



**Addressing Health System Navigation
Challenges in Ontario:
A Position Paper**

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“ Home care is the lynchpin in our plan for health care. We will be counting on CCACs not only to continue doing the great work you have been doing, but to persistently push yourselves to do even better to deliver to Ontarians the care that they need.”

The Honourable George Smitherman
Ontario Minister of Health and Long-Term Care
June 6, 2005

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EXECUTIVE SUMMARY

The determination of the Government of Ontario to transform the Ontario health care system represents an opportunity for all health care providers to collectively improve the standard and the operation of health care services in the province. Current weaknesses in the alignment of programs and services have made it difficult for some system users to locate and secure the services they require in a timely manner. While the introduction of programs such as the Ontario Health Line are helpful, they do not eliminate the need for continuous improvement in the ease of navigating Ontario's health care system.

The intent of this paper is to examine Ontario's system navigation function, and to identify enhanced roles for CCACs and their partners in its execution. Presently, the concept of system navigation is benefiting from wide discussion. It has particular relevancy in light of the provincial direction to communities to integrate regionally, and to plan and coordinate the delivery of local services more effectively and efficiently.

In Ontario, some 46 per cent of gross revenue is directed at the provision of health care services for 12.4 million people. While widely admired, system-wide weaknesses in the formal connections among service providers remain a characteristic of the current system. In spite of the existence of formal or informal associative agreements or practices, individual medical practices in primary care, large multi-site hospital systems, municipally operated public health departments and neighborhood-based community support organizations are all structured and operated primarily as independent entities.

At the core of the ongoing health transformation agenda is an initiative to regionalize the planning, coordination and funding of services. The creation of 14 geographically based Local Health Integration Networks (LHINs) is intended to bring clarity, simplicity, cost containment and a customer-centric approach to the user-friendly accessing and navigation of these services. While integration initiatives will redefine geographical boundaries and should reduce the number of points of user entry, system navigation remains a challenge.

In 1997, local home care programs and placement services were combined to form Community Care Access Centres, serving as the single point of entry organization both for home care and facility services, and providing health services information. Fundamental to the role of CCACs is an imperative to establish working relationships and partnerships across the wide health care system. Over an eight-year existence, CCACs have initiated many new coordination projects. Positive working relationships have been forged among CCACs, their local hospitals, health departments, community organizations and local long-term care facilities. CCACs believe that, through new or enhanced partnerships, they can contribute significantly to the transformation process, and help build a foundation on which the navigation issue can be successfully addressed.

System navigation is a function of case management, and there are very few references in the literature which discuss the concept outside of a program context. In a paper developed in 2003, an Ontario source described five inter related functions, which were

present in all navigation services and programs reviewed. They are: single point of access, information and referral, linking, coordination and education. After almost eight years of experience in 42 Ontario locations, CCACs have introduced a number of initiatives which have successfully alleviated the pressures on clients and families to find the right service in the right location in a timely manner. Many CCACs have developed specialized teams with reduced caseloads to enable case managers to assist clients in navigating a highly complex system. Case managers also provide a service coordination function for comprehensive action plans involving a variety of service providers. As case manager specialists, they have developed a comprehensive knowledge of services available in each silo and across silos. This knowledge is the key to the development and implementation of a successful action plan.

Based on a review of programs in several provinces, it appears that navigation challenges are being addressed, and that system navigation is not a health system issue. Manitoba and Saskatchewan, for example, have a central point of access to community care with sufficient information and case management capacity to direct and support people to locate required services. Within a provincial framework that includes regional health authorities or districts, there is defined point of access and a direct link to other health and community services. Experience indicates that defined points of access like these tend to lessen the need for navigation assistance.

In undertaking the establishment of LHINs, the Ontario government recognized that “the individual Ontarian must navigate a system that has numerous unaligned programs and services.” Fourteen single day facilitated workshops were held in the fall of 2004 to begin the local LHIN planning process and to prepare a report for the Ministry of Health and Long-Term Care. It is clear from a review of these reports that system navigation and its related elements are concerns for all LHIN planning groups. Many of the LHIN reports contain specific initiatives to address system navigation. It is important that CCACs work with their service partners to advance such improvements.

Some current assumptions assert that a better organized health delivery system or readily available information and education may alleviate the need for assisted navigation. Others believe that well developed care paths and disease management programs will alleviate the need. While all of these efforts may have a significant impact on navigation needs, they will require substantial time to develop, implement and test. Furthermore, what works in one jurisdiction or geographical area may not be appropriate in another.

This paper has attempted to add to the understanding of the health navigation challenges in Ontario as it transforms its health care system. Clearly, there are outstanding access and disease management issues, as well as a need for comprehensive strategies for specific populations. New developments in each of these areas will contribute to the alleviation of current navigation challenges. With the assistance and cooperation of partners and support from the Ministry of Health and Long-Term Care, CCACs and their partners are well positioned to introduce key navigation initiatives within a short time frame, having an immediate and positive impact.

The report recommends the following six actions:

- Improve system access by expanding the CCAC information and referral function;
- Introduce and include CCAC case managers in Family Health Teams;
- Merge the roles of hospital discharge planner and CCAC hospital case manager;
- Initiate planning processes among partners to develop disease management strategies;
- Advocate for the development of province-wide health strategies for sub populations;
- and
- Initiate a process to develop evidence- based best practices for all these initiatives.

1.0 INTRODUCTION

The commitment of the Government of Ontario to health system transformation is an opportunity for all health care providers to utilize their collective experiences to improve health care in the province. The current weakness in the alignment of programs and services has made it difficult for some individuals and families to locate and secure the services that they require in a timely manner.

The introduction of new programs such as the Ontario Health Line has been helpful, but these innovations have compounded, not eliminated, the need for help in navigating the system. The issue has a particular relevancy as the provincial government directs communities to integrate regionally, and to plan and coordinate the delivery of local services more effectively and efficiently.

The concept of health system navigation is a familiar one to Community Care Access Centres (CCACs) across Ontario. As case managers for more than 500,000 individuals each year, CCACs are first-hand witnesses to the challenges of system navigation, and have worked independently and with partners to overcome system navigation challenges.

Nonetheless, there is much more that can be done. In order to serve as a catalyst for further action, Ontario's 42 CCACs and their association have commissioned this paper. Its intent is to examine the system navigation function and identify enhanced roles for CCACs and its partners in its execution. It also defines navigation in an Ontario context, explores it conceptually, and discusses who requires it and who delivers it. It also proposes how CCACs can help directly in addressing navigation challenges.

2.0 SUPPORTING THE CASE FOR SYSTEM TRANSFORMATION

2.1 Background

Canada's publicly funded health system is the envy of many. Universal availability and access to emergency and acute care, primary care, treatment and rehabilitation, home care, disease management, and long term care is beyond the dream of most of the world's people. While issues such as wait times will always emerge, Canada's publicly funded, single tier system is admired world wide.

In Ontario, 46 per cent of gross public revenue is directed to health care services for 12.4 million people. In so doing, Ontario provides health services in a comprehensive service continuum for more people than any other jurisdiction in North America. Nonetheless, a key characteristic of the system is a weakness in the connection among service providers. Individual medical practices in primary care, large multi site hospital systems, municipally operated public health departments and neighborhood-based small community support organizations all are structured and operated primarily as independent entities.

