LITERATURE REVIEW

OF

BEST PRACTICES

IN

CONTINUING and COMMUNITY CARE

Joint Initiative of the Simcoe York
and
Durham Haliburton Kawartha and Pine Ridge
District Health Councils

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EXECUTIVE SUMMARY

Context

In May 2002 planning staff of the Simcoe York and Durham Haliburton Kawartha and Pineridge District Health Councils met to discuss issues of common interest with respect to planning for Long-term Care (LTC) services and the development of LTC Multi-Year Plans. The task of prioritizing and recommending multi-year phasing of strategies to address the large number of important community-identified pressures was identified as a common and increasingly difficult task for DHCs. It was agreed that planning decisions based solely on current utilization data was insufficient as service use and availability are heavily influenced by the level of resources available, particularly given multiple years of fiscal constraint in many health organizations. A consistent and supportable methodology for setting priorities for LTC service enhancements considering qualitative information, industry best practices and utilization data is required. It was agreed that identification of current thinking on best practices and priorities would be a logical starting point for development of a methodology for priority setting.

Prior to embarking on this joint initiative the two DHCs and the MOHLTC Central East Regional Office had agreed that the approach for development of the LTC Multi-Year Plans would be population/consumer focused and examine the full spectrum ('the continuum') of health services required by the consumers.

Objective:

As a first step in the development of a methodology for priority setting, it was agreed that a joint information search of academic literature, agency initiatives and government policy for best practices in the provision of services to four LTC population groups would be conducted. The primary intent of the information search was to identify commonly stated or generally agreed to priority service enhancements for seniors, adults with disabilities, children and youth with longer-term health care needs and the caregivers of these consumer groups.

A secondary objective was to identify information on the critical factors for successful implementation of priority strategies. It was also hoped that the information search might provide useful information on current thinking regarding the management of demand for LTC services. The findings of the information search will be used by the DHCs in the development of a framework for the identification of local priorities for enhancements.

Scope:

The Joint United Nations Program definition of best practices was adopted for this information search. The UN defines best practices as “the continuous process of learning, feedback, reflection and analysis of what works (or does not work) and why.”
The information search was not limited to Canadian examples. In total approximately 200 current (year 2000 – 2003) relevant information sources were identified. It was found that there were relatively more published resources related to the needs of seniors and caregivers compared to those available for adults with disabilities and children and youth with longer-term health care needs. A substantial reference/resource list, including web-based resources, was generated.

**Themes Identified**

Several common themes emerged which were relevant to all population groups:

- The need for a truly ‘client centred’ approach to service delivery. In particular the importance of considering the health service and support needs of the entire family/caregiving unit and the anticipation of changing needs/requirements overtime were emphasized;

- The essential need for planned, coordinated care and monitoring of changing needs through ‘case management’ by the most appropriate person whether that be the individual consumer, a parent or a paid service provider;

- The continued need to simplify entry into and navigation of the health system by those who need services through identification of simplified/single access points;

- The importance of recognizing that the specific health service being delivered to the consumer/caregiver as only one component in a broad spectrum/continuum of health services that are used or will be required by the consumer/caregiver as their needs change;

- The importance of identifying and developing appropriate approaches/services that provide relief (respite) and support to caregivers in their on-going role in supporting the needs of the consumer that they care for;

- The positive impact of stable, adequate and flexible resources/funding in the delivery of appropriate health care services to consumers.

**Conclusions**

The information search was successful in that a variety of current best practices for service delivery and support of LTC consumers and caregivers were identified. The report identifies services principles, models and policies and essential components of service delivery, strategies and action planning.

A goal of best practices research is to build knowledge which can be applied to help design, develop, implement and evaluate efficient and effective health services and supports that maximize the health and quality of life of consumers. This report is a first step to assist DHC long-term care planning activities toward achievement of this goal.
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LITERATURE REVIEW OF BEST PRACTICES IN CONTINUING AND COMMUNITY CARE

1 INTRODUCTION

1.1 BEST PRACTICES: PURPOSE OF LITERATURE REVIEW

The Durham Haliburton Kawartha Pine Ridge and the Simcoe York District Health Councils jointly initiated an information search for recent research on best practices in the continuing and community care sector. The purpose of the project was to identify a series of commonly or generally agreed to priority service enhancements for each of the long-term care consumer groups including seniors, adults with disabilities, children and youth with special needs and caregivers along the continuum of care. The results would be used to assist planners and the long-term care multi year planning committees in the discussion and identification of relative priority and appropriate phasing of multi-year service improvements for long-term care consumer groups.

1.2 DEFINING BEST PRACTICE FOR THIS REPORT

The first part of the exercise was to explore and discuss what “Best Practice” means. The Joint United Nations Program has developed the most relevant definition for the purposes of this review. It is defined as, “The continuous process of learning, feedback, reflection and analysis of what works (or does not work) and why. Examples of best practice include a policy, an activity, a project, legislation, and a manual or research paper. Simply put, it can be anything that works, in full or part, and that can be useful in providing lessons learned.”

This definition is pragmatic, understandable, and comprehensive and is very applicable to this project.

Best practices can be at a system, agency and/or client level. Most of the documents reviewed in this project endorsed the principle that best practices should include the perspective of clients, their families, and caregivers so efforts have been made to include it.

1.3 SCOPE AND ORGANIZATION OF REPORT

The search for relevant sources included documents provided by the District Health Council (DHC) planners and information sources identified by specific people in community agencies. In addition, a number of web sites were reviewed. It is estimated that approximately 200 sources were researched as part of the literature review.

Resource material included a range of types of sources, such as: reports, newsletters, policies, websites, guidelines, briefs, research documents, provincial and professional associations, services providers.
The first four chapters are devoted to best practices for the four long-term care population groups: seniors, adults with disabilities, children and youth with special needs and caregivers. The next pertain to three selected sectors: hospice palliative care services, aboriginal communities, and diversity and cultural competence. Each chapter is divided into two main sections:

1) Key Themes – Services, and
2) Key Themes - System.

Chapter 9 discusses the essential features and major impacts of an integrated continuum of care.

At the end of the report, references are listed according to chapter headings to provide resource material for further review and exploration.

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1 www.unaids.org
2 BEST PRACTICES: SENIORS

2.1 INTRODUCTION

This chapter will first review best practices in relation to community based programs for seniors and then will look at seniors and mental health services. Of all the sectors, the seniors’ area contained the most literature on best practices and it was the most accessible. It is a key area for planning as the number and proportion of elderly people of advanced age (75 years or older in the population) is rapidly increasing.

In this chapter home and community care services will also be discussed, as the majority of their clients are seniors. The term “continuing/community care” is used throughout the report. The term is used by Hollander in a series of reports that analyzed interfaces along the continuum of care and are summarized in a final report. “The term continuing refers to care that continues over time and care that continues across service components. The term community refers to a philosophical preference for care provision in the community and in client’s homes, while the term care means that the primary needs of the individuals…are generally for care, support and enablement rather than cure.”

2.2 KEY FEATURES: SERVICES

Features of Best Practice Models

In 1999 the national report, Innovations in Best Practice Models of Continuing Care for Seniors outlined features of best practice models for continuing care. Although the definition of continuing care includes facility-based care, the findings still directly apply. The study gathered information on recent initiatives from agencies across Canada. The respondents of the survey were asked to give their ideas on what features composed a best practice model. The following elements were identified and ranked in order:

1. Consumer/client focus: the degree to which the client’s right to provide input into service planning is recognized and the extent to which services are relevant to the client’s needs

2. Coordination and Integration: the ability to provide uninterrupted, coordinated service across programs, practitioners, organizations and levels of service, over time

3. Efficiency and Flexibility: achieving the desired results with the most cost effective use of resources, as well as the degree to which the program, service, or organization is capable and flexible
4. Program Assessment and Evaluation: a measure of outcomes consisting of collecting information to inform decision-making and assess the effectiveness of strategies and programs

5. Education: the level of staff competence and ensuring that the knowledge and skills of the service provider are appropriate to the service being provided for the quality of care

6. Access: the ability of the individual to obtain services at the right place and at the right time, based on respective needs

Incorporating these features could provide a useful framework for developing or redesigning best practice service delivery models.

