Long-term Ventilation

Service Inventory Program

Final Summary Report

July 31, 2008

Ontario

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Acknowledgements

The Long-term Ventilation (LTV) Service Inventory Program (SIP) wishes to thank the many individuals and organizations that contributed unselfishly to the success of this report.

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Executive Summary

In 2004/05, as part of its Access to Services and Wait Times Strategy, the Ministry of Health and Long-Term Care (the ministry) launched a four-year Critical Care Transformation Strategy aimed at improving the quality of care and system performance in adult critical care services in Ontario.

An early finding of this work was that many intensive care unit (ICU) beds in Ontario were occupied by ventilator-assisted individuals[1] who were otherwise medically stable and did not need the critical care services. In 2005, the Ontario Chronic Ventilation Strategy Task Group (the task group) was established to identify effective short-term strategies to facilitate the transfer of these individuals out of Ontario's ICUs and into a more appropriate care setting and to prepare care strategy for this population.

In spring 2007, the ministry announced an investment of $5.2 million annually primarily to fund additional inpatient resources for ventilator-assisted individuals. Funding was also allocated to the development of long-term ventilation (LTV) information system and educational programs for providers and ventilator-assisted individuals. The ministry asked the Toronto Central Local Health Integration Network (TC LHIN) to coordinate the development and implementation of the provincial LTV strategy. Through a Steering Committee, the TC LHIN developed an Action Plan[2] for the implementation of the LTV strategy in Ontario.

The Action Plan stated four goals, two of which drove the need for an inventory and gap analysis of services and educational opportunities. This report documents the results of these investigations.

Methods

The TC LHIN engaged the University Health Network's (UHN) Shared Information Management Services (SIMS) to develop the inventory and gap analysis under the auspices of the Long-Term Ventilation Service Inventory Program (SIP). This work was undertaken through:

- A suite of surveys completed by 66 ICUs, 37 other inpatient facilities, 28 attendant service providers and 14 community care access centres, and
- Focus groups in all 14 LHINs and supplementary telephone interviews to solicit input from care providers, ventilator-assisted individuals, family members and non-family caregivers. A total of 261 individuals participated in these consultations.

The LTV SIP project team established a clinical advisory committee to provide guidance on the planning of the surveys and focus groups and to review the summary report.

[1] Based on feedback from consultations with stakeholders, the LTV Steering Committee preferred the term "ventilator-assisted individuals" over "chronically-ventilated patient".

[2] Long-Term Ventilation Strategy Development for Ontario, Prepared for the Ministry of Health and Long-Term Care by the Toronto Central Local Health Integration Network, Final Report, January 2008.

Description of Ventilator-Assisted Population

A ventilator-assisted individual is someone who is mechanically ventilated either invasively (i.e., through a tracheostomy tube inserted directly into the trachea) or non-invasively (i.e., with nasal or full face mask).

Two populations were of interest for this study:

- Ventilator-assisted individuals. For the purpose of this work, the task group's definition was used: *"those patients suffering from a severe respiratory impairment who require ventilatory support for more than six hours per day for more than 21 days, but who do not require additional services provided by a critical care unit (i.e., patients who are otherwise medically stable)."*
- At-risk individuals. The definition was adopted from the task group's work as follows: *When an individual is already in the care of a physician (e.g., general practitioner, neurologist, respirologist, pediatrician) before the disease has advanced to the stage where the patient requires mechanical ventilation.*

The cost to care for ventilator-assisted individuals varies significantly depending on the care setting and the individual's care needs, ranging from an estimated $3,745 per day in an ICU bed in a tertiary care centre to $205 per day in supportive housing with attendant services.

Highlights of the Survey Results

ICU beds are highly utilized at 93% average occupancy among the 66 hospitals responding to the survey, of which nine percent are ventilated. The average length of stay in ICU for LTV patients in Ontario was 195 days (with one ICU reporting a total stay of 1,531 days), with average of 129 days from the day the individual was deemed appropriate for an alternative level of care until discharge.

In total, responding facilities reported an additional 107 invasively ventilated and 16 non-invasively ventilator-assisted individuals in either chronic assisted ventilatory care, complex continuing care, respiratory care, home ventilation training or progressive weaning centres and programs in Ontario. Of these 123 individuals, 27 (22%) were deemed eligible for community-based care.

The 28 attendant service providers who responded to this survey reported providing attendant care services to 30 invasively and 69 non-invasively ventilated clients in Ontario. All 14 community care access centres (CCACs) responded to the CCAC survey. In total, there are 58 invasively ventilated and 35 non-invasively ventilated LTV clients supported by CCACs in Ontario.

Based on the survey results, we identified a total of 453 ventilator-assisted individuals in Ontario who are cared for by the surveyed organizations, as shown in Table 1.

Table 1: Summary of the LTV Population as Reported by Survey Respondents, Ontario

	Invasively ventilated	Non-invasively ventilated	Total
In hospital	185	32	217
In the community[3]	110	126	236
Total	295	158	453

Summary Priorities from Stakeholder Focus Groups

Although all of the gaps and barriers identified by the participants were identified as priorities for action and investment, there was general consensus on several high level themes as being the most pressing needs for all LHINs. These priorities represent the opinions of the survey respondents, participants in the focus groups and telephone interviews. They are not intended to be the opinion of the ministry or its representatives.

The overriding message from ventilator-assisted individuals, their families and care providers was that a community setting (i.e., supportive housing or in home) is preferred to inpatient care from the individual's perspective (i.e., improved quality of life) and a system perspective (i.e., decrease in use of critical care resources for this population). Many of the stated priorities are around ensuring that the health care system can:

- **Avoid**, wherever possible, hospital admissions due to respiratory failure for those at risk of long-term invasive ventilation,
- Help those who have been admitted to hospital to **return** to the community, and
- Provide the supports and services needed for the individual to **stay** in the community safely and as long as possible.

Priorities for Care and Services

Five major priorities for the delivery of care and services for ventilator-assisted individuals were identified by providers, ventilator-assisted individuals and their families and caregivers.

1. **Increase the capacity for and choice of community living.** Twenty-two percent of ventilator-assisted individuals in hospital were deemed eligible for community living. The lack of available and appropriate community care settings is a major barrier to timely discharge from hospital and contributes to reduced quality of life for ventilator-assisted individuals.
2. **Provide respite for caregivers.** When ventilator-assisted individuals live with their family, the burden of care is often overwhelming for the caregivers. Many families believed they could have cared for their children or spouses in the home for a longer period of time if they had had access to respite. The preference is for in-home respite, although inpatient respite is sometimes needed for extended family absences.

[3] Number includes individuals on direct funding. The reader is cautioned that some individuals may receive services from more than one agency; therefore, this total might be overstated. On the other hand, participants reported many non-invasively ventilated individuals living in the community who are not counted in this survey. For example, West Park Healthcare Centre, The Ottawa Hospital and London Health Sciences Centre reported that they follow 529 ventilator-assisted individuals (of which 418 are non-invasively ventilated) in the community,

3. **Create intermediate care beds.** The creation of intermediate care beds in an acute setting (ideally close to the ICU to facilitate access to services if needed and to support staff) is a preferred alternative to keeping these patients in the ICU. Many LHINs suggested the development of "flexible" beds to fill short-term needs for ventilator-assisted individuals. These beds could serve multiple purposes such as weaning, high acuity care, home ventilation training, reassessment and respite care.
4. **Review Assistive Devices Program (ADP) policies and processes for ventilator equipment and supplies.** Existing ADP policies do not cover ventilator equipment for inpatients, which is a major financial barrier to many hospitals and complex continuing care centres that would otherwise accept these individuals. Existing ADP approval processes are believed to be contributing to delays in discharge from hospital while the patient waits for the home ventilator to be approved and shipped. As well, there is a need for a broader range of equipment (e.g., cough assist devices, back up batteries, portable ventilators) to be included on the approved equipment list and more frequent upgrades allowed for individuals with degenerative diseases.
5. **Fund existing programs and services appropriately.** Many of the services provided to ventilator-assisted individuals are currently funded through the hospitals' global budget and, therefore, not necessarily sustainable. These services include, for example, outpatient clinics for the at-risk population and unfunded chronic assisted ventilatory care (CAVC) beds.

Priorities for Education

Participants identified three major priorities for education:

1. **Reach the at-risk population.** There is a need to identify individuals with a chronic disease that will inevitably lead to respiratory failure and who are, therefore, at risk of long-term invasive ventilation and refer them to an appropriate service for counselling on the disease and care options so that they can make informed decisions.
2. **Provide training for community-based care providers.** The high turnover rate among community care providers results in a need for frequent training, which is not always available and, therefore, places a significant burden on the ventilator-assisted individual or family to train new providers. Participants expressed a desire for a hospital-based training program that would provide consistent training to ventilator-assisted individuals, their families, community-based nurses and personal support workers. This training must be tailored to the needs of the individual who will be receiving the care.
3. **Develop and distribute standards of care.** Inconsistency in the interpretation of the Regulated Health Professionals Act creates artificial barriers to finding adequate numbers of community care providers. It was suggested that the development of provincial standards of care might help to alleviate the discomfort among some agencies in allowing unregulated professionals to provide this care (e.g., tracheostomy suctioning).

Priorities for Planning

The scope of this work was to solicit views on priorities for care and services and for education for this population. However, many participants noted that some of these services could not be effectively planned without some supports. These enablers are described below:

1. **Develop and implement the Long-Term Ventilation Information System.** An information system is needed to provide real time data that is easily accessible to all providers. This system would facilitate the delivery of care (e.g., for emergency department staff), provide a basis for capacity planning and system evaluation, and provide an inventory of services across the province.
2. **Support the LHINs in developing regional capacity plans.** Many participants recognized the necessity of better understanding the needs of ventilator-assisted individuals in their LHIN and developing medium- and long-term plans to meet these needs. Participants suggested that a standard template for a needs assessment and capacity planning and/or assistance in facilitating this process would be useful.

Other Observations

The focus group facilitators made several observations that were not necessarily explicitly raised as issues, but do contribute to the challenges of developing tailored solutions to caring for this population:

- The LTV population is not a homogenous group. Their individual circumstances vary according to the nature of the underlying condition and the individual's preferences; these needs can and do change over time.
- Because of the very complex needs of these individuals, they require highly specialized resources, which are typically only available at tertiary centres. Although this population is small, the burden of care, both on caregivers and the health care system, is great, and it is unlikely that their care needs will ever decline and most likely that they will increase gradually over time.
- The policies and supports that have been developed for community-based care were developed for a far less medically complex population. Over the past decade or two, ventilator-assisted individuals are increasingly residing in the community, which is straining the existing policies and programs related to this population.

Participants also reported that access to care and services is not equitable across Ontario:

- The description of care and services available varied significantly from LHIN to LHIN. As this population has grown, individual care providers and organizations have developed one-off programs and services to meet these needs, resulting in inequitable access to these services across the province.
- Limited funding for some support services (e.g., direct funding and attendant care) has created an environment where waiting lists for these services is prohibitively long, resulting in inequitable access to these supports.

Summary of Priorities

The identified priorities and the expected timelines are summarized in Table 2. The time horizon reflects the minimum time frame in which results could be expected.

Table 2: Summary of Priorities

Priority	Time horizon*
Priorities for Care and Services	
Increase the capacity for and choice of community living.	Medium to long term
Provide respite for caregivers.	Short term
Create intermediate care beds.	Short term
Review ADP policies and procedures for ventilator equipment and supplies	Short term
Fund existing services appropriately	Short term
Priorities for Education	
Reach the at-risk population	Short to medium term
Provide training for community care providers	Short term
Priorities for Planning	
Develop and implement the LTV Information System	Short to medium term
Support the LHINs in developing regional capacity plans	Short term

* Estimated time until the system begins to experience the associated benefits, assuming immediate implementation.
Short term – within 18 months,
Medium term – one to three years, and
Long term – longer than three years.

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1.0 Introduction

1.1 Background

In 2004/05, the Ministry of Health and Long-Term Care (the ministry) launched a four-year Critical Care Transformation Strategy as part of its Access to Services and Wait Times Strategy. The purpose of the transformation strategy was to improve the quality of care and system performance in adult critical care services in Ontario.

As a first step, the ministry convened the Ontario Critical Care Steering Committee (the committee) with a mandate to conduct a comprehensive review of the state of these critical care services and to prepare recommendations for a system-wide transformation.

During its research, the committee confirmed that many intensive care unit (ICU) beds in Ontario were occupied by ventilator-assisted individuals[4] who were otherwise medically stable. These individuals did not need the critical care services available in an ICU, and did not receive the rehabilitative and other services they did require. However, no adequate alternative setting was available for these individuals.

Accordingly, the committee identified the need for a detailed care strategy and associated resource allocation recommendations to address the needs of these individuals. The Ontario Chronic Ventilation Strategy Task Group (the task group) was established to address the committee's recommendations.

The task group's immediate mandate was to identify effective short-term strategies to facilitate the transfer of medically-stable, ventilator-assisted individuals out of Ontario's ICUs and into a more appropriate care setting. The task group's mandate included the preparation of a detailed care strategy and associated resource allocation recommendations to address the needs of ventilator-assisted individuals.

In spring 2007, the ministry announced an investment of $5.2 million annually primarily to fund additional inpatient resources for ventilator-assisted individuals:

- Fourteen new long-term ventilation[5] beds for ventilator-assisted individuals who cannot live at home, and
- Two additional weaning beds at Toronto East General Hospital's Progressive Weaning Centre.

The funding was also intended to support:

- West Park Healthcare Centre to act as a Long-Term Ventilation Centre of Excellence to improve care and services for ventilator-assisted individuals and those at risk of becoming ventilator assisted, and

[4] The Critical Care Steering Committee (and the Chronic Ventilation Strategy Task Group that followed) referred to these individuals as "chronically-ventilated patients". Based on feedback from consultations with stakeholders, the preferred term when referring to this population is "ventilator-assisted individuals".

[5] In keeping with the discontinuation of the term "chronically ventilated", the term "long-term ventilation" is used replace "chronic assisted ventilatory care".

- Toronto East General Hospital to act as a Weaning Centre of Excellence to provide clinical leadership to improve weaning practices across Ontario.

1.2 LTV Action Plan

Based on the task group's final report, the ministry designated the Toronto Central Local Health Integration Network (TC LHIN) to coordinate the development and implementation of this provincial strategy by:

- Creating an electronic information system (i.e., the LTV Information System) to facilitate the coordination of care for these high-need individuals.
- Establishing a Long-term Ventilation Strategy Secretariat.
- Developing a process for the allocation of funds earmarked for education and training.
- Working with the Centres of Excellence to develop work plans and budgets.

Through a steering committee, the TC LHIN developed an Action Plan[6] for the implementation of the LTV strategy in Ontario. The Action Plan stated four goals, two of which articulated the need for an inventory and gap analysis of services and educational opportunities, as shown in Table 1.

Table 1: LTV Action Plan, Goals 1 and 4

Goal	Action Item
1. To ensure that every ventilator-assisted and at-risk individual is matched to an appropriate level of care and services and has timely access to the needed care and services.	To develop an inventory of existing services and a needs assessment and gap analysis as part of regional and provincial capacity planning processes.
4. To ensure that health care professionals and other care providers in hospitals and the community, ventilator-assisted individuals and family members/caregivers in the home have the knowledge, skills and supports to provide or manage care for this population.	To understand the educational needs and the current capacity to meet those needs through a comprehensive survey designed to create an inventory of existing education and training programs and to develop a needs assessment.

The four goals are listed in Appendix A.

1.3 LTV Information System

The development of a web-based LTV Information System will be instrumental in helping health care professionals and administrators anticipate the short and long term care needs for ventilator-assisted individuals (and those at risk of becoming ventilator-assisted) and will promote care in the most appropriate setting.

The primary objectives of the LTV information system are:

1. Avoid inappropriate utilization of ICU beds by providing ventilator-assisted individuals and their care providers information on services available and facilitating

[6] Long-Term Ventilation Strategy Development for Ontario, Prepared for the Ministry of Health and Long-Term Care by the Toronto Central Local Health Integration Network, Final Report, January 2008.

communication and patient transfers between care settings so that these individuals can receive the appropriate level of care in the appropriate setting.

2. Provide data to inform future capacity planning for the province.
3. Help clinicians identify and support individuals that are at high risk of becoming ventilator assisted (e.g., initiate elective non-invasive ventilation) to better manage their condition and to delay or potentially avoid acute respiratory failure resulting in the initiation of invasive ventilation and an ICU admission
4. Provide information to clinicians and at-risk individuals to make informed decisions regarding options for future care, including offering at-risk individuals the choice of whether to become invasively ventilated or not.

1.4 Service Inventory Program

One of the recommendations of the task group included the establishment of a long-term ventilation network with representation from all centres and organizations in Ontario that provide services to individuals who are, or who are at risk of becoming, ventilator assisted. The Service Inventory Program (SIP) was developed to support the network through the collection of service and program information related to the care of these individuals.

The objectives of the SIP initiative are two-fold:

1. To collect information on organizations that provide programs and services to ventilator-assisted individuals across the province. This information will be incorporated into the LTV Information System, to facilitate timely and effective clinical decision-making by users of the system.
2. To review the needs and gaps within these programs and services through focus group sessions with relevant stakeholders across the province (representing all LHINs), in order to provide the province recommendations for sustainability of these programs and services.

This report documents the first two tasks undertaken within the Service Inventory Program to begin the development of the inventory and gap analysis:

- A suite of surveys of care and service providers.
- Focus groups and telephone interviews with care and service providers and with ventilator-assisted individuals and their families and caregivers.

It is expected that this report will be used for three general purposes:

- This report can be used by care and service providers, in collaboration with their LHIN, to develop a regional capacity plan for these individuals, and, as appropriate, support a business case for additional funding for this population.
- This report will be submitted to the ministry as one input to inform future investments to manage critical care resources as effectively as possible and to provide appropriate and quality care for this population.
- The findings from the surveys and consultations will be one input to a business case for future investments in the LTV Information System.

1.5 Organization of this Report

The contents of this report represent a summary of the detailed data and information that was provided by respondents to the survey and participants in the focus group sessions. The opinions and comments expressed in this document reflect the experiences and views of the participants, and are not intended to represent the ministry's policy or position on any issue.

This report is organized as follows:

- Chapter 2 presents a description of the detailed methods used for the surveys and focus groups.
- Chapter 3 provides a short overview of the target population and current organization of care for these individuals.
- Chapter 4 presents a summary of the survey results.
- The findings from the focus groups are presented in three chapters:
    - Chapter 5 provides a description of the gaps in care, services and education as identified by the focus group participants. The focus in this chapter is on the identification of services that are needed but are **not currently available**.
    - Chapter 6 provides a description of **barriers to accessing existing services**.
    - Chapter 7 presents observations by the focus group facilitators that do not relate directly to the inventory and gap analysis, but do present **challenges for the planning and delivery** of services for this population.
- Chapter 8 provides a summary of the most frequently identified gaps and barriers, reflecting the priorities identified by the focus group participants.

2.0 Methods

As noted earlier, the Toronto Central LHIN has accepted the responsibility to lead the implementation of the LTV strategy on behalf of the ministry and all 14 LHINs. The TC LHIN has engaged the University Health Network's[7] (UHN) Shared Information Management Services (SIMS)[8] to develop the inventory and gap analysis under the auspices of the Long-Term Ventilation Service Inventory Program (LTV SIP).

The LTV SIP project team established a clinical advisory committee to provide guidance on the planning of the survey and focus groups and to review the summary report.

The members of the LTV SIP project team and the clinical advisory committee are provided in Appendix B.

2.1 LTV SIP Surveys

The LTV SIP surveys were undertaken in the following steps:

- A master contact list was created to include any program or organization that was known to provide services to the target population anywhere in the province.
- Four surveys were developed and validated in consultation with the advisory committee, building on the surveys used by the task group in 2005.
- A rigorous follow up protocol was followed using email and telephone calls. As well, focus group participants were asked to identify additional or more appropriate contacts to help complete the surveys as required.

2.1.1 LTV SIP Survey Development

The LTV SIP surveys were designed to create an inventory of care and services as recommended by the task group. Four distinct surveys were developed to capture specific data for the various types of care and service providers along the continuum of care:

- Intensive care units (ICU survey),
- Ministry funded providers of short-term acute and rehabilitative services and long-term in-hospital care (facility survey).
- Independent providers of attendant care in supportive housing or group homes and outreach attendant care in the community (attendant services survey).
- Community care access centres (CCAC survey).

The surveys included questions from the following categories of services:

1. Counselling and disease management for at-risk population and their families and caregivers

[7] University Health Network consists of the Toronto General Hospital, the Toronto Western Hospital and Princess Margaret Hospital.

[8] Building on a long standing patient/client referral relationship, the Toronto Central Community Care Access Centre (CCAC) and University Health Network (UHN) joined information management and information technology (IM/IT) services in 2004. Since then, 11 additional facilities have joined the partnership. This amalgamated entity is now called Shared Information Management Services (SIMS).

2. ICU capacity (ICU survey only)
3. Identification and management of ICU patients eligible for weaning (ICU survey only)
4. Weaning services
5. Identification and management of ICU patients eligible for an alternative inpatient bed (ICU survey only)
6. LTV in-hospital care and services (ICU and facility surveys only)
7. Identification and management of ICU patients eligible for community-based care and services (ICU survey only)
8. Preparation for discharge to home (e.g., Home Ventilation Training and Rehabilitation) (ICU and facility surveys only)
9. Community-based care (e.g., nursing, respiratory therapy), by setting (e.g., long-term care home, nursing home, private home, supportive housing) (CCAC and attendant services surveys only)
10. Community-based services (e.g., assistance with daily living, attendant care, ventilator equipment and maintenance) (CCAC and attendant services surveys only)
11. Outpatient or outreach care (e.g., reassessments) (Facility, CCAC and attendant services surveys only)
12. Respite care

Additionally, to provide a foundation for the focus group sessions to follow, questions addressing views on gaps in the provision of the care or service, wait times, wait lists, funding issues and staffing issues were also included in the surveys.

Follow-up conference calls were scheduled to obtain information that was not obtained through the survey.

The four surveys are provided in Appendix C.

2.1.2 Survey Distribution and Follow Up

The LTV SIP surveys were distributed on April 28, 2008 to 189 organizations that provide emergent, acute, rehabilitative and long-term (community- and hospital-based) care to the target population. The number and type of surveyed organization is summarized in Table 2. The survey was distributed using the Survey Monkey web application (www.surveymonkey.com).

The overall response rate for the surveys was 76%, ranging from 55% for the facility survey to 100% for the CCAC survey, as shown in Table 3. A list of responding organizations is provided in Appendix D.

Table 2: Number and Type of Surveyed organizations

Organization		Survey type
#	Type	
74	Intensive Care Units (primarily Level 3)	ICU survey
14	Chronic Assisted Ventilatory Care (CAVC) Units	Facility survey
44	Complex Continuing Care (CCC) Units	Facility survey
1	Progressive Weaning Centre (Toronto East General Hospital)	Facility survey
3	Home Ventilation Training and Rehabilitation Programs	Facility survey
4	Respiratory Care Programs	Facility survey
1	Outreach / Outpatient Program (Royal Victoria Hospital)	Facility survey
14	Community Care Access Centres	CCAC survey
35	Attendant Services Providers	Attendant services survey

Table 3: LTV SIP Survey, Response Rates

Survey Type	Sent	Returned	Response rate
Intensive Care Units	74	66	89%
Facilities	66	36	55%
Attendant Services Providers	35	28	80%
Community Care Access Centres	14	14	100%
All surveys	189	144	76%

2.2 LTV SIP Focus Groups

The second data collection task was to conduct focus groups in each of the 14 LHINs. In each LHIN, at least two focus groups were held with care and service providers:

- The first session provided preliminary results of the LTV SIP surveys and built on these results to explore gaps and barriers to care and services within the LHIN.
- The second session explored the gaps and barriers related to educational opportunities for providers and for the target population.

These focus groups were coordinated with the assistance of a designated representative in each LHIN. The LHIN representative was provided with a description of the purpose and scope of the sessions, a preliminary list of potential invitees to the focus groups, and additional background and supporting materials as required. Each LHIN was asked to refine the invitation list and manage the logistics for the focus group sessions.

At each session, a request was made for at least one participant to act as a clinical contact for the ongoing work of the LTV strategy.

A total of 196 community and institutional clinicians and administrators and 19 LHIN representatives participated in the provider focus groups. A list of the dates of each focus group and lists of the participants at each provider focus group are presented in Appendix E.

Each LHIN was also provided the opportunity to host a focus group with ventilator-assisted individuals and their families and caregivers. Potential participants were identified through

clinicians, attendant service providers, CCAC case managers and two patient advocacy groups (the Canadian Paraplegic Association and Muscular Dystrophy Canada). In six LHINs[9], a focus group was held; in the other eight LHINs, individuals or their caregivers were interviewed by telephone.

A total of 261 individuals participated in the patient focus groups and telephone interviews, as summarized in Table 4.