A decade ago, the government characterized the community based system as fragmented and in need of reform. This analysis resulted in projects in the community sector, in mental health, in cancer services, and in the restructuring of the hospital sector. In some sectors, there were multiple reform projects. In addition, the Ontario government initiated its largest expansion of institutional long-term care. This period of change resulted in significant system restructuring and a substantial increase in system complexity. New sector specific structures were also created, such as acute hospital networks, rehabilitation, cardiac and children's health networks, and an integrating agency for cancer care. While each of these was considered to be necessary as a means of improving service, the increased complexity has resulted in greater difficulty for people to access the right services in the right place at the right time.

The current government has given considerable attention to this challenge. It has set upon a path of health system transformation. At the core of the transformation is a major initiative to regionalize the planning, coordination and funding of services. It has also embarked on the reorganization of primary care with a vision that a new primary care system will provide a gatekeeper role – a door of entry to the health care system. Central to the success of this role is a capacity to facilitate and direct patients to the right care/service in the right place at the right time. The creation of 14 geographically based Local Health Integration Networks (LHINs) is intended to bring clarity, simplicity and cost containment to the problem of accessing services. Integration initiatives with redefined geographical boundaries should assist in reducing the number of points of entry. Improved connections among provider organizations should alleviate some of the complexity that makes access so difficult for so many. Most importantly, the government's commitment to using technology as the tool to cut through this complexity should positively impact most change efforts.

2.2 The Community Care Access Centre Perspective

Initiated in 1997, CCACs were a sector-specific reform that merged local home care programs and placement services to form a single point of entry organization both for in-home care and facility services; it also provided information on health services. Local CCACs built upon the successes of predecessor home care and placement programs. As independent entities, they began working locally with providers across the system. New coordination initiatives emerged, many of which were initiated by CCACs. Positive working relationships were forged between CCACs and their local hospitals, health departments, community organizations and long term care facilities. These experiences became the foundation for the successful health system responses to critical issues like the SARS outbreak in 2002. In addition, CCACs formed their own provincial association as an enabler to work together and with other sectors on a province wide basis. Serving more than 500,000 people per year, CCACs are among the first to identify the trends and the challenges faced by Ontario citizens in this quickly evolving and highly complex environment.

In part, the successes of the CCAC sector over the past eight years can be attributed to their readiness to seek out opportunities to coordinate services across the system. Too often, CCAC case managers are assigned clients who are not receiving the services they require because the system is just too complex to be navigated. The coordination of services across health sectors is a primary function of CCAC case managers. Front line frustrations and challenges frequently resulted in CCAC leaders advocating for innovations that create greater integration and coordination.

The CCAC sector welcomes the initiative of the provincial government to address the challenges of a health system “that has numerous unaligned programs and services”¹. It welcomes the goal of a more patient-centred system. It shares the vision of the creation of a truly integrated health system. It looks forward to the opportunities to work with the new LHINs and with Ministry staff to bring such a new health care vision to life.

The issue for this paper is not to address the work that will be undertaken by each of the LHINs. Rather, it is to raise concern and constructive options for addressing the system and client navigational challenges as quickly as possible. What can be done in the short term to alleviate the barriers for Ontario’s citizens to access the right services in the right place at the right time? CCACs believe that they can contribute significantly to alleviating these barriers and to building a foundation upon which LHINs can help address the navigation issue in the longer term.

¹ Ontario Ministry of Health and Long Term Care (October 2004). “Local Health Integration Networks-Bulletin No. 1”, p. 4

3.0 CASE MANAGEMENT, SYSTEM NAVIGATION, SYSTEM TRANSFORMATION

3.1 Case Management

3.1.1 Definition

In the summer of 2004, the OACCAC contracted with health policy expert and author Carol Kushner to prepare a discussion paper to facilitate the further evolution of CCAC case management². Kushner started from a single definition, but found several. Her paper makes reference to three. The earliest was found in a 1981 American legislative source. Case management there is defined as “the coordination of a specified group of services for a specified group of individuals.” The Ontario Association of Case Managers developed its own definition in 1999: “Case management is a collaborative service consisting of inter-related processes to support clients in their efforts to achieve optimal health and independence in a complex health, social and fiscal environment.”³ Kushner also referred to a definition found in an OACCAC discussion paper in which the focus is more sector-specific and includes an emphasis on managing resources and support for self care.

While the CCAC mandate includes case management, many other service providers consider it to be a function of their own role. Family physicians, hospital and community nurses, mental health workers, agencies serving those with chronic diseases and community workers ... all provide elements of case management. Recent reports from many of these groups make reference to the case manager function as their own.

3.1.2: Who Does Case Management?

The delivery of a health care service is not a single event. Most often it involves an action that requires follow up. Once a practitioner engages in multiple contacts with an individual regarding a single episode, he or she may refer to this as case management. Family physicians engage in case management as they assess, monitor, and treat their patients both with acute and chronic illnesses. Hospital admitting physicians and nurse case coordinators who ensure that all of the required services are administered at the right time during a hospital stay consider themselves to be managing cases. Some hospitals have created a new role of Case Manager to ensure patients with complex circumstances move as quickly to discharge as possible. Organizations with special focus, be it mental health, cancer or a chronic debilitating illness, also employ case managers.

For many years a debate has taken place among home care service providers as to who should best serve in a case manager role. In fact, recent papers from both RNAO and

² OACCAC (September 2004). “Reviewing the Case for Case Management: A Discussion Paper” prepared by Carol Kushner

³Ibid. 2

OCSA make reference to their role as case managers. In a recent submission to the Managed Competition Review, the Ontario Community Support Organization takes the position that, in a home care context, the “assessment and care management role” be the responsibility of service providers.⁴ In an RNAO submission of March 7, 2005, the same review group recommends that the case management role now carried by CCACs “be performed by an RN from the provider organization in a care provider role”⁵. In addition, the vision developed for Family Health Teams⁶ by the Ontario government includes the role of case management.

3.1.3 Case Management Functions

Kushner does not spent time trying sort out ownership issues. Instead, she makes reference to the role and function of case management as it is being carried out across the CCAC system. The roles identified may not be specific to each case manager in every CCAC, but it is a comprehensive list of functions which serves to define it. The roles are:

Identification and Engagement;
Assessment, Service Planning and Goal Setting;
Accessing Resources and Linking; Implementation and Coordination;
Monitoring and Reassessment;
Evaluation of Outcome; and
Discharge.

Her paper also refers to various models of case management and to the work of others who have articulated the special skills of a case manager. There are also important references to initiatives with special populations where case management has been effective.

3.1.4 Other References

Other authors make reference to a case management process being necessary to administer effective care to those in the community with chronic conditions. Programs to support those with chronic disease, the elderly, and those with disabilities have used case management models to address the needs of their respective populations. More recently, programs with greater emphasis on long-term case management have resulted in the reduced use of more costly health interventions. While the literature does not provide a great deal of evidence regarding the impact of case management, jurisdictions are developing new programs and services in which case manager functions have become a critical component.

⁴ Ontario Community Support Association (February 2005) “Submission to the ‘Managed Competition Review’ ”p.12

⁵ Registered Nurses’ Association of Ontario (March 2005) ”RNAO Submission to CCAC Procurement Review”.p.19

⁶ Ontario Ministry of Health and Long Term Care (October 2004). “Introduction to Family Health Teams”.p.1

3.2 System Navigation

The term “system navigation” is not a concept that typically finds definition in the sector literature. In a 2002 Health Canada report entitled *Investigation and Assessment of the Navigator Role in Meeting the Information Needs of Women with Breast Cancer in Canada*, a thorough literature search of some 4000 references found very few references to the role of a patient navigator. The role of a navigator was described, but was most often “associated with medical technological procedures, with the exception of the patient navigator, which was related to breast cancer screening in under serviced populations.”⁷ Rather than the term “navigator”, authors made reference to a clinical care coordinator or a case manager and to the need for coordinated care, continuity of care, improved communication and much improved information. There are also references to the desire to have care managed and to the need for assistance to navigate complex health care systems for cancer patients, but formal references to navigation services were limited. Instead, there were many references to what might be considered to be navigation assistance in program descriptions and discussions of case management.