Ranked #1 above, the concept of a “client-centred approach” is noted throughout the literature review of best practices. As noted in The Analysis of Interfaces Along the Continuum of Care. Technical Report 5: Seniors, “the adoption of the client-centred service approach would ensure that clients with complex need would receive the right service at the right time by the right person.”

The client-centred approach is a guiding principle for the development of strategic directions and future actions in response to an aging population. The Strategic Direction and Future Actions Report developed by Alberta Health and Wellness (2000) was based on the results of stakeholder, public and departmental analysis. The Report suggests that the client-centred approach would:

- Endeavour to understand and meet client and family needs, work in partnership with clients, and ensure client choice where possible
- Acknowledge the client’s right to dignity and self determination
- Ensure reasonable access to a variety of affordable services and have their needs met in a flexible, timely and responsive manner
- Respect the client’s right to privacy of space and person
- Recognize and respond to the physical, psychological, spiritual and social aspects of health

Another common theme across the literature is the need for recognized national standards for home and community services at the federal, provincial and territorial level. Common standards would facilitate equality of access and facilitate integration of services.
In a brief in 2001, the Canadian Home Care Association and the Canadian Association for Community Care identified a basic set of required core services in home and community care as the following:

1. Case management- the assessment of needs, coordination of services
2. Professional care - the services of nurses, social workers, physiotherapists and other professionals, plus access to geriatric assessments and consulting physicians and pharmacists
3. Assistance with activities of daily living - personal care
4. Assistance with the instrumental activities of daily living - home support
5. Caregiver support - respite and advice
6. Organized volunteer activities
7. Palliative care
8. Necessary medical supplies and equipment
9. Day programs
10. Self-managed care option

In 1999, the Ontario Community Support Association (OSCA) updated written standards, criteria and indicators for personal support and homemaking services for long-term care and community support services. They include standards for meal services, adult day services, transportation and volunteer management. The OSCA standards promote implementation of best practices, high quality services and greater accountability to the client, general public and funders.

OSCA and The Ontario Case Managers’ Association worked collaboratively to develop case management standards and guidelines. These standards and guidelines are based on the key functions and activities of case management. Working together, they facilitate the delivery of quality case management practices.

In 1997, a report was prepared for the National Advisory Council on Aging assessing the impacts of health reforms on seniors. Seniors identified issues of importance related to their health care and then discussed their expectations related to service and service providers.

Seniors expected services to be the following:

- Effective
• Sufficient
• Available
• Continuous, predictable
• Acceptable
• Flexible, adaptive
• Affordable
• Accessible
• Timely

Expectations related to service providers included such things as:

• Clear communication
• Caring
• Goes the extra mile
• Anticipates future needs

The seniors’ perspective is individualistic, concerned with front-line care and the experiential meaning of that care. It is their reality; it is their real world. When planning for services we need to keep the senior consumer’s viewpoint in the forefront.

2.3 KEY FEATURES: SYSTEM

Integration along the Continuum of Care

The report *Analysis of Interfaces Along the Continuum of Care. Technical Report 2: Seniors* captures the recommendations that are prevalent in various documents. The report identifies five best practices or components needed to ensure integration along the continuum of care including:

• Single entry assessment model
• Coordinated, integrated case management
• Single administrative and funding structure
• Coordinated assessment, placement and coordination
• Consistent client classification system

With these features in place there is an opportunity to facilitate change as well as achieve the goal of an integrated, comprehensive service delivery model. This may be the catalyst to resolve the complex and diverse challenges that face seniors and service providers.

Best Practices to facilitate effective patient discharge from the hospital to home care were developed in *Substudy 15 of the National Evaluation of Home Care*. It was estimated in the study that, across Canada, approximately one-third of all home care is acute care service. The study proposes a set of eleven factors (listed below) important to best discharge practice.
Formal Systems:

1. Legitimization of the relationship between acute care and home care
2. Access to compatible and/or common information systems
3. Flexible use of resources

Relationships and Informal Networks:

4. Formal opportunities for communication and the development of working relationships
5. Continuity and stability of staff assignments
6. Boundary spanning positions

System Capacity:

7. Program resources
8. Access to home care – availability of referral and assessment service
9. Home care supports
10. Community supports
11. Continuum of care

The study recommends a local approach to creating a discharge framework and process. “There is a need to recognize the unique characteristics of each jurisdiction and to capitalize on opportunities to strengthen relationships between the sectors and develop a common focus.” Further research is required to investigate the interfaces and impacts of discharge practices in relation to informal caregivers, community support services and emergency departments of hospitals.

The national study of case managers, Substudy 6, provided best practices for programs that are designed to substitute home care for residential care placements. Critical success factors may include the following practices:

- Support clients who live alone in the community; provide consistent, quality home care
- Work with hospitals to provide step-down or transitional care so that clients can recover enough in hospital to go back home rather than being prematurely placed into residential care
- Develop 24 hour crisis care in the community
- Involve case managers in placement decisions

A successful example of an integrated system of continuing care is described in Substudy14. This Study evaluated the cost-effectiveness of the quick response team program of Saskatoon District Health. The Quick Response Program provided individuals timely access to community-based care as an alternative to hospital admission.
In this jurisdiction one organization administers acute care, long-term care, community-based care and public health services. The findings concluded that the Quick Response Program:
- Provides an appropriate, client focused method of providing access to community based services
- Costs less than hospital stay
- Demonstrated success because it exists within an integrated health delivery system

Cost Effectiveness of Home Care

The National Evaluation of the Cost-Effectiveness of Home Care involved 15 Sub-Studies. The synthesis report has a full discussion of all the findings. For the purposes of this report there will be a brief summary of the findings germane to this discussion paper. The Report states that:

1. There is fairly strong evidence that home care can be a cost-effective substitute for long-term care for people with ongoing care requirements.

2. The cost-effectiveness of home care compared to hospital care, primarily for short-term care clients is mixed. Short-term home care is often provided as a substitute or adjunct to hospital services.

3. It may be possible to provide better care and save money by funding initiatives to monitor and quickly re-stabilize clients, as stable clients cost less.

4. In the integrated care delivery systems, home care has the potential to be a major force in increasing the cost-effectiveness of the overall health care system.

5. The assumption that better quality care will be more costly may not always be valid. It may be possible to provide better care, at a lower cost, through innovative home care programs.

According to the Report to the Annual Premiers’ Conference in August 2002, there is a misperception that there is consensus on what constitutes best practices in the home and community sector. The Report recommends that provinces and jurisdictions share information about projects, client needs and outcome data so that best practices can be widely circulated. The plan identified five strategies that could be worked on collectively to determine what constitutes best practices in order to strengthen home and community care services and systems.

The five strategies include:

1. Supporting caregivers

2. Expanding use of in-home technologies to improve home and community care delivery to benefit clients, caregivers and providers
3. Expanding new models for home care in supportive living arrangements

4. Achieving better integration between home and community care and other parts of the health care system

5. Improving quality and availability of information on home and community care services

Healthy Aging and Mental Health

Best or promising practices in the community that promote healthy aging and positive mental health of seniors were listed in a national study, Seniors’ Mental Health and Home Care, published by the Canadian Mental Health Association in January 2002. The programs were identified by the participants in the study and cover a wide range of home care and community support programs including:

- Wellness clinics
- Adult day programs
- Exercise
- Caregiver support
- Health services
- Information
- Nutrition
- Hospice/palliative care and bereavement support
- Respite for caregivers
- Socializing
- Volunteer programs
- Advocacy
- Tele-health
- Pastoral and spiritual care.

The Report also outlines key features of a home care system that is proactive in addressing the mental health needs of seniors. Key features include:

- Holistic view of clients
- Service integration and coordination
- Reinvestment in home support services
- Standards of care that include mental health
- Role of navigator
- Staff training and education
- Addressing social isolation
- Improved support for family caregivers
- Involving seniors and caregivers in decision-making
- Advocating on seniors behalf
2.4 SUMMARY

Seniors as caregivers or clients should be able to readily access a responsive system of continuing/community care services to enhance their quality of living and healthy aging. In order to receive the right services at the right time by the right person, services must be client centred and respond to the physical, psychological, spiritual and social aspects of health. Seniors must be involved in the decision making about their own health care needs. The importance of case management, community and in-home supports to assist the older person throughout the continuum of care is essential.


ii Ibid.p 2.

iii Federal/Provincial/Territorial Committee (Seniors) for the Ministers Responsible for Seniors (March 1999). Innovations in Best Practice Models of Continuing Care For Seniors. Ottawa.


xi Ibid.p.v.


