencing/Website – use of E-mail.
- involve members by ensuring their needs are met – prioritize the activities to meet the stakeholders needs, then re-prioritize as you move along.
- E-mail minutes of DN meetings/updates of the DN to all who originally expressed an interest (but did not join the network)
- website – post all notes of DN
- local DN activity on ASO website
- regional components of DNs, i.e. some work may need regional input vs. local work/input to ensure we are not duplicating work

#### Benefits:

- overview of the continuum and better advocacy for the continuum
- lighten the workload for all involved.
- umbrella group (in rural areas) with several committees
- comprehensive scope of what already exists in the community in terms of resources available in the community
- awareness of existing services.
- representatives on networks can provide up-date in other committee sectors. Better information sharing.
- promotes other collaboration and partnerships in other initiatives.
- buy-in by involving the community other than just the initial partners, i.e. consumers, public
- physician support appears to strengthen a dementia network (need to give physicians a reason to participate e.g. access to specialty services, ground rules for accessing services that will benefit patients)

#### Challenges:

- struggling with membership on Steering Committee – administrator vs. service provider.
- caregiver attending meeting - mixed experiences - some found discussion too much a system level,

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- definition of network – one approach is to keep it loosely defined (i.e. anyone who delivers dementia services) - they may not know they are a member of the network
- divestment of responsibility to Dementia Network members (from Alzheimer Society who brought members together) to members accepting responsibilities, divesting work, taking lead
- buy-in to get Dementia Network started
- Alzheimer Society chairing and co-chairing DN and sub-committees and Steering Committees
- one group does everything – how to get other members to the table.
- work overload
- time – a lot of hands-on work to do and others don't have the time to devote
- resources available (people, \$, etc.)
- distance (100's of kilometers apart)
- some people at every table – major overlap with other initiatives/committees
- tried to extend DN initiatives to the agenda of existing committees but no interest in doing this as this dilutes the focus of existing groups or committees.
- special project work means only so much time to complete the work (i.e. DN directory) and resources (human and financial) therefore, development of DN or future of DN not the focus.
- how to keep involvement, meet local needs in a large geographic area –populations

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### **Theme F - Knowledge-Info Exchange**

- What are some possible methods for knowledge/information exchange and their associated benefits and challenges?

#### Methods:

- DN provincial website
  - suggest have capacity to personalize for a constituency
- need for repository of information
  - website
  - inventory
  - *caremapsforseniors.ca*
- caregiver/family – what key messages? – communicating about the DN – mass media to general public
- template provided to service providers, physicians
- best practices – conferences, newsletters
- feed into newsletters that go to seniors
- effectiveness of newsletters? Fact sheets with a few sentences and where to go for other info – diagram that can be posted at key places might less likely “gather dust”
- First Link in Ottawa makes the first call and disseminates information to families
- regular bulletin – virtual network
- attend nontraditional events, car show, food show
- radio station; mainstream magazines, i.e., House and Home
- use of different terminology, avoid short forms and language complexity
- making appointments with physicians, dentists, real estate agents to disseminate information
- targets for KE –
  - community of providers
  - community of users/consumers
  - linking networks across province
  - linking between service providers
- low tech –
  - prescription pad for physicians
  - radio show
  - PEC – help consumers/service providers access to information
  - face-to-face, telephone
  - partner with utilities information mailed to each household to decrease \$ in rural communities

#### Benefits:

- make use of information that's already available, not replicate
- didn't want to add the expectation of having to be at meetings in order to receive information
- importance of role of consumer in access of information
- need to know more about what services are being provided and by whom
- with good KE – know who does what; learn and share from each other

#### Challenges:

- issues re exchanging information in North due to distances
- finding time to visit websites, etc.; also many providers/consumers may not have access to the web
- some concern about not knowing about status of plan to create DKE, what it's focus is, etc.?
- web – only useful for those who are interested
- challenges without good knowledge exchange:
  - redundant referrals
  - services available – no referrals
  - clients who fall through the gaps
  - not right balance of information
  - overlap of committee work/meetings



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### **Theme G - Service Mapping**

- What are the perceived process, benefits and challenges of mapping a network of services?

#### Process:

- hiring student to do this
- refining inventory tool to send out to collect the information from agencies
- one network developed technical maps on demographics and services
- build sustainability into role of PRC
- look at linking to CCAC to update
- looks like all are using web based inventory so why can't this be done provincially
  - each group is putting considerable resources so can't these resources go provincially for a more cost effective development of web site
  - start with a map of Ontario for people to click on areas of the province for information.
- \*\*\*WANT PROVINCIAL ROLL-OUT OF THIS COMPONENT
- Toronto took an "asset" based approach and then identified gaps. Linked with 211 exchange through the Toronto Information Centre. The 211 exchange was not fully beneficial then moved on to developing a Dementia Network - did a "clients' need mapping" to stay focused
- Huron developed a directory guide of services written in very simple language and distributed at support groups and day centres
- Sudbury – developed a brochure profiling an inventory of services - this inventory of services will be made available, translated in various languages – French, Italian, Finish
- Thunder Bay - visual service mapping throughout the continuum of care (at various stages of dementia/Alzheimer Disease)
- The London area network has already developed a continuum of services that some networks will look at in their process of "service mapping".
- sorted by issue (e.g. transportation, nutrition, etc.)
- to keep it more up to date will have agency names , but no names of individuals.
- committee to re-look at it every 1-2 years to ensure it is up to date; to look at the issues and challenges
- because using inserts – easier to update.
- one networks hoping that individual service providers will contribute to costs of it.
- committee is responsible for keeping took up to date. (subcommittee of DN – Steering Committee)

