REHABILITATION GAPS AND NEEDS ASSESSMENT EASTERN HEALTH December 4, 2009



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This project required extensive input and collaboration:

- The Steering and Advisory Committees provided advice and direction for the project. The Advisory Committee included representatives from The Heart and Stroke Foundation NL, Canadian Paraplegic Association NL, Brain Injury Association, Independent Living Resource Centre, Easter Seals NL, Seniors Resource Centre, Parkinson's Society as well as consumers.
- Managers of the Rehabilitation Program located data and previous reports.
- Larry Kelly, Director of the Rehabilitation Program, provided consultation and data.
- Professional Practice Consultants of Eastern Health contributed human resource and waiting list data as well as advice to the project.
- Jordan Pike, Librarian, St. Clare's Hospital, completed the literature search.
- John Knight and Rosalie Haire of the Newfoundland and Labrador Centre for Health Information identified provincial health data and developed a health services report for rehabilitation.
- Mark Austin, research assistant, compiled and analyzed indicator data.
- Approximately 660 rehabilitation providers, managers, patients and families within Newfoundland and Labrador from St. John's to Stephenville to Goose Bay contributed data to the project.

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EXECUTIVE SUMMARY

Rehabilitation is aimed at enabling people disabled by injury or disease to obtain their optimal physical, intellectual, psychological and social functioning. It requires an integrated team of health professionals using a bio-psycho-social model of health across the continuum of care. An aging population, emphasis on chronic disease management, and the move towards community living for people with disabilities requires the reevaluation of rehabilitation services. The purpose of the Rehabilitation Gaps and Needs Assessment was to outline existing rehabilitation services, identify areas to improve care, and to provide the foundation for a strategic plan for rehabilitation within Eastern Health. Due to the tertiary role of Eastern Health, provincial input was sought and some recommendations made for other health authorities that would help improve services throughout the province.

Primary data was gathered from patients, families, managers, administrators, and rehabilitation providers using surveys, focus groups and key informant interviews. Secondary data was analyzed from provincial and regional health indicators and databases, previously completed human resources and rehabilitation reports, and rehabilitation reports from other provinces. The research process and results were directed by community stakeholders, managers and other experts in the field.

The results showed that, other than the physical facilities, existing inpatient and outpatient services at the L.A. Miller Centre were adequate overall. The greatest need identified was community-based rehabilitation; rehabilitation in homes, long term care facilities and personal care homes. Findings suggested that there is a need for inpatient restorative care for the elderly, for community-based management programs for people with chronic disease (cardiac, pulmonary, arthritis, obesity, etc.) and for vocational and cognitive rehabilitation for people with brain injury. Access to rehabilitation is polarized along rural and urban lines with rural areas having very limited access to inpatient, outpatient and community rehabilitation. We found that for people with rehabilitation needs, over half were readmitted to hospital within a year. There were 19,418 alternate level of care days for rehabilitation patients in 2005-2006. Gaps in rehabilitative care cause impairment in patient flow through the system and ultimately limit the person's ability to live independently at home. These substantial improvements in rehabilitation services would require an action plan over a period of 5-6 years.

There are ways to improve recruitment and retention of rehabilitation providers, including therapists, nurses and physical medicine and rehabilitation specialists across the province. There are also methods such as reducing clerical duties and improving health record and patient information technology that have the potential to improve efficiency.

We found that gaps in the system can be improved through enhanced communication, patient navigation and development of a coordinated provincial rehabilitation network. Admission criteria designed to identify the most appropriate patients for a service, especially at the L.A. Miller Centre, causes confusion for health providers, patients and families and ultimately creates gaps. It is essential that we avoid a silo approach to care and ensure that patients and their families find the most appropriate rehabilitation service for them.

INTRODUCTION

The World Health Organization¹ states,

"Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination."

Principles that guide current knowledge and thinking about rehabilitation include:

- Rehabilitation services cannot be logically separated from the broader determinants of health: those personal, environmental, economic and social factors that play a large role in affecting and/or determining health. These factors include income and social status, social support networks, education, employment and working conditions, physical endowment, biology and genetic endowment, personal health practices and coping skills, healthy child development and the availability of health services ².
- The aim of rehabilitation is to improve the quality of life and participation in society for people who have impairments, activity limitations or participation restrictions resulting from illness or injury.
- In order to improve individuals' opportunity for participation in society, it is necessary for rehabilitation services to be client-centered with clients being active participants in setting goals that address their bio-psycho-social needs in keeping with their social and environmental contexts.
- Rehabilitation does not rely solely on medical interventions and medicine but rather on a multidisciplinary and interdisciplinary approach to health that considers the physical, psychological, social and environmental factors that affect health.
- The rehabilitation process occurs within and outside of institutions; therefore services need to be built around "places" within a system, rather than beds.

The World Health Organization no longer views disability as merely the result of impairment. The social model of disability has increased awareness that environmental barriers to participation are major causes of disability. The *International Classification of Functioning, Disability and Health* (ICF) ³ includes body structure and function but also focuses on 'activities' and 'participation'. It includes five environmental factors that can limit activity or restrict participation: products and technology, natural environment and human made changes to it, support and relationships, attitudes, and services and policies. No nation has eliminated all of the environmental factors that contribute to disability. However, we need to be moving toward a system that supports equity, social justice and the best health outcomes possible with the resources that we have

Despite progress that has been made to improve services in Newfoundland and Labrador, many people with disabilities in this province do not have access to basic rehabilitation services and are not enabled to participate equally in education, training,

work, recreation or other activities in their communities. Ongoing efforts need to continue toward equalization of opportunities and social inclusion of all people with disabilities.

Newfoundlanders and Labradorians of all ages use rehabilitation services. These services are provided in a variety of private and publicly funded settings including adult and children's acute care hospitals, rehabilitation units, long term care facilities, community based programs and private clinics. Seniors use a larger percentage of rehabilitation services; however the need for rehabilitation can occur at any time throughout the lifespan as a result of illness or disease, or following an injury at work or play. For some people the need for rehabilitation begins at birth and continues intermittently throughout their lives, while others may require a one-time intervention following a surgical procedure such as joint replacement. Several factors contribute to a growing need for both preventative and restorative rehabilitation services.

- The trend toward independent living for persons with disabilities and the shift from institutional to community care;
- The emphasis on prevention of disease, early detection and intervention, and advances in medical treatment and technology;
- The increasing demand for rehabilitation services resulting from an aging population with chronic conditions.; and
- Increased pressure from groups that do not receive equal opportunity to receive rehabilitation services either because of where they live or because of the type of diagnosis/disability they have.

To meet the challenges of accommodating this growing need for rehabilitation services within an environment of fiscal restraint, the health care system must design services that are responsive to positive health outcomes and are provided in the most cost effective manner. Growth and development of rehabilitation services must also be designed to respond to the varied needs within the region and the province.

PURPOSE

The purpose of this study was to outline existing rehabilitation services and to provide a vision for necessary growth and development within the region and province, based on the previously discussed principles of rehabilitation. It builds on existing strengths, outlines opportunities for improvements, and identifies issues that require collaborative resolution in order to build strong rehabilitation programs that are designed to meet the current and future needs of Newfoundlanders and Labradorians. The report will propose service development within the Rehabilitation Program that should have access points in rural and urban areas within the Eastern Health region.

CURRENT EASTERN HEALTH REHABILITATION SERVICES

THE LEONARD A. MILLER CENTRE (LAMC)

The L.A Miller Centre, Rehabilitation Program, provides all levels of adult inpatient and outpatient rehabilitation services for the region and tertiary services for the province. It is the major provincial rehabilitation referral center treating approximately 350 inpatients and providing about 30,000 outpatients visits annually. In addition to clinical care, nurses, therapists and physicians act as provincial experts in rehabilitation, providing education, advice and consultation to their counterparts regionally and provincially particularly in complex seating, spinal cord injury, traumatic brain injury and stroke. The Rehabilitation Program at the L.A. Miller Centre is the best resourced rehabilitation service in the province. However, in comparison with other rehabilitation programs across the country, the L.A. Miller Centre has less breadth of services.

Services at the L.A. Miller Centre include:

Inpatient Services

Specialized Tertiary Rehabilitation (18 beds):

This service specializes in higher intensity (3-4 hours therapy per day) rehabilitation for patients with spinal cord injury, brain injury, stroke and other neurological conditions. Due to the specialized nature of this service and the need for a critical mass of patients to maintain expertise, the L.A. Miller Centre is the only site providing this service in the province.

General Rehabilitation (24 beds):

This service provides rehabilitation for patients both regionally and provincially. In this service, patients with orthopedic conditions such as joint replacements, fractures, and amputations and patients with brain injury, stroke or other disabling conditions receive 2-3 hours of therapy per day.

Low Intensity Rehabilitation (20 beds):

This low intensity, long duration rehabilitation service admits patients referred from St. John's hospitals. This service is designed for individuals with physical and cognitive limitations who do not have the endurance or tolerance for higher intensity rehabilitation. It is expected that patients will ultimately transfer into a higher intensity rehabilitation service, or be discharged home or to long term care. It is expected that individuals will have the tolerance, endurance and motivation for one hour of combined therapeutic intervention each day. Most patients using this service are elderly with multiple health problems.

Outpatient Services

Rehabilitation Day Hospital:

The Rehabilitation Day Hospital provides services for clients who require an interdisciplinary team approach with all services being provided concurrently. The Rehabilitation Day Hospital is primarily a neuro-rehabilitation service and is appropriate for clients (many of whom are discharged from inpatient services) who are able to live at home but still require daily therapeutic interventions.

Rehabilitation Outpatient Services

The Outpatient Service provides single discipline and multidisciplinary (occupational therapy, physiotherapy, speech language pathology, psychology, social work, recreation and nutrition) rehabilitation services. The outpatient team also works collaboratively with the Neurology clinic for patients with multiple sclerosis and Parkinson's disease. Community groups are facilitated for people with Parkinson's disease, Multiple Sclerosis, Traumatic Brain Injury, and Stroke. There is a seating program for patients with complex seating needs as well as a fee-for-service driving assessment program.

Centre for Pain and Disability Management (CPDM):

The Miller Center has the only comprehensive chronic pain program in the province. The CPDM program offers an interdisciplinary bio-psycho-social approach to pain and symptom management for patients. It promotes an active rehabilitation approach for self-management as a way of regaining control of pain symptoms and adequately and effectively managing pain. The program includes a five-week group format in addition to an individual discipline stream to meet the needs and goals of clients. Currently, there is a task force reviewing the need for chronic pain services in the province.

Prosthetics and Orthotics:

The Miller Center has the only publicly funded and accredited prosthetic service in the province. Prosthetic, orthotic and assistive devices are manufactured, fitted, modified and repaired as necessary at the L.A. Miller Center and the Orthotic department at the Janeway Children's Health and Rehabilitation Centre. Orthotic services such as cranial remolding for phagiocephaly, serial casting to enhance joint movement, and the manufacture, fitting and modifications to splints and braces are provided for children at the Janeway Centre and for adults at the L.A. Miller Centre. Additionally, traveling clinics are held four times per year throughout the province. The work of the children's orthotic department and the traveling clinics are collaborative initiatives between the Adult Rehabilitation Program and the Development and Rehabilitation Division (Children's Rehabilitation Center) in the Child and Women's Health Program at Janeway Children's Health and Rehabilitation Centre. Prosthetic services for adults and children are provided at the L.A. Miller Centre.

THE JANEWAY CHILDREN'S HEALTH AND REHABILITATION CENTRE, DEVELOPMENT AND REHABILITATION DIVISION

The Development and Rehabilitation Division of the Janeway Children's Health and Rehabilitation Centre provides specialized rehabilitation services to the children of the province on an outpatient basis. There is ongoing planning for the transfer of approximately 100 disabled young adults who have reached 18 years from the children's services to adult services within Eastern Health.

ST JOHN'S ACUTE CARE HOSPITALS (ST. CLARE'S AND HSC)

The Health Sciences Centre and St Clare's Hospital provide a variety of rehabilitative services that address the immediate needs of people on a short-term basis by assisting them in transitioning to home after interventions for acute or chronic medical conditions or surgical procedures. Emphasis is placed on beginning the necessary rehabilitation while inpatients are awaiting access to the Miller Center or returning to their regional hospital or service. The majority of patients having joint replacement receive their short-term rehabilitation in acute care units. Various diagnostic specific outpatient rehabilitation services are available, for example pulmonary and cardiac rehabilitation programs, rheumatology services, orthopedic clinics for hand therapy, and audiology. Interdisciplinary and multidisciplinary teams are responsible for the provision of inpatient rehabilitation services. After acute care needs are met, these teams refer patients to rehabilitation services at the L.A. Miller Centre, to services provided in the community, and to their own outpatient rehabilitation services (usually individual discipline allied health outpatient services). Wait lists for outpatient physiotherapy and occupational therapy are long.

REGIONAL HOSPITALS

Inpatient General Rehabilitation

Some general secondary rehabilitation services are provided at the Carbonear General Hospital, Placentia Health Care Centre, Burin Peninsula Health Care Centre, GB Cross Memorial Hospital for patients with stroke and some orthopedic problems. Limited rehabilitation staff is available at these facilities to provide the entire spectrum of care for their discipline at that facility. Not all hospitals have speech language pathologists or psychologists. Patients are seen on a priority basis with acute care needs being met first. Rehabilitation staff also provides outpatient services, services to the community and long term care.

Outpatient and Community Rehabilitation

The Carbonear General Hospital, Placentia Health Care Centre, Burin Peninsula Health Care Centre, GB Cross Memorial Hospital and the Bonavista Health Care Centre

provide some outpatient single discipline rehabilitation (assessment, treatment and follow-up) through their hospital outpatient services and also provide limited community rehab as well as services to long term care as discussed below. Waiting lists are long and caseloads are large. Urgent or emergent referrals receive priority and other patients can wait up to a year for service.

LONG TERM CARE

Residents in long term care (LTC) who experience an acute illness or injury are treated in an acute care hospital and transferred back to long-term care facilities as quickly as possible. The majority of residents in long-term care facilities require level three care (assistance for activities of daily living), and frequently require rehabilitation of a low intensity nature. The types and intensities of rehabilitation services for residents of long-term care facilities are under-resourced and inconsistent.

There are currently 3.5 occupational therapists, 4 physiotherapists and 8 physiotherapy support workers, 3 dietitians, and one psychologist providing rehabilitation services to 1378 residents in these facilities. There are no occupational therapy support workers or speech language pathologists. Services are limited with long waits. Some residents are referred to external departments for specialized services. For those residents able to pay, some services are contracted from private rehabilitation providers. Outside St. Johns, limited rehabilitation services are provided to residents in LTC facilities by therapists working in nearby regional hospitals.

COMMUNITY REHABILITATION

In the province of Newfoundland & Labrador, community rehabilitation is almost non-existent. There is very few rehabilitation staff and few community rehabilitation services offered. In the St. John's region, there are 2 physiotherapists and 4 occupational therapists offering limited post-acute care services. There is no service offered in Conception Bay South. There are social workers and nurses in community health but none dedicated to rehabilitation. There are no psychologists or speech language pathologists employed in community. In rural areas of Eastern Health, community-based rehabilitation services are integrated with acute and long-term care in selected areas while in other areas, there are no allied health community services at all. There are some private rehabilitation providers in larger centers for patients who have insurance or who can pay.

PERSONAL CARE HOMES

In the St. John's region, there are 27 personal care homes with 982 residents. In rural Avalon, there are 23 homes with 673 beds (about 450 occupied presently). These personal care homes admit residents who need level I and II care (assistance with meal preparation, housekeeping and some personal care). Residents of these homes have a

broad range of post-acute needs. Many have had a stroke, orthopedic problems, or have multiple medical conditions. There is a recognized need for rehabilitation services for many of these people and there are many who have equipment needs (walkers, wheelchairs, bathroom equipment). There are approximately 2 PTs and 2 OTs with Community Health and Nursing Services, and 2 OTs with Community Living And Supportive Services (CLASS) in the St. John's area that provide limited rehabilitation services, otherwise, residents must pay for private care.

REHABILITATION IN CONTEXT

Regional Demographics Profiles of Newfoundland and Labrador ⁴ indicate:

- A declining fertility rate the total fertility rate is 1.3, the lowest in Canada.
- An aging population the median age for the province increased from 20.9 years in 1971 to 42 years in 2007.
- Increased urbanization the geographic distribution of the population of the province is changing with rural communities declining and urban areas remaining stable or growing.

There will be challenges for health care associated with these changes. There will be increased pressure on long term care, home supports, pharmaceuticals and rehabilitation. There will also be labour market imbalances, with the demand for workers overtaking the supply. An older workforce is likely to result in increased workplace injuries and higher rehabilitation costs.

Rehabilitation is an important part of the continuum of care and influences patient flow at each stage, from emergency rooms to acute care to long term care. Inadequate access to appropriate rehabilitation impedes patient transition from one level of care to another and ultimately affects timely discharge.

At present, rehabilitation is provided through a patchwork of services from a variety of locations and programs within Eastern Health. Access to services is inconsistent and wait times for some services are excessively long. Each area within the region is attempting to meet the needs of the people they serve but there is no coordination of services, no established standards for the delivery of rehabilitation and no standard outcome measures in use throughout the region. Additionally, there is no overall comprehensive method for assessing the population needs for rehabilitation in the Eastern region. The development of standards, indicators and information management in the rehabilitation sector are recognized areas for development.

The importance of rehabilitation as a specialty with very complex dimensions is not well understood within the health care system. There is no consistent method by which rehabilitation resources are identified and approved, and in most cases approval of resources is based on competition with other services, forcing planners and administrators to make difficult decisions in setting priorities. Recruitment and retention of all rehabilitation staff is challenging and in some areas prolonged vacancies exist; for example, there has been a Physiatrist vacancy at the Miller Center for more than two years. There is high turnover in most rehabilitation disciplines, which creates

inconsistencies in the continuity of care and contributes to an imbalance in the novice to expert staff ratio.

Many of the facilities in which rehabilitation is provided were built for different purposes and are inadequate for rehabilitation. Most of the facilities are not barrier-free, are overcrowded, have mixed populations, and do not have the space, equipment or technological capacities to develop rehabilitation programming. This impedes the fundamental basis of rehabilitation, which is the promotion of independence. Parking and access to buildings are problematic for people with disabilities, the elderly, and for those utilizing mobility aides.

Research in rehabilitation is at an infancy stage in Newfoundland and Labrador and has a huge potential to improve the quality and efficiency of health care. We are now starting to see some research in rehabilitation done at a local level at the L.A. Miller Centre and through the Memorial University School of Medicine. The continued promotion of research in rehabilitation that is relevant to our population with its unique culture and geography is vital.

METHODOLOGY

1. IDENTIFICATION OF STEERING AND ADVISORY COMMITTEES

Two committees were established to guide the development and progress of this project. See Appendix A for terms of reference and membership of these committees.

Rehabilitation Steering Committee: The purpose of this committee was to oversee the rehabilitation needs assessment for the Rehabilitation Program of Eastern Health, approve the development of a needs assessment plan, review and provide feedback on the primary and secondary research findings of the rehabilitation needs assessment and the draft report, and approve the rehabilitation needs assessment results. It was also responsible for evaluation of the rehabilitation needs assessment process. The Committee consisted of managers of rehabilitation services or professionals with expertise in this area. It was chaired by the Rehabilitation Program Director of Eastern Health, who was responsible for reporting to the COO on the activities of the Committee.

Rehabilitation Advisory Committee: The purpose of the Rehabilitation Needs Assessment Advisory Committee was to provide stakeholder advice and feedback on the Rehabilitation Needs Assessment to the Rehabilitation Needs Assessment Steering Committee of Eastern Health. The Advisory Committee consisted of individuals representing organizations that support the health and well-being of individuals who require or have required interdisciplinary rehabilitation. The committee was facilitated by the co-investigators who were responsible for arranging meetings. The facilitator was responsible for reporting to the Steering Committee.

2. PRIMARY DATA COLLECTION

A. DEVELOPMENT AND DISTRIBUTION OF SURVEYS

Three separate surveys were developed to seek feedback from patients and families, publically-funded care providers, and private rehabilitation care providers.

Adult Rehabilitation Needs and Gaps Survey for Care Providers:

A survey for rehabilitation care providers was developed (Appendix B). It consisted of positive statements about rehabilitation services, structures, and working conditions with respondents being asked to rate their agreement or disagreement with each statement. Respondents were given an opportunity to comment in each case. The surveys were sent electronically to all care providers in Eastern Health asking that only rehabilitation care providers respond. It was estimated that there were possibly 500 employees whom would consider themselves rehabilitation care providers. Respondents were asked to indicate where they provided rehabilitation services:

St. John's Hospitals (St. Clare's Hospital, Health Sciences Centre)

Community (Continuing Care, Community Living and Supportive Services (CLASS),

Community Support Program)

L A Miller Centre Rehabilitation Day Services

L A Miller Centre Inpatient Services

Long Term Care

Regional Hospital/Health Care Centre (Clarenville, Carbonear, Burin etc.)

Mental Health

Child Health

Chronic Pain and Disability Management

Adult Rehabilitation Needs and Gaps Survey for Patients and Families:

A survey was developed for patients or family members of patients who had received rehabilitation services within the past year at one or more sites in Eastern Health (Appendix B). A self addressed stamped envelope was included with each survey. Surveys were sent to all patients seen in the Rehabilitation Program at the L. A. Miller Centre in the past year. Packages of surveys were also sent to other facilities within Eastern Health to have distributed to their patients. The survey consisted of positive statements about rehabilitation services. Respondents were asked to rate their agreement or disagreement with each statement and were given opportunity to comment in each case.

Adult Rehabilitation Needs and Gaps Survey for Private Rehabilitation

Providers: A survey was developed for private rehabilitation providers who provide rehabilitation services within the Eastern Health Region seeking their input into services provided by Eastern Health (Appendix B). Providers were sourced from the Eastern region yellow pages directory. The Survey consisted of four positive statements about rehabilitation services. Respondents were asked to rate their agreement or disagreement with each statement and were given an opportunity to comment in each case. Forty

surveys with self addressed stamped envelopes were mailed to private physiotherapists, occupational therapists, speech language pathologists, psychologists and multidisciplinary clinics.

B. FOCUS GROUPS

Providers and managers within Eastern Health were sent emails requesting participation in focus groups. In addition, all surveys requested volunteers to participate in focus groups. All managers within the province with a rehabilitation portfolio were contacted to help identify focus group participants and arrange regional focus groups. Focus group questions and consent can be found in Appendix B. A series of 12 focus groups were conducted across the province. Groups consisted of 10 to 19 participants, including rehabilitation service providers (i.e. physiotherapists, occupational therapists, speech language pathologists, psychologists, dietitians, recreation specialists, social workers, nurses and physicians), and patients and family members. Using semi-structured open interviews, participants discussed needs and gaps in rehabilitation services as well as strategies to address issues identified. All sessions were facilitated by one coresearcher while notes were taken by the other. Participants completed consent forms. Conversations were audio-taped, transcribed verbatim and analyzed using NVIVO 8 (QSR International). Emerging themes were determined and classified into categories.

C. KEY INFORMANT INTERVIEWS

Face-to-face and telephone key informant interviews were conducted across the province with individuals in key positions of influence or expertise in health care and rehabilitation to obtain their opinions concerning rehabilitation gaps and needs. Key informants were given an opportunity to have input through individual or group discussion. Detailed notes were kept on all interviews. Issues and responses were analyzed for agreement/disagreement with other responses collected through surveys and focus groups. Appendix B contains the detailed list of interviewees.

3. SECONDARY DATA COLLECTION

A. PREVIOUSLY PUBLISHED PROVINCIAL REPORTS

Within Newfoundland and Labrador, all known rehabilitation and rehabilitation-related reports and documents were obtained from directors, managers, clinical leaders and professional practice consultants. There was no time limit placed on the age of these documents. These documents were reviewed and content analyzed (Appendix C). Of particular interest were reports listed in Table 1, "Adult /Geriatric Rehabilitation Services, Province of Newfoundland" completed by IMB Associates in1993 and "The Provincial Framework for Adult Rehabilitation Services" completed by a Department of Health expert group in 1996. Both of these documents provided a framework of

rehabilitation needs for the province. Most of the recommendations of these reports were never acted upon but support the findings of this document.

Table 1: NL Rehabilitation Reports 1990-2008

Report	Author(s)	Date
Proposal for General Hospital Head	Discipline representatives in Neuro	1990
Injury Program	Sciences at General Hospital Corp. of	1,7,70
	St. John's	
Adult/Geriatric Rehabilitation	IMB Associates Inc.	Dec
Services, Prov. of Newfoundland	Title / issociates life.	1993
Focus Group Report :	Physicians, Staff and managers	1995
Rehabilitation	representing rehab services comprising	1775
(Program Management)	HCCSJ	
Provincial Framework for Adult	Department of Health Committee,	1996
Rehabilitation Services	Janet Squires, Brenda Head and Pat	1550
Trondomation Services	Coish-Snow (reviewed previous IMB	
	Associates report and made	
	recommendations)	
Senior's Care Program	Focus Group Report	Feb 12,
Final Report, Phase II	Facilitator: Sharon Barns	1996
(Program Management)	1 definator. Sharon Burns	1770
(1 Togram Wanagement)		
Traumatic Brain Injury Team	Traumatic Brain Injury Planning	June
Proposal	Committee of the HCCSJ	1998
Report of the Regional	9 managers from Community Health,	1999
Rehabilitation Committee	HCCSJ, Long Term Care and Dept. of	
	Health.	
Rehabilitation Needs of Young	Brenda Head	Sept
Adults with Physical Disabilities	Rehabilitation Program, HCCSJ	2000
From the Ground Up:	Staff of the Strategic Social Plan and the	2002
Strategic Social Plan	Newfoundland and Labrador Statistics	
Newfoundland and Labrador	Agency in cooperation with The Govt.	
	of Newfoundland and Labrador and	
	Memorial University	
Healthier Together, A Strategic	Dept. of Health and community	2002
Health Plan for Newfoundland and	services, Government of Newfoundland	
Labrador	and Labrador	
Current Supply and Gaps in Service	Allied Health Human Resource Sub	Aug
for PT, OT and SLP professions in	Committee	2003
Newfoundland and Labrador		
Working Together for Mental	Government of Newfoundland and	Oct
Health: A Provincial Framework for	Labrador Document.	2005
Mental Health & Addictions	Colleen Simms	
Services in Newfoundland and		
Labrador		
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Provincial Healthy Aging	Newfoundland and Labrador Aging and	2007
Implementation Plan	Seniors Division	
Year 1: 2007-2008		
Building a Foundation		
Therapeutic Intervention &	Blenda Dredge	Oct
Rehabilitation Services	Regional Director	2006
A Proposal	Therapeutic Services and Rehabilitation	
	Labrador-Grenfell Regional Health	
	Authority.	
Rehabilitation of People with	Working Group of Rehabilitation	Jan
Traumatic Brain Injury in	Program of Eastern Health	2008
Newfoundland and Labrador:		
Towards Community Re-		
engagement		

B. REVIEW OF REPORTS FROM OTHER PROVINCES

Using the key word "rehabilitation", the St Clare's Hospital librarian searched all literature including best practice guidelines, grey literature, and government and community reports published within the past 20 years (see Table 2). Those involving pediatric rehabilitation, alcohol rehabilitation and mental health rehabilitation were excluded. These reports were reviewed and content analyzed (see Appendix C for details).

Table 2: Rehabilitation Reports in Canada

Report	Author(s)	Date
The Implementation And Evaluation Of	Carmen J McKell	Oct
Selected Strategies Of The Rehabilitation	Evalu-Plan Consulting Inc.	2000
Service Plan In New Brunswick	For The Health Transition	
Final Report	Fund, Health Canada	
The Health and Community Services Plan	Department of Health and	Apr
for New Brunswick	Community Services	1994
Hospital Report 2007 - Rehabilitation.	Ontario Hospital Assoc.	2007
	Govt. of Ontario and CIHI	
Rebuilding Ontario's Health System:	Health Services Restructuring	July 23
Interim Planning Guidelines and	Commission	1997
Implementation Strategies		
Home Care, Long Term care, Mental		
Health, Rehabilitation, and Sub-Acute Care		
Greater Toronto Area Strategic Plan 2005-	Greater Toronto Area Rehab	June
2008	Network	2005
Rehabilitation in the Greater Toronto Area:	Greater Toronto Area Rehab	June
A vision for the future 2005-2006	Network	2005
GTA Network Rehab Definitions	Greater Toronto Area Rehab	April
Conceptual Framework	Network	2008
Winnipeg Regional Health Authority	PWC Consulting	July
Rehab Services Role Review Final Report		2002

Rehabilitation Configuration Report to the	Winnipeg Regional Health	June 23
ABC Committee (Achieving Benchmarks	Authority	2004
through Collaboration)		
Calgary Brain Injury Strategy; Foundations	Collaboration of	Nov
for Direction	Calgary Health Region	2005
	Alberta Government	
	Alberta Seniors and	
	Community Supports	
Strategic Directions for Adults/Older Adult	Vancouver/Richmond Health	2000
Rehabilitation in Vancouver/ Richmond	Board	
Health Region		
Fraser Health Acquired Brain Injury	Fraser Health	May 4
Services Strategic Plan 2007-2010		2007
Community Brain Injury Directional Plan	Vancouver Coastal Health	Aug
		2005
Acquired Brain Injury: Service Delivery	Vancouver Coastal Health	May
Framework for VCH		2006

C. SATISFACTION SURVEYS

Following discharge from inpatient and outpatient services at the L.A. Miller Centre, patients and families are mailed a satisfaction survey. Results from April 2007 to March 2008 and from April 2008 to March 2009 were analyzed. See Appendix C for details.