For the informed individual with a presenting problem for which a response is available, information serves as the bridge. In jurisdictions where health services are organized into large health authorities, this type of information is readily available. Access points are also well known. For those with special needs, information is not readily available. In addition, these populations often need more than information. It is important to note that the failure of existing structures to address the needs of these special populations has frequently resulted in the establishment of specialized programs such as cancer care that include a navigation component.

The concept of navigation in a human services context is evolving. It has been difficult to find material in the literature which discusses the concept outside of a program context. In 2003 paper, prepared for the Durham, Haliburton, Kawartha, and Pine Ridge and the Simcoe York District Health Councils, Louise Pope reviewed several programs in Canada in which navigation is a key component. However, all were embedded in generic services or targeted programs.⁸ The author did extrapolate five inter related functions which were present in all services and programs. They are:

Single point of access;
Information and referral;
Linking;
Coordination; and
Education.

It is important to note that all of these activities are contained within Kushner’s list of case management functions.

⁷ Health Canada (2002): “Investigation and Assessment of the Navigator Role In Meeting the Information Needs of Women with Breast Cancer in Canada”.p.4

⁸ Pope, L. (November 2003) “Report on Health System Navigation Models”

3.2.1 Navigation Issues in Other Canadian Jurisdictions

Based a review of programs in several provinces, it appears that navigation challenges are being addressed and that system navigation is not a health system issue. The likely reason for this is that many Canadian jurisdictions do have a central point of access to community care with sufficient information and case management capacity to direct and support people to locate required services. Within a provincial framework that includes regional health authorities or districts, there is a defined point of access and a direct link to other health and community services. Often, within one community, both the access point for community health and other human services are located in the same building or office. In Quebec, the local CLSC is the access point for both health and social services. The Saskatoon Health Region and the Winnipeg Regional Health authority offer two examples.

The Saskatoon Health Region provides a full range of health services, including hospital care, primary health centres, emergency response, supportive care, long term care, home care, community support services, public health, mental health and rehabilitation services to a population of 300,000 living in 100 cities, towns, villages and First Nation communities. It also provides tertiary care for anyone living in Saskatchewan. Client Patient Access Services (CPAS) is the Health Region's single access point and provides information and service access to a full range of community services. Case management is delivered in two ways. Client care coordinators serve as hospital discharge planners and also as case managers once their patients are discharged. Community coordinators provide services to community referrals and inquiries. While supporting independence is a goal, there is no limitation as to how long a case manager may be involved with clients.

The Winnipeg Regional Health Authority (WRHA) provides health care services to 650,000 people. The description of their services is much the same as those of the Saskatoon Health Region. Recently, the WRHA has entered into a joint access program with the department responsible for family services and supportive housing. The Community Access Model provides a single access point for health, social service and housing services. The program is being implemented at each of the 12 community area sites. "The model represents a shift from a program based organizational model to an integrated, neighborhood team structure."⁹ There is an expectation that WRHA and Family Services and Housing (FSH) will co-locate within each of the geographical areas. The program is described as follows: "Citizens are able to obtain information about a full range of services offered by both partners through in-person contact with a service navigator, which may be supplemented by written and electronic information."¹⁰ The role of the service navigator is to appropriately access presenting needs, be knowledgeable about the full range of services, to make referrals and arrange for appointments with the appropriate program specialist or intake worker for any of the services covered by the

⁹ Winnipeg Regional Health Authority web site (2004). The Winnipeg Integrated Services Initiative: The Conceptual Framework.

¹⁰ Ibid.

sponsors. There are also ongoing expectations about ‘participation in the community network of services and the interdisciplinary service teams’.¹¹

With operational responsibilities at the health district level, many provincial departments of health have developed navigation initiatives to be employed province wide. Cancer Care Nova Scotia’s Patient Navigation Program and the Chronic Care Management strategy in British Columbia offer two examples.

Cancer Care Nova Scotia has implemented a patient navigation program “to address a wide range of physical, social emotional, and practical needs”¹². The program was developed because cancer patients were finding it difficult to navigate the cancer system maze. The program uses the disease trajectory and determines the needs of clients and families from diagnosis to cure or to death. The role of the navigator is to support families and act as the linkage between the family and the cancer system. Their role includes providing information, and serving as case manager, counselor and liaison/advocate for as long as the family requests the service. An additional component was added to the program to address the special needs of diverse communities. The program employs community liaisons to work these communities.

In British Columbia, a chronic care management framework has been developed that has a broad prevention/ health promotion strategy as well as a program approach to the management of specific diseases. These disease management programs have multidisciplinary teams addressing client needs on a medium to long term basis. This model is based upon the chronic care model developed in the United States and endorsed by the World Health Organization. The National Health Service in the United Kingdom has developed a National Services Framework for Older People, a comprehensive set of programs and services to ensure the elderly receive the “right care in the right place at the right time”¹³. Again the approach includes the use of a multidisciplinary team, known as the Change Agent Team, serving a local population with special needs.

3.2.2 System Navigation in Ontario

The issue of system navigation as it presents itself in Ontario is unique among provincial and territorial jurisdictions across Canada.

In the absence of a single regional health structure, access to services is gained at several points. When CCACs were first established, the creation of a single access point was a primary goal. Despite successful partnerships in local communities across Ontario, there remain multiple entry points with different roles and different information. For example, hospital discharge planners focus on the immediate issue of discharge arrangements. While there is often a CCAC case manager at the hospital site, the focus of their work is to arrange for services upon discharge. Patients who are viewed by the treatment team as

¹¹ Ibid.

¹² Cancer Care Nova Scotia web site (2004). Patient Navigation.p.1

¹³ National Health Service United Kingdom (2004).”Changing Times: Improving Services for Older People.” P.4

not requiring in-home services are not referred to the CCAC hospital case manager. The medium and longer-term needs of the discharged hospital patient are not a priority. For this group, when the need arises, they must navigate the system on their own. The same situation arises when new health needs emerge in people being served by a single service community-based agency. The workers may engage the family physician or encourage the client to go to the emergency service at the local hospital. There, the problem will be addressed on an acute basis independent of those community service providers and significant others. Again, any further action becomes the responsibility of the client. For a person of advancing age or with a chronic disease or a family with a seriously ill child, this can be particularly difficult.

With the exception of Ontario, all jurisdictions in Canada are served by regional health organizations that have in place single governing bodies for a range of local and regional health services. While the governance arrangement itself is not directly responsible for alleviating system navigation challenges, it is responsible for locating and accessing the most efficient and effective approaches to the delivery of health care. Maintaining a system of multiple organizations with separate governing structures allows for competing priorities and conflicting strategic directions and can create navigation challenges. The very nature of the structure of a health system can either alleviate or contribute to the navigation challenges of its users.