Table 4: Summary of Patient Focus Group or Telephone Interview Participation

Representing	Focus Group	Telephone Interview
Individuals at risk of becoming ventilator-assisted	1	3
Ventilator-assisted individuals	11	5
Family members (spouse, parent, child) of a ventilator-assisted individual	21	1
Caregiver (non-family member)	4	0
Institutional care providers	132	0
Community care providers[10]	64	0
Local Health Integration Network representatives	19	0
Total participants	252	9

2.3 Reporting

The LTV SIP survey results were reported as follows:

- Each LHIN received the preliminary results of the LTV SIP surveys for their LHIN at the time of the provider focus groups.
- Each LHIN will receive a LHIN-specific package documenting the final results.
- All survey results will be incorporated into the LTV Information System that is currently under development.
- The provincial highlights are included in this report. (See Chapter 4.)

The LTV SIP focus groups were reported as follows:

- After each focus group, the participants were provided with a summary of the comments made during the session.
- These comments were then consolidated into a provincial picture to form the basis of Chapters 5, 6 and 7 of this report.
- Each participant will be given a copy of this summary report.

2.4 LTV SIP Next Steps

Based on the results of the LTV SIP surveys and focus groups, SIMS will:

- Incorporate relevant information into LTV Information System, and
- Develop a content maintenance process for the LTV Information System.

[9] Champlain, Erie St. Clair, North Simcoe Muskoka, North West, South West and Toronto Central.
[10] Includes Community Care Access Centres, attendant service providers, home oxygen companies, nursing agencies and patient advocacy groups.

3.0 Current Organization of Care in Ontario

This chapter presents a brief description of the ventilator-assisted population as background to the survey results and focus group summaries that follow. A more comprehensive description of this population can be found in the Chronic Ventilation Strategy Task Group Report.[11] Some of the material in this chapter is from that report.

3.1 Description of Ventilator-Assisted Population

Three of the more common causes of the need for mechanical ventilation are:

- Degenerative neuromuscular diseases (NMDs).
- A high spinal cord injury.
- Chronic Obstructive Pulmonary Disease (COPD).

With degenerative diseases, the individual's condition gradually deteriorates over time, until the he or she becomes fully dependent on mechanical ventilation. In general, the deterioration of the respiratory system accompanies the decline in neuromuscular function. Therefore, these individuals, in addition to the ventilatory requirements, are often in need of special assistive devices and total care.

The ventilator-assisted individual can be either invasively or non-invasively ventilated:

- For non-invasive ventilation (NIV),[12] the interface between the patient's respiratory system and the ventilator is a mask covering the nose (i.e., nasal mask) or a mask covering the nose and mouth (i.e., a full face mask).[13] .
- For invasive ventilation, the interface is a tracheostomy tube that is inserted through the individual's neck directly into the trachea. The care of these patients is relatively complex due to the maintenance and cleaning of the equipment and the invasive interface.

Two populations were of interest for this study: ventilator-assisted individuals and individuals at risk of becoming ventilator-assisted.

For the purpose of this work, the Chronic Ventilation Strategy Task Group definition was used for ventilator-assisted individuals:

> *"those patients suffering from a severe respiratory impairment who require ventilatory support for more than six hours per day for more than 21 days, but*

[11] Chronic Ventilation Strategy Task Force. Final Report. June 30, 2006. http://www.health.gov.on.ca/english/providers/program/critical_care/docs/report_cvtg.pdf

[12] Noninvasive ventilation (NIV) is continuous or intermittent mechanical support (commonly the latter) to maintain or assist breathing through a variety of indirect interfaces.
Invasive ventilation (IV) is continuous or intermittent mechanical support to maintain or assist breathing through direct communication with the trachea, i.e., a tracheostomy tube.
Source: Chest. Supplement. 'Mechanical Ventilation Beyond the Intensive Care Unit. Report of a Consensus Conference of the American College of Chest Physicians. 113,5. May 1998

[13] Individuals using bi-level pressure support are included in this definition. Although individuals using continuous pressure were included in the definition for the purpose of the survey, most respondents did not include this population in the reported statistics. The advisory committee has suggested that individuals using continuous pressure not be included in this population.

who do not require additional services provided by a critical care unit (i.e., patients who are otherwise medically stable)."

The definition for at-risk individuals was adapted from the same report as follows:

> *When an individual is already in the care of a physician (e.g., general practitioner, neurologist, respirologist, pediatrician) before the disease has advanced to the stage where the patient requires invasive mechanical ventilation.*

During the at-risk period, individuals might elect to use ventilatory support to increase longevity and quality of life. This "elective" use of ventilation will, in most cases, substantially delay or avoid altogether admission to an ICU. The elective initiation of ventilation is usually non-invasive, and most of these individuals initially require ventilatory support only at night.

3.2 The LTV Care Path

This section provides a brief overview of the typical care path followed by a ventilator-assisted individual. It is not intended to define the ideal situation, but only to illustrate for those unfamiliar with this population how care is currently delivered in Ontario. For a full discussion of the issues and challenges identified along the entire continuum of care for the population the reader is referred to the Chronic Ventilation Strategy Task Group Report.

Most at-risk individuals will eventually arrive at an emergency department due to respiratory failure.[14] They are typically intubated, and eventually given a tracheostomy to begin invasive mechanical ventilation. As the individual recovers from the acute event, the option of weaning the individual from the ventilator is considered and tried if appropriate.

If the individual is deemed unweanable, an alternative care setting is identified:

- If no alternative setting is secured, the individual stays in the ICU until one can be found or until the individual succumbs to the underlying disease or related complications.
- If an alternative setting is found in the community (e.g., the family's home, supportive housing, group home), the individual, the family and other community-based care providers are provided with home ventilation training to prepare them for discharge from the hospital.
- If an alternative setting is found in a hospital (e.g., a complex continuing care (CCC) unit or a chronic assisted ventilatory care (CAVC) unit), the individual is transferred as soon as he or she is medically stable and the receiving unit is ready to provide care (e.g., has the needed equipment, staff are trained, a bed is available).

The typical care path for this population is shown graphically in Appendix F.

3.3 LTV Care Providers

This section provides a brief overview of the organizations that provide care for ventilator-assisted individuals. At times, the needs of the ventilator-assisted population are highly

[14] Note that the goal of identifying the at-risk population is to manage the disease progression to potentially avoid or delay invasive ventilation or to at least avoid an emergency department visit when invasive ventilation is initiated. At this time, most individuals with these diseases do not have access to this care.

complex and require specialized expertise, which is usually centralized in a tertiary care centre. Once the individual is medically stable, the care can be provided by trained, but less specialized care providers, which can usually be found closer to home. If the individual is living at home, much of the care is provided by the individual's family or personal attendants.

3.3.1 Intensive Care Units (ICUs)

The ICU is the most common point of entry into the LTV care continuum. When an individual experiences an acute event, he or she is admitted to the ICU and placed on ventilation if necessary. The purpose of the ICU is to provide immediate medical support to individuals who require intensive care; it is not within the mandate of the ICU to provide long-term care to individuals.

3.3.2 Weaning Services

Weaning is attempted for ventilator-assisted individuals who are medically stable, cognitively intact and deemed "weanable" by the ICU's medical and clinical staff. This service is intended to reduce the individual's dependency on mechanical ventilation and, eventually, liberate the individual from this dependency.

Toronto East General Hospital's Progressive Weaning Centre is the only formally designated and funded weaning centre in Ontario. Most ICUs provide weaning services for ventilator-assisted individuals.

3.3.3 Rehabilitation and Home Ventilation Training

This service helps individuals who are ventilator-assisted and medically stable, but do not show potential for weaning, and prepares them for successful community or institutional living.

The only designated and funded Rehabilitation and Home Ventilation Training program in Ontario is located at West Park Healthcare Centre in Toronto.

Most individuals discharged to the community are training for home ventilation either in the ICU or in a CCC or CAVC unit.

3.3.4 Outreach and Outpatient Services

Several of the larger LTV services in the province provide outreach and outpatient services for ventilator-assisted individuals. The North Simcoe Muskoka Community Care Access Centre (CCAC) is the only CCAC to provide in-home visits by a respiratory therapist, under an arrangement with the Royal Victoria Hospital. Several of the tertiary centres with a long-term ventilation service follow ventilator-assisted individuals primarily through their outpatient clinics, with hospital admissions for reassessment as needed.

3.3.5 Chronic Assisted Ventilatory Care (CAVC) Units

When adequate supports for community living are not available or have failed, or if the individual's condition has deteriorated beyond what the family can manage, the individual might be admitted to a CAVC bed, which is typically within a continuing complex care (CCC) unit. CAVCs provide medical care and other supports for ventilator-assisted individuals in an institutional setting.

If no inpatient bed is available when community living is no longer a viable option, the ventilator-assisted individual will eventually arrive at an emergency room and subsequently be admitted to an intensive care unit.

Six hospitals in Ontario have a designated CAVC service:

- West Park Healthcare Centre, which is the only dedicated unit for ventilator-assisted individuals in Ontario. (28 beds)
- Toronto East General Hospital (10 beds)
- Sisters of Charity, Ottawa (10 beds)
- Parkwood Hospital, London (five beds)
- St. Joseph's Healthcare Hamilton. (three beds of which two are funded)
- Grand River Hospital, Kitchener. (six beds of which two are funded).

Some CCC units accept ventilator-assisted individuals even though they do not receive funding to cover the incremental costs of providing care for this population.

3.3.6 Community Care Access Centres

Community Care Access Centres (CCACs) arrange in-home care for eligible patients. Their services are regulated under the Long Term Care Act, and they are mandated to provide nursing (visiting and shift), personal support and homemaking, physiotherapy, occupational therapy, nutrition, speech therapy and social work, as well as medical supplies and medical equipment. The mandated services are available at the client's request. Respiratory therapy is not a mandated service.

When an individual has been deemed suitable for community living, the discharging hospital will send a request to the CCAC to arrange the necessary in-home supports and services.

3.3.7 Attendant Services

Attendant services provide three types of services to enable persons with disabilities to live independently:

- Attendant outreach for individuals in a community setting,
- Assisted living in supporting housing, in which the individual lives in an apartment (typically rent-geared-to-income) or a group home.
- Training in skills for independent living.

In some parts of Ontario, attendant service providers will accept ventilator-assisted individuals, subject to availability of suitable housing (for the supportive housing and group home options) and sufficient funding to cover the costs of delivering this care.

3.4 Cost of Care

The cost to care for ventilator-assisted individuals varies significantly depending on the care setting, ranging from an estimated $3,745 per day in an ICU bed in a tertiary care centre to $205 per day in supportive housing with attendant services, as shown in Table 5.

Table 5: Approximately Cost for LTV Care by Setting, ($/day)

Care setting	Approximate cost ($/day)
Intensive care bed[15]	
In an academic health science centre	3,745
In a community hospital	2,024
Weaning centre bed[16]	1,500
Rehabilitation and Home Ventilation Training[17]	1,228
Chronic assisted ventilatory care bed	714
Complex continuing care bed[18]	548
Supportive housing[19]	205

[15] Source: Ontario Case Cost Initiative data. 2004/05, as reported in the Chronic Ventilation Strategy Task Group Report. Includes direct and indirect costs.
[16] Toronto East General Hospital, 2004/05, as reported in the Chronic Ventilation Strategy Task Group Report. Includes direct and indirect costs.
[17] West Park Healthcare Centre, 2004/05, as reported in the Chronic Ventilation Strategy Task Group Report. Includes direct and indirect costs.
[18] Based on annual funding of approximately $200,000 as reported by focus group participants. Note, however, that this level of funding does not cover the incremental costs of caring for a ventilator-assisted individual.
[19] Includes a 50% premium on an estimate of $132/day for 4 hours of care per day, as documented in Unleashing Attendant Services: Enhancing People's Potential, Reducing Wait Times in Acute and Long-Term Health Care. Attendant Services Advisory Committee of the Ontario Community Support Association. July 2008.

4.0 Highlights of LTV SIP Survey Results

This chapter presents the summary results by LHIN and the provincial average values for each of the four surveys. The reader is reminded that these surveys were designed to capture a single point in time. Focus group participants noted that the census and other variables can fluctuate significantly, and the reported results might not be representative of current or even typical activity.

Survey respondents were invited to submit written comments on gaps and barriers to care and services. These comments have been incorporated into the summaries of the focus group results in the following chapters and are not repeated here.

This chapter also includes an estimate of the at-risk population by LHIN, as provided by the Ventilator Equipment Pool and the number of ventilator-assisted individuals who receive direct funding from the ministry.

4.1 Survey Highlights

ICU beds are highly utilized at 93% average occupancy among the 66 hospitals responding to the survey. Survey respondents reported 78 invasively ventilated and 16 non-invasively ventilated LTV patients in ICUs at the time of this survey. This represents approximately nine percent of the total reported ICU beds.

The average length of stay in ICU for LTV patients in Ontario was 195 days, with average delays of 129 days (and as high as 400 days) waiting for discharge to an alternative setting.

In total, responding facilities reported an additional 107 invasively ventilated and 166 non-invasively ventilator-assisted individuals in either chronic assisted ventilatory care, complex continuing care, respiratory care, outreach/outpatient,[20] home ventilation training or progressive weaning centres and programs in Ontario. Of these 123 individuals, 27 (22%) were deemed eligible for community-based care.

The 28 attendant service providers who responded to this survey reported providing attendant care services to 30 invasively and 69 non-invasively ventilated individuals in Ontario. All 14 community care access centres (CCACs) responded to the CCAC survey. In total, there are 58 invasively ventilated and 35 non-invasively ventilated LTV individuals supported by CCACs in Ontario.

Based on the survey results, we identified a total of 453 ventilator-assisted individuals in Ontario who are cared for by the surveyed organizations, as shown in Table 6. The breakdown of these individuals by LHIN is provided in Appendix G.

[20] Royal Victoria Hospital was the only hospital that included its outreach/outpatient program in its survey response.

Table 6: Summary of the LTV Population as Reported by Survey Respondents, Ontario

	Invasively ventilated	Non-invasively ventilated	Total
In hospital			
ICU	78	16	94
Facility	107	16	123
Total in hospital	185	32	217
In the community			
Attendant services	30	69	99
Direct funding	22	22	44
CCAC	58	35	93
Total in community[21]	110	126	236

Source: ICU, facility, CCAC and attendant services surveys

In response to concerns that the at risk population (e.g., non-invasively ventilated and living in the community) was not captured in its entirety in the survey, three of the larger tertiary centres that provide outreach and outpatient care were asked to provide data on this population. As shown in Table 7, these three programs follow 418 non-invasively ventilated adults in the community. These individuals would be a subset of the total at-risk population.

Table 7: Outreach and Outpatient Adult Client Volumes at Three Tertiary Centres, by LHIN, July 2008

	West Park Healthcare Centre			The Ottawa Hospital			London Health Sciences Centre[22]			Total for 3 centres		
LHIN	NIV	IV	NIV+IV	NIV	IV	NIV+IV	NIV	IV	NIV+IV	NIV	IV	NIV+IV
Central	38	15	53	1	0	1			0	39	15	54
Central East	26	11	37			0			0	26	11	37
Central West	28	4	32			0			0	28	4	32
Champlain	1	1	2	137	6	143			0	138	7	145
Erie St Clair	2	1	3			0			0	2	1	3
Hamilton Niagara	5	2	7			0			0	5	2	7
Mississauga Halton	37	11	48			0			0	37	11	48
North East	5	1	6			0			0	5	1	6
North Simcoe Muskoka	16	0	16			0			0	16	0	16
South East	1	0	1			0			0	1	0	1
South West	3	4	7			0	70	35	105	73	394	1127
Toronto Central	36	18	54	3	0	3			0	39	18	57
Waterloo Wellington	9	2	11			0			0	9	2	11
Total	207	70	277	141	6	147	70	35	105	418	111	529

Source: West Park Healthcare Centre, The Ottawa Hospital, London Health Sciences Centre

[21] The reader is cautioned that some individuals may receive services from more than one agency. Therefore, this total might be overstated.

[22] London's data were not available by LHIN, however, most of these individuals are in the South West LHIN.

4.2 ICU Survey Results

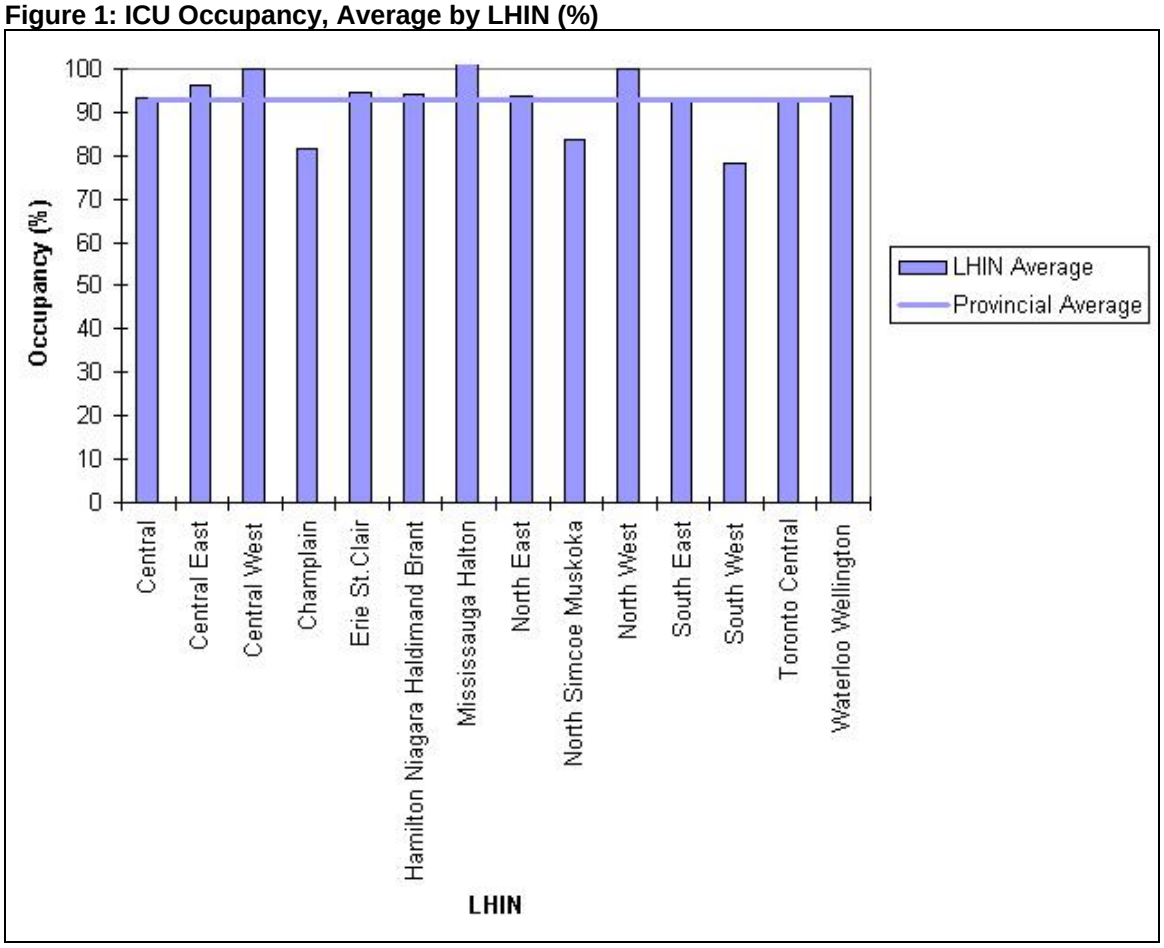
ICUs in 66 hospitals responded to the ICU survey, for a response rate of 89%. These ICUs represented a total of 1,089 ICU beds.

4.2.1 ICU Occupancy

Of the reporting ICUs, the overall occupancy for the 1,089 ICU beds in the 66 reporting hospitals in the province was 93% (as shown in Figure 1), compared to a target occupancy of 80%.[23] Three LHINs reported an average occupancy of 100% for all reporting ICUs in the LHIN; only one LHIN (South West) reported an average below 80% (at 78%).[24]

32 ICUs (43 percent of responding ICUs) reported 100% occupancy; 52 ICUs (70 percent) reported occupancy of 90% or greater.

Figure 1: ICU Occupancy, Average by LHIN (%)



Source: ICU survey

4.2.2 ICU LTV Population

For the purpose of the ICU survey, a long-term ventilated individual (LTV) was defined as a patient in an ICU who requires mechanical ventilation assistance for at least 6 hours per day

[23] Consensus recommendation of the Critical Care Leads.

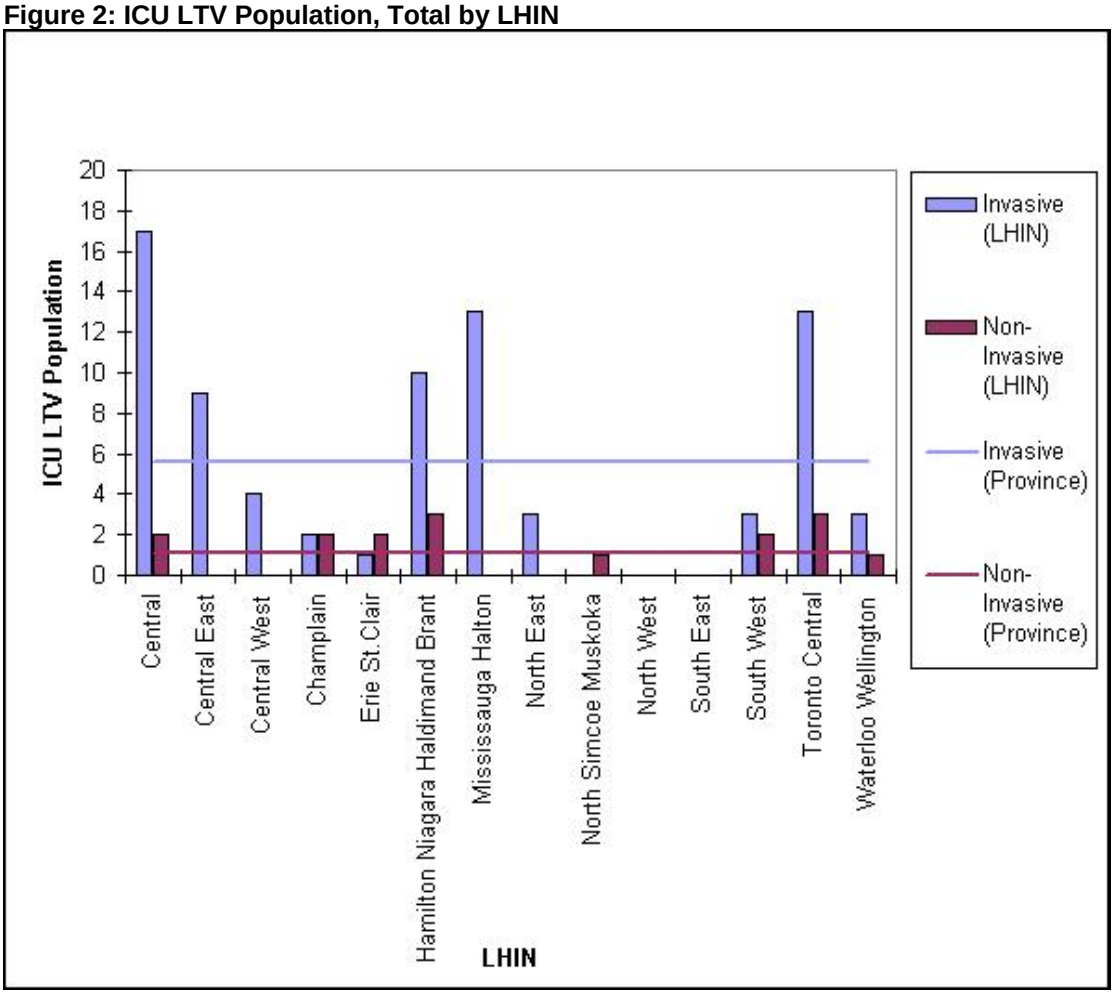
[24] The South West LHIN ICU average occupancy rises to 93% if Grey Bruce Health System, which had no patients in its six-bed ICU at the time of this survey, is removed from the calculation.

for a period no less than 21 days, but is otherwise medically stable.[25] Participants in the focus group suggested that this definition might overstate the number of individuals who will be ventilated in the long-term because it includes those individuals who are still candidates for weaning.

Survey respondents reported 78 invasively ventilated LTV patients in ICUs at the time of this survey. This represents approximately eight percent of the total occupied ICU beds. As shown in Figure 2, these individuals are concentrated in five LHINs in the Greater Toronto Area (GTA),[26] which collectively account for 62 of the invasively-ventilated LTV individuals reported in ICUs in Ontario. Two LHINs[27] reported no invasively-ventilated individuals in their ICU at the time of the survey.

Survey respondents also reported 16 non-invasively ventilated LTV patients in ICUs at the time of this survey.

Figure 2: ICU LTV Population, Total by LHIN



Source: ICU survey

[25] This is the definition used by the Chronic Ventilation Strategy Task Force.
[26] Central, Central East, Hamilton Niagara Haldimand Brant, Mississauga Halton and Toronto Central.
[27] North West and South East.

