

Chronic Ventilation Strategy Task Force

Final Report

June 30, 2006

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Executive Summary

Introduction

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

During its research, the Committee discovered that many intensive care unit (ICU) beds in Ontario were occupied by chronically-ventilated patients who were otherwise medically stable. Although these patients did not need the critical care services available in an ICU, and were not receiving the rehabilitative and other services they did require, there appeared to be no adequate alternative setting for these patients. Accordingly, the Committee identified the need for a strategy for the care of these chronically-ventilated but medically-stable patients.

Following the acceptance of the Committee's final report, the Ministry established the Ontario Critical Care Expert Advisory Panel, under the direction of Dr. Alan Hudson (Lead, Access to Services and Wait Times Strategy), to oversee all aspects of the Critical Care Transformation Strategy. The Expert Advisory Panel in turn established the Ontario Chronic Ventilation Strategy Task Group (the Task Group) to address the Committee's recommendations.

The Task Group's Mandate

The Task Group's immediate mandate was to identify effective short-term strategies to facilitate the transfer of medically-stable, chronically-ventilated patients 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 chronically-ventilated patients.

For the purpose of this work, the target patient population was defined as ventilator dependent patients. The Task Group chose the following specific definition for these patients:

“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).”

The Task Group's strategy was to include recommendations about the nature and scope of the investments required to address the needs of these patients in Ontario, as well as proposed funding criteria for the Ministry's consideration. Funding recommendations to specific facilities were outside the Task Group's mandate.

Methodology

The Task Group undertook five major types of research and analysis to support its recommendations:

- A review of published literature on this patient population.
- Research of how these patients are cared for in other jurisdictions.
- Five surveys in Ontario:
 - All acute care hospitals regarding critical care services provided to ventilator-dependent patients and information about these patients.
 - All complex continuing care hospitals.
 - All Community Care Access Centres (CCACs).
 - A sample of ventilator-dependent patients living in the community.
 - All hospitals regarding outreach and outpatient services provided to this patient population.
- Demand projections.
- A cost analysis.

Key Findings

The Task Group found ample evidence to support the generally held view that there is insufficient capacity in the system to meet demand at this time. We determined that the demand by this patient population for ICU beds would grow between 92 and 120% over the next 25 years. The number of ventilated patients living in the community, some of whom will eventually experience an acute episode that brings them to the ICU and, potentially, to long-term institutional care, is also projected to place an increasing burden on our healthcare institutions. Without a major change in how we manage these patients, the investment needed to provide adequate – much less quality – care for these patients will be significant.

In ICU beds across the province, we found 45 patients who were waiting for alternative care, but there is insufficient capacity for weaning, rehabilitation and complex continuing care for these patients, with waiting lists as long as two years for one major centre. Some of the current capacity is underfunded and is, therefore, at risk of further reductions in the level of service. The Task Group estimated that between 1,000 and 2,000 additional ICU admissions could be accepted into current facilities if medically-stable chronically-ventilated patients were discharged in a more timely fashion to a more appropriate setting. This number will increase significantly over time if there is no change to how these patients are managed.

Every year, patients with degenerative neuromuscular diseases are admitted to an ICU somewhere in the province when they experience an acute episode of respiratory failure, at which time a decision must be made to initiate invasive ventilation or not. Too often, these patients have not been fully informed about their disease, its prognosis, and the benefits and draw backs of invasive ventilation so that they can make informed choices about their long-term care before a crisis occurs.

Health care professionals have a legal, moral and ethical obligation to discuss the prognosis, the likely course of action, and advanced planning of treatment with their patients. However, physicians are not well trained to have these types of conversations and are often reluctant to provide the patient with what the physician perceives to be a bleak prognosis. The

conversation is either delayed or avoided altogether until the patient has an acute episode and requires intubation and eventual placement of a permanent tracheotomy. These conversations should be revisited frequently to ensure that the patient and family are making informed decisions about the patient's long-term care.

In Ontario, there are approximately 1,400 ventilator-dependent patients who are living in the community. However, the medical, psychosocial and spiritual needs of these patients are sometimes very complex and require care providers with a high degree of training and specialization. The low patient volumes sprinkled throughout the province and the need for highly skilled health care professionals (especially physicians, nurses and respiratory therapists) severely limits the ability to provide safe and cost-effective care close to home for many of these patients.

The Task Group found both well-established and newly-created services providing high quality services locally and provincially to these patients along the full continuum of care. However, there is no coordinated strategy for the delivery of care; these services were developed and sustained by the commitment and passion of independent teams of health care professionals.

Accordingly, there is wide variation in access to services across the province, with much of the inpatient capacity for these patients located in the Greater Toronto Area and smaller centres in London and Ottawa. Outside of these cities, patients have few options for long-term institutional care.

The Task Group heard of inadequate home care supports for ventilator-dependent patients. Although it is generally believed that the patient enjoys a higher quality of life in the home or other community setting than in the hospital, the necessary supports for successful home placements— including respite for the caregivers – are not in place.

Recommendations

Recommendation 1: That the Ministry of Health and Long-Term Care immediately establish six new beds for weaning and up to 20 new beds for institutional long-term care for medically-stable, ventilator-dependent patients at facilities that are capable of opening these beds in the very short term. Patients in an ICU would have priority access to these beds. Each expanded site should dedicate at least one of the new beds to respite care and designate some of the additional capacity for reassessment of patients living in the community. This capacity should be made available as quickly as possible, preferably within six months.

Recommendation 2: That the Ministry of Health and Long-Term Care, in addition to creating additional institutional capacity, ask all institutions (including intensive care, chronic assisted ventilatory care and complex continuing care units) to identify any ventilator-dependent patient in their care who would prefer to be in a community setting and their medical condition would allow discharge to an appropriate community setting. For each of these patients, a supportive care (attendant housing) option should be provided if the patient and family are agreeable and an appropriate placement can be established. Where demand is high, these services could include beds for respite care.

This capacity should be made available as quickly as possible, preferably within six months.

Recommendation 3: That the Ministry of Health and Long-Term Care fund all inpatient beds for chronically ventilated patients identified in this report (existing and proposed) according to the average cost of the existing programs (i.e., at a rate that reflects the incremental costs of providing care for these patients beyond the average cost for a step-down or complex continuing care bed) and include reimbursement for ventilator equipment and supplies required by the patient. All outpatient clinics and outreach programs for this patient population should be funded according to the resources required to staff these programs to meet expected demand.

Recommendation 4: That the Ministry of Health and Long-Term Care establish a Chronic Ventilation Network that includes all centres and organizations in Ontario that provide services to patients who are, or who are at risk of becoming, ventilator dependent. The Network's responsibilities would include:

- Working with Local Health Integration Networks (LHINs) to assess the on-going need for these services and the adequacy of the services provided and to develop solutions that reflect the unique characteristics of the local network.
- Identifying and documenting best practices for the care of ventilator-dependent patients across the continuum of care.
- Facilitating the timely flow of communication between all providers in the service continuum.
- Advising the Ministry on the needed supports and infrastructure for successful community living.
- Fostering the development and delivery of training programs for health care professionals to care for this patient population.

The Network should be supported through the development and operation of a central patient registry to collect a minimum data set on all chronically ventilated patients (whether in the community or an acute care or long-term care institution) to support continuity of patient care at any of the multiple participating institutions in the province, the evaluation of the proposed strategy, planning for future capacity, and key areas of research, especially those identified by this Task Group as needing attention.

Recommendation 5: That the Ministry of Health and Long-Term Care designate one centre as a provincial Centre of Excellence in the weaning of ventilator-dependent patients that would serve to assist and train health care professionals in other parts of the province (where the need justifies the investment and the resources are available to provide the service) to deliver as close to their communities as possible the highly specialized care needed to wean ventilator-dependent patients.

Recommendation 6: That the Ministry of Health and Long-Term Care work with the Centre of Excellence and other health care provider and education partners to develop and implement a formal training program for physicians (e.g., respirologists, critical care specialists, general internists, pediatricians, neurologists, general practitioners) and allied health professionals (e.g., registered nurses, respiratory therapists, nurse practitioners,

occupational therapists and physiotherapists) to care for this patient population. This program would have a provincial mandate.

Recommendation 7: That the Ministry of Health and Long-Term Care work with health care education partners to develop and launch an education program for health care professionals in the community (e.g., physicians, respiratory therapists, registered nurses, personal support workers and therapists) to help them identify those patients who are at risk of developing respiratory failure. The program should include the importance of referring these patients to an appropriate clinic or, if there is no clinic in the immediate area, the program should provide the education and training the physician will need to plan and manage patient-centered care for these patients, including end-of-life decision making.

Recommendation 8: That the Ministry of Health and Long-Term Care and appropriate stakeholders support and enhance, in cooperation with patient advocacy groups including, for example, the Canadian Lung Association, the ALS Society, Muscular Dystrophy Association, Heart and Stroke Foundation, existing educational programs and, where needed, develop and launch new educational programs for patients and caregivers regarding options for care to enable informed decision making for their long-term care.

Recommendation 9: That the Ministry of Health and Long-Term Care and, in due course, the Local Health Integration Networks, improve the support provided for ventilator-dependent patients living in the community by:

- Providing and funding additional services for ventilator-dependent patients living in the home. These additional services would include respiratory therapist services. These services could be delivered through CCACs or a hospital-based service.
- Establishing a higher limit on the number of hours (i.e., a total of eight hours per day) of care that can be made available to the patient and family in a given period for other services including shift nursing.
- Providing and funding, through either the Assistive Devices Program and its Ventilator Equipment Pool or CCACs, the full range of equipment and supplies required by ventilator-dependent patients living in the community. Consideration should be given to the funding of equipment that will support the management of non-invasive ventilation, such as cough-assist devices and equipment used for volume augmentation.
- Subsidizing the incremental costs incurred by having a ventilator-dependent patient in the home (e.g., incremental hydroelectric use for the ventilators and related equipment, and transportation).

1.0 Introduction

1.1 The Ontario Critical Care Steering Committee

In 2004/05, the Ministry of Health and Long-Term Care (the Ministry) launched a four-year Critical Care Transformation Strategy as part of a broader Access to Services and Wait Times Strategy. The purpose of the strategy was to improve quality of care and system performance in adult critical care services in Ontario. In the first year of this strategy, the Ministry established 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. The Committee's final report was presented to the Minister in March 2005.

During its research, the Committee discovered that many intensive care unit (ICU) beds in Ontario were occupied by chronically-ventilated patients who were otherwise medically stable. Although these patients did not need the critical care services available in an ICU, and were not receiving the rehabilitative and other services they did require, there appeared to be no adequate alternative setting for these patients.

Accordingly, the Committee identified the need for a detailed care strategy and associated resource allocation recommendations to address the needs of these chronically-ventilated but medically-stable patients. As the report states:

“The Committee is concerned about the number of long-term ventilated patients in Ontario ICU beds who do not require ongoing critical care support. Maintaining these patients in critical care beds limits access to critical care for Ontarians who may need it, and is an inefficient and inappropriate use of valuable healthcare resources. In addition, this situation has a detrimental effect on the quality of life of these patients. Long-term ventilated patients receive better care when they are treated by a healthcare team experienced with meeting their unique needs.”¹

The Committee also made one specific recommendation regarding the delivery of care for chronically-ventilated patients that:

The Ministry of Health and Long-Term Care enhance the capacity of critical care resources in Ontario by increasing the number of chronically ventilated beds in Ontario in a timely fashion. These beds should be sited where the need is the greatest. In addition, the Ministry should support the expansion of innovative chronic ventilatory services such as home ventilation to meet the needs of these patients. (Recommendation #8)

Following the acceptance of the Committee's final report, the Ministry established the Ontario Critical Care Expert Advisory Panel, under the direction of Dr. Alan Hudson (Lead, Access to Services and Wait Times Strategy), to oversee all aspects of the Critical Care Transformation Strategy. The Expert Advisory Panel in turn established the Ontario Chronic

Ventilation Strategy Task Group (the Task Group) to address the Committee's recommendations.

1.2 The Task Group's Mandate

The Task Group's immediate mandate was to identify effective short-term strategies to facilitate the transfer of medically-stable, chronically-ventilated patients 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 chronically-ventilated patients. The Task Group's terms of reference are provided in Appendix A. The Task Group's membership is provided in Appendix B.

For the purpose of this work, the target patient population was defined as ventilator-dependent patients. The Task Group chose the following specific definition for these patients:

“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).”

This would include patients in the recovery phase of the acute respiratory distress syndrome (ARDS) and those recovering from an exacerbation of chronic obstructive pulmonary disease (COPD), as well as patients with progressive degenerative neuromuscular diseases and spinal cord injuries who could potentially be transferred to alternate care outside of a critical care unit.

The Task Group's strategy was to include recommendations about the nature and scope of the investments required to address the needs of these patients in Ontario, as well as proposed funding criteria for the Ministry's consideration. Funding recommendations to specific facilities were outside the Task Group's mandate.

At its discretion, the Task Group could choose to provide recommendations regarding the management of chronically-ventilated patients while in the critical care unit, such as strategies to optimize patient flow, to meet the needs of patients on the waiting list in the intensive care unit, and to facilitate the discharge of patients from the critical care unit.

The original mandate was to study the adult patient population. However, during its deliberations the Task Group realized that the needs of pediatric and adult patients were very similar and that many adult patients begin as pediatric patients. The Task Group has commented on specific pediatric issues that were raised during the course of our research.

Palliative care for ventilator-dependent patients was outside the scope of this study.

Similarly, the care of medically-stable but ventilator-dependent patients who are in a persistently vegetative state is also outside the scope of this Task Group's mandate. The Task Group recognizes that the existing chronic assisted ventilatory care services in Ontario

are not currently equipped or staffed to effectively monitor these patients. The medical, ethical and legal issues regarding these patients will be discussed as part of another work package being undertaken by the Critical Care Secretariat on the bioethical issues of critical care in general.

1.3 Organization of the Report

The remainder of this report is organized as follows:

- Chapter 2 describes the methodology used by the Task Group for its research and analysis.
- Chapter 3 describes the patient population, including a clinical description of the various subgroups and a description of their care needs.
- Chapter 4 describes how the care of these patients is currently organized in Ontario and identifies issues related to the current delivery.
- Chapter 5 presents a discussion of what the Task Group learned about how care is delivered to this patient population in other jurisdictions.
- Chapter 6 presents the evidence base, both published and unpublished, that informed the Task Group's deliberations.
- Chapter 7 presents the Task Group's conclusions and its recommendation.
- The recommendations are listed in Chapter 8.

A glossary of technical terms is provided at the end of this report.

2.0 Methodology

The Task Group undertook five major types of research and analysis to support its recommendations:

- A review of published literature on this patient population.
- Research of how these patients are cared for in other jurisdictions.
- Five surveys in Ontario:
 - All acute care hospitals regarding critical care services provided to ventilator-dependent patients and information about these patients.
 - All complex continuing care hospitals.
 - All Community Care Access Centres (CCACs).
 - A sample of ventilator-dependent patients living in the community.
 - All hospitals regarding outreach and outpatient services provided to this patient population.
- Demand projections.
- A cost analysis.

The methodology used for each of these tasks is provided in the following sections.

2.1 *Published Literature*

For the purpose of the published literature review, we defined the ventilator-dependent patient as an adult patient (greater than 16 years old) who is dependent on a mechanical ventilator for at least six hours daily for greater than 21 days, but is otherwise medically stable (i.e., single organ failure).

Five separate reviews were undertaken to answer the following questions related to ventilator-dependant patient:

- What are the primary reasons for delayed discharge from the intensive care unit (ICU)?
- What types of discharge planning strategies have been used to improve outcomes (e.g. ICU/hospital length of stay (LOS), quality of life (QoL), mortality, morbidity, costs)?
- Does the presence of an intermediate care unit in an acute care hospital improve outcomes?
- What are the benefits of home mechanical ventilation (HMV) compared to the acute or complex continuing care settings, including a discussion of:
 - Which particular patients benefit from HMV?
 - What is the burden of HMV on caregivers and families?
- What policies and strategies have been employed by other jurisdictions (within and outside of Canada) to improve the management and outcomes?

For each literature search, we used Medline, restricted to articles published in North America, Europe, the United Kingdom, Australia or New Zealand. There was no limit established for the publication date.

2.2 Research of other Jurisdictions

To understand further the policies and strategies used in other jurisdictions, a review of unpublished literature and interviews complemented the literature review.

This research included a general Internet search and a review of public websites for health authorities in the United States, Australia, and the United Kingdom. Interviews were conducted with representatives of programs along the continuum of care in other provinces (e.g., British Columbia, Alberta, Saskatchewan, Manitoba, and Quebec).

2.3 Surveys

The Task Group developed five questionnaires, one for each of the following targets:

- The 80 acute care hospitals representing 139 critical care units that can provide invasive mechanical ventilation (the critical care survey).
- All five complex continuing care hospitals that might have CAVC services and Toronto East General Hospital that has recently established a 10-bed CAVC service (the CAVC survey).
- The 42 Community Care Access Centres (CCACs) for home ventilated patients (the CCAC survey).
- A sample of 350 patients (all of the 132 invasively-ventilated patients and a stratified random sample – by client age – of 218 non-invasively ventilated patients) in the Ontario Ventilator Equipment Pool (VEP), living at home (the home vent survey). Note that we did not survey all of the 1,405 patients registered with the VEP.
- All hospitals regarding outreach and outpatient services (the outpatient/outreach survey).

Critical care units were asked about their bed capacity, monthly occupancy rates, the number of ventilator-dependent patients during September 2005 and on November 1, 2005, and, for each of those patients, detailed information such as the patient's age, date of admission and discharge, ventilation start and stop dates, source of admission and discharge disposition from the critical care unit. They were also asked about the types of services provided, as well as their perceptions and practices surrounding this patient population.

For the CAVC survey, participating facilities were asked about the types of services they provided, eligibility criteria for these services, the number of patients in their care, the relationship between capacity and demand in their area and their interest in expanding their service. The facilities were also asked to provide detailed information on the individual patients, including age, admitting diagnosis, method and frequency of ventilator support and history of hospitalization.

The CCACs were asked about referral sources, patient volumes, discharge planning times, and challenges in accepting and providing service to ventilator-dependent patients. For each patient receiving CCAC services, the CCACs were asked to provide demographic information, as well as the type and duration and hours per day of mechanical ventilation, specific services provided, and the costs to the patient of these services. All patient-specific

data were requested for patients in the service or being provided with home-care services on November 1, 2005.

The VEP clients were asked for demographic and ventilatory care information as well as information on the professional services provided to the patient. This survey also requested information about the primary caregiver for the individual using home mechanical ventilation.

During the course of its research, the Task Group identified an issue around access to outpatient and outreach services for ventilator-dependent patients living in the community. To better understand this issue, the Task Group conducted a fifth survey of all hospitals to identify the nature and scope of outpatient and outreach services delivered as routine or non-routine services for this patient population.

The number of surveys sent, the response rates, and the number of facilities that reported serving the target population are presented in Table 1.

Table 1: Surveys Sent, Response Rates and Facilities Serving the Target Population

Service	Number sent	Responses received		Respondents providing services for target population	
		#	%	#	%
Critical Care	135*	103	76%	30**	29%
CAVCs	6	5 ⁺	83%	4	80%
CCACs	42	35	83%	20	57%
Home ventilation	323 ⁺⁺	98	30%	N/A	N/A
Outpatient/outreach	155	118	76%	14	12%

ICU = Intensive Care Unit, CAVC = Chronic Assisted Ventilatory Care, CCAC = Community Care Access Centre, N/A = not applicable

Responses as at Feb 6, 2006 except for the Outpatient/outreach survey, which is current to Feb 24, 2006.

The reader should note the low response rate (30%) for the home vent survey of ventilator-dependent patients living in the community.

2.4 Demand Analysis

The Task Group engaged Dr. Eric Nauenberg from the Ministry's Integrated Planning and Policy (IPP) Division to develop needs-based projections for this patient population to the year 2031.

* A total of 139 surveys were sent, but four units reported they no longer supported patients on invasive mechanical ventilation or the unit no longer existed.

** Reported one or more ventilator-dependent patients during September 2005.

⁺ Sisters of Charity in Ottawa is known to have an eight-bed CAVC service, but did not respond to the survey.

⁺⁺ Three hundred and fifty surveys were sent out to a sample of the 1,405 patients registered with the VEP. Twenty-seven were returned by Canada Post (26) or by a family member (1) of a deceased patient.

Separate projections were made for three distinct patient groups: patients in an ICU, non-invasively home-ventilated patients, and invasively home-ventilated patients. The patient group in CAVC services was too small to be projected separately and was included in the invasively-ventilated home population.

The needs-based projections were developed using the Ontario Ministry of Finance's population growth projections by five-year age category, based on the Statistics Canada 2001 census data. Three scenarios were examined: the reference (or base line) projection, a low growth and a high growth scenario.

The starting values for each population were taken from the survey responses. It was assumed that the occupancy data provided for September 2005 were representative of the patient population throughout the year. To simplify the analysis, it was assumed that there was no excess or shortage of capacity in the system in 2005.

Although the survey response rates were less than 100%, it is assumed that the number of patients reported by those who responded is a reliable estimate of the total need at this time. We also discovered during our research that some ventilated patients are receiving services in hospital wards (i.e., not in the ICU or CAVC service), and these patients were not captured in the formal survey. This patient population is believed to be small.

The projections were adjusted to reflect expected changes in the incidence of some diseases (e.g., COPD as the impact of historical increases in smoking is felt) and prevalence (e.g., muscular dystrophy as these patients enjoy a longer life expectancy). These adjustments were made based on recently published literature.

2.5 Cost Analysis

Dr. Nauenberg was also engaged to conduct a cost analysis of providing care for this patient population in different settings. Per diem costs for hospital settings were collected from a variety of sources:

- Per diem costs for ICU beds were provided by the Ontario Case Cost Initiative (OCCI). Separate direct and indirect costs were provided for ICU costs in academic health science centres and for community hospitals.
- Per diem costs for chronically-ventilated patients in an ICU were assumed to be lower than the costs for more acutely ill patients. Estimates for a community hospital setting were provided by officials at Mount Sinai Hospital.
- Direct and indirect costs for a CAVC service were estimated based on experience from one hospital that had a critical volume of chronically-ventilated patients. An estimate of the cost of rehabilitation and home-ventilator training program beds were also estimated by the same hospital.

These cost estimates were compared to the reported costs and cost comparisons (by setting) in published literature from Canada, the United States and Europe.

2.6 Secondary Review

The Task Group's research, analysis and recommendations were documented in a final draft report. This report was sent to a secondary review panel comprising clinicians and administrators, along the entire continuum of care, and across the province. The comments provided by these reviewers were incorporated into the Task Group's final report.

A list of the secondary reviewers is provided in Appendix C.

3.0 The Ventilator-Dependent Patient

3.1 Patient Profile

There are three main types of diagnosis for patients who become ventilator dependent:

1. Acute lung injury/acute respiratory distress syndrome (ARDS).
2. Chronic Obstructive Pulmonary Disease (COPD).
3. Non obstructive ventilatory failure, which includes the following conditions:
 - a) Degenerative neuromuscular diseases (NMDs)
 - b) Thoracic cage deformities (e.g., kyphoscoliotics)
 - c) A high spinal cord injury.

The onset of some of these diseases is during childhood (e.g., muscular dystrophy), while others are more likely to affect the individuals as young adults. With these diseases (except spinal cord injury, which is the result of trauma), the patient's condition gradually deteriorates over time, until the patient 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.

3.1.1 Invasive versus Non-invasive Ventilation

For invasive ventilation, the interface between the patient's respiratory system and the ventilator is a tracheostomy tube. The insertion is made through the neck directly into the trachea. For non-invasive ventilation, the interface is a mask covering the nose (i.e., nasal mask) or a mask covering the nose and mouth (i.e., a full face mask).