D. HEALTH INDICATORS

Co-researchers met with epidemiologists from the Newfoundland and Labrador Centre for Health Information (NLCIHI) to obtain health statistics of people requiring rehabilitation. In coordination with these individuals, a coding system was developed to match patient codes from National Reporting System (NRS) to those used by the Canadian Institute for Health Information (CIHI). All CIHI health record codes were hand searched and matched to NRS patient codes by a co-investigator. Data from adult patient admissions in each of the provinces health regions in 2005-06 and 2006-07 was evaluated.

E. NATIONAL REHABILITATION REPORTING SYSTEM (NRS) DATA

The Rehabilitation Program at the L.A. Miller Centre has been collecting and contributing to the NRS (a division of CIHI) database since 1997. The NRS collects, analyses and reports the health outcomes and demographic information of patients receiving rehabilitation in Canada. This reporting is mandated by legislature in Ontario. We analyzed NRS annual reports for the L.A. Miller Centre for April 2005- March 2006 and April 2006- March 2007. Since the rehabilitation unit at the O'Connell Centre in Western Health does not contribute to NRS, only L.A. Miller Centre data could be analyzed.

F. REHABILITATION PROGRAM INDICATOR REPORTS

The Rehabilitation Program collects quality indicators on a quarterly basis, including number of admission/visits, length of stay, human resources, and adverse events. Data from 2005-2006, 2006-2007 and 2007-2008 were analyzed.

G. HUMAN RESOURCE REPORTS FROM PROFESSIONAL PRACTICE CONSULTANTS

Detailed human resources planning documents concerning the numbers of professionals required throughout the region were received from occupational therapy, physiotherapy, speech language pathology, nutrition, recreation therapy and respiratory therapy professional practice consultants in Eastern Health. Social work and psychology professional practice consultants also provided data concerning existing staff complements in Eastern Health.

RESULTS

Through this assessment, input concerning rehabilitation gaps and needs was received from approximately 660 rehabilitation managers, health providers, patients and families from across the province.

1. PRIMARY DATA

A. ADULT REHABILITATION NEEDS AND GAPS SURVEY FOR CARE PROVIDERS

Surveys were sent electronically to all care providers in Eastern Health asking that only rehabilitation care providers respond. It was estimated that there were possibly 500 employees who would consider themselves rehabilitation care providers Reminder emails were sent. 189 surveys were returned with a 38% return rate which would be considered typical for this type of survey. Returns from the various areas are shown in Table 3 below.

Table 3: Health Provider Respondents by Area

Site	Number Responding
St. John's Hospitals (St. Clare's, HSC)	40
Community	37
L A Miller Centre Rehabilitation Day Services	26
L A Miller Centre Inpatient Services	29
Long Term Care	19
Regional Hospital/Health Care Centre	17
Mental Health	8
Child Health	6
Chronic Pain and Disability Management	4
Unknown	3
Total	189

Surveys returned were analyzed per site and as a whole. Since all questions were worded positively, we were able to calculate the average disagreement rate. Any items scoring higher than this average disagreement rate were considered to be an item of concern. The top five issues at each health service are **bolded** in Table 4 below.

Table 4:	t Rehabili	ehabilitation Needs and Gaps Survey for Care Providers								
Issue (Mean disagreement rate)	St John's Hospitals	Community Services	LTC (50%)	Child Health	Regional Hospitals	Mental Health	In Patient LAMC (43%)	Day Patient LAMC (38%)	CPDM (35%)	Survey Summary Results (51%)
Pts have access to affordable accessible housing	88%	82%	NA	100%	73%	80%	85%	91%	50%	85%
Pts have access to home support workers	71%	92%	NA	83%	54%	71%	77%	87%	100%	81%
Sufficient rehabilitation staff where I work to provide appropriate rehab	72%	100%	89%	83%	100%	60%	68%	25%	50%	74%
Pts have access to community support services (rehab)	57%	62%	NA	80%	54%	60%	81%	91%	66%	70%
Timely provision and funding of equipment renovations and home supports for patients.	65%	53%	67%	60%	64%	100%	82%	84%	66%	70%
Reasonable wait times when referring to other rehab services.	62%	65%	63%	75%	57%	75%	52%	70%	0%	65%
My pts have equitable access to rehab services. (general)	58%	89%	83%	60%	63%	57%	52%	25%	0%	60%
My pts discharged with equipment, renovations and home supports they need to live independently and safely.	39%	89%	82%	50%	43%	60%	61%	65%	66%	60%
Pts have access to wheelchair accessible transportation	45%	59%	53%	50%	77%	0%	60%	88%	50%	60%
Pts have access to the rehab services needed post discharge if issues arise.	46%	77%	86%	50%	80%	100%	61%	32%	33%	56%
Reasonable wait times for rehab services at site where I work.	59%	75%	94%	60%	57%	66%	27%	42%	100%	55%
My pts have equitable access to Tertiary Rehab Services at the LAMC	45%	60%	88%	100%	60%	100%	NA	NA	50%	52%
I have a clear understanding of the rehab services being provided at other sites	41%	54%	59%	100%	27%	50%	46%	48%	75%	52%
My pts receive the rehab services they need.	58%	77%	78%	0%	81%	57%	17%	20%	0%	51%
My patients are discharged in a timely way.	50%	42%	NA	100%	44%	43%	55%	44%	0%	48%
I provide or know where to refer pts for vocational support.	44%	57%	NA	33%	58%	14%	38%	50%	0%	47%
The rehab services provided where I work are appropriate for this level of rehab.	46%	86%	76%	50%	53%	80%	21%	8%	0%	45%
am provided with ongoing education to keep ne up to date with standards of practice.	49%	27%	44%	66%	71%	25%	58%	46%	75%	45%

	St John's Hospitals	Community Services	LTC	Child Health	Regional Hospitals	Mental Health	In Patient LAMC	Day Patient LAMC	CPDM	Survey Summary Results
(Mean Disagreement rate)	(50%)	(51%)	(50%)	(52%)	(52%)	(36%)	(43%)	(38%)	(35%)	(51%)
My patients receive follow up after discharge.	54%	47%	38%	0%	40%	17%	63%	28%	0%	44%
Pts are transferred easily to and from where I work.	37%	56%	73%	60%	43%	43%	36%	32%	50%	43%
I communicate regularly with rehabilitation services providers at other EH sites about service provision.	50%	50%	29%	0%	50%	40%	38%	38%	75%	43%
When making pt referrals to other rehab services I have a clear understanding of the appropriate patient served by that site	31%	59%	50%	75%	8%	50%	42%	38%	50%	42%
Discharge criteria are consistent where I work.	30%	38%	NA	80%	79%	29%	64%	35%	25%	42%
I have adequate clerical support	21%	51%	67%	50%	80%	72%	41%	8%	25%	42%
My work Space is adequate for the provision of rehab	41%	54%	59%	100%	27%	50%	46%	48%	75%	52%
I have the tools (technology, equipment) to do my work.	37%	23%	58%	66%	47%	25%	26%	24%	0%	34%
Pts know who to contact if they have further rehab care needs.	20%	44%	50%	40%	35%	43%	32%	19%	0%	34%
Where I work pts/families receive adequate emotional support.	30%	50%	39%	33%	29%	29%	34%	13%	0%	33%
My patient caseload is manageable	24%	41%	76%	33%	40%	0%	10%	4%	50%	29%

Note:

St. John's Hospitals – St. Clare's and HSC
Community Services – Continuing Care, CLASS, and Community Support Program
LTC – Long Term Care
Regional Hospitals – Hospitals in Clarenville, Burin, Carbonear, Bonavista
CPDM – Centre for Pain and Disability Management

SUMMARY POINTS

- 4 of the top 5 concerns related to inadequate community supports (availability of housing, home support workers, equipment, renovations and rehabilitation services) to provide appropriate and safe discharge.
- Most respondents felt that there was insufficient rehabilitation staff to meet the needs.
- For respondents outside the L.A. Miller Centre, rehabilitation services were felt to be inaccessible.

B. ADULT REHABILITATION NEEDS AND GAPS SURVEY FOR PATIENTS AND FAMILIES

Surveys were sent to all patients seen in Rehabilitation at the L.A. Miller Centre in 2007-08. In administering the survey, it was difficult to identify patients and families in communities and facilities outside the L. A. Miller Centre, therefore packages of surveys were sent out to Regional Hospitals, Community Health, and Long Term Care Facilities within Eastern Health to have distributed to their patients. There were 266 surveys returned out of possible 800 that we believe were sent, with a 33% return rate. 167 respondents reported receiving rehabilitation, 72 reported being a family member of someone who had received rehabilitation and 27 respondents could not be identified. Some patients reported receiving care at one site and some received care at more than one site. Table 5 identifies where patients reported to have received rehabilitation services.

Table 5: Patient and Family Respondents by Service Area

Location of Services	Number of patients who reported receiving service at this site
Inpatients at LAMC	101
Rehab Day Services LAMC	96
Inpatient Rehab at another site in	32
Eastern Health	
Outpatient Rehab at another site	29
in Eastern Health	
Community	18
Nursing Home	30
Centre for Pain and Disability	10

The mean disagreement rate was calculated for each question and those items scoring above the mean disagreement rate were considered to be an "item of concern" (see Table 6). Below are the items that were of significance above the mean disagreement score for the patient and family survey. Overall, patients and families responded positively to most statements as compared to health providers.

Table 6: Patient and Family Survey Results

Adult Rehabilitation Needs and Gaps Survey for Patients and Families				
Significant Item	Disagreement			
(Above Mean Disagreement Rate 13.5%)	Rate			
After I (my family member) was discharged from inpatient rehabilitation, I (my family member) received rehabilitation services while at home	39%			
I (my family member) had follow-up visits after discharge from rehabilitation.	34%			
I (my family member) have (has) access to accessible transportation (example – wheelchair accessible) when needed.	28%			
Funding that I (my family member) needed for equipment /home renovations/home supports was available in time for me (my family member) to go home when ready	24%			
I (my family member) am (is) able to take part in community social and recreational activities.	24%			
After discharge I (my family member) had reasonable access to the community resources needed.	23%			
I (my family member) have (has) wheelchair access in my community to business and recreational buildings	22%			
How I (my family member) would be able to work in my (his/her) job was discussed during my (his/her) rehabilitation program.	20%			
I (my family member) have (has) access to affordable accessible housing if required (example – wheelchair accessible).	17%			
I (my family member) was given information about services in the community that would help	15%			
I (my family member) achieved what I expected in my (his/her) rehabilitation program	14%			
When I (my family member) went home, I (he/she) had everything needed (equipment, home support, home renovations) to live safely in the community	14%			

SUMMARY POINTS

- Overall patients and families did not identify areas of concern in actual provision of rehabilitation services in Eastern Health
- The main issues of concern related to post discharge services, follow-up and safe community living.

C. ADULT REHABILITATION NEEDS AND GAPS SURVEY FOR PRIVATE REHABILITATION PROVIDERS

Forty surveys were sent to private physiotherapists, occupational therapists, speech language pathologists, psychologists and multidisciplinary clinics. Fifteen surveys were returned with a return rate of 38%. Table 7 outlines the results of this survey.

Table 7:

Adult Rehabilitation Needs and Gaps Survey for Private Rehabilitation Providers				
Question	Disagreement Rate			
Rehabilitation patients have equitable access to the rehabilitation services they need within the public health care system	90%			
Patients and families are happy with the rehabilitation services provided within the public health care system (range of services, intensity, waiting times, expertise etc.)	75%			
I provide a service not offered in the public health care system	23%			
I am able to communicate and collaborate with my counterparts in the public health care system as needed	15%			

SUMMARY POINTS

- There are very few private rehabilitation providers servicing this group of patients.
- Most private service providers provide services that are also provided in the public system.
- Most respondents felt that their patients and families were not happy with public rehabilitation services nor did they have equitable access to those services.

D. FOCUS GROUPS

Most focus groups consisted of allied health disciplines such as physiotherapists, occupational therapists, speech pathologists, dietitians, psychologists, social workers, as well as nurses, and physicians. Three focus groups also included patients and family members and two focus groups consisting *only* of patients and family members. Table 8 outlines the location and composition of groups. Table 9 outlines the major themes identified.

Table 8: Focus Group Details

Date	Location	Topic	Attended By
Dec 8, 2008 –	1 st floor	Focus Group 1 -	16 participants representing
Monday	Conference RM	Human Resources	PT, OT, RT
,	Veterans	and Working	Dietetics, SW and Patient/family
	Pavilion, LAMC	Conditions for	
		Rehabilitationists	
		in Eastern Health	
Dec 9, 2008 –	1 st floor	Focus Group 2 -	13 participants representing
Tuesday	Conference RM	Community	PT, OT, REC, NS, SW,
•	Veterans	Supports,	Telemedicine, Medical Research
	Pavilion, LAMC	Accessible	
		Housing, and	
		Transportation	
Dec 10, 2008 -	1 st floor	Focus Group 3 -	16 participants
Wednesday	Conference RM	Who falls through	SLP, PT, OT, PSY, SW, NS and
	Veterans	the cracks?	Professional Practice
	Pavilion, LAMC		
Dec 11, 2008 –	1 st floor	Focus Group 4-	15 participants
Thursday	Conference RM	Rehabilitation	NS, PT, OT, SLP, PSY, SW,
	Veterans	Services in	Professional Practice and Admin
	Pavilion, LAMC	Community and	
		Long Term Care	
Dec 15, 2008 –	Board Room,	Focus Group 5 –	13 Participants
Monday	Interfaith	Gaps and Needs	PT, OT, NS, SW, Medicine,
	Citizen's Home,		Dietetics, Patient Educator, Admin
I 45, 0000	Carbonear	F 0 0	0 - 12 - 14 - 14 - 14 - 14 - 14 - 14 - 14
Jan 15, 2009 –	Conference	Focus Group 6 –	9 participants representing
Thursday	Room, Burin Peninsula	Gaps and Needs	PT, OT, NS, SW, Patient
	Health Care		
	Centre		
Jan 16, 2009 –	Conference	Focus Group 7 –	6 participants representing
Friday	Room	Gaps and Needs	PT, OT, NS, SW, SLP, and Dietetics
	Park Place	Capo ana moduo	1 1, 51, 110, 511, 521 , 4114 21515155
	Clarenville		
Jan 2009			
	Cafeteria	Focus Group 8	7 participants
	Cafeteria Conference	Focus Group 8 Gaps and Needs	7 participants Patients and family members
Feb 4, 2009	Conference		
	Conference Room LAMC	Gaps and Needs	Patients and family members
	Conference Room LAMC Grand Falls	Gaps and Needs Focus Group 9-	Patients and family members 19 participants representing
Feb 4, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital	Gaps and Needs Focus Group 9- Gaps and Needs	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient.
	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook	Focus Group 9- Gaps and Needs Focus Group 10 -	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT,
Feb 4, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western	Gaps and Needs Focus Group 9- Gaps and Needs	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient.
Feb 4, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial	Focus Group 9- Gaps and Needs Focus Group 10 -	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT,
Feb 4, 2009 Feb 5, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial Hospital	Focus Group 9- Gaps and Needs Focus Group 10 - Gaps and Needs	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT, NS, SLP, and SW
Feb 4, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial Hospital Goose Bay (St.	Focus Group 10 – Gaps and Needs Focus Group 10 – Gaps and Needs Focus Group 11 –	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT, NS, SLP, and SW 14 participants representing
Feb 4, 2009 Feb 5, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial Hospital Goose Bay (St. Anthony,	Focus Group 9- Gaps and Needs Focus Group 10 - Gaps and Needs	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT, NS, SLP, and SW
Feb 4, 2009 Feb 5, 2009 March 19, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial Hospital Goose Bay (St. Anthony, Labrador City)	Focus Group 9– Gaps and Needs Focus Group 10 – Gaps and Needs Focus Group 11 – Gaps and Needs	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT, NS, SLP, and SW 14 participants representing NS, SW, SLP, OT, PT, Medicine
Feb 4, 2009 Feb 5, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial Hospital Goose Bay (St. Anthony, Labrador City) Goose Bay (St.	Focus Group 10 – Gaps and Needs Focus Group 10 – Gaps and Needs Focus Group 11 – Gaps and Needs Focus Group 12 –	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT, NS, SLP, and SW 14 participants representing NS, SW, SLP, OT, PT, Medicine 12 participants - Patients and
Feb 4, 2009 Feb 5, 2009 March 19, 2009	Conference Room LAMC Grand Falls (Gander) Grand Falls Hospital Corner Brook Western Memorial Hospital Goose Bay (St. Anthony, Labrador City)	Focus Group 9– Gaps and Needs Focus Group 10 – Gaps and Needs Focus Group 11 – Gaps and Needs	Patients and family members 19 participants representing SW, PT, OT, NS, SLP, Dietetics, Administration, and patient. 10 participants representing PT, OT, NS, SLP, and SW 14 participants representing NS, SW, SLP, OT, PT, Medicine

Table 9: Focus Group Themes Summary Table (Includes 12 focus groups, sorted by number of references)

Theme	Sources	References	Words
	(# of focus groups)		
Rural/urban inequities	6	158	19824
Rehabilitation philosophy vs.	8	113	17965
medical model			
Financial issues and support for	10	107	11349
patients			
Lack of community rehabilitation	10	103	15367
Lack of rehabilitation in LTC	9	74	10831
Special populations/ people who do	9	61	8879
not have equitable rehabilitation			
access			
Patient access to equipment and	10	58	6879
home modifications			
Home care workers	9	58	5507
Lack of accessible transportation	7	52	4235
Inadequate discharge planning	11	51	5485
Lack of community supports	11	49	5713
Lack of rehabilitation in acute care	10	46	5489
hospitals			
Inadequate rehabilitation for the	12	41	6115
elderly			
Integration of rehabilitation services	9	40	6880
across the continuum of care			
Inadequate treatment space	7	40	3616
Problems navigating the health	6	38	6668
system			
Inadequate follow-up after discharge	11	35	3316
Lack of cognitive and psychosocial	6	35	6141
support/rehabilitation			
Education and continuing	8	34	2577
competency			
Issues with the LAMC	9	28	2123
Discharge from urban to	6	26	2513
rural/regional			
Recruitment	8	23	1770
Criteria for admission to the LAMC	6	21	4418
Inadequate treatment equipment	7	21	2075
Patient information systems	6	19	2202
Lack of accessible housing	6	18	2081
Long waiting lists	7	18	1495

Inadequate clerical support	6	18	1476
Educational opportunities	5	17	1179
Technology (computer) support	2	16	1248
Educational leave	5	15	1084
No coverage while on leave	2	11	432
Rehabilitation support workers	2	10	579
Need for mentorship	4	9	1082
Patient care issues	6	9	3037
Human resource issues	4	8	370
Measuring referral and patient	2	8	604
statistics in rehabilitation			
Inadequate computer terminal access	4	8	361
Electronic health record	3	6	669
Physicians and medical support	4	5	606
Accessibility of hospitals	2	7	399
Working conditions (general)	2	5	30
Time off	2	3	126

E. KEY INFORMANT INTERVIEWS

Key informant interviews were carried out across the province. Twenty-four individuals were interviewed and discussion themes were analyzed and compared to focus group feedback. Information from interviews was found to be in general agreement with information collected from focus groups. For information concerning those interviewed see Appendix B.

2. SECONDARY DATA

A. REHABILITATION PROGRAM PATIENT SATISFACTION SURVEY SUMMARY

April 2007- March 2008

2 North (specialized neurorehabilitation)

Overall, patients and families are satisfied (87%-100%) with the care they receive; domains include admission process, helpfulness, communication, respect, physical comfort, safety and security, team work, nursing, therapists, doctors, spiritual, discharge, goal, outcome, and quality.

Especially positive comments were made about the quality, competency and friendliness of nursing and therapy staff.

Especially negative comments were made about food, uncomfortable beds and inadequate bathrooms, and lack of follow-up after discharge.

2 South (orthopedic and regional rehabilitation)

Overall, patients and families are satisfied (84%-100%) with the care they receive; domains include admission process, helpfulness, communication, respect, physical comfort, safety and security, team work, nursing, therapists, doctors, spiritual, discharge, goal, outcome, and quality.

Especially positive comments were made about the quality, competency and friendliness of nursing and therapy staff.

Especially negative comments were made about food, inadequate bathrooms, lack of communication and continuity of care. Some patients felt they did not have enough to do to fill their time.

Outpatient Services (Day Hospital, Day Services, Prosthetics/Orthotics and Chronic Pain Services)

Overall, patients and families are satisfied (77%-100%) with the care they receive; domains include access, personal caring, communication, facilities and equipment, convenience, and quality. If the issue of parking was removed from the survey (77%), satisfaction would range from 90%-100%.

Especially positive comments were made about staff competency, compassion and caring.

Especially negative comments included inadequate parking, smoking near the main entrance, inaccessible washrooms and waiting areas, and crowded treatment space with no privacy (particularly in Physiotherapy). Patients and family had difficulty finding their way around and they wanted more therapy for longer.

April 2008- March 2009

2 North (specialized neurorehabilitation)

Overall, patients and families are satisfied (90%-100%) with the care they receive; domains include admission process, helpfulness, communication, respect, physical comfort, safety and security, team work, nursing, therapists, doctors, spiritual, discharge, goal, outcome, and quality.

Especially positive comments were made about the quality, competency and friendliness of nursing and therapy staff.

Especially negative comments were made about cosmetics of the facility, need for more therapy, quality of food, inadequate bathrooms, and communication with the team.

2 South (orthopedic and regional rehabilitation)

Overall, patients and families are satisfied (77%-100%) with the care they received; domains included admission process, helpfulness, communication, respect, physical comfort, safety and security, team work, nursing, therapists, doctors, spiritual, goal,

outcome, and quality. Notably, discharge planning and preparation scored the lowest with 23% of respondents indicating "fair" to "poor".

Especially positive comments were made about the quality, competency and friendliness of nursing and therapy staff. Patients enjoyed recreational activities.

Especially negative comments included too many patients sharing one bathroom (up to 6), cramped space, quality of food and communication between and with the team.

Outpatient Services (Day Hospital, Day Services, Prosthetics/Orthotics and Chronic Pain Services)

Overall, patients and families are satisfied (94%-100%) with the care they receive; domains include access, personal caring, communication, facilities and equipment, convenience, and quality.

Especially positive comments were made about staff competency, compassion and caring.

Especially negative comments included long waiting times, distance to travel to get services, inadequate parking and inaccessibility of facility, crowded treatment space and cosmetics of the space. Patients and family wanted more therapy closer to home.

B. NATIONAL REHABILITATION REPORTING SYSTEM (NRS) DATA

NRS data has been collected at the L.A. Miller Centre since 1997. Substantial improvements were made to Day Services and inpatient rehabilitation in 2005. Collection of this data after 2005 has been inconsistent. Not all patient care units were reporting NRS data nor was there complete data for remaining units. While this problem has now been corrected, there was only one year of accurate data that could be used for this project, April 1, 2005 to March 31, 2006 (Tables 10-12). Despite this being 05-06 data, there has been no major shifts in trends (as seen through other means of data collection) since that time and this data should be fairly representative of today. Table 13 shows partial 2007-2008 NRS data to demonstrate consistency.

L. A. Miller Centre NRS Review

April 1, 2005 to March 31, 2006

Admission Information

312 admissions to inpatient rehabilitation on 2 North and 2 South 97% of admissions were from acute care services.

Average age 67.6 yrs compared to 67.5 yrs in peer facilities and 70.8 yrs nationally. Pre-event, 80 % of patients were living at home; an additional 12.3 % with health

services. This is similar to national values.

Table 10: Number of admissions by client group compared to peer and national facilities April 1, 2005 – March 31, 2006

Admission Client	L.A. Miller Centre	Peer Facilities	National Facilities
Group	Number and % of	Number and % of	Number and % of
	total	total	total
Orthopedic	113 (36.2)	4516 (38)	18957 (52.1)
conditions			
Stroke	70 (22.4)	2104 (17.7)	5299 (14.6)
Medically	40 (12.8)	785 (6.6)	2963 (8.2)
Complex			
Amputation	23 (7.4)	708 (6.0)	1210 (3.3)
Spinal Cord	19 (6.1)	798 (6.1)	1087 (3.0)
Injury			
Brain Dysfunction	15 (4.8)	927 (7.8)	1460 (4.0)

Notes: In comparison to other facilities, the L.A. Miller Centre has a higher percentage of people with stroke (22% vs. 17.7%) or medically complex (12.8% vs. 6.6%) diagnoses.

Table 11: Functional Change (FIM score) from Admission to Discharge April 1, 2005 to March 31, 2006

Admission	L.A. Miller Centre			Peer Facilities		National Facilities			
Client									
Group									
Functional									
Status (FIM									
Score/126)									
	Admit	D/C	%	Admit	D/C	%	Admit	D/C	%
			change			change			change
All groups	78.9	102.6	34.7	83.4	104	29.2	85.9	105.5	26.3
Orthopedic	83.8	108.3	32.2	86.9	109.4	28.1	89.0	109.6	20.3
Conditions									
Stroke	71.7	95.4	40	75.4	97.2	35.6	76.9	98.4	34.7
Medically	80.1	100.8	27.5	86.6	103.6	22.9	86.9	103.7	21.9
Complex									
Amputation	97.6	114.5	19.7	95.1	108.1	15.3	92.4	106.3	16.8
Spinal Cord	63.3	95.2	51.9	75.7	97.1	31.8	76.9	97.6	30.6
Injury			_						
Brain	66.2	90.9	49.8	77.8	99.5	40.5	79.6	100.2	36.9
Dysfunction									

Note: Functional Independence Measure (FIM) scores range from 7 to 126. Patients scoring lower than 77 are considered moderately to severely disabled. Compared to other facilities, patients at the L.A. Miller Centre are admitted with lower functional scores. This is most noticeable in people with spinal cord injury and brain dysfunction. At discharge, patients at the L.A. Miller Centre show more improvement than similar patients in other rehabilitation facilities.

^{*}D/C - discharge

Table 12: NRS Discharge and Utilization by Client Care Groups April 1, 2005 to March 31, 2006

Admission	L.A. Miller	Centro	ntre Peer Faciliti			Facilities National Facilities			
Client Group									
	Onset to admission (days)	LOS	D/C home without services (%)	Onset to admission (days)	LOS	D/C home without services (%)	Onset to admission (days)	LOS	D/C home without services (%)
All groups	48	42	64.4	69	39	41.1	38	27	33.9
Orthopedic	21	31	68.3	16	25	51.2	12	18	41.1
Conditions									
Stroke	72	46	64.1	40	48	36.5	30	38	29.2
Medically	60	33	65.8	85	39	22.4	42	26	17.9
Complex									
Amputation	56	75	80.0	70	38	32.9	58	36	28.2
Spinal Cord Injury	20	76	57.9	267*	64	36.2	210*	54	34.2
Brain	85	57	41.2	101	68	38.8	77	54	34.0
Dysfunction									

Note:

- The L.A. Miller Centre has a longer interval from onset of condition to admission than national facilities but shorter interval than peer facilities with similar mandates. This is most notable for people with stroke. Patients with other disorders wait about the same or less to be admitted to rehabilitation at the L.A. Miller Centre compared to national institutions.
- Overall LOS is longer at the L.A. Miller Centre for most diagnoses, especially amputation and SCI.
- With the exception of people with brain dysfunction diagnosis, the majority of patients are discharged without any formal health services in place. In fact, the rate is about double that of other facilities.

^{*} The number of days from onset to admission for Spinal Cord Injury seems large however is correct for this reporting period.

^{*} LOS – Length of stay

^{*} D/C - Discharge

L.A. Miller Centre NRS Review

April 1, 2007 to March 31, 2008

Incomplete data, for comparison to 2005-2006 data in table 10

Admission Information

136 admissions, 97.1% from acute care services.

Average age 66.5 yrs compared to 67.0 yrs peer facilities and 71.0 yrs nationally. 78.3 % were living at home, additional 14.5 % with health services, similar to national values.