4.2.3 ICU Hospital Workflow

Survey respondents were asked to estimate the average length of stay for LTV patients in the ICU broken down into two separate periods:

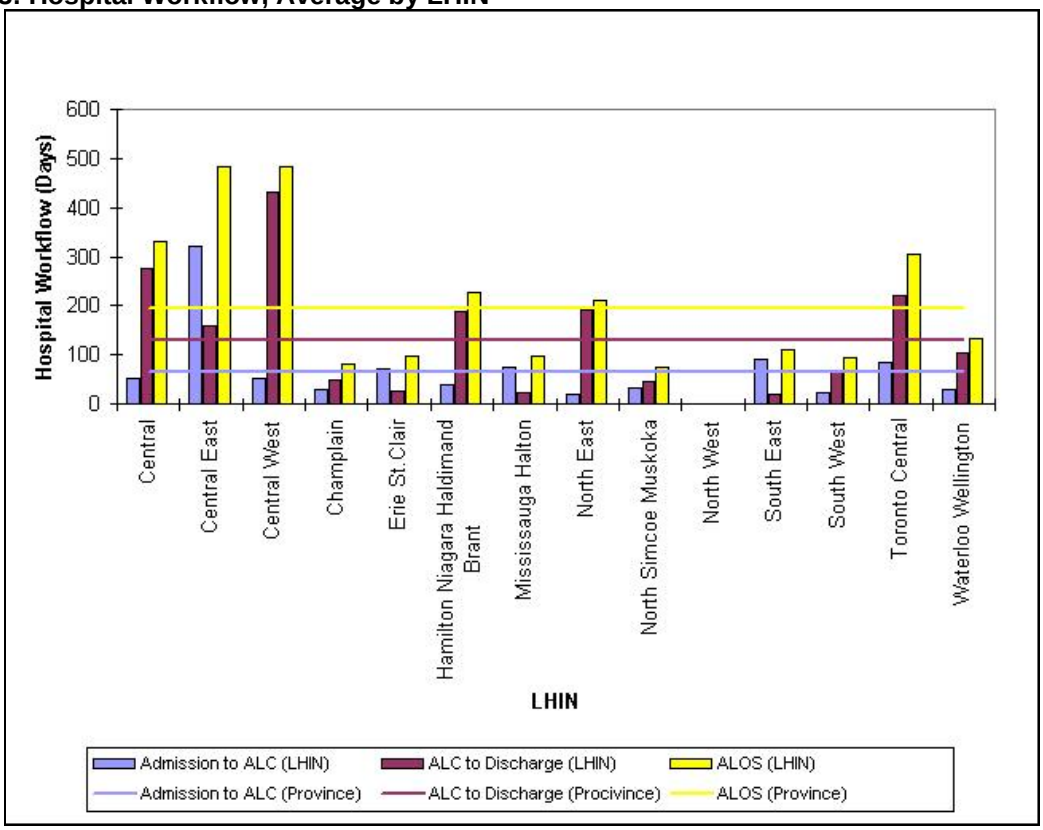
- The length of time from admission to the ICU until the individual is identified as a candidate for discharge from the ICU (i.e., the patient was deemed more appropriate for an alternative care setting). This interval is referred to as "Admission to ALC".
- The length of time from identification of the individual for discharge from the ICU and actual discharge. This interval is referred to as "ALC to Discharge."

The average length of stay in ICU for LTV patients in Ontario was 195 days:

- The average length of time from Admission to ALC was 66 days, and
- The average length of time from ALC to Discharge was 129 days (approximately four months).

As shown in Figure 3, three LHINs reported an average time from identification for discharge to actual discharge of greater than 200 days: Central West (433 days), Central (277), and Toronto Central (220). One responding ICU reported a length of stay of 1,531 days (approximately 4.2 years).

Figure 3: Hospital Workflow, Average by LHIN[28]



[28] Hospital workflow is calculated as the length of time between admission to ICU and identification for discharge and the length of time between identification for discharge and actual discharge for LTV patients. The total length of stay for LTV patients is calculated as the sum of these two values. The workflows of ICUs in each LHIN were averaged to determine the Hospital Workflow (days) for that LHIN.

Source: ICU survey

Hospital workflow statistics by LHIN are provided in Appendix G**.**

4.3 Facility Results

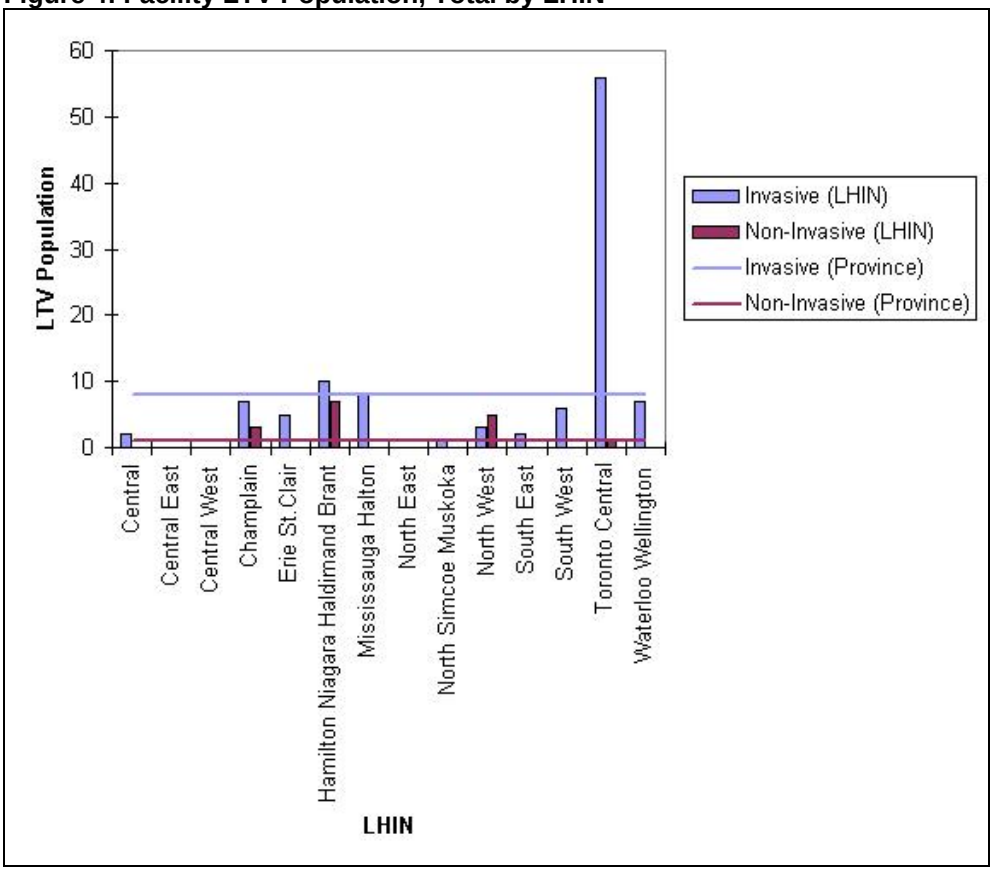
Thirty-six units in acute, rehabilitation and complex continuing care facilities responded to the facility survey, for a response rate of 55%.

4.3.1 Facility LTV Population

In total, responding facilities reported 107 invasively ventilated and 16 non-invasively ventilated LTV individuals currently in chronic assisted ventilatory care, complex continuing care, respiratory care, home ventilation training or the progressive weaning centre and programs in Ontario.

As shown in Figure 4, most of the invasively-ventilated individuals are in the Toronto Central LHIN. The Central East, Central West and North East LHINs reported no ventilator-assisted individuals within their non-ICU facilities.

Figure 4: Facility LTV Population, Total by LHIN[29]



Source: Facility survey

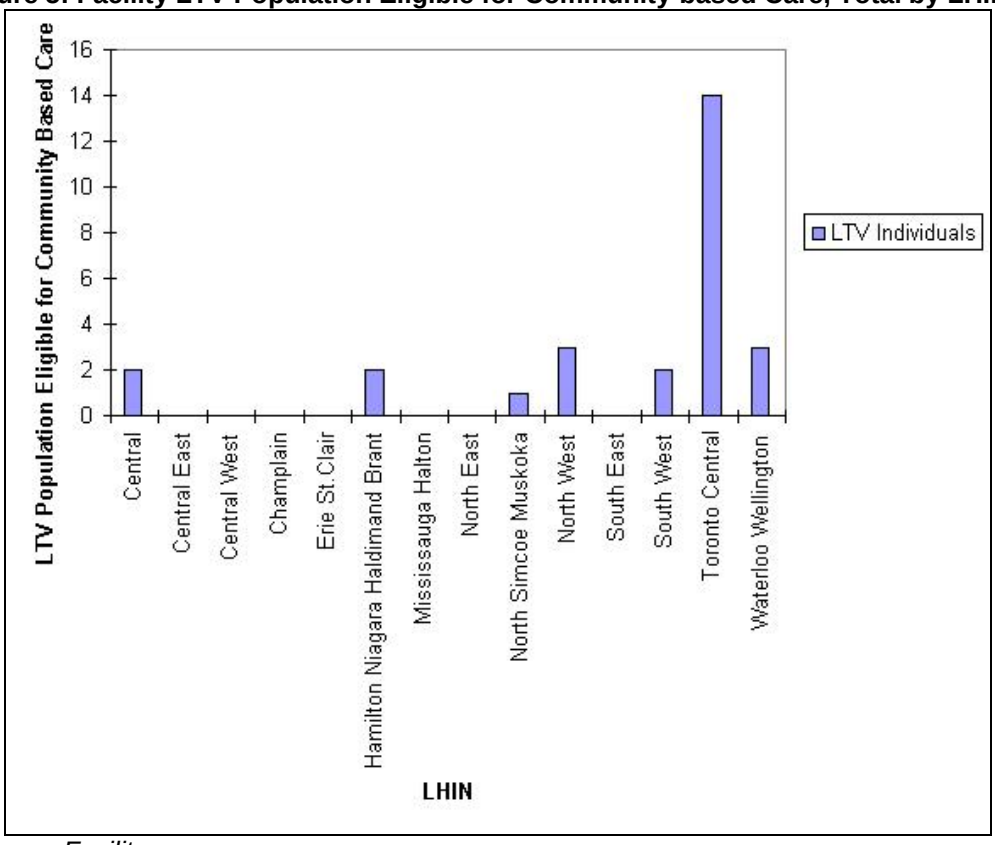
[29] LTV population is calculated as the sum of the number of Invasively Ventilated LTV individuals and the sum of the number of Non-invasively Ventilated LTV individuals. The LTV populations of Facilities in each LHIN were totalled to determine the LTV population (persons) for that LHIN.

4.3.2 Facility LTV Population Eligible for Community-Based Care

The responding facilities reported a total of 27 LTV individuals in their facilities across Ontario (out of a total reported census of 123 reported in the survey) who are eligible for community-based care. This is 22% of LTV individuals in an institutional setting in Ontario at the time of this survey. As shown in Figure 5, 14 of these individuals were identified in the Toronto Central LHIN, which represents 25% of the LTV individuals in a non-ICU facility in this LHIN (which is consistent with the provincial average).

Clinicians in the Toronto Central LHIN reported that there are insufficient community supports to facilitate transition of these individuals to the community. Some examples cited include a lack of home care resources and lack of experienced home care teams to look after ventilator-assisted individuals in the community. Additionally, there appears to be a gap for patients requiring long term non-invasive ventilation in the community setting.

Figure 5: Facility LTV Population Eligible for Community-based Care, Total by LHIN[30]



Source: Facility survey

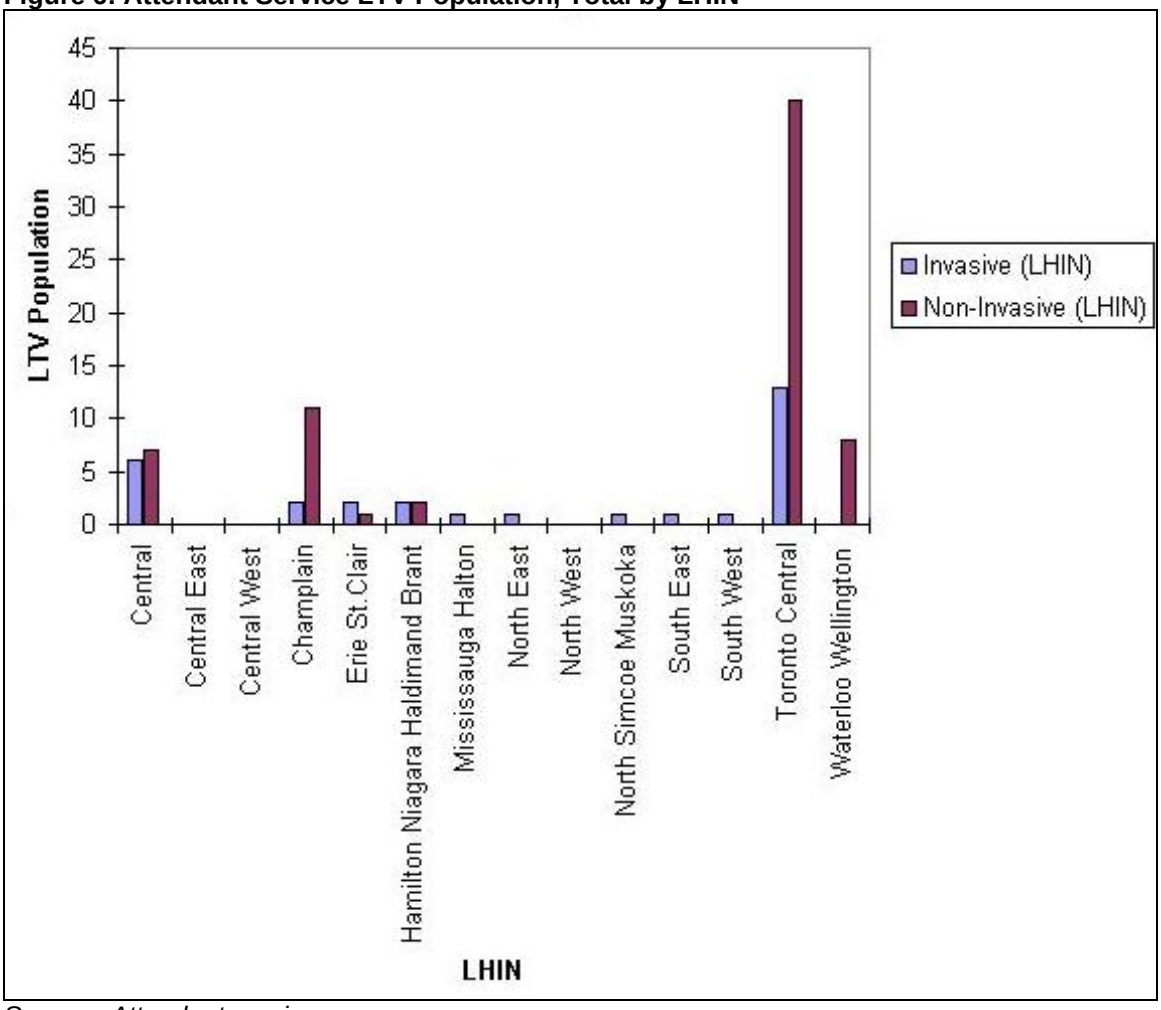
4.4 Attendant Services Results

Twenty-eight out of 35 attendant service providers responded to the attendant services survey, for a response rate of 80%.

[30] LTV population eligible for Community-Based Care is calculated as the sum of the number of LTV individuals who are appropriate for care either at home or within the community. The Facility LTV populations eligible for Community-Based Care in each LHIN were totalled to determine the LTV population eligible for Community-Based Care (persons) for that LHIN.

The providers who responded to this survey reported providing attendant care services to 30 invasively ventilated and 69 non-invasively ventilated LTV individuals in Ontario. Most of these individuals are in the Toronto Central LHIN, as shown in Figure 6. Central East, Central West and North West reported no services being provided to ventilator-assisted individuals in the community.

Figure 6: Attendant Service LTV Population, Total by LHIN[31]



Source: Attendant services survey

4.5 CCAC Results

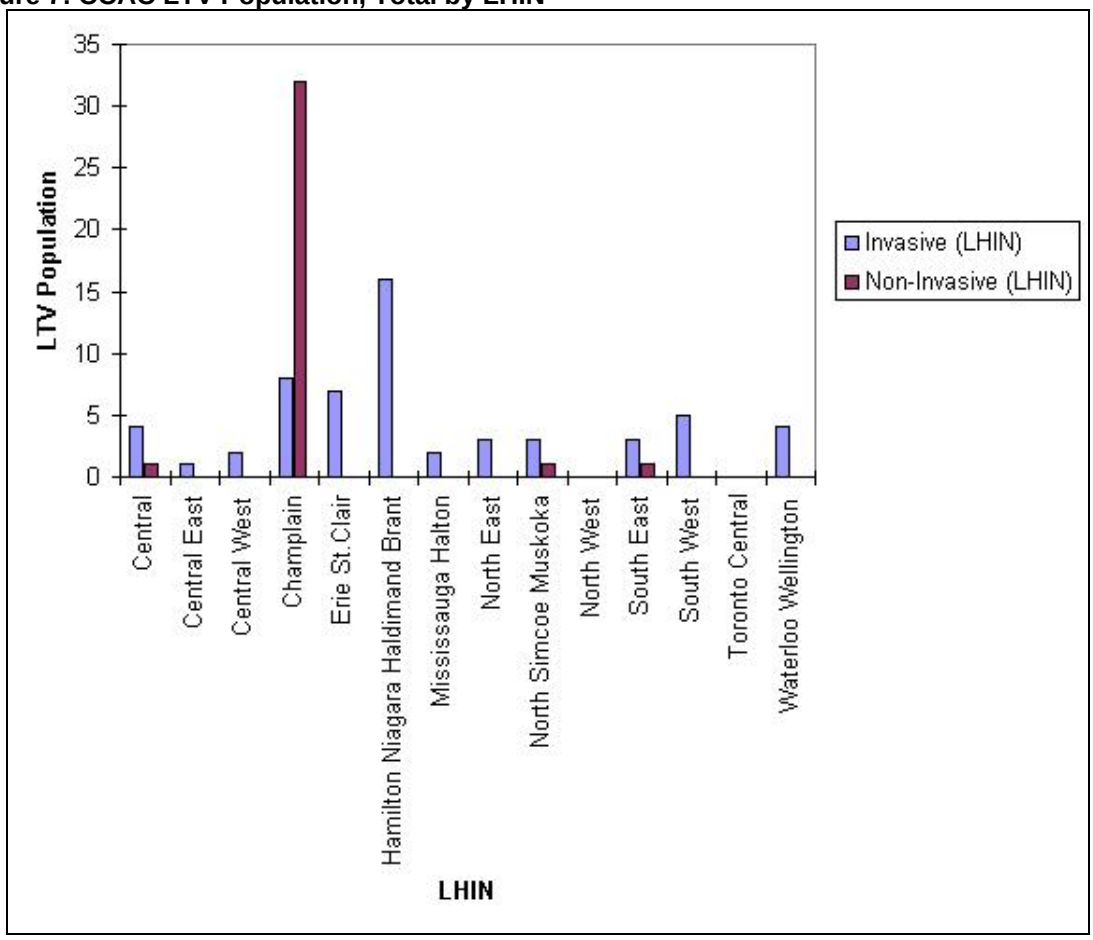
All 14 community care access centres (CCACs) responded to the CCAC survey.

In total, 58 invasively-ventilated and 35 non-invasively ventilated LTV individuals are supported by CCACs in Ontario. The Hamilton Niagara Haldimand Brant LHIN has the highest number of invasively-ventilated individuals (15) receiving care in the community; the Champlain LHIN has the highest number of non-invasively ventilated individuals (32) receiving care from the CCAC in the community, as shown in Figure 7. Toronto Central

[31] LTV population is calculated as the sum of the number of Invasively Ventilated LTV individuals and the sum of the number of Non-invasively Ventilated LTV individuals. The LTV populations of Attendant Services in each LHIN were totalled to determine the LTV population (persons) for that LHIN.

CCAC reported that it does not provide services to any ventilator-assisted individual in its region.

Figure 7: CCAC LTV Population, Total by LHIN[32]



Source: CCAC survey

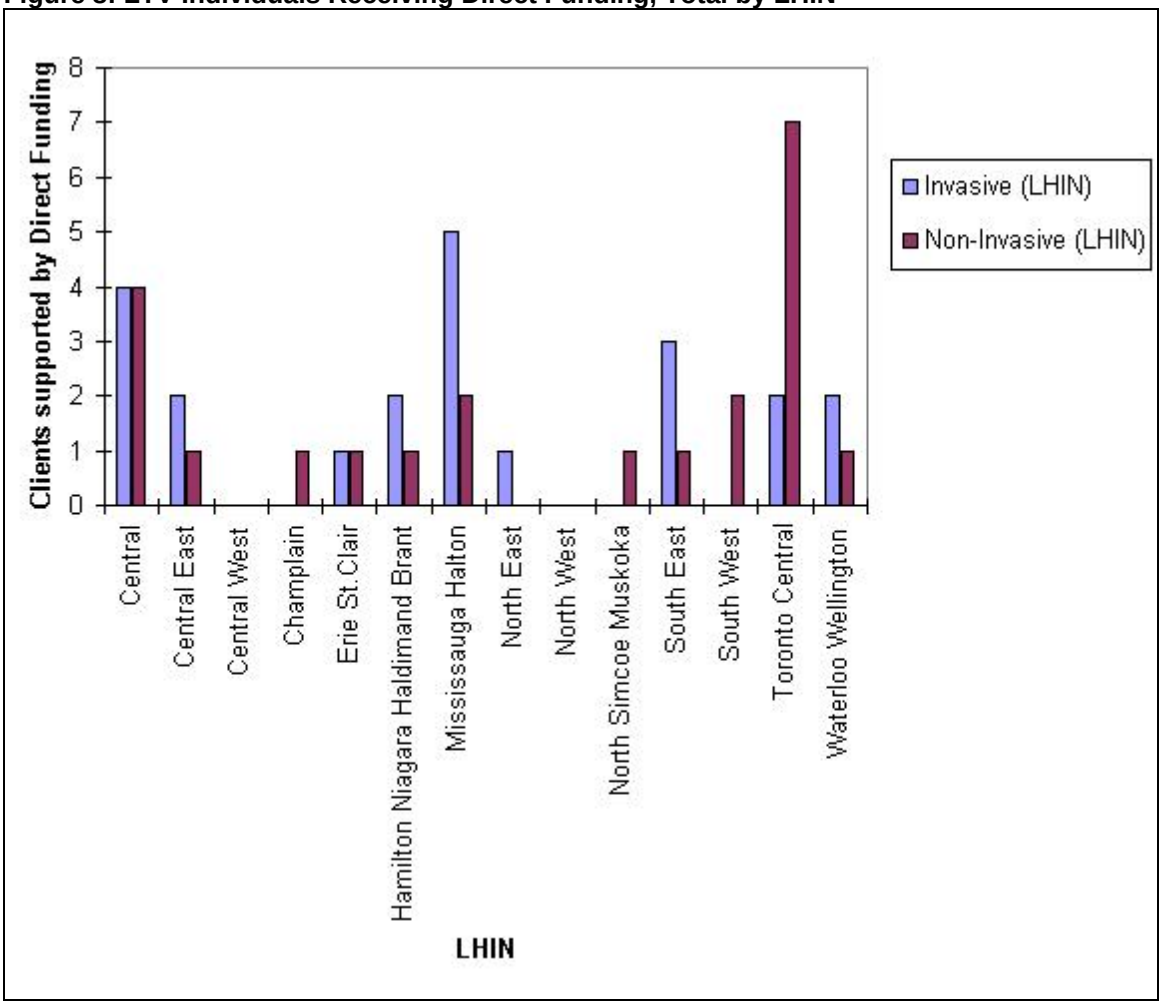
4.6 Direct Funding Program

The Direct Funding Program enables adults with physical disabilities to manage independently the funds allocated for their care. Funding for these services is provided directly to the ventilator-assisted individual or designate, who employs and schedules attendants as needed. Attendants assist with routine activities of daily living such as dressing, grooming, bathing and tracheostomy and ventilator care.

In total, 22 invasively-ventilated and 22 non-invasively ventilated LTV individuals are supported by direct funding in Ontario, distributed by LHIN as shown in Figure 8. Additionally, there are three invasively ventilated and 22 non-invasively ventilated LTV individuals on the Direct Funding Program waitlist.

[32] Number of LTV clients was calculated as the number of LTV clients reported by each CCAC. The number of LTV clients reported by each CCAC was then referenced to their respective LHIN to determine the number of LTV clients (persons) for that LHIN.

Figure 8: LTV Individuals Receiving Direct Funding, Total by LHIN[33]



Source: Direct Funding Program

[33] LTV population is calculated as the sum of the number of Invasively Ventilated LTV clients and the sum of the number of Non-invasively Ventilated LTV clients supported by Direct Funding. The LTV populations supported by Direct Funding in each LHIN were totalled to determine the LTV population (persons) supported by Direct Funding for that LHIN.