The choice of interface between the ventilator and the patient is made by patient, with advice from the healthcare professionals, specialists in respiratory medicine, and will depend on both medical needs and the patient's comfort, as these individuals are on long-term ventilation.

The care of invasively-ventilated (i.e., tracheostomized) patients has an element of complexity related to the maintenance and cleaning of the equipment and the interface with the patient. When these patients reside in the community, training of the patients and caregivers is needed.

Both invasively and non-invasively ventilated patients have complex care needs, particularly as the disease progresses and the patient's function is compromised. Caregiver(s) will likely require additional assistance in the form of home visits by health care professionals and respite care services.

3.1.2 Mandatory versus Elective Ventilation

Mechanical ventilation is requisite to sustain life for those patients who experience an acute episode of respiratory failure, which might occur as the underlying disease progresses or after

a catastrophic event (i.e., spinal cord injury). These patients are always admitted to a critical care unit and mechanical ventilation is initiated there.

Elective ventilation might be initiated in patients with a degenerative disease who choose 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 Patient Needs

3.2.1 Elective Ventilation

Patients with progressive degenerative diseases (especially patients with degenerative progressive neuromuscular diseases), their families, and primary healthcare providers need education regarding the natural progression of the disease. The type of education needed includes the following topics:

- How the patient’s condition will inevitably deteriorate to the point where the patient must be mechanically ventilated on a continuous basis. The demise of these patients is usually related to the natural progression of the disease. End-of-life planning, especially the initiation or not of elective ventilation, and palliative issues should be discussed early in the course of the disease.
- The realities of the quality of life that can be expected as a ventilator-dependent patient. Patients and families should be fully informed about the care requirement and the limitations that will be associated with the ventilator dependency, as well as the progressive loss of function with neurological disease. Respiratory failure occurs at the same time as the patient loses the ability to communicate, has lost the ability to swallow (and has to be fed through a tube inserted directly into the stomach) and has completely lost muscular function. With early education, the patient and family have an opportunity to determine what level of care they want to have.
- The advantages of elective ventilation. Electively ventilated patients can improve their quality of life, extend their life and frequently avoid admission to a critical care unit* through elective ventilation. By choosing to be ventilated on a part-time basis, the patient can likely avoid the risks and trauma of a critical care unit admission.
- Attitudes and treatment trends regarding long-term ventilation.
- Management and care options for those patients who chose not to be ventilated.

By discussing these issues before an acute event, the patient and family can be fully educated on the benefits and risks of the options available and the long-term implications of their decisions. Full education about these issues might avoid the need for the family, and sometimes the patient, to make such an important – and perhaps inappropriate – decision during a life-threatening situation full of stress and anxiety.

* The term “critical care unit” includes all intensive care units (ICUs) such as medical, surgical and trauma ICUs or burn units. Ventilator-dependent patients could come from any one of these locations.

3.2.2 The Critical Care Unit

When the critical episode is over and the patient is medically stable, even if the patient is still ventilator dependent, the critical care unit is not the best environment. Both the patient and the family might be reluctant to move the patient because they believe the medical resources that are available in the critical care unit are necessary for survival. However, this setting is not appropriate for these patients for the following reasons:

- The critical care unit is designed to deliver critical care. Once the patient is medically stable, the medical and clinical staff may not have the skills or an appropriate environment to meet the patient's ongoing medical, rehabilitative, nutritional and psychosocial needs.
- The critical care unit's physical environment is also inappropriate. The unit is typically noisy, with no routine to distinguish night from day and little privacy. Patients are often heavily sedated. The risk of nosocomial infections is also very high in a critical care unit, particularly for mechanically-ventilated patients.

At this stage in the patient's care, there is a need to ensure that the patient and caregivers are comfortable with leaving the critical care unit and that there are appropriate rehabilitation services to accept these patients.

3.2.3 Rehabilitation of the Medically-stable, Ventilator-dependent Patient

The National Institute of Health (NIH) has defined respiratory rehabilitation as follows:

“Multi-dimensional continuum of services directed to persons with pulmonary disease and their families, usually by an interdisciplinary team of specialists with the goal of achieving and maintaining the individual's maximum level of independence and functioning within the community.”²

Respiratory rehabilitation requires healthcare providers who are skillful in both rehabilitation and chronic ventilatory care.

Respiratory rehabilitation services include the following:

- Education for the patient and family about the patient's medical condition, the treatments needed to stabilize or improve the condition, and the role of the patient and family in achieving these goals.
- Breathing strategies and chest physiotherapy.
- Training of the patient and family in the activities of daily living (depending on the patient's degree of physical impairment).
- Exercise training whenever indicated to improve functional status as much as possible.
- Psychosocial support. If psychosocial issues such as depression are not dealt with, the patient's rehabilitation can be compromised.

Because these patients are mechanically ventilated, additional needs include:

- Swallowing assessment, especially for neurologically impaired patients. If the patient cannot swallow, a feeding tube may be needed.
- Upper airway assessment including assessment of communication means for the patient if he or she is unable to speak.
- Nutritional assessment and support.
- Assessment for assistive devices (e.g., seating, wheelchair, environmental access).

3.2.4 Long-term Care

It is generally believed that a home or community setting provides a higher quality of life for these patients. Several respondents to the home ventilation survey reported that home mechanical ventilation helped to keep the family together and improved the ventilator-dependent patient's quality of life, although the respondents were not specific about how their quality of life was improved other than "keeping the family together". However, depending on the patient's medical condition and the availability of appropriate home supports, the patient may need to be institutionalized.

In general, patients are only institutionalized when they do not have the necessary home supports (e.g., do not have a family or the family is too elderly or frail to care for the patient, or group home or attendant care facilities are not available for placement). Most patients are able to direct their own care – a necessary prerequisite for living at home. The medical condition and needs of patients are generally the same whether the patient is in an institution or community placement.

Whether the patient is in the community or an institution (e.g., a chronic assisted ventilatory (CAVC) service or a long-term care facility), the patient has certain on-going needs that are similar to the needs described in the previous section on rehabilitation:

- Frequent assessment by a healthcare specialist to determine whether the ventilatory needs have changed and care needs to be adapted (e.g., the patient might become more or less ventilator dependent over time, or the required ventilation may change from intermittent to continuous or non-invasive to invasive). For heavy care individuals, this requires inpatient beds for reassessment.
- Clinical services, including respiratory therapy services.
- Psychosocial support.
- Regular assessment for assistive devices needs.
- Funding.

If the patient is in the community, many of these services can be delivered by the caregiver(s), the Community Care Access Centre (CCAC), private services, hospital-based outpatient or outreach services, or not-for-profit agencies through a variety of referral mechanisms including centres for independent living.

Both the patient and the caregivers need training to prepare for home, community or institutional ventilation. In this context, the term “caregiver” refers to:

- Staff in the CAVC service.
- Staff in attendant care facilities, supportive housing, and group homes.
- Private caregivers who have been hired by the patient or family.
- Family members.

The type of training needed includes the follow areas:³

- Ventilator functioning and troubleshooting, and maintenance of ventilatory support by manual ventilation (e.g., bagging) in the event of a failure.
- Maintenance and care of circuits and accessories (e.g., connections to avoid leaks and cleaning of equipment).
- Pulmonary hygiene and airway maintenance, especially for tracheostomized patients, including suctioning, cleaning and changing the tracheostomy tube.
- Personal care (e.g., toileting, dressing, safe transfers, oral feeding or other routes).
- Full range of motion to avoid contractures.
- Positional changes to avoid tissue trauma.
- Wound care (decubitus ulcers or the areas of skin breakdown).
- Bladder and bowel routines.
- Management of medications.
- Management of an emergency situation.
- Communication techniques if the patient is unable to speak.

The patient will also need ventilator equipment and supplies and mobility aids. There is some funding available through the Ministry’s Assistive Devices Program (ADP) to cover these expenses. In the event of a power failure, the patient (especially if continuously ventilated) may also need an alternate power source.

Caring for a ventilator-dependent patient is very demanding of the caregiver(s). The caregiver(s) often are not able to sustain care over a long period of time without adequate supports, including periodic respite services. Task Group members acknowledged the burden placed on the caregivers and recognized the need for caregiver support in the community.

4.0 Utilization of Mechanical Ventilation in Ontario

There is no registry of all ventilator-dependent patients in Ontario. The Ventilator Equipment Pool (VEP), a service that loans ventilator equipment and supplies to ADP-approved patients living in the community, reported that it is currently supporting 1,405 ventilator-assisted individuals, which is the best estimate available for the total community-based population. Thirteen percent are pediatric patients.

Based on the surveys of ICUs and CAVCs and discussions with the Progressive Weaning Centre at Toronto East General Hospital,^{*} we estimate that an additional 80 ventilator-dependent patients are cared for in hospitals, for a total of approximately 1,500 in Ontario.

Much of the descriptive material in the following sections is based on the responses to our surveys. The reader is reminded that where the response rate was not 100%, the information must be interpreted with caution. The organizations and individuals that responded to our survey may not have been representative of the total population. As well, the number of patients has not been prorated to estimate the total patient population.

4.1 The Critical Care Population

As at November 1, 2005, 30 of the 103 critical care units responding to our survey reported having one or more patients who were medically-stable but still ventilator-dependent in their ICU on November 1, 2005, for a total of 45 patients. COPD (14%) and Amyotrophic Lateral Sclerosis (ALS) (12%) were the two most commonly reported most responsible diagnoses for ventilator dependence.

Most patients (78%) required continuous ventilation and 33% were expected to remain ventilator dependent for more than the five years. The most common admission sources were from a ward or unit within the hospitals (33%), the emergency department (20%), and the operating room (20%). On average, the patients were on mechanical ventilation for 141 days,^{**} with one patient on ventilation for 1,753 days (almost five years).⁺

4.2 The Home Ventilation Population

To estimate the number of ventilator dependent patients living in the community, we used the number of patients registered with Ontario's Ventilator Equipment Pool (VEP). The breakdown of the VEP registered clients by diagnosis is provided in Table 2. Although not all of these patients have conditions that ultimately lead to an acute episode and respiratory failure, they are all mechanically ventilated and meet the definition of a chronically-ventilated patient developed for this report.⁺⁺ Therefore, they will all require services, but to varying degrees of intensity.

^{*} Toronto East General Hospital has both a weaning unit and a CAVC service.

^{**} For patients that were still in the unit on November 1, duration was calculated for the period from ICU admission to November 1, 2005.

⁺ Based on point prevalence, November 1, 2005.

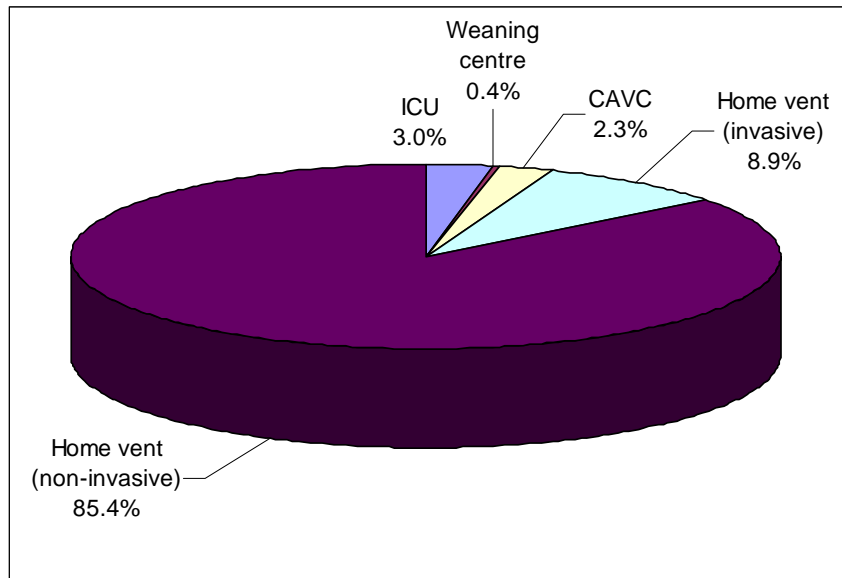
⁺⁺ Based on survey date (as presented in Table 3, all registered clients are ventilated for six or more hours per day.

Table 2: Profile of VEP Clients by Diagnosis

Diagnosis	Percent of clients
Neuromuscular disease	20.2
Chest wall/thoracic cage disorders	7.5
COPD	6.3
Spinal cord injury	2.5
Sleep-related disorders	28.9
Respiratory insufficiency (hypoventilation)	31.9
Other	2.7
Total	100.0

Ninety-five percent of the ventilator-dependent patients in Ontario* are currently living in the community, as shown in Figure 1. Most of these patients (86%) are non-invasively ventilated.

Figure 1: Ventilator-dependent Patients by Care Setting, Ontario, as at November 1, 2005**



ICU = Intensive Care Unit, CAVC = Chronic Assisted Ventilatory Care
Source: CVTG surveys. Responses as of February 6, 2006.

Respondents to the home ventilation survey were an average of 37 years of age (invasively-ventilated) and 48 years (non-invasively ventilated), ranging from one year old to 80 years, as shown in Table 3.

* Percentages apply only to those patients who are registered with the Ventilator Equipment Pool.

** Does not include any patients who might be in hospitals that did not respond to our surveys.

Table 3: Profile of Home-ventilated Patients

Characteristics	Invasive (n=52)		Non-invasive (n=46)	
	Number	Percent	Number	Percent
Average age (yrs)	37 (min 1, max 76)		48 (min 4, max 80)	
Male	34	65	28	61
Will remain vented > 5 yrs	43	83	40	87
Daily ventilation				
Only when asleep	12	23	20	44
6 to 12 hours	5	10	21	46
12 to 23 hours	9	17	3	7
24 hours	26	50	1	2

Source: Home ventilation survey. Responses as at February 6, 2006.

The invasively-ventilated population is relatively young, with almost one-half (48%) of the patients currently under the age of 30. The non-invasively ventilated population is older, with 60% of the patients over 50 years of year, which is more similar to the patients in ICU beds.

Most (63%) were male, and 85% are expected to remain on a ventilator for more than five years. Twenty-eight percent of the patients require continuous ventilation (i.e., 24 hours a day).

Although these patients are medically stable, their condition can deteriorate over time. The 98 respondents reported 66 hospital admissions, of which 45 were ICU admissions, over the past year, as shown in Table 4. Nine of the hospital admissions were for respite care.

Table 4: Hospital and ICU admissions of VEP clients within past year

	Invasively vented*		Non-invasively vented
	To Hospital	To ICU	To ICU
Illness	44	23	1
Elective procedures	13	6	-
Respite care	9	3	6

Source: Home ventilation survey. Responses as at February 6, 2006.

Most invasively-ventilated patients reported that they received additional specialized therapies. Specifically, they reported receiving:

- Suctioning (92%)
- Tube feeding (62%)
- Physiotherapy (33%)
- Supplemental oxygen (31%).

* For three patients (representing six ICU admissions) the distinction between ICU admission for elective investigation or illness was not made.

Respondents reported that their caregivers were predominantly female (78%) and a parent of the patient (54%), as shown in Table 5. Many were retired (27%) or unemployed (19%). Almost one in five (19%) work full-time. Caregivers of invasively-ventilated patients were more likely (64%) to have an alternate caregiver than those of non-invasively ventilated patients (48%).

Table 5: Profile of Caregivers for Home Ventilated Patients

Characteristics	Invasive (n=44)		Non-invasive (n=23)	
	Number	Percent	Number	Percent
Average age (yrs)	52 (min 33, max 76)		58 (min 32, max 76)	
Age of alternate caregiver (yrs)	45 (min 35, max 76)		53 (min 37, max 74)	
Female	33	75	19	83
Relationship to patient				
Spouse	17	39	9	39
Parent	25	57	11	48
Child	2	4	1	4
Employment Status				
Full time	9	20	4	17
Part time	8	18	2	9
Self employed	3	7	3	13
Retired	11	25	7	30
Unemployed	10	23	3	13
Alternate caregiver available	28	64	11	48

Source: Home ventilation survey. Responses as at February 6, 2006.

The average age of caregivers was 52 years for invasively-ventilated patients and 58 years for non-invasively ventilated patients. Some caregivers were as old as 76 years of age.

4.3 The CAVC Population

Four CAVC services in Ontario reported a total of 34 patients as at November 1, 2005, most of which (20) are at West Park Healthcare Centre in Toronto. The most common reasons for ventilator dependence was muscular dystrophy (40%), ALS (30%) and COPD (9%). Many (68%) require continuous ventilation, and most (88%) are also expected to remain ventilated for more than five years.

The average duration of mechanical ventilation was 3.2 years (minimum 4 months, maximum 16 years). The average age of these patients was 57 years (minimum 20, maximum 84).

Seven patients were re-hospitalized in an acute care setting since admission to the CAVC, including 13 admissions in the previous 12 months. This shows a much lower rate of readmission to an ICU than among the invasively home-ventilated patient population, as

shown in Table 6. **These statistics should be interpreted with caution, however, as the survey did not ask if the admission to acute care was due to respiratory illness or not.**

Table 6: Comparison of Admissions* to Acute Care, CAVC vs. Home-vent Populations

Characteristics	CAVC	Home Ventilated Patients	
		Invasively ventilated	Non-invasively ventilated
Number of patients or respondents	34	52	46
Admission to acute care in past year**	13 (13)	52 (38)	14 (7)
Average ICU admissions per patient	0.38	0.73	0.15

Source: CAVC and Home ventilation survey. Responses as at February 6, 2006.

4.4 Projected Growth in Demand for Chronic Vent Services to 2031

4.4.1 Projecting Growth Rates

Using the survey data as a starting point, the growth in demand for ventilator-dependent patients was projected using population projections by five-year age and sex breakdowns, as well as adjustments to the prevalence of muscular dystrophy and incidence of COPD. These projections were made using the following assumptions:

- No changes are made to how care is delivered to this patient population.
- The responses to the various surveys include the entire patient population (i.e., no adjustment was made to extrapolate to a larger number if the response rate was less than 100%).
- The reported patient volumes for the month of September 2005 was assumed to be more representative than the point prevalence provided for November 1, 2005.

Because of these assumptions, the resulting projections are useful for understanding the overall expected growth rate and how it varies by patient population. It is less useful for understanding the absolute number of patients today or in 2031.

Separate projections were made for three populations:

- ICU admissions
- Invasively-ventilated patients living in the community
- Non-invasively ventilated patients living in the community.

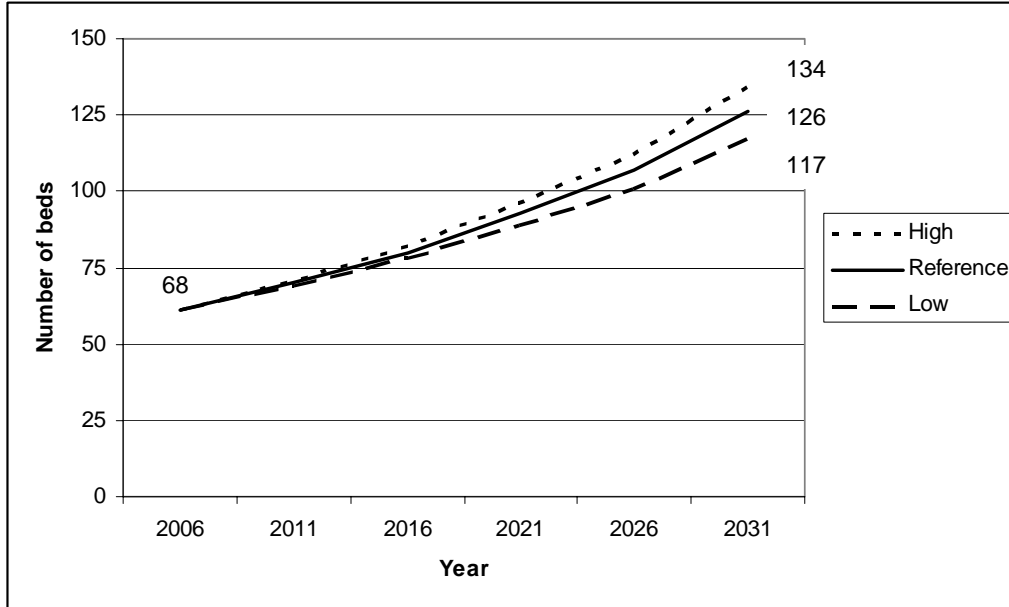
The number of ICU beds that are occupied by ventilator-dependent patients is projected to increase by a total of 107%, which is an annual average increase of 4.3%, as shown in

* Including ICU admissions.

** Figure in brackets is the number of admissions that were to an ICU. All admissions to acute care from a CAVC service are assumed to be to an ICU.

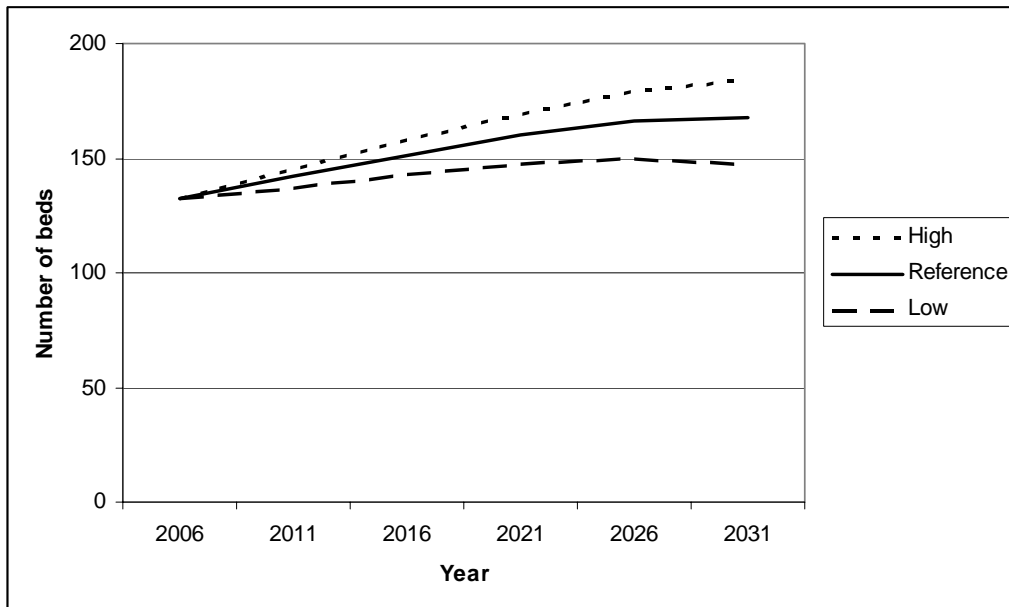
Figure 2. A small part of this growth (0.45%) is attributable to the expected increase in incidence of COPD over this period.

Figure 2: Needs Based Forecast for ICU Beds for Ventilator-dependent Patients in Ontario, 2006-2031



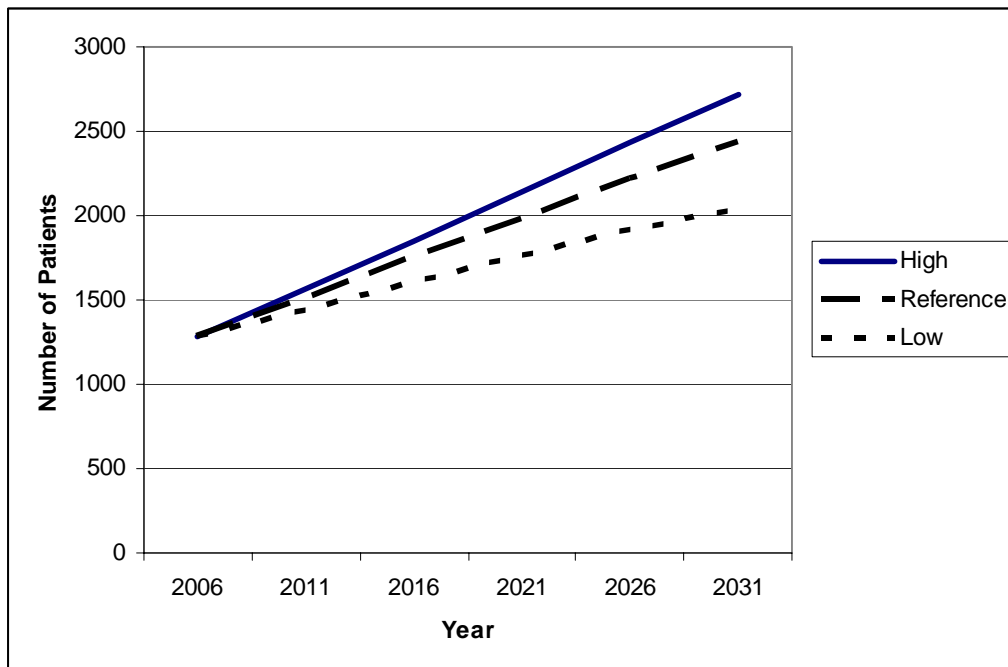
The projected increase in invasively-ventilated patients living in the community is much lower than for ICU beds at a total projected increase of 27% from 2006 (132 patients) to 2031 (168 patients), representing a 0.95% average annual increase. As shown in Figure 3, the growth in patient volumes slows after 2026 due to a combination of the effects of a declining birth-rate and escalating numbers of people dying among the baby boom population.

