

GROWING TOGETHER FOR THE FUTURE

Proceedings from the

Ontario Dementia Network Conference

October 20, 2003

Toronto

Moving Dementia Networks Forward

&

**Provincial Advice to the
Dementia Networks Advisory Committee**

How do we ensure at a local level that Dementia Networks continue to develop, move forward and link?

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Comments from Afternoon Small Group Discussions

Key issues to take back to individual local dementia networks:

- Could other initiatives within the Strategy help the dementia networks?
 - PRCs → having designated people involved in the development and sustainability of the DNs is important. Role of PRC –they continue to play a role in the Dementia Network
 - Challenge with PRCs when not full-time and not helping facilitate DN
 - There is ongoing support to the networks through the positions that have been funded through the Strategy (PRC, PEC)
- Commitment of partnering agencies to be at the table. Projects that are achievable and useful to partner agencies so they see the value and use and need for DN. Project developments be seen as an important role of Dementia Network
 - Providers need to support each other and ideas for supporting clients and their families
 - Linking is easier when links are natural and people have things of value to share
 - We are not alone
 - Open communication is most important thing among network members
 - Need Network participants to be at the level where participants have trust to be honest. Suggest case studies on what went wrong or right can help with this
 - Making sure that all of the relevant people are around the table
 - Continuity is the enthusiasm –it's only as good as the people involved
 - Significant collaboration among specialty groups can be used to engage participation
 - Network can identify priorities and then work to develop something to address the gap and concurrently, can advocate to the ministry for meeting this need (stronger voice together)
 - Must be “community driven” rather than “agency driven”
 - Continue to review membership in the networks – this should be a dynamic process given the changing needs of the community.
- Sharing workload, e.g., co-chairs, minutes, etc.
 - Committee members have to have ownership over the network to keep it going
 - e.g., rotate the co-chair
- Use work groups with specific tasks with interested persons so interest is maintained and workload is distributed and time limited
 - Meeting client needs is different than service providers. Diversity issues can overwhelm some organizations making it difficult to identify leads. Work groups break down tasks – pull in volunteers on an as needed basis
 - How can we get acute care involvement? Groups have hospital representatives but think there is a need for more involvement; work groups/task groups can be used to pull persons in for specific tasks
 - Members willing to do a project; members not willing to meet just to meet—need to do something for the clients
 - People need to see reasons—concrete things—in order to continue—especially at the beginning (later, less concrete outcomes may be alright)
 - Make projects time limited → evaluate what they have done and determine where to go next (e.g., education standards; directory of service)
 - Projects that appeal to different types of people
 - Service mapping
- Sharing – what others have done and concrete resources
 - Networks are at different levels of development
 - Educate ourselves on First Link information and talk about it among our communities

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- Need avenue to share projects and learn from nearby networks or other provincial networks and therefore save money by not reinventing the “program”
- Some things could be coordinated → e.g., use what Toronto has done re inventory of services → pool seed funding
- Build on what already exists in the community
 - Do link to other things that are out there –where there’s some accountability for reporting, etc. (e.g., DHC)
 - Need to look at ways of maximizing existing community partners
 - Insist upon DHC support→ in some networks, the DHCs are not active in the network, while others have provided a lot of support (minutes, etc.)
 - Place the Dementia Network on the agenda of the LTC Committees of the DHC and ensure a LTC health planner sits on the Dementia Network.
 - Question the fact that there are many different networks and groups with similar members and often similar clientele → need to look at how do we coordinate the activities that are happening such as share network plans about specific projects with the various groups—therefore engaging individuals to participate from different groups to work on the specific task
 - Important to keep the continuum as part of the discussion—to strive for
 - Various networks (stroke, cancer, palliative care) have local networks → build awareness of other local networks and look at links to reduce duplication; efficiencies, etc.
 - Inviting researchers to give 15 min. presentations to Dementia Network as way of linking with academics; academics can also be attracted if they see they can make connections with others who might be involved in their research
 - Need to network the networks – how to do this? → By coordination at a higher level?
- Costs – in one network all members agreed to provide some funds from their budgets to support the network at a minimum level
 - Attach network to existing agency with large enough budget to help sustain the program
 - Possible funding source – unrestricted grants from drug companies but this could be limited
 - Look at collaborative resource commitment
 - Ensure Alzheimer Society play lead roles in sustainability of Dementia Network (i.e., extra annual funding to support meeting, travel, admin costs, etc. → \$5000 annually)
 - Ask ASO to advocate for provincial projects funding (i.e., “Driving with Dementia” so not all Alzheimer Societies are each working on the same project)
 - To address funding issues for forums to meet a couple times a year → each agency host whenever possible (gift in kind)
 - Issue is continued funding; sustainability of funding (perhaps link in with CCAC information & funding?)
- Need strong leadership—cannot assume someone will call a meeting
 - Natural leaders need to step forward
 - Need to have someone take a lead to call meetings, etc.
 - Local Alzheimer Society should take the lead as Chair to ensure a good start to the development of a Dementia Network. PRC should also have a key role in the initiative and development of a Dementia Network
 - Important that Alzheimer Society always be front and centre
- Structure –having something consistent
 - Assign terms to Steering Committee to keep new involvement
 - Set-up formal mechanisms with respect to the network to help people feel ownership