As referred to, the Ontario Ministry of Health and Long-Term Care has recognized the confusion and challenges faced by many Ontarians and has initiated a health transformation process in which the development of regional structures is a key. In the fall of 2004, the Minister announced his intention to establish 14 Local Health Integration Networks (LHINs). The new LHINs are expected to work with local health care providers to create new structures and programs to alleviate some of these challenges.

3.2.3 Human Services Connections

The focus of this paper is limited to navigation within and across the health care system in Ontario. It does not address the multitude of social service, housing, educational, and recreational services that are used by many health system clients. In fact, health status is more often linked directly to income, housing and lifestyle than to the availability of health care. In addition, recovery and disease management is dependent on social and community supports. In the absence of the availability of a full range of human services, a health system becomes dysfunctional. Making the necessary links with other providers is often the greatest challenge for many clients. Any strategic or programmatic responses to the challenges of system navigation should include building bridges with the rest of the human services sector.

3.3 Navigation Challenges and the Elderly

Issues associated with aging are among the most significant health care challenges in Ontario. More than 60 per cent of hospital bed days are occupied by persons over the age

of 65. The percentage of CCAC caseloads represented by people over 65 varies from 50 to 75.

The combination of advanced age and the presence of a chronic or life ending disease often increases the need for a complex response. With longer life spans, increases in the incidence of chronic conditions and diseases continue in significant numbers. This group has frequent and sustained difficulties in accessing the care and services they require. While health care systems have been built upon an acute care frame of reference, elderly clients require a sustained ongoing relationship with the system. If Ontario is to adequately address its navigation issues, a health strategy appropriate for and responsive to the needs of the elderly must be at its core.

4.0 CCAC EXPERIENCES AND FINDINGS

4.1 History of Community Care

The province of Ontario has actively funded home care for more than 30 years.

The service began as a limited in-home health service provided primarily on a post acute basis. Most patients were recently discharged from an acute care facility. The range of services was limited. Hospital stays were longer and services such as rehabilitation and intravenous therapy were provided prior to discharge. Frail elderly people and those who were unable to live independently utilized homes for the aged, nursing homes and rest and retirement homes.

In the 1980's, changing environmental factors altered the nature and type of home care services. A shift in community attitude resulted in more elderly people choosing to remain in their own homes instead of entering institutions. By the late 1980s, the Ontario government gave formal recognition to homemaking after a hospital stay as a service required by many elderly people to make maintain community living. The fiscal pressures on governments in the early 1990's resulted in the closure of significant numbers of hospital beds, significant reductions in lengths of stay, and a dramatic increase in the number of referrals to the home care system. The pressure from a growing elderly population resulted in the recognition of a need to develop appropriate infrastructure to support unprecedented demand for services from the frail elderly. Existing home care mandates and organization structures were viewed as inadequate to manage the pressures. As a response to all of these factors, in January 1996, the Minister of Health announced his intention to establish the CCAC system across Ontario. Assuming responsibility for home care, facility wait lists and placement in a long-term care facility, and the development of a health information and referral service, 42 CCACs were established across the province.

The new sector faced the challenge of helping clients to navigate Ontario's complex health services system. Situations presented on a daily basis resulted in a continuous search to alleviate barriers to service and service gaps which became more apparent. The nature of the client challenges resulted in frontline staff seeking new relationships across the health care spectrum. When the same issues continued to repeat themselves, CCAC managers began to seek strategic solutions. Whether it involved establishment of specialized teams of case managers, or seeking coordination opportunities, or working in partnerships to develop multi service programs, CCACs pursued solutions. The intent of this section is to highlight some of these CCAC initiatives that have been successfully addressing the health and human service navigation challenges in Ontario.

4.2 Population-Based Case Management Teams

The demographics of the 38 health districts in Ontario have considerable variance. As a generality, newer more suburban communities have younger populations with diverse backgrounds. They also suffer from overburdened health care services that have not grown to the same extent as the population. CCACs serving older communities and those communities in more rural, remote, and northern areas service populations with a greater percentage of elderly. Most rural and remote communities suffer from a lack of medical services and a lack of informal family support as younger family members move to the cities to seek employment. The aging of rural and remote residents and their longer service times have had an upward impact on CCAC caseloads. The same is the case for specialized populations.

Urban areas are characterized by more diverse populations and are typically the first home for immigrants to Canada and Ontario. Urban areas also have a concentration of tertiary services that attract people requiring services and supports. High population densities also create a complexity of social circumstances that also challenge successful navigation.

In response, many CCACs have developed specialized teams with reduced caseloads to enable case managers to assist clients to navigate complex systems. This approach enables case managers to become population specialists and better assist clients to navigate an array of services. They also find themselves as the service coordinator of comprehensive action plans involving many service providers. As case manager specialists, they have developed a comprehensive knowledge of what is available in each silo and across silos. This knowledge is the key to the development and implementation to a successful action plan.

The following are descriptions of specialized teams and case examples that demonstrate their effectiveness in addressing navigation challenges.

4.2.1 Children and Family Services

Children up to the age of 21 years receive services from CCACs for varying diagnoses and conditions. Children with special needs have access to a variety of programs from different funders including governments. The maze created by this complex array of services is often quite overwhelming for parents with an ill child. Locating the right care/services close to home and in a timely manner is often beyond the family's capabilities. Most CCACs have developed a specialized team of case managers to assist families. The range of conditions of children who require CCAC intervention is broad. Here are notes from a few examples:

1. Ali is a ten-year-old boy with Crohns Disease. His weight was below the 10 percentile. He was referred to CCAC to have a nurse teach his parents how to feed him through a nasogastric tube (a tube from his nose to his stomach) as well as to follow the diet plan that the hospital had prescribed. When the case manager home visited she

realized that Ali was the only member of the family that spoke English. He had 2 younger siblings. His father was suffering from heart disease and was unable to work. His mother, in her 40s was pregnant with her 4th child. After paying their rent for their two-bedroom apartment, there was only \$10 left to buy food for the month.

The case manager quickly realized that the boy had been carrying an immense burden in his family. The case manager quickly began using a translator so the boy did not have to discuss the details of his family problems. The family was referred to area food banks, and a crisis referral was made for Social Work. The case manager advocated with Ontario Works for transportation to medical appointments, income and provisions for the new baby. The CCAC social worker assisted the family with housing applications, legal advice for the father's appeal to the Ontario Disability Support Program, referrals to Assistance for Children with Severe Disabilities (ACSD) for the boys' medical costs, as well as to charitable organizations. The nurse that visited the home also visited Ali's class before he went back to school to explain about the tube in his nose, and talk to them about integrating him back into class.

The CCAC case manager referred Ali to an Occupational Therapist (OT) to consult with his school, as he was so weak, he needed energy conservation techniques. The teacher had one child stay in at recess to play chess with Ali, so he could have some social interaction. The case manager advocated for busing for him and his sisters until he was strong enough to walk to school. The OT also referred the children in the family to Parks and Recreation programs (for free), so they did not have to stay in the tiny apartment over the summer. The CCAC case manager referred the mother to a Public Health Nurse, as she had a high-risk pregnancy and did not have a crib or any preparations for the baby. The mom was linked to a volunteer that spoke her language as well as a prenatal program that offered bus tickets and milk. Ali did gain weight and the NG tube was eventually removed. The mom had a healthy baby, but this large family continues to live in a two-bedroom apartment.