Figure 3: Needs Based Forecast for Invasively-ventilated Patients in Ontario, 2006-2031



The number of non-invasively ventilated patients living in the community is projected to grow by 90% from 2006 (1,283 patients) to 2031 (2,431), for an annual increase of 3.6%, as shown in Figure 4. This projection includes an adjustment for increasing prevalence of muscular dystrophy in Ontario of between nine to 24 patients annually, attributable largely to the increasing life span of these patients over the projection period. Through its research, the Task Group found that this patient population was far larger than it had expected and, as their disease progresses, these patients consume a significant amount of health care resources, especially if they undergo a tracheostomy. The high projected growth points to increased pressures on the health care system to deliver quality care to these patients.

Figure 4: Needs Based Forecast for Non-invasively Ventilated Patients in Ontario, 2006-2031



Based on above projections, the Task Group estimated the growth rate in demand for inpatient and community services for ventilator-dependent patients to the year 2031 if no changes are made to how these patients are currently managed. The projections are also based on the assumption that current capacity is sufficient to meet current need (i.e., there is no capacity shortage today). These projections are summarized in Table 7.

Table 7: Summary of Projected Growth Rates from 2006 to 2031

	Growth Rate (%)		
	Low	Reference	High
ICU beds	92	107	120
CAVC beds	50	38	58
Home ventilated patients:			
Invasively ventilated	11	27	39
Non-invasively ventilated	59	89	112
Total home-vent patients	54	84	105

These projections do not distinguish between the number of patients who can be cared for in the home and those who will need an alternate setting (e.g., supportive housing or institutional care). Concern has been expressed that the demand for institutional beds will increase as the caregivers of ventilated patients living at home become too old to care for these patients any longer. Historically, this has not been an issue, but with the lengthening life expectancy of patients with muscular dystrophy, for example, the aging of the parents who care for these patients has become a major concern. At some point, the parents will no longer be able to care for these patients, and an alternate setting (e.g., supportive housing or institutional care) will be needed.

4.4.2 Estimating Demand

The Task Group was unable to develop a reliable estimate of the current steady-state demand for chronic ventilation services in Ontario. Through the surveys, discussions with Task Group members and other investigations, we did find evidence that there is insufficient capacity in the system to meet demand at this time. Specifically, we found a high number of patients currently in ICU beds waiting for transfer to an alternative setting. We also found long wait times to access CAVC services and West Park’s Rehabilitation and Home Ventilation Training Program.

Therefore, we know that an immediate expansion of capacity is needed. However, we have been unable to quantify the capacity that would be needed today for three main reasons:

- The Task Group was not able to develop a definitive estimate of the number of ventilator-dependent patients in Ontario because we did not have a 100% response rate to all of our surveys.
- The wait time for transfer to Toronto East General Hospital Hospital’s weaning program is about three months, which would suggest that a modest increase in beds would reduce the wait considerably. However, not all centres in Ontario appear to be aware of this service, and demand might rise if awareness were improved.
- Estimating the demand for long-term care placements is further confounded by the fact that there are several options for care (e.g., home, group home, attendant care or hospital), and the Task Group does not know at this time what the optimal mix of capacity in these settings might be. Indeed, the mix would likely vary by LHIN,

depending on the case load, existing infrastructure and services for these patients, and patient preferences.

Without a baseline for 2005, it is impossible to develop a reliable projection to 2031. This effort is further frustrated by factors that are beyond the control of the Task Group that complicate the projections. For example, the projections were developed using low, reference and high growth rates. For some patient population, the resulting range is very wide. For example, the number of non-invasively ventilated patients was estimated to be 1,283 in 2005, based on VEP records. Depending on the growth assumptions used for this population, the projected demand in 2031 is between 2,037 and 3,721 patients. The capacity needed for 2,037 patients is far less than the capacity needed for 3,721 patients.

The strategy proposed by the Task Group includes more disciplined identification of patients at risk of becoming mechanically ventilated and counselling for these patients and their families so that they can make informed decisions about their long-term care. We are also proposing formal respite care to relieve the burden on the caregivers, which could result in a reduced need for institutional care. It is unknown what impact these initiatives will have on the overall demand for care by ventilator-dependent patients.

5.0 Delivery of Chronic Mechanical Ventilation Services in Ontario

The previous section described the ventilator-dependent patient and the medical, physical and psychosocial needs of those patients during the course of their disease. This section describes how the delivery of the needed services is organized in Ontario today and highlights the issues associated with the current delivery as identified by the Task Group through its research.

The goal in caring for patients with chronic ventilatory failure is twofold:

1. To stabilize the ventilatory system, and
2. To optimize the health-related quality of life for individuals.

The delivery of this care involves a multi-dimensional continuum of services, by an interdisciplinary team, throughout the course of the patient's disease. It is generally accepted that these patients enjoy the highest quality of life when they are cared for in a community setting (although there is currently no literature to substantiate this statement except for pediatric patients).

5.1 The "At Risk" Population

With the exception of patients who are chronically ventilated because of an acute catastrophic event, the patient is typically already in the care of a physician (e.g., general practitioner, neurologist, respirologist, pediatrician) even before the disease has advanced to the stage where the patient requires mechanical ventilation. The Task Group chose to refer to this period in the patient's continuum of care, before mechanical ventilation has been started, as the "at risk" period.

Issues

Few centres in Ontario were found to have a formal service for these "at risk" patients. These services offer the types of education described in Section 3.2.1 regarding the progressive and terminal nature of the disease and the patient's options for short-term and long-term care. Patients outside of the catchment area of these few centres do not have local access to this type of service. Even within these catchment areas, not all patients are currently referred to these programs. See Appendix D for a description of a sample of these programs.

Although some patients are counselled to begin elective ventilation before an acute episode, Task Group members reported that many of these patients who arrive in an ICU have not been informed of their prognosis and options for care. Health care professionals have a legal, moral and ethical obligation to discuss the prognosis, the likely course of action, and advanced planning of treatment with their patients. However, physicians are not well trained to have these types of conversations and are often reluctant to provide the patient with what

the physician perceives as a bleak prognosis. The conversation is either delayed or avoided altogether until the patient has an acute episode and requires a tracheotomy.*

Consequently, it is believed that many patients who are admitted to a critical care unit during an acute episode could have avoided this admission if the disease had been managed differently. There is an opportunity to avoid some emergency admissions, saving the patient and family from a very stressful and risky situation, as well as saving the system the costs of a critical care admission.

Task Group members who work with patients either in the critical care unit or when they are discharged from the critical care unit reported that many of these patients have not been educated regarding long-term mechanical ventilation. As a consequence, the decision to initiate a tracheostomy as the preferred option for long-term ventilation support is often made in haste during a crisis situation.

The healthcare professionals who offer these services believe that most patients, when given sufficient information to make an informed decision about their long-term care, will choose not to be invasively ventilated as a long-term care strategy (although they may still opt for intubation as a short-term strategy or non-invasive ventilation, if practical, as a long-term strategy). This type of advanced directive could potentially result in a decrease in ICU admissions and long-term invasive ventilation (either in an institutional or community setting) for this patient population. However, at this point, no formal research has been conducted to confirm this anecdotal evidence.

The issues identified for the “at risk” patient population are summarized graphically in Figure 5. The issues are highlighted with red stars.

5.2 Critical Care

Many patients begin long-term ventilation in a critical care unit. Twenty-eight ICUs reported having one or more ventilator-dependent patient (total of 45 patients) in their care on November 1, 2005.** The average age of these patients was 63 years, and the average time on a ventilator was 141 days, as shown in Table 8.

* Personal communication with Dr. Laura Hawryluck, Physician Leader, Ian Anderson Continuing Education Program in End-of-Life Care, University of Toronto.

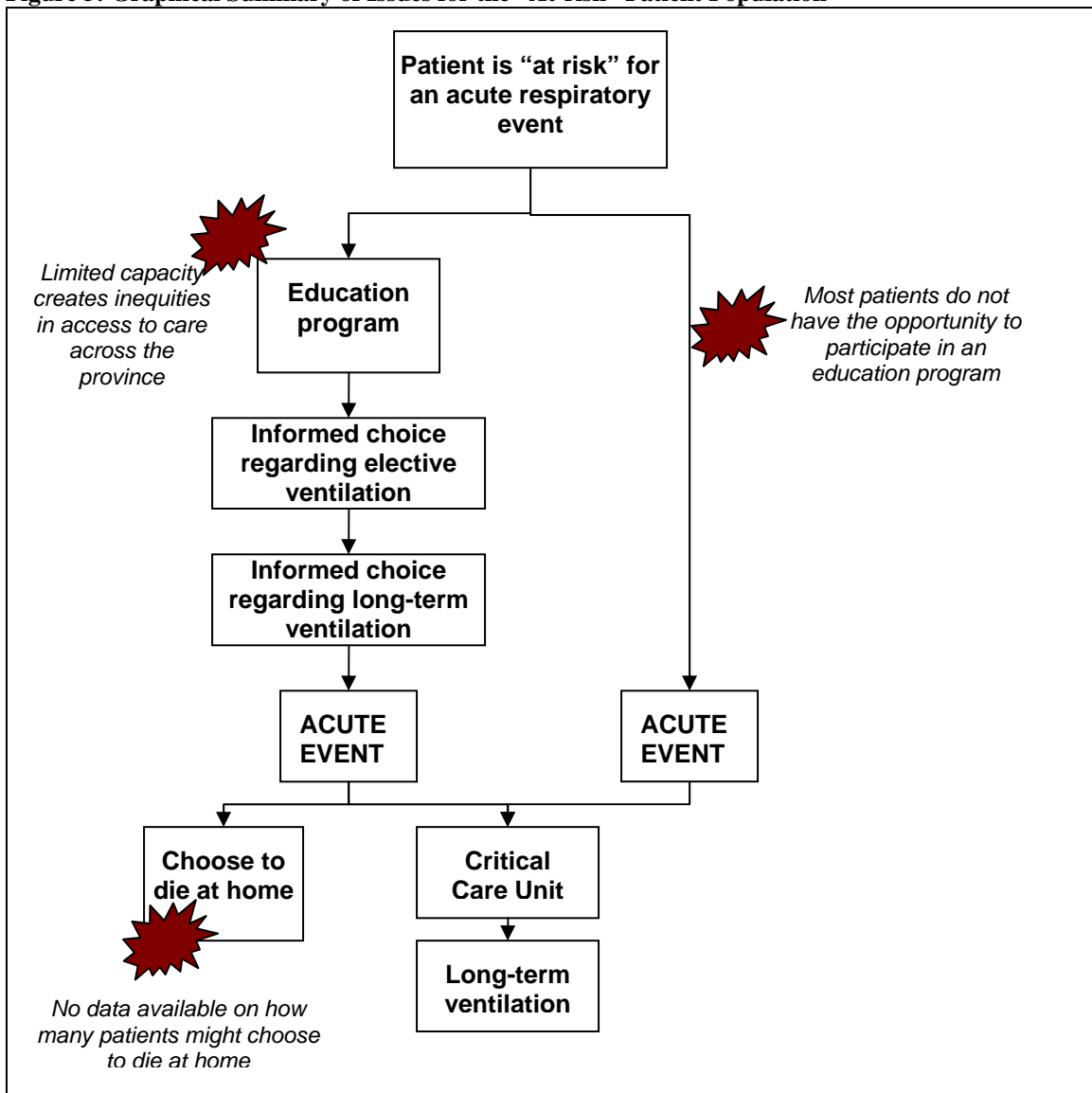
** The point prevalence is used for the description of the patient populations because more information was requested in the survey for this group than for the patients reported during the month of September 2005.

Table 8: Description of the Ventilator Dependent Patients in ICUs, November 1, 2005

Mean age (min, max)	65 years (min 20, max 88)
Mean time on mechanical ventilation	141 days (min 23, max 1,753)
Diagnosis	
COPD	14%
ALS	12%
Require ventilation 24 hours a day	78%
Source of admission	
Ward	33%
Emergency room	22%
Operating room	20%

Source: Critical Care survey. Responses as at February 6, 2006.

Figure 5: Graphical Summary of Issues for the “At-risk” Patient Population



Issues

As noted in the previous chapter, once the patient is medically stable, the ICU environment is no longer appropriate for these patients, and they should be transferred to another setting as quickly as possible. Unfortunately, there is often no immediate alternative location for these patients.

The Task Group estimated that between 1,000 and 2,000 additional ICU admissions could be accepted annually into current facilities if medically-stable chronically-ventilated patients were discharged in a more timely fashion to a more appropriate setting. (See Appendix E for the source of this estimate.) If there are no changes to how this patient population is managed, the ICU capacity that will be consumed by this patient population will grow significantly over the projection period.

It was estimated that 29% of these 45 patients might be successfully weaned in the ICU.* (See Table 9.) The remaining 71% (32 patients) were believed to be transferable to an alternative setting. There is limited capacity to decant these patients from the ICU:

- Only five hospitals reported that they provide long-term care for ventilated patients, and those that do provide such care are operating at capacity.
- Not all patients have appropriate home care supports and must, therefore, remain in a hospital setting. Two of the 45 ventilator-dependent patients in critical care units were thought to be good candidates for home ventilation. However, delays in arranging for adequate supports can delay the discharge from the critical care unit to home and, therefore, prolong the stay for these patients.

Table 9: Alternative levels of care for ICU Ventilator-dependent Patients, November 1, 2005**

Preferred alternative	Reported Patients	
	#	%
Discharge to long-term care	17	38
Remain in critical care until weaning is achieved ⁺	13	29
Palliative care in the ICU or another setting within hospital	7	16
Discharge to a weaning unit or weaning centre	6	13
Discharge to home	2	4
Total	45	100

Source: Critical Care survey. Responses as at February 6, 2006.

As a consequence, patients often remain in a critical care unit long after they are medically stable, at great personal cost to the patient and family and at great financial cost to the

* It is possible that the respondents indicated that weaning should take place in the ICU because there is no alternative weaning service available in the area.

** These data do not include any patients that might be in the ICUs of the 32 hospitals that had not responded to the survey as at February 6, 2006. In March 2005, the Ontario Critical Care Steering Committee reported a total of 1,788 adult critical care beds in 129 individual hospital sites and 210 units. Of these beds, 61% (1,096) were equipped to treat critically ill patients who required mechanical ventilation.

⁺ It is possible that the respondents indicated that weaning should take place in the ICU because there is no alternative weaning service available in the area.

healthcare system. Two ICUs reported having at least one patient that had been in the ICU for almost five years. One ICU reported having eight beds (out of 24) occupied by chronically ventilator-dependent patients. Another reported three chronically ventilated patients out of 22 beds.

For patients who do have appropriate supports and can live at home, the burden on the caregivers is tremendous. In the words of one parent of a chronically-ventilated young adult, the caregiver is “excessively burdened both physically and emotionally.”* If the patient needs to be monitored 24 hours a day, there is little relief for a sole caregiver. In the event that the caregiver needs a break (e.g., a vacation), the only option for many patients at this time is to ask to have the patient admitted to a critical care unit to provide the needed respite. Even though a critical care unit is an inappropriate and costly option for respite care for these patients, survey respondents reported that five home-ventilated patients out of the 98 who responded to the survey had been admitted to an ICU (for a total of 10 admissions) in the past 12 months to provide respite for the caregivers.

Home-ventilated patients also appear to have a high degree of ICU admissions for illness and infections, based on our survey responses. However, there is no published literature to support a relationship between the quality of care provided in the home and the likelihood of an ICU admission, or on whether the ICU readmission rate is higher for home ventilated patients than patients in a CAVC service.

Sixty-eight percent of respondents to the critical care survey reported that they either “agreed” or “strongly agreed” with the statement “Ventilator dependent patients are a major burden on bed resources in a critical care unit.” A similar number of respondents (65%) either agreed or strongly agreed with the statement “Based on past occupancy rates, I anticipate that caring for a ventilator dependent patient in this unit will, in general, result in refused admissions to this unit due to a lack of available beds.”

Respondents further articulated the following impacts on critical care staff of having ventilator dependent patients in the unit for a prolonged period of time:

- There are difficulties in adapting to chronic care within the critical care setting.
- Staff are frustrated that they are unable to give the type of care the ventilator-dependent patient needs – staff are better at providing acute rather than chronic care. They are also frustrated that these beds could be used for more acutely ill patients.
- There is a sense of staff complacency regarding on-going care for these patients.
- Staff are frustrated that patients tie up beds and consume physician resources that could be used for more acutely ill patients.

Respondents were asked to rate various system changes on the potential to improve patient care based on a scale of one to seven, where a rating of one is extremely unimportant and a rating of seven is extremely important. The following changes were rated, on average, greater than five out of a possible seven:

* Letter from a private citizen to the Task Group. December 6, 2005.

- Increase the number of beds at CAVCs (6.4)
- Improve communications (6.1)
- Increase the number of CAVCs (6.0)
- Expand home mechanical ventilation (5.9)
- Create regional weaning centres (5.4).

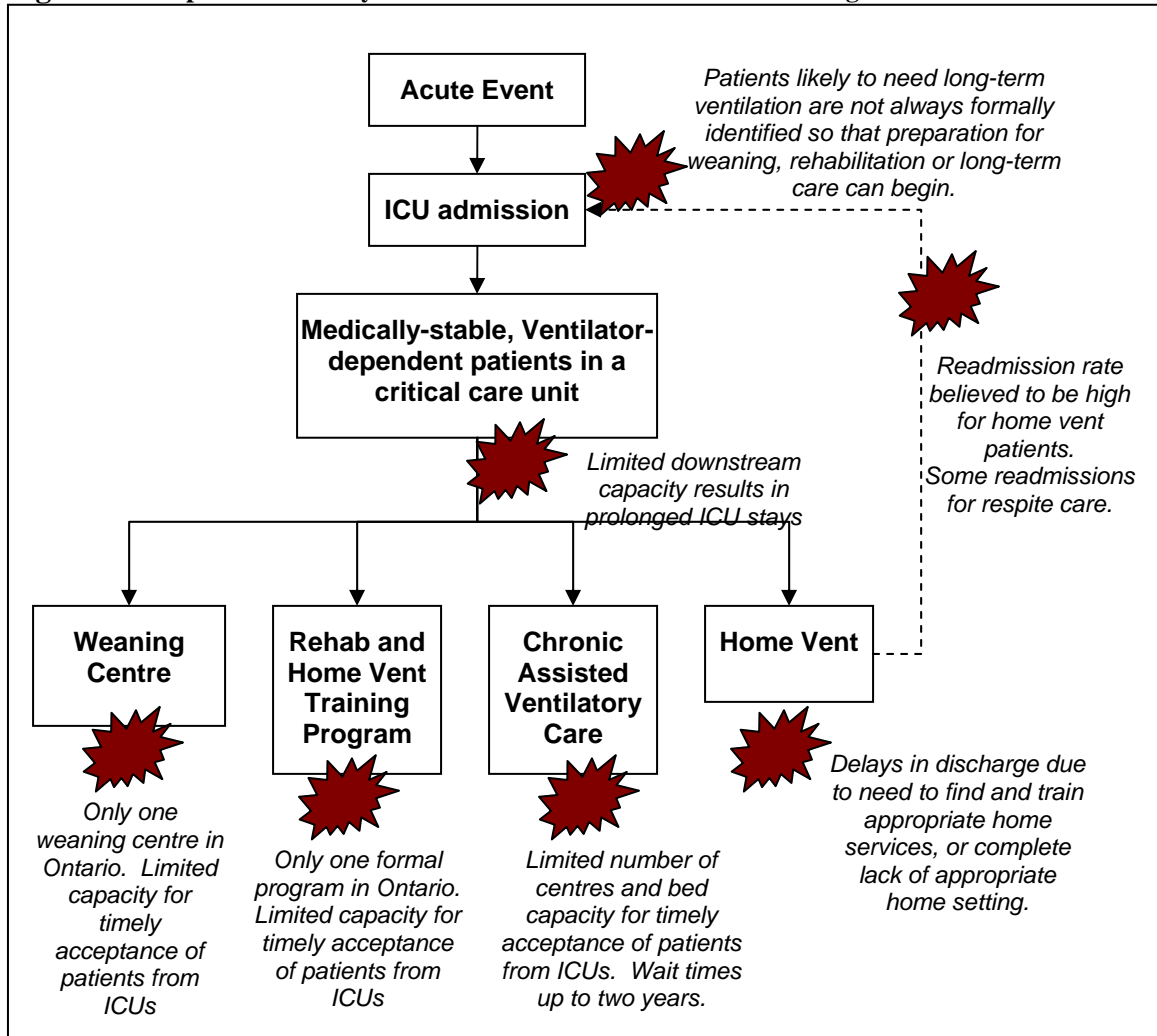
Respondents also provided ideas for system improvement:

- Enhance the expertise available for caring for ventilator-dependent patients (e.g., respiratory therapist, respirologist) by providing more education and training. Some of the secondary reviewers confirmed the survey findings through their emphasis on the role of the respiratory therapist in successful home ventilation and the challenges in finding and funding these resources.
- Increase the resources available to these patients by increasing the number of beds at existing complex continuing care facilities and increase the number of beds and centres regionally supporting chronically-ventilated patients.
- Address public perceptions of rights of patients to receive care in the ICU (e.g., the ethical debate regarding the futility of care).
- Develop strategies to improve communication across the care continuum.

Although the definition of a chronically ventilated patient is one who has been ventilated for longer than 21 days, it is usually obvious within the first day or so of the patient's ICU stay that the patient will need long-term ventilation. There is currently no widely adapted protocol to identify these patients and to begin the transition process to a more appropriate care setting. Delaying this process can contribute to a longer than necessary ICU stay even if the downstream capacity is available.

The issues related to ICU admissions and discharges for chronically-ventilated patients are summarized graphically in Figure 6. The red stars signify issues at each point in the continuum of care.

Figure 6: Graphical Summary of Issues after an Acute Event to Discharge from the ICU



5.3 Weaning

For the purpose of this report, the term weaning is used to refer to the process of reducing the patient’s dependency on mechanical ventilation and, eventually, liberating the patient from this dependency.

The only formal weaning program in Ontario at this time is the Progressive Weaning Centre at the Toronto East General Hospital (TEGH). The six-bed service provides weaning services to medically stable, cognitively intact, chronically ventilated (more than 21 days) patients who are deemed weanable by the Weaning Centre’s medical and clinical staff. A copy of the admission criteria is provided in Appendix F.

All patients are referred to the centre from an ICU. After three months, if no progress is shown, or the patient deteriorates, the patient is transferred back to the referring ICU. If the

patient's condition deteriorates rapidly, the patient might be readmitted to TEGH's ICU if the patient cannot be transported.