3 BEST PRACTICES: ADULTS WITH PHYSICAL DISABILITIES

3.1 INTRODUCTION

This chapter will start with services for adults with physical disabilities and then move on to a discussion about programs for persons with acquired brain injury.

After reading the literature review and extensive bibliography prepared by Hollander it was apparent that the most recent and relevant material is contained in this report. As he notes “it was found that there was relatively modest literature specifically for adults with disabilities.” Along the same vein, there are a small number of documents that discuss services or systems of care developed.

3.2 KEY FEATURES: SERVICES

Self Managed Care

The major theme in all the readings and reports is based on the philosophy that adults with physical disabilities have a desire and commitment to be independent, manage their own care, and live in the community. The ongoing debate is to what extent they should and could have the right to manage their own care.

There have been several studies comparing the independent living model in which persons with disabilities manage their own care as opposed to a system where agencies provide the services. As an example, Mattson and Prince (1997) found that a self-managed group had significantly better health outcomes and fewer re-hospitalizations for preventable complications. The self managed group also had greater satisfaction, and received more hours of paid assistance, but when all health related costs were calculated, their overall costs were significantly lower than for people who received their care from an agency.

Consumer directed care was the topic of a research study that reviewed recognized surveys and studies in the United States, Austria, France, Germany and the Netherlands. Most of the findings emerging from the studies support the premise that persons with disabilities experience a better quality of life if they have opportunities to manage their own long-term care. At the same time, the study results underscore the importance of ensuring that the programs remain flexible by providing beneficiaries with a range of management options.

Another model that supports independence is the individualized funding model that provides flexibility and control for the consumer. An example is the Ontario Direct Funding Program. Through this program the individual directs his/her own care, hires and supervises the support worker(s) and manages the funding that is allocated from the Ministry of Health and Long-Term Care.
Client Centred Approach

Services and programs that are client centered have an emphasis on the social model of support rather than the medical model. They place more importance on psycho-social aspects as opposed to physical health. Stakeholders in the Hollander study noted that the “social model of support makes more sense because of the emphasis on ongoing support to enable independence in the community.”

The concept of a client centred approach was found in various reports, mission statements, principles of agencies and associations providing services for the physically disabled, including the Canadian National Institute for the Blind, Canadian Hearing Society, Canadian Paraplegic Association, as well as local community groups and agencies.

The recently published “Service Standards for Attendant Services for Persons with Physical Disabilities” is a current example of the application of the client centred approach. The use of a Personal Outcome Measures approach in developing the standards reflects the commitment to be responsive to an individual’s unique priorities and preferences. As an example, one of the overall service standards is Daily Routine, Continuity and Security. It is then broken down into three specific standards that are described as:

- Choice of daily routine
- Continuity of service
- Choice of services

Once the standard is described a value is assigned. For example, a value for the first standard “choice of daily routine” is “people with disabilities make decisions about their routine daily activities as do people without disabilities.” As well, each standard is further delineated by an explanation of various supports that are necessary for the implementation of the standard. In this example it reads, “each person develops a personal schedule of daily activities based on their individual identities, preferences and desires.”

The Disabled Persons Community Resources, Ottawa 2002, echo this statement in a submission to the Romanow Commission on the Future of Health Care in Canada. Part of the conclusion states that people with disabilities want:

- A new definition of health care that addresses life, quality of life, and death, which is not limited to hospital and physician care.
- A commitment from all governments that they will address the linkages between health and socio-economic indicators.

The area of adult rehabilitation services has been studied to further develop the concept and parameters of client centred care. A literature search and focus groups for adults with chronic disabling conditions comprised the methodology of a study by the Arthritis Community Research and Evaluation Unit. The study concluded that client centred rehabilitation refers to:
Clients being actively involved in managing their health care and their rehabilitation process in partnership with service providers.

An approach to care that strives to incorporate the client’s perspective into the provision of services.

The report outlines the components of client centred rehabilitation at both the client level and system level. The parameters are focused on such concepts as client participation, evaluation, accessibility, family involvement, coordination and continuity, and an interdisciplinary approach.

Essential Services and Supports
After conducting consultations across Canada, the Hollander Report lists essential services and supports for people with physical disabilities as:

- Acute care needs – access to specialist services (timely, physical and financial ease of access)
- Community-based support
- Self-managed attendant services
- Attendant services
- Homemaker services
- Care coordination
- Home care nursing
- Community physiotherapy and occupational therapy
- Technical aids, equipment and supplies
- Transportation services
- Supportive housing
- Life and social skills for independent living
- Income assistance
- Vocational support
- Respite for caregivers if required
- Long term care (facility based) needs – access to respite beds (for caregiver if necessary), congregate living residences (when and if necessary)

There are other services that facilitate access to care and support to adults with physical disabilities. These include enhanced information awareness and communication, support groups, and crisis support. Knowing ‘where to turn’, and ‘how
best to do it’ is essential to the effective and appropriate support for adults with physical disabilities. xii

The consultation also found that availability of meal programs; accessible transportation and adult day programs were critical elements if adults with physical disabilities are to live successful and independent lives in the community.

3.3 KEY FEATURES: SYSTEM

Integration of Services
Integration of services at the individual community, provincial and federal level is sadly lacking. As well, persons with physical disabilities must work their way around a complex and diverse range of services with different access points, eligibility criteria and funding resources. There is discussion in the literature about the need for the community support services to be integrated around the support needs of the individual. This model would require further research and planning.

Hollander very aptly puts it when he says, “coordination is the linchpin for integration, achieved through effective case management.”xiii This implies that the adult with disabilities must be an effective self-advocate. If this is not feasible then there needs to be a case manager or care coordinator from the formal system or a caregiver who can act as a client advocate.

3.4 SUMMARY

With the wide array of service sectors providing care and support it is a definite challenge for adults with physical disabilities to advocate and live independently in the community. Basic to the implementation of Best Practices is the overriding philosophy that adults with a physical disability have a desire and commitment to be independent, manage their own care and live in the community.

3.5 BEST PRACTICES: ADULTS WITH ACQUIRED BRAIN INJURY

3.5.1 INTRODUCTION

This section will highlight recent efforts made through the Toronto Acquired Brain Injury Network to identify best practices for adults with acquired brain injury. The Best Practice Initiative received funding for the development of a Comprehensive Best Practice Brain Injury Model from the Ontario Neurotrauma Foundation and the Government of Ontario and the first report was published in November 2000.
3.5.2 KEY FEATURES: SERVICES & SYSTEM

The Toronto ABI Network best practice study was established in 1999. “The long-term objective of this initiative was defined as the identification, implementation and validation of empirically based best practices guidelines to be used by treating professionals for individuals with BI from the time of the individual’s hospital admission to his/her reintegration into the community.” The plan was to use the guidelines throughout the Toronto ABI Network and to focus on the following areas:

- Assessment
- Outcome Measurement
- Client/Family Involvement
- Program Development

In the first phase (in 2000), eleven recommendations were developed through a multifaceted approach. This included consultation with providers, site visits to well-known programs in Canada and the United States, and consultation with clients and their families. The recommendations address key factors in a system with a continuum of care and approaches to care. The recommendations that pertain most closely to the multi-year plans are:

- A coordinated system of outcome measurement should be selected by agencies and implemented across the continuum of care
- Programs should be based on goals which are client and family driven and, hence, assess outcome relevant to clients and their families
- A mechanism should be established Network-wide to regularly obtain feedback from clients and families with an aim to make use of this information for integration of the client and family perspective in program design, improvement, changes and evaluation
- Initiation of community re-integration should occur in the early (and all) phases of rehabilitation
- Service needs to be matched to service recipient needs over time and services should be available for the full course of recovery
- Expansion and enhancement of empirically validated programs and treatment for persons with a Brain Injury be encouraged
- Community based services to meet population demands that are non-medical in nature should be available for persons following traumatic brain injury. These may include clubhouses, day programs and social skill development, supported living programs, educational programs and case management.
There are two additional phases to the Best Practice research funded by the Neurotrauma Foundation and the Government of Ontario. Phase II has just been published. It introduces the specific outcome measures and implementation process for the agencies in the Toronto ABI network. Phase III is underway now and involves staff orientation, development of agency templates and preparing staff for data collection.

