HNHB Dementia Networks

Creating a Permanent Memory

Dementia Networks Five Year Plan

Crafted by the HNHB Dementia Networks

October 2007

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HNHB Dementia Networks Five Year Strategic Plan

The HNHB Dementia Network is the collective voice of Dementia Networks located with the Hamilton Niagara Haldimand and Brant Local Health Integrated Network. Together, they provide leadership, coordination and information sharing on programs, client needs and policy issues for clients and families within the continuum of dementia services.

For additional information on the HNHB Dementia Network, please contact:

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Introduction

About the HNHB Dementia Network

The HNHB Dementia Network is the collective voice of Dementia Networks located with the Hamilton Niagara Haldimand and Brant Local Health Integrated Network. Together, they provide leadership, coordination and information sharing on programs, client needs and policy issues for individuals with dementia and families within the continuum of dementia services.

About the Planning Model

The Planning Model used for the network planning day is based up on the work of the Institute of Cultural Affairs. The model consists of the following five key questions:

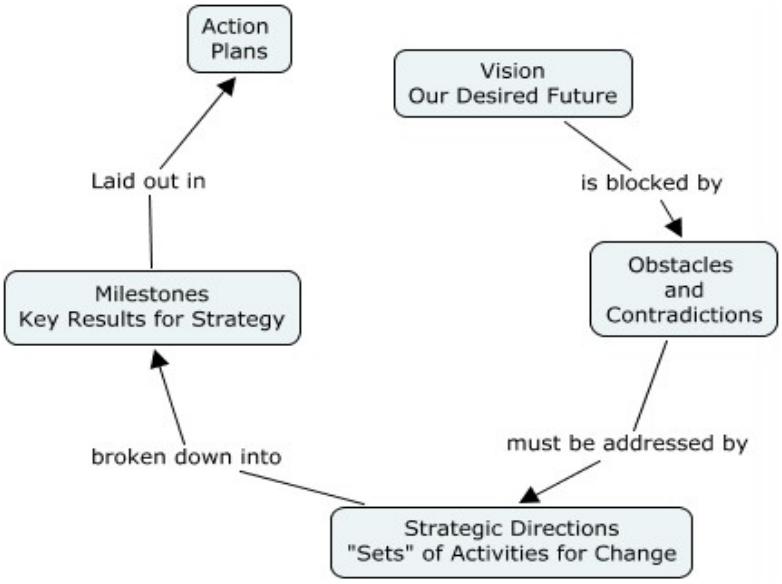

Figure 1 - ToP Facilitated Planning Process

Vision – What is the practical vision for the organization?

Obstacles – What are the current obstacles that block the organizations from achieving the vision?

Strategic Directions – What are the actions that must be taken to address the obstacles?

Milestones – What are the key results that must be achieved over the next three to five years to implement the strategies?

Action Plans – What will be done to implement the first set of Milestones to move the plan into action?

The strategic planning process represents a process designed to enable an organization to move from vision to action through a series of steps. Figure 1 captures the following explanation of the strategic planning process.

The vision outlines the organization's desired future. The future is blocked by obstacles and contradictions that must be addressed by a comprehensive set of strategic directions. The directions are broken down into Milestones which are laid out into action plans so work can begin as soon as possible.

About the Report

The planning report is divided into the following four sections, consistent with our planning framework.

- **Practical Vision** – the vision outlines what will be in place, from a network perspective at the end of five years.
- **Obstacles** – the obstacles represent the real and known barriers that can stop the network from realizing the vision
- **Strategic Directions** – the directions outline where the network will focus its resources to address the barriers.
- **Three Year Outlook** – the outlook provides a road map of what will be completed in each of the next three years to implement the identified strategic directions.

Our Thanks

We would like to thank everyone who participated in our strategic planning day and continued to work on refining the planning document.

Practical Vision

The networks work collectively to ensure services for individuals with dementia and families throughout the HNHBLHIN are coordinated, responsive and reflective of emerging needs. The practical vision provides a snap shot of results the network will see in five years from today. The vision includes:

- A comprehensive education strategy[1] that is recognized for its ability to reach people throughout the region with the information they need to make informed decisions regarding dementia.

- A clear path through the continuum of care that is integrated, easy to understand and accessible for clients and their families.