The centre reports that about one-third of the patients are weaned and transferred to a regular hospital ward or to the community, one-third are deemed unweanable and repatriated to the ICU or transferred to a more appropriate setting, and one-third experience a deterioration in their condition and die within one-year.

Issues

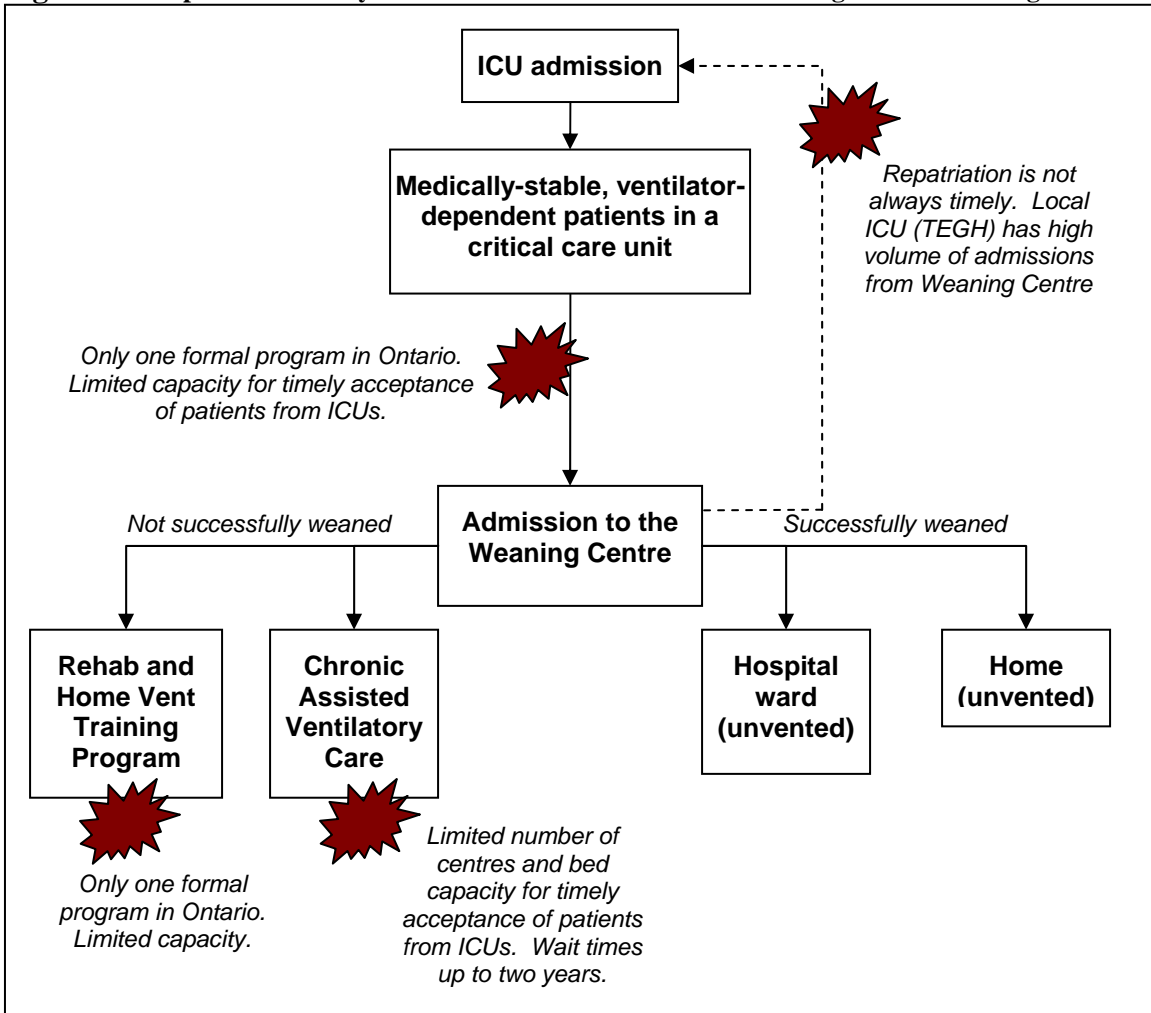
The weaning centre is operating at 100% of capacity, with patients sometimes waiting up to about three months to be admitted to the unit. There are usually between eight to 12 patients on the waiting list. Based on responses from the Critical Care survey, the Task Group suspects that many ICUs are not aware of the services offered by this centre, which only opened in January 2004.

The Weaning Program establishes formal repatriation agreements with the referring ICU in the event the patient cannot be weaned. Unfortunately, the transfer back to the referring hospitals is not always as timely as would be desired. Without more effective repatriation agreements, or more capacity in alternate settings (e.g., CAVC service) to accept these patients, there is a risk of this program (and the ICUs affiliated with this program) becoming full of patients who cannot be repatriated.

With only one weaning centre in Ontario, this service cannot be provided close to home for most patients. The high degree of specialization needed to provide this type of service, and the lack of those resources in Ontario limit the ability to develop more of these centres in the short term.

The issues related to weaning services, including discharge challenges, are shown graphically in Figure 7.

Figure 7: Graphical Summary of Issues from Admission to the Weaning Unit to Discharge



5.4 Rehabilitation and Home Ventilation Training

West Park Healthcare Centre offers the only funded inpatient Rehabilitation and Home Ventilation Training program in the province. This four-bed program accepts ventilator-dependent patients who are medically stable, do not show potential for weaning, but have the necessary supports for successful community living. Admission criteria for existing respiratory programs for chronically ventilated patients are provided in Appendix G.

Issues

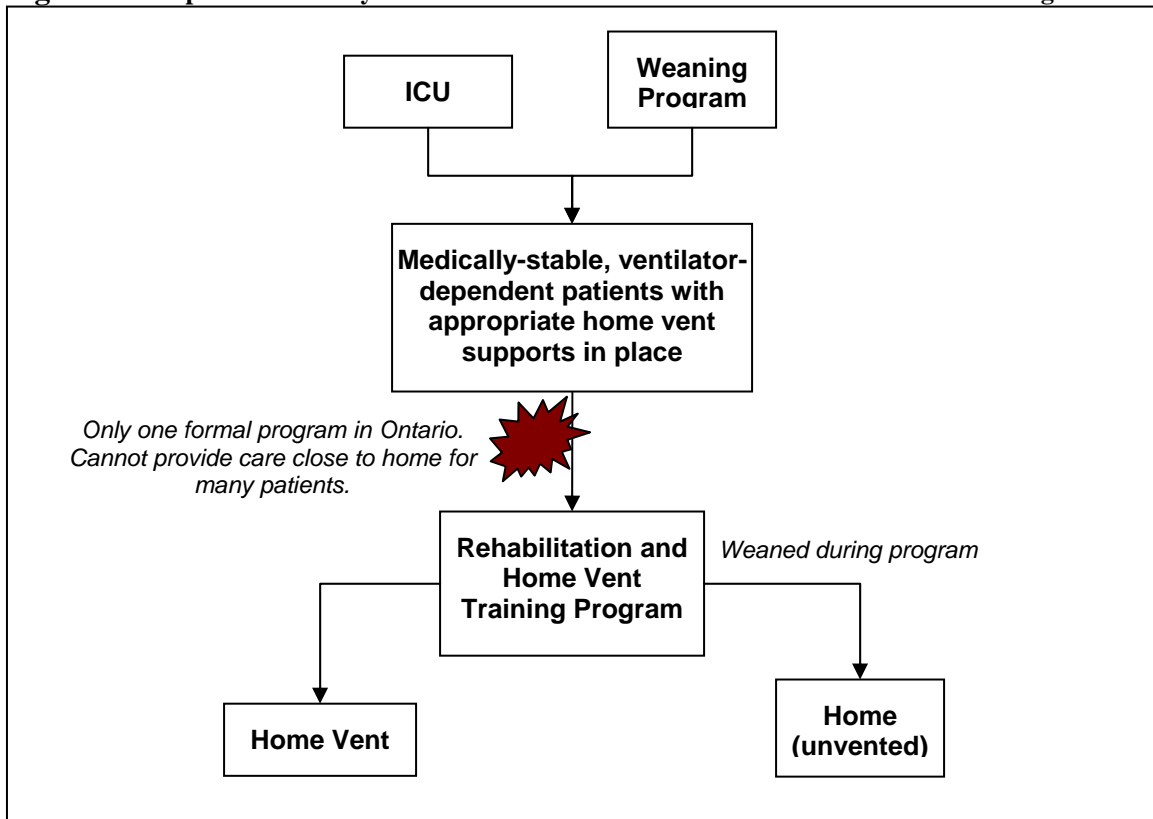
As the only funded inpatient rehabilitation and home ventilation training program in Ontario, West Park's four-bed program has limited capacity to meet the demand for this service across the province. In February 2006, there were 10 patients waiting for this program. The longer patients must wait for this service, the longer they must be cared for in an institutional setting, which is believed to provide lower quality of life for the patient and higher cost of care for the health care system. Also, this program cannot be provided close the patient's home, except for area residents.

Representatives from West Park have reported that the capacity limiting factor for this service is its inability to staff the four beds seven days a week. Even if more beds were available for this type of program, the shortage of health care professionals with the respiratory rehabilitation expertise presents a challenge in delivering this type of program successfully.

This program has a unique role in the continuum of care for ventilated patients. The expertise and reputation of the program is widely recognized. There is an opportunity for the staff of this program to play a role in the education and training and the mentoring of other services for this patient population so that the best practices and expertise developed within this program can be shared with other health care professionals.

The issues related to Rehabilitation and Home Ventilation Training Programs are summarized graphically in Figure 8.

Figure 8: Graphical Summary of Issues for Rehabilitation and Home Ventilation Training



5.5 Home Ventilation

The medically-stable, ventilator-dependent patient can be transferred to a number of different locations:

- Complex continuing care hospitals, in a chronic assisted ventilatory care service.

- Nursing home. The Task Group was not aware of any nursing homes or long-term care homes in Ontario that had been retrofitted to accommodate ventilator-dependent patients.
- Group homes. These homes generally have three or four patients living together, one of whom might be ventilated. An attendant is on-site 24 hours a day, and other healthcare professionals visit the house on an as-needed basis. There is a precedent in Ontario for successful group homes that serve a high-need but small patient population, such as the program for Acquired Brain Injury (ABI) patients in Peel Region. This is not a commonly available option for ventilator-dependent patients.
- Attendant care (supportive housing) facilities. These facilities are typically a studio apartment equipped with ventilatory equipment. The apartment complex has 24-hour attendant care, with periodic visits to each apartment throughout the day. These facilities allow patients who are able to arrange for and direct their own care to live relatively independently. As with the supportive housing, this option is not widely available for ventilator-dependent patients.
- Private homes.

The remainder of this section describes the delivery of care for home ventilated patients and the issues associated with this care. The next section addresses the institutional settings for long term care.

The Ontario Ventilator Equipment Pool (VEP) (See Section 5.5.4) reported 1,405 ventilator-dependent patients participating in the VEP, 13% of which are pediatric patients. Most of the patients (91%) are non-invasively-ventilated and almost all of them live at home. A small number of patients living in attendant care and group homes were identified during the Task Group's research.

These patients receive services from Community Care Access Centres (CCACs), the Assistive Devices Program (ADP) and its Ventilator Equipment Pool (VEP), and a variety of primarily hospital-based outreach and outpatient programs, all of which are described in later sections.

Issues

As noted earlier in this report, it is generally believed that these patients enjoy the highest quality of life in a community setting. If the family is unable to provide the needed in-home care or cannot afford the additional financial costs of keeping the patient at home, and no other community-based setting is available (e.g., group home or attendant care), there is no alternative but to keep the patient in a hospital. It has been suggested that some of these patients might manage quite well in a group home or attendant care facility, which are not generally available in Ontario for this type of patient.

Many of the ventilator-dependent patients living in the community are cared for by a parent. As the parents age, the burden of care becomes more difficult to sustain. At a certain point, the parent will no longer be able to provide a safe home environment for the patient, perhaps even with enhanced home-care supports. At this time, if there is no community-based

alternative (e.g., group home, attendant care facility), the patient will have to be admitted to hospital.

In addition to the client section, the home vent survey also included a section to be completed by the caregiver. Of the 98 responses received, 52 caregivers completed this section. They were asked to report on difficulties they experienced as a result of their caregiver responsibilities. One-half of the respondents reported experiencing social, physical or emotional strain “often” or “all the time”, as shown in Table 10.

Table 10: Caregiver Responses on Difficulties Experienced

	Caregivers reporting they experience it “often” or “all the time”	
	Number	Percent
Experience social strain	34	51
Experience physical strain	34	51
Experience emotional strain	33	49
Experience financial strain	22	33
Experience strain on family relationships	18	27
Feel overwhelmed by caregiver responsibility	18	27

Source: Home ventilation survey. Responses as at February 6, 2006.

The reported burdens were summed to yield a summary burden score, with a maximum possible score of 30. Caregivers of invasively-ventilated patients scored an average of 20.3 points (minimum 10, maximum 30). Caregivers of non-invasively ventilated patients scored lower with an average of 15.5 points (minimum five, maximum 22).

Caregivers were also asked to report on the extent of their need for services. The top six services identified were (ranked from highest to lowest):

- Financial support
- In-home nursing services
- Respite care
- Emergency support
- In-home respiratory therapy services
- Transportation support.

Again, these scores were summed to yield a service need score, with each item having a maximum possible score of five, for a maximum service need score of 30 per caregiver. Caregivers of invasively-ventilated patients scored an average of 17.2 points (minimum six, maximum 29). Caregivers of non-invasively ventilated patients scored lower with an average of 14.3 points (minimum five, maximum 27).

The lack of formal respite care for the caregivers results in two significant problems:

- When respite is needed, the patient might be admitted to a critical care service to provide the needed break for the caregivers.

- If no respite is provided, the caregivers may not be able to sustain the home environment and the patient will need to be readmitted to the hospital. Anecdotal evidence suggests that the stress of providing home care for these patients can result in medical and psychiatric problems for the caregivers.

5.5.1 Community-based Living

For patients who wish to live in the community but would prefer not to live with their parents, group homes and attendant care facilities offer an attractive and cost-effective alternative.

Many Task Group members and secondary reviewers felt that many patients would prefer this setting, and it would definitely ease the burden on the patient's family. There is potential to integrate ventilator-dependent patients into existing supportive housing programs. Space could be made available for both permanent residents and respite care. Although some staff training would be required, it was felt that these services could be upgraded for ventilator-dependent patients with relative ease.

The Ministry does not generally provide differential funding to supportive housing and group home providers to cover the costs of the unique needs of ventilator-dependent patients. Many providers simply cover the incremental costs of these services from current budgets.

5.5.2 Community Care Access Centres

Community Care Access Centres (CCACs) arrange for 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/homemaking, physiotherapy, occupational therapy, nutrition, speech therapy and social work, as well as medical supplies and medical equipment. The CCACs' mandate does not include the provision of respiratory therapy, an important service for ventilator-dependent patients.

To be eligible for CCAC funding, the patient must meet the following criteria:

- Have a valid Ontario Health Insurance Plan (OHIP) number.
- Live in the catchment area of the CCAC.
- Have a medical condition that can be managed in a home environment.
- Have a suitable home environment and supports.
- Have a responsible physician.
- Be committed to being involved in the care (family and patient).

The CCACs that responded to our survey reported that they provide services to 74 home ventilated patients. Of these, most (77%) were adults, most (74%) were male and most (70%) required ventilator support 24 hours a day. The major diagnoses for ventilator dependence were muscular dystrophy and ALS.

The average age of patients receiving CCAC services was 44 years (minimum 18, maximum 83), and they had been on a ventilator for an average of 7.4 years (minimum 1 month, maximum 28 years). Most (86%) of the patients were expected to remain ventilator dependent for more than five years.

The CCAC is typically invited to participate in the discharge planning for the patient and works closely with hospital staff to plan and manage the transition to home. During the discharge planning period, the patient and family receive the training they need to operate and maintain the ventilator and other educational needs as required. The hospital social worker and the CCAC case manager will also advise the patient on securing additional financial support if the costs exceed the publicly funded program. CCACs reported that the discharge planning process can take two to three weeks (35% of the cases) or even longer (46% of the cases).

Service plans are based on client need, within the regulations for nursing and personal support. For visiting nursing, clients can receive a maximum of 28 visits per week (e.g., four hours per day). If a client requires shift nursing and is not receiving any visiting nursing, the client could be eligible for 43 hours of service performed by a registered nurse (RN), 53 hours of service performed by a registered practical nurse (RPN), or 48 hours of service performed by an RN or RPN. For personal support, the CCACs provide a maximum of 60 hours per month. There is no limit to how long a patient can receive care from the CCAC, as long as the patient continues to meet the eligibility criteria.

Most (73%) ventilator-dependent patients are referred to the CCAC from acute care hospitals. Within the past two years, no CCAC reported having to refuse admission to any ventilated patients. However, three CCACs reported that discharge from the acute care centre was delayed because appropriate care providers were not available.

Respondents to our survey reported providing the following in-home services to patients:

- Personal support worker services (49%)
- Nursing services (47%)
- Occupational therapy services (26%)
- Respiratory therapy services (16%)*
- Physiotherapy services (14%).

With the exception of nursing and personal support services, in most cases the professional services provided were infrequent and were provided on an “as needed” basis.

Issues

The CCACs participating in the survey reported a total of 74 ventilator-dependent patients receiving in-home care from a CCAC. Most of the patients have either muscular dystrophy or ALS and most (68%) require ventilator support 24 hours a day. This volume of patients suggests that only five percent (69 of 1,405) of ventilator-dependent patients living in the community receive services from a CCAC.** It is believed that many of these patients

* Although the provision of respiratory services is outside of the CCAC’s mandate, one CCAC does arrange for these services using respiratory therapists from the local hospital.

** This calculation is based on the number of patients reported by the 85% of CCACs who responded to the survey. If the estimate is adjusted to account for the six CCACs that did not respond (assuming the same patient profile for the non-responding CCACs), the estimate of ventilator-dependent patients living in the community that receive services from a CCAC is 5.8%.

receive additional care from private services (purchased by the patient) and from not-for-profit organizations.

Based on the CCAC survey results, the most commonly used service was personal support worker, with 50% of patients using this service on average 20 hours per week. Nine patients (13%) received in-home respiratory therapy services, with therapists coming to the home only “as needed” in most cases. With 132 invasively ventilated patients living at home in Ontario (as identified by the VEP), this means that only seven percent of these patients are receiving respiratory therapy services in the home, and only on an “as needed” basis.

Since the amount of care that a CCAC can provide is limited, the patients needing continuous ventilation typically need additional support, which must be arranged at the patient’s expense, either through private insurance, personal finances, or a charitable or volunteer organization. If the family cannot afford the additional services, the patient may not be a good candidate for living in the community and will likely return to (or would not have been discharged from) the hospital.

Of the invasively home ventilated patients, only 84% reported having a back-up ventilator and only 73% reported having back-up power in the home. For non-invasively ventilated patients, only 18% had a back up ventilator and 25% had backup power. During the recent prolonged power failures in Ontario, patients arrived at local hospitals to secure a continuous source of power. Patients, particularly those needing continuous ventilation, need at least short-term reliable back-up power in the home and a suitable plan for long-term interruptions. At this time, the purchase of a back-up generator is at the patient’s expense.

CCACs are not mandated to provide respiratory therapy support and services, and only one CCAC in Ontario (Simcoe County) has chosen to do so, using respiratory therapists contracted from the Royal Victoria Hospital. The availability of a respiratory therapist is particularly important for ventilator-dependent patients (i.e., those with a tracheotomy) because of the higher maintenance requirements. Although some nurses may have some of this training, the respiratory therapist will, in general, have a much higher level of expertise to offer the patient.

These patients should have access to a respiratory therapist on an ongoing basis. The therapists can be a resource for education and information for patients and families regarding mobility and travelling with a ventilated patient. Therapists can also provide options to improve quality of life for patients and families. The respiratory therapist also has the technical knowledge to make improvements and adjustments to the technology.

The availability of respiratory therapy support and services for patients is believed to be an important predictor of success for invasively-ventilated patients and to contribute to a lower rate of readmissions. The CCAC survey respondents noted that respiratory therapy services should be made available to home-ventilated patients.

Instances were reported where the discharge from hospital was delayed while the CCAC tried to locate healthcare professionals who were willing to work with a ventilated patient

and who had the requisite training to do so. Using respiratory therapists for these services would help to address this shortage. Further, a respiratory therapist could provide greater continuity of care. One family in the Toronto area reported that the care providers sent by the CCAC may have basic but not adequate skills in this area. The family had to provide additional training for the hired caregivers, which was compounded by the high turnover. The family further reported having 24 different registered practical nurses assigned to the patient within a one-year period.

Respondents to the home ventilation survey also reported a general lack of resource support for home ventilated patients and their caregivers. Few healthcare professionals provide in-home visits. Those patients who receive in-home visits reported that the frequency is limited or inadequate. They further report that the financial support to cover the cost of supplies (e.g., gauze tapes, supplies for tracheostomy) and hydro is particularly lacking. In the words of one respondent: “Money provided by government or ADP does not reflect reality of costs. List of items must be reviewed to reflect need and where most of the cost is spent.”

Respondents to the CCAC survey reported 33% of their patients use family resources to fund the costs of home ventilation, in some cases as much as 90% of the total cost. Private or voluntary sources were also reported for some of the professional in-home services (e.g., nursing, occupational therapy and personal support).

Patients responding to the home ventilation survey reported that they “often” or “very often” cover transportation costs (44%) for patients or their caregivers and home alterations (21%). They also reported that they “sometimes” or “very often” cover costs associated with private assistance. In most cases, these costs were not reimbursed.

Respondents to the CCAC survey were asked to rank the most important barrier to discharging eligible patients from the acute or chronic care setting to the community. The top four barriers reported all involve the lack of appropriate supports in the community:

- Lack of appropriate community nursing staff (20%)
- Insufficient family/caregiver support (20%)
- Lack of suitable home environment (17%)
- Insufficient respite resources (14%).

Respondents also reported regional disparity in resource allocation for these patients. Comments included: “Home mechanical ventilation is a godsend but we need better resources in the North.” Another patient reported: “Living in Northern Ontario has its drawback.”

5.5.3 Outreach and Outpatient Programs

Through the survey of all hospitals in Ontario, we identified 14 hospital-based programs that provided services to ventilated patients in the community. Each region had at least one such service except Central West (Mississauga and area). Collectively, these programs provide services to 138 invasively and 551 non-invasively ventilated patients, as shown in Table 11. Based on the VEP estimate of 132 invasively-ventilated patients living in the community in

Ontario, it would appear that all of these patients are receiving at least some support from hospital-based* outreach and outpatient programs.

Table 11: Outpatient/outreach Programs in Ontario

Facility	Invasively ventilated	Non-invasively ventilated	Total patients
Adult patients:			
West Park Healthcare Centre	59	156	215
Kingston General Hospital	5	130	135
The Ottawa Hospital	4	79	83
London Health Sciences Centre	18	27	45
Hamilton**	18	39	57
Other adult programs	7	12	19
Subtotal adult programs	111	443	554
Pediatric patients:			
The Hospital for Sick Children	23	100	123
Bloorview McMillan	4	8	12
Subtotal pediatric patients	27	108	135
Total patients	138	551	689

Source: Outpatient/outreach survey. Responses as at February 8, 2006.

Most of the larger services have a multidisciplinary team that includes, at a minimum, a respirologist, a respiratory therapist, and a registered nurse. Most also include a general practitioner, physiotherapist, social worker, occupational therapist, nutritionist and pharmacist as needed. Most of the 13 services reported that they provide both outpatient and outreach services.

Issues

These ad hoc services are only available to residents within the catchment areas of the facilities that have developed these programs. For example, there were no reported outpatient or outreach programs for residents of Central West (Mississauga and area), and only one service at St. Joseph's General Hospital in Thunder Bay for all of the North. A patient who lives outside of the catchment area does not have equal opportunity to access these services.