5.0 Focus Group Findings: Service Gaps

This and the following chapter present a summary of the comments made by participants in the focus groups in each of the 14 LHINs. The two chapters present a discussion of:

- Gaps in the delivery of care and services along the continuum of care (i.e., where needed services do not exist), and
- Barriers to accessing existing services (i.e., where services exist but are not easily accessible).

The comments are based on the perceptions and experiences of the focus group participants and do not represent the ministry's position on any policy or issue.

Although the provider focus groups were held separately from the focus groups with ventilator-assisted individuals and their families or caregivers, the comments have been combined in this summary as the themes and issues were consistent across all sessions. Similarly, although the provider sessions were structured to address concerns around care and services separately from educational opportunities, this distinction was blurred in practice, and both topics have been combined in this summary.

Discussion topics have been organized around general themes and are not necessarily presented in the order of priority. A summary of the priorities identified by the participants is provided in Chapter 8.

Although the focus of much of the discussions was on issues and challenges in meeting the needs of this population, the facilitators learned of many innovative and successful programs and services that had been implemented at a local or regional level. A brief description of these initiatives and contact information for representatives knowledgeable about the service are provided in Appendix H.

Participants provided information that could be of interest to stakeholders in other LHINs. This information has been provided as reference material in the appendices to this report:

- Appendix I provides a list of resources that are publicly available, mostly on the Internet.
- Appendix J lists suggested projects for the two centres of excellence.
- Appendix K briefly describes outstanding proposals for investment in this population and relevant contact information provided to the facilitators by focus group participants.
- Appendix L has a list of other reports and studies that were noted during the discussions that might be of interest to policy makers and other stakeholders as well as current ministry priorities with which the LTV strategy is well aligned.
- Appendix M includes a list of innovations in the delivery of care and services for other populations that could be relevant for the LTV population.

5.1 Gaps in the Continuum of Care

Focus group participants identified many areas where the needs of this population and its care providers are not being met because the necessary programs and services do not exist.

5.1.1 At-risk Individuals

Many participants noted that they are aware of many individuals in the community who are at risk of becoming invasively ventilated due to the nature of their disease (e.g., amyotrophic lateral sclerosis or ALS, muscular dystrophy). This group includes those who are not yet ventilated and those who are non-invasively ventilated. These individuals need to be identified as being at risk of respiratory failure and of becoming invasively ventilated so that they can be referred for information and counselling regarding:

- The disease and its likely course (e.g., risk of respiratory failure and possible admission to an ICU, followed by a tracheostomy)
- Options for care and the implications of each option (e.g., what it is like to be invasively ventilated for the long term, with attention on the ventilator-assisted individual and the family).
- Development of an advance care plan to clearly articulate the individual and family wishes in the event the individual's condition deteriorates. This plan could include a "do not resuscitate" order or instructions for palliative or end-of-life care.

These discussions need to be ongoing, and the decisions that individuals make following counselling must be reviewed regularly and systematically due to the changing nature of the individual's condition. In the absence of such advance planning, the decision to ventilate is often being made when individuals are admitted to the emergency department during an acute crisis.

A number of options were proposed for delivering this counselling:

- The family physician was thought to be in the best position to provide this information. However, the existing Ontario Health Insurance Plan (OHIP) schedule does not remunerate family physicians for this time-intensive care, and many physicians are not comfortable providing this type of counselling.
- A centralized referral centre with specialized expertise in this area, such as the clinic at The Ottawa Hospital Rehabilitation Centre (see Appendix H).
- Both providers and ventilator-assisted individuals and families noted the value of having access to a peer network to discuss the realities of living with a ventilator, as is offered by volunteers from the ALS society. It was also suggested that a video showing vignettes of individuals living with a ventilator would help families make informed decisions.
- The Critical Care Response Teams that have been established in Ontario hospitals have the resources and skills to provide this service to inpatients. It was suggested that the mandate of these teams could be extended to provide counselling to outpatients as well.
- Most LHINs have identified chronic disease prevention and management as a priority. The LTV population should be explicitly included in any initiatives related to this overall work.
- Health Canada has a website with information on advance care planning that is accessible to anyone. (See Appendix I.)

5.1.2 Intermediate Care

Whenever feasible, weaning the individual from the ventilator is the preferred option for care. In 2007, the ministry established the Progressive Weaning Centre (PWC) at the Toronto Eastern General Hospital as a centre of excellence for weaning. Although some hospitals in the Greater Toronto Area (GTA) have access to the PWC, it is not intended to provide weaning services for ventilator-assisted individuals throughout Ontario. As well, most individuals outside of the GTA do not want to travel to Toronto for the approximately three-month weaning program.

Similarly, when the individual cannot be weaned but is a good candidate for living at home, he or she can be referred to West Park Healthcare Centre in Toronto for home ventilation training. West Park has the only funded program designed to train ventilator-assisted individuals and their families for the transition from a hospital to the home. Participants found that West Park's program was not meeting the needs of some of their patients for the following reasons:

- Individuals and their families do not want to relocate to Toronto for the six to eight week program.
- The waiting list to be admitted to program was described as "three to six months for an initial assessment of suitability for the program and another three to six months for admission after the assessment." Although some participants cited shorter wait times, decisions are often made on the perception of long waits times.[34]
- The admission criteria for the home ventilation training program (e.g., the need to have identified at least five caregivers such as family, friends, or hired personal support workers for the training program), are perceived as too strict and limit the number of individuals who can be referred to the program.[35]

Consequently, most individuals are weaned or trained for home ventilation at their local hospital, usually in the ICU because no other part of the hospital is equipped or staffed to accept individuals on a ventilator. Participants identified a number of issues regarding the challenges in delivering this type of care in an ICU:

- Weaning practices are usually inconsistent from physician to physician. As the physicians cycle through their shifts in the ICU, the weaning plan can change as often as daily.
- Because the ventilator-assisted individual is medically stable, other more acutely ill patients are necessarily given a higher priority, which greatly prolongs the home ventilation training process. One ICU patient reported that he had not been assessed by a physician for five months.

[34] West Park submitted a proposal to the ministry in November 2006 to increase capacity and to improve utilization through resource enhancement in its Home Ventilation Service. This is a four-bed program that has two beds allocated for assessment and training to prepare the individual, family and caregivers for reintegration into the community. The other two beds are used for reassessments to help divert these individuals from acute care. However, only one of the two training beds and one of the reassessment beds are budgeted to meet the needs of individuals requiring total care. Thus, in reality there is only one funded bed for new home ventilation training referrals that have these care requirements, typically the invasively ventilated individual from ICU.

[35] The need for five caregivers is for individuals that require access to onsite care 24 hours a day, seven days a week. Having five caregivers provides some buffer for replacement in case one caregiver is unavailable (e.g., needs a break, becomes ill). West Park has advised that this requirement could be reduced if community supports (e.g., respite) were increased.

- In general, ICU staff does not know what best practices are for ventilator-assisted individuals who are difficult to wean or for home ventilation training. It was suggested that the two centres of excellence should make this information widely available.
- ICU clinicians are often motivated by the challenges of treating critically ill patients and are most satisfied when clear and rapid progress is reported. The care plan has a much longer duration with weaning or home ventilation preparation, which can frustrate the staff.

Nine LHINs stated a need for some form of intermediate care unit, which would be unit of four to eight beds in an acute care setting that could provide any number of short-term care to these individuals once they are medically stable but either in transition or requiring other short-term care such as:

- Weaning.
- Home ventilation training.
- Reassessment.
- Respite.

Clinicians in several LHINs asked for protocols and best practice for these areas of care such as home ventilation and preparation for transfer from the ICU. Clinicians also suggested that a half-day session with representatives of the Progressive Weaning Centre would enable interested clinicians to learn about best practices for weaning. (See Appendix J.)

5.1.3 Lack of Community-based Living Options

> *"If I won the lottery, I would build supportive housing for these patients close to their home."*
>
> *"(Long-term institutional care) was not our vision for our child."*
>
> *"He was in no man's land. No one could take him."*
>
> *Parents of ventilator-assisted individuals*

In general, if the family is unable to care for the individual in the home, the individual cannot stay in the community. In some LHINs, ventilator-assisted individuals can live in the community in supportive housing and group homes, or in their own home with attendant outreach services, but these options are infrequently available in some LHINs and not available at all in other LHINs due to:

- The limited funding provided to these organizations.
- The challenge of finding appropriate housing for this population.

In addition, some attendant care agencies do not accept ventilator-assisted individuals because they are concerned about liability issues in the absence of well-articulated standards of care for this population. Some participants felt that if the centres of excellence could release provincial standards of care, such a document might help overcome these barriers.

Community-based care is also preferable from the health system's perspective because it is less costly than in-hospital care. The current annual funding for a CAVC bed is approximately $250,000,[36] compared to an average for supportive housing with attendant services estimated at between $50,000and $75,000.[37] Several providers of attendant services expressed interest in serving this population, or expanding existing services for this population, if the above challenges were addressed.

The lack of institutional options results in these individuals staying in an ICU or CAVC unit for an inappropriately long time. As noted earlier, approximately 22% of all ventilator-assisted individuals identified in the facility survey were deemed eligible for community-based living.

Ventilator-assisted individuals who are in a CAVC unit expressed regret at not being able to live in the community and the reduced quality of life associated with the loss of this option, including the loss of privacy, independence and personal belongings. Ventilator-assisted individuals who live in the community, either with attendant outreach or in supportive housing, reported a high level of satisfaction with this arrangement.

5.1.4 Support in the Community

> *"It's a nonstarter to try to go home based on the CCAC support…"*
>
> *Ventilator-assisted individual*

The four most commonly noted gaps in services for ventilator-assisted individuals living in the community (particularly at home) and their families were:

- The lack of respite for caregivers,
- Lack of respiratory therapy services in the community,
- General lack of supports for the family,
- Palliative and end-of-life care, and
- Care coordination.

Respite

Some CCACs reported that they can provide up to two eight-hour shifts a week for respite. Often, in-home respite is preferred for several reasons:

- It is usually difficult to move the individual and the ventilator equipment, so having someone come to the home for respite is much easier on the caregiver.
- Ventilator-assisted individuals often prefer to stay in their own home rather than to move temporarily (e.g., possibly even for one evening) to a strange place. When the

[36] Long-term Ventilation Strategy Development for Ontario. Review of Current annual costs for LTV Inpatient Care. Companion document to the LTV Action Plan Final Report. December 31, 2007.
[37] Long-term Ventilation Strategy Development for Ontario. Attendant Service Options for Ventilator-Assisted Individuals, Companion document to the LTV Action Plan Final Report. December 31, 2007 and estimates provided by focus group participants.

family is absent for a longer period (e.g., vacation or other need to travel), in-hospital care might be the preferred option.

A few LHINs offer or have offered limited respite services in a variety of settings (e.g., supportive housing, hospital acute or complex continuing care unit, long-term care home, ICU), but these services were not offered consistently within a LHIN or across the province. Sometimes this service was discontinued after an initial trial. Some hospitals were reluctant to take ventilator-assisted individuals for respite care because they feared that the family would "abandon" the individual in the hospital when the family could no longer cope.

Respiratory Therapy

> *"Exhausted families may miss signs and they (the ventilator-assisted individual) may end up in hospital."*
>
> *Community Care Provider*

Many families and clinicians believed that having access to respiratory therapy (RT) services while in the community (at home or in supportive housing) would be beneficial. A respiratory therapist would be able to monitor and maintain the equipment as well as identify and assess changes in the individual's condition. It was suggested that the therapist should visit at least once a month for optimal care.

Several options were suggested regarding how to deliver this service in the community:

- The North Simcoe Muskoka Community Care Access Centre has an arrangement with the Royal Victoria Hospital whereby the CCAC contracts with the hospital to provide hospital therapists to make home visits to ventilator-assisted individuals. Although the CCAC is not specifically funded to provide this service, its board has continued to set aside funds for this service. (See Appendix H.)
- Home oxygen companies already send respiratory therapists on home visits to individuals requiring oxygen. However, these individuals cannot currently provide this type of care because they are not remunerated to provide it, nor do they have liability insurance for this type of work. However, this is an already mobile group that could play a role in this area. One LHIN had established a joint venture between a tertiary care hospital and a home oxygen supplier to provide this service. (See Appendix H.)

Participants related a story about a ventilator-assisted individual who was only able to successfully move into supportive housing because the respiratory therapist at the hospital agreed to make periodic home visits after discharge. This therapist makes these visits on his own time, and at his own expense, which includes purchasing liability insurance since this care is not covered hospital's insurance.

On a broader scale that would also address the need for periodic assessment by a primary care practitioner, it was suggested that each LHIN or region develop a core team of clinicians (e.g., respiratory therapist, registered nurse, primary care practitioner, specialist physician) that would be available for a variety of services for this population, including home visits when required. One LHIN already has a program in which a respiratory therapist and an advance practice nurse make home visits to periodically assess vented

individuals. These families expressed a high level of satisfaction with this service. (See Appendix H.)

Other hospitals had informal outreach services on an as needed basis. In each case, this service was credited with helping the individuals to thrive in the community and was believed to have contributed to reduced emergency department visits and ICU admissions.

In one LHIN, it was suggested that the respiratory therapists' scope of practice be expanded to allow RTs to make some adjustments to ventilator levels without a physician's order.

Support to Families in the Community

> *"…all the advice at the hospital was: you're thinking about it, but don't do it…"*
>
> *Parent of ventilator-assisted individual*

Clinicians and families reported that the number of hours available for in-home care was inadequate:

- The CCAC provides staff for tracheostomy and other nursing care, in-home respite, and personal care. However, the number of hours allowed per individual is inadequate to meet the needs of this population. These limits were established at a time when individuals with such complex needs were rarely discharged from hospital.
- Attendant care outreach services can also be provided in the community. However, attendant care organizations are also subject to limits on the number of care hours and may not have the funding necessary to deliver adequate care for such high needs.
- Many ventilator-assisted individuals and their families expressed a desire for direct funding. Those individuals who are on the Direct Funding Program express a high level of satisfaction with not having to rely on agencies to meet their attendant care needs. Unfortunately, the wait list to qualify for direct funding is so long that this option is not a practical option for most families.

Families also noted that they do not have access to other services that would be helpful:

- Counselling, including time with a social worker. Although this service is available, most families reported that a social worker was not made available to them or that, if assigned to a social worker, there were very limited services provided.
- Physiotherapy. CCACs can provide in-home physiotherapy services, which would benefit some ventilator-assisted individuals. Only one user reported having access to chest physiotherapy on an ongoing basis to prevent infections. This service was only provided because of the continued advocacy of the individual's spouse.
- Ongoing follow up (e.g., reassessment). In larger communities, the respirologist at the tertiary centre often provides periodic (e.g., semi-annual or annual) follow up for ventilator-assisted individuals. In smaller and remote (e.g., northern) communities, this service is seldom available.
- Peer support network. Many families believed that a peer support network would be beneficial, especially during the transition from one care setting to another. This type of support is available in some locations through patient advocacy groups.

- Twenty-four hour telephone support from specialized, knowledgeable staff. The Ventilator Equipment Pool provides a 24-hour hotline for support on topics related to the ventilation equipment. Families and clinicians felt it would be useful to have access to a similar service for questions that are not specific to the equipment.

Many families found the financial burden to be excessive. The types of expenses included:

- The opportunity cost of the family member not working any longer so that he or she could care for the ventilator-assisted individual. Family members are not reimbursed for the time they spend caring for another family member. Many families felt they should be paid for providing this care.
- The cost of a back up battery.
- The cost of ventilator supplies. These costs are covered if the individual is on the Ontario Disability Support Program (ODSP) or receiving nursing services from CCAC, but otherwise are an additional expense to the family.

5.1.5 Palliative and End-of-life Care

These individuals should all have access to palliative care that would include two main elements:

- For individuals identified as being at risk of invasive ventilation (see Section 5.1.1), a care plan and an advance care plan should be created and revised on a regular basis.
- For ventilator-assisted individuals who have decided that they no longer want to live with a ventilator, they should have the services and supports needed to receive end-of-life care when, how and where they desire it.

Most LHINs have an established an End-of-Life Care Network with an initial mandate to meet the needs of cancer patients. Some participants felt that these networks could be very helpful for the LTV population if the mandate of these networks were expanded accordingly (with appropriate resources). However, other participants felt that the existing end-of-life services would not be well suited to the unique needs of the LTV population.

In some LHINs, palliative care units will not accept ventilated patients, even if they have chosen to discontinue ventilation. Therefore, their only choice is to return to an ICU to die.

5.1.6 Care Coordination

> *"You shouldn't get discouraged when you are turned down. Home and vehicle renovations are never approved the first time around…."*
>
> *"You need a full-time advocate and you can't possibly know all the loops and hoops and there must be people so lost in the system."*
>
> *"I feel as if I am on a treadmill trying to deal with all the agencies in the system."*
>
> *Ventilator-assisted individuals*

During many of the focus groups, particularly with ventilator-assisted individuals and their families, the participants spent some of the time exchanging information about services that

were available in the local community. This lead to a request for an inventory of services, including descriptive information regarding the service and contact information, that would be made widely available to all stakeholders.

Similarly, during some of the provider focus groups, some of the hospital-based providers were unaware of what options and support services were available for community living. During several provider sessions, the idea of an inventory of local, regional and provincial services was raised as a needed service.

The LTV information system was originally designed to hold this type of information. These sessions have confirmed the need for such a registry of services.

Many participants also pointed to the need for a system navigator to help these families identify what services are available and to help them acquire these services. The value of this role could be, for example, to help the individuals and families apply for services. Some participants noted that they have figured out successful strategies when applying for services, which can include persistence.

5.2 Training for Community-based Caregivers

> *"Sometimes the CCAC case manager calls me and says: who should I call to train the nurses?"*
>
> *Parent of a ventilator-assisted individual*

5.2.1 Nursing and Attendants

Many clinicians and families raised the issue of needing to train community-based care providers in the care of a ventilator-assisted individual. Two levels of training are required:

- A general introduction to long-term ventilation and care of the ventilated individual, and
- Care needs specific to the condition of the ventilator-assisted individual.

Training is needed when the care provider first begins to work with the ventilator-assisted individual, and frequent refresher training should also be available. Both the availability and cost of this training were raised as issues. This training should include alternative communication strategies if the individual is non-verbal.

In some cases, the nursing agency will provide some training on long-term ventilation care needs for its nurses, and attendant care services will provide similar training for its personal support workers. However, in many cases, the individual or family reported having to provide both levels of training.

Turnover is often high among community-based care providers (see Section 6.1.1), resulting in a frequent and ongoing need for this training, which is a significant burden on the family and the care agencies.

It was suggested that tertiary centres that provide care for the LTV population should be funded to provide this training. It was also suggested that representatives from the

paediatric academic health sciences centres should be invited to participate in the development of any educational materials.

Some of the larger LTV centres currently provide training for community-based providers. For example, West Park reported holding 16 off-site training sessions for community and institutional providers in 2007/08. West Park also provides on-site care (e.g., support for tracheostomy care and assessment for decannulation) at one Toronto area hospital and is in discussions with two other hospitals to arrange education sessions.

5.2.2 Medical Care

Due to the small number of ventilator-assisted individuals in Ontario, it is often difficult for physicians to be aware of current best practices and options for care for this population. One individual reported that he had been invasively ventilated for eight years before he learned that non-invasive ventilation was an option (which he successfully pursued). Other individuals spoke of a general lack of awareness of non-invasive technologies among physicians and inconsistent care plans from one physician to another.

The needs of the population are so complex and technologies are changing so quickly that even respirologists who work infrequently with these individuals might not be aware of best practice.

The health care system should train more physicians in the care of these individuals or ensure that physicians seek advice from appropriately experienced respirologists when caring for a ventilator-assisted or at-risk individual.

5.3 System Gaps

Several gaps were identified that were not specific to the delivery of care and services, but were important at a system level to plan or enable the planning and delivery of care for this population.

5.3.1 Information Needs

As noted earlier, there is a need for a registry of services available to this population, including a description of the service and contact information.

There is also a need for a provincial information system with a minimum data set of information about individuals who are at risk of becoming invasively ventilated and those who are ventilator-assisted. This system should include an electronic medical record that provides real time and up-to-date information on the ventilator-assisted individuals for the planning and delivery of care, particularly in an emergent or urgent situation. It was suggested that a medic alert bracelet might be a viable option for this population.

An important first step in developing such a registry is to develop meaningful, useful and specific definitions of the LTV population to facilitate future survey efforts and to ensure that all LHINs are consistent in defining this population and in assessing the resources needed to deliver quality and timely care. Participants identified four issues regarding definitions for this population:

- There was confusion over the definition of an at-risk individual. An at-risk individual is someone with a degenerative disease that will inevitably lead to respiratory failure. Although the official definition (based on the Chronic Ventilation Strategy Task Group

report) was someone at risk of **mechanical** ventilation, the term was often used in discussions to refer to individuals who we at risk of **invasive** ventilation.

- There was also confusion over whether an individual who had been on a ventilator for longer then 21 days but was an excellent candidate for weaning was considered part of this population. This was particularly troublesome for people completing the ICU survey as they did not feel that these weanable individuals were part of the LTV population.
- Similarly, there was confusion over whether individuals on continuous positive airway pressure (CPAP) should be included in the definition of ventilator-assisted. Although they were included in the definition for the purpose of this survey, many respondents reported that they did not include this population in their survey responses.
- The definition of medically stable might vary according to the care setting. For example, an individual might be considered medically stable by an intensive care unit and, therefore, ready for discharge to an alternative level of care, but still have a higher level of acuity than can be safely managed in a complex continuing care unit or in the community.

5.3.2 Planning Needs

The information system described above would provide a basis for developing demand projections for future services to support regional capacity planning. Several LHINs expressed concern that this population was believed to be growing rapidly, based on the number of at risk individuals in the population (e.g., known numbers of diagnosed cases of ALS where the individual is not yet ventilated or is non-invasively ventilated.

Many LHINs were concerned about the expected growth of the population and the associated impact on the number of transitions, and the need for services (e.g., community-based living options, CAVC beds, respite). Representatives from paediatric academic health science centres were particularly concerned about recent growth rates in the paediatric LTV population.

One LHIN suggested that it would be very useful to have a template for developing a needs assessment (based on a forecast of regional demand) and regional capacity plan for its LTV population. The value of a template would be to ensure that all of the LHINs were being consistent in their assessment and would provide support to those LHINs that chose to use it for this purpose. This template could be expanded to include support for the development of a Health Services Improvement Pre-proposal (H-SIP) or business case for submission to the LHIN.

It was also noted that it would be useful to have a comprehensive care map to show the patient flow through the continuum of care at the LHIN level to assist in regional capacity planning. Such a map could also be used to identify points on the continuum where education and training are needed.

5.3.3 Managing Expectations

The need to manage the family's expectations was raised in several LHINs, particularly relating to access to ICU beds. Clinicians felt that the critical care team was obliged to offer a tracheostomy to a person with respiratory failure, even if that course of action was not necessarily appropriate. Emergency room and ICU clinicians often try to save a life at all costs, without considering that this might not be the most appropriate action. Similarly,

families, once given the choice of a having a tracheostomy, will seldom say no to the effort required to save their loved one's life. There is a need to educate clinicians on their obligations and to provide them with an ethical framework to understand their options in these situations. As well, clinicians need to communicate well with families to explain what is appropriate, and to manage the family's expectations around the patient's care. (See Section 5.1.5 on end-of-life planning).

The second major issue around managing expectations related to the desires of the patient to remain in an ICU bed when an alternative setting has been offered. Sometimes, the alternative setting is not desirable from the family's perspective because it is too far from the family home. It may also be too far from the patient's cultural, spiritual or ethnic community that is very important to the patient. Families have come to expect that they have the right to stay in an ICU, despite the potentially devastating impact on the hospital's ability to meet the critical care needs of the surrounding community. Clinicians and hospital administrators need direction on how to manage these situations.

5.4 Needs of the Paediatric Population

Many of the focus groups had representatives from LTV services for paediatric patients or parents of ventilator-assisted children and youth.

In one LHIN, there was no ICU that would accept a child or youth on a ventilator. In the event of a medical emergency, the family had to bring the child to The Hospital for Sick Children in Toronto. In a similar circumstance in another LHIN, the child would be taken by Criticall anywhere in the province.

Several other gaps were identified that are also gaps for adults, but were thought to be more of an issue for children and youth than for adults:

- Institutional care is seldom the first choice for a child with a chronic medical condition. Indeed, a CCC unit is not a pleasant environment for a child or youth who is surrounded by geriatric patients. Parents are typically very motivated to keep their child at home, often at great personal and financial sacrifice. These families are asking for more support in coping with the personal and financial burden of caring for their children.
- Many families felt that direct funding would be a better option for them than CCAC or attendant outreach services, particularly for the transition period from paediatric to adult care.
- In addition to the medical needs of this population, there is need to address the educational, social and recreational needs of these individuals.
- Similarly, children tend to lead more active lives than adults, increasing the need for a portable ventilator, a piece of equipment currently not covered by the Assisted Devices Program.
- One element of the training of caregivers in the home should be on how to work within a family. It is stressful to have a ventilator-assisted child or youth in the family; bringing non-family caregivers into the home adds additional stress. These caregivers need to be trained to recognize that they are "strangers in the home" and to be sensitive to this dynamic when providing care to this population.