- A LHIN wide, community centered focus on dementia that enables everyone to clear state, "I know what it is!" when it comes to the topic dementia and its impact.

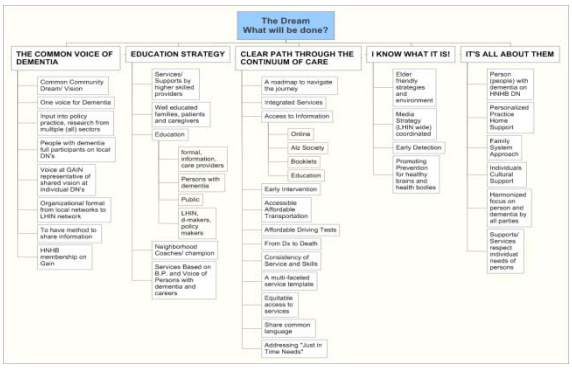

Figure 2 - Vision Chart (See Appendix 1)

- An acknowledgement and ongoing support of the network by others as the common voice of dementia throughout the LHIN

- A public focus on the most important fact about dementia, it's all about them! It is about the people we serve, we know and care about each and every day!

[1] Throughout the document, phases with underlines represent the key consensus points from the planning day. The consensus points are summarized in the tables and charts found in the Appendices.

Obstacles to the Vision

Obstacles represent the barriers and challenges that must be addressed by the network in order to achieve the vision. The network identified the following obstacles that block the network at the present time.

- The network has <u>inadequate resources to sustain services or address emerging needs</u> in the community.

  The network is a collection of networks consisting of organizations working together to coordinate existing services within the community. Resources consist of people, funding, knowledge and equipment to support services. The growing demand for services coupled with competition for limited resources continues to create a limit on the existing resources. The current inventory of resources is far less than the demand for services.

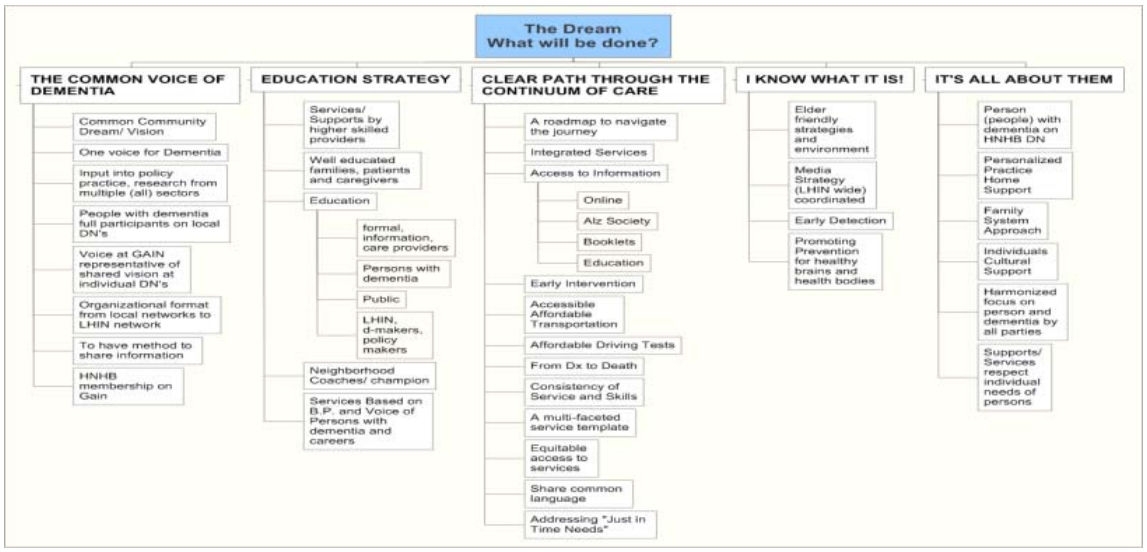

Figure 3 - Obstacles to the Vision (Appendix 2)

- <u>Important information is not reaching the full audience which makes it hard for people to make decisions about care.</u>

  It is very important that people have access to the correct information about dementia in a timely manner. However, there is inconsistency in the information provided coupled with the inability to reach the diverse and complex communities throughout the LHIN. In most cases, important and timely information is not reaching people.

- The disease is not recognized or acknowledged as a critical issue in society or for policy makers.