Even for those areas where the patient has access to this type of service, the type and level of support varies significantly from program to program. Some services only accepted non-invasively-ventilated patients; others had only outpatient services and no capacity for home visits.

All of the programs that responded to our survey reported that they funded the service using funds from the hospital's global budget. This results in uncertain funding from year to year

* All but one of the programs were hospital based. In Simcoe County, the CCAC contracts with the hospital's respiratory therapist to provide these services to the CCAC's clients.

** Total of all patients under the care of Hamilton Chedoke, McMaster, and St. Joseph's.

and the risk of closure for the service. Three services had an affiliation with respiratory equipment vendors, but the contribution in most cases was not substantial (e.g., some supplies). One centre charged a nominal fee for respite that was applied towards the program.

In addition to the need for committed funding, the following issues were raised many times in the responses, even by some centres that did not have a service:

- The shortage of healthcare professionals
- Shortage of home/community placement opportunities
- Need for inpatient beds for assessment, training and potential inpatient need as the patient's condition deteriorates.
- The need for formal respite care programs and beds to address caregiver burnout.

These patients have the same need for periodic discussions about their options for care (e.g., advanced directives, desire to have or avoid a tracheostomy). As with the “at risk” patient population, the health care providers have a legal, moral and ethical obligation to have these discussions with the patients at regular intervals.

5.5.4 Assistive Devices Program

The Ministry's Assistive Devices Program (ADP) provides financial assistance to Ontario residents who have long-term physical disabilities for the purchase of personalized assistive devices. To qualify for this assistance, the patient must have a valid Ontario Health Insurance Plan (OHIP) number and a physical disability lasting six months or longer. In general, ADP pays up to 75% of the cost of equipment and up to 100% of the cost of related supplies.

The program covers a wide range of respiratory equipment and supplies:

- Apnea/heart rate monitors (rented only)
- Compressors
- Drainage boards
- Percussors
- Resuscitators
- Specified disposable supplies
- Suction machines
- Tracheostomy tubes
- Ventilatory equipment

The program also covers some mobility aids (e.g., wheelchairs, positioning devices such as cushions, back and head supports, walkers).

In 1994, the Ministry established the Ventilator Equipment Pool (VEP) as a centralized equipment pool to allow for the recycling of ventilator equipment. All ventilators prescribed

through the ADP are now delivered to the patient through the VEP, which lends volume ventilators and bi-level devices to home-ventilated patients.

The equipment is provided at no cost to the patient; the patient must pay 25% of the cost of associated supplies. Patients also have access to a toll-free hotline that is staffed 24 hours a day, seven days a week. In fiscal 2004, the hotline received almost 4,000 calls, including calls from patients and caregivers (e.g., family members, personal support workers, attendants) and health professionals seeking technical assistance for equipment-related issues, health care professionals (e.g., respiratory therapists and physicians) looking for educational guidance and assistance, and the general public looking for disease-specific information, funding information, or assistance with forms.

Issues

The ADP funds up to 75% of the needed supplies. One centre routinely advises its patients to expect to spend approximately \$150 per month on disposable supplies, including tracheostomy and suction supplies and some ventilator equipment replacement parts.

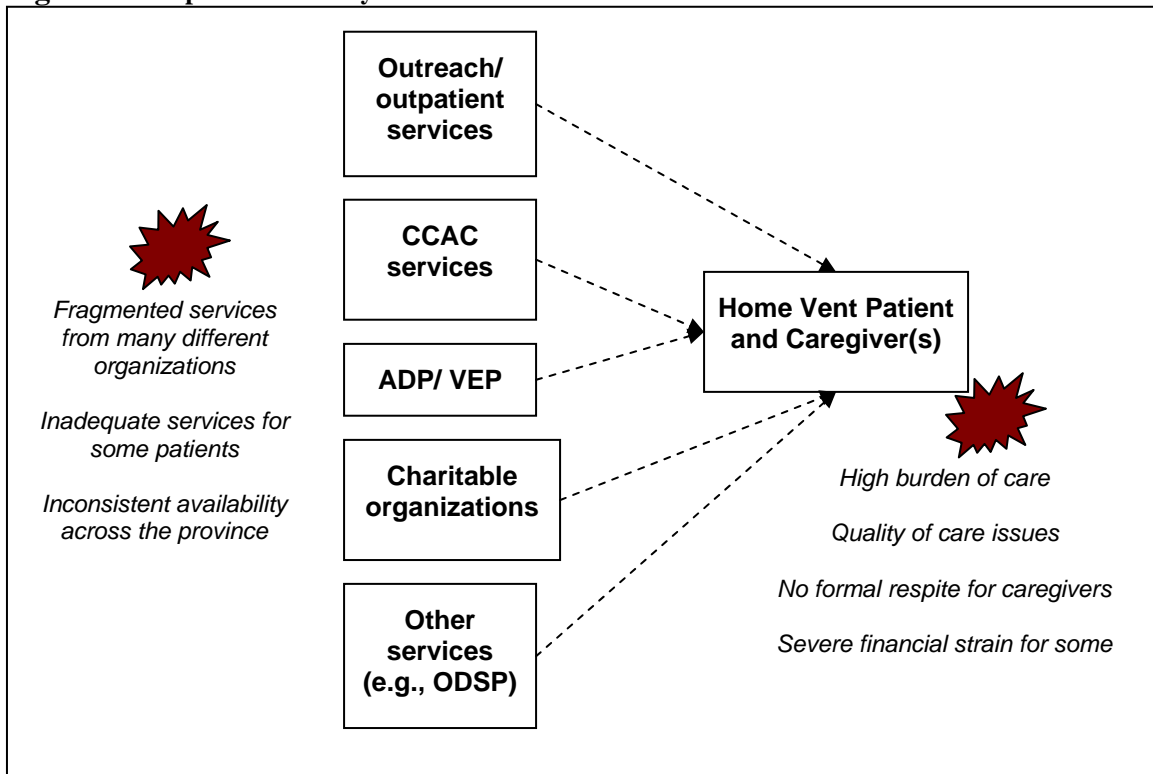
Because of specific disabilities associated with the medical condition of ventilator-dependent patients, they may require funding from more than one branch of the ADP (e.g., respiratory equipment, mobility aids). The patient may also receive assistance from a charitable organization, private insurance or other government program (e.g., Ontario Disability Support Program). Each program adds another layer of complexity in the management of the patients needs.

Concerns were also raised about the inability to acquire equipment or supplies, especially in a timely fashion after the equipment is requested from the ADP. One centre had arranged for an equipment supplier to provide a “loaner” until the patient’s equipment arrived to facilitate a timely discharge to home. The procurement process is a two-step process:

1. The written request for equipment is first sent to the ADP for adjudication. If any information is missing from the application, it will likely be delayed. The adjudication process typically takes one or two weeks, but can take much longer.
2. Once the application is approved, the request is forwarded to the VEP. The sourcing and delivery of the equipment typically takes another week, resulting in an elapsed time from request to delivery of a minimum of two to three weeks.

The issues related to the delivery of care for ventilator-dependent patients living in the community are summarized graphically in Figure 9.

Figure 9: Graphical Summary of Issues for Home Ventilation



CCAC = Community Care Access Centre, ADP = Assistive Devices Program, VEP = Ventilator Equipment Pool, ODSP = Ontario Disability Support Program

5.6 Complex Continuing Care

When adequate supports for community living are not available, or if the patient's condition has deteriorated beyond the skills of the patient's family, the patient might be admitted to a chronic assisted ventilatory care (CAVC) service in a complex continuing care (CCC) hospital. Only five of the six complex continuing care (CCC) hospitals in Ontario that responded to our survey have chronic assisted ventilatory care services, with the largest of these being West Park Healthcare Centre in Toronto.

Collectively, these centres reported the willingness to increase the number of beds from 36 in 2005 to a total of 66 beds if they were appropriately funded.

Issues

Four of the five responding hospitals reported occupancy rates for their services of 95% or greater, as shown in Table 12. West Park Healthcare Centre, the largest of the CAVCs, reported a waiting time from referral to admission of approximately two years, with 29 patients on the waiting list; Toronto East General Hospital reported a waiting list of 24. One patient was waiting for admission to St. Joseph's in London. In total, assuming there are no patients on more than one waiting list, 54 patients are currently waitlisted for a CAVC bed in Ontario.

Table 12: Beds and Occupancies, CAVC Services, 2005

Facility	Location	Number of beds	Average Occupancy
West Park Healthcare Centre	Toronto*	22	98%
Toronto East General Hospital	Toronto	10	95%
St. Joseph's Health Care (Parkwood)	London	3	98%
St. Joseph's Health Centre	Guelph	1	96%
Total beds		36	

Source: CAVC survey. Responses as at February 6, 2006.

As suggested by the Critical Care survey respondents, there are insufficient CAVC beds to meet the current need for ventilator-dependent patients in Ontario. All CAVC survey respondents felt it was “very important” to “extremely important” to increase the number of beds in these CAVC services.

Through our surveys, we discovered that Peterborough Regional Health Centre has approval for a four-bed chronic assisted ventilatory care service to open in mid 2008, subject to post construction operating plan (PCOP) approval and funding. Another centre that did not yet complete the survey but is reported to have a four-bed service has indicated that it is considering closing the service because of inadequate funding.

With only four locations in Ontario, these services are unable to provide care for many of these patients close to their home. Unfortunately, the relatively small number of patients and the highly specialized nature of this care and lack of availability of healthcare professionals with this specialized training, create challenges for a more regionalized approach to delivering this care. All CAVC survey respondents felt it was “somewhat important” to “extremely important” to increase the number of facilities that care for this patient population.

Some of the patients in these services could be cared for in a community setting. However, the needed supports for community living are not currently available. As well, there are no good alternatives to home ventilation or hospital care (e.g., supportive homes, attendant care facilities) that are widely available in the province. As a result, these patients must remain in an institutional setting. Survey respondents had mixed views regarding the importance of expanding capacity for home mechanical ventilation.

Most of the patients in these services are elderly, with an average age of 57 years. It has been suggested that these settings are not appropriate for pediatric clients because they are not designed to meet the recreational and social needs of younger patients.

All CAVC survey respondents felt it was “very important” to implement strategies to improve the communication across the continuum of care for this patient population. Respondents also identified a lack of resources to support these patients. Specifically, they felt there was a shortage of:

- Appropriate (qualified) staff

* Although this unit is located in Toronto, it receives referrals from all over Ontario.

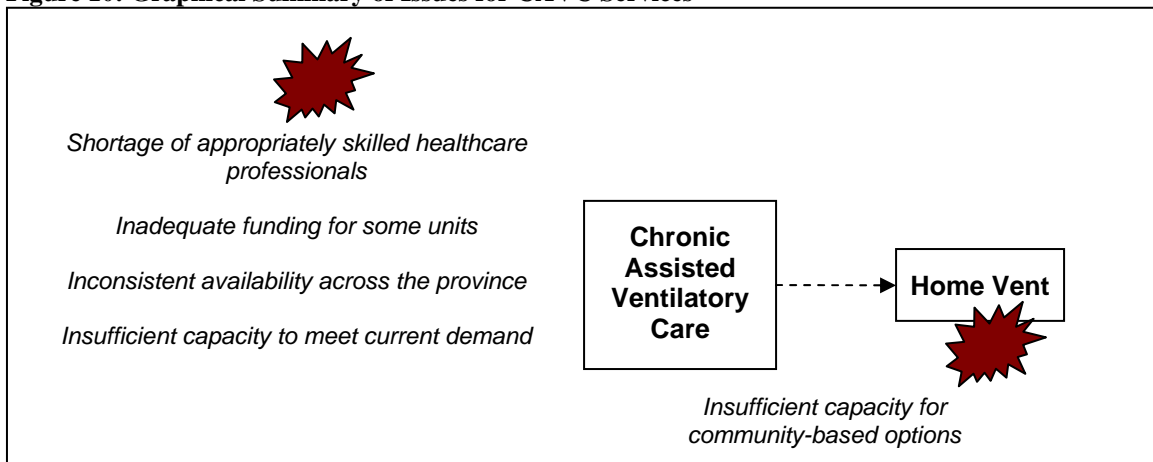
- On-site availability of diagnostic and respiratory therapist support
- Respite care and other support for patients in the community.

They also indicated a need to establish training of specialized staff (e.g., respirologists, respiratory therapists) to maintain the skill required to care for these patients.

Healthcare providers have an obligation to discuss the patient’s long-term care (e.g., advanced directives). This type of conversation should be encouraged on a frequent basis.

The issues identified for complex continuing care for these patients are summarized graphically in Figure 10.

Figure 10: Graphical Summary of Issues for CAVC Services



5.7 The Setting of Choice for Long-term Care

The Task Group discussed at length what the most appropriate setting is for chronically ventilated patients. Although most panel members – and some respondents to the surveys – believe that the best quality of life is achieved in the home or other community setting, it is not cost-effective to provide in the home the level of care needed by some patients.

A comparison of the key costs and benefits of providing care in the home, another community setting (e.g., group home or attendant care facility) or an institution (i.e., CAVC service) is shown in Table 13.

Table 13: Comparison of Options for Long-term Care

	Home care	Attendant care/ Supportive housing	CAVC service
BENEFITS			
Quality of care	High if family is motivated and well supported Otherwise can be very low	Some concerns about current quality, but could improve with appropriate attention and infrastructure	High
Quality of life for patient	Believed to offer the highest quality of life among the three options.	Can be higher than in an institutional setting and higher than in the home if a young patient wants independence from the parents.	Depends on amenities and environment within the CAVC
Care offered close to home	Yes. In home.	Yes. Potential to be closer to family than hospital-based care	Only for patients living close to hospital with such a program.
COSTS			
Burden on caregiver	Very high	Low	Low
Cost of care (on-going)	High, if you include cost borne by patient, cost of hospital admissions for infection, illness and respite, and a higher level of home care than currently provided.	Potentially lower cost than home or CAVC setting.	High (about \$800 per day)
Capital investment required	Minimal cost the healthcare system. Can be significant cost to the patient.	Some cost to retrofit for vented patients.	Depends on available capacity for retrofitting.

Issues

Feedback from the surveys and the collective experiences of the Task Group members provided evidence that some patients and caregivers in the community require more support than is currently provided to sustain the arrangements for living at home. There was also limited evidence of better outcomes (e.g., fewer readmissions to acute care) for patients in a hospital setting than patients living at home. The Task Group also heard that one cannot make generalizations about what setting is most appropriate for all patients.

The Task Group found that the success of a home placement depended very much on the patient's condition, the type of care and/or interventions needed and the family's motivation to keep the patient at home. Where the family support was weak, the clinical condition was somewhat stable but complex enough that frequent emergency interventions were required, and there was little opportunity to consult with professional health care providers except at

the emergency department, the experience of the Panel members suggested that more frequent emergency admissions and extended stays in the ICU were more likely.

The Task Group discussed group homes and attendant care homes as a potential middle ground that could capture some of the quality of life of a home setting, at lower cost than in a hospital. It was agreed, however, that the choice of setting would ultimately be determined by:

- The patient's condition.
- The patient's preferences.
- The availability of the home supports and the family's commitment to caring for the patient at home.
- The availability of group homes and attendant care facilities as an alternative to either a home or institutional placement.

The availability of supporting infrastructure for community placements will vary by LHIN. With such small patient populations in each LHIN, the best approach is for the LHIN to develop its own strategy for these patients, taking into consideration the number of patients, their needs and the availability resources and infrastructure to meet those needs to develop cost-effective approaches to managing these patients as close to home as practical.

6.0 The Evidence Base

This chapter provides a summary of the information that was collected through the formal literature reviews, research into and discussions with representatives from other jurisdictions, and an analysis of cost data for these services.

6.1 Discharge Planning Strategies

One of the questions we sought to answer with a literature review was: What types of discharge planning strategies have been used to improve outcomes (e.g., ICU/hospital length of stay (LOS), quality of life (QoL), mortality, morbidity, costs) for ventilator-dependent patients?

Only one study⁴ was found that explicitly implemented a discharge planning strategy as part of an attempt to improve outcomes. The specifics of the discharge planning strategy were not detailed in the article, although it did state that it was a comprehensive package that involved a general practitioner, district nurses and social services and included the following services:

- An open readmission policy
- A 24-hour telephone helpline for patients and caregivers
- Readmission at regular intervals to assess progress or changes in status.

The study did not involve a control group, so the authors were not able to make any statements about the program's outcomes relative to the status quo. However, it is somewhat understood that the status quo would be a prolonged (potentially until death) stay in a critical care unit. Therefore, any benefit can be compared to an indefinite stay in such a unit.

The authors reported the outcomes shown in Table 14, which may reflect an associated weaning program more than the discharge planning.

Table 14: Results of a Discharge Planning Strategy

	At admission	At discharge
Mean hours per day of ventilatory support	19.9	6.7
Number on 24-hours ventilatory support	30	1
Number on no assisted ventilation	4	11

Source: Adapted from Smith and Shneerson, 1995.

Only one study⁵ described an approach that included discharge planning in an inpatient unit in which the goal was to wean patients from mechanical ventilation or, where this was not possible, to prepare the patient and his or her caregivers for ventilator-dependent living at home. The setting for this program was a Respiratory Special Care Unit (ReSCU) at the Cleveland Clinic Foundation. The details of the discharge planning process were not described in the article.

Although the reported outcomes from ReSCU cannot be attributed solely to the discharge planning, the combination of special weaning units and preparation for home ventilation

shows promise. The authors reported the following outcomes, which are implicitly compared to the expected outcomes if the patient had stayed in the critical care unit, as shown in Table 15.

Table 15: ReSCU Results

	Percent
Death	18%
Complete ventilator independence	60%
Ventilator dependent	13%
Partial ventilatory support	9%

Source: Thompson, 1991.

A third study provided a comprehensive description of best practices for planning the discharge, care and rehabilitation of ventilator-assisted individuals.⁶ The planning should begin in the ICU, and the planning team should involve the patient and his or her family, and representatives from both hospital and community care organizations that will be involved in the patient's care after discharge. Mechanism for on-going communication among all stakeholders and service providers is also important for successful community living.

6.2 Benefits of Intermediate Care Units

A second question we attempted to answer with a literature review was: Does the presence of an intermediate care unit in an acute care hospital improve outcomes for chronic mechanically ventilated patients?

The term "intermediate care units" was found to have different meanings in different jurisdictions. Our Task Group was primarily interested in those units that accepted patients from an ICU setting with the expectation that the patient would benefit from short-term weaning or rehabilitative services (e.g., a weaning unit, a respiratory special care unit).

Many patients who require prolonged mechanical ventilation do not need the sophisticated monitoring or other life-supporting therapy that is available in an ICU. Unfortunately, ventilator-dependent patients have been found to account for only three percent of ICU admissions, but almost 40% of the total patient days⁴, which limits the availability of ICU beds for more acutely ill patients.*

The literature supported the Task Group's assertion that ICUs are not an optimal setting for these patients because the ICU staff is not specifically focused on the care of chronic ventilated patients and may lead to suboptimal quality of care.⁷ The ICU, lacking any rehabilitative focus, is not an ideal environment for patients who are clinically stable but ventilator dependent.⁸

Four studies reported that intermediate care units allow for a more efficient and cost-effective approach to care for this patient population than an ICU without any decrease in the quality of care or any adverse outcomes.^{7,9,10,11} The financial savings can be primarily attributable to

* These numbers reflect ICU admissions and total patient days at the University Hospitals of Cleveland, Ohio in 1991.

the lower nurse-to-patient ratio required in the intermediate care unit of 1:3 or 1:4 during the day and up to 1:4 or 1:5 during the evening and night shifts.⁹ The economic impacts of an intermediate care unit also include the indirect advantage of better utilization of the ICU that can be used for more acutely ill patients.¹²

The literature review also found evidence of the following benefits:

- After the closure of an intermediate care unit, Byrik et al found that the number of non-emergency admissions increased from 18 to 27% and the severity score of the patients, measured by APACHE II, decreased significantly.¹³
- Intermediate care units were found to offer greater privacy and easier visitor access, which was thought to contribute to the recovery process and to facilitate discharge from the hospital.¹⁴
- Fifty percent of thirty survivors in an intermediate care unit reported their quality of life as “good” or “excellent”.¹⁵
- Three studies^{7,16,17} provide evidence of a longer survival time in the intermediate care unit. In two of these studies, the results are statistically significant.

The proportion of patients who gained independence from their ventilator varied from 38% to 87%, depending, most likely, on the patient population accepted to the unit.

It was recommended that the intermediate care unit be linked geographically and functionally with an ICU. An open setting was also recommended to accommodate a lower nurse to patient ratio.¹⁴

From this literature review, we concluded that intermediate care units have proven to be a cost-effective alternative to the ICU. They have been shown to increase survival time and enhance the likelihood that patients will become ventilator independent. There is also some support for a decrease in the mortality rate.

The patients most likely to benefit from intermediate care units include those who are ventilator dependent due to a spinal injury, acute lung injury, chest wall disease and neuromuscular disease. Studies consistently report that these units experience the least success with COPD patients.

6.3 Benefits of Home Ventilation

In the search to improve the quality of patients’ lives and reduce health care costs, home mechanical ventilation (HMV) has emerged as a method for treating stable chronic respiratory failure, particularly restrictive neuromuscular diseases. The goal of HMV is to help ventilator-dependent individuals function at their highest possible level, while decreasing hospitalization and improving quality of life for patients.

The Task Group conducted a literature review to answer the following questions about HMV:

- What is the benefit (compared to the acute or complex continuing care settings) of HMV for ventilator-dependent patients?
- Which patients benefit from HMV?
- What is the burden of HMV on caregivers and families?

6.3.1 The Benefits of HMV

The literature supported four main criteria for successful HMV:

- **Clinical stability.** Good candidates for HMV are patients who have a stable disease course, with little or no air flow limitation requiring frequent changes of ventilator settings.¹⁸ In addition, co-existing diseases must be controlled, and adequate nutrition and the absence of significant dyspnea and infection must be ensured. Patients who are not optimal HMV candidates include those with concomitant medical conditions that require frequent monitoring and medical intervention, and those with progressive diseases that require frequent changes in ventilator settings.¹⁹
- **Patient and family desire for HMV.** Patients receiving HMV will benefit from strong motivation, optimism, resourcefulness, self-determination, flexibility and adaptability.¹⁸ A second study found that the level of family communication and degree of family commitment were also important adaptation factors.¹⁹
- **Ability to learn and perform the care needed.** Because the care responsibilities may require care 24 hours a day, 365 days a year, the psychosocial resources of the patient and the family are important elements in its success.²⁰
- **Accessible resources.** The patient must be able to use appropriate rooms, and a safe emergency evacuation route must be available. The home's electrical circuits must be adequate for the HMV equipment and other essentials must be in place (e.g., adequate storage space, a safe water supply, telephone service and, in some cases, a call system.)¹⁸

Four studies found that HMV was associated with good to excellent results for quality of life, both for physical function and vitality and perceived health, as shown in Table 16.

There was also evidence of a reduction in the number of hospitalizations where non-invasive home ventilation was initiated, as shown in Table 17.

The literature also provided evidence of good results for survival. In a study of 24 HMV patients in four Swiss centres, Chevrolet et al found that HMV had excellent results for survival, provided the indications for this technique were consistent with the recommendations in the literature.²¹ Chonabayashi et al specifically identified that the prognosis for patients with chronic respiratory failure can be improved with a long-term program for respiratory care that includes home mechanical ventilation and home oxygen therapy.²²

Table 16: Quality of Life Outcomes from Home Mechanical Ventilation

Authors	Type of Study	Level of Evidence *	Patient Population	Findings
Domenech-Clar et al, 2003	Cohort	High	45 patients with restrictive respiratory diseases including thoracic wall diseases (n=27) and neuromuscular diseases (n=18) undergoing 18 months of HMV treatment.	Several categories of health-related QoL indicators, including physical function and vitality, improved significantly. These improvements persisted over the entire 18 months. Social function and mental health improved initially and declined subsequently.
Markstrom et al, 2002	Cross Sectional	Moderate	91 HMV patients living in the county of Stockholm Sweden with post-polio dysfunction, neuromuscular disorder, and scoliosis.	Patients reported a high level of disability in most areas of the Sickness Impact Profile, indicating severe functional disability, yet reported quite good perceived health in the Health Index.
Chevrolet et al, 1991	Case Series	Low	24 HMV patients in 4 centers in Switzerland.	HMV had excellent results for QoL, provided the indications for this technique were consistent with the recommendations in the literature.
Salahuddin et al, 2005	Cohort	High	11 HMV patients in the Aga Khan University Hospital in Karachi from January 2000 to December 2004.	Patients reported a reasonably good QoL with proportionately more problems related to independence compared to overall well-being.