Currently, there is a Request for Proposals in process from the Ontario Neurotrauma Foundation for the development of Best Practices in Community Support Systems for Persons Living with the Effects of Acquired Brain Injury. The results will be most useful for future planning purposes.

Recommendations from Families

The role that families play in the rehabilitation process is both very important and challenging. There is recognition in the literature that family participation in rehabilitation can maximize outcomes and client satisfaction.

Families are asking for specific information about the injury or illness, the prognosis, what they might do, and help with knowing what community resources are available. In developing recommendations for the Best Practice Initiative, families indicated that they needed:

- Training in self advocacy
- Participation in goal setting and treatment planning
- Respite care – for planned and crisis situations
- A guide/case manager
- Links with other families
- Flexibility in service
- Information at all phases of the service continuum
- Functional skill training for clients
- Ongoing follow-up

The District Health Council in Waterloo Region, Wellington and Dufferin completed a report in May of 2002 that looked at the service and support needs of Adults with ABI. The recommendations of this study are similar to the previous discussion and include:

- Need for information by families and clients
- Importance of continuity of care
- Expansion of community support programs
- Design of programs to fit the client needs at different phases in their life
- Call for a coordinated and comprehensive system of services.
3.5.3 SUMMARY

Adults with Brain Injury need a wide range of community support and specialized services to live as safely and independently as possible in the community. Continued research on Best Practices is crucial if services are to match the needs of the client through the process of recovery and reintegration into the community.

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ii Ibid. p.37

iii Ibid. p.38


vii Ibid. p.16

viii Ibid. p.17


xii Ibid. p.36-37

xiii Ibid. p.21

xiv Toronto Acquired Brain Injury Network (May 2002). Development of a Comprehensive Best Practice Brain Injury Model Phase II. Toronto. p.i


Suggested Reference:
Gov’t of Canada Report, Dec. 2002: "Advancing the Inclusion of Persons with Disabilities"
4 BEST PRACTICES: CHILDREN AND YOUTH WITH SPECIAL NEEDS

4.1 INTRODUCTION

This chapter focuses on services for children and youth with special needs and their families with an emphasis on rehabilitation services. In the past several years, reports and studies have included extensive literature reviews and they are listed in the references at the end of the chapter. Overall, this service sector has not been well researched. The literature has mainly focused on issues and challenges related to caring and working with children/youth with special needs rather than best practices in service delivery.

4.2 KEY FEATURES: SERVICE

Family-Centred Approach

A “family centred approach” is one of the major themes across this sector. The report Analysis of Interfaces Along the Continuum of Care: Technical Report 5: Services for Children and their Families notes that programs for children with special needs and their families have characteristics that distinguish them from programs and services for other groups such as seniors or persons with disabilities. To begin with, the service is focused on the family, not on the individual. Secondly, the specialized care that is required is associated with not only a diagnosis but to developmental ‘ages and stages.’ It is well recognized in the literature that it is critical in the development of a child to have the right services at the right time available close to home.

CanChild Centre for Childhood Disability Research conducted an Ontario-wide survey about family-centred service delivery in 1999-2001. Part 3 looked at the factors affecting family-centred service delivery for children with disabilities. “The findings strongly suggest that family-centred services should be considered a best practice approach to meeting the needs of children with disabilities and their families.” The study further states, “since family centeredness is also linked to better outcomes for children and better parent well-being, policies endorsing a family centred approach will have important payoffs for children and their families.” The study concluded that family centred principles could serve as the underpinning for policies in this sector.

A list of how to implement family centred practices in organizations was discussed in the above report including:

- Formally adopting a family-centred approach
- Designating the lead role to a specific person or team
- Providing information to families
- Changing procedures to be family friendly and include families in goal setting
The family-centred approach is endorsed by many organizations providing services to child/youth with special needs. It has been noted in several articles that more research needs to be done around the impact of the transfer of roles of therapist and case manager to the families.

A literature review was completed for a recent report, Simcoe County and York Region Children’s Rehabilitation Services System Rehabilitation Planning, submitted in November, 2002 to the Ministry of Health and Long-Term Care. In this document, parents and service providers developed principles for service delivery and organizational structure. The principles are comprehensive, collaborative and could be considered generic to the wide range of children/youth services. The principles covering service delivery and organization include:

- Ease of access
- Individualized lifelong planning
- Families/individuals are equal members of the service delivery team
- Shared outcomes for children, youth, families and providers
- Service system is respectful
- Capacity building
- Cross sector-care plan coordination and integration

The Canadian Association for Community Care developed a best practices guide, entitled Respite Services for Children (1996). It describes best practices in the areas of:

- Values and principles
- Delivery of respite care
- Access and eligibility
- Public awareness and advocacy
- Standards and Quality Improvements
- Recruitment, training and evaluation
- Funding and Bureaucracy
- Transition to Adulthood
- Family centredness
- Flexibility

4.3 KEY FEATURES: SYSTEM

A major theme that is prevalent in all the literature is the issue of lack of integration and lack of coordination of services for this sector. The Durham Haliburton Kawartha and Pine Ridge District Health Council noted in their submission to the Romanow Commission that “children’s services have been described by the community on a number of occasions as very fragmented.” In a provincial study, Role Review of Children’s Treatment Centres, authors notes “families think of their child as a single individual requiring a coordinated set of services. They are left facing a complex array of
services and service systems that divide up their child either by the disability they have, the services they require or by the funding service that is available.\textsuperscript{vii}

The most extensive survey in this area is the Hollander Report\textsuperscript{viii} that surveyed key informants and consumers across Canada. Among a number of findings was the "silo" organization of services by ministry, departments and regions, which often sets up barriers to integration and communication. The survey respondents recommended mechanisms to link services amongst various jurisdictions such as the following:

- Single or central point of access/entry to the system of services
- Availability of Care Coordinators (case managers who have the mandate and authority to coordinate services across ministries and/or departments)
- Care/case conferences to include families/caregivers
- Flexibility in funding and guidelines so that parents can direct or manage their own care
- Established processes for communication with other elements of the service delivery system
- Ongoing education for all workers about the service work of others in the system
- Attention to the improvement of parent-to-parent links and the roles of advocates
- It is the linkages that make the system a system

As outlined in the Simcoe York report, Children’s Rehabilitation Services System Implementation Plan, the parents and service providers considered best practices in the formation and management of systems of care in developing the recommended model. The framework that was chosen as best practice by this group was the supported health-planning model developed by the Roeher Institute.\textsuperscript{ix} The underlying principles for implementation of the model include six key outcomes:

- Individuals and families have timely access to health and social supports that are coordinated in a way that is responsive to their particular needs as they define them
- Needs assessment has been based on a comprehensive view of the person and his/her own environment, and has not been limited to functional evaluation or medical diagnosis
- There has been a mechanism put in place for the effective sharing of information to ensure that the individual is the guardian of the information
- Individuals and families have had control in decision-making (and adequate support to do so)
- A health promotion approach has been used, and health status improves
Community capacity to include and support individuals with special needs has been strengthened and supported.

4.4 SUMMARY

Because of a lack of an integrated system, children/youth and families face significant gaps in services particularly at transitional stages from preschool to school age and from childhood to adulthood. The Children and Youth Homecare Network (CYHN) remarked in a brief to the Romanow Commission that “for many children and youth, the site of care shifts between hospitals, treatment centers, schools, day cares and home through their life span, and therefore it is imperative that this care be integrated across institutional and community settings.”

It is crucial that children/youth and families with special needs can access services that are truly integrated, comprehensive and available close to home. The development of an overall policy framework for children/youth with special needs is paramount to ensure the services are well coordinated and are based on a family centred approach.

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iii Ibid. p.13


5 BEST PRACTICES: CAREGIVERS

5.1 INTRODUCTION

Caregivers are the primary resource for maintaining dependent individuals in their own homes. Their work is unpaid, highly invisible and ever increasing. The definition for caregivers developed by the Canadian Caregiver Association is “caregivers are individuals who provide the ongoing care and assistance, without pay, to family members and friends in need of support due to physical, cognitive, or mental health conditions.” The literature review showed that there has been interesting research initiatives and projects for this target group developed in the past five or so years. The issue of caregiving is prominent, given that one in five Canadians report that they care for a family member. Currently caregivers provide, on average, 28 hours of care per week in the home.