Challenges that are unique to the paediatric population include the following:

- The transition from paediatric care to adult care is often difficult. The number of services available is reduced, and the individual is faced with having to educate an entirely new care team. There is currently no process or service in place to assist families in this transition.
- Children with disabilities are eligible for services from several ministries (e.g., Ministry of Health and Long-Term Care, Ministry of Children and Youth Services, Ministry of Community and Social Services). The myriad of programs and services, each with different eligibility and funding policies, makes it difficult to navigate through the system. It was suggested that a care coordinator role would be very helpful for this population.

5.5 Summary of Reported Gaps

The primary gaps in care and services for the LTV population as identified by the focus group participants are shown in Table 8. The table shows which LHINs identified each issue as a priority.

As shown in the table, the most frequently identified issues are:

- The lack of community supports for ventilator-assisted individuals and their families and caregivers, which was identified in all 14 LHINs as an issue, including respite (13 of 14 LHINs), support for families (12) and in-home respiratory therapy (11).
- Education for at risk individuals, a priority in 13 LHINs.
- The need for training of nurses and attendants, identified in 13 of the 14 LHINs as an issue.
- More options for community living (e.g., supportive housing, group homes, enhanced supports for in-home care) in 12 LHINs.
- Regional planning (11 LHINs) and intermediate care (9 LHINs).

Table 8: Summary of Reported Gaps in Service and Education

	LHIN														
	C	**CE**	**CW**	**CH**	**ESC**	**HNHB**	**MH**	**NE**	**NSM**	**NW**	**SE**	**SW**	**TC**	**WW**	**Total**
Gaps in the continuum															
Education for at-risk individuals	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	13
Intermediate care including home ventilation training		✓	✓			✓	✓		✓		✓	✓	✓	✓	9
Options for community living	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓	12
Support in the community															
Respite	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	13
Respiratory therapy	✓	✓	✓	✓	✓	✓	✓			✓		✓	✓	✓	11
Support for families	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	12
Palliative and end-of-life care	✓		✓		✓	✓						✓	✓		6
Care coordination	✓			✓		✓					✓		✓		5
Training gaps															
Nurses and attendants	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	13
Physicians	✓			✓			✓		✓	✓		✓	✓		7
System Gaps															
Information management system					✓					✓		✓		✓	4
Planning for care		✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	11
Managing expectations	✓			✓	✓								✓		4
Paediatric needs				✓	✓	✓		✓	✓	✓		✓	✓		8

LHIN = Local Health Integration Network
C = Central CE = Central East CW = Central West CH = Champlain ESC = Erie St. Clair
HNHB = Hamilton Niagara Haldimand Brant MH = Mississauga Halton NE = North East NSM = North Simcoe Muskoka
NW = North West SW = South West TC = Toronto Central WW = Waterloo Wellington

6.0 Focus Group Findings: Barriers to Access to Care

The previous chapter documents comments from focus group participants about gaps in the delivery of care for the LTV population. This chapter presents the comments made regarding barriers to services that already exist.

As in the previous chapter, these issues are organized around common themes and do not necessarily reflect the priorities assigned to these issues by the participants.

6.1 Capacity Issues

Two major barriers to access to care for these individuals are the shortage of community-based providers and the lack of capacity for long-term inpatient care.

6.1.1 Shortage of Community-based Providers

Most LHINs were concerned about the overall nursing shortage and the shortage of primary health care practitioners in their region. This shortage is more pronounced in the community as nurses and personal support workers (PSWs) earn higher wages and benefits in institutions. Most LHINs noted the need for a health human resources strategy to address these shortages.

Nurses and Attendants

Participants in most LHINs reported an overall shortage of nurses and attendant care workers in the community and an even more acute shortage of these care providers with the skill to work with ventilator-assisted individuals. Some participants noted that although a family qualified for the full allowable hours from the CCAC, they received far less because there were no nurses available to fill the approved shifts.

In addition to the overall shortage (particularly for nurses), there are barriers to attracting and retaining these care providers to work with the LTV population:

- The care of this population is intimidating for many nurses, especially if they have no ICU experience. They are required to work relatively independently with individuals with complex needs. Some providers are concerned about potential liability for the care they provide.
- Once novice nurses and personal support workers have gained experience in the community, they are sometimes drawn to the higher wages and benefits in an institutional setting. This contributes to high turnover, which has implications for continuity of care and the need for initial and ongoing training of these care providers to work with this population.

CCAC Policy

There is great discrepancy in the community regarding persons authorized to care for ventilated patients, specifically in the area of tracheostomy suctioning. For example, the CCAC only allows nurses to perform suctioning. In contrast, attendant service providers allow attendants (unregulated health care providers) to perform these activities, as well as changing tracheostomy tubes and similar tasks. Likewise, ventilator-assisted individuals report that they train family members, their children, the neighbours' children and, in one case, even a janitor when necessary.

Suctioning a person beyond the larynx is a controlled act, according to the Regulated Health Professions Act[38]. However, since the act of suctioning is considered an "act of daily living", this exempts those persons who are not authorized as a member of a regulated profession (e.g. attendants) to perform this act.

> *"We gotta get over this thing that it's in the regulations…we're talking about specific needs here… and less trained people can do it."*
>
> *Ventilator-assisted individual*

Although the CCAC provides both nursing and attendant care services, it has an internal policy that restricts suctioning to registered nurses. This policy was raised in almost every LHIN as a barrier to access to service, especially in light of the current nursing shortage. It was suggested by many that the CCAC revisit its policy in the context of the abovementioned exemption.

There might be an opportunity for the two-year registered practical nurse (RPN) graduate to fill this void.

Attendants

In some LHINs, attendant care providers will not provide services to ventilator-assisted individuals. These providers prohibit their staff from performing controlled acts, even though these acts are exempted in the case of ventilator-assisted individuals.

Family Physicians

Several LHINs noted the shortage of family physicians as a significant barrier to providing adequate care in the community. In some cases, this shortage was attributed to a general shortage of primary care practitioners in the community. In other cases, this shortage was exacerbated by the reluctance of family physicians at take these individuals as patients.

6.1.2 Inadequate Inpatient Capacity

Once admitted to the ICU, if there are no available options for transfer to the community (which is often the case), LTV patients often remain in the ICU because there are no other options in the hospital. Acute and complex continuing care units are reluctant to accept these individuals for several reasons:

- The Ventilator Equipment Pool does not provide ventilators to a hospital. Before a unit can accept a ventilator-assisted individual, it would need to purchase a ventilator. A solution would be for the ventilator to follow the patient regardless of setting, similar to the model used for assistive mobility devices.

[38] Controlled acts are activities that are considered to be potentially harmful if performed by unqualified persons, and, therefore, must be performed only by those regulated health professionals deemed appropriate by the Regulated Health Professionals Act (RHPA). Delegation (i.e., the transfer of authority to a person not otherwise authorized to perform a controlled act) of controlled acts such as suctioning below the larynx can be given to those individuals who do not belong to one of the regulated health professions. However, the RHPA provides several exceptions that allow persons who are not authorized as members of a regulated profession to perform controlled acts. One such exception is "when assisting a person with his/her routine activities of living".

- In addition to the ventilator and related supplies, the hospital also needs specialized beds and mobility aids for these individuals. When the hospital cannot afford these investments, the individual cannot be admitted.
- The hospital staff outside of the ICU typically do not have training in the care of a ventilator-assisted individual. The availability and cost of training is often a barrier to accepting these individuals.
- Many clinicians and hospital administrators are reluctant to provide care for these individuals because of the perceived risks and associated liability (similar to the concerns expressed by the attendant care organizations and nursing agencies).
- In some cases, there is no physician to accept responsibility for the care of these individuals.
- Without additional funding, it is not cost effective for the hospital to retain the additional staffing (e.g., respiratory therapist) to meet the needs of this population.
- Other related services (e.g., blood gas laboratory) are also not readily available.

Only six hospitals in Ontario receive incremental funding to care for these individuals in an acute or complex continuing care setting (See Section 3.3.5). Participants mentioned at least six individual hospitals or long-term care homes that had accepted ventilator-assisted individuals at one time but no longer do so, primarily for financial reasons.

Because of these barriers, individuals who require a CCC or CAVC placement are often forced to move hundreds of miles from home. In addition to the isolation from their community, this distance limits the ability for family and friends to visit frequently and places a financial burden on families. One family reported spending $500 a month on gas alone. The same family was frustrated when new CCC beds opened in the local community, but none were made available to ventilator-assisted individuals.

6.1.3 Capacity to Deliver Culturally Sensitive Care

In several LHINs, the concept of culturally sensitive care was raised in two ways:

- There is a need for care planning to respect the cultural, spiritual and religious needs of the ventilator-assisted individual and the families. Proposing a care option that is contrary to the family's spiritual beliefs will erode the family's trust in the provider.
- There is also a need to provide care in the language of the ventilator-assisted individual. This was raised as an issue specifically for Aboriginals and francophones. One ventilator-assisted individual in the community also expressed concern about the inability to communicate with attendants because their English languages skills were so poor.

Providers noted that is generally easier to provide culturally sensitive care close to the individual's home rather than in a large tertiary centre some distance away. One recent example of building this capacity in the community is in the Hamilton Niagara Haldimand Brant LHIN where an attendant services provider is providing care in French to its francophone clients.

6.2 Access to Equipment and Supplies

The Assistive Devices Program (ADP) must approve all requests for equipment before a ventilator can be delivered to the individual. Participants identified the following barriers to accessing the desired equipment and supplies:

- The ADP will only authorize a new ventilator every five years. Many ventilator-assisted individuals have a degenerative disease; therefore, their condition is not stable and they may have new equipment needs well before the five year renewal period has expired.
- Standby batteries are not funded through the ADP, which means that the family must purchase the battery with its own resources. These batteries are expensive and have a relatively short life span.
- Some ventilator models are not funded. Accordingly, patients have with ventilators that are very heavy and not easily moved, which limits their mobility and quality of life.
- Cough assist devices, considered to be crucial to maintaining respiratory health for invasively-ventilated individuals (and thereby avoiding unnecessary emergency room visits and ICU admissions) are not funded.
- The ADP does not fund supplies for the ventilator. Supplies are sometimes covered through other sources (e.g., ODSP, CCAC).

The ADP only funds equipment that will be used in the home. Clinicians strongly urged the ADP to reconsider this policy and to allow funding to follow the ventilator-assisted individual, regardless of the care setting. This would encourage hospitals to accept ventilator-assisted individuals outside of the ICU. (See Section 6.1.2 on inpatient capacity.)

In addition to challenges in securing the desired ventilator, participants experienced challenges in getting timely access to authorized equipment:

- Some hospitals reported that it takes four to six weeks and sometimes longer for a ventilator request to be approved. Participants felt that the ADP needs to accelerate its approval process for ventilator equipment.
- Discharge to the community is often delayed by waiting for approval of home ventilation equipment, which will only be approved when a discharge date has been set. Training for discharge cannot be completed until the ventilator arrives because the hospital ventilator is different than the home ventilator, and the hospital staff never know what ventilator model will be shipped from the Ventilator Equipment Pool (VEP).
- The ADP does not accept orders for equipment from out-of-province physicians. In the North West LHIN, this has resulted in delays in discharge from the ICU while waiting for equipment.

The Ventilator Equipment Pool (VEP) does not provide an on-site respiratory therapy visit for initial training on the ventilator for invasively ventilated patients. The VEP expects that invasively ventilated individuals will receive adequate training prior to leaving the hospital, which is not always the case.

6.3 Transition Challenges

6.3.1 Institutional Barriers

Although these individuals are medically stable, their condition will deteriorate over time, and there will be periodic episodes when they require hospital care. For example, ventilator-assisted individuals are particularly susceptible to pneumonia, which can be extremely dangerous for this population. Avoiding an ICU admission for this type of problem is preferred, and believed to be possible to some degree with quality care and monitoring in the home. However, not all acute admissions can be avoided.

Several participants spoke of the challenges in overcoming institutional barriers to the transition from one setting to another (e.g., from the ICU to CAVC or home, from CAVC or home to the ICU, or from the CAVC to home and back).

> *"You land up playing ping pong with these patients…"*
>
> *Institutional care provider*

In one LHIN, care providers have developed an agreement between the ICU and the CAVC to recognize this periodic need for more acute care. Both organizations have agreed to accept the individual without delay if that setting is deemed most appropriate. ICU staff are no longer reluctant to accept an individual because they know the CAVC will accept the transfer when appropriate. Conversely, CAVC clinicians willingly accept these individuals knowing that the ICU will readmit them if their condition deteriorates.

6.3.2 Fear of Transition

Clinicians and families spoke of their fear of the transition full circle in the continuum of care. When an individual is in an ICU for longer than a certain period (e.g., six to 12 months), the individual and the family become accustomed to the level of care and monitoring in the ICU and are reluctant to leave this "safe" environment. The transition to home, or even to another hospital setting with a lower level of care, can be frightening. A similar reluctance to move was expressed by individuals in non-ICU hospital settings regarding the transition to home.

This "fear of transition" continues when the individual is in the community. Several ventilator-assisted individuals expressed fear of going to an emergency department because they did not have confidence that the emergency physician would be familiar enough with their condition to treat them effectively. One individual refuses to go to the emergency department unless he is accompanied by his personal support worker, whom he trusts far more than an emergency room physician.

One element that drives this fear is that individuals in transition do not always have good information on the new setting or any supports that are available for the transition or in the new setting.

Six solutions were suggested to deal with these concerns and fear:

- Transfers from the ICU or other hospital setting should be timely so that the individual does not have time to develop dependence on the current level of care being provided. Participants noted that once an individual has been in the ICU for

too long, the individual and the family must be “de-ICU-itized” before they will agree to the discharge.

- Graduated discharges (e.g., overnight and weekend stays) could be arranged, if a ventilator were available to the ventilator-assisted individual to take home.
- Appropriate training and education is needed at each transition point to ensure that the individual and family are informed about and comfortable with the next level of care.
- Where possible, the families should be referred to a peer support network to help them through the transition.
- If emergency department staff had timely access to medical information specific to the individual’s condition, this might help to alleviate this fear.
- Care and service providers should have access to an electronic inventory of programs and services available to ventilator-assisted individuals and their families. Such access would be provided by the LTV information system once it is implemented.

6.3.3 Financial Barriers

One issue was raised regarding the financial impact on the families of a transfer between settings. When an individual is in an ICU, there is no out-of-pocket cost to the family. However, if the individual is transferred to an alternative inpatient setting, a monthly copayment will apply.

If an inpatient is receiving payments from the Ontario Disability Support Program (ODSP), the individual will only receive a nominal allowance to cover out-of-pocket expenses such as television rental and other incidentals.

6.4 Sustainability of Services

Some of the services that are provided or have been provided were funded from the hospital’s global budget, without dedicated funding for the service. In some cases, these services were discontinued because of financial pressures. In other cases, the services continue, but are constantly at risk of review as the fiscal environment continues to be challenging at all hospitals. Even if dedicated funding is provided for beds, these beds must also be protected so that they are not used for other patients when they are temporarily underutilized as the census of ventilator-assisted individuals fluctuates.

Many of the programs and services were developed based on the extraordinary effort of individuals who made it their business to advocate for the population and to make the system work for these individuals through sheer determination. This statement applies to clinicians, administrators and patient advocacy groups who start and often sustain these services as well as family members who make every sacrifice to keep their loved ones at home. These “unpaid heroes” have personally accepted the burden of care, sometimes at great cost.

There was broad discontent among clinicians and families that the health care system could continue to download health care costs to the families and not provide financial assistance to hospitals that direct funds from their global budget to meet the needs of this population.

"It's not right to sustain these services on patchwork, bandaids and volunteerism."

Institutional care provider

Without permanent, dedicated funding, these services cannot be sustained indefinitely. Similarly, as service gaps and barriers to access are addressed, the funding for these new programs and services must also be adequate and sustainable.

6.5 Summary of Access Issues

The primary gaps in access to care and services for the LTV population as identified by the focus group participants is shown in Table 9. The table shows which LHINs identified each issue as a priority.

As shown in the table, the most frequently identified issues are:

- The sustainability of existing programs that are funded through global budgets and appropriate funding of proposed programs and services that have not yet been approved (all 14 LHINs).
- The need for additional inpatient capacity (ideally close to home) for ventilator-assisted individuals, especially in the absence of more appropriate and more widely available options for community living (13 LHINs)
- Improved access to ventilator equipment and supplies through the assistive devices program (ADP) (13 LHINs)
- Institutional, personal and financial barriers to timely and effective transitions from one care setting to another (12 LHINs).
- The challenges of serving this population in the community in light of the shortage of nurses in the community (10 LHINs) and the CCAC policy of using only nurses for certain elements of the individual's care (9 LHINs).

Table 9: Summary of Reported Barriers to Access to Services

	LHIN														
	C	**CE**	**CW**	**CH**	**ESC**	**HNHB**	**MH**	**NE**	**NSM**	**NW**	**SE**	**SW**	**TC**	**WW**	**Total**
Capacity issues															
Community-based providers															
Nurses	✓	✓	✓	✓		✓	✓		✓	✓	✓			✓	10
CCAC policy	✓		✓	✓	✓	✓	✓		✓		✓		✓		9
Primary care practitioners	✓			✓						✓	✓	✓		✓	6
Inpatient capacity	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	13
Access to equipment & supplies	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
Transition challenges	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	12
Sustainability of services	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	14

LHIN = Local Health Integration Network
C = Central CE = Central East CW = Central West CH = Champlain ESC = Erie St. Clair
HNHB = Hamilton Niagara Haldimand Brant MH = Mississauga Halton NE = North East NSM = North Simcoe Muskoka
NW = North West SW = South West TC = Toronto Central WW = Waterloo Wellington

7.0 Observations

The previous two chapters presented the issues and priorities raised by the participants in the focus groups and telephone interviews with ventilator-assisted individuals and their families. Based on the consolidated summaries from all of the LHINs, the facilitators observed similarities among the discussions that were not necessarily clearly articulated as issues.

This chapter presents the facilitators' observations. All of these observations were supported by comments during at least one of the focus groups, but were not broadly discussed. They are included in this report because of their importance in understanding the challenges of delivering care for this population.

7.1 Challenges for Planning and Service Delivery

Understanding the issues is not sufficient to develop an improved approach to service delivery for these individuals and their families. The following characteristics of this population drive the need for tailored solutions.

7.1.1 Heterogeneous Population

The LTV population is not a homogenous group. Their individual circumstances vary according to the nature of the underlying condition:

- Some patients have chronic and degenerative conditions, which result in periods of relative stability, interspersed with periods of acute care needs. In contrast, individuals with an acquired spinal cord injury are typically more stable, with different needs for care. This second group has greater potential for weaning, whereas advanced stage ALS, for example, provides little expectation of weaning.
- These individuals all have a common need for mechanical ventilation. However, the ventilation needs are not always the most difficult to manage. Due to the degenerative nature of some of the underlying conditions, many of these individuals also have physical disabilities that increase their care needs.
- The needs of those ventilator-assisted individuals suffering from a degenerative disease are not stable. As the disease progresses, their needs increase. Consequently, frequent monitoring is needed, and flexibility to adjust supporting services to their fluctuating needs is required.
- Some patients can direct their own care; others (e.g., patients with dementia, Alzheimer's or severe brain injury) cannot. The options for care settings are reduced for this latter population.

Just as ventilator-assisted individuals have unique physical conditions, they also have unique family situations. Every family is different and has different preferences, which has implications for determining the most appropriate setting and the level and nature of services provided. Some individuals prefer to stay in the family home, whereas others prefer the greater independence offered in supportive housing. Unfortunately, with the limited options for community living, the health care system is not always able to respect these needs and preferences.

There is no single solution to delivering care for this population. This diversity complicates the planning and delivery of care, which should be tailored to the individual's personal circumstances and changed over time as needs and preferences change.

It will be important for any future planning exercise to develop clear definitions of the LTV population and, through this exercise, to recognize the various subpopulations (e.g., potential for weaning or likely to need long-term ventilation) that have different care needs. This work should include explicit definitions for the following terms:

- Medically stable, which might vary depending on the care setting (e.g., an individual deemed medically stable in an ICU might not be considered medically stable in a supportive housing environment).
- At-risk population, to aid in identifying this population.

7.1.2 Lack of Critical Mass

The number of ventilator-assisted individuals in Ontario is relatively small and spread out across the entire province. Because of the very complex needs of these individuals, they require highly specialized resources, which are typically only available at tertiary centres. Therefore, although small in number, the burden of care for this population, both for caregivers and the health care system, is great.

This lack of critical mass drives the need to centralize at least some of the services for this population. Unfortunately, many families prefer to have services closer to home and have refused treatment that is offered far from their home (e.g., West Park's Home Ventilation Training and Rehabilitation Program). Participants suggested that this specialized expertise at the centres of excellence should be shared as broadly as possible through site visits, documented standards of care and protocols, web-based resources (e.g., web sites with education or best practice documentation and e-learning modules) and telemedicine to the degree required to reach remote populations (both clinicians and families).

During periods of relative stability (e.g., when the individual is in the community), the care needs are still complex but do not require the high degree of specialization available in a tertiary centre. However, there is some specialized training needed (see discussion on training needs in Section 0). The need to find, train and maintain a team of care providers to work with this population is especially challenging because the census can fluctuate dramatically within a short period of time.

7.1.3 High Resource Consumption

Although there are relatively few ventilator-assisted individuals in Ontario, they have intense needs during acute events, and often remain relatively high need for the duration of the disease, compared to other individuals requiring continuing care. Most often, these individuals have chronic and degenerative diseases; it is unlikely that their care needs will ever decline and most likely that they will increase gradually over time.

The policies and supports that have been developed for community-based care were developed for a far less medically complex population. Historically, these individuals did not live in the community, so there was no requirement for high levels of community-based care. However, over the past decade or two, ventilator-assisted individuals are becoming more vocal about their preference to reside in the community rather than in an institution. This is putting pressure on the existing policies and programs, such as the number of hours of care

that can be provided by a CCAC and the funding allocations to attendant services and the Direct Funding Program.

Participants expressed a desire for policies (e.g., for equipment and supplies and hours of care) to be more flexible to accommodate the high needs of this population.

7.2 Inequitable Access to Care and Services Across Ontario

The description of care and services available varied significantly from LHIN to LHIN. As this population has grown, individual care providers and organizations have developed one-off programs and services to meet these needs, resulting in inequitable access to services across the province. For example:

- At-risk individuals are travelling from many parts of the province to participate in a clinic designed to meet their needs. This service, which is funded through the global budget, is not available in many parts of the province.
- Attendant service providers in some LHINs do not accept ventilator-assisted individuals, whereas this option for care is well developed and successful in other LHINs.
- In-home respiratory therapy services are only offered by one CCAC in the province. Some LHINs have developed innovative programs to deliver this care (usually through a hospital-based outreach program) (see Appendix H), but this service is not consistently available across the province.

In addition, participants reported different interpretations of regulations and policies that contributed to confusion about what supports were actually available and how to access these services.

Limited funding for some support services (e.g., direct funding and attendant care) has created an environment where waiting lists for these services is prohibitively long, resulting in inequitable access to these supports.

8.0 Summary Priorities

Although all of the gaps and barriers identified by the participants were identified as priorities for action and investment, there was general consensus on several high level themes as being the most pressing needs for all LHINs.

The reader should also note that many participants expressed concern that a piecemeal solution would not solve these problems. A system solution is needed that addresses the bottlenecks across the entire continuum of care for this population.

As noted earlier, these priorities represent the opinions of the survey respondents, participants in the focus groups and telephone interviews. They are not intended to be the opinion of the ministry or its representatives.

8.1 Priorities for Care and Services

Five major priorities for the delivery of care and services for ventilator-assisted individuals were identified by providers, ventilator-assisted individuals and their families and caregivers.

1. **Increase the capacity for and choice of community living.** Twenty-two percent of ventilator-assisted individuals in hospital were deemed eligible for community living. The lack of available and appropriate care settings in the community to accept ventilator-assisted individuals is a major barrier to timely discharge from hospital and contributes to reduced quality of life for these individuals. The preferred options for community living are:
    a. Supportive housing with attendant services (which gives the individual the highest degree of independence), or
    b. In-home with sufficient supports to allow the individual to live with family. These supports include additional in-home care (e.g., access to respiratory therapy, primary care, increased nursing or PSW hours) and potentially financial support (e.g., remuneration for care provided, greater access to direct funding).
2. **Provide respite for caregivers.** When ventilator-assisted individuals live with their family, the burden of care is often overwhelming for the caregivers. Many families believed they could have cared for their children or spouses in the home for a longer period of time if they had had access to respite. The preference is for in-home respite, although inpatient respite is sometimes needed for extended family absences.
3. **Create intermediate care beds.** Many individuals in ICUs do not need to be there, but there is no safe alternative setting for them. The creation of intermediate care beds in an acute setting (ideally close to the ICU to facilitate access to services if needed and to support staff) would be a preferred alternative. Many LHINs suggested the development of “flexible” beds to fill short-term needs for ventilator-assisted individuals. These beds could serve multiple purposes, including:
    - Weaning.
    - High acuity care (i.e., when the individual no longer needs to be in an ICU but still requires a higher degree of care than is available either at home or in a CAVC unit).