QoL = Quality of Life, HMV = Home mechanical ventilation

Sources: Various^{23, 24, 25, 26}

Table 17: Reduction in Hospitalizations from Home Mechanical Ventilation

Authors	Type of Study	Level of Evidence *	Patient Population	Findings
Leger et al (1994)	Cohort	High	276 HMV patients with scoliosis, post-tuberculous lung disease, and Duchenne muscular dystrophy.	There were significant reductions in the number of days spent as an inpatient for ≥ 2 years after initiation of NIV at home.
Tuggey et al (2003)	Before-After	High	13 British HMV patients with COPD.	With home NIV hospital days fell from 78 \pm 51 days to 25 \pm 25 days (p=0.004), number of admissions from 5 \pm 3 to 2 \pm 2 (p=0.007), and ICU days fell from a total of 25 to 4 (p=0.24).

HMV = Home mechanical ventilation, COPD = Chronic obstructive pulmonary disease, NIV = non-invasive ventilation, ICU = Intensive care unit

Sources: Various^{27, 28}

* Based on a hierarchy of evidence from lowest to highest level of evidence: case series (lowest), ecological study, cross sectional study, case-control study, cohort study, randomized control trial (highest).

The American College of Chest Physicians, in its consensus conference on mechanical ventilation outside an ICU identified significant benefits of HMV for pediatric patients.⁶ The Consensus Conference stated that the ability to attend school contributed significantly to the child's quality of life and developmental potential.

A more recent study identified similar benefits of home care for pediatric ventilator-dependent patients along physical, emotional, psychological and social dimensions.²⁹

6.3.2 Patients Who Benefit from HMV

Home mechanical ventilation has improved both the survival rate and quality of life in patients with polio, scoliosis, and neuromuscular diseases.^{30,31,32,33,34}

The use of home non-invasive ventilation in stable severe COPD patients is controversial. There have been four randomized studies on the use of this therapy in severe stable COPD^{32,35,36,37}; but only one³⁶ of these studies reported favorable results in terms of daytime gas exchange, total sleep time, sleep efficiency and quality of life. However, Jones et al³⁸ have suggested that home non-invasive ventilation may reduce both hospital admissions and clinic visits in severe COPD with hypercapnic respiratory failure. In addition, Clini et al³⁹ have shown that the addition of non-invasive ventilation to long-term oxygen therapy significantly reduces ICU admission in patients with severe COPD and hypercapnia. Nevertheless a long-term randomized control trial of nocturnal non-invasive ventilation in outpatients with severe COPD has shown that this therapy does not affect the natural course of the disease.⁴⁰

6.3.3 Caregiver Burden

In a 1994 study of ventilator-dependent patients, Sevick et al²⁰ found that because of limited bed availability, family members were pressured to take patients home, sometimes when the support for their daily care at home was inadequate.

Families and patients using HMV do not always have the abilities and information they need to use it successfully. Moreover, patients and families frequently underestimate the burden imposed by home mechanical ventilation. In a study of 20 caregivers, Smith et al⁴¹ (1994) found that family caregivers spent, on average, 7.3 hours daily on direct care, with little assistance from either extended family or professionals. Although they had been taught survival skills, these caregivers felt they needed more information about HMV. Disrupted schedules, financial strain, burden, and negative reactions to care giving were associated with more hours of ventilator use. However, both patients and caregivers reported satisfactory family function. There were no differences by gender in perceived learning needs, family function, and care giving tasks.

A more recent study²⁰ of 277 primary family caregivers in 37 states found a much higher average number of hours spent each day in caring for HMV patients – 11.4 hours.

Many caregivers are not satisfied with the current facilities and education system for home mechanical ventilation. They evaluate the induction of this therapy positively, but express the need for a better home care nursing system, more information on home mechanical

ventilation (i.e., related emergency care management and medical technique), doctors who respond to house calls, and an improvement in economical and educational environments. These caregivers, although happy to live with their children by virtue of this therapy, also want a reduction in their anxiety and fatigue.⁴² This conclusion was supported in a meta analysis, which found that although parents who care for medically-complex children in the home express satisfaction, they also report challenges, including health impacts on the primary caregiver(s).²⁹

From this literature review, we concluded that the benefits of HMV for ventilator-dependent patients include improved quality of life, decreased hospitalization and increased survival. The patients most likely to benefit from HMV include those who are ventilator dependent due to polio, scoliosis and neuromuscular disease. Studies consistently report that patients with COPD benefit least from HMV. Since families play a huge role in the success of HMV, it is imperative that health care providers ensure that families have the abilities, information and support needed to use HMV successfully.

These studies generally compare quality of life with non-invasive ventilation (i.e., elective ventilation) compared to quality of life before elective ventilation. Except for the articles on pediatric patients, we did not find any literature on the relative merits of caring for these patients in a home or community setting versus in an institutional setting.

6.4 Policies and Strategies in Other Jurisdictions

6.4.1 Inpatient Care

The published literature confirmed the value and growing interest in intermediate care units as a cost-effective alternative to an ICU that also better met the patient's needs. In our discussions with other jurisdictions, the value of a weaning unit was confirmed. Within the Canadian context, we found dedicated weaning units in Alberta and Quebec. Both used a multidisciplinary team approach to the deliver of weaning services.

In the United States, about 200 Long-Term Acute Care (LTAC) facilities serve the needs of an estimated 15,000 ventilator-dependent patients. These facilities were established to meet the needs of patients with prolonged, complex medical conditions after the Health Care Financing Administration in the United States created a long-term care exemption from Medicare. Although most of these centres are focused on chronically-ventilated centres, some were more similar to a weaning unit, with daily rounds, weaning and other protocols, and an intensivist or critical care physician on campus. One centre reported having an ICU on-site. This centre reported that if the patient has not been weaned in four to five weeks, he or she is transferred to a lower level of care.

Examples of dedicated weaning units were also identified in England. The care model involved multidisciplinary services with intensivists, senior nurse specialists and senior physiotherapists.

6.4.2 Home Care

Several jurisdictions in Canada and one in England reported having a variety of home support services, most of which involved providing equipment and some home visits from healthcare professionals. In some jurisdictions, equipment and respiratory therapy services were delivered by the same agency. Some also included additional supports including, for example, a 24-hour hotline to provide medical and equipment advice.

6.5 Costs by Setting

6.5.1 ICU Costs

Based on the Ontario Case Costing Initiative (OCCI) data, the average per diem cost for an ICU bed in an academic health science centre is \$3,745 (including direct and indirect costs), as shown in Table 18. For ICU beds in a community hospital, the average cost much lower at \$1,724.

Table 18: Average Direct and Indirect costs of an ICU bed, Ontario, 2004/05, \$s per patient day

	Academic Health Science Centre	Community Hospital
Direct costs	2,700	1,724
Indirect costs	1,045	300
Total per diem costs	3,745	2,024

Source: Ontario Case Cost Initiative data. 2004/05.

All data provided by the OCCI are average costs for all patients in the ICU, including chronically-ventilated patients. Officials at Mount Sinai Hospital have estimated that, based on the lower acuity of chronically ventilated patients compared to the more typical acutely ill ICU patients, the average daily costs for ventilated patients would be in the range of \$1,500 to \$2,000 per day.

However, officials at the Toronto East General Hospital have estimated that these costs are somewhat low and have suggested that more representative per diem cost estimate would be over \$2,300, which would include direct treatment costs of \$1,563, nursing costs of \$732* assuming a 1:1 nurse to patient ratio, and an additional cost for allied health workers and indirect costs and overheads.

Toronto East General Hospital also noted that when a patient is in the ICU but is stable and chronically vented, the unit tries to assign a 2:1 ratio, which would reduce the per diem costs somewhat. This is not always possible because of the geography of the unit. On occasion, the unit can double step-down patients with a chronically-ventilated patient to achieve reductions in the nurse:patient ratio.

* Based on \$30.48 per hour times 24 hours per day).

6.5.2 Hospital-based Non-ICU Care

The OCCI does not collect data for beds in a weaning program, a CAVC service or an inpatient rehabilitation and home-vent training program. Therefore, the Task Group used estimated costs from the Toronto East General Hospital's Progressive Weaning Centre and the actual costs from the largest CAVC unit in Ontario (i.e., West Park Healthcare Centre).

Based on the Toronto East General's experience, the average daily direct cost for the inpatient weaning program is approximately \$1,200 (plus an additional cost for allied health workers). Based on West Park's experience, it was estimated that the cost of CAVC care was \$714 per day (based on a 22-bed unit) and the cost of the inpatient home-vent training program was \$1,228 per day (four-bed service), as shown in Table 19.

Table 19: Average Direct and Indirect costs of CAVC, Rehabilitation and Home-Ventilation Training Program Beds, Ontario, \$s per patient day

	Progressive Weaning Centre (6 beds) (estimated 2005/06)	Rehabilitation and Home-vent Training (Inpatient) (4 beds) (actual 2004/05)	CAVC (22 beds) (actual 2004/05)
Direct costs	1,200*	903	538
Indirect costs	300	325	176
Total per diem costs	1,500	1,228	714

Source: Toronto East General Hospital and West Park Healthcare Centre

The higher cost of the Rehabilitation and Home-vent Training Program reflects the intensive of the rehabilitation and training required to prepare the patient for placement in the community. The length of stay for these programs is typically about four weeks for the rehabilitation program and about five days for the home ventilation training program.

Seneff et al,⁷ Elpern et al,⁹ Dasgupta et al⁹ and Scheinhorn et al¹¹ all found that a CAVC environment can provide the same quality of care as an ICU for chronically-ventilated patients. The literature further supports the estimate of lower costs for CAVC-type care compared to caring for these patients in an ICU:

- In a 1996 Canadian and U.S. based study, Jacobs et al⁴³ estimated a cost of ICUs at \$1,850 US per day compared to the cost of CAVC-type care at \$485 per day.
- Seneff et al,⁷ Elpern et al,⁹ estimated a \$2,000 (US dollars) decrease in daily costs in a CAVC unit^{**} compared to an ICU.
- In a prospective 2005 study of ICUs and CAVCs, Bertolini et al⁴⁴ estimated the cost of an ICU bed to be 1,507 Euros⁺ per day, compared to 754 Euros in a CAVC (p<0.0001).

* Additional costs for allied health workers are not shown.

** The comparison is to a long-term acute care (LTAC) facility or intermediate care unit.

⁺ One Euro equals is approximately \$1.38 Canadian dollars (As at February 7, 2006).

These studies confirmed that the primary savings between an ICU unit and some form of CAVC care is the reduction in the nurse:patient ratio, which is usually 1:1 in an ICU setting and can be as high as 1:3 or 1:5 in a CAVC setting. Indeed, Bertolini et al⁴⁴ estimated a saving of 10.5 hours of nurse time for each COPD patient admitted to a CAVC instead of an ICU.

6.5.3 Home-Ventilation Costs

It is difficult to estimate the cost of home ventilation for three main reasons:

- The level of care and support needed varies significantly depending on the patient's condition (e.g., degree of disability, other comorbidities).
- The patient needs also vary depending on whether the patient is invasively or non-invasively ventilated.
- There are also many costs that are not borne by the healthcare system but are very real financial costs (e.g., the hydro costs to run a ventilator, hiring additional help in the home) and personal costs (e.g., caregiver burden) that are borne by the patient and family.

The cost of home care is estimated at more than \$800 per day if the caregiver time, hydro costs and unnecessary hospitalizations are included in the cost of care.

The Hamilton Community Care Access Centre provided the following cost estimates for home care:

- Direct treatment costs of \$142 per day (which includes, for example, shift nursing, PT, OT, personal support) Ventilator-dependent patients with the Hamilton CCAC are currently receiving 27 to 50 hours of shift nursing per week, one visit per week by an occupational or physiotherapist, and 25 to 60 hours per month of personal support and/or in-home respite care.
- Indirect treatment costs are estimated at \$46/day, which includes the CCAC overheads but does not include the costs of equipment and supplies.

These estimates cover only the CCAC's costs and do not include the following potentially substantial costs borne by the patient and family:

- Other out-of-pocket costs for additional in-home services, some equipment supplies not covered by the VEP funding (estimated by one centre to be approximately \$150 per month), the additional hydro costs to operate the ventilator (estimated to be about \$50 to \$60 per month for a patient who is both ventilator dependent 24 hours per day and using home oxygen by way of an oxygen concentrator), and other costs (e.g., transportation).
- The burden of care on the family. Published literature supports an estimate of 7.3 hours per day (Smith et al⁴¹) and 11.4 hours per day (Sevick et al²⁰).

- The opportunity cost of lost wages for the caregiver who cannot work outside of the home because he or she is caring for the patient.

These estimates also do not include the cost of any inpatient or outpatient services that might be received by home-ventilated patients. As noted earlier in this report, it would appear that most of the invasively-ventilated patients are also being followed by hospital-based outpatient or outreach programs. These patients also experience a high degree of readmissions to an ICU for illness (e.g., infections) or respite care or to a CAVC service for periodic reassessment or respite care. It has also been estimated that the annual cost for outpatient clinic services for a non-invasively ventilated patient is approximately \$1,700.*

* Based on the outpatient clinic at The Ottawa Hospital.

7.0 Conclusions and Recommendations

7.1 Conclusions

In ICU beds across the province, we found 45 patients who were waiting for alternative care, but there is insufficient capacity for weaning, rehabilitation and complex continuing care for these patients, with waiting lists as long as two years for one major centre. This has resulted in a bottleneck in the system at considerable ongoing cost. Some of the current capacity is underfunded and is, therefore, at risk of further reductions in the level of service. A summary of the bed capacity currently available is provided in Appendix H.

Every year, patients with degenerative neuromuscular diseases are admitted to an ICU somewhere in the province when they experience an acute episode, at which time a decision must be made to initiate invasive ventilation or not. Too often, these patients have not been fully informed about their disease, its prognosis, and the benefits and draw backs of invasive ventilation so that they can make informed choices about their long-term care before a crisis occurs.

Health care professionals have a legal, moral and ethical obligation to discuss the prognosis, the likely course of action, and advanced planning of treatment with their patients. However, physicians are not well trained to have these types of conversations and are often reluctant to provide the patient with what the physician perceives to be a bleak prognosis. The conversation is either delayed or avoided altogether until the patient has an acute episode and requires intubation and eventual placement of a permanent tracheotomy. These conversations should be revisited frequently to ensure that the patient and family are making informed decisions about the patient's long-term care.

In Ontario, there are approximately 1,400 invasively and non-invasively ventilator-dependent patients who are living in the community. However, the medical, psychosocial and spiritual needs of these patients are complex and often require care providers with a high degree of training and specialization. The low patient volumes sprinkled throughout the province and the need for highly skilled health care professionals (especially physicians, nurses and respiratory therapists) severely limits the ability to provide safe and cost-effective care close to home for many of these patients.

The Task Group found both well-established and newly-created services providing high quality services locally and provincially to these patients along the full continuum of care. However, there is no coordinated strategy for the delivery of care; these services were developed and sustained by the commitment and passion of independent teams of health care professionals.

Accordingly, there is wide variation in access to services across the province, with much of the inpatient capacity for these patients located in the Greater Toronto Area and smaller centres in London and Ottawa. Outside of these cities, patients have few options for long-term institutional care.

The Task Group heard of inadequate home care supports for ventilator-dependent patients. Although it is generally believed that the patient enjoys a higher quality of life in a community setting than in the hospital, the necessary supports for successful home placements – including respite for the caregivers – are not in place.

7.2 Guiding Principles for the Recommendations

The Task Group identified seven guiding principles for its recommendations:

- Enable the chronically ventilated patient to make informed choices about his or her long-term care.
- Meet the patient’s medical, psychosocial and spiritual needs.
- Provide appropriate options for care in different settings, depending on the patient’s clinical condition, the patient and family’s preferences for long-term care and the availability of human resources and infrastructure to support the patient in the community or an institution.
- Provide services as close to home as reasonably possible, recognizing that the lack of critical volume and required specialization of healthcare providers and facilities may limit decentralization of some services.
- Ensure equitable access to services across the province.
- Deliver care at the right place and the right time, for the right patient (e.g., ensure appropriateness and maintenance of capacity).
- Ensure fiscally responsible use of costly and limited health care resources.

7.3 Overall Thrust of the Recommendations

Within the guiding principles noted in the previous section, the Task Group members agreed on the following general priorities for an effective strategy for the delivery of services for ventilator-dependent patients in Ontario:

- **Meet the immediate need for capacity** by increasing the number of weaning and CAVC beds to create capacity to transfer the approximately 45 ventilator-dependent patients currently in ICU beds across the province to a more appropriate setting, thereby improving the patients’ quality of life and liberating ICU beds for more acutely ill patients.
- **Manage patients proactively** to avoid admission to an ICU through interventions while the patient is still living in the community and outreach programs to inpatient wards.
- **Ensure that the ICU stay is as short as practical.** If an ICU admission is necessary and the patient meets the criteria of ventilator dependence, by facilitating timely access to safe weaning protocols and rehabilitation services that should begin in the ICU. Long-term care planning should begin after the first 24 hours in the ICU.
- **Support the patient in an appropriate institutional or community setting,** depending on the patient’s medical condition, the availability of home supports and

the patient's wishes. Sufficient capacity for institutional and community settings must be made available, with appropriate supports for community living where desired. We must also recognize the potential for the patient's condition to change and the need for ongoing monitoring and periodic reassessment by a qualified healthcare professional.

- **Fund all services appropriately** to ensure that services are sustained regardless of competing priorities in the hospital's global budget.

The Task Group found that ventilator-dependent patients need many different types of support beyond medical care, including education, care, equipment, financial assistance, social support and recreation, and mental health assistance, as well as on-going monitoring by qualified health care professionals and expert follow up in recognition of the potential for the patient's condition to change over time. There is also a strong need to support the caregivers through counselling, as well as formal and easily accessible respite service and ongoing social and mental health support to ensure caregiver wellbeing.

Although the Task Group was asked to develop a provincial strategy for this patient population, we recognize that the recommendations must respect the mandate and boundaries of the newly established Local Health Integration Networks (LHINs). A provincial network of organizations and individuals who provide care for this patient population should be established to coordinate and plan services at a regional (i.e., LHIN) and provincial level.

7.4 Recommendations

7.4.1 Meeting the Immediate Need for Capacity

Recommendation 1: That the Ministry of Health and Long-Term Care immediately establish six new beds for weaning and up to 20 new beds for institutional long-term care for medically-stable, ventilator-dependent patients at facilities that are capable of opening these beds in the very short term. Patients in an ICU would have priority access to these beds. Each expanded site should dedicate at least one of the new beds to respite care and designate some of the additional capacity for reassessment of patients living in the community. This capacity should be made available as quickly as possible, preferably within six months.

Recommendation 2: That the Ministry of Health and Long-Term Care, in addition to creating additional institutional capacity, ask all institutions (including intensive care, chronic assisted ventilatory care and complex continuing care units) to identify any ventilator-dependent patient in their care who would prefer to be in a community setting and their medical condition would allow discharge to an appropriate community setting. For each of these patients, a supportive care (attendant housing) option should be provided if the patient and family are agreeable and an appropriate placement can be established. Where demand is high, these services could include beds for respite care. This capacity should be made available as quickly as possible, preferably within six months.

Recommendation 3: That the Ministry of Health and Long-Term Care fund all inpatient beds for chronically ventilated patients identified in this report (existing and proposed) according to the average cost of the existing programs (i.e., at a rate that reflects the incremental costs of providing care for these patients beyond the average cost for a step-down or complex continuing care bed) and include reimbursement for ventilator equipment and supplies required by the patient. All outpatient clinics and outreach programs for this patient population should be funded according to the resources required to staff these programs to meet expected demand.

On November 1, 2005, 45 medically-stable, ventilator-dependent patients were in an ICU bed in Ontario. This environment is inappropriate for these patients, and these beds are urgently needed for more acutely ill patients. Alternative settings are needed quickly to transfer these patients from the ICU to a more appropriate setting. Because these beds are needed quickly, it may be most expeditious to add these beds to existing services. Regardless of where they are located, they should be developed in sufficient critical mass to support appropriate programming to ensure quality of life for the patients.

Although one setting for these patients would be in the community, the Task Group believes that it will take considerable time to develop the needed supports and infrastructure for successful community living for many of these patients. Therefore, the most appropriate short-term solution is to expand the existing capacity for institutional care for these patients. Additional capacity is needed for patients who have the potential for weaning and for patients who are deemed unweanable and require long-term care.

The Task Group discussed the possibility of transferring patients with few complications to general medical wards that are equipped with alarm systems. In general, the Task Group did not feel that a general medical ward in an acute hospital was an appropriate setting for these long-term patients. The members felt that these patients require a more attentive environment such as a geographically circumscribed group of rooms in a specialized ward (e.g., respiratory or other specialized ward) with knowledgeable staff who are capable of monitoring the patients and ventilators. These patients do not necessarily require an ICU or formal step down unit, but do require a level of specialization and organization above a general medical ward.

The focus of the short-term recommendations is on addressing the immediate need to decant patients from ICUs across the province. The strategy for creating additional capacity for these patients is to support and expand the existing programs, which can be accomplished more quickly than establishing new programs and is, therefore, the most expeditious way to create capacity in the very short term.

Once a patient is medically stable, he or she no longer needs to be in an ICU setting. Although the patient is not usually discharged to a weaning or CAVC service until the patient has been ventilator-dependent for 21 days, the planning for the patient's discharge can begin as soon as ICU staff can identify the patient as a candidate for long-term ventilation.

Some of the hospitals that currently provide both inpatient and outpatient services for this patient population expressed frustration at the lack of dedicated funding that recognizes the unique and significant costs of these services – as well as the potential to avoid high cost tracheostomies through interventions with the at-risk population. There was also concern expressed that physician remuneration did not reflect the unique demands of working with these patients (e.g., additional time required for the type of patient and family education and counselling recommended in this report, long-stay patients in an ICU or weaning unit, home visits to ventilated patients.) Without stable and appropriate funding, these existing services are at risk of being closed by the host institution, which would further compromise the ability to provide quality and timely services. There is also a very real risk that these programs will choose not to expand their capacity or physicians may choose not to work in these programs if the funding and remuneration is not perceived to be adequate to cover the true costs of caring for this patient population.

7.4.2 Organizing to Ensure Quality Care

Recommendation 4: That the Ministry of Health and Long-Term Care establish a Chronic Ventilation Network that includes all centres and organizations in Ontario that provide services to patients who are, or who are at risk of becoming, ventilator dependent. The Network’s responsibilities would include:

- Working with Local Health Integration Networks (LHINs) to assess the on-going need for these services and the adequacy of the services provided and to develop solutions that reflect the unique characteristics of the local network.
- Identifying and documenting best practices for the care of ventilator-dependent patients across the continuum of care.
- Facilitating the timely flow of communication between all providers in the service continuum.
- Advising the Ministry on the needed supports and infrastructure for successful community living.
- Fostering the development and delivery of training programs for health care professionals to care for this patient population.