Table 13: Number of admissions by client group compared to peer and national facilities

Admission Client	L.A. Miller Centre	Peer Facilities	National Facilities
Group	Number and % of	Number and % of	Number and % of
	total	total	total
Stroke	41(30.1)	2104 (17.7)	5299 (14.6)
Orthopedic	35 (25.7)	4516 (38)	18957 (52.1)
conditions			
Debility	8 (5.9)		
Medically	7 (5.1)	785 (6.6)	2963 (8.2)
Complex			
Amputation	23 (7.4)	708 (6.0)	1210 (3.3)
Spinal Cord	19 (6.1)	798 (6.1)	1087 (3.0)
Injury			
Brain Dysfunction	15 (4.8)	927 (7.8)	1460 (4.0)

Note: There appears to be about 150 admissions missing from this data set. This may be due to the fact that NRS data submission was changed to a different provider at this time. No further analysis of this data was performed.

D. REHABILITATION PROGRAM INDICATOR REPORTS

April 1, 2005 - March 31, 2006

Table 14: A	Table 14: Admission Data 2005/2006						
	Inpatien Services		Outpatio	Outpatient Services			
	2 North/ 2South	Low Inten- sity Rehab Unit	Day Hospital	Out- patient Services	Chronic Pain & Disability Mgmt.	Orthotics	
Total Number of Patients	2N =172 2S =205	N/A	Admitted = 110 Visits = 1270	Individual stream data not available	Day Hospital = 54 visits (2 quarters only) Individual Stream = 635 visits (2 quarters only)	Visits = 1043 (2 quarters only)	
Occupancy Rate (%)	2N = 98 2S= 98.25	N/A	N/A	N/A	N/A	N/A	
Average Length of Stay (days)	2N = 46.63 2S = 39.63	N/A	N/A	N/A	N/A	N/A	
Total % Accepted Referrals	78.25	N/A	62	N/A	N/A	N/A	
% Accepted from City	92.25	N/A	95.5	N/A	N/A	N/A	
% Accepted from Outside of City	7.75	N/A	4.5	N/A	N/A	N/A	

Table 15: Admissions by Diagnosis 2005/2006						
	2 North/2 South Total (% Total)	Day Hospital Total (% Total)				
CVA/Stroke	96 (25.5)	66 (60)				
Spinal Cord Injury	14 (3.8)	8 (7.5)				
Head Injury	11 (2.9)	7 (6.3)				
MS/Other Neuro	14 (3.7)	18 (16.3)				
Amputee	23 (6.2)	0				
Hip Fracture	55 (14.5)	0				
Knee/Hip Replacement	35 (9.3)	0				
Other Orthopedics	47 (12.5)	8 (7)				
Other	72 (19.2)	3 (3)				
Total	367	110				

April 1, 2006 - March 31, 2007

Table 16: Admission Data 2006/2007						
	Inpatient		Outpatient Services			Prosthetics/
	Services					Orthotics
	2 North/ 2South	Low Intensity Rehab Unit	Day Hospital	Outpatient Services	Chronic Pain & Disability Mgmt.	
Total Number of Patients	2N =160 2S = 177	N/A	Admitted = 112 Visits = 2081	Visits =11903	Day Hospital = 53 visits Indiv.Stream = 3691 visits	2222 visits
Occupancy Rate (%)	2N = 98.25 2S = 98	N/A	N/A	N/A	N/A	N/A
Average Length of Stay	2N = 54.4 2N = 42.7	N/A	N/A	N/A	N/A	N/A
Total % Accepted Referrals	79.75	N/A	60	N/A	N/A	N/A
% Accepted from City	88.5	N/A	85	N/A	N/A	N/A
% Accepted from Outside of City	11.5	N/A	15	N/A	N/A	N/A

Table 17: Admissions by Diagnosis 2006/2007			
	2 North/2 South Total (% Total)	Day Hospital Total (% Total)	
CVA/Stroke	110 (32.7)	74 (66.5)	
Spinal Cord Injury	17 (5.1)	3 (2.5)	
Head Injury	5 (1.4)	3 (3)	
MS/Other Neuro	15 (4.4)	13 (12)	
Amputee	33 (9.7)	0	
Hip Fracture	28 (8.3)	0	
Knee/Hip Replacement	26 (7.7)	0	
Other Orthopedics	51 (15.2)	0	
Other	52 (15.5)	18 (16)	
Total	337	111	

April 1, 2007 - March 31, 2008

Table 18: Admission Data 2007/2008						
	Inpatient Services		Outpatient Services			Prosthetics/ Orthotics
	2 North/ 2South (days)	Low Intensity Rehab Unit (4 th Q only)	Day Hospital	Outpatient Services	Chronic Pain & Disability Mgmt.	
Total Number of Patients	2N=125 2S= 149	29	Admitted = 124 Visits = 2593	Visits= 10999	Day Hosp=34 visits Indiv.Stream= 2875 visits	Visits = 2769
Occupancy Rate	2N = 98 2S = 95	86	N/A	N/A	N/A	N/A
Average Length of Stay	2N = 65 2S = 48	48	N/A	N/A	N/A	N/A
Total % Accepted Referrals	2N = 84.5 2S = incomplete	N/A	62	N/A	N/A	N/A
% Accepted Referrals from City	2N = 85 2S = incomplete	100	95	N/A	N/A	N/A
% Accepted Referrals from outside city	2N = 15 2S = incomplete	0	5	N/A	N/A	N/A

Table 19: Admissions by Diagnosis 2007/2008				
	2 North/2 South Total (% Total)	Day Hospital Total (% Total)		
CVA/Stroke	104 (37.9)	71 (57.25)		
Spinal Cord Injury	23 (8.3)	7 (5.5)		
Head Injury	17 (6.2)	23 (18.75)		
MS/Other Neuro	20 (7.3)	7 (6)		
Amputee	19 (7.1)	6 (4.75)		
Joint Replacements	5 (1.8)	N/A		
Orthopedic	48 (17.4)	N/A		
Other	38 (14)	10 (7.75)		
Total	274	124		

In summary, the Rehabilitation Program of Eastern Health located at the L.A. Miller Centre sees approximately 350 inpatients per year. Most inpatients have either stroke or an orthopedic problem such as fracture or joint replacement. Occupancy of inpatient rehabilitation beds rarely falls below 98%. Most inpatients (90%) are referred from St. John's and surrounding area and about 80% of all referred inpatients are accepted for services.

The Rehabilitation Day Hospital, serves about 115 people annually. Most of the patients have had stroke (approximately 70 %). The remaining patients are receiving rehabilitation for problems associated with multiple sclerosis, brain injury, amputation, and spinal cord injury. Because patients need to have their own accommodations, most referrals are from St. John's and surrounding area. Sixty percent of referrals to Day Hospital are accepted and most of those who are not accepted are streamed into outpatient services for individual discipline therapeutic intervention. Outpatient Services, including single discipline services, prosthetics and orthotics, and the Centre for Pain and Disability Management account for approximately 20,000 visits per year (2005-2007 data).

Waiting Times

Table 20: Average Waiting Times for Inpatient Rehabilitation Services at the L.A. Miller Centre

(from date referred to date admitted)

Year	From city hospitals (days)	From regional hospitals (days)	Overall (days)
April 1 2005- March 31, 2006	unknown	unknown	8.2
April 1, 2006- March 31, 2007	unknown	unknown	7.4
April 1 2007- march 31, 2008	9.8	24.9	12.5
April 1, 2008- march 31, 2009	6.3	13.1	8.5

Notes: wait times overall have not changed from about 8 days since 2005. However, since specific regional data has been collected (2007), patients referred from outside city hospitals wait twice as long as those within the city. When evaluating where this extended wait occurs, in 2008-2009 it happened mainly between acceptance to admission.

E. NEWFOUNDLAND AND LABRADOR CENTRE FOR HEALTH INFORMATION (NLCHI) DATA

(Prepared by the Centre for Health Information, June 19th, 2009)

CIHI-ICD diagnostic codes were hand searched and matched to the National Rehabilitation Reporting System (NRS) codes (see pages 47-50). The most current year data available was 2006-07. In order to capture one year readmission rate, the previous year (2005-06) was analyzed.

In summary, in 2005-06 in Newfoundland and Labrador there were approximately 7855 admissions for disabling and chronic conditions (Table 21). Approximately 5000 were from Eastern Health (Table 23). About 40% were readmitted in one year (Table 27). Fourteen percent of these separations had ALC days (Table 28). In these separations, ALC days account for about 50% of the total length of stay.

Table 21: Number of Acute Care Hospital Separations for Selected Diagnostic Categories, Newfoundland and Labrador, 2005/06

Diagnostic Category	Number of Hospital Separations
Cardiac	2420
Pulmonary	1631
Orthopedic Conditions	1341
Rehabilitation	867
Stroke	746
Arthritis	310
Brain Dysfunction	215
Spinal Cord Dysfunction	86
Amputation of Limb	39
Major Multiple Trauma	23
Burns and Other Debilitating Impairments	9
Neurological Conditions	
Parkinson's Disease and extrapyramidal	
and movement disorders	51
Multiple Sclerosis	34
Polyneuropathies and Other Disorders of	
Peripheral Nervous System	17
Cerebral Palsy and Other Paralytic	
Syndromes	9
Guillain-Barre and Other Demyelinating	
Conditions	6
Other Neurological Conditions	51
Total	7855

Table 22: Total Length of Stay for Acute Care Hospital Separations for Selected Diagnostic Categories, Newfoundland and Labrador, 2005/06

Diagnostic Category	Length of Stay	Average LOS
	(Days)	(Days)
Cardiac	25,417	10.5
Pulmonary	17,450	10.7
Orthopedic Conditions	16,348	12.2
Rehabilitation	29,289	33.8
Stroke	15,845	21.2
Arthritis	2413	7.8
Brain Dysfunction	4164	19.4
Spinal Cord Dysfunction	1569	18.2
Amputation of Limb	323	8.3
Major Multiple Trauma	196	8.5
Burns and Other Debilitating		
Impairments	75	8.3
Neurological Conditions		
Parkinson's Disease and extrapyramidal		
and movement disorders	1003	19.7
Multiple Sclerosis	305	9.0
Polyneuropathies and Other Disorders		
of Peripheral Nervous System	235	13.8
Cerebral Palsy and Other Paralytic		
Syndromes	98	10.9
Guillain-Barre and Other		
Demyelinating		
Conditions	69	11.5
Other Neurological Conditions	673	13.2
Total	115,472	14.7

Table 23: Number of Acute Care Hospital Separations for Selected Diagnostic Categories¹, by Regional Health Authority of Service, Newfoundland and Labrador, 2005/06

Regional Health Authority	Number of Hospital Separations	
Eastern	5021	
Central	1151	
Western	1331	
Labrador-Grenfell	352	
Total	7855	

Table 24: Total Length of Stay for Acute Care Hospital Separations for Selected Diagnostic Categories¹, by Regional Health Authority of Service, Newfoundland and Labrador, 2005/06

Regional Health Authority	Total Length of	Average LOS
	Stay	
Eastern	70,164	14.0
Central	18,046	15.7
Western	23,521	17.7
Labrador-Grenfell	3741	10.6
Total	115,472	14.7

Source: Clinical Database Management System, Centre for Health Information, 2005/06

Table 25: Number of Acute Care Hospital Separations for Selected Diagnostic Categories¹ involving Patient Transfer to the L.A. Miller Centre, by Regional Health Authority of Service, Newfoundland and Labrador, 2005/06

Regional Health Authority	Number of Hospital Separations
Eastern	209
Central and Labrador-Grenfell	<5
Western	0

¹ See p47 for listing of diagnostic categories

Table 26: Number of Acute Care Hospital Separations for Selected Diagnostic Categories¹ involving Patient Transfer from Facility '001' to Another Facility, by Regional Health Authority of the Receiving Facility, Newfoundland and Labrador, 2005/06

Regional Health Authority	Number of Hospital Separations	
Eastern	414	
Central	22	
Western	10	
Labrador-Grenfell	14	
Out-of-Province	11	
Unknown	81	
Total	552	

Notes:

- 1) Facility '001' includes Health Sciences Centre, St. Clare's Mercy Hospital and Waterford Hospital
- 2) For Eastern RHA, 32 of the 414 patients were transferred elsewhere within Facility '001'
- 2) Unknown RHA indicates either: unclassified nursing home, community care or personal care

Table 27: Number of Acute Care Hospital Separations in 2006/07 for Patients Previously Hospitalized for Selected Diagnostic Categories¹ in 2005/06, by Regional Health Authority of Service, Newfoundland and Labrador

Regional Health Authority	Number of Hospital	% Readmissions at One
(2006/07)	Separations (2006/07)	Year
Eastern	1845	36.7
Central	627	54.4
Western	611	45.9
Labrador-Grenfell	187	53.1
Total	3270	41.6

Source: Clinical Database Management System, Centre for Health Information, 2005/06

Note: Number of hospital separations in 2006/07 (for any reason) for patients hospitalized for selected conditions in 2005/06 was determined by linking patient health care number for 2005/06 and 2006/07 hospital separations. Note that 103 patients hospitalized in 2005/06 had missing or invalid health care numbers and thus hospital separations for these people in 2006/07 could not be determined.

¹ See p47 for listing of diagnostic categories

Table 28: Number of Acute Care Hospital Separations for Selected Diagnostic Categories with Alternate Level of Care Days, Newfoundland and Labrador, 2005/06

Diagnostic Category	Number of Hospital Separations with Alternate Level of Care Days	
Cardiac	110	
Pulmonary	132	
Orthopedic Conditions	361	
Rehabilitation	118	
Stroke	177	
Arthritis	28	
Brain Dysfunction	36	
Spinal Cord Dysfunction	19	
Amputation of Limb	<5	
Major Multiple Trauma	5	
Burns and Other Debilitating Impairments	0	
Neurological Conditions		
Parkinson's Disease and extrapyramidal		
and movement disorders	11	
Multiple Sclerosis	5	
Polyneuropathies and Other Disorders of		
Peripheral Nervous System	<5	
Cerebral Palsy and Other Paralytic		
Syndromes	0	
Guillain-Barre and Other Demyelinating		
Conditions	<5	
Other Neurological Conditions	6	
Total	1017	

Table 29: Length of Stay for Acute Care Hospital Separations for Selected Diagnostic Categories with Alternate Level of Care Days, Newfoundland and Labrador, 2005/06

	Length of Stay (Days)		
Diagnostic Category	Total Length of Stay	Alternate Level of Care Length of Stay	% ALC Days of Total LOS by Client Group
Cardiac	4364	2117	48.5
Pulmonary	5343	3132	58.6
Orthopedic Conditions	7391	3629	49.1
Rehabilitation	6673	4130	61.9
Stroke	7174	4117	57.4
Arthritis	563	247	43.9
Brain Dysfunction	2305	1017	44.1
Spinal Cord Dysfunction	725	437	60.3
Amputation of Limb	16	8	50
Major Multiple Trauma	72	21	29.2
Burns and Other Debilitating Impairments	0	0	0
Neurological Conditions			
Parkinson's Disease and extrapyramidal and movement disorders	597	360	60.3
Multiple Sclerosis	114	37	32.5
Polyneuropathies and Other Disorders of Peripheral Nervous System	96	41	42.7
Cerebral Palsy and Other Paralytic Syndromes	0	0	0
Guillain-Barre and Other Demyelinating Conditions	50	14	28.0
Other Neurological Conditions	267	111	41.6
Total	35,750	19,418	54.3

Note: Total length of stay is the sum of acute length of stay and alternate level of care days.

Table 30: Number of Acute Care Hospital Separations for Selected Diagnostic Categories¹ with Alternate Level of Care Days, Newfoundland and Labrador, by Regional Health Authority of Service, 2005/06

Regional Health	Number of Hospital	% of Total Separations
Authority	Separations (with ALC)	
Eastern	722	14.4
Central	135	11.7
Western	152	11.4
Labrador-Grenfell	8	2.3
Total	1017	12.9

Table 31: Length of Stay for Acute Care Hospital Separations for Selected Diagnostic Categories¹ with Alternate Level of Care Days, by Regional Health Authority of Service, Newfoundland and Labrador, 2005/06

	Length of Stay (Days)		
Regional Health Authority	Total Length of Stay	Alternate Level of Care Length of Stay	% ALC Days of Total LOS by Health Authority
Eastern	17,471	7613	43.6
Central	7387	4816	65.2
Western	10,544	6773	64.2
Labrador-Grenfell	348	216	62.1
Total	35,750	19,418	54.3

Source: Clinical Database Management System, Centre for Health Information, 2005/06

General Notes:

- 1) Hospital separations for patients under 16 years of age at admission are excluded from the data
- 2) A patient may have been hospitalized more than once in a fiscal year and thus number of hospital separations may be greater than the number of patients hospitalized.
- 3) Hospital separations include only acute care (inpatient) hospital separations with a most-responsible diagnosis code or principal intervention code falling into one of the diagnostic categories below. If a hospital separation was associated with an intervention code and a diagnosis code in different categories below, it was categorized according to the diagnosis code so that the hospital separation was not double-counted.

¹ See p47 for listing of diagnostic categories

Diagnostic Categories

Stroke:

ICD-10-CA Diagnosis codes:

- I60 Subarachnoid hemorrhage
- I61 Intracerebral hemorrhage
- I62 Other non-traumatic intracranial hemorrhage
- I63 Cerebral infarction
- I64 Stroke, not specified as hemorrhage or infarction
- I68 Cerebrovascular disorders in diseases classified elsewhere
- I69 Sequelae of cerebrovascular disease

Brain Dysfunction:

ICD-10-CA Diagnosis codes:

C71 Malignant neoplasm of brain

D33 Benign neoplasm of brain and other parts of the Central Nervous System

Excluding

D33.4 Benign neoplasm of spinal cord

D43 Neoplasm of uncertain or unknown behaviour of brain and the Central Nervous System Excluding

D43.4 Neoplasm of uncertain or unknown behaviour of spinal cord

F06 Other mental disorders due to brain damage and dysfunction

G46 Vascular syndromes of brain in cerebrovascular diseases

S06 Intracranial injury

S07 Crushing injury of head

T58 Toxic effect of carbon monoxide

T71 Asphyxiation

Spinal Cord Dysfunction

ICD-10-CA Diagnosis codes:

- B91 Sequelae of poliomyelitis
- C72.0 Malignant neoplasm of spinal cord
- C72.1 Malignant neoplasm of cauda equina
- C72.8 Overlapping malignant lesion of brain and other parts of the Central Nervous System
- C72.9 Malignant neoplasm of Central Nervous System, unspecified
- D33.4 Benign neoplasm of spinal cord
- D43.4 Neoplasm of uncertain or unknown behaviour
- S32 Fracture of lumbar spine and pelvis
- S34.1 Injury of lumbar spinal cord
- S34.2 Injury of root of lumbar spinal cord
- S34.3 Injury of cauda equina
- S34.4 Injury of lumbosacral plexus

Amputation: of Limb:

ICD-10-CA Diagnosis codes:

- S48 Traumatic amputation of shoulder and upper arm
- S58 Traumatic amputation of forearm
- S78 Traumatic amputation of hip and thigh
- S88 Traumatic amputation of lower leg
- S98 Traumatic amputation of ankle and foot
- T87 Complications peculiar to reattachment and amputation

Arthritis:

ICD-10-CA Diagnosis codes:

Pyogenic Arthritis, multiple sites: M00.00, M00.10, 00.20, 00.80, 00.90

Direct infections of joint in infectious parasitic diseases classified elsewhere, multiple sites M01.00, M01.10, M01.20, M01.30, M01.40, M01.50, M01.60, M01.80

Post-infective and reactive arthropathies in diseases classified elsewhere, multiple sites M03.00, M03.10, M03.20, M03.60,

M05 Serpositive rhematoid arthritis

M06 Other rhematoid arthritis

M07 Psoratic and enteropathic arthropathies

M08 Juvenile arthritis

M09 Juvenile arthritis in diseases classified elsewhere

M45 Ankylosing spondylitis

M46 Other inflammatory spondylitis Excluding M46.4 Discitis

M47 Spondylosis

M48.0 Spinal Spondylosis

M48.1 Ankylosing hyperostosis

M48.3 Traumatic spondylopathy

M48.90 Spondylopathy, unspecified, multiple sites in spine

M49.4 Neuropathic spondylopathy

M49.5 Collapsed vertebra in diseases classified

Orthopedic Condition (Diagnosis code and/or intervention code present):

ICD-10-CA Diagnosis codes:

M86.00 Acute haematogenous osteomyelitis, multiple sites

M86.10 Other acute osteomyelitis, multiple sites

M86.3 Chronic multifocal osteomyelitis

M86.4 Chronic osteomyelitis with draining sinus

M86.4 Other osteomyelitis

M86.9 Osteomyelitis, unspecified

CCI Intervention Codes:

1.VA.73.^^ Reduction, hip joint

1.VA.74.^^ Fixation, hip joint

1.VC.73.^^ Reduction, femur

1.VC.74.^^ Fixation, femur

1.VA.53.^^ Implantation of internal device, hip joint

1.VG.53.^^ Implantation of internal device, knee joint

Cardiac:

ICD-10-CA Diagnosis codes:

I24 Acute myocardial infarction

I25 Subsequent myocardial infarction

I50 Heart Failure

197.1 Other functional disturbances following cardiac surgery

Pulmonary:

ICD-10-CA Diagnosis codes:

J42 Unspecified chronic bronchitis

J43 Emphysema

J44 Other chronic obstructive pulmonary disease

Burns and Other Debilitating Impairments:

ICD-10-CA Diagnosis codes:

T29 Burns and corrosions of multiple body regions

(excluding first degree burns and corrosions – T29.1 and T29.5)

T30 Burn and Corrosion, body region unspecified

(excluding first degree burns and corrosions – T30.1 and T30.5)

T31 Burns classified according to extent of body surface

(excluding those covering less than 10% of body – T31.00 and T31.10)

T32 Corrosions classified according to extent of body surface

(excluding those covering less than 10% of body – T32.00 and T32.10)

E66.2 Extreme obesity with alveolar hypoventilation

E66.9 Other obesity

Major Multiple Trauma:

ICD-10-CA Diagnosis codes:

Y85 Sequelae of transport accidents

Y86 Sequelae of other accidents

Y87 Sequelae of intentional self-harm, assault and events of undetermined intent

S44 Injury of nerves at shoulder and upper arm level

S47 Crushing injury of shoulder and upper arm

S54 Injury of nerves at forearm level

S57 Crushing injury of forearm

S67 Crushing injury of wrist and hand

S69 Other and unspecified injury of wrist and hand

S74 Injury of nerves at hip and thigh level

S77 Crushing injury of hip and thigh

S84 Injury of nerves at lower leg level

S87 Crushing injury of lower leg

S97 Crushing injury of ankle and foot

T02 Fractures involving multiple body regions

T03 Dislocations, spains and strains involving multiple body regions

T04 Crushing injuries involving multiple body regions

T05 Traumatic amputations involving multiple body regions

T06 Other injuries involving multiple body regions

T07 Unspecified multiple injuries

Rehabilitation:

ICD-10-CA Diagnosis codes:

Z44 Fitting and adjustment of external prosthetic device

Z50 Care involving use of rehabilitation procedures

Excluding alcohol and drug rehabilitation (Z50.2 and Z50.3)

Z54 Convalescence

Neurological Conditions:

ICD-10-CA Diagnosis codes:

Multiple Sclerosis:

G35 Multiple Sclerosis

Parkinson's Disease and other Extrapyramidal and Movement Disorders:

G20-G26 Extrapyramidal and movement disorders

Polyneuropathaies and Disorders of the Peripheral Nervous System:

G60 Hereditary and idiopathic neuropathy

C61 Inflammatory polyneuropathy

C62 Other Polyneuropathies

C63 Polyneuropathy in diseases classified elsewhere

Guillain-Barre Syndrome and Other Demyelinating Disorders:

G36 Other acute disseminated demyelination

C37 Other demyelinating diseases of the Central nervous System

Cerebral Palsy and Other Paralytic Syndromes

G80 Infantile cerebral palsy

G81 Hemiplegia

G82 Paraplegia and tetraplegia

G83.2 Monoplegia of upper limb

Other Neurological Conditions

F82 Specific developmental disorder of motor function

G09 Sequelae of inflammatory diseases of the Central Nervous System

G10-G13 Systemic atrophies affecting the Central Nervous System

G54 Nerve root and plexus disorders

G55 Nerve root and plexus compressions in diseases classified elsewhere

G56 Mononeuropathies of upper limb

G57 Mononeuropathies of lower limb

G73 Disorders of myoneural junction and muscle in diseases classified elsewhere

- 4) '<5' indicates a cell count less than 5 is suppressed due to confidentiality policies
- 5) A patient with Alternate Level of Care Days has finished the acute care phase of his/her treatment but remains in an acute care bed, usually awaiting placement in a chronic unit, nursing home or home care.

DISCUSSION

PHILOSOPHY

Rehabilitation Scope of Practice

The 'scope of practice' is the range of knowledge and skills that a provider can draw upon to help a person optimize their function after injury or due to a disease or a disorder. We heard that because of a lack of human resources and vacant positions, especially in rural areas and in the community, the scope of practice for the remaining rehabilitation service providers has narrowed. This means that they focus on emergent issues, falls, injuries, equipment prescription and place less emphasis on prevention, best practice, maintaining health, and planning. Rehabilitation providers constantly feel their ethics challenged when they have to prioritize patients; when they know all the patients on their caseload or waiting lists have genuine rehabilitation needs.

"There is nothing more frustrating when you receive an email for trigger 3. Discharge as many people as you can. They are there because they still need care. Professional judgment and standards are compromised."

Promoting a Rehabilitation Philosophy

We heard mainly in focus groups (113 references in 8 of 12 groups) that rehabilitation providers are frustrated with practicing in a health model that they feel promotes curing of illness rather than achieving health. Providers feel that rehabilitation is without direction in the province. Key informants and focus group participants were concerned that there is no provincial rehabilitation framework. Providers and patients feel that rehabilitation should be delivered where the person needs it. A rehabilitation model of care is very different than a medical model. The focus is on health, independence and quality of life. We heard that more patients are now discharged home from emergency and acute and rehabilitation care who would have stayed in hospital 20 years ago. There are concerns that the health care system has put meager resources in place to support people who are at home. It was recognized that, after a severe injury, people need help to solve their challenges at home, such as managing money, finding bus routes, preparing meals, etc. In general, this does not happen.

Rehabilitation providers, patients and families felt that independence and mobility could be fostered to a greater extent in LTC, rehabilitation and acute care. Patients should be encouraged to be mobile. They should receive help to go to the washroom instead of catheters and diapers. Patients are not walked to the washroom enough.

"A lot of the incontinence we see is environmental incontinence"

It was felt that every care provider should identify areas in which patients can learn independence. Nursing staff, in particular, at all levels of the continuum, need encouragement and education to foster a rehabilitation model of care. Respondents suggested simple steps such as informing patients that they must have pants, slippers and socks because they will be out of bed as much as possible.

Because the complex nature of disability, many team members are required. We heard that there is a 'silo approach' to thinking, "well rehabilitation is your job, not mine"; not realizing that every provider, the family and the patient has a role to play regardless of where they are along the continuum. We can promote independence or dependence; this is a choice and a philosophy. In some settings, such as LTC and acute care, a rehabilitation approach to care takes more coordination, more communication and more time to assist a person to do for themselves. However, over time, with a consistent approach, the person will be able to do more themselves. There is an 'up front' investment for long term gain.

Many processes in place in our system do not foster a 'client-centered' approach to care. We heard that vulnerable patients and distressed families must navigate a complex health system and community supports process to find rehabilitation, safe equipment and housing. The issue of health care system navigation was highlighted in survey findings with 52% of providers indicating they were not sure where and how to access the most appropriate rehabilitation service for their patients. Navigation difficulties were identified in 6 of 12 focus groups with 38 references. For example, clients waded through complicated phone message boxes only to be told they did not qualify for community supports. For example, application forms for financial eligibility assessment are up to 25 pages long.

We heard that because rehabilitation resources are scarce, there is little time for prevention. It was clear that prevention and health promotion in the disabled population is not addressed because everyone is scrambling to provide post-event service. This occurs despite recognizing that most rehabilitation patients (stroke, amputees, medically complex) have co-morbidities including cardiovascular disease and diabetes, which have contributed to their event. Education in the community is not a priority. We need nurses, physicians, nutritionists to work together to identify people at risk.

ACCESS TO SERVICES

Equitable Access

Equity of access to services based on need is a defining element of the Canadian Health Care System ². Issues limiting equitable access to services by individuals requiring rehabilitation generated many comments in all surveys. Sixty percent of rehabilitation service provider respondents did not feel that their clients had equitable access to rehabilitation services. Of note, 89% of service providers from the community and 83% of service providers in long term care did not feel that their clients had equitable access to rehabilitation while 90% of private service providers did not feel their clients had equitable access. Eleven percent of patients and family respondents felt that they did not have reasonable access to the rehabilitation services they needed.

Focus groups also generated a significant amount of discussion on this issue. There were 284 references to this topic in the 12 focus groups. People discussed special populations that do not have equitable access, as well as inadequate access to rehabilitation services in acute care, community, and long term care. Many providers took issue with criteria for L.A. Miller Centre admission; indicating that the criteria were restrictive, excluding people who had significant rehabilitation needs.