5.2 KEY FEATURES: SERVICES

Caregiver as a Client and as a Team member

Findings of the National Respite Care Project concluded that the caregiver must be accepted as a legitimate client of the community and long-term care. Traditionally a needs assessment has focused only on the client. The services that are provided are designed to replace the care and services provided by the caregiver. The study concluded that a needs assessment of the caregiver must take place in order to ensure that appropriate programs are considered for both the caregiver and the care receiver. It also has been found that eligibility criteria that focus only on the care receiver create barriers that prohibit caregiver access to services.

In the first part of this three-year study, 424 caregivers were assessed and provided with service. The research conducted by Dr. N. Chappell of the University of Victoria found that the majority of caregivers provided daily care and twenty-five percent provided care 24 hours a day. One of the significant findings was that 40% of the caregivers managed completely on their own, without any kind of formal or informal support. (There was no mention in the report as to whether the caregivers had been offered any support services.)

Interestingly, preliminary results from a similar study on need of caregivers, caring for persons with Alzheimer disease or related dementia, also found that overall, half (50%) of the caregivers in Ontario are not making use of the formal community support services that are offered to them.

A study in southern Vancouver Island confirmed that family caregivers and care receivers are minimal users of the community health system. Also notable was the finding that caregivers access services outside the home only when the care receiver’s condition worsens and becomes more complex.
In the literature the stress and toll on the emotional and physical health and financial well being of the caregiver is well documented. The Canadian Caregiver Coalition states that “although caregiving can be a rewarding and fulfilling experience, when the demands exceed the caregivers ability to cope, the results can be stress, declining health, financial loss, and mental anguish." On this basis, the Coalition recommends that services have:

- a focus on caregivers as integral partners in care, and
- genuine choice for the caregiver with services that are flexible, accessible, integrated and culturally appropriate.

The concept of the caregiver as a team member is also discussed in a study that looked at the health status of informal caregivers. The researchers recommended that the following strategies should be implemented by community agencies:

- Increase community awareness of resources
- Direct community services to both the caregiver and care receiver
- Consider informal caregivers as part of the care team

In the previously discussed National Study on Respite Care the dominant need indicated by most caregivers was respite from/help with personal care. In the Ontario study with a more specialized target group of caregivers for people with Alzheimer’s disease the top four requested services (in order of frequency) were:

1. Home health care
2. Adult day away programs
3. In-home respite services
4. Homemaker services

In the past, respite has been defined as a service provided either by informal caregivers or by formal programs such as in-home care, adult day programs or out of home residential programs. More and more, respite for caregivers is seen as an outcome rather than a specific service (Chappell and Hillman, 2000). This shift in perspective has resulted in a wider and more holistic goal definition. Rather than a description of a specific service, it’s aim is to provide supports and services so that the caregiver can carry on with their role and not experience too much stress and burnout. Simply put, respite is a break for the caregiver.

In various reports and newsletters there is considerable discussion about the effectiveness of support groups including on-line, telephone and group support. The Canadian Association for Community Care (CCAC) received funding in 2000 to develop and test a practical model of empowering and supporting isolated caregivers of chronically ill persons at home. Internet access was provided and caregivers could access on-line information and support groups. Research findings indicated that the program did meet many of the needs and expectations of caregivers. The CCAC hopes
to promote this model of support nationally as “clearly this model has great benefits for both caregivers and their families” and works in both rural and urban areas.

In another current initiative the Victorian Order of Nurses has embarked on the Learning to Listen-Listening to Learn Project. The key question under consideration is “how do we as service providers actively engage caregivers as partners in care to improve the outcomes for caregivers and their families?” The goal of the three-year project is to develop best practice strategies to support family caregivers and a model of service delivery that will engage the caregiver in a meaningful partnership role.

Other ideas from caregivers are to:

- Make better use of volunteers
- Use personalized videotapes as teaching tools for caregivers and the care receivers
- Encourage all doctor’s offices to have caregiver information available
- Access case management services if needed

5.3 KEY FEATURES: SYSTEM

Comprehensive, Coordinated, Integrated System

In a number of surveys, focus groups and studies, caregivers and service providers have called for comprehensive, coordinated and integrated services for caregivers. For example, participants in the project “Community Care for Seniors: Helping Family Caregivers of Seniors Overcome Barriers to Respite” recommended a National Caregiving Strategy to Health Canada. Recommendations included the following:

- Incorporate respite within an integrated and social policy framework
- Launch a national public education campaign to heighten awareness of family caregiving and to help build supportive communities
- Promote best models of practice that will (1) increase access to respite that is responsive to individual caregiver need; and (2) promote the provision of the right services at the right time in the right place and by the right service provider.

The Canadian Caregiver Coalition in a policy paper recommended that “home and community care must be a part of a continuum of health care to ensure a smooth transition from the home to the institution and vice versa.”

Caregivers in focus groups in Technical Report 5 on Seniors indicated that there needed to be improved access and coordination for community services, particularly home care. They also stated that there needed to be improved communication between the service sectors and between families and service systems.
A report to the Annual Premiers’ Conference in August 2002 recommended that supporting caregivers be the first strategy of a plan of action to strengthen the home and community care sector and its role in the continuum of care. The tasks would include “exploring options that will provide support and assistance to family and their caregivers who care for people in the home. Options would include flexible work arrangements, elder care leave, respite care, and training and education required to support caregivers in their role.” Each province/territory would share their experiences and projects with each other. Through this collaborative process best practices for supporting caregivers would be identified and shared across the provinces/territories.

5.4 SUMMARY

Caregivers have a myriad of issues and challenges to address every day. There are minimal supports for caregivers to assist them in their role as a care provider and care team member. Caregiver needs must be included in combination with the care receiver in developing plans of care.

The literature show that now is a prime opportunity to expand traditional services, create innovative caregiver support programs and integrated service delivery models.

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i www.ccc-ccan.ca


iii Canadian Association for the Fifty Plus (CARP) (1999). Putting a Face on Homecare.


vi Smale, B., Dupuis, S. (June 2002). Needs of Caregivers of Persons with Alzheimer Disease or a Related Dementia and Community Support Services in Ontario. p.27.


x Smale, B., Dupuis, S. (June 2002). Needs of Caregivers of Persons with Alzheimer Disease or a related Dementia and Community Support Services in Ontario. p. 25.


xiv Canadian Association for Community Care (August 2002). Give Me a Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite.Ottawa.


6 BEST PRACTICES: HOSPICE PALLIATIVE CARE SERVICES

6.1 INTRODUCTION

The development of best practices in the area of hospice palliative care services has been a consensus building process that has taken ten years. The Standards Committee of the Canadian Hospice Palliative Care Association involved individuals, agencies, associations, committees and governments across Canada to lead the collaborative process. The result was the publication, A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. It is intended to be a guide to assist locally based agencies and groups in the development of their own standards of practice. The document defined palliative care as the nationally accepted term to describe care aimed at relieving suffering and improving quality of life for those who are living with, or dying from, an illness.

6.2 KEY FEATURES: SERVICES

Providing care is defined in the above report as “a process for creating ‘wanted’ change.” The process is the interaction between the caregivers and the patient and the family. The report outlines the principles that guide all aspects of hospice palliative care to include:

- Patient family focused
- High quality
- Safe and effective
- Accessible
- Adequately resourced
- Collaborative
- Knowledge-based
- Advocacy based
- Research-based

How care is provided is broken down into six essential steps that must be completed during each interaction between the caregivers and the patient. The steps include:

- Assessment
- Information sharing
- Decision-making
- Care planning
- Care delivery
- Confirmation

For each of these steps specific principles and norms of practice have been developed. Norms are defined as “simple statements that present usual or average practice.”
For example, the first principle under Assessment is “assessment guides clinicians to identify and understand each of the issues, risks and opportunities related to the patient’s and family’s illness and bereavement experiences, and their associated manifestations and predicaments.” The associated practice norm is “screening questions are used to assess all domains of care and identify all active (unresolved or new) or potential issues and opportunities of importance to the patient, family and caregivers.”

Inherent to the practice norms is the premise that services are client and/or family centred. Early on in the document it is indicated that the consensus-based, collaborative process was based on patient and family issues/needs rather than a focus on existing models of service and funding mechanisms.

The next step for individual agencies or groups is to use the principles and norms of practice in the report as a basis to develop their own standards of practice for implementation and evaluation purposes.