- Home ventilation training (i.e., an inpatient stay of six to eight weeks based on the model in use at West Park).
- Respite.
- Reassessment (when this requires an inpatient admission).

These beds would not be used for long-term stays and would ultimately require discharge to the community or transfer to a CAVC unit. These beds could be centralized in one location per LHIN, depending on the expected need within each LHIN. The need for these beds would be confirmed by a business case specific to each LHIN's needs. Several LHINs have already submitted proposals for such a unit (see Appendix K). Once funded, these beds should be protected when the census is reduced so that they are always available when needed.

4. **Review ADP policies and processes for ventilator equipment and supplies.** Existing ADP policies do not cover ventilator equipment for inpatients, which is a major financial barrier to many hospitals and complex continuing care centres that would otherwise accept these individuals. Existing ADP approval processes are believed to be contributing to delays in discharge from hospital while the patient waits for the home ventilator to be approved and shipped. As well, there is a need for a broader range of equipment (e.g., cough assist devices, back up batteries, portable ventilators) to be included on the approved equipment list and more frequent upgrades allowed for individuals with degenerative diseases. Participants asked for the following changes to the mandate and policies of the ADP:
    - The approval process should be streamlined to allow more timely approval and delivery of ventilator equipment.
    - Equipment should be funded regardless of the care setting (i.e., the ADP should fund ventilators and supplies if the individual is in hospital).
    - An exception should be made regarding the five-year minimum for changing of equipment.
    - Back up batteries should be funded for safety and quality of life, and portable ventilators should be made available on request. Approved units should include a broader range of equipment such as cough assist devices to ensure optimal health for ventilator-assisted individuals.
    - Supplies should be funded through the ADP.
    - The VEP should expand its in-home ventilator training service to include invasively ventilated individuals[39].
5. **Fund existing programs and services appropriately.** Many of the services provided to ventilator-assisted individuals are currently funded through the hospital's global budget. These services include, for example, outpatient clinics for the at-risk population and unfunded CAVC beds. To ensure that these services are sustainable, they should receive appropriate funding.

[39] Currently, the VEP sends a respiratory therapist into the home to train individuals who receive a non-invasive ventilator on its use and maintenance. As noted in Section 6.1.3, this service is not provided to invasively ventilated individuals, as it is assumed that this training was provided by the discharging hospital.

8.2 Priorities for Education

Participants identified three major priorities for education:

1. **Reach the at-risk population.** There is a need to reach individuals with a chronic disease that will inevitably lead to respiratory failure and who are, therefore, at risk of requiring long-term invasive ventilation. These individuals could be identified through community health care practitioners and referred to an appropriate service for counselling on the disease and care options so that the individual and family can make informed decisions about care options. The Respiratory Program at the Ottawa Hospital (see Appendix H) was identified as an excellent example of this type of program.

   This concept is totally consistent with the priority in most LHINs to develop strategies for chronic disease prevention and management.

2. **Provide training for community-based care providers.** The high turnover rate among community care providers results in a need for frequent training, which is not always available and, therefore, places a significant burden on the ventilator-assisted individual or family to train new providers. Participants expressed a desire for a hospital-based training program that would provide training to ventilator-assisted individuals, their families, community-based nurses and personal support workers. This training must be tailored to the needs of the individual who will be receiving the care. Once established, this training could also be used for hospital staff as required.

3. **Develop and distribute standards of care.** Inconsistency in the interpretation of the Regulated Health Professionals Act creates artificial barriers to finding adequate numbers of community care providers. It was suggested that the development of provincial standards of care might help to alleviate the discomfort among some agencies in allowing unregulated professionals to provide this care (e.g., tracheostomy suctioning).

8.3 Priorities for Planning

The scope of this work was to solicit views on priorities for care and services and for education for this population. However, many participants noted that some of these services could not be effectively planned without some supports. These enablers are described below:

1. **Development and implement a long-term ventilation information system.** An information system is needed to provide real time data that is easily accessible to all providers. This system would facilitate the delivery of care (e.g., for emergency department staff), provide a basis for capacity planning, and provide an inventory of services across the province.

2. **Support the LHINs in developing regional capacity plans.** Many participants recognized the necessity of better understanding the needs of ventilator-assisted individuals in their LHIN and developing medium- and long-term plans to meet these needs. Participants suggested that a standard template for a needs assessment and capacity planning and/or assistance in facilitating this process would be useful.

8.4 Summary of Priorities

The identified priorities and the expected timelines (short-, medium- or long-term initiatives) are summarized in Table 10. Participants indicated that work should begin on all of the

identified priorities immediately. The time horizon reflects the minimum time frame in which results could be expected if implementation were to begin immediately.

Table 10: Summary of Priorities

Priority	Time horizon
Priorities for Care and Services	
Increase the capacity for and choice of community living.	Medium to long term
Provide respite for caregivers.	Short term
Create intermediate care beds.	Short term
Review of ADP policies for ventilator equipment and supplies	Short term
Fund existing services appropriately	Short term
Priorities for Education	
Reach the at-risk population	Short to medium term
Provide training for community care providers	Short term
Priorities for Planning	
Develop and implement the LTV information system	Short to medium term
Support the LHINs in developing regional capacity plans	Short term

* Estimated time until the system begins to experience the associated benefits, assuming immediate implementation.
Short term – within 18 months,
Medium term – one to three years, and
Long term – longer than three years.

Appendix A: LTV Action Plan Excerpt: Strategic Goals

Table A-1: LTV Strategy – Summary Goals and Objectives

Objective	Timeline*
Goal 1: Ventilator-assisted and at-risk individuals are matched to appropriate levels of care and have timely access to programs and services that enhance their quality of life.	
1. To match ventilator-assisted and at-risk individuals to the most appropriate setting	Short
2. To develop programs that enable individuals who use long-term ventilation and those at risk of becoming long-term ventilated, to live in the most appropriate setting	Medium
3. To work closely with the Critical Care Secretariat to support the appropriate use of critical care resources	Short to medium
4. To provide advice to policy makers on the equipment and service needs of this population to facilitate regulatory change as required	Short
5. To document and monitor the true costs of caring for this population	Short to medium
6. To develop weaning capacity across the province	Medium
Goal 2: Ventilator-assisted and at-risk individuals experience seamless and timely transitions from one care setting to another.	
1. To develop processes for the timely movement of individuals from one care setting to another	Short to medium
Goal 3: The care of individuals who are at risk of respiratory failure is managed to avoid an acute crisis.	
1. To develop processes and programs to support individuals at risk of becoming ventilator assisted	Short
Goal 4: Health care professionals and other care providers in hospitals and the community and family members/caregivers in the home have access to training programs and other supports to care for this population.	
1. To develop training and educational programs for health care professionals working across the continuum of care	Short, medium and long
2. To further enhance educational programs for ventilator-assisted individuals, families and other care providers	Short

* Short term – within 18 months
Medium term – within one to three years
Long term – longer than three years.

Appendix B: SIP and Clinical Advisory Committee Members

Clinical Advisory Committee

Dr. Monica Avendaño, Respirologist, Assistant Professor, Department of Medicine, University of Toronto, Respirology Program, West Park Health Care Centre

Dr. Ian Fraser, Chief, Department of Medicine, Program Medical Director, Medicine Health Service, Toronto East General Hospital

Janet Fraser, Respiratory Therapist, West Park Healthcare Centre

Dr. David Leasa, Respirologist, London Health Sciences Centre

Dr. Douglas McKim, Associate Professor of Medicine, University of Ottawa; Medical Director, Respiratory Rehabilitation Services; Associate Director, Ottawa Hospital Sleep Centre

Elaine McNaughton, Executive Director, Personal Choice Independent Living and Representative for the Ontario Association of Independent Living Service Providers

Donna Renzetti, Director, Program Operations, West Park Healthcare Centre

SIP Project Team

Rachel Solomon, (Acting) Director of Community Engagement and Communications, Toronto Central Local Health Integration Network

Mark Casselman, Senior Project Manager, Shared Information Management Services, University Health Network

Naqaash Pirani, Project Analyst, Shared Information Management Services, University Health Network, LTV SIP Project

Beverley Aron, Focus Group Facilitator

Marcella Sholdice, Focus Group Facilitator

Appendix C: LTV SIP Surveys

LTV SIP ICU Survey
LTV SIP Facility Survey
LTV SIP Attendant Services Survey
LTV SIP CCAC Survey

LTV SIP ICU Survey

1. LTV SIP ICU Survey

The purpose of this survey is to perform an inventory and needs assessment for ICUs across the province with a focus on the care and management of Long-Term Ventilated (LTV) patients. Please take the time to accurately answer the following questions.

* 1. Contact Information

Name:

Position:

Organization:

Site (If Applicable):

Email Address:

Phone Number:

* 2. Description of the population served:

Organization Location (by LHIN):

* 3. Description of the Care or Service:

	ICU Level	ICU Type	Vented ICU?
Description:			

* 4. Does your organization provide respite care for LTV patients living in the community or at home?

- Yes
- No

* 5. Capacity Measure

Current Occupancy:

Maximum Occupancy:

Number of Nurses for each patient requiring long-term ventilation:

Number of invasively ventilated LTV patients:

Number of non-invasively ventilated LTV patients:

6. Are you aware of LTV patients in any other units/wards at your hospital? (If so, please list these locations)

* 7. Hospital Workflow:

Average Length of Stay for LTV patients who have been deemed more appropriate for other care settings (Days):

Average time between admission to ICU and identification for discharge for LTV patients (Days):

Average time between identification for discharge and actual discharge for LTV patients (Days):

8. Does your organization provide educational programs for LTV patients (ex/ equipment training)? (If so, please describe these programs)

LTV SIP ICU Survey

2. LTV SIP ICU Survey - Identification and Management

1. Please describe the processes involved in the identification and management of ICU patients eligible for weaning.

2. Please describe the processes involved in the identification and management of ICU patients eligible for a LTV bed.

3. Please describe the processes involved in the identification and management of ICU patients eligible for community-based care and services.

LTV SIP ICU Survey

3. LTV SIP ICU Survey - Follow-up Questions

1. Please discuss your views on any gaps in the provision of care for LTV patients.

2. Please describe where you have experienced wait times in transfering LTV patients.

3. Please discuss any funding issues you have experienced with respect to the provision of care.

4. Please describe any other limitations you have experienced in the provision of care (ex/ staffing, resource availability etc.)

LTV SIP Facility Survey

1. LTV SIP Facility Survey

The purpose of this survey is to perform an inventory and needs assessment for facilities that provide Long-Term Ventilatory (LTV) care and services. Please take the time to accurately answer the following questions.

Additionally, if your program or facility has outlined admission criteria please email all relevant documentation to naqaash.pirani@uhn.on.ca

* 1. Contact Information

Name:

Position:

Organization:

Email Address:

Phone Number:

* 2. Description of the population served:

Organization Location (by LHIN):

* 3. Service Type:

Type:

4. Duration of Program (Days - If Applicable):

Duration:

* 5. Capacity Measure:

Current Occupancy:

Maximum Occupancy:

Number of Nurses for each individual requiring long-term ventilation:

Number of invasively ventilated LTV individuals:

Number of non-invasively ventilated LTV individuals:

6. Cost per day to reside at your facility (If applicable):

Cost for Direct Care of LTV individual($/day):

Cost for Indirect Care of LTV individual ($/day):

* 7. How many LTV individuals at your facility are eligible for community based care and services?

Number of LTV Individuals:

8. Where have LTV individuals been discharged to from your facility?

- [ ] 24-hour Supportive Housing
- [ ] Home Care
- [ ] Attendant Care
- [ ] Self Management
- [ ] Outreach/Outpatient
- [ ] Other (please specify)

*** 9. How often are reassessments done for discharged individuals by your facility or program?**

Reassessments:

*** 10. Do you provide respite care for LTV individuals living in the community or at home?**

- ( ) Yes
- ( ) No

11. Does your facility provide educational programs for LTV individuals (ex/ equipment training)? (If so, please describe)

LTV SIP Facility Survey

2. LTV SIP Facility Survey - Follow-Up Questions

1. Please discuss your views on any gaps in the provision of care for LTV individuals.

2. Please describe any wait times you have experienced in transferring LTV individuals.

3. Please describe any funding issues you have experienced with respect to the provision of care.

4. Please discuss any other limitations you have experienced in the provision of care (ex/ staffing, resource availability etc.)

1. LTV SIP Attendant Services Survey

The purpose of this survey is to perform an inventory and needs assessment for Attendent Services that provide support for Long-Term Ventilated (LTV) individuals. Please take the time to accurately answer the following questions.

Additionally, if your program or facility has outlined admission criteria please email all relevant documentation to naqaash.pirani@uhn.on.ca

* 1. Contact Information

Name:

Position:

Organization:

Email Address:

Phone Number:

* 2. Description of the population served:

	MOH Descriptor:	Organization Location (by LHIN):
Population Served:		

* 3. Capacity Measure (please input values only and do not include text in responses - this includes decimal points and commas. Please round your cost per day to the nearest dollar to avoid requiring decimal values):

Number of clients served to March 31, 2008:

Number of funded spaces:

Cost per client as at March 31, 2008 (please omit "$" in response):

Cost per day per client (please omit "$" in response):

* 4. Do you currently provide services to ventilated individuals?

- ◯ Yes
- ◯ No

5. If you answered "Yes" to Question 4 - Please indicate the number of invasively ventilated and non-invasively ventilated (including C-pap) clients your organization currently supports.

Number of invasively ventilated clients:

Number of non-invasively ventilated clients:

6. If you answered "No" to Question 4 - Please indicate if your organization has provided services to ventilated individuals in the past:

- ◯ Yes
- ◯ No

7. If you answered "Yes" to Question 6 - Please indicate if your organization has provided services to invasively ventilated and/or non-invasively ventilated (including C-pap) individuals in the past:

- [ ] Invasively-ventilated individuals:
- [ ] Non-invasively ventilated individuals:

8. If you answered "No" to Question 6 - Please indicate if your organization has ever been approached to serve the ventilated population:

- ◯ Yes
- ◯ No

9. If you answered "No" to Question 8 - Please indicate under what conditions your organization would consider serving this population:

- [ ] A) Current consumer whose needs change
- [ ] B) Ventilated individual is referred/self-refers
- [ ] C) With regards to A and B - I would have adequate supports

10. In regards to Queston 9 - What would you consider to be adequate supports

- [ ] Client is otherwise appropriate for independent living
- [ ] I can access appropriate training resources, including funding for on-going training, for staff
- [ ] I can access differential funding for the individual using ventilation
- [ ] I can access 24 hour informational support
- [ ] A discharging facility is willing to actively facilitate the discharge with training/knowledge exchange
- [ ] I have simplified access to reassessments of the individual's needs
- [ ] Other (please specify)

2. LTV SIP Attendant Services Survey - Follow-Up Questions

1. If you do provide services to ventilated individuals - Please describe any problems you may have faced in providing services to ventilated individuals:

2. If you do not provide services to ventilated individuals - Please indicate what your major concerns would be in serving this population

* **3. Would you consider providing respite services to ventilated individuals?**

- ◯ Yes
- ◯ No

Additional Comments

4. What would your major concerns be in potentially providing respite services to ventilated individuals?

5. Additional Comments:

LTV SIP CCAC Survey

1. LTV SIP CCAC Survey

The purpose of this survey is to perform an inventory and needs assessment for CCACs across the province with a focus on of Long-Term Ventilated (LTV) clients. Please take the time to accurately answer the following questions.

* 1. Contact Information:

Name:

Position:

Organization:

Email Address:

Phone Number:

* 2. Description of the Population Served

Organization Location (by LHIN):

* 3. Capacity Measure

How many invasively ventilated LTV clients does your organization currently support?

How many non-invasively ventilated LTV clients does your organization currently support?

How many invasively ventilated LTV clients are waiting to be transferred to the community that you are aware of?

How many non-invasively ventilated LTV clients are waiting to be transferred to the community that you are aware of?

What is the average wait time to be transferred to the community for invasively ventilated LTV clients by your organization (Weeks)?

What is the average wait time to be transferred to the community for non-invasively ventilated LTV clients by your organization (Weeks)?

* 4. Do you provide respite care for LTV individuals living in the community or at home?

- Yes
- No

LTV SIP CCAC Survey

2. LTV SIP CCAC Survey - Follow-Up Questions

1. Please discuss your views on any gaps in the provision of care for LTV individuals.

2. Please discuss any wait times you have experienced in transferring LTV individuals.

3. Please discuss any funding issues you have experienced in the provision of care.

4. Please discuss any other limitations you have experienced in the provision of care (ex/ s availability etc.)

Appendix D: LTV SIP Survey Respondents

Table D-1: ICU Survey Responding Organizations

LHIN	Hospital Name	Site
Central	Humber River Regional Hospital	Church Site
Central	Humber River Regional Hospital	Finch Site
Central	Markham Stouffville Hospital	Markham Site
Central	North York General Hospital	General
Central	Southlake Regional Health Centre	
Central	St. Joseph's Health Centre	Toronto Central
Central	York Central Hospital	Richmond Hill
Central East	Lakeridge Health Oshawa	Oshawa
Central East	Peterborough Regional Health Centre	Hospital Drive
Central East	Rouge Valley Health System	Ajax and Pickering
Central East	Rouge Valley Health System	Centenary
Central East	The Scarborough Hospital	Grace
Central East	The Scarborough Hospital	General Site
Central West	William Osler Health Centre	Brampton Civic Hospital
Central West	William Osler Health Centre	Etobicoke
Champlain	Children's Hospital of Eastern Ontario	
Champlain	Cornwall Community Hospital	
Champlain	Pembroke Regional Hospital	
Champlain	Queensway Carleton Hospital	
Champlain	The Ottawa Hospital	General Site and Civic Campus
Erie St. Clair	Bluewater Health	
Erie St. Clair	Chatham-Kent Health Alliance	Chatham
Erie St. Clair	Hotel Dieu Grace Hospital	CCU
Erie St. Clair	Leamington District Memorial Hospital	
Hamilton Niagara Haldimand Brant	Brant Community Health Care System	Brantford General
Hamilton Niagara Haldimand Brant	Hamilton Health Sciences	Hamilton General Hospital - ICU East/South
Hamilton Niagara Haldimand Brant	Hamilton Health Sciences	Hamilton General Site ICU West
Hamilton Niagara Haldimand Brant	Hamilton Health Sciences	Henderson ICU
Hamilton Niagara Haldimand Brant	Hamilton Health Sciences	McMaster University Medical Centre (MUMC)
Hamilton Niagara Haldimand Brant	Niagara Health System	Welland Hospital Site
Hamilton Niagara Haldimand Brant	Niagara Health System	Greater Niagara General
Hamilton Niagara Haldimand Brant	Niagara Health System	St. Catharines General
Hamilton Niagara Haldimand Brant	St. Joseph's Health Care, Hamilton	Charlton Site
Mississauga Halton	Halton Health Care Services	Milton
Mississauga Halton	Halton Health Care Services	Oakville Trafalgar
Mississauga Halton	The Credit Valley Hospital	
Mississauga Halton	Trillium Health Centre	Mississauga

LHIN	Hospital Name	Site
North East	Kirkland and District Hospital	Kirkland Lake
North East	North Bay General Hospital	Scollard
North East	Sault Area Hospital	
North East	St. Josephs	General Hospital
North East	Sudbury Regional Hospital	Memorial Site
North East	Sudbury Regional Hospital	St. Joseph's Health Care
North East	Timmins & District Hospital	
North East	West Parry Sound Health Centre	
North Simcoe Muskoka	Collingwood General and Marine Hospital	
North Simcoe Muskoka	Huronia District Hospital	
North Simcoe Muskoka	Muskoka Algonquin Healthcare combined sites	Huntsville Bracebridge
North Simcoe Muskoka	Royal Victoria Hospital	
South East	Brockville Central Hospital	Charles St.
South East	Kingston General	ICU
South East	Quinte Health Care	Belleville General
South West	Grey Bruce Health Services	Owen Sound Site
South West	Grey Bruce Health Services	Wiarton (Temp Location)
South West	London Health Sciences Centre	Victoria Hospital
South West	London Health Sciences Centre	University Hospital
South West	Middlesex Hospital Alliance	Strathroy Middlesex General Hospital
South West	St. Thomas Elgin General Hospital	
South West	Tillsonburg District Memorial Hospital	
South West	Woodstock General Hospital	Woodstock
Toronto Central	Mount Sinai Hospital	
Toronto Central	St. Michael's Hospital	Medical Surgical Intensive Care Unit
Toronto Central	Sunnybrook Health Sciences Centre	
Toronto Central	Toronto East General Hospital	
Toronto Central	Toronto Western Hospital	
Toronto Central	University Health Network - Toronto General Hospital	Coronary Intensive Care Unit
Toronto Central	University Health Network - Toronto General Hospital	Medical Surgical Intensive Care Unit
Waterloo Wellington	Cambridge Memorial Hospital	
Waterloo Wellington	Guelph General Hospital	Guelph
Waterloo Wellington	St. Mary's General Hospital	

ICU = Intensive Care Unit CCU = Critical care unit

Table D-2: Facility Survey Responding Organizations

LHIN	Type	Name
Champlain	CAVC	Sisters of Charity of Ottawa Hospital (St. Vincent site)
Champlain	CAVC	St. Francis Memorial Hospital
Erie St. Clair	CAVC	Chatham-Kent Health Alliance
Erie St. Clair	CAVC	Windsor Regional Hospital
Hamilton Niagara Haldimand Brant	CAVC	St. Joseph's Health Care Hamilton
Hamilton Niagara Haldimand Brant	CAVC	McMaster Children's Hospital
North West	CAVC	St. Joseph's Care Group
South West	CAVC	Grey Bruce Health Services
South West	CAVC	St. Joseph's Health Care, London (Parkwood site)
Toronto Central	CAVC	Bloorview Kids Rehabilitation
Toronto Central	CAVC	Toronto East General Hospital
Toronto Central	CAVC	West Park Healthcare Centre
Waterloo Wellington	CAVC	Grand River Hospital
Central	CCC	York Central Hospital
Central East	CCC	Northumberland Health Care Corporation
Champlain	CCC	Sisters of Charity Ottawa (SCO) Health Service
Erie St. Clair	CCC	Leamington District Memorial Hospital
Erie St. Clair	CCC	Windsor Regional Hospital
Hamilton Niagara Haldimand Brant	CCC	Brant Community Healthcare System
Hamilton Niagara Haldimand Brant	CCC	Hotel Dieu Shaver
Hamilton Niagara Haldimand Brant	CCC	St. Joseph's Healthcare Hamilton
North East	CCC	Hôpital régional de Sudbury Regional Hospital
North East	CCC	Smooth Rock Falls Hospital
North Simcoe Muskoka	CCC	Bluewater Health
North West	CCC	The McCausland Hospital
North West	CCC	St. Joseph's Care Group
South East	CCC	Providence Continuing Care Centre, Kingston
South West	CCC	St. Joseph's Health Care London
South West	CCC	Strathroy Middlesex General Hospital
Waterloo Wellington	CCC	Grand River Hospital
Waterloo Wellington	CCC	St. Joseph's Health Care, Guelph

LHIN	Type	Name
Hamilton Niagara Haldimand Brant	HVT	Hamilton Health Sciences Centre
North East	HVT	North Bay General Hospital
Toronto Central	HVT	West Park Healthcare Centre
North Simcoe Muskoka[40]	Outreach/ Outpatient	Royal Victoria Hospital
Toronto Central	PWC	Toronto East General Hospital
Central West	Respiratory Care	Headwaters Health Care Centre
Hamilton Niagara Haldimand Brant	Respiratory Care	West Lincoln Memorial Hospital
Mississauga Halton	Respiratory Care	The Credit Valley Hospital

CAVC = Chronic assisted ventilatory care
HVT = Home ventilation training
CCU = Critical care unit
CCC = Complex continuing care
ICU = Intensive Care Unit

Table D-3: CCAC Survey Responding Organizations

CCAC Name
Central CCAC
Central East CCAC
Central West CCAC
Champlain CCAC
Erie St. Clair CCAC
Hamilton Niagara Haldimand Brant CCAC
Mississauga Halton CCAC
North East CCAC
North Simcoe Muskoka CCAC
North West CCAC
South East CCAC
South West CCAC
Toronto Central CCAC
Waterloo Wellington CCAC

CCAC = Community care access centre

[40] Patient counts not included in facility totals.