There were a number of issues and circumstances affecting access for different groups of patients:

1. They wait too long in acute care after injury thereby missing the 'window of recovery'.

Fifty-five percent of health providers indicated that wait times for rehabilitation were not reasonable particularly in community health (77%), LTC (94%), and Chronic Pain services (100%). Although most providers agreed that waiting times for the L.A. Miller Centre have decreased over the past few years, providers in rural areas felt that their patients wait longer for admission than patients referred from city hospitals. Although admission to a rehabilitation bed is based on both patient urgency and position on the waiting list, in practice, pressure by acute St. John's hospitals affects admissions at the L.A. Miller Centre. People waiting for admission are often displaced by patients who need to be discharged from the Health Sciences Centre. This was confirmed when evaluating the days waiting for admission to the L.A. Miller Centre for patients from St. John's hospitals versus regional and rural centers. In 2007-2008 patients from city hospitals waited 10 days while those outside the city waited 25 days from acceptance to admission. In 2008-2009, this improved, with city-referred patients waiting 6 days while those outside the city waiting 13 days. Only 10-15 % of the total number of referrals to the L.A. Miller Centre comes from outside St. John's. NLCHI data support that there are almost no transfers from other regional health authorities outside Eastern Health to the L.A. Miller Centre. This disparity between waiting times is believed to be due to pressure, primarily from acute services at the HSC, to move patients to the next level of care to make more acute care beds available. This crisis situation is almost a weekly occurrence. We heard that patients can wait for months to be admitted to rehabilitation at the O'Connell Centre at Western Health.

"I am from Labrador City. My wife had a major stroke last year, we waited 5 weeks in the HSC for a bed at the Miller Centre. Stroke victims of a lesser degree (they could talk and get around by themselves) were sent to the Miller Centre before my wife. These were locals (Bell Island, St. John's). This was a big expense to me, staying at a hotel."

2. They do not meet 'tertiary rehabilitation criteria'.

Many respondents felt that there was limited access to the tertiary rehabilitation services located at the L.A. Miller Centre. Fifty-two percent of rehabilitation provider respondents felt that their patients did not have equitable access to tertiary rehabilitation. They felt that the criteria were too restrictive, ever-changing and vague. Of particular significance, 100% of respondents from Child Health and Mental Health and 88% of respondents from

Long Term Care did not feel their clients had equitable access to tertiary services at the L.A. Miller Centre. There were 21 references specifically about dissatisfaction with Miller Centre criteria in 6 of the 12 focus groups. When assessing the percentage of patients accepted to the Miller Centre, we see that about 80% of patients referred are accepted to the inpatient service and about 60% accepted to the day hospital. We do not know what the outcome for the patients not accepted nor do we know the extent to which patients are pre-screened by their health providers and never referred to rehabilitation. Anecdotally, it was reported that those patients not accepted to Day Hospital were placed more appropriately in the single discipline outpatient stream. We heard in focus groups that many patients in acute care are not referred to tertiary services because they are destined for LTC, they have severe deficits or they are 'not motivated'. In actual fact, all these patients should be at least assessed by a navigator or rehabilitation coordinator in order to determine true regional and provincial rehabilitation needs and the best service for that patient. Despite these concerns, it was reported that the process of referral, assessment and admission seems to have become more transparent and better communicated.

Inclusion criteria exist to help referral sources identify which patients can benefit most from rehabilitation services at the Miller Centre. The L.A. Miller Centre has moved to a central referral/intake system with updated criteria. Even though this information is posted on the Eastern Health Intranet and the discharge coordinator holds regular information sessions, health providers especially outside Eastern Health do not know how to access services. Fifty—two percent of rehabilitation providers surveyed indicated that they did not have a clear understanding of rehabilitation services provided at other sites. Although designed to be clear, elements of the admission criteria can be interpreted in different ways (e.g. 'need for a discharge plan', 'ability to understand and learn', 'motivation to participate'). It was reported that people who have family to care for them and advocate for them seem to be more successful getting into the L.A. Miller Centre. In focus groups, families reported extreme frustration in trying to 'get in' to the L.A. Miller Centre. Problems navigating the health system were raised in 6 of the 12 focus groups with 38 references.

There are many sub-groups of patients that have specialized needs that do not receive rehabilitation in a coordinated way. Services at the L.A. Miller Centre are geared

[&]quot;There is very limited access to this service."

[&]quot;Criteria for admission need to be reviewed. It needs to be as objective and documented as possible."

[&]quot;In-services would be beneficial concerning services offered and criteria for admission".

[&]quot;Criteria create gaps".

[&]quot;Because the criteria is so tight we can't get to access or to send them where you want to send them"

toward those with intensive tertiary rehabilitation needs; those with stroke, amputation, complicated fractures, spinal cord injury etc. Young adults with developmental disability, for example, are a special group that, after transitioning from Child Health, generally have need for follow-up or have vocational and/or social/recreational needs. Services to this group are best done from community. However, we know this does not exist.

Many patients are turned away from the services at the L.A. Miller Centre if they have an unstable mental health problem due to the lack of psychological and psychiatric services available at this site. There is no coordination between Mental Health and Rehabilitation despite significant overlapping care requirements especially for people with brain injury (see below for continued discussion).

It is also difficult for patients from long term care to access tertiary rehabilitation services. Some rehabilitation providers reported that patients referred for tertiary services from long term care experience a longer wait time and they do not receive equitable service. Also, following acute care, because patients are destined for long term care, they are sometimes not referred for tertiary services. While there is often a need for long term care residents to access tertiary rehabilitation following an injury or illness, the residents' follow-up or maintenance is most appropriately done in the long term care facility or community, and not through highly specialized intensive service. Despite a person's level of disability, there may be room for improvement to a level such that they would require less care. Unfortunately there are simply too few rehabilitation providers in LTC and community to provide rehabilitative care.

Surveys indicated that respondents believe that there is limited access to specialty tertiary rehabilitation services such as chronic pain management, specialty seating, driving etc. or services of disciplines in short supply, such as psychology, prosthetics and orthotics services. Waiting lists for outpatient services especially specialty services such as seating and driving are very long- up to 8 months. Waiting lists for therapy at the L.A. Miller Centre ranges from 2 weeks for urgent cases to 6 months for non-urgent cases.

3. They live too far away from a rehabilitation site (St. John's, Corner Brook) and either they or their family cannot relocate.

We heard that in order to receive inpatient rehabilitation, patients and their families must live or relocate to St. John's or Corner Brook. There is a hostel as well as extended stay apartments in St. John's however they are user-pay and transportation to and from the L.A. Miller Centre is costly. Focus groups and surveys confirmed a rural/urban divide in access to rehabilitation. It generated the highest number of references (158) in 6 of the 12 focus groups. Some felt that people from outside the St. John's area did not have equitable access to tertiary services because of the high costs of transportation and accommodations involved for them to attend. Labrador and St. Anthony have critical issues around transportation. The cost of commercial aircraft and Medivac flights limits the patient's ability to access rehabilitative care.

Many patients and their families, after receiving care in their regional hospital, choose to stay in their regional or primary health facility. NLCHI data and Rehabilitation Program indicators show that very few people are transferred to the L.A. Miller Centre from outside Eastern Health. We did not analyze O'Connell Centre data which may indicate that patients in Central, Western and Labrador Grenfell transfer there for rehabilitation. We heard that patients choose to remain home knowing that they will

receive very limited or no rehabilitation. They choose between receiving family support or the necessary rehabilitative care. Unfortunately we see a disparity between Eastern Health and other regional health authorities in readmissions of rehabilitation patients. NLCHI data show that about 37% of patients with rehabilitation-matched health codes are readmitted to hospital within one year in Eastern Health. Readmission rate is 54.4% in Central Health, 45.9% in Western Health and 53.1% in Labrador Grenfell Health.

"Well I know for me, one of the options when my Dad was in St. Clare's in St. John's was to continue rehab in the L.A. Miller Centre. But he's 81 years old, he wasn't in a position to speak for himself so he needed an advocate there. And for us as a family, we had been in St. Clare's, myself traveling back and forth from Happy Valley-Goose Bay, my brothers and sisters from Toronto, at different intervals in order to be there for him. But to continue on with rehabilitation at the L.A. Miller Centre was not an option. For one factor was cost and for two, just to leave him there on his own. It wouldn't have been good for him and he really needed someone to speak for him."

"For one thing, I am from St. Anthony, I was at the Miller Centre for six weeks. The therapy there was excellent. But there are no living accommodations. We didn't have any family, nothing."

"We have a gentleman in Port aux Basques who is in long term care and he is 56. He had a burn injury and needs intensive therapy. He has no family but could live in the community with the right supports. We have no OTs in Port aux Basques. He has ended up there because of circumstances. There is nowhere for him to go"

"I don't like to drive to Burin two or three times a week for physio. There is a perfectly equipped room in Grand Bank but no staff. I want to be walking like yesterday"

"But there are no services available in rural Newfoundland and you just can't pick up and run off to St. John's. A lot of us don't have family in there and even if we do have family, it is a really burdensome thing. We need to have a facility that we can avail of in our region that the people can have access and we can have access to professional services. A lot of it is, I find, is basically talking."

"A comment was made to me that once my father comes home there will be less services to him. Like he is better off staying in the hospital for as long as he can because he will get more physiotherapy there. I am reluctant to take him out because I want him to get as better as he can."

"There is no speech pathologist in Labrador City. Me, I'm limited in my speech so there is no speech pathologist here so I did without my speech. There is no psychology anywhere."

"I know in Cartwright you can't get no benefits to travel from Cartwright to St. Anthony for medical reasons. It's like he's supposed to go and see a doctor next week but you just can't afford it. Who can take \$1400 and travel to St. Anthony for an appointment?"

4. <u>Patients' needs are in a sub-specialty area and there is no provincial program or limited and inadequate service to meet their needs.</u>

There are specific groups of patients, albeit small in numbers, who have intensive rehabilitation needs. There are other groups that have lobbied for years for services but remain in need. This issue was raised in 9 of the 12 focus groups with 61 references.

Life skills/vocational training

Young adults with developmental disability and adults with brain injury require a community-based program that focuses on learning or relearning life skills such as money management, child care, meal preparation, socially appropriate behavior and decision-making. Issues around cognitive and psychosocial rehabilitation were raised in 6 of the 12 focus groups with 35 references.

Young adults with disability often referred to as Children's Rehab Graduates, have lived with their parents into adulthood and often have not learned the skills required to live independently. These young adults were accustomed to having their care arranged for them by parents and health providers. However, when they reached 19 years they were expected to initiate that interaction independently-a huge chiasm.

"The other thing too, I have noticed a lot of their kids (Children's Rehab) have a lot of significant issues and when they do discharge them, they don't really fall under any specific program, per se. Before they were so used to having everything catered to them at the Janeway and their traveling clinics that once they leave, once they become adults, they don't know where to go. The family struggles after that."

"While we service a pediatric population, parents of 20, 30 even 40 year olds will call us frustrated or not knowing where to turn or unable to travel to St. John's or to have a suitable place to stay if they can get there. We feel there is a definite gap in service and care for individuals > 16 years with developmental issues which affect mobility and their ability to avail of rehabilitation. These individuals require care and services in the community; otherwise they remain in hospital, creating extra burden and expense to the hospital system."

Another group of individuals who are chronically underserved are people with brain injury (both traumatic and non-traumatic) who wish to integrate back into their communities. Brain injury causes not only physical impairments but also behavioral, personality and intellectual change. There is no supportive work or living environments that help patients learn skills to become independent. Organized vocational rehabilitation for people after stroke or other injury is a specialty that we no longer provide. The L.A. Miller Centre does not provide structured cognitive rehabilitation despite evidence that cognitive rehabilitation can improve functioning as much as physical rehabilitation in people with stroke and brain injury ⁵.

"If you are very lucky you have an insurance plan that pays for that"

"We discharge these people. They are not back to work, not back to school, and at the last meeting, its like 'well you're done now'. I feel we are misleading them all the way along"

Patients with both cognitive behavioral and psychiatric needs

Our findings indicated that people with unstable mental illness who also need physical or cognitive rehabilitation do not always receive the care they need. They are often not accepted into rehabilitation and if they are, it is without the support of a mental health team.

There is another group of mild brain injured patients who also do not receive adequate rehabilitation. At times mild brain injury may result in intellectual and behavioral changes that are undetected in an emergency room or during a brief hospital stay. Many of these patients have neuropsychiatric needs; their behavioral and cognitive changes leave them unable to fulfill their former roles in family and work. The needs of these individuals are varied and they are usually never referred for rehabilitation. Unfortunately some become involved in the justice system.

"The walking wounded, one of my clients calls himself"

"Dave, at 59, has fallen right in the middle where there is no help at all; he is not geriatric and he is not a child. There is nowhere for him to go. At the Waterford he was with dementia patients, Alzheimer's patients. I saw my husband go from happy go lucky to a basket case".

"There is NO Long Term Rehab Program for brain tumor survivors. This needs coordination for audiology, neuro-psychology, neuro-psychiatry. 50% of my elderly patients have hearing issues. My Husband is a long-term Brain Tumor Survivor with NO access to appropriate rehab."

"There are few supports for clients with head injuries to help them reintegrate into the community".

Other special populations

In some cases the patient, family and their health providers are not aware that they could benefit from rehabilitation. For some diagnostic groups there are no services offered or services that are offered are underdeveloped, emerging or inadequate to meet their rehabilitation needs. The services that are available may be inadequately promoted and service providers are not aware that they exist or how to access them. Survey respondents, focus group participants and interviewees identified several patient groups that need rehabilitation. As sub-groups they are small in number and it is not clear where they should receive rehabilitation. On review of the needs of these groups, some common themes emerge; 1. They have chronic conditions, 2. They require help to safely increase their physical activity tolerance and ability to do their daily activities 3. They need help to learn to self-manage their symptoms (pain, shortness of breath, weakness) and improve their lifestyle.

These include:

- patients with morbid obesity (bariatric)
- patients with cancer (i.e. post mastectomy, lymphoedema patients, patients who have long term complications following radiation, etc)
- patients requiring cardiac rehabilitation (those without surgical intervention)
- patients who are de-conditioned due to long hospital stay, etc
- patients with arthritis (OA/RA)
- patients with orthopedic problems (total hip replacements, total knee replacements etc.)
- patients requiring pulmonary rehabilitation, (Cystic Fibrosis patients especially pre/post lung transplant)
- patients requiring rehabilitation following vascular surgery
- patients requiring back care in combination with other health problems
- patients with burns requiring rehabilitation
- patients with chronic pain
- patients requiring chronic disease management

The Rehabilitation Program has not promoted the referral of these special groups, nor does it have the space or human resources to offer services. There are some limited services available in other programs in Eastern Health for some people who meet their criteria (e.g. Pulmonary Rehabilitation, Cardiac Rehabilitation), however services are fragmented with limited human resources, space and equipment. The lack of critical masses of patients within specific diagnostic groups precludes diagnostic-specific rehabilitation programs, common in larger provinces. It is clear from many fronts that the criteria must be more inclusive; that the needs of each rehabilitation patient should be evaluated with every effort to obtain service for them. In order to provide adequate accessible rehabilitation services for these groups, to enable them to maintain their independence and mobility, we need to assess where services have fallen short and endeavor to provide the services needed. Failure to address the issue of chronic diseases at the rehabilitation stage will only serve to increase demand on already overburdened acute care services. Inclusive outpatient rehabilitation programs for high risk groups such as those above should be equipped with appropriately trained staff with appropriate equipment in an accessible space.

QUALITY, SAFETY AND APPROPRIATENESS OF SERVICE

Comments in the surveys related to the quality, safety and appropriateness of rehabilitation services outline several inadequacies in the services provided throughout the region. Seventy-four percent of rehabilitation providers reported that there was not enough staff to provide appropriate rehabilitation at their site. This was most pronounced in Community (100%), LTC (89%), regional hospitals (100%) and acute care (72%). Forty-five percent of rehabilitation service provider respondents felt that the care given at

their site was not appropriate or of sufficient quality. This was particularly significant for Community Services where 86% of respondents disagreed that services were appropriate or of sufficient quality, Mental Health where 80% of respondents disagreed, Long Term Care where 76% of respondents disagreed, and regional hospitals where 53% disagreed.

It was felt that because of insufficient rehabilitation staff and high caseloads at all sites, patients rarely get the amount or intensity of rehabilitation services that they require. Insufficient and inadequate equipment as well as inappropriate space for providing rehabilitation can also affect the quality of rehabilitation at some sites. It was stated frequently that clients require more timely access to service, be seen more intensively and would benefit from follow-up and maintenance services. Staff at all sites throughout the region including L.A. Miller Centre staff had these concerns. Interestingly, in surveys, patients and families did not take issue with quality and intensity of rehabilitation services at the L.A. Miller Centre. L.A. Miller Centre satisfaction surveys suggested patients were concerned about the physical space (accessibility, crowding), food quality and communication with the team.

Rehabilitation Services in Acute Care Settings (St. John's and Regional Hospitals)

Lack of rehabilitation services in acute care generated 46 comments in 10 of the 12 focus groups analyzed. Newfoundland and Labrador Centre for Health Information (NLCHI) data indicate there were 7855 acute hospital separations in NL for diagnostic groups matched with National Rehabilitation Reporting System (NRS) codes. The majority of these discharges were within facilities in Eastern Health (63.9%). In acute care settings, services are predominantly focused on assessment and discharge planning. Due to the large volume of patients, those requiring ongoing intervention often become lower priority. Patients requiring mobility and balance training, cognitive assessment, equipment prescription and swallowing assessment are seen for short periods, a maximum of only 15-20 minutes per day, usually at the bedside. The focus for nurses and rehabilitation staff is to improve the individual's health status so they can return home. Physiotherapists and occupational therapists may see up to 20 people in a day. Because relief staff positions are unavailable, it is common for staff to be covering the caseloads of other colleagues who are on leave, or for vacant positions.

"When I was in St. Clare's I found they were so busy they spent very little time with you doing therapy but they did come to see you once a day but you didn't get what you required or what you would feel like you'd get."

Health providers indicate that more acute care patients have multiple health problems; they are not able to go home without health services and their inpatient acute care stay is often extended. Communities have changed. Residents are older on average and there are fewer adult children to assist with care or to make changes to the home. Patients therefore have increased lengths of stay while waiting for LTC beds, home renovations, admissions to rehabilitation, or home support services. Thirty-nine percent of patients and families surveyed indicated they were concerned about post-discharge

services (equipment, follow-up). These findings are supported by NLCHI data which indicate that about 14% of the total length of stay for rehabilitation-matched diagnostic codes was actually alternate level of care days. In these cases, about 55% or 19,418 days were ALC days. This suggests that some patients with these codes (7855 discharges in 2005/2006), although stable medically, needed further care to prepare for home or they were awaiting a bed in LTC. Furthermore, about half of these discharged patients will be readmitted to hospital within a year.

The challenge for health providers in acute care is that they have more patients with greater rehabilitation needs on their service. In general, patients who are awaiting rehabilitation or require LTC are given less priority than the acute urgent cases. Staff, including nurses, indicate that in acute care, the primary focus is providing personal care (dressing, bathing, eating) as efficiently as possible. Independence and initiation is not encouraged as the process of teaching and learning takes time. The philosophy is toward illness and not health and independence. It is clear that acute care is not the appropriate place to provide intensive rehabilitation services. Those patients who are medically stable should move to a service or program that specializes in rehabilitation; where physicians, nurses, therapists and support staff are trained to provide that level of care. Since there are waiting lists for rehabilitation beds at the O'Connell Centre in Corner Brook and the L.A. Miller Centre in St. John's with lengths of stay comparable to NRS standards, there are likely not enough rehabilitation beds in our health system. This is complicated by the fact that community rehabilitation is at sub-standard levels in our province (see following topic). Other provinces have well-developed or developing community rehabilitation teams and community access centers that facilitate earlier acute and rehabilitation discharge.

"On a 30 bed unit, let's say you have 4 or 5 people who need assistance with their care. I haven't got the staff to go in and spend a half an hour with every patient in order to get their morning care done. I just haven't got it"

"Well if two nurses go in and wash that person they can have it done in 5 minutes whereas if they are going in to encourage that person to wash themselves and to promote their independence, they are looking at a half an hour's work"

"My husband is 59 and has a brain injury. I was the 24/7 caregiver and he ended up having a fall and is now in the HSC. I know they will want me to take him home, go to the Miller Centre or send him to a nursing home soon. Wherever he goes I want him to have lots of rehabilitation. After two weeks at HSC, physio were up once with three people to try and get him up. Then about a week later they got him out into a chair for 10-15 minutes and that's it for two weeks."

"Some patients receive the services they need but it is often those with the greatest need, with no way to advocate for themselves that get the least services, i.e. the elderly shut-in who may not be literate and who may not have a support network."

"Rurally, there is a strong need for the CSP (Community Supports Program) team to be expanded to include OT/PT at the community level, thus enhancing our ability to

meet client's need in their home environment, thereby preventing admission to acute care and/or LTC facilities."

While St. John's hospitals as well as regional hospitals provide some rehabilitation services for patients, for many with conditions such as arthritis, cancer, lymphoedema, osteoporosis, hip and knee replacements, frozen shoulder etc., we should be providing a lot more. These patients are generally not being referred to the L.A. Miller Centre for treatment and at present the treatment they do receive is fragmented and inconsistent. It was felt that many of these patients need a more coordinated team approach to improve their condition, perform activities of daily living, live safely and prevent further injury. Integration of rehabilitation across the continuum of care was an issue in 9 of the 12 focus groups with 40 references. Some patients and families felt that they had not received appropriate or timely treatment and for various reasons did not achieve what they could have in rehabilitation.

"Services are not integrated".

"My husband was released from the program far too early with no services available to him in our community waiting list were long."

"My family member was left too long before being attended to after having a stroke."

Rehabilitation providers felt that the elderly are often a neglected group in rehabilitation when in fact they can benefit the most. Inadequate care of the elderly was the only theme that occurred in all 12 of the focus groups across the province with 41 individual references. Older people tend to have more health conditions and take longer to convalesce after procedures such as hip replacement or following admission for a health crisis. We heard that there is a strong need for Restorative Care. This level of care is sometimes called Continuing Care, Complex Continuing Care, Convalescent Care, Restorative Care, Sub-Acute Care or Transitional Care depending on the province where you live. Most provinces have some level of sub-acute care. Presently this service does not exist in our health system, although in practice, many hospital beds in acute and regional hospitals are filled with elderly patients who require restorative care. The L.A. Miller Centre opened a low-intensity, long duration rehabilitation unit on 3 South in 2008 with 20 beds in response to this growing need. In focus groups we heard that providers were concerned that the elderly were perceived as 'bed-blockers' rather than having a genuine need for a slower paced rehabilitation approach. We heard in most facilities, elderly people revisit emergency departments with no one analyzing what the overall issues are with the person and their family. We heard that, in time, these patients become 'social admissions'.

"Often times we are making decisions on them, I think, prematurely, before we have really given them adequate time to maximize their potential".

[&]quot;Ageism is alive and well in our system"

Tertiary Rehabilitation (Dr. L.A. Miller Centre)

Issues concerning services at the L.A. Miller Centre generated 28 comments in 9 of the 12 focus groups analyzed. The L.A. Miller Centre has struggled with a negative public perception since the 1960's when it was the General Hospital. For many elderly people, it is associated with death and dying, not rehabilitation. The fact that the palliative care unit is housed at the L.A. Miller Centre continues to challenge the perception of the facility as a rehabilitation site. Patient and family satisfaction surveys for the past 5 years indicate the same challenges: inaccessible and crowded clinical spaces and lack of parking. However, in satisfaction surveys, patients and families are very pleased with the competency of staff and the quality of care they receive. Often they report being pleasantly surprised at the care they receive at the L.A. Miller Centre. Even though patients are satisfied with the services they receive, they did report in focus groups and satisfaction surveys that they were bored and not challenged enough outside of scheduled therapy sessions. Patients reported that on admission, they were not sure of the routines and the roles of providers and would like a better orientation. Satisfaction surveys suggested that patients would like better communication with the team while at the L.A. Miller Centre.

"I think I was very lucky in a way because I ended up in St. John's on an emergency basis, I was Medivaced out. I had emergency surgery and I was very fortunate to get into the Miller Centre almost immediately and fortunate enough to leave the Miller Centre on my own steam. So I didn't need a lot. But for the most part, my experiences through the whole process were positive. I found things happened quickly and the people I dealt with were top notch; they really knew what they were doing. There are a few things with the Miller Centre that could be improved, but other than that, I was quite fortunate."

"For instance, for a weekend, when there was no staff there, I wasn't given anything to do. On a weekday there was rarely more than one hour per day"

The Rehabilitation Program at the L.A. Miller Centre has long-standing service issues that were identified in provincial reports beginning in 1993. Some issues that remain outstanding from other reports include lack of a physical medicine specialist (physiatrist), inadequate space and equipment, and the absence of a therapeutic pool.

"There is not enough inpatient staff at the LAMC to provide the intensity of rehabilitation required and there isn't a Physiatrist".

Some of the patients in outpatients at the L.A. Miller Centre could be more appropriately seen in their own homes. Outpatient services at the L.A. Miller Centre have been providing community rehabilitation for people in Conception Bay South (outside the 'zone' for community physiotherapy and occupational therapy) for many years.

Rehabilitation providers in the province depend on staff at the L.A. Miller Centre to provide consultation and education, especially around best practice. They expect teleconferencing and distribution of patient education material. We heard in focus groups

and key informant interviews that rehabilitation providers are not satisfied with the level of provincial education and consultation being provided by the Rehabilitation Program at Eastern Health. They feel education opportunities are not widely known and sessions are often held in St. John's with no teleconference available. Issues around continuing education and competency were raised 34 times in 8 focus groups.

Community Rehabilitation

The World Health Organization promotes development of community based rehabilitation for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities⁶. Across Canada many provinces are moving to more community based rehabilitation services. New Brunswick's extramural hospital system has been in place for many years. Extensive planning took place in the mid-90's to enhance rehabilitation resulting in the building of the Stan Cassidy Rehabilitation Centre. Ontario, Manitoba, Saskatchewan, and Alberta have Community Access Centres as well as outreach programming for specialty groups (i.e., cognitive /behavioural therapy for brain injury, vocational rehabilitation).

In general the goals of community rehabilitation are

- to prevent unnecessary admissions to hospital,
- to help people live safely in their homes
- to maximize independence and quality of life at home.

The most glaring and serious gap in service for rehabilitation patients in Eastern Health and in the province is community-based rehabilitation and follow-up. Limited access to community rehabilitation services in Eastern Health was a concern expressed throughout all three surveys and generated a huge number of negative comments concerning the adequacy of services provided. It was cited by many as a significant weakness of Eastern Health. Seventy percent of rehabilitation service provider respondents felt that there was not enough access to community rehabilitation services. In 10 of the 12 focus groups, there were 103 references to the lack of community rehabilitation.

National Rehabilitation Reporting System data indicate that about 64% of patients from the L.A. Miller Centre are discharged without any follow-up health services compared to 41% nationally. This is despite the fact that L.A. Miller Centre patients are discharged, on average with slightly lower functional ability (higher disability, lower FIM score) than nationally. It is clear that there is no coordinated system in place to help people manage at home after hospital discharge.

"Much more is needed in the community to support patients after discharge."

Patient/family surveys indicated that 39% of patients /families did not feel they had access to community rehabilitation services. This was the highest disagreement rate for any item on the patient/family survey. Thirty four percent of patients and families felt they did not receive the follow-up care after rehabilitation discharge that they needed.

Focus group respondents indicated there was inadequate follow-up of patients discharged to rural areas after rehabilitation (6 focus groups, 26 references).

"There are no rehabilitation services available in our area. The nearest centre is 2 hours away."

"There are some community rehab resources but they are not sufficient or timely. It is a growing problem."

"My condition and my rural address don't give me the opportunity to participate (I need help to get there and back home)."

Comments indicated that there is a strong rural/urban split, showing that patients living in St. John's have more access to outpatient and community rehabilitation than those in rural areas. For those rehabilitation-matched code groups with ALC days (Table 31), NLCHI data suggest that in Central, Western and Labrador Health, patients spend more actual days in ALC (64%) versus Eastern Health (44%). Rehabilitation service providers, patients and families complained about the general lack of services in the community and outside the St. John's region. There are approximately 2.2 FTE physiotherapists and 6.9 FTE occupational therapists presently allotted to provide community rehabilitation for the approximately 250,000 people in the Eastern Health region and some of these positions move back into acute care as the need arises. We heard that Western Health, in particular, has made important strides in rural community-based occupational therapy. Patients in the community wait excessively long periods of time for service. Combined with this, many acute care and inpatient rehabilitation health providers simply no longer send referrals to community rehabilitation providers in Eastern Health because the service is inadequate.

"We have stopped sending referrals (to community therapists). We know they are just doing emergency kinds of things."