2. Mary was 1 year old when she was first referred to the CCAC. She had been hospitalized for aspiration pneumonia. She was referred to CCAC with hypotonia (low muscle tone) and swallowing difficulty. She was not yet able to sit independently. When Mary was born, she was a "floppy" baby and her mother almost died of a hemorrhage during childbirth. Due to her birth history, she was referred for a genetic consultation where she was diagnosed with myotonic dystrophy. It was discovered that her mother, Janet, also carried the gene. As a child Janet was described as slow and lazy at school. As an adult, she was having difficulty caring for Mary and taking care of her 80 year old mother, Emma. Janet had pain in her hands and back and had difficulty lifting her hands over her head. Janet's husband worked night shift about 1 hour out of the city. They had financial problems, which caused marital stress. Janet found that she was crying frequently, had difficulty sleeping and completing tasks. Janet's mother, Emma, was suffering from end-stage heart disease, and multiple orthopedic problems. She lived in the basement of Jane's home. She slept upright in a chair to assist her breathing. She was on oxygen at all times.

The case manager developed a plan to address the needs of the child, the mother, and the grandmother. She utilized CCAC funded services (personal support and therapies) for all three family members and made referrals to seven different programs for Mary. The family physician was consulted for medical and mental health follow up, and a referral was made to a social worker for financial and marital counseling. The grandmother was referred for a geriatric assessment. The Child and Family case manager conferred with colleagues at various points during the service plan, including mental health, palliative care resource case managers as well as placement coordinators. The care was delivered in a comprehensive, interdisciplinary team approach.

3. J. D., male, age 2 months, diagnosed with CF (cystic fibrosis) and failure to thrive at Hospital for Sick Children (HSC). He was returned to the local area hospital on tube feedings and, subsequently, discharged to the community. A CCAC hospital case manager at HSC completed an assessment at time of discharge and arranged nursing visits, and supplies. HSC social worker had already assisted parent to apply for Assistance for Children with Severe Disabilities (ACSD) for drug benefits. Dietician support continued through HSC by phone and return appointments. This baby subsequently was assigned to a specialized CCAC case manager in her home community. A visit was made approximately four weeks after the baby returned home. At that time mother was competent with infant's care and nursing visits for teaching purposes were discontinued. The case manager suggested a referral to the local Health Unit Infant Development program for ongoing, long term monitoring of the child's growth and development. Information was also provided on how to apply for Special Services at Home funding, for Hope Air, and the Easter Seals for travel assistance to and from Toronto. After assessing support systems and other factors (i.e. another young child in home), the case manager set up short term respite in the form of Registered Practical Nurse (RPN) level complex care (shift nursing) for 4-8 hours weekly and provided information to mother regarding who to contact at Children's Rehabilitation Centre for long term in and out of home respite. The case manager also discussed the Enhanced Respite fund for which CCACs are responsible for determination of eligibility, but do not administer. This infant subsequently qualified for this fund as he continued to require 24 hour monitoring and intervention. (With the Enhanced Respite program, the parents are responsible for all recruitment and training of their own respite staff plus invoicing for reimbursement of funds spent etc.)

The CCAC case manager kept the file active for 10 months with regular contact. The parents separated during this period and the mother was provided with information regarding crisis counseling and shelter and also how to apply for rent geared to income housing. Though the case is now officially closed, the CCAC continues to be responsible for the annual reassessment of eligibility for the Enhanced Respite fund and is therefore in a position to monitor progress.

A fifteen-year-old medically fragile male with ataxia required in-home services from Occupational therapy (OT), Physiotherapy (PT), and personal support worker (PSW) services, and at school, OT and PT consultation. Initially, CCAC provided services through a contract provider of in home rehabilitation. Later, the Case Manager referred

the family to the local children's Centre, which serves young people with physical disabilities. The mother who is the primary caregiver was later diagnosed with the same familial neuro-degenerative condition, a terminal condition in adults. She was placed on CCAC services for OT, PT, PSW and SW. The family also includes father and a younger brother. The family members are new Canadians. Both language and cultural differences had to be addressed. During the service period, the family was referred and linked to ten different organizations by the case manager. The case manager provided assessment, coordination, education, information, and referral services for this complex client and family. Information about each service needed to be explained to the family. The case manager also organized several case conferences with the organizations involved to ensure the services were coordinated.

While these examples may appear to be extreme, they are representative of hundreds of children across the province who are living in the community with severe health problems. As the examples point out, the impact of their conditions and their extensive care needs affect their families for the greater part of every day. CCAC case managers across the province serve as system navigators for each of these families.

4.3 Hospital Case Management Services

The acute care/community care linkage has been addressed by the locating of CCAC case managers in hospitals.

Hospital case managers are available to receive referrals. They work with hospital staff and physicians to assess and arrange for in home services to enable the patient to be discharged. More recently, CCAC hospital based case managers have undertaken to complete assessments and applications for long-term care facilities. In the last several years, the combination of funding limitations, reduced acute care beds, and a significant increase in the need for in patient care has resulted in the need for every hospital to reduce average lengths of stay. Early discharge is often dependent upon the availability of care, equipment, and medical supplies at home. The role of the hospital based case manager has become particularly pivotal in ensuring that services are in place to enable an early discharge. For those frail elderly individuals, who are unable to return to home, CCAC hospital based staff also facilitate the placement process for long term care. In 2002/03 the facility application process was added to the role of CCAC hospital case managers. Timely assessments and applications for long term care often reduce lengths of stay in acute care hospitals. Assisting families who often have very little information about long-term care is a vital navigation activity. Two case examples follow.

1. A 77-year-old female with chronic bipolar disorder with multiple admissions was admitted in NYGH for psychosis, suicidal and homicidal ideation. The client threatened her spouse, behaved aggressively, attempted to burn down home by leaving pot on stove and refused to take her medication. At the time of admission client was legally considered to be competent. There were standing issues regarding poor family dynamics and

behavioural difficulties in the community. The CCAC hospital case manager was requested to attend several family meetings to provide options for discharge planning and assisting the client and family to cope and manage in the community. Contact made with hospital staff in regard to progression, stability of client's mental health status. Meetings were held with daughter, spouse and client listening to all concerns. The case manager assessed client as eligible for Mental Health RN to monitor client's medication compliance with delegation to personal support worker if appropriate and linkages to community supports. A Community Treatment Order was referred to the doctor, but contact was made by CCAC hospital case manager with the Canadian Mental Health Association (CMHA) coordinator to coordinate what was available to assist client. A worker from the CMHA was available 2-3 times per week to ensure medication compliance. Contact was made to the coordinator in charge of the community treatment order to clarify the roles of the CCAC and the CTO roles. A referral was made to Psychiatric Day Hospital and the CCAC hospital case manager had to liaise with the Team Leader at the Day Hospital to ensure that the client was on the list and what days that the client had been scheduled. A referral was also made to Community ACT team to place the client on the wait list for daily visits by the ACT team to ensure medication compliance and monitoring for the ACT team psychiatrist. Once the client was discharged and the service arrangements were made, the case was transferred to a district case manager.