  Recognition of the disease is a problem. There is a fair amount of stigma and denial associated with dementia. The inability of everyone to recognize dementia as a chronic disease and its impact on individuals, families, communities and the economy make it hard to create focus and support for programs in the community.

- There is no shared leadership or coordination of the care continuum/ system.

  A wide variety of organizations and agencies are working throughout the community to provide services to clients. Yet, there is limited coordination of the "system" to ensure clients[2] obtain the services they need in a timely manner. Instead, coordination is left to agencies, providers and individuals to coordinate on an ad hoc basis.

- Silos and pockets of care make it hard for clients to get a full care experience in the community.

  Care is inconsistent throughout the LHIN area. The level of care and type of care is dependant on the organization, available resources and programs offered. Inconsistent care creates challenges and hardships for individuals seeking the best quality of services for themselves and/or family members. Excellent service options in one area can and do appear as inequality of limited access to services in another area of the HNHBLHIN.

- Individuals with dementia and caregivers are challenged to obtain timely services.

  Individuals and caregivers can be overwhelmed when trying to find the right services at the right time in a system that is hard to navigate. The system is not "user friendly" or easy to understand for people who need access to current information and services.

[2] Clients are the individual, natural caregivers (neighbour, church member), families

Strategic Directions

The HNHB Network identified four key strategic directions to address the barriers and ensure the vision can be realized in five years.

Direction: Effective and Early Intervention

The network will focus on promoting and communicating the importance of intervention to ensure everyone in HNHBLHIN has access to information and services in a timely manner.

Direction: Common Education Strategy

The network will focus on building a shared framework for local education to support access to information and services at the community level. Our will work will support creating a knowledge and understanding with policy leadership on how to use education to make a significant

difference in the lives of people living with dementia.

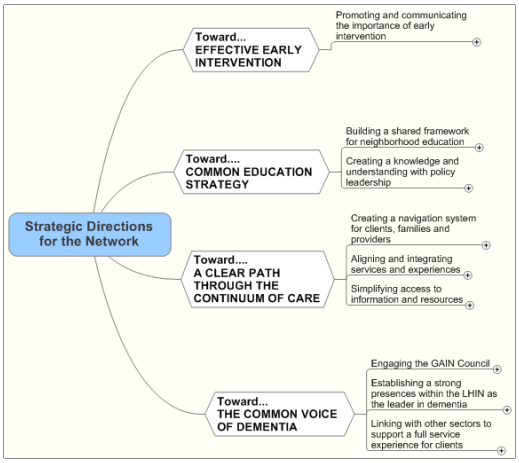

Figure 4 - Strategic Directions (See Appendix 3)

Direction: A Clear Path through the Continuum of Care

The network will focus on creating a navigation system for individuals with dementia, families and providers to work together as a system. Our work will encourage aligning and integrating services and experiences and simplifying access to information and services.

Direction: The Common Voice of Dementia

The network will focus on engaging the GAIN to support ongoing work for everyone within the LHIN. Our tasks will include establishing a strong presence within the LHIN as the leader in dementia as well as linking with other sectors to support full service experience for clients.

Three Year Outlook

The Three Year Outlook Table is under construction. It is anticipated the table will be completed and released in early January 2008.

Strategic Direction and Strategy	Time Frame			Anticipated Results
	07/08	08/09	09/10	

Figure 5 - Three Year Outlook Table

Continuing the Planning Journey

The networks will continue work on the plan.

In the coming months, work will focus on building a three year outlook to support the identified strategic directions.

For additional information on the work of the networks or how to get involved, please contact:

