



An External Review of the Provincial Respiratory Outreach Program

January 2009

Life-giving mechanical ventilation for
people with disabilities living in the community

Review funded by the
Social Services Partners in Organizational Development
Ministry of Health

Thank you to the Social Services Partners in Organizational Development and the Ministry of Health for their generous support with this review process and report.



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Contents

Introduction.....	4
PROP Overview	5
Our Beginnings.....	5
Where we are Today	5
Our Team's Expertise.....	5
Summary of Activities	6
PROP • Services at a Glance	8
External Review Report.....	10
Recommendations	17
Summary	18
Summary of Challenges	19
Meeting Client Demand	19
Respiratory Equipment Replacement	19
Client Needs and Concerns	20
Medical Recommendations	20
Our Goals	20
Conclusion.....	20

Part 2

Appendices to this review are available in a separate document. Please contact BCITS if you would like to receive a PDF copy.

The appendices contain:

- original surveys sent out to clients and respirologists
- additional data showing survey results
- questions and answers from a focus group

I was amazed and humbled at the incredible work [PROP] has done. The unique program you have is as successful as it is, I believe, because the clients are the drivers of it and the staff are exceptionally diverse, compassionate, professional and caring. I regard your program as the benchmark for all of Canada and look forward to sharing ideas/strategies with you over the next few years.

Connie Brooks
Aids to Independent Living
Respiratory Consultant
Alberta

Introduction

In early 2006, our Board of Directors decided it was time to perform a review of BCITS programs and services, including the Provincial Respiratory Outreach Program (PROP).

We set out to see how well we were meeting our mandate, particularly from our clients' point of view, but also from the point of view of health professionals. We also took this opportunity to take a global look at how we have grown and operational changes we may need to make to continue to serve our clients.

We conducted the review, which is summarized in this report, with an eye to the future: to hear about the changing and expanding needs of our clients—and people with disabilities who are not yet our clients—and to identify what we can do as a client-centred program to meet these evolving needs.

This report contains the results of our own internal review process and also the report of the external review led by Dr. Douglas McKim.

We are grateful for this opportunity to evaluate PROP, and thank the Social Services Partners in Organizational Development and the Ministry of Health for funding support.

PROP Overview

Our Beginnings

The Provincial Respiratory Outreach Program (PROP) began as a dream forged out of a crisis. In February 1998, people with disabilities living in the community and managing their needs for assisted ventilation found their sole support program was slated for closure.

People with disabilities using the Pearson Hospital Respiratory Program—many of whom needed 24-hour ventilation support—received a form letter stating that the program would close within 30 days. People who needed assistance after that point would need to call 911.

Instead of accepting the closure and the loss of safety and independence, users of the program came together and challenged the hospital system and the Ministry of Health. The closure was put on hold and community groups and consumers coalesced around the ideal of a provincial respiratory outreach program based in the community and the expertise of people who use assisted ventilation.

In 2000, the Ministry of Health announced that \$1.25 million annually would be made available through the administration of the Vancouver Coastal Health Authority to provide for a provincial respiratory outreach program.

With the collaboration of Technology for Independent Living (TIL), a proposal was made by the community to house a new Provincial Respiratory Outreach Program (PROP) with TIL. The implementation process went on for almost a year.

The unique history of PROP's development shapes not only its present function, but also its future. The ownership of the program belongs with the consumers who made it happen and who placed their faith not in others, but in themselves.

Where we are Today

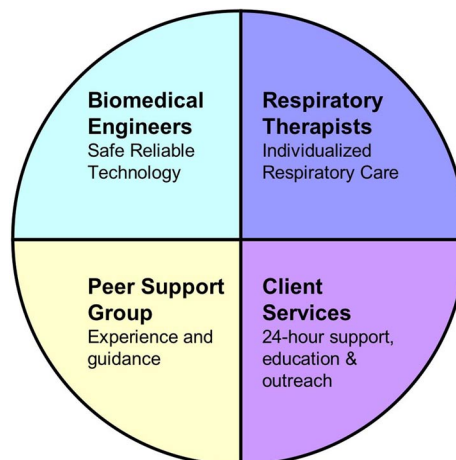
PROP is at a crossroads. Though our client base has grown by over 58% since we began, funding has remained at 2001 levels supplemented by the Ministry of Health with cost of living and staff compensation/benefit increases.

Our present base funding level is \$1,365,000. We have worked diligently to maintain and improve our services by maximizing efficiencies within our operations. The cost per client has been reduced from \$4721 to \$4177. Capital equipment grants from Vancouver Coastal Health have sustained us for the past 4 years. We now hope to secure stable funding based on our present needs.

Our Team's Expertise

PROP has developed a tightly integrated team that shares information and directs its services collectively. We believe this enables us to provide excellent service and expertise to our clients and to the health care providers who support them.

Our Client Services, Respiratory Therapists and Biomedical Engineering Technicians have distinct roles, but they work together in an integrated whole to serve clients with the guidance of our fourth component, the Peer Support Group. We also have the ongoing clinical expertise of a Respiratory Specialist who assisted with development of our program eligibility criteria and clinical standards, and a Respiratory Therapy consultant.



BCITS offers outstanding client-centred services to this small but critical population to improve quality of life and independent living. It was obvious during my recent visit that this can only be achieved by experienced professionals and individuals with vision and passion.

Carole LeBlanc, Professional Practice Leader, Ottawa General Hospital

This year, RTs performed 856 home visits, 700 phone consultations and answered 210 calls to our 24 On-Call Service. Our BETs made 837 service calls.