The Network should be supported through the development and operation of a central patient registry to collect a minimum data set on all chronically ventilated patients (whether in the community or an acute care or long-term care institution) to support continuity of patient care at any of the multiple participating institutions in the province, the evaluation of the proposed strategy, planning for future capacity, and key areas of research, especially those identified by this Task Group as needing attention.

Recommendation 5: That the Ministry of Health and Long-Term Care designate one centre as a provincial Centre of Excellence in the weaning of ventilator-dependent patients that would serve to assist and train health care professionals in other parts of the province (where the need justifies the investment and the resources are available to provide the service) to deliver as close to their communities as possible the highly specialized care needed to wean ventilator-dependent patients.

Recommendation 6: That the Ministry of Health and Long-Term Care work with the Centre of Excellence and other health care provider and education partners to develop and implement a formal training program for physicians (e.g., respirologists, critical care specialists, general internists, pediatricians, neurologists, general practitioners) and allied health professionals (e.g., registered nurses, respiratory therapists, nurse practitioners, occupational therapists and physiotherapists) to care for this patient population. This program would have a provincial mandate.

Where the needed services are already provided at a number of locations across the province, a network structure appears to be an effective approach to providing quality standards and assistance to the Ministry in the planning of care for the province.

All centres that provide any of the following services will be invited to participate in this network:

- Services for at-risk patients and patients who are invasively or non-invasively ventilated and living in the community. This would include CCACs, the VEP, not for profit organizations and outreach programs.
- Rehabilitation and home ventilation training programs.
- Chronic Assisted Ventilatory Care.
- Long-term care of ventilated patients in any other setting, including group homes and supportive housing.

The Government of Ontario has provided funds to develop palliative care networks and care delivery models in each region in Ontario. The Chronic Ventilation Network should work with these palliative care networks to coordinate care for ventilator-dependent patients nearing the end of their life.

The recognition of a single centre as a “Centre of Excellence” in the province can be very useful when there is only one existing centre providing a service, and there is a desire to add capacity at other centres. The Task Group felt that this situation applied to weaning services in Ontario, but not to the entire continuum of care.

The Chronic Ventilation Network and the Centre of Excellence for Weaning will have responsibilities beyond direct patient care as follows:

- Develop standards for the delivery of care. This might include, for example, the establishment of the infrastructure required at a chronic ventilation program such as a sleep lab.
- Develop and implement educational material and sessions for medical and clinical staff who work in weaning centres across the province.
- Act as an information resource for health care professionals in other centres.
- Develop and maintain quality assurance programs for new programs as they are established across the province.

- In consultation with the Ministry, review and revise, if necessary, the funding formula for these services to reflect the resources needed to deliver this care and the additional responsibilities of the Centre of Excellence and the Network members.
- Assist the Ministry in the evaluation of ad hoc or invited proposals for additional capacity for these specialized services.
- Develop criteria and operational considerations for the establishment of new centres.
- Advise the Ministry on the development a minimum data set for planning, evaluation and research (see Recommendation 4).

The Chronic Ventilation Network (see Recommendation 4) and the Centre of Excellence for Weaning (see Recommendation 5) will work together to educate and support existing ICU health care professionals on the identification and preparation of patients who may require prolonged mechanical ventilation. This process should include the development and dissemination of a process template to transition patients from ICU to a more appropriate setting. Inreach teams from the Chronic Ventilation Network and Centre of Excellence for Weaning should be established to plan and facilitate a smooth and timely transition out of the ICU once the candidate patients have been identified. In larger centres, these inreach teams could be in a dedicated area within the hospital, outside – but in close proximity to – the ICU, with a dedicated staff to provide continuity of care.

Consideration should be given to the Toronto East General Hospital’s Progressive Weaning Centre to be the Centre of Excellence for Weaning because it has the largest established weaning centre in Ontario.

A major obstacle to developing this strategy for ventilator-dependent patients was the lack of data on the patients (e.g., patient volumes, demographics, primary diagnosis). There was also little literature on the best practices for some of the services described above.

The Task Group identified the following areas where more research is needed to better understand the needs of this patient population and the best practices for delivering care:

- Methodologies for qualitative and quantitative assessment of quality of life, including the social and environmental factors that affect quality of life, and methodologies for incorporating quality of life measures into cost/benefit analyses, especially when comparing home, other community and institutional settings.
- The benefits of elective ventilation for “at risk” patients, as measured by the changes in quality of life, clinical outcomes, and costs such as hospital admissions.
- The relationship between quality of life and the care setting (e.g., home or institution) and the factors that contribute to quality of life.
- The relationship between quality of care and the care setting.
- The unique needs of pediatric patients who are ventilator dependent and their families.

These patients use a variety of services across the entire continuum of care and in multiple institutions. A patient registry would facilitate the exchange of clinical and other information needed to effectively manage these patients. A minimum data set is also needed to facilitate this research, support the evaluation of service delivery, and provide a base line and trending for future planning. A sample minimum data set is provided in Appendix I.

The delivery of the services described above requires multi-disciplinary teams that include physicians, registered nurses, respiratory therapists, physiotherapists, occupational therapists, and speech language pathologists with highly specialized skills. In many parts of the province, there are not sufficient numbers of these care providers, or sufficiently trained care providers to deliver the proposed services.

Formal educational programs are required for health care professionals who work with this patient population. This could be organized through the University of Toronto in association with West Park Healthcare Centre and Toronto East General Hospital, or as a collaborative program among many universities (e.g., the University of Toronto, the University of Western Ontario, the University of Ottawa, Queen's University, McMaster University). The courses should address the ethical, legal and medical issues unique to this patient population.

Concern was expressed that training efforts could be compromised by staff turnover, especially in regions with small patient populations. It was suggested that it might be more effective to focus on the wider-spread use of one discipline (possibly respiratory therapists) to work with these populations and to support the other clinicians caring for them. Narrowing the expertise to a discipline accessible across the province has the potential to effectively address staff turnover and duplication of training, and access to services across the province. This is the approach taken in Simcoe County, with the use of respiratory therapists as an alternative to generic training for these clients. The Chronic Ventilation Network is encouraged to explore this model of care as part of its educational mandate.

7.4.3 Managing the At-Risk Population

Recommendation 7: That the Ministry of Health and Long-Term Care work with health care education partners to develop and launch an education program for health care professionals in the community (e.g., physicians, respiratory therapists, registered nurses, personal support workers and therapists) to help them identify those patients who are at risk of developing respiratory failure. The program should include the importance of referring these patients to an appropriate clinic or, if there is no clinic in the immediate area, the program should provide the education and training the physician will need to plan and manage patient-centered care for these patients, including end-of-life decision making.

Recommendation 8: That the Ministry of Health and Long-Term Care and appropriate stakeholders support and enhance, in cooperation with patient advocacy groups including, for example, the Canadian Lung Association, the ALS Society, Muscular Dystrophy Association, Heart and Stroke Foundation, existing educational programs and, where

needed, develop and launch new educational programs for patients and caregivers regarding options for care to enable informed decision making for their long-term care.

It is generally believed that appropriate education and care for the “at risk” patient population can reduce the number of acute events and, therefore, reduce ICU admissions. To achieve this result, we will need to identify these patients and provide the needed education and supports, both in the community and hospital settings. The Critical Care Secretariat has established Critical Care Response Teams to work with patients who are in-hospital and at risk of an ICU admission. These teams identify and counsel patients and their families on alternatives before the patient experiences respiratory failure. The Task Group endorses the development and implementation of these teams as a means to managing ICU capacity.

All families should be given the support and counselling to draft a proposal that will outline what the patient and family wishes are if the caregiver(s) were to die, become ill, need respite, or need to travel for short period of time. This document should outline in detail where patient will be cared for and how that will happen. These documents should be reviewed annually to ensure updated information is incorporated into the plan.

The educational programs could be modeled on programs offered at centres that have demonstrated expertise in specific areas of managing at risk patients including, for example, non-invasive ventilation to prevent or delay the need for a tracheostomy.

7.4.4 Delivering Long-term Care

Recommendation 9: That the Ministry of Health and Long-Term Care and, in due course, the Local Health Integration Networks, improve the support provided for ventilator-dependent patients living in the community by:

- Providing and funding additional services for ventilator-dependent patients living in the home. These additional services would include respiratory therapist services. These services could be delivered through CCACs or a hospital-based service.
- Establishing a higher limit on the number of hours (i.e., a total of eight hours per day) of care that can be made available to the patient and family in a given period for other services including shift nursing.
- Providing and funding, through either the Assistive Devices Program and its Ventilator Equipment Pool or CCACs, the full range of equipment and supplies required by ventilator-dependent patients living in the community. Consideration should be given to the funding of equipment that will support the management of non-invasive ventilation, such as cough-assist devices and equipment used for volume augmentation.
- Subsidizing the incremental costs incurred by having a ventilator-dependent patient in the home (e.g., incremental hydroelectric use for the ventilators and related equipment, and transportation).

The Task Group members discussed whether respiratory therapy services were better provided through a hospital-based service or through a community-based service (e.g.,

CCACs or private agency). Some members believed that a hospital setting was attractive because it can provide a broader scope of work and professional development than working exclusively in a community setting. However, we agreed that it was extremely important to make these services available to the patients, regardless of how the delivery is organized.

Because of the high degree of uncertainty in estimating current and future demand (see Section 4.4.2), the Task Group is recommending an initial investment to increase capacity in the existing programs to relieve the pressure on ICUs. After this new capacity has been in place for three years, the Chronic Ventilation Network and the Centre of Excellence for Weaning will:

- Work with the Ministry and LHIN representatives to assess whether additional capacity is required for ventilator-dependent patients within each LHIN. This assessment will include a review of case volumes, wait times, the number of ICU beds occupied by ventilator-dependent patients and access to care in the local area.
- Assist LHIN representatives in identifying service gaps and issues and developing strategies to address these needs.

If the capacity issues have been satisfactorily resolved with the additional capacity, then no further centres should be established at that time. These issues should be monitored annually so that trends in usage can be identified in a timely fashion and additional capacity can be brought on-stream when it is needed.

Although the Task Group is recommending that the Ministry wait three years to reassess the capacity needed at a provincial level, there may be urgent needs for additional capacity in certain regions before this three-year period is over. The Ministry should consider all proposals from interested parties and evaluate each on its own merit, in consultation with the Chronic Ventilation Network.

The Task Group agreed that, whenever appropriate, the healthcare system should try to place the patient in the community, with all of the necessary supports. Supportive housing (attendant care) should be considered wherever practical to provide that additional capacity when home care is not an option, where the burden on the caregiver is onerous, or when the patient prefers independent living. Although a home setting is believed to provide high quality of life, it can also place undue financial and personal strain on the family and caregivers. Even with up to eight hours of care provided per day, caregivers for high-need patients would still not be able to take on full-time employment. Supportive housing is an attractive and cost-effective alternative to institutional care for the patients, their families, and the health care system.

All of the services and programs described in the preceding sections are only available to patients who are able to direct their own care. For the small number of patients who cannot direct their own care (e.g., persistently vegetative, advanced degenerative neurological disease) or who cannot summon help if needed (e.g., cannot operate a call bell), an alternative setting is required that provides 24-hour monitoring. These patients will generally

be cared for in a CAVC service that has the necessary monitoring equipment and is staffed appropriately.

7.5 Other Considerations

7.5.1 Operational Considerations

If there is still insufficient capacity to provide timely and quality care for this patient population after the existing programs are expanded, or when additional capacity becomes needed sometime in the future, the following activities will need to take place to ensure successful introduction of these expanded services:

- Explicit admission criteria must be developed for all new programs. These criteria should be modelled on the admission and discharge criteria at West Park Healthcare Centre and Toronto East General Hospital, which are provided in Appendices D and H.
- For new weaning programs, explicit discharge criteria must also be established. Appropriate and actionable repatriation agreements must be developed and implemented to ensure ongoing timely access to these programs.
- All ICUs in the province must be notified of the availability of new and existing programs and the admission and discharge criteria noted above.
- Best practices for all of the services (i.e., elective ventilation, weaning, rehabilitation and home ventilation training, chronic assisted ventilatory care) must be identified and disseminated to ensure consistency and maximum effect of the services provided. The Chronic Ventilation Network and the Centre of Excellence for Weaning will be responsible for developing the best practice guidelines and monitoring compliance.
- Explicit repatriation agreements must be developed between the weaning service and the hospitals that are sending these patients and a streamlined referral process to a CAVC service in the event the patient does not make the transition to the community. This would require a formal established relationship between the weaning service and a CAVC service.
- A formal relationship with an area ICU must be established by every centre offering services to ventilator-dependent patients to facilitate access to an ICU bed should the patient's condition deteriorate during the program.

For patients living in the community, there is a need to coordinate with local and regional authorities (e.g., Local Health Integration Networks (LHINs), municipal emergency planning) to ensure they are aware of the unique needs of these patients who are living in the community and have arrangements in place to accommodate their needs in the event of an emergency (e.g., emergency power and transportation).

The Government of Ontario should work towards eliminating administrative barriers and streamlining processes for the patient when dealing with the multiple government agencies that provide services (e.g., the Assistive Devices Program, Community Care Access Centres, Canada Pension Plan Disability, Ontario Disability Plan).

CCACs could provide case management services to these clients – including initial assessment, information, referrals, service planning and ongoing management of the care

For all chronically-ventilated patients, whether they are in the community or an institutional setting, there should be a process to ensure that the patients and their caregivers have an opportunity at least annually to reassess their choices for care, including end-of-life planning where appropriate.

The Ministry will need to establish a full-time coordinator position to work with the Chronic Ventilation Network and the Centre of Excellence for Weaning to coordinate the activities described in this report.

7.5.2 Selecting Sites for New Centres

Considerations in the selection of centres to host new programs for ventilator-dependent patients should include the following requirements:

- The availability of a critical volume of the specialized health care providers (especially physicians, nurses and respiratory therapists) needed for these programs is a critical success factor. A new program should only be established in an institution that has an established respiratory care program and supporting infrastructure.
- Many of these patients (especially in weaning units) will need to be transferred to an ICU when their condition deteriorates during their hospital stay. The capacity and willingness of the local ICU to accept these patients – at least on a temporary basis until they can be repatriated – should be a necessary condition for establishing a new program for this patient population. ICU capacity may need to be increased anywhere that a new weaning program is established.
- It will be important for any new weaning unit to have access to a CAVC service to accept complex patients who cannot be weaned, but who should not be returned to the referring hospital that might not have the needed resources to care for this patient, at least initially.
- Because of the highly specialized resources required to provide these services, and the relatively small number of patients who require the services, it is essential to ensure that the location selected will have a critical volume of patients to sustain the program. Ideally, more than one type of service (e.g., weaning, rehabilitation, chronic assisted ventilatory care) should be located at any new centre.
- Particularly for long-term care (e.g., chronic assisted ventilatory care services), consideration should be given to ensuring that the size of the service allows for appropriate programming to ensure that the recreational and social needs of the patients are met. This important element of quality of life is difficult to achieve with a small number of beds.
- Any new centre for the management of ventilator-dependent patients should have access to a registered sleep laboratory and other diagnostic services necessary for a full assessment of these patients.

- The committee recognizes and underscores the potential for academic growth if the new services are located in a university-affiliated hospital that will provide a unique opportunity for vital research into these areas.

8.0 Recommendations

The final recommendations of the Chronic Ventilation Strategy Task Group are listed below.

Recommendation 1: That the Ministry of Health and Long-Term Care immediately establish six new beds for weaning and up to 20 new beds for institutional long-term care for medically-stable, ventilator-dependent patients at facilities that are capable of opening these beds in the very short term. Patients in an ICU would have priority access to these beds. Each expanded site should dedicate at least one of the new beds to respite care and designate some of the additional capacity for reassessment of patients living in the community. This capacity should be made available as quickly as possible, preferably within six months.

Recommendation 2: That the Ministry of Health and Long-Term Care, in addition to creating additional institutional capacity, ask all institutions (including intensive care, chronic assisted ventilatory care and complex continuing care units) to identify any ventilator-dependent patient in their care who would prefer to be in a community setting and their medical condition would allow discharge to an appropriate community setting. For each of these patients, a supportive care (attendant housing) option should be provided if the patient and family are agreeable and an appropriate placement can be established. Where demand is high, these services could include beds for respite care. This capacity should be made available as quickly as possible, preferably within six months.

Recommendation 3: That the Ministry of Health and Long-Term Care fund all inpatient beds for chronically ventilated patients identified in this report (existing and proposed) according to the average cost of the existing programs (i.e., at a rate that reflects the incremental costs of providing care for these patients beyond the average cost for a step-down or complex continuing care bed) and include reimbursement for ventilator equipment and supplies required by the patient. All outpatient clinics and outreach programs for this patient population should be funded according to the resources required to staff these programs to meet expected demand.

Recommendation 4: That the Ministry of Health and Long-Term Care establish a Chronic Ventilation Network that includes all centres and organizations in Ontario that provide services to patients who are, or who are at risk of becoming, ventilator dependent. The Network's responsibilities would include:

- Working with Local Health Integration Networks (LHINs) to assess the on-going need for these services and the adequacy of the services provided and to develop solutions that reflect the unique characteristics of the local network.
- Identifying and documenting best practices for the care of ventilator-dependent patients across the continuum of care.
- Facilitating the timely flow of communication between all providers in the service continuum.
- Advising the Ministry on the needed supports and infrastructure for successful community living.

- Fostering the development and delivery of training programs for health care professionals to care for this patient population.

The Network should be supported through the development and operation of a central patient registry to collect a minimum data set on all chronically ventilated patients (whether in the community or an acute care or long-term care institution) to support continuity of patient care at any of the multiple participating institutions in the province, the evaluation of the proposed strategy, planning for future capacity, and key areas of research, especially those identified by this Task Group as needing attention.

Recommendation 5: That the Ministry of Health and Long-Term Care designate one centre as a provincial Centre of Excellence in the weaning of ventilator-dependent patients that would serve to assist and train health care professionals in other parts of the province (where the need justifies the investment and the resources are available to provide the service) to deliver as close to their communities as possible the highly specialized care needed to wean ventilator-dependent patients.

Recommendation 6: That the Ministry of Health and Long-Term Care work with the Centre of Excellence and other health care provider and education partners to develop and implement a formal training program for physicians (e.g., respirologists, critical care specialists, general internists, pediatricians, neurologists, general practitioners) and allied health professionals (e.g., registered nurses, respiratory therapists, nurse practitioners, occupational therapists and physiotherapists) to care for this patient population. This program would have a provincial mandate.

Recommendation 7: That the Ministry of Health and Long-Term Care work with health care education partners to develop and launch an education program for health care professionals in the community (e.g., physicians, respiratory therapists, registered nurses, personal support workers and therapists) to help them identify those patients who are at risk of developing respiratory failure. The program should include the importance of referring these patients to an appropriate clinic or, if there is no clinic in the immediate area, the program should provide the education and training the physician will need to plan and manage patient-centered care for these patients, including end-of-life decision making.

Recommendation 8: That the Ministry of Health and Long-Term Care and appropriate stakeholders support and enhance, in cooperation with patient advocacy groups including, for example, the Canadian Lung Association, the ALS Society, Muscular Dystrophy Association, Heart and Stroke Foundation, existing educational programs and, where needed, develop and launch new educational programs for patients and caregivers regarding options for care to enable informed decision making for their long-term care.

Recommendation 9: That the Ministry of Health and Long-Term Care and, in due course, the Local Health Integration Networks, improve the support provided for ventilator-dependent patients living in the community by:

- Providing and funding additional services for ventilator-dependent patients living in the home. These additional services would include respiratory therapist services. These services could be delivered through CCACs or a hospital-based service.
- Establishing a higher limit on the number of hours (i.e., a total of eight hours per day) of care that can be made available to the patient and family in a given period for other services including shift nursing.
- Providing and funding, through either the Assistive Devices Program and its Ventilator Equipment Pool or CCACs, the full range of equipment and supplies required by ventilator-dependent patients living in the community. Consideration should be given to the funding of equipment that will support the management of non-invasive ventilation, such as cough-assist devices and equipment used for volume augmentation.
- Subsidizing the incremental costs incurred by having a ventilator-dependent patient in the home (e.g., incremental hydroelectric use for the ventilators and related equipment, and transportation).

Ontario Chronic Ventilation Strategy Task Group Terms of Reference

Background:

In 2004/05, the Ministry of Health and Long-Term Care (MOHLTC) launched a four-year Critical Care Transformation Strategy as part of the broader Access to Services and Wait Times Strategy. The purpose of the strategy is to improve quality of care and system performance in adult critical care services in Ontario. As part of Year One of the strategy, MOHLTC established the Ontario Critical Care Steering Committee and gave it the mandate of conducting a comprehensive review of the state of these critical care services and of preparing recommendations for a system-wide transformation. The Committee's Final Report was presented to the Minister in March of 2005.

Amongst its recommendations, the Committee identified the need for a detailed care strategy and associated resource allocation recommendations to address the needs of chronically ventilated patients. In general, the target patient populations can be defined as those suffering from a severe respiratory impairment who require ventilatory support greater than 6 hours per day for more than 21 days but who do not require services of an intensive care unit (i.e., patients who are otherwise medically stable). This would include patients with progressive degenerative diseases, spinal cord injuries, and Acute Respiratory Distress Syndrome patients who could potentially transition to alternate care outside a traditional intensive care unit. As the reports states:

The Committee is concerned about the number of long-term ventilated patients in Ontario ICU beds who do not require ongoing critical care support. Maintaining these patients in critical care beds limits access to critical care for Ontarians who may need it, and is an inefficient and inappropriate use of valuable healthcare resources. In addition, this situation has a detrimental effect on the quality of life of these patients. Long-term ventilated patients receive better care when they are treated by a healthcare team experienced with meeting their unique needs. (p. 40)

The Committee goes on to recommend that:

The Ministry of Health and Long-Term Care enhance the capacity of critical care resources in Ontario by increasing the number of chronically ventilated beds in Ontario in a timely fashion. These beds should be sited where the need is the greatest. In addition, the Ministry should support the expansion of innovative chronic ventilatory services such as home ventilation to meet the needs of these patients. (Recommendation #8)

Following the acceptance of the Committee's Final Report, MOHLTC established the Ontario Critical Care Expert Advisory Panel, under the direction of Dr. Alan Hudson (Lead, Access to Services and Wait Times Strategy) to oversee all aspects of the Critical Care Transformation Strategy.

Mandate:

The Ontario Critical Care Expert Panel is establishing the Ontario Chronic Ventilation Strategy Task Group and directing it to prepare a detailed care strategy and associated resource allocation recommendations to address the needs of chronically ventilated patients.

The strategy should include, as supporting information:

1. a clinical delineation of the relevant patient populations
2. a review of the scientific literature regarding care models for these patient populations (including strategies hospitals have employed to facilitate the discharge of these patients from intensive care units)
3. a review of how comparable jurisdictions have addressed the needs of these patients
4. a study of chronically ventilated patients in intensive care units in Ontario

5. a study of chronically ventilated patients receiving complex continuing care in specialty hospitals (including West Park and Toronto East General in Toronto, Parkwood in London and Sisters of Charity in Ottawa)
6. a study of chronically ventilated patients who are living at home with home care supports
7. a demand forecasting model for these patient populations
8. a capacity analysis of the specialty hospitals providing complex continuing care
9. a cost/benefit analysis of ICU care, complex continuing care and home care options

The core of the strategy will be recommendations as to the nature and scope of the investments required to address the needs of chronically ventilated patients in Ontario, as well as proposed funding criteria for MOHLTC's consideration. Specific funding recommendations to specific facilities are outside the Task Group's mandate.

In addition, the Task Group may choose to provide recommendations regarding the management of chronically ventilated patients while in the intensive care unit. This would include strategies to optimize patient flow, to meet the needs of patients on the waiting list in the intensive care unit, and to facilitate the discharge of patients from the intensive care unit.