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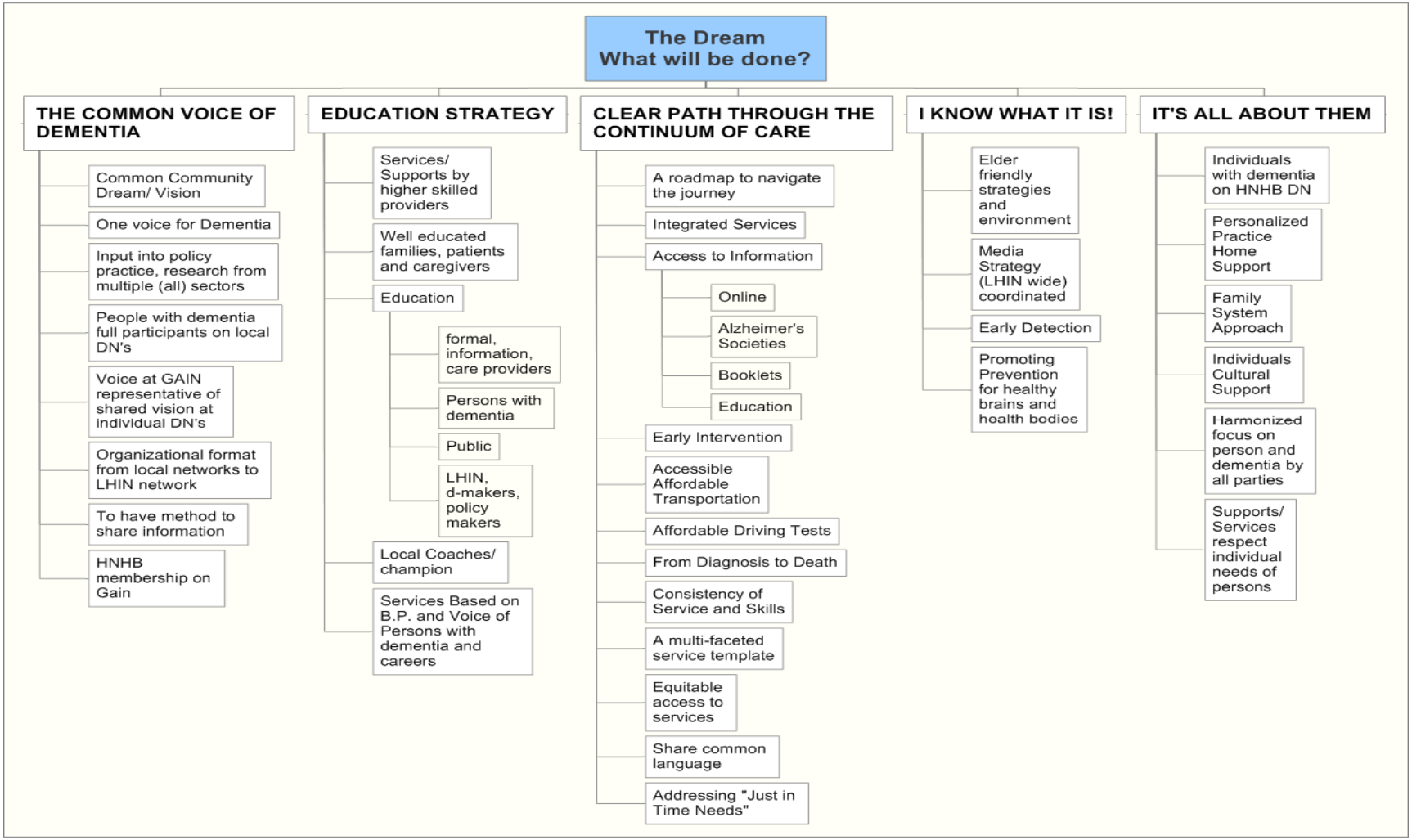
File Reference:

C:\Documents and Settings\Jerry\My Documents\My Maps\DementiaNetwork\StrategicPlanningReport_DementiaNetwork_FinalReport2.docx

Facilitated by The Desk, Solutions for Strategic Questions

Appendix 1 – Practical Vision



THE COMMON VOICE OF DEMENTIA

- Common Community Dream/ Vision
- One voice for Dementia
- Input into policy practice, research from multiple (all) sectors
- People with dementia full participants on local DN's
- Voice at GAIN representative of shared vision at individual DN's
- Organizational format from local networks to LHIN network
- To have method to share information
- HNHB membership on Gain

EDUCATION STRATEGY

- Services/ Supports by highly skilled providers
- Well educated families, individuals with dementia and caregivers
- Education
- formal, information, care providers
- Public
- LHIN, decision makers, policy makers
- Local Coaches/ champions
- Services based on Best Practices and voice of individuals with dementia and carers

CLEAR PATH THROUGH THE CONTINUUM OF CARE

- A roadmap to navigate the journey
- Integrated Services
- Access to Information
- Online
- Alzheimer's Societies
- Booklets
- Education
- Early Intervention

- Accessible Affordable Transportation
- Affordable Driving Tests
- From Diagnosis to Death
- Consistency of Service and Skills
- A multi-faceted service template[3]
- Equitable access to services
- Share common language
- Addressing "Just in Time Needs"

I KNOW WHAT IT IS!