This integration allows us to develop solutions and expertise quickly in areas such as:

- **equipment characteristics** relating to service and use
- **new equipment trials.** Example: PROP trialed the first European “Legendair portable ventilator” in North America. This information was shared with respiratory departments at GF Strong and Vancouver General Hospital, and other health care providers throughout BC improving their ability to make informed equipment purchases.
- **individualized respiratory solutions** for on-call and home ventilation
- **disability related expertise.** Example: Clients with ALS have particular home respiratory needs that create greater demands on staff time. PROP is continually developing expertise about these clients’ needs and is able to provide more efficient supports for better respiratory care at home. The result: less demand on acute care and emergency departments.
- **innovations in mobility and portability**
- **service inspired by peers** whose experience, ideas and compassion support clients
- **developing home ventilation standards.** There are currently no home ventilation standards within North America. The PROP team is compiling data toward the development of these standards for BC.

Summary of Activities

- Since opening our doors in November 2001, PROP has developed a unique and comprehensive community-based respiratory program. We serve people with a range of disabilities and medical conditions residing in all the health regions of BC. Our services enable people to live well and safely in the community reducing costs to other health care sectors, particularly acute care. The bullets in this section provide figures for this operating year.

- In 2001, PROP was successfully merged with the TIL program. This created a centralized service for clients, many of whom use both programs, as well as efficiencies in equipment use and our Biomedical Engineering Technologists’ (BETs) time. For example, TIL provides the technical expertise for PROP clients.
- A **24-hour On Call service** was established to provide a centralized service for clients throughout the province. A PROP Respiratory Therapist (RT) is available around the clock to provide individualized information and advice. During 2007/08, **210** calls were made to the after hours service.
- We have established an **equipment pool** of ventilators, BiPaps and auxiliary equipment, as well as an inventory of supplies and parts. The original pool was composed of client-owned equipment as well as Ministry assets. We were grateful to receive \$1.5 million in 2007/08 from the Ministry of Health for the purchase of new ventilators to replace obsolete ones.
- **RTs visit clients** in their homes throughout BC to provide individualized care. In 2007/08, RTs performed **856** home visits and **700** phone consultations, along with reviewing reports, ventilator training courses, education for community partners and various other duties. Each client receives at least one visit per year; clients who require more assistance receive the hours they need. These visits include our in-home education sessions as needed or on an annual basis (see next bullet).
- An **education program** has been designed to provide workshops to clients, families and caregivers, including health care professionals who work with PROP clients. Our RTs provide

information and training on home respiratory equipment care, emergency preparedness, and other topics to allow clients to manage their own care without reliance on the health care system. Classroom and in-home education is offered in a client-centred, hands-on format. (**14 classes/124 participants**).

- Our BETs **maintain and repair all respiratory equipment** for clients, including mounting ventilators on wheelchairs. We ensure that equipment used by our clients is available, safe and operational. This in-house capability is extremely cost and time-efficient (**837 service calls**, not including mounting units on chairs, cabling and trouble shooting).
- Our **team works with acute care units** to transition ventilator-dependent clients into the community. We tailor the discharge planning process to fit with the mix of services required by individual centres in the various health regions.
- We have developed a wide range of **educational materials** to assist and inform clients and plan more to meet identified needs:
 - Balance **newsletter**, published 3 times/year
 - **website** (www.bcits.org/aboutus/prop.htm)
 - **Booklets**: PROP User Guide–About PROP, Beginners Guide, Your Contacts and Emergency Planning; Safety Checklist,
 - **Manuals**: Discharge Planning Guide; Ventilator Options: A guide for people considering mechanical ventilation for their medical condition or disability
- Program and services **brochures**
- PROP maintains a detailed **client database** to ensure accurate information, including equipment settings, service records and inventory.
- Our team has developed a **unique level of expertise** in providing the complex supports needed by people living with ALS. This client group requires substantially more RT and BET than other client groups we serve.
- We have developed **strong and cooperative working relationships** with health service providers in all health care regions of the province. This strengthens the net of safety and support for clients.
- A **new RT** was hired in 2008.



"My care aides, and my family, went to the PROP training courses. I think the good care that I receive is because of this."

PROP client

PROP • Services at a Glance

The following graphs give a quick overview of PROP's clients and services:

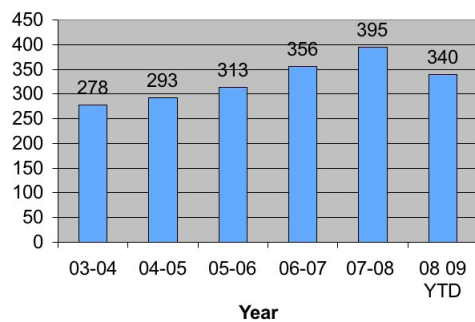
- overall client numbers
- services by diagnosis
- services by region

To Note

- **Increases in number of clients served in each of the last 6 years**
- **The large proportion of RT and BioMed services devoted to people with ALS**