Chair and Participants:

Chair: Dr. Gregory Downey, Task Group Chair

Members: Dr. Monica Avendaño (West Park representative)
 Ruth Boulianne (Sisters of Charity representative)
 Janice Cosgrove (Parkwood representative)
 Dr. David Leasa (University of Western Ontario)
 Melody Miles
 Jane Montgomery
 Dr. Carmine Simone (Toronto East General representative)
 Dr. Jeff Singh (University of Toronto)
 Cathy Szabo
 Marnie Weber

Timeframe and Accountabilities:

The Task Group will begin its work in August of 2005 and endeavour to complete its work in February 2006, submitting its report to the Ontario Critical Care Expert Advisory Panel.

Remuneration:

MOHLTC will reimburse the Task Group members their transportation and accommodation costs, as appropriate.

Staff Support:

The Task Group will be supported by the Critical Care Secretariat, Health Results Team, MOHLTC. In consultation with the Secretariat, the Task Group may hire on additional content experts as required to complete its report in a timely fashion.

APPENDIX B: Chronic Ventilation Task Group Membership

Gregory Downey, MD (Chair)	Respirologist, Division of Respiriology, University Health Network, Director, Division of Respiriology and Vice-Chair, Department of Medicine, University of Toronto
Monica Avendaño, MD	Respirologist, Assistant Professor, Department of Medicine, University of Toronto, Respiriology Program, West Park Healthcare Centre, Toronto
Ruth Boulianne	Director, Complex Continuing Care Program, Sisters of Charity, Ottawa
Janice Cosgrove	Director, Complex Continuing Care Program, Parkwood Hospital, London
David Leasa, MD	Respirologist and Program in Critical Care, Department of Medicine, London Health Sciences Centre
Melody Miles	Executive Director, Community Care Access Centre, Hamilton
Ginny Myles	Respiratory Therapist, Royal Victoria Hospital, Barrie
Jane Montgomery	Manager, Respiratory Therapy and Respiratory Community Care Services, London Health Sciences Centre
Regina Pizzuti, RRT	Manager, Ontario Ventilator Equipment Pool
Carmine Simone, MD	Intensivist, Department of Surgery (ICU), Toronto East General Hospital
Jeff Singh, MD	Intensivist, Toronto Western Hospital
Cathy Szabo	Executive Director, Community Care Access Centre, Etobicoke-York
Marnie Weber	Regional Director, Toronto Region Acute Services, Ministry of Health and Long-Term Care
Christine Bérubé	Hospital Consultant, Toronto Region, Ministry of Health and Long-term Care
Robert McKay	Project Manager, Critical Care Implementation Strategy, Critical Care Secretariat, Health Results Team
Andrea Hill	Project Coordinator, Evaluation and Research, Critical Care Secretariat, Ministry of Health and Long-Term Care
Marsha Pinto	Project Officer, Critical Care Secretariat, Health Results Team
Marcella Sholdice	Report Writer

APPENDIX C: Secondary Review Panel Membership

Anne Bell, Executive Director (or Director of Client Services), Simcoe County CCAC

Robert S. Bell, MD, President & C.E.O, University Health Network

Paula Cripps-McMartin, RRT, MSc(c), Manager Allied Health, Toronto Western Hospital

Sandra Dial, MD, Respiratory Epidemiology and Clinical Research Unit, Montreal Chest Institute McGill University

Barbara Gibson, PT, PhD, Researcher

Roger Goldstein, MD, Director, Divisional Program in Respiratory Rehabilitation, Division of Respiratory Medicine, Department of Medicine, University of Toronto, West Park Healthcare Centre

Toby Harris, Executive Director, Participation House, Waterloo-Wellington

Deb Hellyer, MD, Program Advisor, Pulmonary Rehabilitation, Windsor Regional Hospital

Douglas Maynard RRT, Executive Director, Canadian Society of Respiratory Therapists

Douglas McKim, MD, Medical Director, Respiratory Rehabilitation Services, Associate Professor, Department of Medicine, University of Ottawa

Barry Monaghan, Executive Director, Toronto Central Local Health Integration Network

S.O. Pugsley, MD, Deputy Director of Clinical Services at the Firestone Institute for Respiratory Health, Director of the Collaborative Respiratory Care Program at St. Joseph's Healthcare, Associate Clinical Professor of Medicine at McMaster University

Thomas Stewart, MD, Director, Critical Care Medicine, Mount Sinai Hospital and University Health Network

Peter Webster, MD, Respirologist, Respiratory Medicine, Sunnybrook and Women's College Health Sciences Centre

APPENDIX D: Description of Specialized Services for Ventilator-Dependent Patients in Ontario

London Health Sciences Centre

London Health Sciences Centre (LHSC) has a Respiratory Community Care Service within the scope of Respiratory Therapy Services and under the Critical Care Program umbrella. Through a formal partnership with a respiratory homecare company in the community, a hospital-based homecare respiratory therapist is available for discharge planning and consultation for the centre's respiratory care patients, including the discharged ventilator-dependent patients. As well, the ventilator-dependent patients are seen on an appointment basis in a Ventilatory Care Out-Patient Clinic by a physician, a homecare respiratory therapist and clinic registered nurses for status monitoring and routine assessments.

Since 1996, LHSC has successfully discharged to the community or assisted in the placement of 30 adults using an interdisciplinary assessment and discharge planning process. This process was established to try to manage the situation where a person who was clinically stable but ventilator dependent had to remain in the ICU setting. While this process has been successful for some, discharge has not been an opportunity for all patients. There are barriers that prevent discharge from the ICU setting.

The team includes critical care experts and is mobilized when there is a need to assess the possibility of community placement. They evaluate if the patient, given his or her complex care and ventilator dependency, can be safely cared for in the community, whether it is in the home with family, in a supportive housing environment or in a complex care facility. There are clinical criteria (e.g., oxygen < 40%, minimal or no PEEP, appropriate established airway) and home environmental criteria (e.g., available care providers, sufficient funding, home access, emergency supports) that guide this decision.

The Rehabilitation Centre of the Ottawa Hospital offers an outpatient service for patients with neuromuscular diseases and spinal cord injuries. Each patient undergoes a comprehensive neuro respiratory assessment to determine the best therapeutic interventions for the patient. This assessment is performed by a respirologist, a respiratory therapist and a nurse.

The service includes extensive education sessions for the patient and family delivered by a Registered Respiratory Care Practitioner (RRCPC). The clinic is becoming well known across Ontario as working with the patient to avoid invasive ventilation if at all possible.

West Park Healthcare Centre

The Respiratory Program at West Park Healthcare Centre has a multidisciplinary team that provides a continuum of care to patients with respiratory conditions. This includes inpatient, outpatient assessments and follow-up services. The Home Ventilation Assessment and Training Service is part of the Respiratory Program. Referrals come from across Ontario, from ICU's, our own Respiratory Rehab Service, our Chronic Assisted Ventilatory Care Service and respiratory medicine specialists in the community, when a patient is identified as

a ventilator dependant individual and there is a realistic expectation for return to the community.

Patients are assessed in hospital to determine their ventilatory and general care needs, this involves assessment of ventilatory requirements including sleep studies (modality, appropriate interface, equipment). The equipment is then requested from the ventilator pool. Funding for other assistive devices is requested from different sources including ADP and on occasion, private insurance coverage. The patient and caregivers receive education about the disease process, how to care for personal and equipment needs and how to prevent and manage emergency situations. The care team may recommend modifications to living accommodation and/or mobility aids to improve independence. The team also helps make arrangements for community support services and keeps the community physicians up-to-date.

This initial training program lasts between four to six weeks. Routinely patients are readmitted 1-2 days for reassessment, 3 months after discharge. Subsequently, all patients are readmitted at least yearly. These reassessments are conducted over a two-day period, providing the patient with ample opportunity to review the treatment program with the health care team and make any necessary changes. A repeated sleep study might also be part of the reassessment. In addition, the service's care coordinator contacts patients regularly by phone to monitor progress. When required, respiratory therapists will make home visits and training of attendants will be provided, or patients will be advised to return for outpatient visits to be reassessed by the staff Respiriologists.

The Respiratory Program offers outpatient clinics/services including the sleep laboratory, the tracheostomy clinic and the oxygen clinic. When appropriate, some of the younger ventilated patients who apply to attendant care facilities are referred to the West Park Healthcare Centre's off site transitional living program before they return to live independently in the community. These are usually young adults that have resided in institutions for most of their lives and therefore, need training in "living skills."

For over twenty years West Park Healthcare Centre has been providing Home Ventilation Training. Historically, we have provided this service to close to 500 individuals. Currently a multidisciplinary team supports 215 ventilator dependant individuals in the community across Ontario. Of these, 59 are on invasive ventilatory support (hence tracheostomized) and the remaining on non-invasive ventilation.

APPENDIX E: Estimate of Blocked ICU Beds

Table E-1: Estimated Number of ICU Patients that Could be Admitted If Medically Stable Chronically Ventilated Patients were Discharged at 21 Days

	Variable/Formula	Source	Conservative	Aggressive
Data inputs:				
Total bed days occupied by chronically ventilated patients in September 2005	A	ICU Survey	1,536	1,536
Desired maximum ALOS in ICU for chronically ventilated patients (days)	B	Expert Opinion	42	42
Typical ICU ALOS for non-ventilated patients (days)	C	Expert Opinion	10	7
ALOS in ICU for chronically ventilated patients (days)	D	ICU Survey	130	130
Estimated utilization of beds made available by earlier discharge of chronically ventilated patients	E	Expert Opinion	100%	100%
Potentially available bed days calculation				
Proportion of bed days that can be avoided for chronically ventilated patients	$F = (1 - B / D)$		68%	68
Potential bed days that can be avoided (Sept 2005)	$G = A * F$		1,040	1,040
Potential bed days that can be avoided in one year	$H = G * 12$		12,477	12,477
Potential bed days that can be expected to be utilized by other patients	$I = H * E$		12,477	12,477
Potential capacity of freed bed days				
Total ICU patients that could be admitted using these bed days/yr	$J = I / C$		1,248	1,782

ICU = intensive care unit

ALOS = average length of stay

ICU Survey = survey conducted by the Chronic Ventilation Strategy Task Group for this report.

Notes to the table:

- The number of chronically-ventilated medically-stable patients is based only on ICUs that responded to the survey. Therefore, totals might be understated.
- The ALOS for ventilated patients is only for those patients who were discharged. Patients who remain in an ICU indefinitely would not be captured in the ALOS calculation. As a result, the potential to save bed days might be understated.
- This analysis assumes that 100% of the bed days that would become available could be utilized for other patients. This assumption might result in an overstatement.

The estimated additional capacity depends on the assumptions used for:

- The average length of stay for these patients before they are medically stable enough to be transferred to another setting and
- The estimate of how much of the available capacity can be reasonably assumed to be occupied by other patients.

We conducted sensitivity analyses to assess the impact of changes in these two key variables. The results show that the number of bed days that might be utilized could vary from as low as just under 900 bed days to as high as 2,200 bed days, depending on the assumptions used, as shown in Table E-2.

Table E-2: Results of the Sensitivity Analyses

	Variable	Conservative	Aggressive
Base Case		1,248	1,782
Scenarios			
Desired maximum ALOS in ICU for chronically ventilated patients 21 days	B	1,545	2,208
Estimated utilization of beds made available by early discharge	E		
70%		873	1,248
80%		998	1,426
90%		1,123	1,604

ICU = intensive care unit

ALOS = average length of stay

APPENDIX E: Admission Criteria for the Progressive Weaning Centre at Toronto East General Hospital



Progressive Weaning Centre Medicine Health Service

Admission Criteria

Definition:

This program is designed to provide care to medically stable patients who require prolonged effort to wean from mechanical ventilation. Patients will be admitted for a maximum length of stay of three months.

Target Population:

Patients who are in ICUs who require ongoing mechanical ventilation. Prolonged mechanical ventilation is defined as ventilator dependence for more than six hours /day for at least 21 consecutive days. Patients who have clearly irreversible disease such as high spinal cord injuries, persistent vegetative states or advanced dementia will not be considered as candidates for admission.

Admission Criteria:

- Meet all the identified criteria for medical and respiratory stability and have been screened by the TEGH Progressive Weaning Centre (PWC) team
- The patient should have the ability to participate and direct his/her own care
- Advanced care planning including advanced directives have been discussed and documented on the health record
- Negative MRSA /VRE screen
- Referring ICU team agrees to repatriate patients after a three month length of stay in the TEGH PWC or if the patient becomes medically unstable and can not be stabilized within 48 hours

Medical Stability (organ dysfunction stabilized for a period of 2 weeks.)

- Sepsis treated and controlled
- Hemodynamically stable-absence of clinically significant hypotension, no inotropes
- No complex arrhythmias, or acute coronary syndrome
- Renal function and acid-base balance stable
- Treatment plan for all medical conditions is in place
- Adequate nutrition program in place; preferably with a PEG tube in place (will consider patients receiving TPN , but must have established maintenance line)

Respiratory Stability

- Is a candidate for active weaning from ventilatory assistance
- Adequate oxygenation ($\text{PaO}_2/\text{FiO}_2 >150-200$; $\text{PEEP} \leq 10\text{cm}$; $\text{FiO}_2 \leq 0.4-0.5$ $\text{pH} \geq 7.30$)
- Tracheostomy tube has been inserted
- Oxygenation stable including during suctioning, repositioning
- Absence of significant aspiration

July 25, 2003

¹ Adapted from TEGH Complex Continuing Care Chronic Ventilation program

Reference: MacIntyre, NR, Evidence Based Guidelines for Weaning and Discontinuing Ventilatory Support. Chest December 2001;120:375S-395S

APPENDIX F: Admission Criteria Existing Respiratory Therapy Programs



January 20th, 2006

Home Ventilator Program Admission Criteria

Clients are admitted under two categories:

- 1) Home Ventilator Assessment and Training of internal and external referrals with complex needs.
- 2) Home Ventilator Reassessment to assess need for mechanical ventilation and to provide routine follow up after training to promote health maintenance.

Criteria for Admission:

- 1) Client is well informed about the program
- 2) Client requires chronic mechanical ventilation all or part of the day
- 3) Client and caregivers are willing to participate in the program
- 4) Client is cognitively intact or has a documented substitute decision-maker.
- 5) Client's medical needs can be met in the community and does not require acute medical intervention.
- 6) Client has well defined and appropriate discharge plans including destination (home or community living center), name(s) of appropriate caregivers, and adequate community support.
- 7) Referring facility must sign a contract agreeing to readmit client if:
 - The discharge destination plans cannot be fulfilled
 - The client has to await placement arrangements
 - The client's needs become more acute in nature.

Addendum A

Information Sheet for Referring Facility

CAVC Admission Criteria

1. Individuals 18 years of age and older who require invasive ventilatory support for all or part of the day
2. Individuals no longer require continuous cardio respiratory monitoring and/or central venous access and are deemed medically stable
3. Individuals who are able to direct their own care.
4. Individuals must be able to physically access a call bell system, with appropriate judgement of when to request assistance. We are unable to provide continuous monitoring.
5. Non Smokers
6. Individuals who are motivated to leave their bedside and participate/interact in the wider hospital environment
7. Able to communicate needs (e.g. use call bell, augmentative and alternative communication and environmental controls to have needs met)

Goals of the CAVC service are:

- To provide a residential setting for patients requiring mechanical ventilation but who are medically stable and no longer require the services of an intensive care unit
- To optimize the resident's level of functioning and independent mobility
- To enhance quality of life and to provide an environment where patients and their families/friends can have a more normalized interaction
- To transition patients back into the community wherever possible

How to prepare ICU patients for transition to CAVC services:

- Encourage patient to become less dependent on 1:1 nursing and constant staff interventions
 - suggest drawing curtains around patient so they do not have constant visual contact with staff
 - decrease use of monitoring equipment (e.g. No constant use of oximeter)
 - reduce therapy time to a maintenance level
 - no weekend physiotherapy unless acutely ill
- Residents are encouraged to wear street clothes, adapted as needed for ease in dressing. Hospital gowns used only during times of illness or during physical or diagnostic exams
- Recommend appropriate footwear if ambulatory
- Ensure patient has a call bell that they can use independently and reliably
- Investigate need for hearing and vision aids
- Discontinue the use of PEEP and supplementary oxygen if possible
- As possible have patient cared for by staff who are unfamiliar with the patients routine and have patient direct their own care
- Swallowing assessment to ensure appropriate route for nutritional intake



APPENDIX F: Admission Criteria Existing Respiratory Therapy Program (cont'd)

Complex Continuing Care/Rehab Health Service

Chronic Assisted Ventilatory Program

Definition:

This program is designed to provide a compassionate and stimulating environment that enhances the quality of life of our ventilator assisted patients.

Target Population:

The patients admitted to the chronic ventilator program require mechanical ventilation for all or part of a 24-hour period.

Admission Criteria:

- Meet all the identified criteria for medical stability and respiratory stability

Medical Stability

Nonrespiratory organ dysfunction stabilized for a sustained period of 2 weeks.

- Sepsis treated and controlled
- Hemodynamically stable; no need for invasive hemodynamic monitoring
- No uncontrolled arrhythmias or heart failure
- Renal function and acid-base balance stable
- Not comatose
- Treatment plan for all medical conditions is in place, and easily transferable to the CCC service
- Adequate nutrition program in place; preferably using enteral route

Respiratory Stability

- Has stable FiO₂ less than or = to 40 %
 - Does not require Peep > 10cm H₂O to help decrease work of breathing
 - Not a candidate for active weaning from ventilatory assistance
 - Safe and secure airway; tracheotomy with a sufficient mature stoma to allow tube changes
 - Able to clear secretions, either spontaneously or with assistance
 - No episodes of severe dyspnea; no sustained moderate or severe dyspnea
 - Oxygenation stable including during suctioning, repositioning
 - Stable ventilator settings and no need for sophisticated ventilator modes i.e. inverse ratio ventilation, independent lung ventilation, high frequency ventilation
 - Absence of significant aspiration
- Require skilled medical management, nursing care and interdisciplinary support
 - Have the ability to direct own care
 - Have the potential and motivation to function at their optimal level of wellness; physical, psychological and spiritual
 - Directive of care has been addressed and documented on the health record

November 27, 2002

APPENDIX G: Summary of Bed Capacity, Ontario

	Location	Existing capacity	Expansion capacity*	Wait List (Nov 2005)
Weaning				
Toronto East General Hospital	Toronto	6	6	3 months
Rehabilitation and Home Vent Training				
West Park Healthcare Centre	Toronto	4		10 patients
Chronic Assisted Ventilatory Care (CAVC)⁺				
West Park Healthcare Centre	Toronto ^{**}	22	14-16	29 patients (2 years)
Toronto East General Hospital	Toronto	10	4	
St. Joseph's Health Care (Parkwood)	London	3	2	1 patient
Sisters of Charity	Ottawa	8	N/A	
St. Joseph's Health Care	Guelph	1	2	
Total CAVC		44	22-24	

N/A = not available, CAVC = Chronic Assisted Ventilatory Care

Although the following centres did not participate in the survey, our investigations found that these institutions are caring for ventilated patients, in either complex continuing care or medical ward beds.

- St. Vincent Hospital, Ottawa
- Windsor Regional Western Campus, Windsor
- Grand River Hospital, Kitchener

Peterborough Regional Health Centre has approval for a four-bed chronic assisted ventilatory care service to open in mid 2008, subject to post construction operating plan (PCOP) approval and funding.

* Each facility was asked how much it could expand capacity without a major capital renovation.

⁺ Some locations do not have a dedicated CAVC unit. Patients are cared for in a Complex Continuing Care Unit.

^{**} Although this unit is located in Toronto, it receives referrals from all over Ontario.

APPENDIX H: Draft Minimum Data Set for Research and Evaluation

ICU Admissions

- Admissions by hospital
- Date of admission
- Underlying diagnosis
- Patient age and sex
- Type of ventilation (invasive or non-invasive)
- Referral source (home, supportive care, attendant care, ward, CAVC, other)
- Date the patient is ready for discharge
- Date of discharge (to calculate length of stay)
- Discharged to (home, supportive care, attendant care, ward, CAVC, deceased, other)
- Date of any previous ICU admissions (at any ICU, not just the reporting hospital)
- Has advanced directives in place

Weaning Programs

- Admissions by weaning centre
- Date of admission
- Underlying diagnosis
- Patient age and sex
- Referral source (ICU, home, supportive care, attendant care, ward, CAVC, other)
- Date the patient is ready for discharge
- Date of discharge (to calculate length of stay)
- Discharged to (ICU, home, supportive care, attendant care, ward, CAVC, deceased, other)
- Patient ventilation status at discharge
- Date of hospital readmission(s)
- Reason for readmission(s)

Rehab and Home Ventilation Preparation Programs

- Admissions by program
- Date of admission
- Underlying diagnosis
- Patient age and sex
- Type of ventilation (invasive or non-invasive)
- Referral source (ICU, home, supportive care, attendant care, ward, CAVC, other)
- Date the patient is ready for discharge
- Date of discharge (to calculate length of stay)
- Discharged to (ICU, home, supportive care, attendant care, ward, CAVC, other)
- Date of hospital readmission(s)
- Reason for readmission(s)

CAVC Admissions

- Admissions by hospital
- Date of admission
- Underlying diagnosis
- Patient age and sex
- Type of ventilation (invasive or non-invasive)
- Referral source (ICU, home, supportive care, attendant care, ward, CAVC, other)
- Date the patient is ready for discharge
- Date of discharge (to calculate length of stay)
- Discharged to (ICU, home, supportive care, attendant care, ward, CAVC, other)
- Date of hospital readmission(s)
- Reason for readmission(s)
- Has advanced directives in place

Outpatient Clinics

- New cases by clinic
- Number of visits by clinic
- Underlying diagnosis
- Patient age and sex
- Type of ventilation (invasive or non-invasive)
- Referral source (neurologist, geriatrician, pediatrician, general practitioner, respirologist)
- Number of patients admitted to ICU and number of admissions to ICU
- Community setting (e.g., home, supportive housing, attendant care)
- Has advanced directives in place
- Date of hospital readmission(s)
- Reason for readmission(s)

Glossary

Chronic Assisted Ventilatory Care (CAVC)	Inpatient care for individuals who require invasive mechanical ventilation
Chronic mechanical ventilation	Mechanical ventilator dependence for at least six hours daily for greater than 21 days in an otherwise medically stable patient.
Critical care unit	The term “critical care unit” includes all intensive care units (ICUs) such as medical, surgical and trauma ICUs or burn units.
Home mechanical ventilation (HMV)	Non-invasive or ventilation via a tracheotomy for a period of greater than three months on a daily basis carried out in the user’s home.
Intensivist	A physician who has completed the Royal College of Physicians and Surgeons of Canada (RCPSC) fellowship training in Critical Care (or equivalent certification) OR a physician who completed training prior to the availability of subspecialty (for example physicians who are board-certified in Internal Medicine, Anesthesiology or Surgery) and who has provided at least six weeks of full-time ICU care annual over the past ten/five years).
Invasive ventilation	Invasive ventilation is accomplished, for example, through the use of intubation (i.e., the insertion of a breathing tube through the nose or throat) or a tracheotomy (i.e., the creation of a breathing hole in the patient’s trachea).
Mechanical ventilation	Mechanical ventilation is used when natural (spontaneous) breathing is absent (apnea) or insufficient. Air is forced into the lungs using mechanical equipment that uses either volume or air pressure to fill the lungs.
Non-invasive ventilation (NIV)	Non-invasive ventilation can be accomplished by a variety of relatively simple approaches such as a nasal or face mask. This includes patients who use BiPAP, but not CPAP.
Tracheostomy	A surgical procedure performed on the neck to create a direct airway through an incision in the trachea (the windpipe). <i>Tracheostomy</i> can also refer to the opening created by this procedure.
Ventilator-dependent patient (VDP)	An adult patient (greater than 16 years old) who is mechanical ventilator-dependent for a least six hours daily for greater than 21 days, but is otherwise medically stable (i.e., single organ failure).
Weaning	Transition from ventilatory support to spontaneous breathing (the process of becoming independent from ventilatory support)

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