Table D-4: Attendant Services Survey Responding Organizations

LHIN	Organization Name
Central	Access Apartments
Central	PACE Independent Living
Central East	Kawartha Participation Projects
Central East	Personal Attendant Care Inc.
Champlain	Personal Choice Independent Living/Choix personnel vie autonome
Champlain	Disabled Persons Community Resources
Erie St. Clair	The Association for Persons with Physical Disabilities Of Windsor and Essex County
Hamilton Niagara Haldimand Brant	Cheshire Independent Living Services
Hamilton Niagara Haldimand Brant	Conway Opportunity Homes Inc.
Hamilton Niagara Haldimand Brant	Participation House-Brantford
Mississauga Halton	Independent Living Halton, Milton
Mississauga Halton	Nucleus Independent Living, Toronto
North East	Independence Centre and Network (ICAN)
North East	Physically Handicapped Adults' Rehabilitation Association
North Simcoe Muskoka	Simcoe County Association for the Physically Disabled
South East	Cheshire Homes (Hastings-Prince Edward) Inc.
South West	Participation Lodge & Community Services
South West	Participation Project Support Services - London and Area
Toronto Central	Canadian Paraplegic Association
Toronto Central	Centre for Independent Living in Toronto
Toronto Central	Clarendon Foundation (Cheshire Homes) Inc
Toronto Central	Gage Independent Living
Toronto Central	Ontario March of Dimes
Toronto Central	Three Trilliums Community Place
Toronto Central	Tobias House Attendant Care Inc.
Waterloo Wellington	Guelph Independent Living
Waterloo Wellington	Independent Living Centre of Waterloo Region
Waterloo Wellington	Participation House-Waterloo Region

Appendix E: Focus Group Session Dates and Participants

Table F-1: LTV SIP Focus Group Dates, by LHIN

LHIN	Date	Number of participants
Central	June 12, 2008	19
Central East	June 24, 2008	11
Central West	June 19, 2008	4
Champlain	June 18, 2008	27
Erie St. Clair	June 11, 2008	26
Hamilton Niagara Haldimand Brant	June 4, 2008	21
Mississauga Halton	June 6, 2008	11
North East	May 27, 2008	13
North Simcoe Muskoka	May 29, 2008	17
North West	May 26, 2008	18
South East	May 5, 2008	13
South West	June 26, 2008	23
Toronto Central – TEGH	May 23, 2008	21
Toronto Central – WPHC	May 9, 2008	11
Waterloo Wellington	June 03, 2008	15
Total participants		252[41]

TEGH = Toronto East General Hospital
WPHC = West Park Healthcare Centre

Central LHIN Focus Group Participants

John Agnew, Canadian Paraplegic Association of Ontario
Evangeline Andaya, Humber River Regional Hospital
Jonathan Cheung, Central Community Care Access Centre
Margaret Czaus, Humber River Regional Hospital
Heather Davis, Southlake Regional Health Centre
Ayesha Federico, Comcare Health Services
Rosalyn Gambell, Cancer Care and Palliative Care, Southlake Regional Health Centre
Heidi Holmes-Ojo, Central Community Care Access Centre
Nancy Hood, Markham Stouffville Hospital
Tamizan Janmohamed, Saint Elizabeth Health Care
Michael Mathieson, Access Apartments
Nancy Merrow, Southlake Regional Health Centre
Carol Paton, Saint Elizabeth Health Care
Maya Ramdhanie, Comcare Health Services
Dr. Kenneth Roberts, Southlake Regional Health Centre
Shirley Rokos, PACE Independent Living

[41] Two individuals participated in two sessions.

Jill Sanderson, SRT Med-Staff
Gerry Sinclair, Central Community Care Access Centre
Leah Walters, Cummer Lodge Home for the Aged

Central East LHIN Focus Group Participants

Diane Bennet, Central East Community Care Access Centre
Irene Bonnar, Critical Care, Lakeridge Health Corporation
Sevi Cesta, The Scarborough Hospital - Grace Campus
Dr. Howard Clasky, CE LHIN and The Scarborough Hospital
Margot DaCosta, Medicine, Rouge Valley Health System
Dr. Jonathan Eisenstat, Lakeridge Health Corporation
Carol Gordon, Kawartha Participation Projects
Joy Husak, Personal Attendant Care - Durham
Dr. David McMillan, Peterborough Regional Health Centre
James Meloche, Planning, Integration and Community Engagement, Central East Local Health Integration Network
Amer Syed, Rouge Valley Health System

Central West LHIN Focus Group Participants

Dr. Paula Chidwick, William Osler Health Centre
Natallie Grant, Etobicoke ICU/CCU
Dilys Haughton, Central West Community Care Access Centre
Kathy Stevenson, William Osler Health Centre

Champlain LHIN Participants

Morning Sessions:

Suzanne Béland, Personal Choice Independent Living
Denis Binette, Queensway Carleton Hospital
Susan Bubb, Queensway Carleton Hospital
Lynne Comeau, Champlain Community Care Access Centre
Renald Drolet, Sisters of Charity Health Service
Laurence Elliott, Ottawa Hospital and Sisters of Charity Health Service
Sharon Hiebert, Queensway Carleton Hospital
Chantal Krantz, Children's Hospital of Eastern Ontario
Kim Kruk, Disabled Persons Community Resources
Elaine McNaughton, Personal Choice Independent Living
Marcel Morin, ALS Society and spouse
Stacey Newell, Canadian Parapalegic Association
Karen Patzer, Champlain Local Health Integration Network
Denise Picard-Stencer, The Ottawa Hospital General
Regina Pizutti, Ventilator Equipment Pool
Cindy St. Louis, St. Joseph's Hospital
Chantal Seguin, Sisters of Charity Health Service
David Spiterie, Medigas
Lisa Spooner, Children's Hospital of Eastern Ontario
Ian Summers, Algonquin College

Afternoon Session:

Ventilator user (1)
Spouse of a ventilator user (2)
Mother of a ventilator user (1)
Laurence Elliott, Ottawa Hospital and Sisters of Charity Health Service
Julie Filion, Champlain Community Care Access Centre
Dr. Doug McKim, Ottawa Rehabilitation Hospital
Colleen Newburgh, Champlain Community Care Access Centre
Karen Patzer, Champlain Local Health Integration Network

Erie St. Clair LHIN Focus Group Participants

Alec Anderson, Erie St. Clair Local Health Integration Network
Paul Brown, ESC LHIN
Lynn Calder, The Association for Persons with Physical Disabilities of Windsor and Essex County
Frank Chalmers, Erie St. Clair Local Health Integration Network
Carol Columbus, Bluewater Health
Lucy Coppola, Leamington District Memorial Hospital
Pete Crvenkovski, Erie St. Clair Local Health Integration Network
Jennifer Demars, Pro Respite
Dr. Anil Dhar, Windsor Regional Hospital
Patricia Easton, Chatham-Kent Health alliance
Valerie Evans, Vital Aire
Ralph Ganter, Erie St. Clair Local Health Integration Network
Linda Lucas, Erie St. Clair Local Health Integration Network
Dawn Maziak, Erie St. Clair Local Health Integration Network
Todd McGivern, Chatham-Kent Health Alliance
Ralph Nicoletti, Windsor Regional Hospital
Sharon Pilon, Windsor Regional Hospital
Lisa Regan, Bluewater Health
Irene Vermey, Cardio-Pulmonary and Respiratory Therapy, Windsor Regional Hospital

Erie St. Clair LHIN Patient Focus Group Participants

Ventilator user (2)
Parent of a ventilator user (2)
Non-family caregiver (3)

Hamilton Niagara Haldimand Brant LHIN Focus Group Participants

Romeo Cercone, St. Joseph's Healthcare Hamilton
Rose-Frances Clause, Hamilton Health Sciences Corporation
Winnie Dolye, St. Joseph's Healthcare Hamilton
Dianne Draper, Brant Community Healthcare System
Elizabeth Draper, Niagara Health System
Dr. Andy Freitag, Hamilton Health Sciences Corporation
Jeannie Kelso, Hamilton Health Sciences Corporation
Yvon Morency, Le Centre de Santé Communautaire Hamilton/Niagara
Sherry Parsley, Hamilton Niagara Haldimand Brant Community Care Access Centre
Carol Paton, St. Elizabeth Health Care
Carole Pelletier, Le Centre de Santé Communautaire Hamilton/Niagara

Leea Romero, Bayshore Home Health
Marlene Slepkov, VON Niagara
Dr. Mark Soth, St. Joseph's Healthcare Hamilton
David St. Amant, Hamilton Health Sciences Corporation, McMaster University Medical Centre
Karen Tribble, Hotel Dieu Shaver Health and Rehabilitation Centre
Renata Vaughan, Chedoke Site, Rehabilitation Services, Hamilton Health Sciences Corporation
Gemeni Ved, Hamilton Health Sciences Corporation
Lorreta Ward, Good Shepherd Centres
Rosalind Tarrant, Hamilton Niagara Haldimand Brant Local Health Integration Network

Mississauga Halton LHIN Focus Group Participants

Judy Bowyer, Performance and Integration, Mississauga Halton Local Health Integration Network
Dr. Laurence Chau, Mississauga Halton Local Health Integration Network
Joanne Flewwelling, Decision Support, Trillium Health Centre
Cindy Hawkswell, Intensive Care Unit, Trillium Health Centre
Carolyn Hitchinson, Children Services, Mississauga Halton Community Care Access Centre
Gail Lang, Respiratory Therapy, Credit Valley
Monita O'Connor, Performance Improvement and Integration, Mississauga Halton Local Health Integration Network
Lina Rinaldi, Emergency and Medicine, Trillium Health Centre
Hugh Stewart, Independent Living
Lynn Varga, Critical Care, Credit Valley
Rebecca Frank, Halton Healthcare

North East LHIN Focus Group Participants

Lise Comtois, Supportive Housing, Independence Centre and Network (ICAN)
Cindy Croteau, Client Services, North East Community Care Access Centre, Sudbury
Carol Ann Goulet, MICs Group (long-term care facilities in Matheson, Iroquois Falls and Cochrane)
Lorna Green, Timmins District Hospital
Kari Kostiw, Intensive Care Unit, Sudbury Regional Hospital
Liette Lajambe, Physically Handicapped Adults' Rehabilitation Association (PHARA)
Sue Lebeau, North Bay General Hospital
Monique Rocheleau, Planning, Integration and Community Engagement, North East Local Health Integration Network
Sue Ryckman, Bingham Memorial Site, MICs Group (long-term care facilities in Matheson, Iroquois Falls and Cochrane)
Valerie Scafone, Independence Centre and Network (ICAN)
Tiz Silveri, North Bay General Hospital
Grace St. Jean, Sudbury Regional Hospital
Clarice Watt, Timmins District Hospital

North Simcoe Muskoka LHIN Participants

Morning Session:

Lori Brown, North Simcoe Muskoka Community Care Access Centre
Sharon Gignac, Huronia District Hospital
Denis Lahaie, Huronia District Hospital
Mary Lee Macmillan, Simcoe County Association for the Physically Disabled (SCAPD)
Heather Mason, Intensive Care Unit, Huronia District Hospital
Ginny Miles, Royal Victoria Hospital

Debbie Roberts, North Simcoe Muskoka Local Health Integration Network
Joyce Thornton, North Simcoe Muskoka Community Care Access Centre

Afternoon Session:

Ventilator users (2)
Parents of a ventilator user (2)
Other family members (2)
Attendant Care Worker (1)
Debbie Roberts, North Simcoe Muskoka Local Health Integration Network

North West LHIN Focus Group Participants

Dr. Biman, Respirologist
Mieke Busman, St. Joseph's Healthcare Group
Brent Dione, Lake of the Woods District Hospital, Kenora
Carolyn Freitag, Critical Care, Thunder Bay Regional Health Sciences Centre
Heather Fukashima, Long-term Care Unit, Meno Ya Win, Sioux Lookout
Heather Gray, North West Local Health Integration Network
Terri Gurney, Specialized Complex Care, St. Joseph's Healthcare Group
Bobby-Jo Huard, Meno Ya Win, Sioux Lookout
Katherine Hughes, North West Community Care Access Centre
Charlene Kuzick, North West Community Care Access Centre
Barb Linkewich, Intensive Care Unit, Meno Ya Win, Sioux Lookout
Donna Makowsky, Lake of the Woods District Hospital, Kenora
Shelley Prevost, St. Joseph's Healthcare Group

Afternoon Session:

Ventilator users (1)
Parents of a ventilator user (1)
Other family members (5)
Attendant Care Worker (1)
Shelley Prevost, St. Joseph's Healthcare Group
Terri Gurney, Specialized Complex Care, St. Joseph's Healthcare Group

South East LHIN Focus Group Participants

Kate Hamilton, Family Member
Paulette Jamieson, Quinte Health Care
Allan Katz, Health Care Network of Southeast Ontario
Adrienne Leach, Kingston General Hospital
Molly Lockridge, Providence Continuing Care Centre
Bernadette MacDonald, Belleville General Hospital
Jo Mather, South East Community Care Access Centre
Maureen McGinn, Providence Continuing Care Centre
Brian Mulvihill, Respiratory Therapy, Belleville General Hospital
Regina Pizzutti, Ontario Ventilator Equipment Pool
Terry Richmond, Cheshire Homes
Maurio Ruffolo, Complex Continuing Care Program, Providence Continuing Care Centre
Marcy Saxe-Braithwaite, Providence Continuing Care Centre

South West LHIN Focus Group Participants

Morning session: Providers

Janice Cosgrove, St. Joseph's Health Care
Carla Crowther, South West Community Care Access Centre
Julie Gagliardi, Parkwood Hospital
Janet Hunt, Parkwood Hospital
Dave Jones, Western ProResp
Susan Jones, Parkwood Hospital
Chris Harris, London Health Sciences Centre
Mike Keim, St. Joseph's Health Care
David Leasa, London Health Sciences Centre
Valerie Marcella, Gray Bruce Health Services
Cathy Mawdsley, London Health Sciences Centre
Daniel McPhee, Alexandra Marine and General Hospital
Ann Rickwood, South West Community Care Access Centre
Valerie Schulz, London Health Sciences Centre
Michael Sharpe, London Health Sciences Centre
Andrea Sikora, Parkwood Hospital
Joanne Smith, London Health Sciences Centre
Laura Smith, Participation House - London
Elizabeth Zarnowiecki, Canadian Paraplegic Association

Afternoon session: Consumers

Ventilator user (1)
Individual who is at risk for becoming a ventilator user (1)
Parents of a ventilator user (2)

Toronto Central LHIN - Toronto East General Hospital Focus Group Participants

Peter Ananthopoulous, Canadian Paraplegic Association
Dr. Amy Bichai, Toronto East General Hospital
Claire Bryden, Bellwoods Centres for Community Living Inc.
Paula Cripps-McMartin, Toronto Western Hospital
Yona Frishman, Tobias House Attendant Care Inc.
Shelley Ishida, Sunnybrook Health Sciences Centre
Krista Keilty, Division of Respiratory Medicine, Hospital for Sick Children
Sarah Kravetz, Clarendon Foundation (Cheshire Homes) Inc.
Marilyn Lee, Intensive Care Unit – Post Anaesthetic Recovery Room (PARR), Toronto East General Hospital
Stacy Lintern, Canadian Paraplegic Association
Ian Parker, Centre for Independent Living in Toronto (CILT)
Cecilia Santiago, St. Michael’s Hospital
Dr. Roland Skrastins, Progressive Weaning Centre, Toronto East General Hospital
Judith Snow
Ingrid Teunissen, Ontario March of Dimes
Lily Yang, Respiratory Therapy Ethics, Bloorview Kids Rehabilitation
Mark Casselman, Long-term Ventilation Service Inventory Program
Naqaash Pirani, Long-term Ventilation Service Inventory Program

Toronto Central LHIN – West Park Healthcare Centre Focus Group Participants

Peter Ananthopoulous, Canadian Paraplegic Association
Dr. Monica Avendaño, West Park Healthcare Centre
Carlos Bautista, CAVC Service, West Park Healthcare Centre
Janet Fraser, West Park Healthcare Centre
Nancy French, Progressive Weaning Unit, Toronto East General Hospital
Michael Moncrieffe, Respiratory Therapy, Sunnybrook Health Sciences Centre
Myrna Moore, Sunnybrook Health Sciences Centre
Donna Renzetti, West Park Healthcare Centre
Carol Ross, CCC and Rehab, Toronto East General Hospital
Laura Watling, Respiratory Therapy, West Park Healthcare Centre
Krisztina Weinacht, Progressive Weaning Unit, Toronto East General Hospital; Ontario Lung Association
Naqaash Pirani, Long-term Ventilation Service Inventory Program

Toronto Central LHIN – Patient Focus Group Participants

Ventilator users (4)
Spouse of a ventilator user (1)
Ian Parker, Centre for Independent Living in Toronto (CILT)

Waterloo Wellington LHIN Focus Group Participants

Heather Camrass, ICU/ACOU Grand River
Terrie Dean, St. Joseph's Health Centre
Heather Gray, Critical Care/Stepdown, Guelph General Hospital
Toby Harris, Participation House
Linda Lopinski, Waterloo Wellington Local Health Integration Network
Dale Mann, RT Services, Grand River Hospital
Andrea Martin, Hospice Palliative Care End of Life Network
Mary Parent, Discharge Planner, Guelph General Hospital
Bryna Rabishaw, Regional Cardiac Care and Chest, St. Mary's General Hospital
Asma Razzaq, Waterloo Wellington Local Health Integration Network
Alena Sarnavka, Grand River Hospital, Freeport site
Kim Siegel, Chest Program, St. Mary's General Hospital
Lynn Voelzing, Critical Care, St. Mary's General Hospital
Anne Waller, Guelph Independent Living
RuthAnn Wassing, Supportive Housing Project, Independent Living Service Provider

Appendix F: Graphic of LTV Patient Flow

1. Categories of Services

Note: Each category is linked to the flow map on the following pages.

At-risk population

1. Counselling and disease management for at-risk population and families/caregivers

Emergency Department:

2. Identification and appropriate referral of patients at risk for long-term ventilation

Critical Care:

3. Education of patient's primary care practitioners and specialists (e.g., neurologists)
4. ICU capacity
5. Early identification and management of ICU patients at risk for long-term ventilation
6. Early identification and management of ICU patients who cannot be weaned and are eligible for LTV bed
7. Early identification and management of ICU patients eligible for community-based care and services

Weaning

8. Weaning services

Rehabilitation and Home Vent Training

9. Preparation for discharge to home for individual and families/caregivers (e.g., Rehabilitation and Home Vent Training)

Long-term Institutional Care

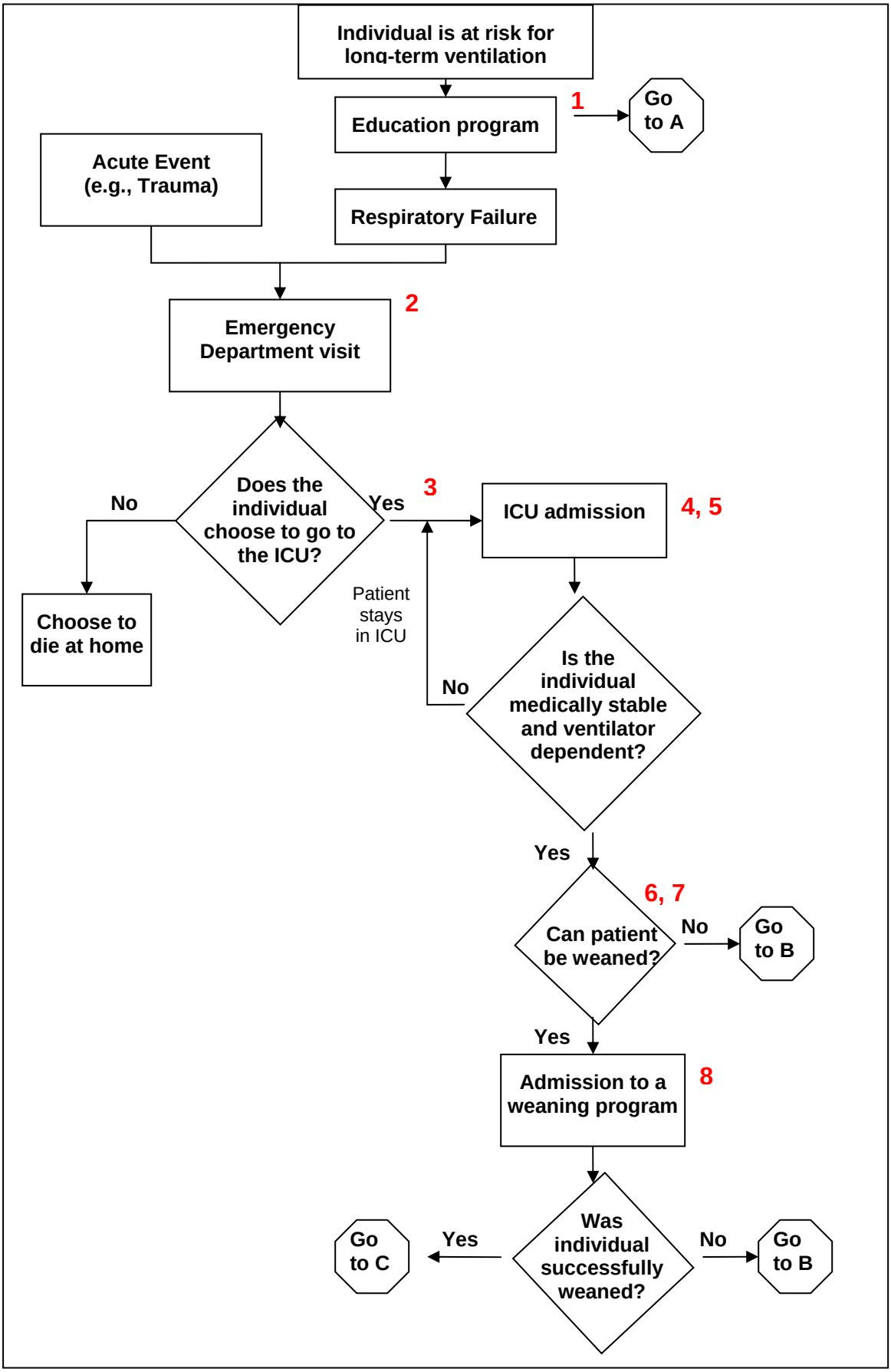
10. LTV in-hospital care and services

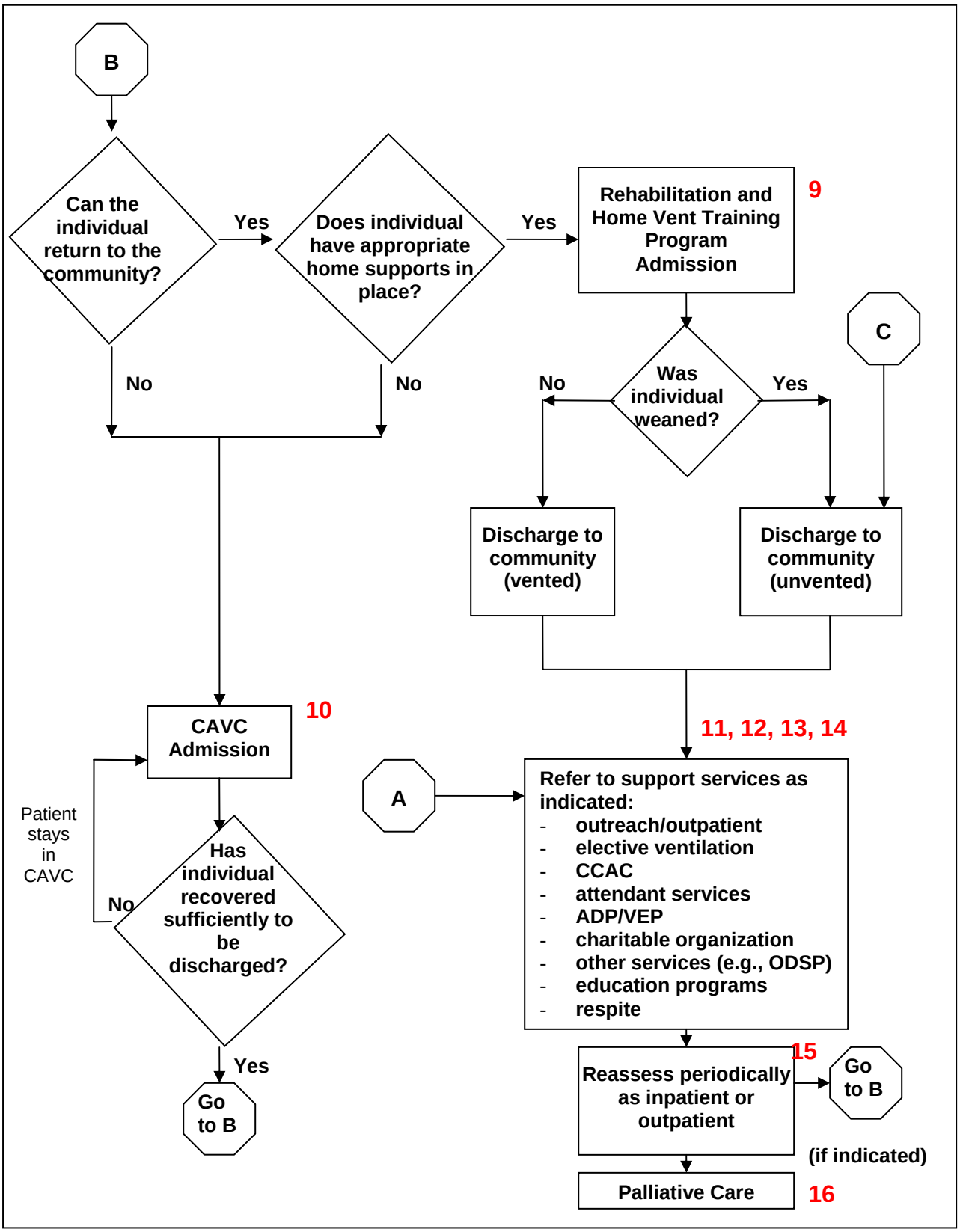
Community-based care and services

11. Community-based care (e.g., nursing, respiratory therapy), by setting (e.g., long-term care home, nursing home, private home, supportive housing)
12. Community-based services (e.g., assistance with daily living, attendant services, ventilator equipment and maintenance)
13. Outpatient or outreach care (e.g., reassessments)
14. Respite care
15. Reassessment (as inpatient or outpatient)

Community-based care and services

16. Palliative and end-of-life care


Individual is at risk for long-term ventilation
Education program
1
Go to A
Acute Event (e.g., Trauma)
Respiratory Failure
Emergency Department visit
2
Does the individual choose to go to the ICU?
No
Yes
3
ICU admission
4, 5
Choose to die at home
Patient stays in ICU
Is the individual medically stable and ventilator dependent?
No
Yes
6, 7
Can patient be weaned?
No
Go to B
Yes
Admission to a weaning program
8
Was individual successfully weaned?
Yes
Go to C
No
Go to B



CCAC = Community Care Access Centre ADP = Assistive Devices Program VEP = Ventilator Equipment Pool
ODSP = Ontario Disability Support Program CAVC = Chronic Assisted Ventilatory Care ICU = Intensive Care Unit

"Community" includes long-term care homes, supportive housing and private homes.