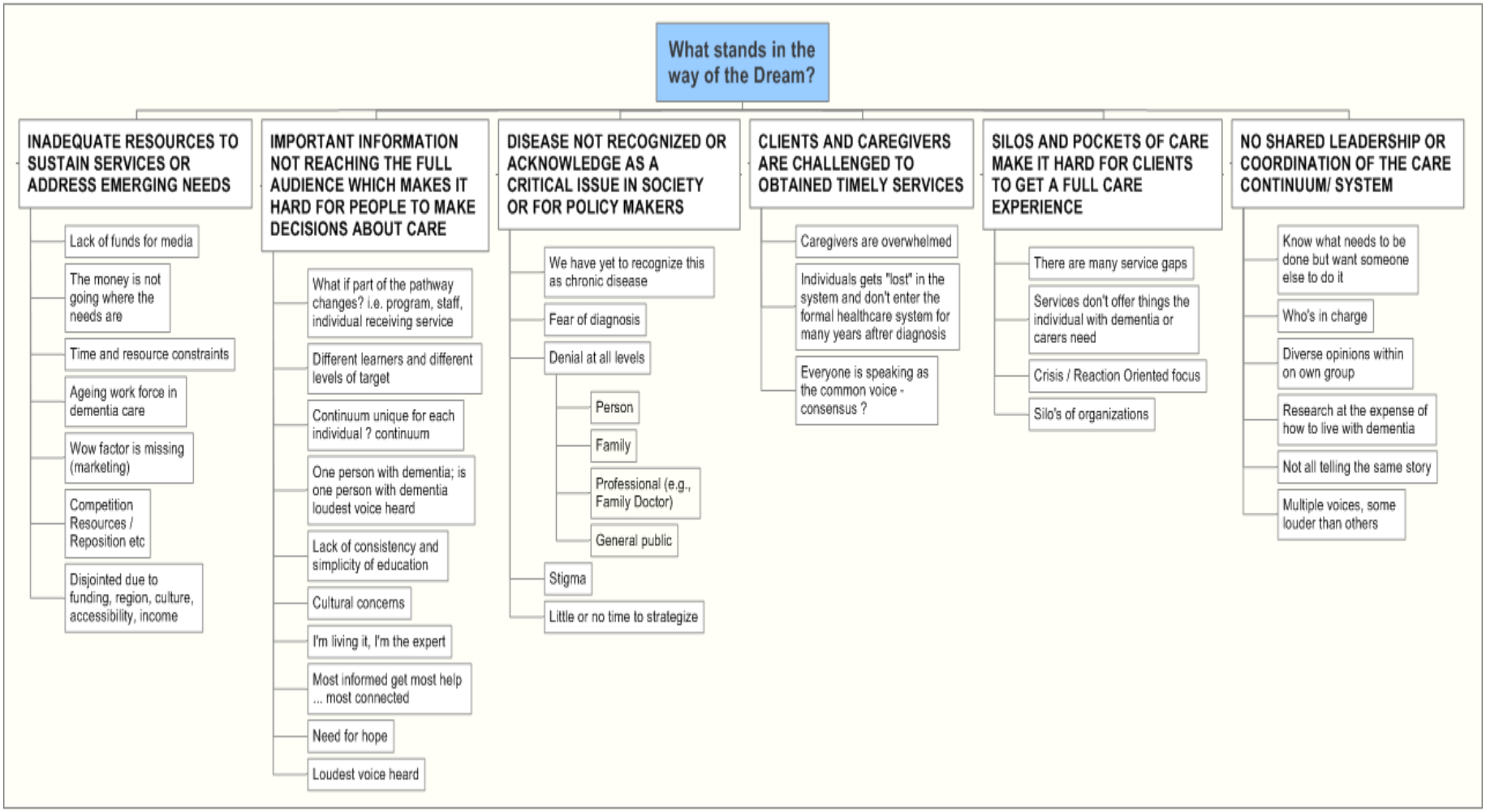
- Elder friendly strategies and environment
- Media Strategy (LHIN wide) coordinated
- Early Detection
- Promoting Prevention for healthy brains and healthy bodies