6.3 KEY FEATURES: SYSTEM

Elements of an Integrated Approach

Key elements for a palliative care system of services are outlined in a document entitled A Guide to End-of-Life Care for Seniors. The elements include both service and system components and are based on the concept of client/patient centred care. The major components are listed as:

- Interdisciplinary, coordinated teams
- Service coordination with an appointed coordinator/advocate across the health continuum
- Continuity of care
- Holistic care
- Care at the appropriate time and place – 7 days and 24 hour
- Bereavement counseling and respite care
- Volunteer programs
- Continuing education and support for staff
- Advice and assistance to families
6.4 SUMMARY

With more and more people preferring to die at home it is important that hospice palliative care services are provided as part of the continuum of care, and are available at the right time and place for the client and his/her family.


ii Ibid. p. 25

iii Ibid. p. 6

iv Ibid. p. 28

7 BEST PRACTICES: ABORIGINAL COMMUNITIES

7.1 INTRODUCTION

A review of best practices for aboriginal communities will focus on two reports. The first report is *Aboriginal Health Policy for Ontario* that was developed over a three-year period of consultation with Aboriginal people and their communities. The policy provides guidelines for Aboriginal community involvement in the planning, design, implementation and evaluation of programs and services. The overall goal is to enhance and improve the health of the Aboriginal population in Ontario.

The second report, *Final Report on First Nation and Inuit Homecare* sponsored by the First Nations and Inuit Health Branch, Health Canada, will be discussed.

Aboriginal Health Policy Framework

The Framework involves three interrelated concepts for understanding the dynamics of Aboriginal health.

1. **Life Cycle**: explains life through the passage of stages, which are celebrated and correspond to the four directions, seasons, elements and gifts. It reflects the interdependency of individuals, families and communities and their responsibilities to each other.

2. **Holistic Health**: incorporates the physical, mental, emotional and spiritual health.

3. **Continuum of Care or Healing Continuum**: incorporates health promotion, prevention, treatment and curative programs and services, and rehabilitation.

As part of the Framework, three key strategic directions were developed from 13 major issues identified during the consultations. They included the areas of health status, access to services, and planning and representation. Recommendations and policies were developed. Two policies that can be considered to be best practice guidelines are outlined below:

1. Health care services for Aboriginal people must be planned, designed and developed by Aboriginal people and be available in locations identified by First Nations/Aboriginal communities.

2. These programs and services must respect accept and incorporate Aboriginal values and beliefs and must be flexible in order to support culturally specific approaches to community health.

The report recommends that funding be focused on three key areas including promotion, prevention and rehabilitation. Recommendations included a range of community support and homecare services including personal support workers, nursing, rehabilitation, transportation, social support, and respite care.
Essential Elements of First Nation and Inuit Home Care

Core elements for a First Nation home care program were identified in a report that studied home care services in five First Nation communities. Essential service elements were developed from the review in the areas of client assessment, homemaking, personal care and nursing delivered on a community basis. The key components identified for home care were listed as:iii

- Formal client assessment
- Case management
- Nursing
- Home support services
- In-home meal preparation
- In-home respite
- Linkages to other health and social services
- Program management capacity

Health Canada has published a guideiv for communicating with Aboriginal seniors. Studies have shown that it is difficult to reach this target group and give them information about federal government programs. Some of the suggestions include developing an understanding that convention for Aboriginal people regarding eye contact, touching, seating arrangements, initiating or ending conversations may differ from non-Aboriginal people. Some Aboriginal people are quite comfortable with periods of silence during conversation. In addition, many aboriginal communities are inclined to seek consensus before agreeing to accept a decision with the result that this may take extra time.

7.2 SUMMARY

Ongoing consultation and direct involvement with First Nations/Aboriginal Communities is essential to ensure that services are culturally relevant and encompass a holistic approach to health at all stages along the healing continuum.

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8 BEST PRACTICES: DIVERSITY AND CULTURAL COMPETENCE

8.1 INTRODUCTION

The Simcoe York District Health Council completed a literature review and developed a diversity strategy that is outlined in the report "An Integrated Addiction Services Treatment Plan for Simcoe York." However, the overall search for relevant material conducted for this study was not very fruitful, pointing out the need for research and public reports concerning cultural competency in the area of continuing community care in Canada.

Diversity Strategy

The diversity strategy outlined in the above Simcoe York DHC report includes three components:

- System Inclusiveness – operational policy, practices and composition that acknowledge support and encourage diversity

- Outreach and Linkages – effectively engaging diverse communities in the planning, delivery and management of services through culturally and linguistically appropriate and accessible materials, mechanisms and vehicles

- Diverse Treatment Approaches – approaches, services and programs, structures that are funded on evidence based practice and regular community consultation policies, procedures, training and education that enable services to be provided in a culturally and linguistically appropriate manner

The implementation of the strategy will facilitate and enhance the development of cultural competence in agencies across the continuing care sector.

Cultural Competence

The Simcoe York District Health Council has also developed a working definition and an assessment tool for cultural competence. It is defined as “the ability to serve and support individuals and families in the community from all cultural backgrounds. Culture, in this context, refers not only to issues of ethno racial and linguistic background, but also to the range of other communities and cultures in which individuals may function either voluntarily or involuntarily. Culture refers to shared values, traditions, norms, customs, arts, history, folklore or institutions of a group of people.”

To be culturally competent, an organization needs to have both the ability and interest to develop and continuously enhance its understanding and appreciation of cultural differences and similarities between and among groups. While there are specific criteria
by which one can assess an organization for such competence, some of the basic attributes or practices include the following:

- Formal recognition that culture shapes behaviours; that cultural differences exist; that diversity within cultures is as important as that between cultures; that the concepts of family and community are different in different cultures; and that people from different cultures are usually best served by persons who are in tune with their culture

- Experience or track record of involvement with the target audience

- Staff who are trained in cultural sensitivity and cultural patterns of those who may receive service

- Community representation in the planning, design and delivery of services

- Availability of services in relevant languages

- Non-judgemental approach to clients

- Availability of audio-visual materials, public service announcements, training guides and materials in relevant languages, at an appropriate level of literacy, and in a culturally appropriate format

- Program evaluation methods and instruments that are consistent with the cultural norms of the groups(s) services.

A report on Language Barriers in Access to Health Care provided an overview of current research in the area of language barriers with respect to the impact on access to health care and quality of care. According to Bowen, the author of the report, there is little research in this area. However, there are several research findings in the report that may be useful to consider when planning and implementing services to facilitate cultural competency.

1. There is compelling evidence that language barriers have an adverse affect on initial access to health services. Patients face significant barriers to health promotion/prevention programs. There is also evidence that they face significant barriers to first contact with a variety of providers.

2. Recent research that includes the variables of both ethnicity and official language proficiency suggests that in many cases, language, rather than cultural beliefs and practices of patients, may be the most significant barrier to initial contact with health services.
3. Direct assessments of recent immigrant communities frequently find that the lack of interpreters or bilingual providers is the greatest barrier to access reported by newcomers.

4. Research has identified the negative effects of language barriers on a range of services including physician and hospital care, long-term care, community nursing, counselling and rehabilitation, home care, support for caregivers and health promotion and prevention.

Based on the findings of this report, it will be important that agencies take the initiative to hire trained interpreters and also to educate agency staff to work with interpreters. Specific strategies are needed to increase the cultural competence of service providers.

A Resource Action Guide has been published by the Canadian Mental Health Association as a guide for their organizational entities in moving towards greater cultural diversity and inclusion. The “Diversity Lens Checklist” was developed for boards and staff to review policies and procedures “with respect to how sensitive they might be to the diverse needs of staff, volunteers, board members and clients.” The process of completing the checklist may help identify and remove systemic barriers that prevent equal access to programs, services and employment opportunities within organizations.

The Diversity Lens Checklist included such areas as:

1. Access to Information
2. Policy and Procedures
3. Recruitment and Evaluation
4. Programs and Services

Following the completion of the checklist a suggested action plan was created for agencies to use when implementing change leading to cultural competence and full inclusion. The objectives of the action plan were identified as the following:

- Develop a strong and visible anti-discriminatory policy
- Identify and remove systemic barriers related to procedures and policies
- Develop procedures to deal with discriminatory expressions and acts
- CMHA will ensure equal access to employment opportunities
- Recruitment of board members and volunteers will be more reflective of community
- CMHA will ensure that its commitment to diversity is made known within the organization
- CMHA will ensure that its services are accessible to the diverse community
- Provide diversity development for CMHA staff, volunteers and board members
- Develop a process to monitor and evaluate the progress of CMHA’s organizational change initiative

For each objective, typical tasks are listed to help with the development of the action plan. The report also outlined effective strategies to promote diversity across programs
and services. An annotated bibliography has been prepared to facilitate organizations achieving cultural competence.