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- Have an education piece along with the DN meeting –helps to draw out members; may help increase the number of front line staff (supervisors may be more likely to let staff go because of the education)
- Identify who are the planners and doers
- In developing the work plan, look at what can be done locally and delegated regionally (should there be one) or project done by a group of networks instead of individually.
- Video Conferences – North Network in rural and remote regions are essential to allow key players to participate
- Tailoring agenda to allow for representatives to come and go as they please given limited time
- Do not have to have same ‘membership’ participate on committees
- Other approach keep everyone up-to-date not on committees
- Issues about turf and political issues that cannot be ignored → need to be careful –give lots of thought up front
- Link where appropriate at regional level, provincial level
- Link with other DNs in regions and work regionally
- Establish goals/look at gaps
 - Focus on improved services for clients and caregivers
 - don't overwhelm people with the work
 - bring them in on a piece that they're interested in
 - be realistic
 - Need to look at where we can improve diversity/culture/language
 - Scope of dementia networks – some groups have narrowed focus to keep things manageable, e.g., in Toronto, academic community has yet to be engaged
 - Importance to prioritize what DNs do
- Communication → ask consumer how services are affecting them and this will guide the sustainability issue – what value is the Dementia Network in the local area?
 - Figure out a communication tool and process –this is the key to sustainability
 - Periodically survey through community forums

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Key issues Dementia Networks can advise the Dementia Networks Advisory Committee on:

- DNAC to continue
 - Advisory Committee should identify common issues to be raised provincially
- Linking locally, regionally and provincially – sharing network activities through a website/clearing house of information
 - There needs to be some structural support at the regional or provincial level –at local level, people are struggling (e.g., website –templates to share; database, learning templates
 - Post templates on the website
 - Seriously consider a province-wide service map such as Toronto
 - Website databases → Toronto DN website expanded to province-wide
 - Newsletter available online to facilitate ongoing network links
 - Access to a central knowledge base – core activities how-tos, definitions, care maps from across the province (e.g., members only logon for more sensitive information), tools (e.g., innovative programs)
 - One point person you can call instead of networks having to contact each other (questions may be fairly operational)
 - Helpful to show outcomes of the networks and to illustrate this provincially, and to share with the local areas to show what can be done
 - The inventory of services done by each network, should be done provincially to create an Ontario web page
 - How does it tie into Dementia Knowledge Exchange?
 - Investigate bringing health agencies in the region together to link web sites.
 - Resist the temptation to be overly centralized
- Annual forum for coming together
 - Provincial Networking is helpful.
 - big challenge for the Northern networks to get-together
- Tools for evaluating your network
- Funding
 - Some networks are not moving forward because they do not know how they will sustain themselves after March 31, 2004
 - Lack of \$ for administrative support –resources are limited; hard to find dedicated resources at the local level – these are needed for meeting costs, administrative costs. These may not be dollars but human resources – could this be mandated as part of “roles” eg. PRC; can there be some efficiencies to link networks?
 - Government/ministry backing required →could there be funds if need to hire a support staff –continuity over one additional year or carry funds over if not yet spent?
 - Funding for Cardiac Network to continue but not dementia network, however, some other networks are not funded yet continue
 - Ensure there is continuing funding, in order to ensure existing DNs do not fall apart (i.e., \$5,000 annually to Alzheimer Society Chapters added to base funding), i.e., ongoing support through an education event – organizations will pay to send someone to education
- Networks are struggling between their roles in helping service providers verses helping clients. Not confident that in meeting with service providers they are solving issues for consumers.

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- Risk of overburdening system at local level with dementia network responsibilities – choose to do what's manageable with no additional resources.
- Mechanisms to identify/develop specific common goals amongst all DNs → this could be presented to government
- PRCs play a critical role, need to find ways of maintaining role within the community – may just be participants in some areas, in others they may take a leading role
 - In larger centers, PRCs may not be able to do this on their own – partner with larger organizations
- Expectation by ministry that different organizations should be part of the network (should be included in their service plan)
 - How do we make sure there's a smooth transition at the end of March 2004? Transition to what?
 - More direction [required] than just “carry on, do what you're doing” – every area will be different – leaves organizations the option to back out – if it's important, expectation re which are the key organizations that should continue to be involved (balancing desire to respond to local situation verses avoiding a structure that's too weak) – stronger sense of “who” into the future
 - Need for government support for a sustainable structure, able to identify priorities
 - Bring in regional offices to find mechanisms to link the DNs together
 - Ministry needs to acknowledge the work of agencies – recognition of the agencies that already have played a key role in Dementia Network development
 - Continued DHC support –give DHC an administrative support role at the Dementia Network table (i.e., minute taking, etc.). Ministry recognize in the DHC's operating plan that Dementia Network development/sustainability is the DHC role (as it is another form of planning)
 - Ministry must take a lead role in sustaining DNs –name a provincial lead for anyone in the province to call.
 - PRC role and their sponsoring agency play a designated role in Dementia Network sustainability.
- Provincial projects –advocated by ASO (“don't reinvent the wheel”) i.e., First Link project across Ontario developed on a provincial proposal; and Driving Tool Kit)