2. A 62-year-old male was admitted to hospital with shortness of breath and difficulty ambulating. He had a history of hepatitis C and Hepatoma and, at the time of the referral to CCAC, he had just been diagnosed with liver cancer. The client lived alone on a disability pension and had few supports in the community and no family doctor. Although he had a brother living in the area, he had lost contact with him over the years as his health declined and as he became less mobile. He reported that he managed his own care most days, but was aware that he was becoming weaker. He identified one friend who would pick up groceries and run errands, but that the friend was moving away so he was not sure how he would manage. He belongs to a church but has not felt well enough to attend for the past few months. He acknowledged a feeling of isolation, but was very clear that his goal was to return home and to stay there for as long as possible. With the client's permission, the hospital Case Manager contacted the client's brother to discuss the client's needs and wishes and arranged to have the two meet with the Case Manager at the hospital to discuss discharge plans. The Case Manager helped the client and his brother to develop a plan that would support the client's goal of returning home to his apartment. The client agreed to the services of the palliative team who would provide professional care including the addition of assistive devices in the home. The client was also referred to a wound specialist because of the high risk of skin breakdown and the need for a pressure relief surface. Personal support and homemaking was also arranged to assist the client in his activities of daily living. The client's brother and wife offered to assist with shopping and to drive him to hospital appointments. The Case Manager arranged for Meals on Wheels three days a week and contacted the parish priest who had been unaware of the client's needs and agreed to visit him at home. The Case Manager also arranged for a visitor from the Hospice Volunteer Visiting program

to provide additional social support. A link was also made with the Pain and Symptom Program to facilitate access to palliative physician home visits as his condition changed.

4.3.2 Hospital Case Management Enhancements

An expansion of the role of hospital case manager has been implemented in several small hospitals across the province. In two areas, local hospitals have contracted with their CCAC to provide discharge planning for the hospital.

As both discharge planner and hospital case manager, the CCAC case manager becomes a full time member of the treatment team and an active participant in discharge planning process for all patients. Often the case manager can identify needs that can be addressed by community services and may prevent future hospitalizations. The role also enables the development of a much closer working relationship with family physicians. This model provides for improved continuity of care, a single access point, and helps alleviate the navigation challenges that are experienced in other locations. The model has been so well received in one community that the hospital also purchases all of its social work services from the CCAC.

4.4 Palliative Care at Home

A decade ago people with end stage illnesses spent their last few weeks in hospital bed. The option of dying at home was not available because the medical equipment was not portable, and the health care system did not have the capacity to provide care outside of a hospital. Advocates for community based palliative care challenged both the providers of community health care and those responsible for funding to develop a capacity to support people who wished to die at home.

Home care programs and the CCACs were among the first to respond. Presently, most CCACs have specialized case managers who work in teams with family physicians, contracted service providers, hospice staff and local hospitals to provide services to client and families who require end of life care. During the last month of life, many families receive as many as four nursing visits a day and overnight support from a personal support worker. This often enables palliative clients to spend their final days at home surrounded by loved ones. The availability of end of life care at home is dependent upon the cooperation of all service providers. Both the time and the availability of knowledgeable physicians and nurses are vital factors. In addition, not all situations are amenable to the service.

Mr. D is a 63-year-old gentleman who was diagnosed with Melanoma in 2000, which spread to his lungs, liver, and brain over a four period. His prognosis in 2004 was months to live. He had previously had oral chemotherapy and radiation to the brain. At the time of the referral his symptoms included fatigue, leg weakness, decreased appetite, pain, and short term memory impairment. His medical history also included epilepsy and

a partial left lung lobectomy in 2003. The client lived with his wife, who had some difficulty caring for him as he weighed 215lbs. He had one son who was getting married in July 2004.

The case manager arranged for weekly nursing, but no personal support since he was independent with his wife's assistance. The case manager began the process of evaluating his private insurance and contacting the insurer, and he was referred to the specialized interdisciplinary palliative team in June 2004. Between June 25th and July 15th the palliative team recommended adding personal support services as he required assistance with bathing and was at risk for falls. A hospital bed and special mattress, commode and a walker with wheels were provided. He exhibited increased weakness, mobility issues, and his wife was unable to cope with his care needs at home. At that time the case manager discussed possible placement in a palliative care unit, and applications for admission were activated. On July 16th he accepted a bed and was transferred to a palliative care unit, but his wife called the next day to say they were both unhappy with the decision that they wanted him back home.

Arrangements were made to transfer him home. Nursing visits were increased to daily for pain and symptom management; personal support services were increased as he was now bedridden, required assistance in positioning transfers, toileting, and personal care; and was also at increased risks for falls. A case conference was initiated by the case manager, and an agreement was reached that the client would be supported at home until the wife could no longer manage. A visiting hospice was also called at that time.

On August 8th, the palliative care on-call nurse was paged who was apprised of Mr. D's deteriorating status, including his inability to swallow, decreased level of consciousness, and reduced urine output; all indicators of last days or hours. The case manager arranged for a pain pump to be ordered, shift nursing was introduced, and the plan was modified with his wife's participation to keep the client at home as long as possible. The case manager also began the process of activating the private insurance, ensuring that the hospice volunteer was notified, and discussed initiating funeral arrangements with the family. Reassessment was suggested again on Monday for possible palliative care unit placement.

On August 9th, the case manager and the team nurse visited the home to discuss options for continuing care at home or in the palliative care unit. At that time, the wife indicated she wished her husband to remain at home to die, and advised that she could manage with the assistance of a personal support worker and hospice workers. Private insurance was approved at this time for shift nursing for pain management. Mr. D. died in his home with his wife and son on August 22nd.

4.4.1 HCPnetwork

In the former City of Toronto, the Toronto CCAC has participated in a unique partnership with the HCPnetwork for the past five years. The CCAC works closely with the five hospices in the area and with the Temmy Latner Centre for Palliative Care, which

provides specialized medical palliative care. An interdisciplinary team including a palliative care physician, two palliative care nursing consultants, and a palliative care case manager, hospice staff and volunteers, provide patient-centered care on a 24 hour 7 day a week basis. They provide pain and symptom management, case management, practical and emotional support and a consultative service for primary care givers. The program has been a leader provincially and nationally in the development of standards of practice. It has also been able to extend the length of service to fit new definitions of end of life. One of the unique benefits of this program is the ability to provide services earlier and for a longer period of time. Earlier intervention in the management of pain and symptoms often will reduce the need for sudden hospital admissions and trips to the emergency departments.

4.5 Disease and Condition-Based Teams

The majority of CCAC clients across the province are elderly. With age comes the increased incidence of chronic diseases and conditions. Several CCACs have joined partner organisations in developing comprehensive programs to address the needs of those with specific diseases or conditions. The following are descriptions of a few of these programs.

4.5.1 Windsor Essex CCAC Oncology Case Management Team

The Windsor Essex CCAC oncology team deals exclusively with clients who are living with or dying from an oncological diagnosis. Their caseload numbers of 70 to 90 reflect clients that require CCAC services and may be served during various times during the course of their cancer disease trajectory -- acute, rehabilitative, maintenance, supportive or end of life. As a result, these case managers have an in depth understanding of the CCAC services as well as other community resources available to this clientele. They also have an extensive knowledge base regarding the resources that are available for informal and formal caregivers. They work with available resource groups to ensure that clients/families are navigated to and exposed to the right resources at the right time.

Because of their vast knowledge in this area the team is seen as a resource in the community with respect to oncology and end of life care. They are involved collaboratively with others in the system in the development of various initiatives and system and process changes that respond to the needs of the oncology clientele. In order to expand the in-office capacity, a new position is being added to this group of case managers. The oncology resource case manager will be stationed in the office in order to facilitate prompt service plan changes for emerging client issues, thereby freeing up the others to have more time available to be assessing in the home. In addition, this will facilitate the CCAC case manager's ability to provide education to clients prior to discharge as to their access to services in the event that their cancer reoccurs or progresses.