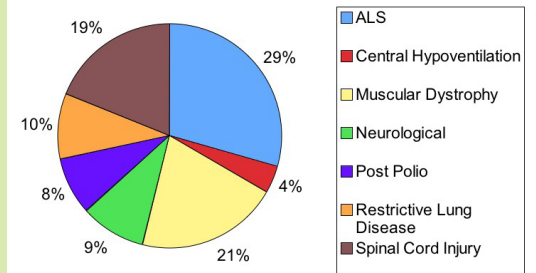
Our Clients

Number of Clients Served

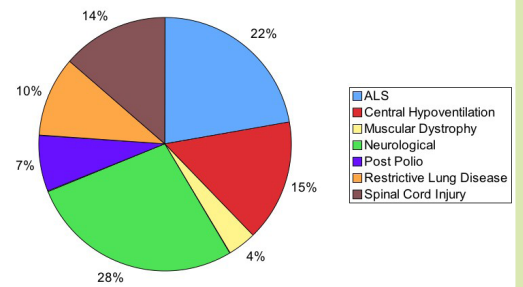


Clients & Services by Diagnosis

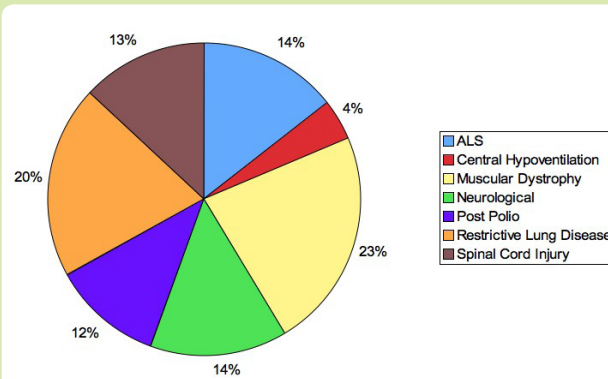
RT Services by Diagnosis



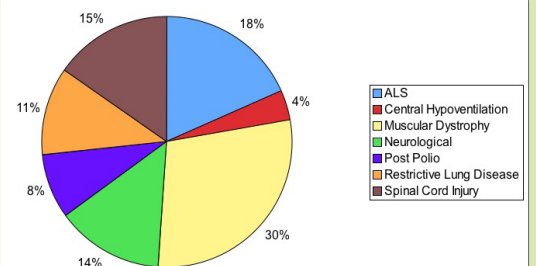
BioMed Services by Diagnosis



Clients by Diagnosis



Materials and Supplies by Diagnosis

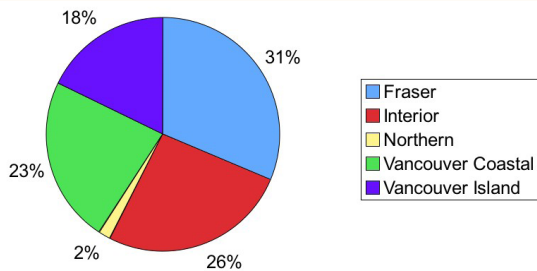


Our population is aging, so this is showing that we can live independently longer in our homes, if we have programs like PROP and TIL. We need to emphasize the importance of these programs.

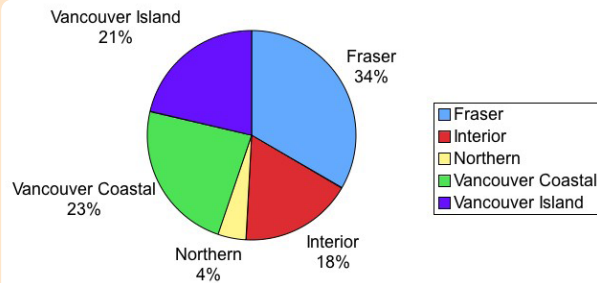
Focus Group Participant

Clients & Services by Region

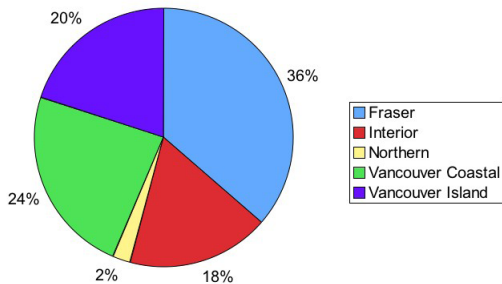
RT Services by Region



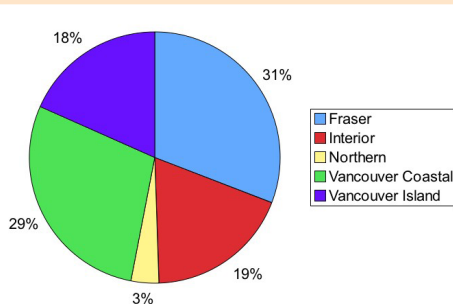
Clients by Region



BioMed Services by Region



Materials and Supplies by Region



The relationships [the PROP program has] forged with the community, acute and long-term care facilities of the province have encouraged the development of practices specific to clients who have long-term ventilator needs and has served to promote their reintegration back into their homes and communities.

These working relationships are patient-centred and work to empower the client, as well as the health care providers; the development of a consistent educational approach to teaching individuals and families how to manage a ventilator in the home is proof of this. All of these strategies have worked to positively impact such issues as client length of stay in hospitals and quality of life.

Elizabeth Goodfellow
Practice Leader
Respiratory Services Depts.
Vancouver Hospital and Health Sciences Centre

External Review Report

External Review of the Provincial Respiratory Outreach Program (PROP) of British Columbia prepared by Douglas McKim MD

September 17, 2008.

Individuals involved in the evaluation process included; Gillian Harney RRT, Dr. John Fleetham, Board Member, Judy Kelly, Directory of Home Care, Kirsty Dickinson, Client Services Manager and most importantly, Client representatives/PROP Clients; Walt Lawrence (Peer Counsellor) and Roger Jones (Independent Business Person).

Introduction and history

Respiratory failure, the inability to sustain one's own capacity to breathe, is one of the most frightening and excruciatingly symptomatic experiences for patients. Imagine our own fear of death from drowning and the anticipation such a daily risk might involve. Appreciate then the bravery and fierce desire for independence that keeps such an individual at home or drives them to leave the support, reassurance and expense of an acute care hospital to seek a productive life in the community. Most often the disorders which commonly lead to respiratory failure are not self-inflicted but are the result of genetic problems, accidents and acquired impairments beyond the control of the individual. The advent of smaller, user-friendly ventilators and the sheer cost of a life-supported patient in a Critical Care hospital bed has fueled the process of home mechanical ventilation (HMV).