Respondents in the patient family survey expressed how hard it is for people who live in smaller communities to access services when there is so little community rehabilitation available. It is not always possible for people to attend the nearest outpatient service. If you have to add in the distance to the nearest outpatient service, the cost and availability of accessible transportation, the cost and availability of accessible accommodations and possible lack of supportive family and friends, it is almost impossible, if not impossible, for many people to access these services. When these patients manage to overcome these obstacles and get to the nearest regional hospital out patient rehabilitation service, they find limited services offered with long wait lists. Waiting list data from Professional Practice Coordinators in Eastern Health show that long waiting lists in outpatient areas are routine. Non-urgent patients for physiotherapy, occupational therapy and speech language pathology can wait 2 years.

Some key informants and focus group participants felt that the move by hospitals to improve clinical efficiency and discharge patients home as quickly as possible is also limiting access to rehabilitation services and putting pressure on almost nonexistent

community services. In order to free up a bed, patients are often sent home too early before they are able to receive the rehabilitation they require. Nurses in community find themselves ordering mobility and adaptive equipment without knowing what exactly will work in the situation.

"The 'GAP' in service I see is with respect to community services."

"People are being discharged into the community at record speeds. The problem is community services weren't put in place to support this, so people are being discharged to NOTHING".

"For those working in community caseloads are too high to permit the type of support and follow-up needed"

"The rehabilitation is supposed to be done at home by nurses with no training in this area and we are scrambling to keep up with the caseload that is just growing. And people fall through the cracks because we can't keep up"

"In order to send a referral I would have to recommend to send him home and then I can't ethically send him home knowing that he is not going to get that service so I ask to keep him until he no longer needs that (community rehab) referral"

"I think community is the area where OT's could do the most and are doing the least. There is really no reason why when somebody is discharged from hospital that the community OT could not be picking up and doing rehab".

"We are scratching the surface of need"

"...because everyone is left so long, by the time I get there. I could carry a caseload of 80 people with home safety assessments"

It is difficult to move toward other roles in the community such as secondary prevention when clinicians are not able to provide basic services. Outpatient services at the L.A. Miller Centre have expanded over the years providing an option for patients living in St. John's. Some patients and families temporarily relocate to St. John's, living with family or in extended stay hotels, to receive continued outpatient service from the L.A. Miller Centre. Discharge is difficult at the L.A. Miller Centre. Since there is very little community-based rehabilitation, vocational or recreational programs for people with disability, people with disability often remain marginalized and dependent on the institution-based health system.

A new model of community rehabilitation is required to meet the increased demand for rehabilitation services from our population. This new model must consider the vast geography, need for professional development and mentorship of health professionals. Although there is presently an illness and crisis management focus, future programs must focus on prevention and health at home and in the community. The reporting structure will be important in order to recruit and retain staff. The optimal

structure should reflect community needs (urban and rural). There is a need for community rehabilitation providers who provide rehabilitation services to people in their own homes, nursing homes, and personal care homes in their region.

Long Term Care (LTC)

Respondents identified a large gap in services for residents of long term care or those who are seen to be destined for long term care. Lack of services to this population generated 74 comments in 9 of the 12 focus groups. Long Term Care has a large population of residents with few rehabilitation professionals offering service resulting in long wait lists and inadequate services.

People are admitted to LTC facilities because they have undergone a health crisis or deterioration that prevents them from living safely at home. It is important to emphasize that residents of LTC have differing physical and cognitive abilities and also differing potentials for improvement. Many people in LTC will have acute health concerns such as a fall or an infection that will require acute care admission. Rehabilitation is often required following acute care to return residents to their previous level of functioning.

Categories of residents in LTC include:

- Elderly people who have had an acute medical illness and cannot live independently due to the level of nursing and personal care required.
- People whose physical or cognitive health has gradually declined beyond their family's ability to care for them.
- Young disabled adults who do not have anyone to care for them or can no longer be cared for by elderly parents.

Our findings suggest that the emphasis on reducing length of stay in acute care hospitals is resulting in rapid and sometimes premature applications for LTC with increasing numbers of patients inappropriately living in these facilities. In many cases, if a patient is seen to be destined for LTC, he/she will be seen as less of a priority for rehabilitation services by rehabilitation professionals in acute care and throughout the system and will not receive the intensity or duration of services that would otherwise be required. Some patients require a longer convalescent time to become ready for rehabilitation services or require a slower-paced rehabilitation service. These people (usually elderly), if given more time to convalesce, or an appropriate slower paced rehabilitation program, may be able to live at home with the proper home supports. Unfortunately after the patient has sold his/her home, and given up many of their assets, it is no longer feasible to return home.

"I was discharged from Hospital too quickly and sent to Miller Centre and could not do rehab required that soon".

"There are older people who took longer to convalesce post-fracture or stroke and have improved while in long term care however they have sold their homes and it is too late."

"It is also a frustrating environment when you see 60-70 year old residents being admitted who you know would improve if given the appropriate services over a longer period of time than offered at the LAMC. With caseload numbers so high, we are addressing maintenance of the elderly who are physically able and who are admitted to LTC facilities."

There are physiotherapists and occupational therapists covering most LTC facilities in the province however the ratios are about 1 therapist per 300 residents. In rural areas, hospital-based therapists can be responsible for up to 11 LTC and Personal Care Homes (PCH). They may be able to visit once every 6-8 weeks. Therapists and families recognize there is only time to assess residents and solve immediate problems. Active rehabilitation is sparse and provided mainly by rehabilitation support workers, where available. Therapists and families indicate that residents do not receive enough exercise, opportunities for leisure and recreation, or encouragement to be independent in self-care. The new bungalows for mild dementia care in Western Health are a good example of quality care promoting active living for older people.

"I think she should be walking by now after a hip replacement. She walked really well (with help) while in hospital. When sent back to (Name of Nursing Home), first they said PT was on holidays - not good enough – Now she is in a wheelchair permanent."

"Just this week we had another example of somebody who was at very high risk, I'm only at that site once a week, had thought I put everything in place, and the resident choked."

"If you are in a home that has a good volunteer base, your recreation is enough. If you go to a home and there is no volunteer base, there's not a lot. Even a simple exercise program doesn't need much funding. You just need someone to round everyone up. An exercise program can keep them from going downhill"

(Western Health bungalows) "Formerly institutionalized people are now baking, gardening, sewing. They are living"

The services of some rehabilitation disciplines are not available at all nursing homes. The lack of speech language pathologists, psychologists and dental hygienists are glaring deficiencies in rehabilitation in LTC. Lack of recreational staff was also an issue for some. Our findings indicate residents with dementia, psychiatric, or psychological problems are rarely assessed by psychiatrists, psychologists or geriatricians. Residents take large amounts of medication but do not receive counseling or other behavioral interventions.

Nursing staff shortages and casualization of staff affects care of the resident. There is lack of continuity and understanding of resident care. For example, it is almost impossible to have all members of the team do a transfer consistently with the resident or strategize around a pressure sore problem. Older LTC facilities are notoriously inaccessible which further limits independence.

"No point in teaching sliding board transfer when staff will all use a mechanical lift"

"My mother can't even wash her face independently because in the nursing home she can't get her wheelchair in the washroom. So she's had her liberty taken away from her. To me the residents are not treated as individuals"

Young disabled adults in LTC

The young disabled adults in LTC are a special group. There was a strong consensus that the care for this group is unacceptable. They require a rehabilitation approach, focusing on independence, participation in age- and interest-appropriate leisure and recreation. Rehabilitation providers felt that current LTC facilities such as the Hoyle's Home were not appropriate for this group of 60 people or so. They felt that these residents could live in small groups in accessible homes with the right level of care and opportunities to participate in society. It is important to find out what lead to institutionalization of this group? Where did the system break down?

"First of all they should never be in a long term care facility because they end up getting lost in the mix-up of a long term care facility with frail elderly and geriatric population, and as a result they do not get the rehab services that they need"

"Your rehab needs should be based on your needs, not where you live".

In general, services to residents in LTC need to be improved. Residents need improved access to all levels of rehabilitation service plus there should be improved access to slow paced longer duration inpatient rehabilitation to prevent inappropriate admission to LTC. Alternate, age appropriate living arrangements (such as group homes) need to be made for the young disabled adult population currently living in LTC.

Personal Care Homes

People living in personal care homes (PCH) are of great concern to rehabilitation professionals. These residents have multiple disabilities and often come to a hospital or outpatient department in crisis. Many PCH residents arrive in emergency or are seen in outpatients at the L.A. Miller Centre with preventable problems such as an injury resulting from a fall. There are no preventative care or risk assessments completed and there are no occupational therapists, physiotherapists or other rehabilitation providers covering these homes. The homes are privately run with minimally trained staff.

Our findings indicate that health providers are concerned that PCH staff do not have the skills to work with people with complex needs and are not trained to address changes in mobility, balance, cognition or behavior, common in this group. We heard of homes having residents with multiple disabilities who have not seen a rehabilitation provider in 25 years or more. Personal care homes require regular access to rehabilitation professionals to provide the rehabilitation services and consultation required.

REHABILITATION SERVICES ISSUES

Waiting Time

Although waiting time was not seen as a significant problem for patients (only 11% felt it was a problem), service providers expressed significant problems with the waiting time of patients for rehabilitation services. 65% of rehabilitation service providers felt that wait times were unreasonable and 55% felt that wait times for rehabilitation services were unreasonable at the site where they were located. Long wait lists generated 18 comments in 7 of the 12 focus groups analyzed.

"Rehab works best when started immediately, even a few weeks wait is too long."

"Waiting Times should be under more scrutiny to see that these wait times should be kept within reasonable limits."

Waiting lists are a common and possibly essential part of our health system. Outpatient and community waiting lists exist throughout the system in physiotherapy, occupational therapy, speech language pathology and nutrition. Most waiting lists are managed by an assessment of urgency with waiting times ranging from 1 week for urgent cases to 2 years to non-urgent or 'chronic' cases. Outpatient lists in hospitals usually include patients with complex needs or those who may not have health insurance.

Therapists in regional centers often carry a mixed caseload of acute, rehabilitation, long term care, outpatients and community patients. Since it is impossible to see all the patients in a day, therapists prioritize by urgency among these groups with outpatients and community referrals having the lowest priority. This is further exacerbated when one of perhaps two rehabilitation professionals is off on leave without replacement or there are vacancies. The longest waiting list we found was in Central Health outpatient physiotherapy with about 700 people from Baie Verte, Springdale, Grand Falls, Gander, Twillingate and Brookfield. The count had been as high as 890 people.

"In local and Regional hospitals wait lists are so long that patients are often back in hospital several times before they are contacted. These admissions could possibly have been prevented had they been seen in a timely manner. When they are contacted their condition has changed, therapy may no longer be appropriate or they no longer want to come for rehab services"

"I had to wait from September 2007 until December 19, 2007 to get in (Burin). This is totally unacceptable!!"

Individuals with chronic conditions experience excessive wait times for outpatient and community rehabilitation services. Cott, Falter, Soever and Wong in a preliminary report on adult rehabilitation and primary health care in Ontario cited the problem of patients waiting in excess of two weeks for these services in Ontario ⁷. In contrast, in Newfoundland wait lists of several hundred with wait times exceeding a year in many

cases are not uncommon and some wait lists are closed. It was expressed by a number of respondents that many physicians have stopped referring patients due to the length waiting time.

"Four months after fracturing her left leg, my mother finally received some physiotherapy to regain her ability to walk."

In St John's Hospitals wait lists for chronic patients in ambulatory care are many months to over a year. Because of this, it was felt that many problems that may have been short term if they had been seen earlier, become long term with all sorts of secondary problems such as adaptive gaits, postural deformities, deconditioning, and chronic pain. Many felt the wait time for Tertiary Rehabilitation was also too long. However wait times from referral to admission to the L.A. Miller Centre inpatient units has been consistent at about 8 days since 2006. Waitlists for outpatient services at the L.A. Miller Centre range from two weeks for urgent cases (falling at home and other safety concerns) to 6 months for non-urgent cases.

"I waited months to get into Miller Centre after having surgery for cerebral hemorrhage/stroke."

"My husband has been waiting for at least 2 months for an appointment at Miller Centre to be fitted for wheelchair. This wheelchair has had brakes broken and have been using for four years."

"The critical time frame after a stroke was spent waiting for a bed at the Miller Center."

"Waiting 6-8 months from time of doctor referral. If a patient has depression with the chronic pain, that amount of time can be crucial."

"Inpatients are often discharged before tertiary rehab is available."

The critical problem is that people who have had a stroke, amputation, spinal cord injury or other disabling condition will usually fall into the 'chronic' category and therefore receive almost no rehabilitation services at their regional hospital. Therapists are not able to prevent complications; they can only deal with the patient once their problem has become an emergency. This practice is obviously not a community wellness model. It instead manages illness rather than health.

Patient Transfer between Services

Forty three percent of rehabilitation service provider respondents felt that processes around transferring patients between services needed improvement. Seventy-three percent of respondents in long term care, 60% from Child Health, and 56% of those responding from community felt that transferring patients efficiently between levels of care was a problem.

There were a number of issues highlighted throughout the survey as cause for concern:

- Patient transfer requires coordination of many staff and leadership direction.
- Moves from acute care and the L.A. Miller Centre to LTC and regional hospital sites often occur without timely notification or the necessary patient information to allow appropriate intervention (if resources would allow).
- Discharge notes are not always on the health record from various disciplines and information often has to be sought/requested prior to initiating treatment at the new site.
- Residents in LTC can be transferred to another LTC site. The resident and family are often not prepared for the move and not aware of rehabilitative and recreation service differences between the sites.

Discharge

Discharge from hospital (both acute and rehabilitation) is a complicated process for someone with a disability, especially if it is newly acquired. Once a person is ready to go home, follow-up, home support workers, renovations, and equipment are some of the arrangements that have to be made, often at a distance. About 60% of patients leave the L.A. Miller Centre without services compared to 40% nationally, either because they do not require services or because services are not available. Sixty percent of providers felt that patients were discharged without the community supports, renovations and equipment that they needed. In surveys, the top five concerns for patients and families were those relating to discharge arrangements; concerns with follow-up, home rehabilitation, transportation, equipment, renovations and home support workers. About a quarter of people were no longer able to participate in community and social activities. Forty eight percent of rehabilitation service providers felt that patients are not discharged in a timely way; 42% felt that there were no consistent discharge criteria in place; and 60% of care givers responded that patients are discharged home without the equipment, renovations and home supports they need to live independently and safely. There were 26 comments concerning discharge in 6 of the 12 focus groups. NLCHI data show that provincially, 1017 out of 7855 rehabilitation-matched code separations in 2005-06 report alternate level of care days suggesting that once the person's medical issues have stabilized, they are awaiting arrangements to go home or to LTC.

"Some individuals are discharged without ever receiving the services from Allied Health Professionals that they require and are sent home unprepared while other individuals receive all kinds of intervention and are not discharged until the team feels it is appropriate. Some doctors feel that a community referral is enough; however waitlists in community are so long that people are back in hospital several times before they are ever seen."

NLCHI data show that about 552 of 7855 rehabilitation-matched code separations are transferred from the HSC to another hospital in the region, in the province, or outside the province. Generally it was felt that there are no clear discharge criteria for any service in Eastern Health that provides rehabilitation services. We heard that discharge timing

differs within the same service depending on which medical team happens to be on service or the physician involved. There is variability among patients as to when they are discharged. Depending upon the service and pressures upon resources at any given time discharge timing will change. We heard dissatisfaction in regional and rural hospitals about the push for discharge especially around Christmas time. It was also common for patients' acute or rehabilitation stay to be extended due to lack of rehabilitation resources in their region or community.

"There are issues at both ends, discharged too soon, held too long."

"Currently discussion (St. John's Hospitals) over capping treatment session numbers."

"Discharge often becomes the focus not rehab."

"Patients often go home with the bare necessities for safety but are unable to obtain all the recommended equipment because of the cost and lack of funding."

Discharge planners exist in some institutions which help to prepare the patient, family and receiving institution for discharge. Our findings indicate that this process is inconsistent. For example, hospital staff in St. Anthony may only find out a spinal cord injured patient has returned to the community after the person arrives in Emergency with a health complication. We heard that in some cases, paper referrals for 'intensive physiotherapy' are sent to rural hospitals without the referee determining if these services actually exist.

"I think that lots of times St. John's may make some very big assumptions based on what their experience is. They don't understand what rural rehab is actually like. We don't have obviously the same facilities or staffing to do what can be done at a rehab center. We operate on a bare bones type of staffing situation and I don't think that that's well understood."

We heard that patients have been discharged from the L.A. Miller Centre to a regional hospital unprepared and unexpected, without treating therapists knowledge. Other patients have been discharged to nearby hospitals in their community from acute care sites in St. John's without any preparations or applications completed (LTC, SAP etc). However, this is variable, since other providers felt that the proper arrangements were made for follow up to support patients' transfer or discharge.

In Burin, there is a pilot program providing a 'basket of services' for 14 days following discharge. This has been effective in getting patients home efficiently and safely. In Burin, the inpatient team, community health nurses, social workers and family physicians collaborate effectively to facilitate safe and efficient discharge. More initiatives such as this throughout Eastern Health would improve the situation for patients and their families.

Follow-up

Follow-up means a visit or a phone call from a health professional after discharge usually for a patient who will likely have ongoing health needs following an intervention or hospitalization. Forty-four percent of rehabilitation service providers and 34% (2nd highest disagreement rate) of patients responding to surveys felt that rehabilitation service follow-up was not being adequately provided. There were 35 comments in 11 of the 12 focus groups analyzed discussing this topic.

In general there is no routine follow-up for patients leaving acute or rehabilitation facilities within Eastern Health. This is the case in most regional health authorities with the exception of the Rehabilitation unit at Western Health and the Day Hospital at the L.A. Miller Centre. Most patients discharged from the O'Connell Centre unit are followed-up by outpatient physiotherapists, occupational therapists or the physiatrist. However, it is common practice to provide discharged patients with contact numbers for key health professionals. They and their families must navigate the system if a problem arises. If they do identify a problem, they wait for months on an outpatient PT or OT waiting list. Unfortunately, due to the complex health problems of this group, they often return to hospital with pneumonia, pressure sores, exacerbations, falls, etc because there is no follow-up in the community.

"Follow-up is dependent on where you received service and where you live in the province and what your problem is. Some rehab services provide limited follow-up or telephone follow-up. Less follow-up is available in rural areas."

"There is no real follow-up and people go home and are left to their own devices"

"Patients are often advised to contact Allied Health/Rehab Departments if further problems arise. When contact is made the patient is put back on a waiting list."

"There is no time for therapists to provide follow up with an already busy schedule. As well, community wait lists are long! Some areas have no OT services at all such as CBS."

We heard in rural and regional areas that it was common for people, discharged from acute care facilities such as the Health Sciences and St. Clare's, to have insufficient or incorrect equipment at home. They may or may not have seen an occupational therapist, social worker or physiotherapist during their inpatient stay. Some patients, their friends and family find ways to get equipment (borrow from neighbors, Red Cross). Clearly, a process should exist whereby patients who need mobility aids, equipment and follow-up are identified by a member of their health care team and the proper arrangements made before they return to their community. All facilities are operating with fewer rehabilitation staff than are necessary to provide all the services required. Priority is placed on urgent needs rather than prevention and planning.

"Someone was supposed to come to "inspect" to see if ramp was suitable and safe. No one EVER did."

"I think one of the problems with the system is you don't realize until you get home what problems you are going to encounter. Even prior to discharge if the health care professional can visit your residence and see what is needed before you actually get there."

"Need more community resources to support follow-up"

"Unfortunately not able to implement all recommendations – would've appreciated a follow-up."

Patient Education/Communication

Client-centered care is a philosophy of care that involves advocacy, empowerment, respecting the client's autonomy, voice, self-determination and participation in decision-making (Ontario Nurses Association Best Practice 2006) ⁸. Although degree of client-centered care was not measured directly in primary or secondary data sources, patient and families' role in setting goals and making decisions arose in focus groups. Health system navigation and lack of psychosocial support were of particular concern. Patient and family focus group participants indicated that there was insufficient information given to them about their condition, progress, and services required.

Overall, patients who are discharged from the L.A. Miller Centre, either from inpatient or outpatient services, feel satisfied with their rehabilitation service (patient satisfaction surveys). In satisfaction surveys from the L.A. Miller Centre, patients and families identify communication with their treatment team as an issue for them.

"Did a lot of research on my own."

"Mom was told the terms but never explained what each condition meant."

"Was already aware of condition, I need more help as to how to adjust and use assists."

"Taught mostly via NL Brain Injury Association -still learning."

"No one told me about support groups. I found out two years later"

"There seemed to be a lack of information provided by all staff, (nursing, rehab and physicians)".

"I didn't have any meetings with doctors about my wife's condition, not even when she was discharged"

"I didn't feel part of the discharge process-just filling out forms. I felt ignored"

"There was a nurse there, a recreation therapist, my psychologist, physiotherapist. There was a round the table conversation. You just kind of agree with everything"

"But it wasn't a team that was there to help you. It was like a team to support the health care system, to make sure what was said was proper to protect the health care system, not me".

Efforts need to be made by rehabilitation staff to:

- provide service orientation for patients and develop and distribute promotional material about the services provided
- involve patients in decision making concerning their care
- provide ongoing updates for patients and families concerning patient's progress and change
- provide information and educational material concerning the patient's condition

Emotional Support

We heard in patient and family focus groups that health providers place emphasis on physical rather than emotional health. While this did not appear to be a significant issue in the patient/family survey, 33% of service providers felt that patients did not receive adequate emotional support throughout the rehabilitation process. There were also 35 comments over 6 focus groups discussing lack of cognitive and psychosocial support in rehabilitation. We heard, especially in regional hospitals, LTC, and community, that in order to cope with large workloads, social workers have narrowed their scope of practice to exclude adjustment and counseling services. Psychologists are a rarity in regional hospitals and do not exist in Community Health. More emphasis must be placed on a bio-psycho-social model of health.

"While many of the nurses, social workers etc. are very compassionate, I don't think there is anything else available besides the "you'll be okay" support for anyone who needs more than this. More caregiver supports would be wonderful"

"This is a huge area of need in Long Term Care. Many families are not prepared for loved ones admission to LTC (in particular if admitted from ER, Acute Care). They need counseling. Also residents are suffering the biggest losses of their lives – their homes, partner, physical well being-there is very little emotional support. Nursing, social work, pastoral care and recreation attempt to fill the void but there is a need for psychology."

"I have referred patients to community Social Work for emotional support only to have SW call me to say they are too busy unless there is something more concrete."

"He still has anxiety – his condition is not improving a great deal – he has problems accepting it after 2 years."

"When I was an inpatient and asked to speak with someone in psychiatry to deal with issues, I was told by staff that it was only available to patients with brain damage/head injuries."

Vocational Rehabilitation Services

Many rehabilitation centres across the country offer vocational rehabilitation services to help people get back to work or adjust to the work environment with changed abilities following a stroke, injury etc. According to service provider survey results, 47% of rehab service providers and 20% of patients and families felt that this was an issue of concern. Very little is offered in Eastern Health or by other agencies to help people with vocational issues and many health providers stated they had no idea where to refer patients for vocational support.

"More information and services need to be made available."

"Eastern Health no longer provides this. Patients can't get vocational support unless they have insurance or pay for it privately."

"Vocational support is not available or available in a very limited way for clients without funding."

"Few options, strict criteria."

"For patients with TBI especially, there are very limited vocational support services available."

"Much more is needed in the community to support patients after discharge, job coaching, successful work supports, support groups etc."

Other Forms of Rehabilitation

Some survey respondents felt there was a need for pre-habilitation and preventative rehab programs. Pre-habilitation refers to the prevention of injury by training the joints and muscles that are most susceptible to injury in an activity. Unlike rehabilitation it deals with injuries before they occur ⁹. Preventative rehabilitation refers to programs offered that are aimed at preventing further injury or complications.

"People require preventative rehab. If one were to consider 'fall prevention' as 'prevention of rehab needs' – there could be a structured and coordinated interdisciplinary effort in this regard. While there has been some work in this area, and some education there is not a comprehensive program with measurable outcomes."

Navigating the Health Care System

Romanow wrote in 2002 that "patients are forced to navigate a system that is a complex, unfriendly mystery, in order to find the right specialist, the nearest facility and the best treatment" ². Throughout the surveys, patient and care givers expressed concern regarding how complicated it was for them to navigate the health care system. While this issue was not addressed directly in a specific question on either survey, there were related questions and a large number of comments made on this issue. Thirty-four percent of service providers felt that patients would not know who to contact if they had further rehabilitation care needs. Ten percent of patients and families reported that they would not know who to contact for further care needs. Thirteen percent of patients felt that they could not easily access rehabilitation services after discharge and 15% said they were not given any information about services in the community that would help. Patients, families and health providers are often unaware of the scope of rehabilitation, who can benefit, and how to access the service. There were 36 comments in 6 of the 12 focus groups concerning problems with navigating the health system.

"Many patients and families are completely unaware that certain rehab services exist and would not know who to contact for what."

"There are not enough services in this area for them to contact anyone. Usually the Allied Health professional is the last point of contact so the patient will contact them for service that is usually not provided."

In focus groups, patients and families were concerned about advocacy. They wanted someone to help them coordinate their care and they wanted honest consistent information about care, discharge and follow-up. We heard that sometimes there were so many people involved that it can become very confusing. Patients report that they want complete information with all the options to be able to make choices. They want social workers or advocates who can help and they feel that the criteria for admission to specific programs seem elusive. Most rehabilitation services outside this province have case manager or patient advocate systems in place to help guide patients through the system.

"I'm not sure seniors I work with really understand the system. There are many people involved and I think they find it overwhelming."

"Knowing who to contact and getting results are two totally different things."

"Not sure if I can call myself or do I need a referral from my doctor."

"Knowing what was available was not the problem. Availing of these services was very much a problem."

"We would have liked a little more time – and felt we were in a maze."

"We contact our MHA."

"Gave up on it, we do the best we can with what we do at home."

"It's hard to do anything when you have these problems. I can't read properly. I can't drive. So that puts a lot of restrictions on me from doing things. And then people make things difficult for me. Make it as simple as possible. We don't have our sons here to help us. We don't have family here to help us"

"I consider myself a very informed health care consumer. For anyone not familiar, the thoughts of being pitched into this headlong is horrendous. When I retire I think the system needs to set up a volunteer group who can steer people through the system"

"You are trying to hold down a job, work for your loved one and trying to deal with the hospital system. It is very exhausting"

We heard that navigating the health care system, both institutional and community-based, is challenging and stressful for people with disability. We heard of one telling incident in a mid-size community. There was a young man living in the community with a disability. His hospital bed, lift and wheelchair were about 15 years old and he had grown and become obese during this time. While using the lift, it broke and the man fell to the floor. The family and community health nurse contacted the Special Assistance Program to try to get another lift. They were told they were to have an occupational therapist assess the equipment. When the SAP staff was told that there weren't any occupational therapists in the area, they recommended that the family try and borrow a lift from the hospital. The family phoned the hospital only to find out that there are only two mechanical lifts for 40 patients and borrowing would be impossible. In the meantime, the fire department returned the man to his hospital bed. After contacting SAP again, they were told that another lift would not be purchased since that would require approval by an occupational therapist, instead the existing lift would be repaired which would take 3 weeks. The man remained in bed until he received the lift.

COMMUNITY SUPPORTS

Community supports are the supports at home and close to home that will enable a person with disability to live as safely and independently as possible. This may include financial assistance, home support workers, training of caregivers, home renovations, equipment and accessible community buildings, to name a few. Seventy percent of rehabilitation providers reported that their patients did not have the necessary community supports in place at discharge. Eighty to ninety percent staff at the L.A. Miller Centre, in particular, reported that their patients did not have adequate community supports at discharge. About a quarter of patients and families surveyed reported that they did not have adequate community supports. This was supported by NLCHI data showing substantial alternate level of care days and hospital re-admissions in rehabilitation codematched groups.

It was clear from the surveys and focus groups that professionals on the front lines have seen community demographics change. Acute medical care has advanced such that more people survive formally deadly conditions and more people are living with chronic illness. There are increased numbers of older people living in the community with fewer adult children who can assume care-giving responsibilities, complete home renovations, or become employed as home support workers. People struggle to live independently at home. Safe environments with the proper support (home care workers, professionals) prevent hospital readmissions.

Home Support Workers

Home support workers underpin successful community living for people with disability. There is a huge shortage of trained support workers in the system. While there are significant problems with shortages of home support workers in St. John's, this is even more of an issue in rural areas. Lack of home support workers generated 58 comments over 9 focus groups of the 12 analyzed. Lack of access to home support workers was second only to lack of affordable accessible housing as the most pressing issue in the needs and gaps survey for providers.