4.5.2 Dementia Assessment and Resource Team CCAC Simcoe County

In response to a proposal from the local District Health Council, the CCAC of Simcoe County established a multidisciplinary team to respond to the special needs of CCAC clients with Alzheimer disease and related dementias in 1998. The team includes a full time case manager, a part time OT, and part time SW. The success of this initiative led to its expansion in 1999 with the team taking on an enhanced assessment role and adding additional full time case managers. Over time, the team has added an educational and a client advocacy role. The team members also work in partnership with other organizations serving this population across the county. In 2002, the CCAC integrated this special team into a larger team of case managers who serve all cognitively impaired clients. It should also be noted that the work of the team led to the establishment of a community assessment centre for those with cognitive difficulties. The following is a case example.

Mrs. R, diagnosed with Alzheimer's disease, was referred the CCAC by her family physician. Her husband is providing full time care, but finds that her angry outbursts and constant need for supervision are impacting upon his ability to care for her. The case manager conducted a home visit to enable her to observe Mrs. R's. behavior and to discuss in detail the needs of the couple. The case manager arranged for an Occupational Therapist to conduct an assessment of her physical, social, intellectual and emotional capacities. The information gained from the assessment was used as a guide for a care plan.

The care plan included personal support services three mornings per week and hooking up Mr. R with a caregiver support group at the local Alzheimer's Society. The family physician also reviewed the OT report and referred Mrs. R. to the Cognitive Impairment and Support Services program for a more comprehensive assessment to ensure the appropriate diagnosis and treatment, including the management of Mrs. R's agitation.

The case manager maintains regular contact with Mr. R for support, and to ensure that the services provided match the needs of this couple.

4.5.3 ABI Team Toronto CCAC

In 1993, the Ontario government decided to cease sending severe brain injury victims to the United States for treatment. As an alternative, several large urban centres were invited to develop proposals to serve these individuals in Ontario. In 1995, additional funding was made available for new clients. The Home Care Program of the former Metropolitan Toronto participated in the development of a program in Toronto. In 1997, the Toronto CCAC agreed to continue and enhance the program on behalf of all six Toronto CCACs.

The program serves adults from 16 to 65 who have had a severe brain injury and require treatment, rehabilitation services and support in the community. The most recent review of the program was conducted in 2002. The team includes the following services: case management, OT, PT, SLP, SW, psychology, behavioral therapy, nursing, nutritionists,

and personal support workers. The program is a member of the Toronto ABI network and is an integral part of the ABI service system in the Toronto area. Many of the clients are also receiving services and liaison from hospital based brain injury programs.

4.6 Partnerships With Primary Care

Where opportunities have existed, CCACs have assigned case managers to work in primary care settings. Several CCACs in urban areas have similar arrangements with Community Health Centres. In each of these situations, specific case managers spend a portion of their week on site. They assess clients referred to them by the primary care team and arrange for services for those who are eligible. They also serve as an information source to Centre staff.

Mr. W. has had a six-year relationship with the CCAC. He was referred by his caregiver, but after the initial meeting with the client and the caregiver, the case manager met with the Community Health Centre family physician and nurse practitioner (NP) to coordinate resources and establish a plan of care. The client has multiple complex medical issues, including cancer; he also has a mild developmental delay. The plan included bi weekly follow up visits by the NP and regular personal support worker visits. The case manager also linked the client to a local organization serving developmentally delayed persons and this resulted in respite support for the caregiver through Extend a Family.

The next year the client was reported as having frequent falls and becoming increasingly disoriented. He also had a fall and injured his shoulder resulting in an admission to hospital and a diagnosis of stroke. The case manager was able to arrange for additional respite from the Independent Living Centre. In home physical therapy was added to assist with reactivation. An assessment from the Community Geriatric Services resulted in a referral to the day hospital for exercise and further strengthening. After completing the day hospital program, the case manager referred the client to a day program for stimulation and additional care giver respite. Over the next two years, services were added as the client's needs changed. Currently, the situation is stable but requires frequent case management review.

4.6.1 Rosedale Clinic Hamilton CCAC

Hamilton is home to a Health Service Organization (HSO) that was funded by the Ontario government almost two decades ago. (For a brief period in the 1980's the provincial government established the HSO program. A very few Centres were funded because of the costs. Further expansion of the program has never occurred.) HSOs are one stop primary health care centres with a multi disciplinary team that may include family physicians, nurses, social workers, psychologists, dieticians, geriatricians, and chiropractors with on site radiology, laboratory and pharmacy services. At the Rosedale clinic in Hamilton, on site case manager services have been a part of the team for 16 years. The case managers are attached to the physician caseloads. Case managers are proactive members of the team, often introducing the availability of in-home services much earlier in the process, which frequently leads to an improved and timelier outcome.

The service for clients is completely integrated, alleviating the navigation challenges experienced in other settings and locations.

Mrs. G, a female patient of a Rosedale physician, is 80 yrs old and lives alone. Her spouse has dementia and resides in a nursing home. The client has severe advanced osteoarthritis and was scheduled for a total knee replacement. Mrs. G. made some physical changes to her home for her return from surgery, and her family physician, based upon the client's wishes, referred her to CCAC for respite care following the surgery until she could return to her home. The case manager met with the client, did a complete assessment and determined that the client did not qualify for CCAC services at that time; nor did she qualify for the funded respite program. The case manager provided the client with information and contact numbers for several facilities in the city that offer private respite service, and also provided a pamphlet with information for a variety of community services that the client might find helpful. The case manager advised the client to contact CCAC prior to her return home from respite for reassessment if she felt she needed any assistance. The case manager called the client the day before the surgery to again offer assistance for her return home and informed her of the process to access CCAC assistance. The case manager also educated the client's physician about the purpose and qualifying criteria for the currently available funded respite beds.

4.6.2 CCAC for the Eastern Counties Primary Care Initiative

More recently, the Eastern Counties CCAC has initiated two special projects at medical located in their catchment area. Case managers have been assigned on a full time basis to each clinic to work with family physicians to provide services to high risk, elderly clients. Case managers serve a caseload of about 40 active clients. They maintain regular contact with the client, families and service providers. A close working relationship has developed between the family physician and case manager resulting in reduced hospital admissions and greater client stability. This program is less than a year old, but feedback is very positive.

5.0 LHIN PRIORITIES AND SYSTEM NAVIGATION

The official launch of the health transformation process in Ontario was announced by the Minister of Health and Long-Term Care in September 2004, with the issuing of the first Bulletin on October 6, 2004. The focus of that bulletin was to announce the intention to establish new organizations called Local Health Integration Networks (LHINs) with the responsibility to “better integrate and coordinate health services at the local level.”¹⁴ While the role is to provide a local capacity for planning, coordination, integration and funding of local health services, LHINs are not intended to be providers of clinical services.

Based upon an “evidence-based methodology”¹⁵ the province of Ontario has been divided into 14 geographical areas to be served by 14 LHINs. In undertaking the establishment of LHINs, the Ontario government recognized that “the individual Ontarian must navigate a system that has numerous unaligned programs and services.”

In the third bulletin issued on November 1, 2004, the Ministry announced its intention to hold 14 one day facilitated workshops, one in each LHIN region, to begin the local planning process. The agenda for these workshops was extensive. In addition to bringing key health care people together, the expected outcome was to develop a first plan integrating and coordinating services across each region. The Ministry also set an expectation that each LHIN would submit a written report articulating the priorities for their local area. The LHINs were given 60 days to complete their reports. It appears that these ambitious timelines were set to ensure that the reports would be ready in time for the scheduled establishment of new LHIN Boards in April 2005.