The Provincial Respiratory Outreach Program (PROP) began in 2001 after ventilator assisted individuals (VIAs) were informed that their program at Pearson Hospital would be discontinued. Their ultimate removal was delayed through the challenge brought to the Ministry by the community and the VIAs affected. The Ministry provided initial funding of \$ 1.25

million annually to provide community-based support for equipment, education and Respiratory Therapy (RT) in order to assist VIAs to live outside of institutions. In the face of looming challenges and with a recognized history of success the Board of PROP felt that an external review was required in order to evaluate effectiveness of the program in meeting its mission and to provide recommendations moving forward that will recognize the increases in work load and enable the program to continue to provide an excellent and sustainable service.

A number of areas of attention will be discussed in this review. There will be some over-lap but they can generally be divided in to; Client needs, Medical Recommendations and Financial/Organizational issues.

Professional Qualifications

The review leader is a fully qualified specialist in Respiratory Medicine with the Royal College of Physicians and Surgeons of Canada with special expertise in Respiratory Rehabilitation, Long Term Ventilation and with Board Certification by the American Board of Sleep Medicine. He is an Associate Professor in the Department of Medicine, University of Ottawa, Medical Director of Respiratory rehabilitation Services and Associate Director of the Ottawa Hospital Sleep Centre. He has over 15 years of experience with ventilation-related issues, cares for approximately 80 ventilator assisted individuals (VAI) in the community and is recognized internationally for clinical and academic work in this area.

The review consisted of information provided by PROP in a summary document, a site visit with an opportunity to speak with Biomedical Engineering technologists at work, a tour of the physical plant as well as a three hour face-to-face meeting with PROP representatives, community home-care representatives and clients.

A very emphatic position was taken on proper preparation and education of clients but recognition of their freedom to evaluate their personal needs and values and maintain their own choices.

Brief Description of the Service

PROP is an arms-length service provided by trained professionals on a contractual basis through Vancouver Coastal Health and therefore the Ministry of Health. It is intended to enable VAIs to live outside of institutions and in the community where health-related costs are far less and the quality of life and independence is recognized to be much greater. HMV therefore provides a win-win situation for clients and Ministerial budgets. Clients are referred by primary care physicians and particularly by respirologists most often when they have developed respiratory failure, often from acute care hospital. As well, individuals who remain in the community but are at-risk of impending respiratory failure requiring mechanical ventilation are assessed and provided this service. Medical criteria must be fulfilled and all applications are reviewed by the Medical Director. Exceptional consideration is given to circumstances that may not be adequately covered by the medical criteria.

For hospitalized patients, where ever possible, continuity of care is maintained by RTs being involved in the discharge planning process while the patient remains in hospital. This facilitates the safe, comfortable, familiar transition home or to an alternative independent living environment. Routine service includes provision of up to two ventilatory support devices, associated disposables (tubing, filters, masks), humidifiers and suction equipment. In addition to hands-on education sessions PROP also maintains a website, publishes a regular newsletter and provides booklets and manuals fundamental to the success of HMV. Clinical care includes Respiratory Therapy, extensive education of patients and caregivers in use of the ventilator and tracheostomy management, airway clearance and 24 hour access to advice from a RT. Equipment exchanges are usually within 24 hours although true respiratory

emergencies are referred to the emergency medical system (EMS).

A routine home visit is provided within the first two days of initiating ventilation in the community and in fact many patients who begin noninvasive ventilation initiate this in the home, a comfortable and cost-effective practice. Home visits include re-evaluation of gas exchange, ventilatory parameters, emergency procedures and addressing questions from VAIs and caregivers. During 2007/8, throughout BC, RTs provided 856 home visits and fielded 700 phone consultations. PROP clients continue to be visited at home at least on a yearly basis. The program remains at the service of clients who call during office hours as well as the on call RT. RTs responded to 210 overnight calls during 2007/8 providing individualized, knowledgeable advice. An excellent level of satisfaction was expressed for these services.

Although it is not a subject of this review, a tremendous value-added feature of PROP is its association with Technology for Independent Living (TIL) who by virtue of their proximity (shared space) can provide comprehensive timely service to PROP clients. This allows the critical application of life supporting ventilators to power chairs and the design and installation of environmental control systems. Experience in other jurisdictions demonstrates lengthy delays in the application of adaptive technologies some of which result in re-hospitalization or significant delays in discharge to the community. The importance of this liaison cannot be over emphasized.

An important relationship also exists between current clients of PROP and users of ventilatory technology in providing experienced, fundamental advice to prospective clients. On-going support and advice with respect to issues of home ventilation are also provided. This is just one more ex-

It is abundantly clear that PROP has been providing a critical, successful and much appreciated service to the VAI [ventilator assisted individuals] community and in an effort to engage in continuous quality improvement an external review was initiated by the Board.

ample of how clients not only benefit from but make an invaluable contribution to the program.

It is abundantly clear that PROP has been providing a critical, successful and much appreciated service to the VAI community and in an effort to engage in continuous quality improvement an external review was initiated by the Board. This included surveys circulated to clients/ caregivers and to referring physicians. Several challenges and objectives have been determined as a result of this inquiry and have been divided in to sections on Client Concerns, Medical Recommendations and Financial Considerations.