Many families/patients experience difficulty in finding and keeping home support workers. Even when home support workers are available, they are often not properly trained for the kinds of care they are expected to provide. Rehabilitation staff often spend time training home support workers to help patients return home after discharge, however there is no formal follow-up and as workers change, there is little retraining. Community health nurses report there is an erosion of methods and techniques among the workers over time. Combined with that, there are almost no rehabilitation professionals in communities who provide training to home care staff in the care of people with disability. Home support workers are required to provide personal care, manage behavioral problems, help with exercise and walking, and supervise medications.

"We couldn't get home care out in Gander. That's why Mom had to go to a home"

"Home support is in a real crisis – too few for too many, most lacking training or knowledge of client needs."

"I was told how to manage but trying to get home support was difficult."

There is limited access to funding for home supports and frequently, even though care givers request more time, there are not enough hours approved to meet the patient's needs, putting the patient at risk in the community. Even when funding is approved there are often no support workers available to hire. This is particularly true for short term home supports with low hours of care approved. Focus group participants agreed that home support workers are chronically under-paid. Many workers are unwilling to incur the cost of travel for only two hours of work daily at a low rate of pay. Also, when patients are in hospital, home support workers are not paid and therefore find other work.

If the patient does not receive enough hours of home care, it may mean that they can't go to the bathroom as often; they may stay in wet diapers for long periods of time, may get pressure sores, have a fall, or develop joint contractures. People with disability reported that they are reluctant to ask the worker to take on extra tasks or to complain since they won't find a replacement if that person leaves. To improve this situation, a more streamlined and timely approval processes for home supports is required. Improved salaries for home support workers and access to education for these workers would also improve this situation.

"There seems to be a shortage of trained competent home care workers even when patients are willing to pay out of their own pockets."

"I think they should be employees of the health care system. I think they should have formal training in a community college because they are required to do OT things, PT things, nursing things, and sometimes they help with medications, cooking, cleaning, transfers etc."

"It's not great out there for the client"

"If you can't keep workers you become a 'placement' issue"

Accessible Transportation

The lack of accessible transportation throughout the region as well as the availability and timeliness of accessible transportation in St John's were among the main complaints expressed by patients and families. The lack of accessible transportation was seen as a growing problem. Sixty percent of service providers and 28% of patients and families listed this as an issue of concern. Lack of accessible transportation generated 52 comments in 7 of the 12 focus groups.

Currently there is a paratransit system operated in St. John's by Wheelway. The cost is \$5.00 return within the city with extra fees outside the city limits. Some communities have a local accessible van operated by an individual, a company, or a community group but these are rare. In general, people who require accessible transportation, who do not have their own van and live outside St. John's, either stay at home or use an ambulance. Because of the problems with transportation, people with disability restrict their travel to essential trips (doctor's visits, grocery shopping). They limit participation in community activities and recreation. While it is not in the purview of Eastern Health to provide public transportation, availability of accessible transportation does affect the services provided and ultimately the health of patients.

The existing paratransit transportation system in the St. John's area is currently being evaluated. The problems identified in this study include:

- People must provide one week's notice to travel which removes spontaneous travel or changes in schedule.
- People can wait two hours for pick up and drop off which is distressing for people who have medical issues such as incontinence, pain or fatigue.

- Vans rides are very bumpy. Travel often causes pain.
- The vans are not equipped with wider lifts and greater weight capacity for people with obesity.
- The vans are used extensively by health care sites and are very difficult to book for leisure pursuits.

"We continue to have complaints about the lack of wheelchair accessible transportation. If patients can get on the Wheelway bus, they often have to go far out of their way to get from A to B. They are often waiting a long time to be picked up and often in less than ideal locations. The variable level of help to get on and off the bus is also a concern."

"Not available when needed, excessive wait times, no spontaneity. Priority to medical/work needs limits ability for leisure pursuits and general community access. Health care system should not be using Wheelway!"

"Accessible transportation in this city and province would be a joke if it was not such a serious issue."

"If you are lucky, a community service group may raise money to help pay for a van. There are some taxi drivers who are amazing. They help people transfer to the cab, lift the chair into the trunk. There should be a transportation subsidy for people with disability."

"I know one family in my community who has an accessible van. They don't have the money to license the van so HRLE sent Wheelway out here for them, put them up in a hotel, and sent them back in Wheelway instead of giving them \$140 for their stickers"

Accessible Affordable Housing

The lack of affordable and accessible housing is a concern for many patients. There are very few accessible accommodations available in St. John's and even fewer outside of the city. There are also long wait lists for what is available. Eighty-one percent of service providers and 17% of patients and families cited this as an important issue. It generated the highest disagreement rate in the rehabilitation provider survey. This issue generated 18 comments in 6 of the 12 focus groups.

In order to be made accessible, homes and apartments must be equipped with wide doorways and halls, large bathrooms to fit a mechanical lift, and ramps. Most homes require extensive modification to become accessible. Unfortunately the Special Assistance Program (SAP) places a cap on the amount of renovation that can be done in one year such that an elderly couple may be approved for bathroom renovations but not a ramp. Many people simply cannot afford these renovations and some ultimately end up in long term care.

The lack of assisted living accommodations for young disabled individuals was also identified as a problem. We heard that people with disability may give up on home

support workers and housing problems and choose to live in a nursing home.

"There are long wait lists for accessible housing. I have encountered numerous patients who crawl up and down stairs."

"We often have patients in NL Housing that is not suitable for elders that are healthy let alone those with conditions that limit them in any way."

"We often hear complaints from patients who are trying to get accommodations on one level without stairs, because of severe OA knees/hips and are on long wait lists. They report that it is "who you know" rather where one is on the wait list that counts."

"Suitable accessible housing for younger people is sadly lacking, in fact, we think the middle aged disabled community has been overlooked – the need for properly supervised, affordable housing is crucial."

Patient Equipment

The inability to access appropriate equipment to live safely in the community was an issue that concerned many patients, families and service providers. Sixty percent of service providers and 14 % of patients and families felt that patients were sent home without the proper equipment to live safely. This topic generated 58 comments in 10 of the 12 focus groups analyzed.

Occupational therapists are the most qualified individuals to prescribe equipment such as wheelchairs, commodes, lifts etc. In many cases, the prescription is straightforward but for people with disability, more specialized wheelchair components, environmental controls, or power mobility may be required. Because there are so few occupational therapists in the community, nurses may be forced, by default, to determine basic equipment and hours of home care required for specific patients. The paperwork and follow-up required is immense. We heard that the equipment provided by the Special Assistance Program (SAP) is bare minimum, low quality equipment (hand cranked hospital beds, heavy wheelchairs, cheap mattresses and cushions). There are waitlists for some equipment such as hospital beds.

"I am a community health nurse, I get OT referrals. I am not an OT"

"I've got a lady in her 50's and she's in a regular old hospital bed, nothing special, and she is paraplegic. She has ulcers on her coccyx, on her ankle, on the side of her foot and on the side of her toe"

There are rules in place at SAP that will not allow people to have both a manual and a power chair. This is despite the fact that it is recommended that people with power mobility have a back-up system for repairs or power outage. Scooters are often a better choice than power chairs because they are more portable but SAP will not consider these at all. Quality of life is not considered.

We heard instances where, after waiting for weeks, the equipment can arrive at the patient's house in pieces 'on the doorstep' and the community health nurse has to figure out how to put it together. Sometimes, SAP will approve different equipment than was prescribed by the professional and have this sent to the patient. Often the substitution will require another assessment by the professional. Hospital occupational therapy and physiotherapy departments routinely lend equipment until the patient's equipment arrives.

The lack of community rehabilitation is sorely felt when specialized equipment needs to be fitted. Having a properly fitted wheelchair improves the maneuverability and safety of the chair and prevents skin breakdown and injury. Adults who require environmental controls (control of light switches, telephones etc) or communication devices do not receive funding support through SAP, even if this equipment will keep them safe and independent in their home.

Equipment suppliers are relied upon to provide temporary equipment, loans, trial equipment, advice and fitting. In St. John's there are enough suppliers to meet needs. In rural areas there are not. The tendering process prohibits companies from loaning or demonstrating equipment 'up-front' since they may not get the tender. This is particularly a problem in rural areas where there may be one or no local equipment vendor. Changes need to be made to overcome this problem.

Delays and Funding Issues Related to Provision of Equipment, Home Renovations and Home Supports.

Many people with a newly acquired disability are unable to work. They may be older and have limited financial resources. Equipment, home modifications or home support workers have substantial up-front and ongoing costs. Of considerable concern to respondents were delays and funding issues related to provision of equipment, home renovations and home supports. Twenty-four percent of patients and 70% of rehabilitation service providers responded that funding for patients requiring equipment, home renovations and/or home supports is not made available within a reasonable amount of time. This issue generated 107 comments in 10 of the 12 focus groups analyzed. Lack of funding or timely funding often does not allow patients to be discharged home or to an alternative living arrangements when ready. We heard that patients are often held longer in hospitals waiting for approval and delivery or arrangement of equipment. They often go home without these supports in place.

"Many patients 'make do' while they are waiting for equipment/renovations putting themselves at risk and/or slowing their rehab recovery."

The length of time and amount of red tape that is required for funding approval for equipment, home renovations and home supports is prohibitive. The wait for reauthorization of routine supplies can also be lengthy. People who run out of routine supplies such as bandage or catheters may wait weeks for reauthorization. We heard that social workers in hospitals spend a great deal of their time determining eligibility and managing the home support system. There are cumbersome processes, much paper work

and long wait times, causing lengthy discharge delays and costing the system a considerable amount of money. It appears that services for facilitating funding, determining equipment needs and home modifications are understaffed, underfunded and very poorly coordinated. There are problems at many levels and all may cause delays and impact time of discharge.

"If something is not checked off, the whole thing is sent back not considering that this poor person is still waiting for services, perhaps unable to get out of bed."

"The paperwork alone is overwhelming. The more equipment and supports a person needs, the longer it takes to have those approved and for the patient to actually receive the equipment or assistance. Patients can wait in hospital 2-4 weeks for a lift and a hospital bed."

"If there were more resources available in the community i.e. professionals, home support workers, funding for renovations and respite, a certain portion of the LTC resident population would not have been admitted."

Overall we heard that health professionals are concerned about chronically inadequate home supports. Improvements need to be made with regard to the SAP application and approval processes. Criteria for funding need to be more inclusive and processes more timely. Recycling of equipment should be more efficient. Fortunately we also heard that the Special Assistance Program and eligibility is being evaluated. Despite this, providers and patients are frustrated with the Special Assistance Program on several fronts:

- Many people, *the working poor* are in fact not eligible for government subsidies for equipment, home renovations or home supports, despite being at almost subsistence level.
- The process of applying and communicating with the SAP is convoluted and complex.
- Therapists, social workers and nurses report that they repeatedly phone and fax SAP to obtain basic equipment for patients.

"Increased demand is impacting the Special Assistance Program's speed of processing as well as the equipment dealer's speed of processing requests."

"Criteria and funding levels are not reasonable."

"The special assistance program, their first master is the treasury board and they are like the librarian who doesn't want to let the books out of the library. All they do is throw up roadblocks to people."

Therapists see older clients desperate to stay at home but are doing so and putting themselves at risk because there are no services for them. They see young people with

[&]quot;Funding was applied for but was not ready when I returned home."

disability that can't arrange home care workers; who have to move to LTC with older people and activities that are not age appropriate for them. They lose their network of friends and lose their former interests.

Community Accessibility

Patients had many concerns about access to public buildings and to community social and recreational activities. Access affects a person's ability to be involved in their community and maintain a healthy lifestyle both physically, socially, and psychologically. A quarter of patient/family respondents felt that they were not able to access and take part in community, social and recreational activities. Many bathrooms are still inaccessible. Ramps, doorways and curbs still present a challenge and require help to get past. Many complaints were also received about buildings owned by Eastern Health. While urban areas still have problems, there have been some efforts to provide accessible buildings and wheelchair accessible transportation. In rural areas there are few, if any, accessible public buildings and no public accessible transportation.

"Most buildings, even HSC, are not easily accessible – the ramps, doorways and washroom are not easy to use while in a wheelchair. Most buildings do not have level entrances through doors (e.g. the main door at HSC, the ramp at the clinic in Whitbourne). Not many restaurants are easy to enter – maybe buildings are old but ramps are not level with the ground. I did not realize this until I had to use a wheelchair."

"Do not have accessibility to any stores in my community because they don't have wheelchair access."

"Services not easily accessible at my home, I will be living with my parents at Bartlett's Harbour, it is the Western Health Services area. My community is located on the Northern Peninsula."

There are almost no community-based exercise or activity programs for people with disability and these same people often don't have the disposable income to pay for these 'luxuries'. People who use wheelchairs, especially those outside the metro St. John's area, cannot afford to pay transportation costs to attend therapy or doctor's visits let alone participate in recreational activities.

"I'd like to find someone who can go to the recreational activities such as the pool, for one hour or so. At the moment I'm only attending one recreational program. Does your program offer recreational swimming program or just the therapists? Because I have a disability."

"I had a patient died of a heart attack at 42. He had spina bifida and high cholesterol and he was writing the Minister to get gym membership for years. He was trying."

"We thank you for your interest and trust you will continue to advocate for those of us, who through no fault of our own, have been denied the pleasures we once had – self pity for sure!"

THE REHABILITATION WORKPLACE

We heard from rehabilitation providers in surveys, focus groups and interviews that the workplace matters to them. It influences the decision to apply for and then stay in a particular position. It was interesting that we did not hear issues about financial compensation. In fact rehabilitation providers felt that one-time incentives were not helpful in retaining staff in their workplace. They placed more importance on education, mentorship, respect, and loyalty.

There were many comments throughout the surveys and focus groups concerning the inefficiencies caused by working conditions. There are improvements that can be made in this regard that would increase patient care time, and improve quality of care and safety for patients.

Human Resources and Recruitment

Seventy-four percent of health provider respondents indicated there was not enough staff in their area to provide adequate rehabilitation services. This level of dissatisfaction increased to 100% in community health and in regional hospitals and 89% in LTC. Lack of human resources was not a major issue in the patient/family survey. Recruitment issues generated 23 comments in 8 of the 12 focus groups. Almost all focus group participants could name a chronically vacant position in their area; usually a rural or community OT or PT. In LTC and Community Health, there is almost no access to some rehabilitation disciplines such as Speech Language Pathology or Psychology. If people can pay, they can find services privately. Long wait lists and wait times throughout the system as well as the inability to provide sufficient and appropriate rehabilitation services for patients is routine.

Because rehabilitation patients access multiple levels of service, from acute care to community, lack of human resources in one area affects the flow of patients through the health care system. For example, lack of resources in community slows discharge in acute care and rehabilitation. Unfortunately there is a silo approach to recruitment with each program or area working to recruit rehabilitation clinicians for its own needs. The increased demand for rehabilitation requires more clinical and support staff and a more integrated approach to treating patients in order to make the best use of the staff we have.

With staff shortages and the pressure being placed on current staff, planning for prevention and for new services such as regional cardiac rehabilitation and lifestyle clinics is difficult to contemplate. Chronic vacancies are a source of frustration for those remaining. They are unable to cover the caseload, waiting lists grow, and they feel pressured not to take time off.

"The lack of OT/PT services to clients in the community because of staffing and inpatient workload – leaves many clients at risk in the community. OT is not accepting any referrals from community and it has gotten to a point where I often advise my high-risk clients to present at emergency and demand to see rehab services before they leave. I have had home support clients wait months for equipment that would improve their safety and that of workers. Rehab services lacking on Burin Peninsula makes my job very difficult."

"Rehabilitation is minimal in community. Therapy is very limited and the best hope is a supportive family who will follow through on treatment plans."

"There is not enough staff for long-term care facilities. They are however providing the best service they can with limited staff that is here."

"Not just the rehab centre but all residents in institutions should receive the OT and PT they need and deserve. We do not have enough OT and PT on staff to cover the need of our aging community. Having their duties shared and only allowing 2-3 days per week at one given facility is TERRIBLE. One full time OT Assistant is not adequate. Wake up people put your money where your mouth is and start CARING!!! Let's give these people in need the therapy they deserve so that they may have a quality of life again."

We found that in most regional health authorities, there were chronic shortages and vacant positions for nurses and rehabilitation professionals. New graduates are often the only applicants for solitary positions. They soon realize that they will not benefit from mentorship, education or support from peers. We heard that large caseloads, loss of job satisfaction, and burn out, as well as the fact that there is generally no coverage for any type of leave, causes increased staff turnover and difficulty recruiting and retaining rehabilitation professionals.

"The number of students coming back to Newfoundland every year, everyone is fighting over. There are not enough warm bodies to go around"

"If I was a new therapist coming out and I had to choose between Gander and Twillingate, where am I going to go? I am going to move where there are people I can learn from, where there are different rotations, there's exposure to different things, because I'm still learning. I'm a new grad"

"And I'm so embarrassed when people come and ask how long till I get in or they call and what do you say, "you're not going to get in". And it makes me feel bad and makes me feel unsatisfied at the end of the day... Because that's why you don't keep people. We don't like this and day after day you finally come to a point where it is not worth it. And that's why we leave."

In Newfoundland and Labrador, recruitment and retention of all health professionals is an ongoing problem. Education programs for most allied health staff are

outside the province as is ongoing education to maintain competency. We do not know if we train enough occupational therapists, physiotherapists and speech language pathologists to meet current and future needs. We also do not know if training in Nova Scotia is the best option for our province. There may be incentives to promote rural practice that have yet to be explored. These issues are beyond the scope of this review however they critically impact rehabilitation in every region of our province.

There were some comments specific to **Physicians and Medical Support**. In general, the rehabilitation staff in hospitals and nursing homes was very satisfied with medical support but there were problems with medical support in specific areas.

- In LTC, rehabilitation providers felt that residents suffered from lack of a comprehensive geriatric assessment. Many residents have multiple medications, dementia, depression and other health conditions that require a specialist's care at least on a consultative basis.
- Foreign trained doctors in some regional hospitals come and go with very little orientation.
 - "..like a revolving door".
 - "They don't know the system. They tell patients that they can get 24 hour home support, promising things that don't exist. Then it's damage control. They just don't know".
- There is a serious problem with lack of specialists in physical medicine and rehabilitation. Providers feel that our patients do not receive the same standard of medical care as those in other provinces.
 - "There is no Physiatrist!"

Rehabilitation Patient Caseloads

We heard that large caseloads for rehabilitation health providers were a particular problem in LTC, Community and the Chronic Pain and Disability Management Program; 76%, 41% and 50% respectively. Caseload fluctuates when leave of a colleague needs to be covered and where there are vacancies. We heard that staff controls caseloads by prioritizing patients and reducing the intensity of service. Increased recruitment and retention efforts and enhanced clerical support and support staff can help make rehabilitation more efficient and effective.

"A waitlist of over 400 chronic patients and a delay in therapy of often 10 to 14 months is way too long, especially when we know there are also populations we are not even beginning to service. The pressure to do purely clinical work does make it difficult to fulfill other aspects of my job."

"In long term care caseloads are immense, e.g. 1 PT for > 200 residents. Admission from acute care and community involve complex medical problems – Younger populations with high expectations too."

"I am definitely not coping well with my patient caseload – resident stats are

increasing, as is travel for urgent consults and inpatient referrals in addition to trying to carry a full outpatient caseload."

"My caseload is manageable when little rehab services are provided."

"My caseload in outpatients is manageable because I can limit the number of patients I see in a day but the inpatient waitlist is not."

Workspace

All sites reported problems with workspace that interfere with the provision of adequate rehabilitation services. Fifty-two percent of service provider respondents felt their workspace was inadequate for the provision of rehabilitation. Inadequate treatment space generated 40 comments in 7 of the 12 focus groups. Satisfaction surveys from the Rehabilitation Program consistently identify inadequate bathrooms and space in patient rooms as an issue.

Rehabilitation, such as kitchen independence training, walking tolerance, strengthening exercise, and bathroom transfer practice requires safe, accessible space. People with disability and their rehabilitation providers require equipment such as wheelchairs, lifts, commodes, walkers, as well as the space to store this equipment. One of the most important skills to relearn after injury is preparing meals. Other than the L.A. Miller Centre and St. Clare's Hospital, there are no accessible kitchens where training can take place. Unfortunately in our older facilities and even newer ones, there are inaccessible washrooms and 3-4 bed patient rooms that will not accommodate equipment.

In many cases, outpatient occupational therapy and physiotherapy treatment areas are located furthest away from the facility main entrance, often in basements with barrier doors. Waiting areas are often too cramped for wheelchairs. In most LTC facilities, physiotherapy and occupational therapy have to share cramped office and treatment space. It is common for therapists to use crowded busy hallways in acute care institutions for treatment space and do exercises at the person's bedside in full view of other patients and their families. In order to bring patients to a treatment area, it most frequently involves bringing the patient including their catheters and tubes through hospital public areas. Some disciplines such as social work, psychology and speech language pathology provide assessment, treatment and counseling in common rooms and dining areas in acute and regional hospitals and nursing homes. Offices are often inaccessible, for example once a person using a wheelchair enters the room; the door cannot close behind them. Furthermore, rooms are usually not large enough to accommodate families or students. We were told that there is no space in some facilities for group work and group education.

There is usually no storage space for required equipment such as wheelchair parts and cushions that are used on a daily basis. Confidentiality and privacy are compromised as phone, computer and workspaces are often located in the treatment room.

As older buildings are replaced, rehabilitation staff, especially occupational therapists, should be consulted. If buildings are designed to meet the needs of the elderly

and the disabled, they will meet the needs of most people. Discussion needs to take place amongst designers, contractors and rehab providers.

"The patient units are very busy and the hallways and patient rooms have too much clutter."

"If you could walk that far, you wouldn't need to be going to physio".

"I have to use an office that is shared with all other staff, with one telephone and computer in that office while attempting to take many verbal orders, private face to face or personal phone calls to family members, discussing patient cases with physicians, etc. etc."

"Interviewing patients/families in a storage area is not adequate when 2-3 nurses have entered to obtain supplies."

"The Orthotic/Prosthetic department is a disaster waiting to happen. Renovations and new equipment is way overdue. Workers from abroad will not stick for long in this kind of environment as it is under standard compared to most facilities anywhere in the country. St. John's has much to offer, especially for a young family like mine. Don't push us out because of substandard working conditions. Other that that, I love the place!!"

"Rehab provided in corridors and stairwell."

"Too small, no ventilation, limited access and electricity in the area

Technology

"Health care technology is a broad concept that can be defined as the set of techniques, drugs, equipment and procedures used by health care professionals in delivering health care to individuals and the systems within which such care is provided. It is generally agreed that health care technology constitutes an important component of health care delivery in advanced countries. Health care technology can improve the speed and accuracy of diagnosis, cure disease, lengthen survival, alleviate pain, facilitate rehabilitation and maintain independence." ¹⁰

Thirty-four percent of staff indicated that they did not have access to adequate technology and equipment to do their jobs. Equipment to aid assessment and treatment is limited and much of it is old, outdated or obsolete. Some rehabilitation care providers reported that they are using outdated equipment and some are even using homemade equipment. The use of outdated equipment inhibits high quality treatment and increases treatment delays as a result of waiting for parts and repairs.

"The tools are there, safety concern on the other hand is the problem."

"My results in rehab were compromised by lack of staff and proper equipment"

Equipment:

Inadequate treatment equipment generated 21 comments in 7 of the 12 focus groups. Respondents in the survey provided lists of the many equipment items required to provide adequate and safe care. Some listed additional equipment and technology that would advance care to a higher level. Basic equipment such as mechanical lifts, wheelchairs, cushions, and walkers are required to get patients safely out of bed, support them into an upright position, and promote recovery. In most acute care facilities, we found there were not enough lifts and lift slings to get people out of bed. We heard that in one facility, people who have suffered a debilitating illness or injury were left in bed because there were not enough mechanical lifts or slings to get them out.

"I worked there and there were 30 beds. That was one lift for those 30 people"

This was not the case in all settings; some newly renovated areas had ceiling lifts, larger rooms to accommodate equipment and accessible washrooms. In most acute and regional hospitals in the province as well as in Long Term Care, there were not enough custom chairs or wheelchairs with safety belts and trays to position patients safely. Equipment was not maintained and there were chairs with torn safety belts and broken wheels placed in hallways. Little was done in preventative maintenance. In community, there is limited equipment to loan and little of it is checked to ensure it operates properly. Staff reported that they have applied for Eastern Health Comfort in Care Grants to add essential equipment. They post notices in departments asking for community donations of wheelchairs, bath benches, and exercise equipment.

"No budget for equipment in LTC, i.e. chairs, wheelchairs, lifts, etc. Residents can be in bed for extended periods of time because of no wheelchair to sit in, – Not acceptable."

"After somebody comes back from the Miller Centre and they pass away, I am bold enough to approach the family to say, 'Can I please have the equipment you are not using because I need it for assessing other client?'. So I have developed my own little library of stuff but it certainly doesn't come close to meeting the need. And it takes so much time."

Even in the L.A. Miller Centre, many of the locally made treatment mats are showing the signs of 20 years of wear. They are slowly being replaced by hydraulic mats that electronically raise and lower to adjust to the needs of the patient. The needs of bariatric clients, those weighing near the 500lb limit for most hospital equipment, are being addressed on an as-needed basis.

Although the L.A. Miller Centre as the provincial rehabilitation centre has relatively spacious treatment areas and adequate equipment, there are problems at this facility as well. Air quality and temperature in treatment areas are ongoing problems. The types of patients that are seen require the use of a hydrotherapy pool which currently does not exist. Because of this, the Rehabilitation Program currently rents the pool at the

Mews Centre, transporting patients by taxi or paratransit. This is often not an option for inpatients therefore they are usually excluded from pool therapy. The use of this pool for hydrotherapy is not ideal due to pool accessibility and water temperature. There are many difficulties in using public spaces for treatment including privacy, confidentiality, accessibility, supervision, quality and safety.

"We need a therapeutic pool. So much could be done with this kind of facility that we cannot do with our little Hubbard tank for those post fractures, total joint replacements, OA, back problems, inflammatory arthritis and many other conditions."

Client Information Systems:

Patient information is conveyed among health providers in several ways;

- 1. Verbally (both formal and informal),
- 2. Written in health records in a patient's room, at a work station, or in a treatment area
- 3. Electronically.

The March 2009 provincial budget allocated 3\$ million towards improvement of the electronic health record. Our findings confirm the need for this investment. This topic generated 25 comments in 6 of the 12 focus groups. Staff reported that there are not enough computers and that the computers they do have are often old, and are shared among too many staff. Inadequate computer technology and access to computer terminals generated 24 comments through focus group analysis.

"I must share a telephone and computer with other staff on the unit while attempting to coordinate patient care."

Day-to-day care of patients, especially those with multiple co-morbidities, requires sophisticated immediate communication among providers. Patients access multiple levels of services (community, acute, rehabilitation and LTC) requiring coordinated communication among these providers. Unfortunately we heard that the communication system is fractured and uncoordinated. Patient information systems at each service level operate independently of one another within Eastern Health, for example, there may be information about a person's health in Meditech (acute and rehab), CRMS (community), Magic system (LTC) inaccessible to each other. Furthermore, regional hospitals within Eastern Health such as Carbonear, Burin and Clarenville, have different and separate health record systems from city hospitals despite the fact that patients move within and between hospitals and community health. Staff report that this disconnect causes patient information gaps and misinformation among health providers. For example, a resident from LTC suffers a fall and is seen in the city Emergency and then subsequently returns to LTC. The staff in LTC report they cannot access the X-ray reports or ER visit notes and they have relied on second-hand reports from the person's family. Another level of disconnection exists when some documentation is written on paper while other health record information is electronic. Staff report several 'close calls' due to misinformation and this gap has the potential to cause harm to patients.

Concerns about modernizing and integrating the health records system include:

- Current electronic systems, particularly Meditech, are not capable of efficient and effective documentation.
- Current training in our electronic health record systems has had a strong nursing focus with little emphasis on charting requirements for rehabilitation professionals and patients undergoing rehabilitation. Allied health staff has not received equitable access to electronic documentation and patient information systems training appropriate for their needs.
- Systems that are used to collect patient data and treatment do not capture data on rehabilitation patient services, types of treatment provided; services referred etc. which make planning difficult.
- Computer availability for rehabilitation staff varies within our current health settings.

Clerical Support

Clerical duties include transcription, typing, filing, arranging appointments, and photocopying. Clerical support allows frontline clinicians to focus on patient care. Forty two percent of rehabilitation service provider respondents indicated that they do not have adequate clerical support. The highest dissatisfaction with clerical support was in regional hospitals outside St. John's (80% dissatisfied). Inadequate clerical support also generated 18 comments in 6 of the 12 focus groups. While some sites feel they have adequate clerical support, others feel that have little or nothing. This is especially true for rural and regional rehabilitation providers that cover multiple areas within a hospital while also covering nearby community health and LTC centers. These frontline clinical staff are performing substantial clerical duties; typing reports, photocopying, taking minutes of meetings, faxing, registering patients, booking appointments and answering the phone. Even though some hospitals are moving toward electronic booking of outpatient appointments, in several cases these modules are implemented without adequate clerical support. Rehabilitation service providers estimate that they spend up to 20% of their time completing clerical duties. In terms of patient care, this equates to about 2 to 4 patients a day that could have been seen from a waiting list or in an inpatient stroke unit. With the vast need for rehabilitation service providers across the system, it does not make sense that we should be using any portion of this scarce resource for clerical work. Requiring rehabilitation professionals to do their own clerical work is an expensive way of having this work done.