IT'S ALL ABOUT THEM

- Individuals with dementia on HNHB DN
- Personalized Practice Home Support
- Family System Approach
- Identifying Cultural Supports
- Harmonized focus on individual and dementia by all parties
- Supports/ Services respect individual needs of persons

[3] Consideration should also be given to inclusion on service templates across all sectors

Appendix 2 - Obstacles



INADEQUATE RESOURCES TO SUSTAIN SERVICES OR ADDRESS EMERGING NEEDS

- Lack of funds for media
- The money is not going where the needs are
- Time and resource constraints
- Ageing work force in dementia care
- Wow factor is missing (marketing)
- Competition for Resources / RFP's etc
- Disjointed due to funding, region[4], culture, accessibility, income

IMPORTANT INFORMATION NOT REACHING THE FULL AUDIENCE WHICH MAKES IT HARD FOR PEOPLE TO MAKE DECISIONS ABOUT CARE

- What if part of the pathway changes? i.e. program, staff, individual receiving service
- Different learners and different levels of target
- Continuum unique for each individual
- One person with dementia is one person with dementia
- Loudest voice heard
- Lack of consistency and simplicity of education
- Cultural concerns
- I'm living it, I'm the expert
- Most informed get most help ... most connected
- Need for hope

DISEASE NOT RECOGNIZED OR ACKNOWLEDGE AS A CRITICAL ISSUE IN SOCIETY OR FOR POLICY MAKERS

- We have yet to recognize this as chronic disease
- Fear of diagnosis
- Denial at all levels

[4] Region also incorporates the size of the LHIN

- Person
- Family
- Professionals (e.g., Family Doctor)
- General public
- Stigma
- Little or no time to strategize

CLIENTS AND CAREGIVERS ARE CHALLENGED TO OBTAINED TIMELY SERVICES

- Caregivers are overwhelmed
- Individuals gets "lost" in the system and don't enter the formal healthcare system for many years after diagnosis
- Everyone is speaking as the common voice - consensus?

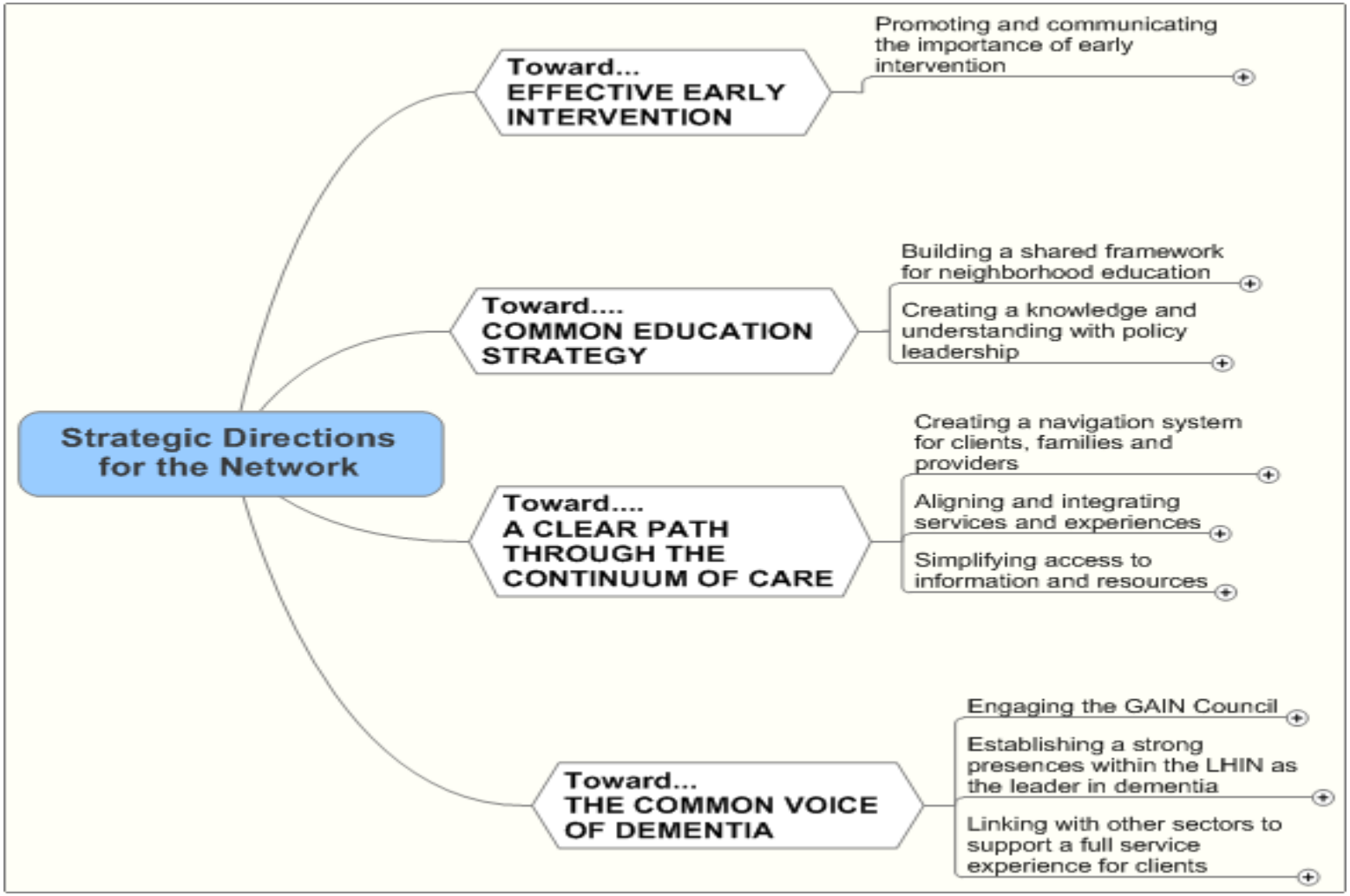
SILOS AND POCKETS OF CARE MAKE IT HARD FOR CLIENTS TO GET A FULL CARE EXPERIENCE