Appendix G: LTV Populations and Hospital Workflow, by LHIN

Table G-1: Summary of the LTV Population as Reported by Survey Respondents, by LHIN

LHIN	Institutional Setting		Community Setting*	
	Invasively ventilated	Non-invasively ventilated	Invasively ventilated	Non-invasively ventilated
Central	19	2	14	12
Central East	9	0	3	1
Central West	4	0	2	0
Champlain	9	5	10	44
Erie St. Clair	6	2	10	2
Hamilton Niagara Haldimand Brant	20	10	20	3
Mississauga Halton	21	0	8	2
North East	3	0	5	0
North Simcoe Muskoka	1	1	3	1
North West	3	5	1	1
South East	2	0	7	2
South West	9	2	6	2
Toronto Central	69	4	15	47
Waterloo Wellington	10	1	6	9
Total	**185**	**32**	**110**	**126**

Source: ICU, facility, CCAC and attendant services surveys

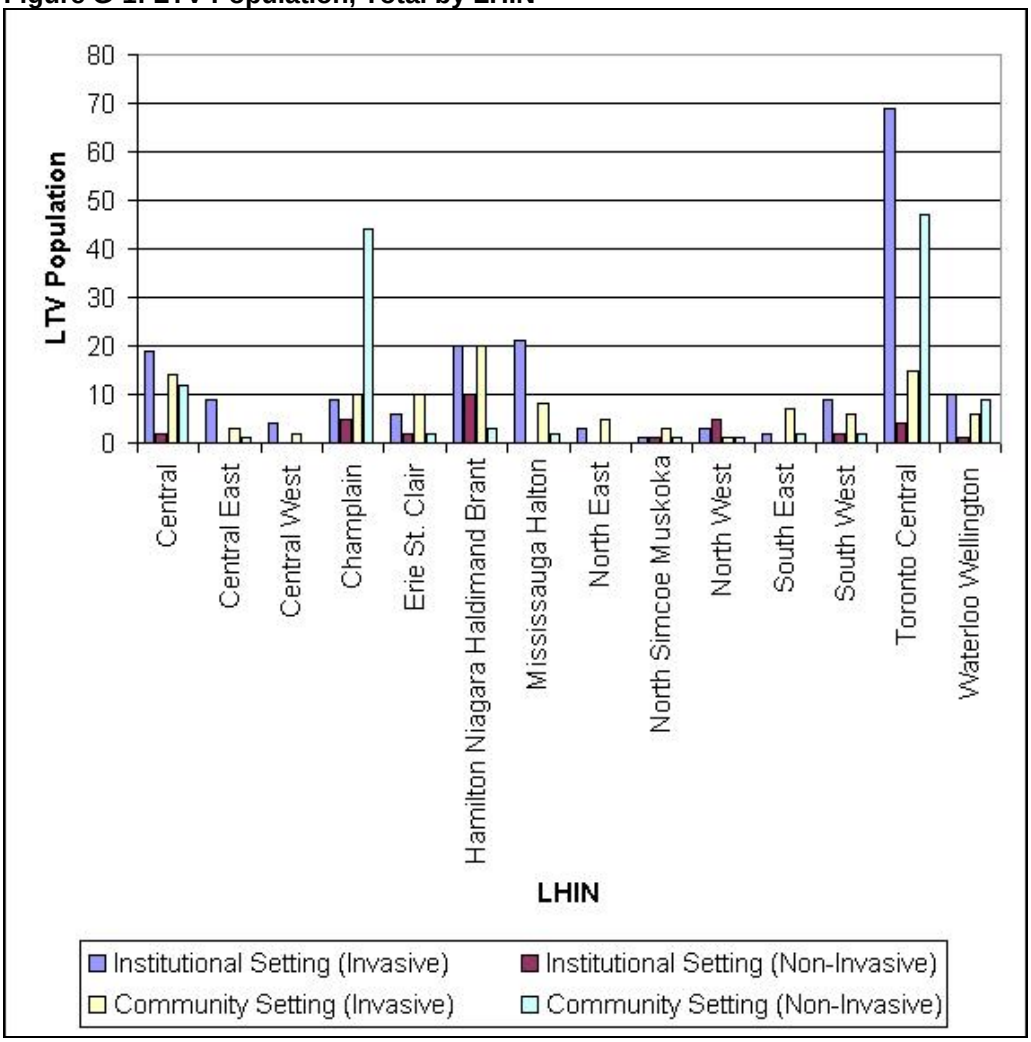
** This column shows the total of individuals reported by the CCACs, attendant service providers and the Direct Funding Program. Some individuals may receive care from more than one agency (e.g., CCAC and attendant services). Therefore, this number might be overstated. Note also that these data do not include individuals who do not receive any services from these organizations.*

Table G-2: Hospital Workflow, Average by LHIN (days)

LHIN	ICU		Facility	
	Admission to ALC	ALC to Discharge	Admission to ALC	ALC to Discharge
Central	76	19	0	2
Central East	66	9	7	0
Central West	38	4	0	0
Champlain	77	4	10	0
Erie St. Clair	26	3	5	0
Hamilton Niagara Haldimand Brant	238	13	77	2
Mississauga Halton	56	13	16	0
North East	75	3	64	0
North Simcoe Muskoka	30	1	28	1
North West	0	0	16	3
South East	27	0	2	0
South West	75	5	4	2
Toronto Central	109	16	44	14
Waterloo Wellington	23	4	4	3
Ontario	**916**	**94**	**277**	**27**

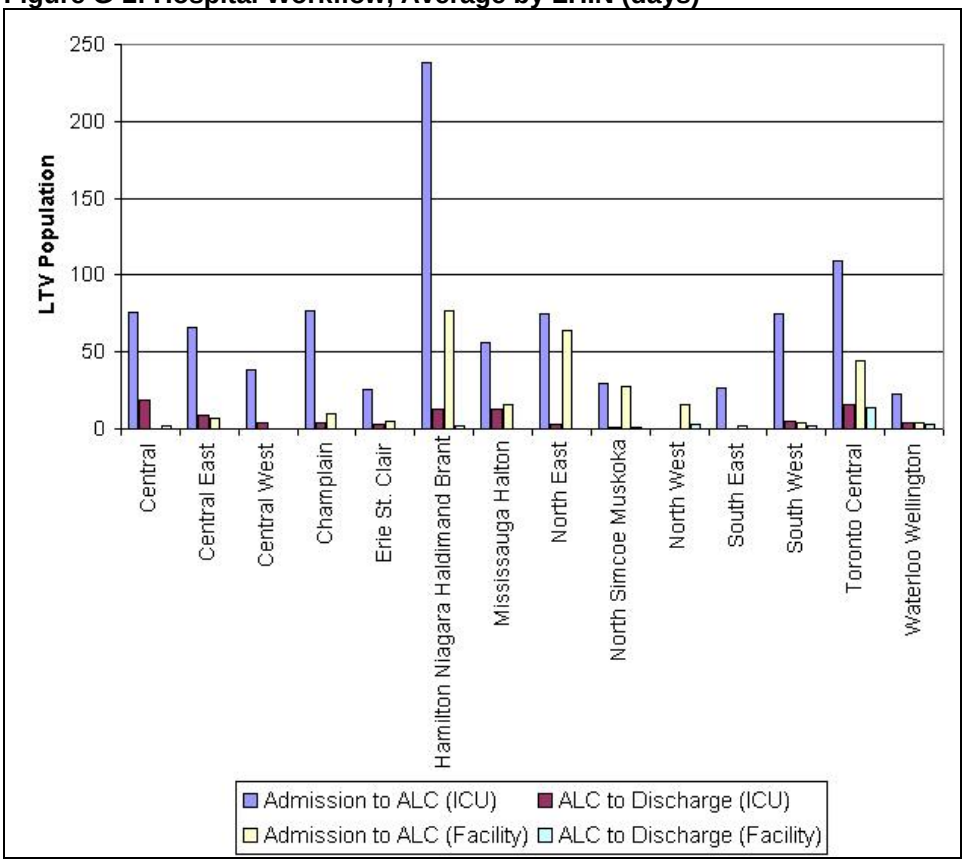
Source: ICU survey, Facility survey

Figure G-1: LTV Population, Total by LHIN



Source: ICU, facility, CCAC and attendant services surveys

Figure G-2: Hospital Workflow, Average by LHIN (days)



Source: ICU survey, Facility Survey.

ICU = Intensive Care Unit ALC = Alternative Level of Care

Appendix H: Innovative Programs and Services

Outpatient and Outreach (At-risk and Ventilator-assisted Individuals)

LHIN	Champlain
Host organization	Ottawa Rehabilitation Hospital
Target population	At risk of becoming invasively ventilated
Description of service	**An interdisciplinary program identifying individuals at risk, while introducing preventive respiratory strategies and elective non-invasive ventilation.**
Outcome	Reduced health care utilization (by avoiding inpatient admissions and delaying or preventing invasive ventilation) Improved critical care access and maintained independence in the home. Forty one patients were placed on noninvasive ventilation in 2007, an increase from 22 in 2005. Of 403 ALS patients, 125 are on non-invasive ventilation, and only 10 are on invasive ventilation
Funding status	Funded from the hospital's global budget
Contact	Dr. Douglas McKim. dmckim@Ottawahospital.on.ca

LHIN	Erie St.Clair
Host organization	Erie St. Clair CCAC
Target population	Clients with extenuating circumstances according to predetermined criteria, such as High Caregiver Burden Scale Score, and Level 1 or 2 Emergency Response Code.
Description of service	**Extenuating Services Policy allows clients to access innovative solutions that may exceed service norms and maximums.**
Outcome	Aim is to avoid unnecessary hospitalizations, delayed hospital discharges and early long-term care admissions (policy implemented January 2008 so outcomes not yet available)
Funding status	CCAC budget
Contact	1 888 447-4468

LHIN	Hamilton Niagara Haldimand Brant
Host organization	Hamilton Health Sciences - McMaster Children's Hospital
Target population	Ventilator-assisted individuals living in the community
Description of service	**Respiratory therapist (RT), Advanced practice nurse (APN), respirologist and paediatrician form a consistent health team that follows ventilator-assisted individuals throughout the continuum of care.** The same professionals support the family throughout initial discharge, provide teaching, then continue to follow them with home visits, clinic visits and telephone support, and communicate with professionals in the community.
Outcome	Avoids hospital visits Increases continuity of care Greatly increases client satisfaction Facilitates re-admissions to hospital when necessary - direct admit when possible
Funding status	Funded from the hospital's global budget
Contact	Jeannie Kelso, RRT/Home Care Coordinator McMaster Children's Hospital; kelso@hhsc.ca 905-521-2100, ext. 73650 OR Rose-Frances Clause, RN/APN (Pediatric Nurse Practitioner) McMaster Children's Hospital clause@hhsc.ca 905-521-2100, ext. 73035.

LHIN	North Simcoe Muskoka
Host organization	North Simcoe Muskoka Community Care Access Centre
Target population	Ventilator-assisted individuals living in the community
Description of service	**CCAC provides respiratory therapy (RT) services in home, by purchasing RT hours as needed from the Royal Victoria Hospital**
Outcome	Continuity of care as the ventilator-assisted individuals are already known to the therapist Increased client satisfaction Improved health outcomes Prevents hospital admissions
Funding status	Funded from the CCAC's global budget
Contact	1 888 721-2222

LHIN	South West
Host organization	London Health Sciences Centre
Target population	Individuals requiring long-term ventilation (LTV), both invasive (IV) and non-invasive (NIV). These are individuals that: • Have been discharged home from ICU on invasive ventilation • Are at-risk with neuromuscular diseases that have been electively started on intermittent non-invasive ventilation. • Transferred from the IV/NIV program at the Children's Hospital of Western Ontario.
Description of service	Monthly outpatient clinic to support and keep ventilator-assisted individuals in a community setting. A respirologist or intensivist and clinical discharge respiratory therapist staff the clinic for scheduled follow up and accept new referrals for assessment.
Outcome	Proactive care of complex medical patients requiring LTV to prevent hospital and ICU admission.
Funding status	Funded from the hospital's global budget
Contact	Dr. David Leasa david.leasa@lhsc.on.ca OR Joanne Smith, RRT joannem.smith@lhsc.on.ca

LHIN	South West
Host organization	Western Proresp
Target population	Ventilator-assisted individuals of London Health Sciences living in the community
Description of service	Joint venture between Proresp (private supply company) and London Health Sciences. Respiratory therapists are employed to educate and support ventilator-assisted individuals living in the community
Outcome	Individuals who live in regions where this partnership exists are discharged home more easily as they are assured of support at home.
Funding status	Unfunded ***(have asked for clarification)***
Contact	Bob Small, Manager or Dave Jones Western ProResp 43-699 Wilkins Street London, Ontario N6C 5C8 519-686-6212

	British Columbia
Host organization	Provincial Respiratory Outreach Program (PROP)
Target population	Ventilator-assisted individuals living in the community
Description of service	The program provides a comprehensive range of equipment and supplies, respiratory therapy, education and peer group support. PROP clients can call a respiratory therapist 24 hours a day.
Outcome	Client moves into the community with a full slate of services to help with ventilator needs and with access to the information needed to make decisions about their own health care.
Funding status	British Columbia Ministry of Health
Contact	1-866-326-1245 prop@bcits.org

Intensive Care Units

LHIN	South West
Host organization	London Health Sciences Centre
Target population	Identification and selection of ICU patients considered to be potential candidates for long-term ventilation (LTV) in a community setting.
Description of service	From within the traditional ICU boundaries of care, London has developed an interprofessional team of care providers (e.g., physicians, nurses, respiratory therapists, physiotherapists, nutritionists, social workers) to transition selected ventilator-assisted individuals from the ICU to other more appropriate community settings in a safe and timely manner. We have been able to overcome the many obstacles inherent in this process.
Outcome	Earlier identification for focused care to selected LTV patients to reduce ICU and hospital length of stay. Safer transfer of patient care to community and family providers.
Funding status	Funded from the ICU budget
Contact	Dr. David Leasa david.leasa@lhsc.on.ca OR Cathy Mawdsley, CNS cathy.mawdsley@lhsc.on.ca

Intermediate Care

LHIN	Toronto Central
Host organization	West Park Healthcare Centre
Target population	Ventilator-assisted individuals who wish to return to live in the community
Description of service	Home Ventilation Training: assessment and training to prepare ventilator-assisted individuals and their caregivers to live in the community. Regular reassessments. Caregiver training both at West Park and off site.
Outcome	Currently providing respiratory follow up for over 270 individuals in the community, 200 of which use non invasive ventilation. Increased number of ventilator-assisted individuals who are prepared for home ventilation and can be safely discharged from hospital. Decreased number days that these individuals stay in an intensive care unit. Decreased number of times that these individuals return to an intensive care unit
Funding status	Ministry of Health and Long Term Care
Contact	Carlos Bautista, Manager – Respiratory Services (416) 243-3600 ext. 2063 carlos.bautista@westpark.org

Appendix I: Other Resources

Several resources (web-based and others) were identified during the focus groups. This appendix provides the web address or other contact information for these resources.

Centre of Excellence for Long-Term Ventilation:

Donna Renzetti
Interim Vice President Programs
West Park Healthcare Centre
416-243-3600 ext. 2063
donna.renzetti@westpark.org

Centre of Excellence for Weaning:

Nancy French
Manager Progressive Weaning Centre
Toronto East General Hospital
416 469 6580 ext. 6103
nfre@tegh.on.ca

Other resources:

- West Park Healthcare Centre's website for its Long-term Ventilation Centre of Excellence is available to providers and users:
  www.ltvcoe.com
- The Respiratory Rehabilitation Service of The Ottawa Hospital also has a website with general information:
  http://www.ottawahospital.on.ca/sc/rehabcentre/servicesclinics/respiratory-e.asp
- Health Canada provides an on-line resource to assist with decision-making in related to end of life care and advanced care plans.
  http://www.hc-sc.gc.ca/hcs-sss/palliat/res/index_e.html
- An organization in the US has developed tips for ventilator users to prepare themselves for an emergency.
  http://www.ventusers.org/vume/intro.html
- Polio Health International in St. Louis provides information for this subpopulation:
  http://www.post-polio.org/index.html
- Algonquin College Health Science Simulation Lab for education of nurses and respiratory therapists. Computerized mannequins with digital video camcorder, which allows recording of training sessions for later review or video-streaming to remote areas.
  http://www.algonquincollege.com/pembroke/programs/BSCN/facilities.htm
- Conestoga College Respiratory Therapy program has a SIMLAB, which is also used for continuing education for nurses. Students have the opportunity to practice tasks such as tracheostomy changes on mannequins.
  http://www.conestogac.on.ca/

  Contact: Karl Weiss, Health Sciences Clinical Learning Centre
  519.748.5220 ex 3457
- The ALS Society publishes a booklet about the disease progression, choices, planning and end-of-life decision making
  http://www.alsont.ca/resources/publications/

Appendix J: Suggested Projects for the Centres of Excellence

Best practices and protocols:

- For home ventilation training
- For end-of-life care and counselling
- Standards of care (for providers to be more comfortable with liability issues)
- Guidelines for discharge planners, including predictors of successful living in the community
- Weaning criteria; how to differentiate between individual with potential to wean versus individual likely to require long-term ventilation.

Description of community living options to inform hospital staff (e.g., physicians, discharge planners).

One-half day session in each LHIN (at the LHIN's request) to discuss weaning protocols and related other best practices.

Hotline for professionals to call for assistance with problem solving and troubleshooting and guidance regarding complicated individuals. (Although the Ventilator Equipment Pool has a hotline, it can only answer questions about equipment.)

Appendix K: Outstanding Proposals for LTV Services

LHIN	Centre	Description
Champlain	The Ottawa Hospital	The Community Noninvasive Ventilation Service: funded outpatient clinic for at risk population
Hamilton Niagara Haldimand Brant	St. Joseph's Health Care, Charlton site	Four-bed weaning unit to provide weaning for stable ventilated patients in a non-ICU environment for improved weaning, rehabilitation, and quality of life at a resource savings. This proposal is currently being revised for submission to include two more beds: an associated bed for elective and emergency respite to facilitate home ventilation of patients and an associated home ventilator training and assessment bed for transition to and maintenance of home ventilation.
North East	Hôpital régional de Sudbury Regional Hospital	Proposal by the complex continuing care unit for a 6-bed CAVC unit
North East	Independence Centre and Network (ICAN), in collaboration with the Hôpital régional de Sudbury Regional Hospital and North East CCAC	Four supportive housing units with attendant services, based on collaborative arrangements with the hospital and CCAC
South East	St. Mary's on the Lake (Kingston)	Funded CAVC beds
South West	London Health Sciences Centre	Funded outpatient clinic for at risk population
South West	London Health Sciences Centre	Ventilator Dependent Rehabilitation Unit

CAVC = chronic assisted ventilatory care
CCAC = community care access centre

Appendix L: Related Studies, Reports and Policies

Chronic Ventilation Strategy Task Force. Final Report. June 30, 2006. http://www.health.gov.on.ca/english/providers/program/critical_care/docs/report_cvtg.pdf
Critical Care Admission, Discharge and Triage Guidelines. Future deliverable of the Ethical Issues of Access to Critical Care component of the Critical Care Strategy. http://www.health.gov.on.ca/english/providers/program/critical_care/cct_access.html
Living Fully in Ontario Communities. People with spinal cord injuries & disease who use respiratory supports. Position paper produced by the Ontario Spinal Cord Injury Solutions Alliance. Version 1 – July 2008. Contact: Peter Athanasopoulos**,** SCI Network and Service Manager**,** Canadian Paraplegic Association Ontario petera@cpaont.org 1 877 422 1112 ext. 260 www.cpaont.org
Long-Term Ventilation Strategy Development for Ontario, Prepared for the Ministry of Health and Long-Term Care by the Toronto Central Local Health Integration Network, Final Report, January 2008 *(under embargo)*
Long-term Ventilation Strategy Development for Ontario. Attendant Service Options for Ventilator-Assisted Individuals, Companion document to the LTV Action Plan Final Report. December 31, 2007 *(under embargo)*
Long-term Ventilation Strategy Development for Ontario. Review of Current annual costs for LTV Inpatient Care. Companion document to the LTV Action Plan Final Report. December 31, 2007. *(under embargo)*
Unleashing Attendant Services: Enhancing People's Potential, Reducing Wait Times in Acute and Long-Term Health Care. Attendant Services Advisory Committee of the Ontario Community Support Association. July 2008. http://www.ocsa.on.ca/

Related Ontario Ministry of Health and Long-Term Care Strategies

Alternative Levels of Care Strategy (ALC)

The government committed to invest $45.2 million in its ALC strategy. The strategy includes three complementary programs :

- The Interim Long- Term Care (LTC) Bed Program, which provides $18 million to create up to 500 interim LTC beds for people who are waiting in hospital for a permanent LTC bed;
- The Convalescent Care Program, which provides $12.7 million to establish up to 340 convalescent care beds in LTC homes for people who no longer need intensive hospital care, but who are not yet ready to return home; and
- The High Intensity Needs Fund (HINF) provides $33 million to purchase equipment and supplies needed for the care of residents who require the highest levels of care in a LTC setting.

End-of-Life Care Strategy

In October 2005, the government committed $115.5 million investment over three years to an End-of-Life Care Strategy to improve care services at home as well as in the community. The achievements under the strategy in 2007-08 included :

- Support for nursing and personal support services in residential hospices in over 34 communities; and
- Over 6,000 more Ontarians began receiving compassionate, end-of-life care in their homes.

Aging at Home Strategy

On August 28, 2007, the government announced the Aging at Home Strategy. The government will invest more than $700 million over the next three years to provide seniors and their caregivers with an integrated continuum of community-based services to enable them to stay healthy and live more independently in their homes.

The Aging at Home Strategy will offer new possibilities for Ontario's culturally diverse population that will emphasize community-based partnerships and an integrated continuum of services and supports for seniors and their caregivers.

LHINs are taking a leadership role to plan, integrate and fund services at the local level to create significant change in the range of health and community care services available for seniors in Ontario.

Source: Results-based Plan Briefing Book 2008-2009
http://www.health.gov.on.ca/english/public/pub/ministry_annual/annual_rep08_09/annual_rep08_09.html

Appendix M: Potentially Relevant Innovations in other Populations

Focus Group participants mentioned a variety of innovative strategies for the delivery of care and services to other patient populations, suggesting that these strategies might be relevant and useful in meeting the needs of the ventilator-assisted population. This appendix lists five of those initiatives.

1. Videoconferencing technology is currently being used to link cardiac patients in remote areas with a cardiologist. For many ventilator-assisted individuals living in the community, it is difficult to attend appointments outside of the home. It was suggested that videoconferencing could be used to enable physicians to "visit" these individuals using this technology.

2. My Care Source technology is currently being used to link cancer patients with physicians via the internet. A web-based program could also be used to monitor ventilator-assisted individuals living in the community, with the ventilators providing information about individual's status.

3. The Ontario Telehealth Network currently provides services across many health issues across the province. There could be a role for the OTN in the care or services specific to the ventilator-assisted population.

4. Ontario's family health teams (FHTs) could provide a model for the interprofessional model of care needed for the at-risk and ventilator-assisted populations.

5. In the Chronic Obstructive Pulmonary Disease (COPD) initiative, pharmacists are sponsoring respiratory therapists to run clinics for this patient population. This model could be used for the ventilator-assisted population as well.