Client Concerns

The clients were represented by Mr. Lawrence and Mr. Jones. These volunteers and users of PROP services made extremely clear, the value that they place on their independence and the spirit of client-centeredness that characterizes PROP. Indeed it was ventilator assisted individuals who spearheaded the establishment of PROP when the program at Pearson Hospital was precipitously closed. A very emphatic position was taken on proper preparation and education of clients but recognition of their freedom to evaluate their personal needs and values and maintain their own choices. The review included 93 responses to a survey sent to 322 clients as well as the summary of a client focus group led by Roger Jones. One can with some confidence suggest that those who did not respond are unlikely to have been significantly dissatisfied with the services provided by PROP as this would likely be a motivating factor to respond. The results of the survey can be summarized as indicating a high level of satisfaction with PROP and an appreciation of it's facilitation of their independence. Those expressing a more neutral stance

Although it was clearly acknowledged that PROP clients would like to see a higher profile for PROP and that more clients have the opportunity to benefit from its expertise and service it was equally understood that, while this is everyone's desire, such progress must be matched with appropriate, sustainable financial support.

may not have a great on-going need for service from PROP.

Clients did express a general desire for more services from the on call RT although these were not specified. Nor is it clear that these are services which are within the mandate of PROP. Selection of equipment and selection of supplies were also highly rated as an issue with some VIAs. Again the specifics are unknown but it was suggested that this desire may be driven by information on the internet and that PROP may need to promote more widely the understanding that sustainability of the program requires economies of scale and one-of purchases are necessarily, carefully scrutinized. At the same time it is appreciated that PROP clients are constantly researching innovative solutions and serve as an invaluable resource to PROP for information on new technologies.

Although it was clearly acknowledged that PROP clients would like to see a higher profile for PROP and that more clients have the opportunity to benefit from its expertise and service it was equally understood that, while this is everyone's desire, such progress must be matched with appropriate, sustainable financial support. Clients of PROP also expressed their willingness to assist in this process. Along a similar vein there was a common concern expressed about the permanence (or not) of PROP and the critical supports they bring to the community. Part of this originates with the very real, historical closing of the program at Pearson Hospital and the remainder undoubtedly stems from the precarious nature of their situation where technologic assistance holds the key to their valued independence and quality of life. Measures (like this review) must be enacted by the Board in order to enlighten government who may be unaware as to the cost-effective nature of these services and the consequences to acute care hospitals and most importantly, critical care units of not providing appropriate funding to transfer and maintain these VIAs in the community.

There was an appreciation that PROP is well recognized and their role understood by some disease-specific societies, e.g. ALS and Muscular Dystrophy but it was also accepted that a broader exposure and awareness would help to bring unidentified clients in to the service of PROP and raise the profile of this fundamental equipment and clinical service.

It has been noted that admissions to hospital whether acute or otherwise are very difficult for PROP clients and that most healthcare practitioners have little or no familiarity for the needs of VAIs from the community. Furthermore requests for well established (in the home) routines are often neglected in hospital due to a failure to realize or accept their wisdom and value or an inability to accommodate them. This unfamiliarity may lead to unnecessary Critical Care admissions for individuals who are not critically ill.

Medical Recommendations

Just over 50% (15/28) of the Respiriologists responded to the survey distributed by the Board. Recommendations for PROP emanate both from these results and from Board members familiar with the services PROP as well as from the Medical Director. The majority of respondents rated the importance of PROP Services as "Very Important" and the Satisfaction level as "Very Satisfied". This speaks to the quality of the services provided and the appreciation expressed by the Medical community. There seems to be a particular appreciation for the utility and value of home assessments and support.

A number of observations and suggestions, as well, were outlined in the survey results. There seems to be an expectation that PROP should play a more active role both in terms of clinical care and more particularly in the provision of ventilation equipment within the acute care setting. Concern was raised about more prolonged hospital stays and extended use of limited hospital ventilators. Further education by

PROP to acute care institutions, small or large, may be advisable in order to clarify the important but limited role PROP is able to play in inpatient management. A similar ventilator equipment pool in Ontario strictly prohibits the use of ventilator equipment in otherwise provincially funded institutions. While a clinical assessment in hospital to bridge the gap between the hospital and the community, enhancing continuity and confidence is a clear goal of PROP, in my estimation, resources can not be devoted to the extended provision of ventilators to globally funded institutions. A brief overlap, using a PROP home ventilator immediately prior to discharge, may encourage the above goals without compromising PROP's mandate to serve the community. The extended availability of equipment to acute care hospitals is beyond the scope of PROP's services unless there is specific funding from the Ministry to expand the pool of equipment to accommodate this need. Even under such circumstances, experience has shown that equipment may not be repatriated as readily as is necessary to maintain inventory.

Referring physicians are requesting the availability of ventilation equipment for individuals with severe COPD. The benefit of bilevel pressure support ventilation is clearly evidence-based in acute exacerbations of COPD requiring hospitalization and has been demonstrated to reduce the likelihood of endotracheal intubation. Chronic respiratory failure in COPD however is another matter. Although, as experienced clinicians, we have anecdotally cared for patients who, in our estimation, benefited from long term ventilation, the literature does not support this contention with the possible exception of patients with recurrent, severely hypercapnic/acidemic exacerbations. The frequency of emergency department admissions may

Measures (like this review) must be enacted by the Board in order to enlighten government who may be unaware as to the cost-effective nature of these services and the consequences to acute care hospitals and most importantly, critical care units of not providing appropriate funding to transfer and maintain these VIAs in the community.

be reduced in this latter population by the introduction of long term positive pressure ventilation. The Board may wish to review the Medical Eligibility Criteria in order to consider this population. It was clearly recognized that the criteria were developed in approximately 1995 and that a review was in order.