The Ministry provided a format for the reports, identifying integration as the major theme. Each report contains recommendations regarding patient care integration and administrative/support service integration. Navigation or system navigation was listed as a service priority, but many viewed it as a means to better integration.

All of the LHINs completed their reports within the time frames. The reports were submitted to the Minister of Health and Long-Term Care and have been made available to the public on the Ministry web site. The contents of the 14 reports vary considerably. Some groups took a strategic approach, while others offered specific suggestions about program development and realignment. The participants and the authors communicate an enthusiasm for the process and a readiness to move forward.

For the purposes of this paper, each report was reviewed in reference to system and client navigation. Half of the LHIN planning reports contained navigation-specific recommendations. Several of these recommendations were listed as a top ten priority, while others developed a recommendation but not as a top ten priority. The nature of the navigation-specific recommendations varied from location to location, but the common element was to introduce actions to minimize system navigation challenges for patients

¹⁴ Ontario Ministry of Health (2004).”Local Health Integration Networks- Bulletin No. 1”p.2

¹⁵ Ibid.p.5

and clients. Other elements included centralizing points of access, increasing the availability of information, and providing a focus on sub populations of vulnerable clients with complex needs. Three other reports included a reference to navigation as an issue, but did not address it in their recommendations. System navigation was not mentioned in the remaining reports.

It is clear from the review of these reports that system navigation and its related elements are concerns for most LHIN planning groups. Many have specific projects outlined to address system navigation. Timing for these improvement initiatives to be implemented is an issue. Before work can commence on any LHIN initiative, the organizations need to be established and operational. This process has just begun with the naming of the Board Chairs and two Board members at the beginning of May 2005. There is an opportunity during the start up phase to provide input from knowledgeable and experienced sources. For this reason it is important that CCACs provide input, and also work with their partners in support of more immediate solutions to system navigation challenges.

6.0 OPPORTUNITIES FOR ACTION

Health care has become a very complex industry that can be quite perplexing to the average user. For people with a simple and clearly definable need, most jurisdictions offer a readily available response. Wait times may be an issue, but a satisfactory response is within the grasp of the consumer. When the consumer's requirements become more complex and longer term, however, he or she may find it more difficult to locate a satisfactory response. This is the process that gives rise to most navigation issues.

There is an assumption that a better organized health system will alleviate the need for assisted navigation. There is also a perspective that readily available information and education can do the same. Still others believe that well developed care paths and disease management programs will alleviate the need for assisted navigation. While all of these efforts may have a significant impact on navigation needs, they take time to develop, implement, and test. Furthermore, what works in one jurisdiction or geographical area may not be appropriate in another.

This paper has attempted to add to the understanding of the health navigation challenges in Ontario as it transforms its health care system. Clearly, there are access issues, disease management issues, as well as the need for comprehensive strategies for specific populations. New developments in each of these areas will contribute to the alleviation of the navigation challenges. Operational LHINs will facilitate change processes, but it will take time. In the eight years of their existence, CCACs have made significant progress in addressing navigation issues. With the assistance and cooperation of partners and support from the Ministry of Health and Long-Term Care, CCACs and their respective partners can introduce several impactful initiatives in a very short time. The following is list of suggested initiatives.

6.1 Improve Points of Access to the System

Expansion of Information and Referral Role

The CCAC mandate includes the provision of an information and referral service available to the public. The vast majority of CCAC inquiries have been via telephone. They typically involve a single interaction that results in information being provided. A useful expansion of this information service would involve arranging for referral appointments and follow up, and establishing a case manager relationship to ensure callers obtain the service or care required. The expanded role would enable case managers to continue a service with clients who are discharged from in home services, as long as case management is required. Marketing the service to the public and service providers would be a key.

Required support: The Ministry of Health and Long-Term Care budgeting process must include funds for this expanded service. The budget submission and approval process needs to redefine performance measures so that longer average lengths of stay do not serve as a disincentive to maintaining longer relationships with clients.

Family Health Teams – Case Management Role

The Ontario government announced the Family Health Team (FHT) initiative last fall as a means of improving access to primary health care. FHTs are to be “locally driven primary health care delivery organizations which will include family physicians, nurse practitioners, nurses, and a range of other health care professionals to provide comprehensive, accessible, coordinated primary health care to a defined population.”¹⁶ CCACs are prepared to participate in the development of each of these new teams and to contract with them to provide case management services to the population served by the FHTs. CCAC case managers are prepared to become full time on site members of the teams.

Required support: Ministry of Health and Long-Term Care endorsement and, in some locations, additional funding.

Integrate Discharge Planning/Hospital Case Manager Services

Hospitals and emergency rooms frequently serve as an entry point to the health system. Treatment and services provided by hospitals are short term, while most conditions require significant treatment and follow up after discharge. The role of the hospital discharge planner is to ensure the necessary circumstances are present to enable the patient to return home. There is often significant pressure to discharge people to make room for the next acutely ill patient. Often people leave hospital without the necessary information or the referral they require.

CCAC hospital case managers make arrangements for in home services. Some case managers are part of the treatment team, while others simply respond to referrals. Too many people leave hospital without the information or assistance they require during their recovery. Integrating the respective roles of discharge planner and hospital case manager would ensure that all patients obtain the information and assistance required for a positive recovery.

Required support: Ministry of Health and Long-Term Care endorsement and OHA encouragement to hospitals to begin contract negotiations with CCACs.

6.2 Disease Management Models

Many CCACs have worked with their respective service providers and local hospitals to develop and formalize care paths for specific conditions. These paths usually focus on acute conditions. There is an opportunity for CCACs to take a leadership role in developing care paths for a number of chronic diseases as well. Too often a client reaches a new level with accompanying acuity. The situation is treated as a new crisis when planned care path and active monitoring could anticipate the change and address or even minimize the acuity.

¹⁶ Ontario Ministry of Health and Long Term Care (2004). “Family Health Teams: Advancing Primary Care”.p.1

Required action: The initiation of coordinated action province-wide to begin to develop chronic disease care paths which could be used in communities across Ontario for disease management planning.

6.3 Health Population Strategies

The focus of health care delivery has been historically focused on the resolution of acute care issues; these attract the majority of available funds. Hospitals, physicians, drugs, and home care have an acute focus. Even governments, who develop policy, set direction and allocate funds, are limited to a four-year mandate. Accordingly, it is understandable that insufficient time is spent on the development of a long-term comprehensive strategy stretching across a continuum. The collective experience of CCACs across Ontario places the sector in a unique position to serve as an advocate for the development of comprehensive strategies for ill children, seniors and those with chronic diseases.

6.4 Best Practices and Continuous Improvement Strategies

The introduction of new programs should also include a commitment to the development of evidence-based best practices. Many CCACs have developed quality improvement strategies and programs. OACCAC has provided leadership in the development of some CCAC best practices, which have been shared province-wide. While these initiatives are important, a commitment to a broad provincial strategy has not yet emerged within the CCAC sector. Implementation of these new initiatives provides a unique opportunity to build evidence-based best practices as they develop.

7.0 NEXT STEPS

OACCAC has scheduled a *Health Provider Forum* for the purpose of widening discussion and facilitating planning and collaboration on navigation challenges in Ontario.

Following the Forum, OACCAC representatives should arrange for meetings with representatives of the Ministry of Health and Long-Term Care to discuss the policy and funding implications of the ensuing proposals.

Thereafter, meetings with respective partners and the LHINs should be convened to begin the planning process and to develop action plans.

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