A report viii prepared by facilitator Paul Kwasi Kafele, Manager at the Centre for Addiction and Mental Health (Toronto), included best practices for the implementation of an agency diversity plan in four major areas:

- Governance and leadership
- Human resources
- Service delivery
- Partnership and stakeholder relationships

For example, the report notes that some of the best practices for delivering the service to an individual or groups may include:

- Policies that require organization to offer an array of service/program modalities and choices that have passed the diversity test, are put in place and are regularly monitored and evaluated

- Results are shared with diversity experts, partners and clients and programs are subject to continual improvement

- Performance measures and outcomes always involve the community, clients and diversity experts, and results are always shared

- Research activities are diversity sensitive and all studies must address the impact on each of the diversity populations

- Research studies include persons from the diversity populations

8.2 SUMMARY

Sound diversity organizational change is a multi-faceted process that requires the participation of clients, staff at all levels, board members and partners in the community. It should include an assessment of the equity and accessibility of an organization that will promote the removal of systemic barriers and inclusive policies and procedures.

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ii Ibid. p.23-24
vi Ibid.p.12
9 BEST PRACTICES: A FRAMEWORK OF CONTINUING COMMUNITY CARE

9.1 Introduction

Ontario (and Canada’s) health care, including community care, frequently lacks qualities of a system. Basic linkages among various parts of health care services depend on individuals and their families to do the connecting.

The final report on the continuum of care by Hollander presents a framework for organizing a service system. The Third Way is a new conceptual framework for promoting a continuum of integrated and community care, with adequate links to hospitals and primary health care. From a planning perspective, it provides a “jumping off point” to create new linkages in the community to support the diverse array of long term care services.

This best practice framework may be adapted for all of the population groups discussed in this literature review. Additionally, it may be modified to reflect local and unique circumstances.

A brief explanation of the prerequisites, best practices and linkages follow Figure 1 below.
### Figure 1: A Best Practice Framework for Organizing Systems of Continuing/Community Care Services

<table>
<thead>
<tr>
<th>Philosophical and Policy Prerequisites</th>
<th>Best Practices for Organizing a System Of Continuing/Community Care</th>
<th>Linkage Mechanisms Across The Four Population Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Belief in the Benefits of Systems of Care</td>
<td>Administrative Best Practices</td>
<td>1 Administrative Integration</td>
</tr>
<tr>
<td>2 A Commitment to a Full Range of Services and Sustainable Funding</td>
<td>1 A Clear Statement of Philosophy, Enshrined in Policy</td>
<td>2 Boundary Spanning Linkage Mechanisms</td>
</tr>
<tr>
<td>3 A Commitment to the Psycho-social Model of Care</td>
<td>2 A Single or Highly Coordinated Administrative Structure</td>
<td>3 Co-location of Staff</td>
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<td>4 A Commitment to Client Centred Care</td>
<td>3 A Single Funding Envelope</td>
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<td>5 A Commitment to Evidence-based Decision Making</td>
<td>4 Integrated Information Systems</td>
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<td>5 Incentive Systems for Evidence-based Management</td>
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<td>Service Delivery Best Practices</td>
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<td>6 A Single/Coordinated Entry System</td>
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<td>7 Standardized, System Level Assessment and Care Authorization</td>
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<td>8 A Single, System Level Client Classification System</td>
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<td>9 Ongoing, System Level Case Management</td>
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<td>10 Communication with Clients and Families</td>
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</tbody>
</table>

#### Linkages with Hospitals

1 Purchase of Services for Specialty Care  
2 Hospital “In-Reach”  
3 Physician Consultants in the Community  
4 Greater Medical Integration of Care Services  
5 Boundary Spanning Linkage Mechanisms  
6 A Mandate for Coordination

#### Linkages with Primary Care / Primary Health Care

1 Boundary Spanning Linkage Mechanism  
2 Co-Location of Staff  
3 Review of Physician Remuneration  
4 Mixed Models of Continuing/Community Care and Primary Care / Primary Health Care

#### Linkages with Other Social and Human Services

1 Purchase of Service for Specialty Services  
2 Boundary Spanning Linkage Mechanisms  
3 High Level Cross-Sectoral Committees
9.2 Philosophical and Policy Best Practice

Based on his research, Hollander has a strong conviction that all stakeholders including clients and policy decision-makers agree with the basic values, philosophy and policies. The following are considered prerequisites for a system of community care:

1. Belief in the benefits of the system - support for integrated health and community services

2. A commitment to a full range of services and sustainable funding - ratify national standards and funding allocations

3. A commitment to the psycho-social model – recognize that clients need care and support in addition to medical services

4. A commitment to client-centred care – ensure that policies benefit the client or caregiver

9.3 Best Practices for Organizing a System of Continuing /Community Care

The conceptual prerequisites noted above are the first component of an overall framework. The second component outline a set of best practices, both administratively and for service delivery.

Hollander claims that a negative impact on current systems is, services are administered and financially controlled in uncoordinated “silo” structures. According to the best practice literature, the full range of services must come under one administrative umbrella with all organizational functions keyed to the system of care.

Administrative and service delivery best practices require the following:

**Administrative Best Practices**

1. A clear statement of philosophy, enshrined in policy – affirm the vision of a truly integrated system in the community

2. A single or highly coordinated administrative structure – reduce the negative impact for clients of “service silos”

3. A single funding envelope – maximize effectiveness, efficiency and accountability

4. Integrated information systems- reduce multiple assessments and provide information for financial accountability, future service and planning directions
5. Incentive systems for evidence based management – promote effective management of services

Service Delivery Best Practices

6. A single/coordinated entry system – support for one stop shopping and consistent intake policies

7. Standardized, system level assessment and care authorization – enhance reliability and validity of care planning, and analysis of data for greater accountability and informed decision-making

8. A single, system level client classification system – provide a comparison of levels of care within and across service components

9. Ongoing system level case management – provide continuity of care amongst diverse services

10. Communication with clients and families – enhance knowledge and involvement of clients and caregivers.

9.4 Best Practices for Linkage Mechanisms

The third component of Hollanders’ framework discusses the importance of linkages across service components within the system of care as well as between the system of care and other health and social services.

Linkages Across Population Groups
Hollander describes three methods for linking services across systems of care:

1. **Administrative Integration** - combine various target groups into one single entity (e.g. seniors and persons with disabilities both come under provincial long term care programs).

2. **Boundary spanning linkage mechanisms** - designate specific personnel positions to access other systems on behalf of clients.

3. **Co-location of staff** - locate staff from separate systems (serving different population groups) in one place and actively facilitate informal networks.

Linkages with Hospitals
Hollander recommends keeping hospitals separate from the continuing/community care system due to its different functions, culture, budget, etc. However, very strong coordinating mechanisms between hospitals and the community care system are required.
This may be accomplished in several ways:

1. *Purchase of services for specialty care* - provide administrative control for services that require special expertise (e.g., community care organizations fund specialty services such as geriatric units and chronic care wards housed in the hospital setting).

2. *Hospital “in reach”* - locate home care staff in hospitals as a bridge between services.

3. *Physician consultants in the community* - facilitate discussions between physicians in hospitals and community.

4. *Greater medical integration of care services* - integrate care for physical and mental illness.

5. *Boundary spanning linkage mechanisms* - set up meetings between senior management of hospitals and continuing/care organizations.

7. *A mandate for coordination* - include service coordination functions in job descriptions and budget.

**Linkages with Primary Care/Primary Health Care**

1. *Boundary spanning linkage mechanism* - designate positions for coordination between primary care and continuing/community care.

2. *Co-Location of staff* - consider co-location of primary care and continuing/community care staff.

3. *Review of physician remuneration* - review appropriateness of fee schedule and method of compensation to ensure people with complex needs receive adequate care (requires longer appointment times and referrals).

4. *Mixed Models of Continuing/Care and Primary Care/Primary Health Care* - consider a range of coordination for services in both care sectors where feasible.