The question of funding CPAP through PROP was also raised. Obstructive Sleep Apnea is an increasingly frequent medical diagnosis and affects at least 2% of adult women and 4% of adult males. It is not at all clear, particularly given the financial considerations to be discussed subsequently, that PROP would be even remotely in a position of funding and providing similar clinical care to individuals with sleep apnea without a broadening of the mandate and a substantial increase in the budget. The less common but related conditions of complex sleep apnea requiring much more costly and sophisticated devices such as bilevel and adaptive servo-ventilators were also discussed. The bilevel devices are already available through PROP but such new patient requirements could constitute a substantial strain on PROP resources. The latter adaptive-servo ventilators have been subjected to only a few comparative clinical trials, none with long term outcomes and in comparison to CPAP are significantly more expensive, at \$ 7000 to \$ 8,000. Their relatively small numbers would also prevent the pricing advantage of bulk purchasing obtained with bilevels and ventilators. Furthermore, in long term trials of an alternative positive pressure treatment, CPAP, in CHF and Cheyne-Stokes respiration, the expected improvements in survival were not demonstrated in spite of improvements in cardiac performance and reductions in sympathetic nervous activity. Sufficient long term investigation has not yet been performed with available positive pressure devices. Even in the presence of compelling outcomes which may yet be demonstrated, PROP must decide if this is a

population that can also be served through a home ventilation program.

A proposal has been made that PROP forge closer relations with the At-Home program. This is a home ventilation program which enables pediatric patients to remain at home with ventilatory assistance. Unlike PROP, care and clinical assessments/adjustments are much more hospital-based without respiratory care in the community. A liaison with PROP would allow a more independent, community-based approach and discourage a dependence on the acute care facilities where appropriate. Very likely, the relative risk management approach adopted by most adult VALs would not be as easily accepted by parents on behalf of their sons and daughters but many may be very comfortable with this transition and significantly benefit from the availability of community respiratory assessment and technologies to support independence. Insofar as this responsibility will increase demand on PROP resources, support will also need to be reflected in the budget. Cost savings are very likely to be realized by the Ministry however as the care provided in the community comes at a lower cost than that provided in hospital. Hospital-based pediatric assessments could then be more focused on those clients who truly require this level of monitoring. Clearly a discussion and agreement from those Pediatricians involved in such clinical care would be fundamental to any consideration around PROP's greater involvement.

There are some important over-riding issues raised by the surveyed Respiriologists which must be approached from a higher organizational perspective. These include; the lack of long term ventilator beds, the extended utilization of (especially smaller) hospital ventilators, the limitations to the Choice in Supports for Independent Living (CSIL) program which may be insufficient to allow some good candidates to return to the community. Under the current mandate, PROP can

only play a limited role in addressing any of these important concerns. These issues must be addressed at the Ministry level and only with a detailed understanding of the numbers and the dynamics of 'at-risk' and ventilator assisted individuals. Solutions would include appropriate funding for home ventilators in acute care facilities (or a specific pool provided through PROP), Independent Living Facilities which would relieve the burden on families which presently prevents discharge and enhancement of knowledge of acute care providers including system navigation for those on ventilators. A generally higher awareness of the at-risk population and enhanced home supports may prevent the acute care emergencies and Critical Care admissions which often result in unintended, long term invasive ventilation.

Financial and Organizational Considerations

A number of publications in the literature have emphasized that managing VAIs in the community is much more cost-effective than the common disposition to acute care beds. In order to meet the economically favourable mandate assigned to PROP, yearly, sustainable funding must be provided. Without an effective means of community support individuals supported by ventilators will be unable to remain in the community and will begin to occupy acute care and Critical Care beds. The latter in particular are very costly and such utilization will prevent the alternative uses of intensive care beds for high risk surgeries and other procedures. According to the Ministry of Health in Ontario, for example, it is estimated that there are approximately 70 long term ventilated patients who are in ICU beds and could be cared for outside an ICU. This is felt to be the equivalent of 1000 to 2000 ICU admissions per year which are prevented because the beds are occupied. The effect of PROP in managing individuals in their homes serves a fundamental

purpose in preventing a similar result in British Columbia.

In spite of the value of such services which are recognized throughout the Western world, PROP remains underfunded. The original base funding of \$1.25 M in 2001 has increased very little in spite of a significant increase in the numbers of clients served. The base funding has increased to only \$1.365 M whereas the operational budget was \$1.691 M for an anticipated client load of 407 individuals. The budget enhancement has been less than 10% for an increase of more than 42% in the numbers of clients that PROP is serving and maintaining in the community, out of acute care. The employees of PROP have become increasingly efficient as well, reducing the cost per client from \$4721 to \$4177. This represents almost a 12% reduction in the cost per client in spite of the relative reduction in overall funding. Certain client groups such as the ALS/Neurological individuals are very complex and while they constitute 14% of the PROP clients they are receiving 29% of PROP and Biomed services. The current funding model does not account for these increases.

The base funding provided by the province did not incorporate a system that would recognize an increase in demand for such a cost-effective and quality of life enhancing service. Any base funding going forward must appreciate the costs of on-going support for every existing client in the program, an additional cost for each client added within a fiscal year and costs for replacement of out-dated equipment. The latter is particularly important as there could be medico-legal ramifications for the Province if out-dated equipment is employed for life-sustaining treatment in the community.

Funding has clearly not kept pace with the increasing costs of gasoline and overnight accommodation. Employees of PROP are often required to use their own vehicles for home visits and are inadequately reimbursed for fuel and mileage. They are

In spite of the value of such services [which maintain VAs in the community] which are recognized throughout the Western world, PROP remains under-funded.

frequently housed in the most frugal of accommodations in order to provide the most economical home assessments. Costs for airfare are rising and this is not accounted for in the current base funding.