#### Benefits:

- client services care map to show people where to go for service in their community and region
- need to increase awareness of services to consumers
- map for clients and physicians
- coordinators can pull it out and look at it and have inserts for each issue.
- tool kit
- product is only part of it; the process is often as or more important. Dispelling myths re: what services are provided and how.
- having opportunity to discuss and work together.
- we expect physicians to be up to date but service providers often aren't
- providers who are more aware of services will benefit families– at least those they are in contact with
- descriptions of each program - appropriate referrals to the various services.
- Service Mapping changed referral patterns
- process helps us to have better understanding of issues

#### Challenges:

- who will do the updates - maintenance of the information
- finding all sources of information to include agencies and source of education
- Web site has to be user friendly to both health care professionals and clients/families.
- hard copy vs. website - most families and staff are not fully technology based.
- finding time and web based expertise

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- getting started is difficult
- big role for Alzheimer Societies, taking time from other programming
- very time consuming and inconsistent information from the same organization
- many networks cover both rural and urban – large geographical area to cover
- the process needs to be understandable for consumers – individual, families, caregivers
- multi-cultural focused in large urban centres, i.e. Toronto
- developing a systematic approach to meet the increasing demands for information and access to services.
- one network started with an inventory of services – but it quickly became out of date- abandoned this.
- another challenge is the size of network– how many sectors are included. With more sectors and services, it is more difficult to keep up to date.
- if not current, it is not meaningful
- web-based easier to maintain and update; costs of maintaining and cost to families to access are issues.
- for some networks/issues, need to consider partner with others in order to get things done
- not re-inventing the wheel

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### **Theme H - *Evaluation of Dementia Networks***

- What is the perceived process for evaluating a dementia network and the associated benefits and challenges?

#### **Process:**

- First Link Program – Ottawa - will ask after 3 months how this program is working – will have developed a set of questions.
  - need to clarify whether will evaluate each step or the overall program.
  - will do evaluation in house by dementia network.
- survey
- evaluation of products the DN develop, i.e. driving assessment toolkit
- evaluation of educational events hosted by DN
- will be looking at evaluating how clients come to the Alzheimer Society but at very preliminary stages.
- evaluation re usage of DN website, and ease of usage and how reliable it is
- community consultations with health professionals in local neighborhoods for gaps and information exchange
  - evaluation of consultations and what people learned.
  - evaluation how involved health professionals are
  - evaluation of issues and whether had an impact on MOHLTC decision making
- wondered whether there could be a repository of evaluations done around the province so any community could learn from groups already completed evaluations.

#### **Challenge:**

- has been to identify projects to move forward – “biggest bang” for programming and then think later on about the evaluation.
- conflict between MOHLTC evaluation instrument “imposed” on communities vs. instruments developed at the local level.
- what is meant by “evaluation” of networks
  - the nature of relationships with service delivery vs. client satisfaction.
  - evaluation of a specific intervention vs. the work of the network.

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### **Theme I - Realistic Goal-Setting**

- What are some realistic goals for the first year of a dementia network?
- What are some realistic goals for future years? (i.e., 2 yr, 5 yr, etc.)

Realistic goals for the first year:

- membership confirmation/engaging persons and gaining commitment.
- setting Terms of Reference
- defining 2 project with champions
- define organization and existing linkages with other groups
- develop mailing list of interested parties
- define sub committees/working groups – e.g., education day
- communication strategy
- to form/convene
- decide degree of formality: steering committee; terms of reference; a few meetings
  - low degree of formality to get going– steering committee (coordinating – organizing committee)
- identified tasks/projects to focus on, i.e. early detection, care maps, driving and dementia

Future Years

- web site development
- using literature review and other sources on what we do not know re service delivery to feed into the District Health Council multiyear planning process.
- address gaps through education day
- issue resource guide
- plan for sustainability investigating sources of funding of (Trillium)
- use identification of gaps to plan work for next years.
- clarify roles and responsibility of steering committee
- focus on large representation (geography and sector)
- bringing goals to more narrow focus
- getting task group focused – able to produce something “doable”
- have a key focus: sustainability
- have used physician newsletter, linkage with – “resource MDs in county”, MD mentor, opinion leaders, peer presenters
- need to discuss identify issues connected with use of pharmaceutical companies’ sponsorship
- involved media person on steering committee – changing membership of steering committee
- clarify benefits of having dementia networks
- evaluation of gaps and availability of services
- linking local networks to regional areas (sharing info)
- advocacy/service sharing