"More and more correspondence is now done by individual therapy staff at the computer because we have little clerical time."

"I consider that 60% of my time is wasted doing clerical work. If I could dictate the many, many reports and letters I have to write, it would speed me up dramatically! As well, I do not consider that mailing and faxing should be part of my job ...BIG TIME WASTER! My time is best spent with clients!! The rest is wasteful, someone else could be paid a lot less to do it!"

Continuing Education and Competency

Rehabilitation research and knowledge, like all other areas of health provision, is advancing and public demand is growing for evidence informed practice. Maintaining competency in best practice can be achieved in a number of ways.

- Independent study and research
- In-house in-service and teleconference by mentors and local educators.
- Provincial conferences and workshops.
- National and international conferences in specialized areas.

Since rehabilitation is a small sub-specialty and most rehabilitation professional training occurs outside of the province, local continuing education is very limited. Nurse educators employed within our health system ensure nursing continued competency but there are no rehabilitation educators. Therefore, rehabilitation providers travel outside the province for relevant continuing education. Forty-five percent of service providers felt that they were not provided with adequate professional education to keep up with standards of practice. This issue also generated 34 comments in 8 of the 12 focus groups. Ongoing professional development is an issue that affects recruitment and retention especially when people are working in rural areas. Staff reports many barriers to maintaining competency:

1. Coverage while on educational leave: Lack of coverage for leave generated 11 comments in 2 of the focus groups. Nurses have very limited replacement available for educational leave and rehabilitation professionals have no coverage. They report reluctance to ask for educational leave because they know their patients will receive less service and their colleagues will be burdened with additional caseload. This is felt most acutely in areas where there may be only one or two providers (LTC, community, and regional hospitals). It is recognized that due to recruitment issues, replacement of allied health disciplines is difficult. Courses are often scheduled for weekends.

"Some managers say you can attend if you can find coverage for your area. Where do they think the coverage is going to come from?"

"You have a hard enough time trying to scratch the surface of the cases you have and then you are asked to share someone else's caseload who is away."

2. Educational leave approval: The approach toward approval for education is inconsistent within and across the organizations. This topic generated 15 comments in 5 of the focus groups. Some managers do not approve educational leave for travel days even when the staff member attends on their own time, on a weekend, and pays for it themselves.

[&]quot;You do it on your own time with your own money".

[&]quot;I was refused an event that was free, local and relevant"

"Not a lot of opportunities available. At times when education does come available, it is a struggle with management to get the leave to attend."

3. <u>Financial support</u>: Cost of rehabilitation courses range from \$200 to \$3000. Most rehabilitation service providers reported that they are expected to pay some of the costs of education along with investing personal time. Most health organizations provided partial support about once a year.

"Although there is funding, one has to come up with a very large part oneself. And if you are not lucky in the funding lottery, one has to pay all. That is too much risk to take and therefore does not encourage people to register for conferences or workshops."

"Often I need to pay for the course as well as give up a weekend."

4. Educational Infrastructure:

- a) Coordination of Education- Education can be sought out through colleagues and professional networks but the process is not easy and not coordinated. Some hospitals have professional development departments who will help organize education but in many cases organizing courses are left to the frontline providers.
- b) Rehabilitation Network- There are rehabilitation professionals within the province with sought-after expertise. A rehabilitation network with online resources, questions and answer discussion boards, lunch and learn teleconferences and research updates would help to disseminate knowledge. This will require coordination at a level beyond the frontline therapist. For example, the rehabilitation nursing lectures recently held in St. John's hospitals should be available to professionals across Eastern Health and other health authorities.
- c) Library Support- Many therapists do independent research with the help of hospital librarians. They read articles at home. This type of learning is 'just-in-time' and relevant to the needs at the moment. However, staff report that with long waiting lists and pressure to see a large caseload of patients, there is very little time to remain current. Survey respondents also reported not having up-to-date reading materials available and no funding to purchase educational materials.
- d) Technology- Rehabilitation providers report that Telehealth can be utilized to present cases and discuss issues around treatment. Telehealth has a wider capability to assist in education that requires visual feedback but unfortunately the technology can only be used for specific patient care issues.

"Not enough education but I understand that we're isolated. Never mind I do not have time to learn as my caseload is too heavy to take the time."

"Very discouraging \rightarrow why a lot of professionals have stopped bothering to apply.

To continue to meet standards of care, continuing education is crucial. We need to promote and support educational endeavors as much as possible and find creative ways to provide education to our health providers without causing them personal hardship. Allocating more money to education is one solution to this problem. Development of a regional or provincial rehabilitation network that seeks out, organizes, supports and promotes education within the province is an additional possible solution to this ongoing problem.

Mentorship/Clinical Leadership

Lack of mentorship and need for clinical leadership generated 9 comments in 4 of the focus groups. In larger health facilities and organizations within the province, there is a hierarchical structure of clinical leadership positions for rehabilitation professionals. These positions are responsible to mentor new graduates; address issues of overall service provision, identify professional development needs, and evaluate services and staff. Front-line health professionals feel that their strength is in clinical provision of service. They are challenged by the fact that in regional areas and community, there are no clinical leaders. Continuing education, mentorship and service evaluation are overlooked. Even in areas where there are clinical leaders (II and III level positions), these individuals often carry full clinical caseloads due to the demands for services, and to provide leave coverage. Our findings indicate that due to the lack of clinical leader positions in rehabilitation (particularly in community, LTC and some regional hospitals) there is a disconnect between recognizing rehabilitation issues and having a voice in making improvements in the quality of patient care. Therapists who work alone or in a very small group need to report to leaders and managers who understand rehabilitation.

Professional Communication

Communication is integral to a safe and efficient health care system. It is obvious from comments received concerning communication throughout Eastern Health that improvement is necessary. Forty-three percent of service provider respondents reported having poor communication with care providers at other sites in Eastern Health. Fifty-two percent of respondents felt they did not have a clear understanding of rehab services being provided at other sites and 42% felt that when making referrals to other sites they didn't have a clear understanding of the appropriate patient served by that site. We heard especially in Western, Central and Labrador Grenfell Health Authority focus groups, that communication with tertiary providers in Eastern Health was a problem.

The current system of providing rehabilitation services is fragmented, lacks coordination, and has inequitable distribution of resources. It reflects the absence of a systematic regional or provincial approach. In rehabilitation, people are working in silos with a lack of communication and coordination across sites. Because care providers work this way they do not see or feel it is their responsibility to address gaps outside their immediate area of responsibility.

"As someone who works across sites, it is often abundantly clear that teams at one site do not support teams at another site. Much work needs to be done to support continuity of care across sites and throughout the continuum of care."

"Staff is receptive to discussion however, limited formal communication takes place."

"Right now there are too many gaps in services. Communication is too time consuming, too irregular and erratic."

Care providers are not always sure what services are available and where they should be referring their patients. There is no agreement concerning the definitions of such terms as "tertiary rehabilitation", "slow stream rehabilitation" and other terms used to describe rehabilitation services or the types of rehabilitation being provided at each site. This causes much confusion and dissatisfaction when trying to decide where to refer patients.

"I have limited understanding of rehab services provided in other regions of the province."

"Rehab services do not have promotional literature, websites, etc. that discuss their service."

We need to transform this system away from working in silos toward a system where rehabilitation professionals across the region work collaboratively to deliver a seamless integrated array of rehabilitation services. In an improved system, information concerning services provided should be clear and easily accessible. It should be clear to patients and care providers which services are provided at which site and how each service fits into the larger picture of rehabilitation. The establishment of a rehabilitation network of care providers to provide a forum for discussion of patient care issues, to improve coordination of services, and to promote education throughout Eastern Health and even the province could be a first step in helping to achieve this goal.

PROVINCIAL AND REGIONAL ISSUES

The issues discussed throughout this report were identified by health providers, patients and families in all health authorities in Newfoundland and Labrador. The issues identified apply to all health authorities in the province however some issues were of greater concern in Central, Western and Labrador Grenfell. NLCHI data indicate that although length of stay is about the same for rehabilitation-matched health codes in all health authorities, there are a larger portion of alternate level of care days (about 65%) and more frequent readmissions within one year (about 50%) in Central, Western and Labrador Grenfell.

NLCHI data show that in 2005-06, there were very few patient transfers to the L.A. Miller Centre from authorities other than Eastern Health. We heard in focus groups and key informant interviews that although patients need rehabilitation, they stay longer

in the regional hospital and choose to go home without rehabilitation rather than move to St. John's or Corner Brook. We heard that some patients who receive their tertiary care in St. John's (injury management or surgery) will more likely go to the L.A. Miller Centre for rehabilitation. Focus groups and key informant interviews showed there were common issues in rural and regional (Burin, Clarenville, Bonavista, Carbonear, Central Health, Western Health, Labrador Grenfell Health) rehabilitation practice that need to be addressed. These include:

- Acute Care Rehabilitation: In general, patients with rehabilitation needs are placed on mixed acute care wards. Therapists may have 20 or more patients to see therefore patients may receive just 15-20 minutes of therapy per day. Acute and orthopedic patients take priority over other patients requiring rehabilitation. Nursing care is focused on efficiency, not promoting independence. NLCHI data indicate that about 13% of total length of stay days for rehabilitation-matched health codes is alternate level of care days. However the proportion of ALC compared to LOS in those groups is less in Eastern Health (43.6%) but greater in Central, Western and Labrador Grenfell Health (65.2%, 64.2% and 62.1% respectively). This suggests that there are a significant number of acute patients with complex needs that are not being met. It is suggestive of resource gaps in Rehabilitation, LTC and Community Rehabilitation.
- Community Rehabilitation: There are few rehabilitation providers in community and primary health centres. Long term care facilities receive occasional visits by rehabilitation providers based in hospitals. Maintenance therapy is provided by support workers in some facilities although it is recognized that residents deserve better care. There are very few dietitians and no speech language pathologists providing community based care. There is no service for residents in personal care homes. Readmission to acute hospital is routine suggesting the community health needs of patients in these diagnostic categories are not effectively met.
- Recruitment and retention of rehabilitation providers in rural areas continues to frustrate health providers. Providers felt that in order to work in rural areas, there must be a support and peer network.
- Speech language pathologists mainly provide pediatric care in most regional health authorities. For adults, scope of practice is limited to assessment and management of swallowing problems. Adults who require speech and language therapy do not receive it unless they relocate to St. John's.
- **PT and OT** waiting lists in regional hospitals are up to 2 years long. Some patients especially requiring home safety assessment and intervention could be better served by community rehabilitation.

In addition, each region had specific rehabilitation problem areas:

Central Health

There is a long standing and recognized need for designated rehabilitation beds in Gander and Grand Falls with nursing and rehabilitation staff trained to provide this level of care. NLCHI data and Rehabilitation Program indicators show that very few patients from Central Health are transferred to the L.A. Miller Centre. We heard that some decide not to have rehabilitation and stay with their families and a small number go to the O'Connell Centre in Corner Brook. There is a need for rehabilitation beds at both sites, but due to the specialized training required, patients may be better served by 10-12 general rehabilitation beds in one of either Gander or Grand Falls.

Western Health

Western Health has been moving toward community-based programming, particularly in occupational therapy where new positions have been added in Stephenville and Humber Valley as well as another in Bonne Bay.

There is an 8 bed rehabilitation unit mainly for patients with stroke, orthopedic problems, and amputations, however, patients can wait months for admission. The speech language pathologist visits about once per week and the emphasis is on swallowing safety and not language therapy. Almost all rehabilitation patients are followed up after discharge by a member of the team. The rehabilitation providers report the need for more community physiotherapy and an outpatient day rehabilitation program.

Labrador Grenfell Health

Patients in Labrador and St. Anthony have the most limited rehabilitation services in the province. NLCHI data show that other than patients who are transported to the HSC for tertiary care, almost no-one is transferred to the L.A. Miller Centre. We heard that very few patients go to the O'Connell Centre. Rehabilitation provision is challenged by vast geography and expensive transportation.

"I feel very sad and very overwhelmed when I go up to see those clients because I'm going there and I see the needs but I can't address them."

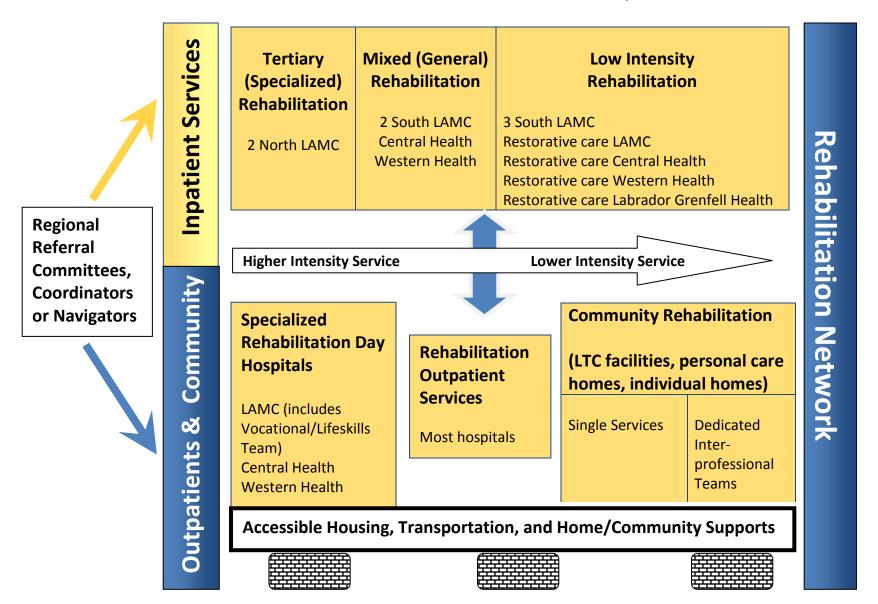
The Labrador Grenfell focus groups and key informant interview highlighted recruitment and retention of rehabilitation staff as a significant issue. There was an expressed need for better recruitment and retention strategies, senior therapist positions for support and mentoring of allied health staff and an increased number of positions. People with rehabilitation needs must travel to St. Anthony and Goose Bay for service. We heard from patients, families and providers that there is an immediate and urgent need for community rehabilitation therapists.

RECOMMENDATIONS

Results of this investigation have made it clear that there is a need for a new, more integrated model of rehabilitation throughout Newfoundland and Labrador. A model where patients have reasonably equitable access to rehabilitation services and where rehabilitation service providers communicate, support and learn from each other.

The figure below illustrates the model proposed.

Newfoundland and Labrador Rehabilitation Conceptual Framework



ADDRESSING NEEDS THROUGH ENHANCED SERVICES

1. Community Rehabilitation

While there is a need for improved rehabilitation services and increased staff across the continuum, the most glaring need is the need for community rehabilitation. The addition of these services in the community will make rehabilitation accessible to more people and relieve some if the pressure for rehabilitation services that is being felt throughout the system. We recommend the development of a new community rehabilitation program/division designed to meet the specialized needs of both urban and rural practice. Such a division/program, with appropriate hierarchy and leadership levels, would allow for appropriate supervision and mentorship and improve recruitment and retention. Since there is no structured program in place, we recommend beginning with a basic model and core human resources.

Community Rehabilitation in this context refers to teams of rehabilitation specialists strategically located at various access sites (clinics, long term care facilities) throughout the community. These teams could provide therapeutic services at the site and would have the ability to visit private homes, long term care facilities and personal care homes as required. Clients would be able to access services closer to home and under certain conditions have home visits as well. These community rehabilitation teams are not meant to replace hospital specialty outpatient services but would take some of the patients presently not considered priority for these services and would likely reduce the hospital outpatient waiting lists significantly over time. They would receive referrals from community physicians, and would also receive referrals from hospital inpatient and outpatient services to complete the final stages of treatment and adjustment to the home and community, check equipment provision and do follow-up as required. Because patients would be seen in the community before issues reach crisis level, visits to emergency should also be reduced.

These Community Rehabilitation teams would report in St. Johns to a new Community Rehabilitation Division of the Rehabilitation Program of Eastern Health and in rural areas to already existing divisions within hospitals and primary care facilities but would exclusively provide services as described above. There may be opportunities to partner with private rehabilitation providers in the community to optimize community-based care.

In Eastern Health St. John's Region, the new Division of Community Rehabilitation within the Rehabilitation Program would include:

- New human resources to service each of the five Urban Avalon regional zones, housed in existing Community Health Offices and the L.A. Miller Centre.
- Current Community Health rehabilitation providers (2 OT and 2 PT)
- Current rehabilitation providers in LTC facilities in St. John's (OT, PT, dietitians, social work, recreation)
- New human resources in LTC facilities (PT, OT, SLP, psychologists, recreation)
- Some current outpatient rehabilitation positions at the L.A. Miller Centre (0.5 OT, 0.5 PT) to assist in servicing that zone.

 Along with the patient, family, their family physician and community health

nurse, we recommend that core community interdisciplinary team members will include OT, OTA, PT, PTA, dietitians, SLP, social workers and psychologists. Rehabilitation assistants (also known as rehabilitation support workers- OTA and PTA) can provide some therapeutic exercise programs in the community. Recreation specialists and recreation therapy workers provide programming mainly in nursing homes and personal care homes. The involvement of pharmacists, dental hygienists and other members of the health care team should be evaluated. It will be important that the core interdisciplinary team be located together in a central area or facility (with appropriate clerical support) to facilitate collaboration.

It should be noted that no service area would lose any service they presently have and staff would still require the space where they are presently working. What we are recommending is that the reporting structure would change and there would be gradual growth of resources to improve services to the necessary level.

There will be new community rehabilitation providers in rural areas outside St. John's; Carbonear and area, Burin, Placentia, Clarenville and Bonavista. In order to recruit and retain these positions, it will be important to provide mentorship, support and opportunities for advancement (appropriate levels of I, II and III positions). Since there is not a critical mass of community rehabilitation providers outside the St. John's region, these rural and regional community rehabilitation providers will report to already existing divisions (with the majority of rehabilitation positions) within hospitals and primary care facilities. These positions must be recognized as distinctly providing community rehabilitation services and not be used to provide leave coverage for institution-based positions. Although this report does not address specific directions for community rehabilitation in other provincial health authorities, it is clear from our findings that community-based rehabilitation in these areas is also lacking.

When viewing the resource recommendations below it is important to keep in mind the following points

- At present community services are largely provided by nurses and social workers in *Community Supports* and *Community Living and Supportive Services* (CLASS). Rehabilitation care including independence training, adjustment and disability counseling are not being provided. The proposed community services are separate and would require additional social workers and nurses who would work as part of community interdisciplinary rehabilitation teams
- Community rehabilitation includes rehabilitation being provided in Long Term Care facilities, Personal Care Homes and individuals' homes in the community.
- Interdisciplinary rehabilitation teams would be developed within communities and zones, including Long Term Care facilities to meet the needs of residents who live there
- Recommendations are based on population (per 10,000), discipline specific rehabilitation standards (see secondary data), density of Long Term Care and Personal Care homes and previous reports on rehabilitation needs.

The first table (Table 32) represents a summary of staff requirements for Community Rehabilitation in Eastern Health. Table 33 outlines a more detailed analysis of data in Table 32.

Table 33 outlines additional staff requirements in each area taking into account existing staff and not using any of the existing nurse or social work positions.

Table 33: Staffing requirements for Community Rehabilitation

Community Rehabilitation Services					
Service	Proposed Staffing	Present Staff	Staff Requirement		
Area	Troposoa starring	available	Starr Requirement		
Burin	2.0 OT	0.9 Recreation	2.0 OT		
(18.1 new	2.0 PT	Specialist	2.0 PT		
positions)	1.0 SLP,	4.0 RTWs	1.0 SLP,		
positions	1.0 SEI, 1.0 SW (rehab),	4.0 K1 W5	1.0 SEI , 1.0 SW (rehab),		
	1.0 Dietitian		1.0 Dietitian		
	1.0 Psychologist		1.0 Psychologist		
	2.0 OTA,		2.0 OTA,		
	2.0 PTA		2.0 PTA		
	4.0 Recreation		3.1 Recreation		
	Specialist		Specialist		
	6.0 RTWs		2.0 RTWs		
	1.0 Rehab Nurses		1.0 Rehab Nurses		
	or Nurse Practitioners		or Nurse Practitioners		
	(Total - 23 positions)				
Clarenville	1.0 OT	1.0 Recreation	1.0 OT		
(10.6 new	1.0 PT	Specialist	1.0 PT		
positions)	0.5 SLP,	1.0 RTWs	0.5 SLP,		
	1.0 SW (rehab),	0.4 Dietitian	1.0 SW (rehab),		
	1.0 Dietitian		0.6 Dietitian		
	0.5 Psychologist		0.5 Psychologist		
	1.0 OTA,		1.0 OTA,		
	1.0 PTA		1.0 PTA		
	2.0 Recreation		1.0 Recreation		
	Specialist		Specialist		
	3.0 RTWs		2.0 RTWs		
	1.0 Rehab Nurses		1.0 Rehab Nurses		
	or Nurse Practitioners		or Nurse Practitioners		
	(Total – 13 positions)		(for Clarenville and		
Danavista	1.0.OT	1 O Decreation	Bonavista Peninsula)		
Bonavista	1.0 OT 1.0 PT	1.0 Recreation	1.0 OT 1.0 PT		
(8.5 new positions)	0.5 SLP,	Specialist 2.5 RTWs	0.5 SLP,		
positions	1.0 SW (rehab),	2.J KI W 5	1.0 SW (rehab),		
	1.0 Sw (tenab),		1.0 Sw (tenab), 1.0 Dietitian		
	0.5 Psychologist		0.5 Psychologist		
	0.5 OTA,		0.5 OTA,		
	0.5 PTA		0.5 PTA		
	2.0 Recreation		1.0 Recreation		

	Specialist		Specialist
	Specialist 3.0 RTWs		Specialist 0.5 RTWs
	1.0 Rehab Nurses		1.0 Rehab Nurses
	or Nurse Practitioners		or Nurse
			Practitioners
	(Total – 12 positions)		r racumoners
Carbonear	5.0 OT	1.0 Dietitian	5.0 OT
(32 new	5.0 PT	2.5 Recreation	5.0 PT
positions)	3.0 SLP,	Specialist	3.0 SLP,
	4.0 SW (rehab),	5.5 RTWs	4.0 SW (rehab),
	5.0 Dietitian		4.0 Dietitian
	3.0 Psychologist		3.0 Psychologist
	2.0 OTA,		2.0 OTA,
	2.0 PTA		2.0 PTA
	4.0 Recreation		1.5 Recreation
	Specialist		Specialist
	7.0 RTWs		1.5 RTWs
	1.0 Rehab Nurses		1.0 Rehab Nurses
	or Nurse Practitioners		or Nurse Practitioners
	(Total – 41 positions)		
Placentia	1.0 OT	2.0 RTWs	1.0 OT
(8 new	1.0 PT		1.0 PT
positions)	0.5 SLP,		0.5 SLP,
	1.0 SW (rehab),		1.0 SW (rehab),
	1.0 Dietitian		1.0 Dietitian
	0.5 Psychologist		0.5 Psychologist
	0.5 OTA,		0.5 OTA,
	0.5 PTA		0.5 PTA
	1.0 Recreation		1.0 Recreation
	Specialist		Specialist
	2.0 RTWs		1.0 Rehab Nurses
	1.0 Rehab Nurses		or Nurse Practitioners
	or Nurse Practitioners		
	(Total – 10 positions)		
Rural	1.0 OT	1.0 OT	1.0 PT
Avalon	1.0 PT	1.0 Dietitian	0.5 SLP,
(6 new	0.5 SLP,		1.0 SW (rehab)
positions)	1.0 SW (rehab),		0.5 Psychologist
	1.0 Dietitian		1.0 Recreation
	0.5 Psychologist		Specialist
	1.0 Recreation		1.0 RTWs
	Specialist		1.0 Rehab Nurses
	1.0 RTWs		or Nurse Practitioners
	1.0 Rehab Nurses		
	or Nurse Practitioners		
	(Total – 8 positions)		

Urban	17.0 OT	5.5 OT	11.5 OT
Avalon	17.0 PT	6.0 PT	11.0 PT
(108 new	8.0 SLP,	5.5 Dietitian	8.0 SLP,
positions)	15.0 SW (rehab),	1.0 Psychologist	15.0 SW (rehab),
	16.0 Dietitian	7.0 PTA	10.5 Dietitian
	9.0 Psychologist	6.5Recreation	8.0 Psychologist
	11.0 OTA,	Specialist	11.0 OTA,
	11.0 PTA	17.5 RTWs	4.0 PTA
	15.0Recreation		8.5Recreation
	Specialist		Specialist
	31.0 RTWs		13.5 RTWs
	6.0 Rehab Nurses		6.0 Rehab Nurses
	or Nurse Practitioners		or Nurse Practitioners
	1.0 Division Manager		1.0 Division Manager
	(Total -157positions)		
Total	264 positions	72.8 positions	191.2 positions

Table 32: Existing and Proposed Community Rehabilitation Resources

Service Area	Current Community Resources	Region and population covered	Proposed Community Services	Reporting to:
Burin	-No community therapists or	Grand Bank,	Blue Crest Home, US Memorial Health	Burin Hospital
	Rehab Nurses. Hospital	Burin,	Centre and community Grand Bank,	
	Physiotherapists (PTs),	Marystown	Burin and south	
	Occupational Therapists		1.0 Occupational Therapist (OT)	
	(OTs), Speech Language	Population	1.0 Physiotherapist (PT)	
	Pathologists (SLPs), and	Approx 22,000	1.0 SLP	
	Dietitian will consult patients		1.0 Social Workers (rehab)(SW)	
	in community in		0.5 Dietitian	
	emergencies.		0.5 Psychologist	
			1.0 Occupational Therapy Assistants	
			(OTA)	
	Recreation & Social Work		1.0 Physiotherapy Assistants (PTA)	
			3.0 Recreation Specialist	
	Community Supports		5.0 Recreation Therapy Workers (RTWs)	
	6.0 - SWs		1.0 Rehab Nurse or Nurse Practitioner for	
			Peninsula	
	Blue Crest Nursing Home			
	0.5 Recreation Specialists		Marystown and North	
	2.0 RTWs		1.0 OT	
	1.0 SWs		1.0 PT	
			0.5 Dietitian	
	US Memorial		0.5 Psychologist	
	0.4 Recreation Specialists		1.0 Recreation Specialist	
	2.0 RTW		1.0 RTWs	
	1.0 SWs			
		l		l

Clarenville	No community therapists or	Clarenville, Port	Long term care facility in Clarenville	Clarenville
	rehab nurses.	Blandford to	and Community Clarenville, Port	Hospital
	Hospital PT, OT, SLP,	Swift Current	Blandford to Swift Current	-
	Dietitian will consult patients			
	in community in emergencies.	Population	1.0 OT	
	0.4 FTE Dietitian – LTC	Approx 13,000	1.0 PT	
			1.0 SW(rehab)	
	Recreation and Social Work		0.5 SLP	
			1.0 Dietitian	
	Community Supports		0.5 Psychologist	
	3.0 -SWs		1.0 OTA,	
			1.0 PTA	
	Long Term Care		2.0 Recreation Specialist	
	1.0 Recreation Specialist		3.0 RTWs	
	1.0 RTWs		1.0 Rehab Nurse or Nurse Practitioner for	
	1.0 SWs		Peninsula	
Bonavista	No rehab nurses	Bonavista,	Community from Bonavista to	Bonavista
	1.0 PT covers hospital, LTC,	Trinity to	Lethbridge area, Golden Heights	Hospital
	community and outpatients	Lethbridge area	Manor	
	SLP from Clarenville Hospital		1.0 OT,	
	will consult	Population	1.0 PT	
	1.0 OT in hospital and	Approx 13,000	1.0 SW(rehab)	
	community		0.5 SLP	
	1.0 Community SW		1.0 Dietitian	
	0.5 Dietitian		0.5 Psychologist	
			0.5 OTA	
	Recreation and Social Work		0.5 PTA	
			2.0 Recreation Specialist	
	Golden Heights Manor		3.0 RTWs	
	1.0 Recreation Specialist			
	2.5 RTWs			