In 2001 PROP was cleverly housed adjacent to the office of TIL. While the clear advantages of this proximity have been discussed the restrictions on space continue to be a serious challenge. Although TIL has likely also experienced growth this was not a topic of review. The space occupied by PROP is presently in a two storey warehouse with only stair access. Every corner and shelf is efficiently used but crammed with equipment. Although the workspaces are clean and well organized there is little room for navigating between sections and employees are constantly required to climb up and down stairs in order to complete their tasks. Parking is also severely limited. Access to Power Wheel Chairs and other disabled transportation is extremely limited. The growth and success of the PROP and TIL organizations have out-stripped their physical plant and are causing both inefficiencies and limited access. A single storey structure with a considerable increase in square footage is urgently required in order to efficiently meet the needs of these clients. The Ventilator Equipment Pool in Ontario, which is responsible ONLY for providing equipment (not clinical care), recently met the same challenge with a new, larger physical plant. It is not a co-incidence that the same economic/health-related issues are driving demand for home ventilation in each province.

Qualities of a Successful Home Ventilation Program (Stuart et al.)

Stuart published an important report after reviewing the world's largest and most experienced HMV program in France. He and his colleagues determined a number of fundamental factors which determine the success of a HMV program. The Provincial Respiratory Outreach Program is exemplary in Canada in meeting many of these successful attributes.

1) Physician leadership; PROP has ample and competent physician leadership. The Medical Director has a vision for the program and provides excellent assessment of candidates. The Medical Director encourages liaison with all levels of health care and actively evaluates clients who do not strictly meet current medical eligibility.

2) Access to affordable personal support workers; This apparently remains a problem in BC as it is in many jurisdictions the CSIL program provides inadequate financial support for the hiring and training of personal care workers

3) Access to equipment and technology; This is the hallmark of PROP providing timely access to up-to-date equipment, ventilators, suction devices and disposables. The proximity of the Technology for Independent Living program (TIL) is a distinct advantage of the program

4) Clinical service 24 hrs daily, 7 days a week; An experienced RT is available for advice 24 hour a day 7 days a week. Home visits are arranged during daytime hours as required. Geographic challenges prevent the availability of 24 hour emergency home visits

5) Respite care; There is no formal system of respite care for ventilated patients and their care givers

6) Routine home visits; Home visits are provided during the transition home and within the first few weeks. Visits thereafter are at least yearly.

7) National/Regional Organization; PROP is organized at a regional level with a provincial healthcare system. There is as of yet no national organization or data base

8) Continuity between ICU, intermediate care and home; PROP provides a clinical assessment in acute care in order to facilitate safe, confident continuity of care from hospital to home

9) Economics of scale; The number of ventilated clients, approximately 330, allows the bulk purchase of equipment in order to minimize the cost per unit.

Recommendations

1) Employees and Board members of PROP need to communicate clearly with members of the provincial parliament that this is a critical, cost-effective service without which the province of BC would be considerably worse off. It must be understood that although this service may have been initiated by ventilator users it benefits all citizens of British Columbia by reducing health-related costs and freeing Critical Care beds. Considering activities that enhance the profile of PROP in both the Medical and the general community would be advantageous. Any expansion of PROP services must be matched with appropriate, sustainable financial support.

2) Those knowledgeable about the role of PROP must educate the public and healthcare providers about the impact and the mandate of PROP. With proper education the value of PROP in the overall delivery of healthcare to the community and the limitations on PROP to provide care outside their mandate will be better understood. If enhanced base funding is provided the mandate could be expanded. Improved education of acute healthcare workers in the appropriate support of VAIs from the community will facilitate more successful, less costly management of acute care admissions.

3) Ensure that clients and caregivers benefiting from the program understand that equipment purchases are made in bulk and that this large scale purchasing allows costs to be minimized. As such, specific devices recommended by such sources as the internet can not be made available in an economical fashion. One-of purchases could threaten the financial viability of the program. The board should consider whether or not it may be feasible to house a number of effective devices such as the CoughAssist™ which could be circulated on an as needed basis for acute respiratory infections. A co-payment system with

insured clients could supplement such a purchase with the devices returning to PROP for re-cycling.

4) It is recommended that the Board consider policies and mechanisms which will ensure that the current philosophy and enthusiasm for the PROP program continues in perpetuity. Succession planning will be critical in order to maintain the foundation of PROP as envisaged by its' clients and adapt to future changes and demands in healthcare. Insightful and understanding medical and political personnel are required and a significant number of clients need to remain on the board to champion this objective.

5) Improvement in base funding must reflect the real costs of providing care to clients of PROP including transportation and related costs for employees. Increasing fuel costs can be expected to have an impact on the overall budget as well.

6) In the overall system of care and management of VAIs consideration must be given to respite care. The assertion is that this is unavailable for most PROP clients and it is recommended that the board continue to explore possibilities with the MOH.

7) As the population who may benefit from home ventilation services expands the Board may consider broadening its' Medical Eligibility Criteria. Such an expansion must confirm adequate financial and physical resources and not threaten those client populations already qualified and should be evidence-based. The expected Canadian Home Ventilation Guidelines may help address a small number of these questions but is not expected to be completed until late 2009.

8) Communication and cooperation with the At Home program should be enhanced.

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The philosophy of hospital dependence for services which can be provided safely and more economically in the community should be updated particularly for the older pediatric clients. Careful inclusion of all stakeholders is important in these discussions in order to encourage participation and most importantly to ensure in advance that the financial and physical resources would be present to facilitate a greater involvement by PROP in the community care of these clients.

9) The physical plant has been out-grown and woefully inadequate to provide efficient, accessible services to PROP clients. A single level structure (or two stories with an elevator) with a significant increase in space, parking and disabled access is strongly recommended.