**Linkages with Other Social and Human Services**

1. *Purchase of services for specialty services* - facilitate integration through purchase of service agreements for specialty services.

2. *Boundary spanning linkages mechanisms* - designate specific positions for coordination functions and cross appointments.

3. *High level cross-sectored committees* - facilitate integration and coordination of policies and resources within government.
There may be one or more best practice systems across the population groups discussed in this literature review. Whether there is one or more than one system, it must be linked through intra-organizational mechanisms.

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ii Ibid. p.51
10 CONCLUDING REMARKS

Long term continuing/community care for seniors, adults with disabilities, children and youth with special needs and caregivers, have become an important and integral part of the health care system. The documents that have been reviewed for this report have discussed the key challenges from the perspective of consumers, caregivers, service providers and the system as a whole.

The report has described a variety of proposed best practices that include such areas as:

- Service principles, models and policies
- Essential components of services
- Strategies and action plans

This literature search has identified many similar needs and best practices in service delivery in continuing/community care across the populations reviewed. Several important themes emerged across all the long-term care population groups.

The common themes include:

- Client centered/family approach
- Coordinated case management
- Single entry or access to services
- Consistent and integrated funding mechanisms
- Respite care
- Coordinated continuum of care

The goal of best practices research is to help design, develop, implement and evaluate services that maximize the quality of life for residents of our local communities. This report is the first phase for planning innovative services that will make a difference to seniors, adults with disabilities, children and youth with special needs and caregivers. It supports a collaborative and more systemic approach to make continuing care a reality.
11 LITERATURE REVIEW: REFERENCES/ RESOURCES

SENIORS


Canadian Association for Community Care and Canadian Home Care Association (2001). *Sustaining Canada’s Health Care System: The Role of Home and Community Care.* Ottawa.


Federal/Provincial/Territorial Committee (Seniors) for the Minister Responsible for Seniors (March 1999). *Innovations in Best Practice Models of Continuing Care for Seniors.* Ottawa.

Fraser Valley Health Authority (2002). *Clinical Services Directional Plan Executive Summary.* British Columbia.


Health Services Utilization and Research Commission Saskatchewan (March 2002). *Conclusive Evidence Elusive for Preventive Home Care*. Saskatoon.


**ADULTS WITH PHYSICAL DISABILITIES /ACQUIRED BRAIN INJURY**


CHILDREN AND YOUTH WITH SPECIAL NEEDS


CAREGIVERS


Canadian Association for Community Care (August 2002). Give Me a Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite. Ottawa.

Canadian Association for Community Care (August 2002). The National Respite Care Project, Executive Summary. Ottawa.


**HOSPICE PALLIATIVE CARE**


ABORIGINAL COMMUNITIES


DIVERSITY AND CULTURAL COMPETENCE


FRAMEWORK OF CONTINUING COMMUNITY CARE


WEB SITES

SENIORS

Alberta Health
www.health.gov.ab.ca

American Society on Aging
www.asaging.org

British Columbia Ministry of Health
www.hlth.gov.bc

Canadian Association for Community Care
www.ccac-acss.com

Canadian Health Network (CHN)
www.canadian-health-network.ca

Canadian Institute for Health Research (CIHR)
www.cihr.ca

Canadian Home Care Association
www.cdnhomecare.on.ca

Canadian Policy Research Network (CPRN)
www.cprn.com

Centre on Aging University of Victoria, BC.
www.coag.uvic.ca

Fraser Valley Health Authority
www.fvhr.org

International Exchange on Home Care and Community Care
www.homecareglobalexchange.com

Institute for Citizen Centred Service
www.iccs-isac.org

Health Canada: Seniors
www.hc-sc.gc.ca/seniors-aines

Health Canada Home and Community Care
www.hc-sc.gc.ca/homecare/english/
Home and Community Care Evaluation and Research Centre
www.hcerc.org

Health Services Utilization and Research Commission Cost-Effectiveness of Home Care
www.sdh.sk.ca/hsurc/Homecarehomepage.htm

Hollander Analytical Services Ltd.
www.hollanderanalytical.com

Medicare to Home and Community (CM-THAC), University of Toronto
www.m-thac.org

National Advisory Council on Aging (Canada)
www.hc-sc.gc.ca/seniors-aines

National Evaluation of the Cost Effectiveness of Home Care
www.homecarestudy.com

Ontario Community Support Association (OSCA)
www.osca.on.ca

Queen’s Health Policy Research Unit, Kingston
www.qhp.queensu.ca

Seniors Safety
www.seniorsafety.com/ontario

Statistics Canada
www.statcan.ca

Seniors Canada on-line
www.seniors.gc.ca

CAREGIVERS

Canadian Association for Community Care
www.ccac-acss.com

Canadian Association for the Fifty-Plus (CARP)
www.fifty-plus.net.com

Canadian Caregiver Coalition
www.ccc-ccan.ca
Canadian Women’s Health Network (CWHN)  
www.cwhn.ca

Centre on Aging Victoria, BC.  
www.coaguvic.ca

European Association of Care and Health at Home  
www.blagussat/ico/homecar.html

How to Care: Your Elder Care Survival Guide  
www.howtocare.com

Maritime Women’s Health Centre of Excellence  
www.medicine.dal.ca/mcew

Prairie Women’s Health Centre of Excellence  
www.pwhce.ca

Victorian Order of Nurses, Ottawa  
www.von.ca

ADULTS WITH PHYSICAL DISABILITIES

Canadian Hearing Society  
www.chs.ca

Canadian National Institute for the Blind  
www.cnib.ca

Canadian Paraplegic Association (Ontario Division)  
www.cpaont.ca

GTA Rehabilitation Network  
www.gtarehabnetwork.on.ca

Ontario Federation for Cerebral Palsy  
www.ofcp.on.ca

Ontario March of Dimes  
www.dimes.org
ADULTS WITH ACQUIRED BRAIN INJURY

Ontario Brain Injury Association (OBIA)
www.obia.on.ca

Toronto Acquired Brain Injury Network
www.abinet.ca

Ontario Neurotrauma Foundation
www.onf.org

CHILDREN AND YOUTH WITH SPECIAL NEEDS

Canadian Association for Community Care
www.ccac-acss.com

CanChild Centre for Childhood Disability Research McMaster University, Hamilton
www.fhs.mcmaster.ca/canchild

Electronic Child Health Network
www.echn.ca

Ontario Association of Children’s Rehabilitation Services (OACRS)
www.oacrs.com

Research Alliance for Children with Special Needs
www.racsn.ca

Roeher Institute, Toronto
www.roeher.ca

HOSPICE PALLIATIVE CARE

Canadian HIV/AIDS Clearinghouse
www.clearinghouse.cpha.ca

Canadian Palliative Care Association
www.c pca.net

Institute of Palliative Care
www.pallcare.org
ABORIGINAL COMMUNITIES

Barrie Area Native Advisory Circle
www.banac.on.ca

Health Canada First Nation and Inuit Health Branch
www.hc-sc.gc.ca/fnihb/cp/

Za-geh-do-win Information Clearinghouse
www.za-geh-do-win.com

DIVERSITY AND CULTURAL COMPETENCE

Across Boundaries, Toronto
www.web.net/~accbound/

Canadian Ethno-cultural Council (CEC)
www.ethnocultural.ca

Canadian Heritage, Multiculturalism
www.pch.gc.ca/multi/index.html

Canadian Mental Health Association National Office
www.cmha.ca

Cultural Competence Works: Using Cultural Competence to Improve the Quality of Health Care for Diverse Populations
www.hrsa.gov/cmc

Diversity Rx Organization
www.diversityrx.org

Transcultural and Multicultural Health Links
www.iun.edu/~libemb/trannurs/trannurs.htm

FRAMEWORK OF CONTINUING CARE

Alberta Health and Wellness
www.health.gov.ab.ca

Hollander Analytical Services Ltd.
www.hollanderanalytical.com
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Canadian Paraplegic Association (Ontario Division)
Toronto

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Ontario Federation for Cerebral Palsy
Toronto

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Toronto

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Richmond Hill

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Canadian Hearing Society -Simcoe York
Newmarket

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Simcoe County Association for the Physically Disabled
Barrie

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Barrie Area Native Advisory Circle (BANAC)
Barrie

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Ottawa
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