- There are many service gaps
- Services don't offer things the individual with dementia or carers need
- Crisis / Reaction Oriented focus
- Silos of organizations

NO SHARED LEADERSHIP OR COORDINATION OF THE CARE CONTINUUM/ SYSTEM

- Know what needs to be done but want someone else to do it
- Who's in charge
- Diverse opinions within our own group
- Research at the expense of how to live with dementia
- Not all telling the same story
- Multiple voices, some louder than others

Appendix 3 - Strategic Directions



Toward… EFFECTIVE EARLY INTERVENTION

Promoting and communicating the importance of early intervention

- Access to full spectrum supports
- Eliminate boundaries and restrictions
- From DX to death
- One point referral information site(such as First Link)[5]
- Equitable access to services
- Addressing "Just in Time" Needs

Toward…. COMMON EDUCATION STRATEGY

Building a shared framework for local education

- Local coaches/champions
- Well educated families, individuals with dementia and caregivers
- individuals with dementia and their families
- Services based on Best Practices and Voice of Individuals with dementia and carers
- Services/ supports by highly skilled providers
- Skills = Knowledge

Creating a knowledge and understanding with policy leadership

- LHIN decision makers, policy makers
- Education
- Public
- informal and natural care providers

[5] First Link is being funded at 8 sites across the province

Toward…. A CLEAR PATH THROUGH THE CONTINUUM OF CARE

Creating a navigation system for clients, families and providers

- A roadmap to navigate the journey

Aligning and integrating services and experiences

- Consistency of service and skills
- Multifaceted service template
- Integrated services
- Respite Care: Plan it, Do it, Feel It

Simplifying access to information and resources

- Online,
- AKE (Alzheimer Knowledge Exchange)
- SHRTN(Seniors Health Research Transfer Network)
- Booklets
- CCAC information
- Newspaper, media etc
- Alzheimer Societies
- Education institutions
- Health care facilities

Toward… THE COMMON VOICE OF DEMENTIA

Engaging the GAIN Council

- Membership on GAIN
- Voice at GAIN - representative of shared vision at individual DN's
- One voice for dementia

Establishing a strong presence within the HNHBLHIN as the leader in dementia

- Organizational format from local networks to LHIN network
- Common community dream/vision
- Share common language
- Individuals with dementia full participants on local DN's
- input into policy, practice, research from multiple (all) sectors
- To have a method to share information

Linking with other sectors to support a full service experience for clients

- Accessible affordable transportation
- Affordable Driving Tests
- Affordable treatment