Summary

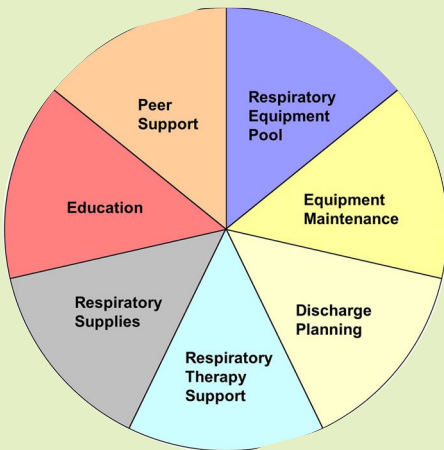
The Provincial Respiratory Outreach Program is a client-initiated, client-focused, cost effective service which adeptly provides the clinical care and equipment to keep VAIs out of hospital and in the community where quality of life is optimized. PROP is a remarkable example for the country and the world in caring for a population for whom technologic advances have enabled the transition from expensive acute care facilities to home. Although it was initiated with thoughtful design and support it's continued mandate has out-stripped the physical plant and financial resources. In order to continue this exemplary work PROP needs timely, proportional funding which recognizes the true costs of the service provided, the number of new clients and equipment added on a yearly basis and the value in preventing prolonged Critical Care and hospital admissions.

Summary of Challenges

Meeting Client Demand

Each new client draws resources from all of our 7 program components, beginning with discharge planning to respiratory therapy visits to education.

Our base funding has not increased (other than increases for staff, benefit and non-wage inflation) since 2001. We have been able to operate extensively through the use of “one time only” annual grants from the Vancouver Coast Health region and in the past 2 years from a one time only grant from the Ministry of Health). For example, our PROP base funding this year was \$1,365,000, but our operational budget was \$1,691,000 for a predicted client load of 407. The shortfall was replaced through a one time only grant.

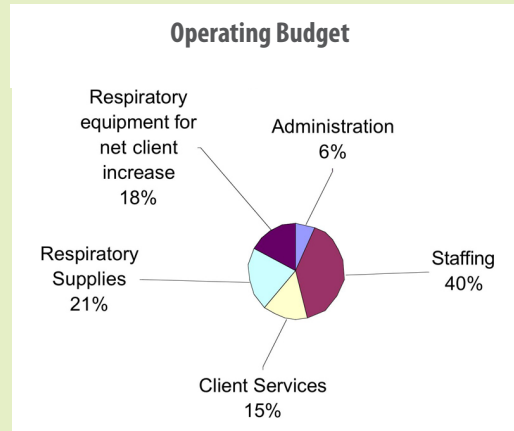


Respiratory Equipment Replacement

We must also account for the aging of equipment in the existing respiratory equipment pool. Manufacturers recommend the useful life of such equipment as 5-10 years, depending on the type of equipment. Replacing such equipment on an annual basis, will give us a sustainable equipment pool that is “up to date” and reliable. Our method of determining the value for equipment needing replacement has been to either replace equipment when it reaches 10 years of age or replace the equipment based on that which was decommissioned in the past year.

Cost-Per-Client Formula

Our operating budget is broken down into 5 major areas: administration, staffing, client services, respiratory supplies and respiratory equipment for new clients.



We recommend establishing a demand-driven funding formula based on predicted client increases. Each client has individual needs and the diagnosis does not necessarily predict the type of equipment or support required. To date, client increases have not been related solely to any particular disability or diagnosis. Our experience suggests it is a combination of our aging population, improvements in treatment for various disabilities and awareness of our program.

A funding formula would allow us to budget our costs based on an increasing or decreasing client load per client which includes new equipment, client support and supplies, etc.

Client Needs and Concerns

1. The security of PROP was a key concern. Clients worry that the program may be dropped or substantially changed with changing governments and priorities. They wonder what will happen to them if this occurs.
2. The client-centred, non-medical approach is greatly valued and clients want PROP to remain client-centred.
3. Clients would like more people to know about the PROP program: people with disabilities who might benefit from services and health professionals who can refer patients PROP.
4. Ways to increase contact and information-sharing among PROP clients and families was seen as a positive idea for the future.
5. Clients would like more choices in technology and ways to regularly find out what these choices are.

Medical Recommendations

1. New national guidelines are being developed by the Canadian Thoracic Society for all respirologists who refer clients to home ventilator programs (PROP). These guidelines may be a basis for evaluating the medical criteria of PROP.
2. New medical criteria could include: a limited number of clients with COPD (who would fall within the national guidelines), people with cystic fibrosis who need ventilator support while waiting for a transplant and clients who have a diaphragmatic pace implant.
3. Begin a dialogue with the At Home Program to look at ways to collaborate and synchronize services to children that eventually transition to PROP.

Our Goals

To secure funding for the three-year period of 2009-2012 based on:

- A cost-per-client formula, to be reviewed annually that will allow us to stabilize our current level of service, allow for expansion to meet identified client needs and maintain a stock of safe and current respiratory equipment.
- To continue to offer a centralized, province-wide program that is extremely successful in ensuring integrated services, meeting clients' needs, providing cost efficiencies in all areas of service and administration, and reducing costs to other health care sectors, including acute care and emergency services.
- To develop a centre of excellence for respiratory outreach to support people living in the community who need mechanical ventilation

Conclusion

We believe that PROP is a win-win program: it works for clients and for the health care system as a whole, both economically and in quality of service.

Our partners tell us we are providing an excellent service. Client surveys and evaluations have been very positive and we continue to learn and modify the program to meet their needs.

We plan to continue providing a provincial program driven by the needs of people living with assisted ventilation in all health regions of BC. ■