	1.0 SWs			
Carbonear	No community therapists or	Old Perlican to	Old Perlican, Heart's Delight,	Carbonear
Carbonear	rehab nurses.	Whitbourne area	Norman's Cove, Come by Chance and	Hospital and
	Hospital PT, OT, SLP will	wintbourne area	Whitbourne area	Whitbourne
	consult patients in community	Population	2.0 OT	Health Centre
	in emergencies.	Approx 41,000	2.0 PT	Treatin Centre
	Dietitian provides some	11,000	2.0 SW(rehab)	
	community consultation		1.0 SLP	
	• • • • • • • • • • • • • • • • • • • •		2.0 Dietitian	
	1.0 Dietitian		1.0 Psychologist	
	For Harbour Lodge, Interfaith		1.0 OTA	
	and Pentecostal Homes.		1.0 PTA	
			1.0 Recreation Specialist	
	Recreation and Social Work		1.0 RTWs	
	Community Supports		1.0 Rehab Nurse or Nurse Practitioner for	
	Social Work-		area.	
	1.0 -Come By Chance			
	1.0 - Old Perlican		Carbonear,	
	4.0 - Bay Roberts		Harbour Grace, Bay Roberts (Harbour	
	2.0 - Harbour Grace		Lodge, Interfaith Homes, Pentecostal	
	3.0 - Whitborne		Home in Clarke's Beach)	
			3.0 OT	
	Pentecostal Home, Clarkes		3.0 PT	
	Beach		2.0 SLP	
	1.5 Rec Specialist		2.0 SW(rehab),	
	0.5 RTWs		3.0 Dietitian	
	0.5 SWs		2.0 Psychologist	
			1.0 OTA	
	Interfaith Home		1.0 PTA	
	0.5 Rec Specialists		3.0 Recreation Specialist	

Placentia	3.0 RTWs 0.5 SWs Harbour Lodge 0.5 Recreation Specialist 2.0 RTWs 1.0 SWs 1.0 OT and 1.0 PT covering LTC, hospital, community, and outpatients	Placentia, Colinet, St. Bride's	Outpatient (hospital), Lion's Manor, and community services 1.0 OT	Placentia Health Centre
	Recreation and Social Work Community Supports 2.0 SWs Lion's Manor 2.0 RTWs	Population Approx 8600	1.0 PT 1.0 SW (rehab) 0.5 SLP 1.0 Dietitian 0.5 Psychologist 0.5 OTA 0.5 PTA 1.0 Recreation Specialist 2.0 RTWs 1.0 Rehab Nurse or Nurse Practitioner	
Rural Avalon	Community 1.0 OT 1.0 Dietitian No PT, Psychology, SLP, Recreation or Rehabilitation Nurse Social Work	Avondale, Holyrood Mount Carmel to Trepassey 24 Personal Care Home (693 beds with 65% occupied)	Avondale, Holyrood Mount Carmel to Trepassey 1.0 OT 1.0 PT 1.0 SW(rehab) 0.5 SLP 1.0 Dietitian 0.5 Psychologist 1.0 Recreation Specialist	New Community Rehabilitation Division, Rehabilitation Program, Eastern Health
	Community Supports	,	1.0 RTWs	

	2.0 SWs	Population	1.0 Rehab Nurse or Nurse Practitioner	
		Approx 8000		
Urban	Community	Population		
Avalon	2.0 OTs	250,000 people,		New Community
(Further	2.0 PTs,	7 nursing homes	SEE DETAILS FOR ZONES BELOW	Rehabilitation
Details in	2.5 Dietitians	and 26 personal		Division,
ZONE	no Psychologist, SLPs or	care homes		Rehabilitation
information)	rehabilitation nurses			Program, Eastern
	spread across 4 of 5 zones			Health
	Long Term Care (986			
	residents)			
	4.25 PTs			
	8.0 PTAs			
	3.5OTs			
	3.0 Dietitians			
	1.0 Psychologist			
	No SLP			
	(Recreation and Social Work			
	details below)			
Zone 1	Recreation & Social Work	St. John's East	6.0 PT	
		including Torbay,	6.0 OT	New Community
	Community Supports	Logy Bay,	6.0 SW(rehab),	Rehabilitation
	8.0- SWs	Portugal Cove,	2.0 SLP	Division,
	Dr. Walter Templeman, Bell	Flatrock	6.0 Dietitian	Rehabilitation
	Island	includes	3.0 Psychologists	Program, Eastern
	1.0 SWs	Hoyle's-Escasoni	5.0 OTA,	Health
	Hoyles Escasoni	St. Patrick's	5.0 PTA	
	2.0 - Recreation Specialist	Nursing Home	6.0 Recreation Specialists	
	8.0 - RTWs	Glenbrook Lodge	13.0 RTWs	
	4.8 - SWs	3 Personal Care	2.0 Rehab Nurses or Nurse Practitioners	

	Glenbrook Lodge	Homes (157 beds)		
	1.0- Recreation Specialist			
	1.0 - RTWs	Population		
	1.0 - SWs	Approx 40,000		
	St Patrick's Home			
	1.0 - Recreation Specialist			
	2.0 - RTWs			
	2.0 - SWs			
	Chancellor Park (30			
	subsidized beds)			
Zone 2	Recreation and Social Work	St. John's	2.0 OT,	
		Downtown	2.0 PT	New Community
	CommunitySupports	2 Personal Care	2.0 SW(rehab)	Rehabilitation
	11.0 - SWs	Homes(60 beds)	1.0 SLP	Division,
		Veteran's Pavilion	2.0 Dietitian	Rehabilitation
	Veterans Pavilion		1.0 Psychologist	Program, Eastern
	1.0 - Recreation Specialist	Population	1.0 OTA	Health
	1.0 - RTWs	Approx 30,000	1.0 PTA	
	1.0 - SWs		2.0 Recreation Specialist	
			3.0 RTWs	
			1.0 Rehab Nurse or Nurse Practitioner	
Zone 3	Recreation and Social	Mount Pearl,	3.0 OT,	New Community
	<u>Work</u>	Paradise, Goulds	3.0 PT,	Rehabilitation
		and Kilbride	2.0 SLP,	Division,
	Community Supports	Includes Masonic	3.0 SW(rehab),	Rehabilitation
	14.0 - Social Works	Park Nursing	3.0 Dietitian	Program, Eastern
		Home	2.0 Psychologist	Health
		10 Personal Care	2.0 OTA	
		Homes (406 beds)	2.0 PTA	
	Masonic Park		2.0 Recreation Specialist	
	2.0 - Recreation Specialists	Population	3.0 RTWs	

	1.0 - RTWs	Approx 35,000	1.0 Rehab Nurse or Nurse Practitioner	
	2.0 - SWs			
Zone 4	Recreation and Social Work	St. John's Central,	3.0 OT	New Community
		and North	3.0 PT	Rehabilitation
	Community Supports	Includes St.	2.0 SLP,	Division,
	10.0 SWs	Lukes, Agnes	2.0 SW (rehab),	Rehabilitation
	Agnes Pratt Home	Pratt	2.0 Dietitian	Program, Eastern
	1.0 - Recreation Specialist		1.0 Psychologist	Health
	2.3 - RTWs		2.0 OTA,	
	1.0 - SWs	Population	2.0 PTA	
	St. Luke's Home	Approx 33,000	3.0 Recreation Specialist	
	0.5 - Recreation Specialist		8.0 RTWs	
	2.0 - RTWs		1.0 Rehab Nurses or Nurse Practitioners	
	2.0 - SWs			
Zone 5	Recreation and Social Work	Conception Bay	3.0 OT,	New Community
		South, Southern	3.0 PT,	Rehabilitation
	Community Supports	Shore to Ferryland	hore to Ferryland 1.0 SLP,	
	7.0 - SWs	CBS – 8 Personal	2.0 SW,	Rehabilitation
		care homes (253	3.0 Dietitian	Program, Eastern
		beds)	2.0 Psychologist	Health
		Southern Shore –	1.0 OTA,	
		3 Personal care	1.0 PTA	
		Homes (86 beds)	2.0 Recreation Specialist	
			4.0 RTWs	
		Population	1.0 Rehab Nurses or Nurse Practitioners	
		Approx 31,000		

2. Enhanced Chronic Disease Management

Our findings indicated there are gaps in service or a need for improved services to patients who have:

- morbid obesity (bariatric)
- cancer (i.e. post mastectomy, lymphoedema patients, patients who have long term complications following radiation, etc)
- cardiac problems (those without surgical intervention)and require cardiac rehabilitation
- have been de-conditioned due to long hospital stay, etc
- arthritis (OA/RA)
- orthopedic problems (total hip replacements, total knee replacements etc.)
- chronic obstructive pulmonary disease and Cystic Fibrosis (especially pre/post lung transplant) who require pulmonary rehabilitation

Rehabilitation services for all these populations have similar objectives and similar resource needs. Medicine, Surgery and Cancer Care Programs are providing some services to select numbers of these patients. Since there are efficiencies to be gained if we do not work in silos, we propose sharing and enhancing the resources (human resources, equipment and space) presently being used by these programs for these types of service and developing a *Healthy People Program*. This program would provide group and individual services to people who have the above types of conditions and live unhealthy lifestyles. It would promote exercise, diet, and lifestyle changes. It would help define exercise risk and push people to move safely toward that risk in order to promote improved function. Exercise training in risk populations will improve ability to do activities of daily living. This level of treatment will require collaboration between the patient/family, their family physician, pulmonary and cardiac testing laboratories, and the *Healthy People Team*. Counseling and emotional support would also be provided.

Patients could be self-referred but may need some prescreening. Other prehabilitation and preventative rehabilitation programs could also be run by this team (i.e. smoking cessation, fall prevention). *The Healthy People Program* would require the services of an interdisciplinary team including nurse practitioners or specialists, physiotherapists, occupational therapists, dietitians, recreation specialists, kinesiologists/exercise physiologists and social workers. Numbers of each discipline needed would require further investigation. The first step would be to initiate dialogue among existing pulmonary and cardiac rehabilitation and diabetes self-management teams. Appropriate equipment and space requirements would need to be discussed.

3. Enhanced Sub-Acute Care and General Rehabilitation Services

Acute care hospitals are not the optimal setting to provide rehabilitative care. Elderly patients and those with complex health problems require short-term rehabilitation (1-4 weeks) following surgery, injury or health crisis by a team specialized in this field. It is clear from our findings that lack of community rehabilitation and inadequate numbers of rehabilitation and sub-acute care beds particularly in rural areas impacts patients flow and acute care patient caseloads. Rehabilitation units must be in place in regional areas and community rehabilitation teams in place in order to move patients from acute care closer to home.

Restorative Sub-Acute Care

Since nomenclature for types of care is inconsistent, for the purposes of this document we will use restorative care to refer to sub-acute care, restorative care, continuing care and complex continuing care. The Ontario Ministry of Health bed benchmark is set at 20 rehabilitation beds per 100,000 population (15 local, 4 regional and 1 transitional living). Sub-acute care bed benchmarks are 14 to 19 bed beds per 100,000 population (See Appendix C: Summary of Available Rehabilitation Reports in Canada).

We recommend that restorative care units with appropriate staff be added to most major health facilities (Table 34). For smaller centers, these additional beds may be combined with rehabilitation beds in the hospital. At the L.A. Miller Centre, an additional 20 bed restorative care unit is required. We recommend 6-8 restorative care beds each for Central, Western, and Labrador Grenfell (St. Anthony and Goose Bay). In total, these approximate 40 beds would not only improve patient care but relieve pressure for acute care beds.

General Rehabilitation

Regional rehabilitation units providing general rehabilitation located in Central Health, Western Health and Labrador Grenfell would ensure patients receive the best care closer to home (Table 34). We recommend that there be 10-12 beds in Central Health, preferably in one location to ensure a critical mass of human resources to develop expertise. Western Health should have an additional 4 beds and Labrador/Grenfell would have a 6 bed unit located in St. Anthony or Goose Bay.

Table 34: Recommended Sub-acute and Rehabilitation beds for NL

	General (local)	Specialized (regional tertiary)	Transitional Living	Sub-acute Care
Required by Ontario standards (500,000 pop NL est.)	75	20	5	75
Actual	LAMC-24 Other EH- 10 Western- 8	LAMC- 18	0	LAMC- Long duration-low intensity unit- 20
Difference	-33	-2	-5	-55
Recommended Additions	Western- 2 Central – 10 Labrador Grenfell- 6	0	Eastern- 4	LAMC- 20 Western- 8 Central- 8 Labrador Grenfell -St. Anthony- 6 -Goose Bay- 6

4. Cognitive/Vocational/Life Skills Training Program

Our research results point to the need for services for brain injured people in the province as well as for young adults with developmental disabilities moving from children's rehabilitation to adult rehabilitation. We do not have a critical mass of patients with traumatic brain injury to have a unit dedicated to services for this population and the needs of the young developmentally delayed population do not match services presently being provided at the L.A. Miller Centre. We propose continuing to provide tertiary services for brain injured patients as we have in the past with an increased focus on cognitive training from psychology and occupational therapy. This would be supplemented by a new cognitive/vocational/life skills outpatient training program that meets the needs of both the brain injured and the young developmentally disabled populations.

This new cognitive/vocational/ life skills program will have the flexibility to address the diverse needs of young adults with developmental disability, people with mild brain injury and those requiring specific vocational training. The program, offered in St. John's, at the L.A. Miller Centre, would require 1 OT, 1 psychologist, 1 social worker, and 1 recreation specialist and would be shared with the transitional living service as outlined below. The services would require meaningful collaboration with the Mental Health program and may be offered in partnership with community groups such as the Brother TI Murphy Centre, The NL Brain Injury Association, Independent Living

Resource Centre and the Easter Seals Horizon Program. There will need to be collaboration with community groups, training programs and employers. This group may be augmented by other specialists as it is evaluated over time such as vocational counselors, physiotherapists etc.

5. Transitional Living

In other provincial rehabilitation centres, selected people with disability are given an opportunity to adjust to living on their own through living semi-independently or completely independently in transitional living apartments. These apartments are accessible and are staffed with support workers for consultation and support as issues arise. By the time people move from these apartments into community living they have identified how to live successfully in an independent living situation. While this is not necessary for all people with disability, for many it is the key to living well. Unnecessary visits to emergency and admissions to hospital and to long term care are consequently avoided.

The Ontario Ministry of Health recommends 1 transitional living bed per 100,000 population (Appendix C). Four new transitional living apartments near or attached to the L.A. Miller Centre will provide an opportunity for people with disability to live independently and learn independent living skills for 2-6 weeks at a time before returning to their community (Table 34). These units would be appropriately staffed with a visiting home support provider and with consultation provided by staff of the cognitive/vocational/life skills outpatient training program.

6. The Needs of Young Adults with Disability Living in Nursing Homes

There are young adults with disability living successfully in the community while others are institutionalized within nursing homes. We are very concerned that the voices of this latter group are not heard. We recommend a task force to determine why so many young adults with disability are residing in elderly-focused Long Term Care institutions. These individuals are among the most vulnerable in our society. What circumstances lead them to this admission? Do they receive adequate and age appropriate services and recreation? Are they satisfied with their care? Are there better living arrangements for this group? The task force should report to the executive of Eastern Health.

7. Physical Medicine and Rehabilitation Specialists

The need for specialists in Physical Medicine and Rehabilitation (also known as Physiatrists) for our province is well-documented. We immediately require four physiatrists for the Rehabilitation Program in Eastern Health, one additional Physiatrist in Western Health and a new position in Central Health. The demand for doctors in this specialty in Canada far exceeds the supply. Due to lack of this specialty, the Rehabilitation Program has very few interns and residents from Memorial University,

Faculty of Medicine. There must be more emphasis on rehabilitation in the School of Medicine. Students should be exposed to rehabilitation during their undergraduate training through lectures, clinic and site visits and shadowing. We must consider new formats of shadowing; student doctors shadowing experienced rehabilitation providers, for example.

Our health care system is complex making discharge and discharge planning an important skill. We cannot assume that physicians trained in other provinces and countries know how to obtain community services and organize post-discharge care. New physicians hired, especially those who have been trained in entirely different health care systems, should have orientation to rehabilitation, the roles of rehab providers and the process of hospital discharge and obtaining community services.

8. Evening and Weekend Inpatient Rehabilitation Programming

As seen from results of patient and family surveys, as well as L.A. Miller Centre satisfaction surveys, patient attending inpatient rehabilitation programs complain of being bored during evenings and weekends. We recommend structured evening and weekend programming for patients and families within rehabilitation inpatient programs to facilitate recovery and promote healthy reintegration into the community. Inpatients at the L.A. Miller Centre and in other rehabilitation units should receive additional enrichment and therapy beyond the regular workday. Furthermore, research confirms that people recovering from injury need intense rehabilitation with enriched environments. Evening and weekend recreation and therapeutic programming should emphasize physical activity, cognitive stimulation, education and peer support.

Patients in rehabilitation often have multiple co-morbid conditions such as cardiovascular disease and diabetes that place them at risk for future health events. National health agencies such as the Heart and Stroke Foundation recommend that these patients receive structured health and lifestyle education to prevent stroke. This does not occur in any inpatient unit we visited in this province. This could possibly be done as part of evening programs.

CLOSING GAPS THROUGH INTEGRATION AND COMMUNICATION

9. Newfoundland and Labrador Rehabilitation Network

Eastern Health, as the tertiary provider of rehabilitation services in the province, must commit more resources to education and networking of rehabilitation health professionals. Although the Rehabilitation Program and specific professional practice groups have organized educational events, these are not coordinated provincially across disciplines. Rehabilitation service providers across the province report feeling disconnected from their peers and having difficulty maintaining competency standards. This ultimately leads to problems with recruitment and retention, and undermines high quality patient care.

A solution that has been shown to work for other groups in Newfoundland and Labrador as well as across the country is the development of a *Newfoundland and Labrador Rehabilitation Network*. This network would include:

Online message boards
Discussion forums
Topic experts
Teleconferences and podcasts
Searchable Library of articles, links, archived materials
Educational opportunities
Telehealth
Research opportunities

The Network could be coordinated virtually and electronically within the Human Resources and Professional Development department at Eastern Health. Virtual and electronic networking using available technology at Eastern Health and the Faculty of Medicine, Memorial University, will help to provide education and support especially for those working at a distance from the L.A. Miller Centre in St. John's. Eastern Health needs to commit resources to this project. A part time (0.5 FTE) educator, knowledgeable in rehabilitation and education technology would be required to develop this service.

10. Case Management/Navigation of the Health System

Our health system in Newfoundland and Labrador is complex and challenging to navigate for providers as well as patients and their families. Barriers such as processes, forms and criteria exists that thwart attempts to obtain services. Processes must be more client-centered and patient friendly. Eastern Health has already moved toward hiring of patient navigators but our findings indicate that rehabilitation patients, especially those who require service across the continuum of care, need advocacy. They also need to have a voice and contribute to setting goals and making decisions. We recommend that there be patient navigator(s) to advocate and help disentangle red tape for the client and family. The number and placement of such navigators needs further investigation.

The navigator's/case manager's role would include:

- transition through continuum of care
- orientation and education
- goal setting
- ensure patient participation in decision making concerning his/her care
- discharge planning
- discharge transition and follow-up

Furthermore, every service and program should critically evaluate how their structure and processes may place barriers for patients and their families (long forms, vague wording).

11. Rehabilitation Program (L.A. Miller Centre) Criteria

Initial criteria for admission to the rehabilitation services at the L.A. Miller Centre were created almost 30 years ago when there were few beds and limited services that could be offered. As the Program has grown, these criteria have been changed and adjusted frequently. The existing criteria for admission to the L.A. Miller Centre have produced gaps by identifying people who will not receive rehabilitation services. Many statements within the criteria are vague and left open to the interpretation of the referral source. Misinformation exists because the criteria continue to change on an almost yearly basis. Acute care health providers have become the gatekeepers; determining which patients fit this criteria. Furthermore, admission or inclusion criteria ensure that there will always be significant numbers of people whose needs are excluded, never evaluated, or recorded.

We recommend that the criteria be simplified, stating that the rehabilitation program serves 'adults who have potential for functional improvement in cognitive or physical domains' with no further qualifying statements. Referrals would be forwarded to the intake committee of the Rehabilitation Program. This committee can identify the most appropriate level and intensity of rehabilitation, i.e. low intensity inpatient, community, outpatients, etc. Individuals whose needs are not clear should be contacted or visited by a member of the intake committee to best determine how their needs can be met. No patient referral should leave this committee without action taken to arrange rehabilitation at some level. In this way, patient who have very specialized needs can be identified, links made to other programs, services put in place, and gaps closed.

12. Rehabilitation Health Information and Outcomes Measurement

Acute care health information is reported to the Newfoundland and Labrador Centre for Health Information and nationally, to the Canadian Institute of Health Information (CIHI). In this province, only the L.A. Miller Centre reports rehabilitation health outcomes data to a national database, CIHI's National Rehabilitation Reporting System (NRS). This information system, with reports available in various formats to contributors and the public, establishes benchmarks and determines if patients in this province receive a comparable standard of care. We recommend mandatory reporting of rehabilitation data to NRS. We also recommend that the Department of Health review NRS data from each of the province's health authorities to ensure equitable standards of care across the province.

MAKING THE MOST OF REHABILITATION SERVICES THROUGH EFFICIENCY

13. Reducing Non-Patient Care for Frontline Rehabilitation Providers

Patient documentation is currently coded as 'patient-care' in the workload measurement system so it is difficult to monitor how much time is truly spent writing reports. There are no known benchmarks for clerical support requirements. Eastern Health managers must evaluate how much time therapists, nurses and rehabilitation support workers spend doing clerical duties. Duties such as copying, faxing, organizing appointments should be delegated to clerical support staff. If paper documentation is required, it should be dictated and transcribed by clerical staff.

Frontline rehabilitation providers, including rehabilitation assistants, should be performing negligible clerical work. Their efforts should be in patient care. Every team should have access to adequate clerical support and more if there is an outpatient department. Clinical staff should be using electronic documentation and audio taping patient reports for later transcription. We recommend a minimum of 1.0 FTE clerical staff per 10 professional FTEs.

Effective use of technology especially electronic charting and use of patient information systems should save time and ensure completeness. It is important that rehabilitation providers link with Information Technology to identify the technology needs of rehabilitation and develop electronic efficiencies.

- Eastern Health is working on the development of one electronic chart and health information system that will be used across the region. This needs to happen as quickly as possible to improve efficiency and safety.
- Designers need to plan in advance and work with clinicians, including rehab professionals, to design effective documentation tools
- \bullet Designers should consider more current easy-to-use technology, for example a mouse rather than complicated key codes, wireless and hand-held input devices. Consider that patient information may also include digital photographs (wound healing, equipment, home accessibility).
- Systems that are used to collect patient data and treatment should also be able to capture collective data on patient services, types of treatment provided, services referred etc. The minimum data set should be expanded to include rehabilitation indicators with input from the providers themselves.
- It is important that all staff have access to computers placed strategically for privacy and limited distractions. There should be no more than three staff assigned to a terminal.
- Rehabilitation professionals charting requirements need to be considered when implementing new or changed health records systems. Rehabilitation professionals should be included in the implementation team and have equitable access to electronic documentation and patient information systems training appropriate for their needs.

14. Home and Community Supports

Although funding of home care, housing, transportation, and equipment are not part of the business of Eastern Health, inefficiency and inadequacy of these home and community support systems seriously affect discharge from hospital and safety in the community. Therefore Eastern Health must advocate for changes to these programs/services. Although this report is not intended to recommend changes to the Special Assistance Program (SAP) or to Newfoundland and Labrador Housing, it is clear that critical evaluation must take place. Although there has been some review done in the past, systemic inefficiencies and inequities exist causing many barriers for patients and rehabilitation providers. It is recommended that findings of this report be forwarded to relevant government agencies including Newfoundland and Labrador Housing. We also recommend that the SAP's mission, structure and process be evaluated specifically addressing the following areas

- Criteria for financial eligibility
- Creation of a simplified user-friendly system for ongoing evaluation, funding and provision of routine expendable equipment and supplies such as catheters, etc.

One of the key ingredients to living at home and participating in one's community is accessible transportation. The type, cost and administration of transportation services will depend on the needs of disabled people in a municipality. We understand that there is presently a review of the paratransit system underway by the Paratransit Committee of the City of St. John's. We recommend that findings of this report be forwarded to this committee.

Another key ingredient to living successfully in the community is available accessible housing. There is a severe lack of accessible housing in St. John's and other communities in Eastern Health. To improve this situation, Eastern Health must advocate for increased affordable accessible housing and more assisted living accommodations for young disabled adults. A copy of this report should be made available to the Newfoundland and Labrador Housing Corporation, which needs to evaluate and improve this situation.

Appropriate training of home support workers will make home environments safer for people with disability. Home support workers work at varying levels of competency with no standards to protect the public. Home care workers who are expected to provide nursing and therapeutic services should be properly trained and paid to do so. We recommend that findings of this report be conveyed to Department of Health.

15. Recruitment and Retention of Rehabilitation Health Professionals

Therapists are difficult to recruit especially in rural and sole-charge positions. Results of the research outlined in this document indicate that therapists in these positions need adequate mentorship and require access to a professional network. Appropriate reporting structures that allow mentoring and foster continued professional development are required. Therapists working alone in rural and community settings should be connected professionally and administratively to the local hospital or health centre. Health authorities must consider recruitment strategies that will help improve the work life of rural therapists including enhanced educational leave, financial support and

opportunities for advancement.

Rehabilitation nursing is a specialized field. Additional training and completion of a national certification exam is required to become a 'Rehabilitation Nurse'. However, nurses are not recognized financially or otherwise for completion of such a program. We recommend that nurses in senior rehabilitation positions complete this training and receive a regular bonus for this credential. This training should be available through self-study on the Provincial Rehabilitation Network.

16. Space and Equipment

Rehabilitation therapists and nurses need appropriate and accessible space that allows them to provide services that meet standards of care guidelines for rehabilitation. Unfortunately, in our old health facilities, treatment offices that will not accommodate wheelchairs, inaccessible washrooms, and old underserviced treatment equipment are the norm. Clearly, old buildings, designed for patients who did not use wheelchairs, mechanical lifts and other equipment are inadequate today.

Unfortunately new buildings are being designed and built without the benefit of the expertise of rehabilitation professionals. The expertise of rehabilitation providers, especially experienced occupational therapists (who are aware of all aspects of accessibility) is invaluable during design and renovation of health structures. We recommend that consultation with users occur and that occupational therapists in Eastern Health be involved at every stage from design to furnishing.

We recommend that our Eastern Health Buildings be evaluated for accessibility with input from an occupational therapist. In conjunction with this, all spaces used for rehabilitation services in Eastern Health should also be evaluated and upgraded as appropriate to allow for accessibility and appropriate standards of care.

The L.A. Miller Centre facility will need to be evaluated for continued appropriateness as the site for tertiary rehabilitation services for the province. Improvements required are:

- Increased and upgraded therapeutic space and equipment
- Larger patient rooms to allow room for movement of wheelchairs and use of other equipment.
- More accessible washroom space.
- Increased space for equipment storage.
- Therapeutic pool.
- Walking track.
- Safe, covered outdoor recreation space (gardens).
- Larger, more accessible main entrance with appropriate doors.
- Access to hostel space.
- Nearby transitional living space.
- Group and education space.

BEST PRACTICES AND CONTINUING COMPETENCE ENSURE QUALITY

17. Education

Professional education in rehabilitation methods and best practice ensures continued competency and the best quality of care for patients. In today's world, we have constantly changing and growing professional knowledge bases, rapidly growing technology and educated consumers. It is more critical than ever that service providers remain current. A consistent approach to educational leave and financial support is required across Eastern Health. As a minimum starting level, travel days to and from a course should be designated as paid educational leave. Most education that is local and relevant should be approved. Rehabilitation providers should be expected to have a minimum of five days of education per year.

Space to provide education especially hands-on practical training is almost non-existent in health care facilities. Future new building and renovations should consider the needs for lecture and teaching space for clinical staff. At the L.A. Miller Centre, there is lecture space in the School of Nursing in Southcott Hall but this space is only available in the evenings or on the weekend. Health Sciences staff can borrow lecture space in the Faculty of Medicine. We recommend that until new spaces are built, staff at the L.A. Miller Centre should be able to book unused educational space in the School of Nursing.

18. Rehabilitation Research

Most rehabilitation centers in Canada have well-developed research departments offering opportunities for staff and patients to become involved in clinical trials. Research projects are a strong recruitment attraction and also provide opportunity to fund and obtain emerging technology. The L.A. Miller Centre recently hired a researcher. In future it will become increasingly important to grow in this area with appropriate space and staff and to have a strategic partnership with Memorial University. Ideally a rehabilitation research laboratory is required within the rehabilitation facility.

Potential Research Questions

- What are the health and discharge outcomes for people not accepted to Rehabilitation?
- To what extent are patients pre-screened for rehabilitation referral? How does this affect outcomes?
- What is the optimal long term care structure for young adults with disability?
- Do chronic disease wellness programs decrease hospital admissions and improve quality of life?
- Do vocational rehabilitation programs lead to workplace integration?

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LIST OF APPENDICES

Available on request

Appendix A: Planning and Committee Information

- 1. Work Plan
- 2. Committee Terms of Reference

Appendix B: Primary Data

- 1. Focus Groups
- 2. Key Informant Interviews
- 3. Survey Information

Appendix C: Secondary Data

- 1. Allied Health Human Resources
- 2. Rehabilitation Program Satisfaction Surveys
- 3. Health Indicators
- 4. Reviews of Other Reports