

The Provincial Respiratory Outreach Program

A Brief History

The Provincial Respiratory Outreach Program began as a dream forged out of a crisis experienced by people with disabilities who were living in the community and managing their needs for assisted ventilation. In many cases, they had left care facilities by voluntarily signing release forms stating that they would take full responsibility for the risks associated with their decision to live in the community and they were using their own knowledge, ingenuity and self-help networks to maintain their equipment and to manage their changing respiratory needs. The Pearson Hospital Respiratory program was the only resource available to them and the services that it offered were fragmented, inequitable, and seemingly oblivious to the urgency of their reality.

On February 24, 1998 the users of this program, many of whom needed 24-hour ventilation support, received a form letter stating that the Pearson Program would close within 30 days and that people who needed assistance after that point could call 911. There was a sense of consternation and despair among the community of people with disabilities that this abrupt closure of the only resource available might signal the end of independent living and a forced return to facility care.

However instead of waiting helplessly for this nightmare scenario to occur, the users of the Pearson program came together and challenged the hospital system and the Ministry of Health in a memorable meeting at the Creekview Housing Co-op on April 7, 1998. This meeting revealed that the meager respiratory resources available for the community had been subject to mismanagement, indifference and reckless game playing on the part of administrators trying to increase their budgets. Consumers were shocked that the equipment, supplies and respiratory supports that held their lives in the balance had been so precariously and callously governed.

By the end of this meeting the Ministry of Health promised to temporarily reinstate the Pearson program and to design a new provincial program that would meet consumers' needs. However the fact of the meeting, and the realization that arose from it that no one could have the knowledge and commitment that they did, led to an awakening that if a new program was going to be developed then consumers had to be the ones to do it.

A Consumer Working Group, facilitated by the BC Coalition of People with Disabilities, began work almost immediately after the 1998 Creekview meeting, with the goal of developing the kind of Provincial Respiratory Outreach Program that would enable them to take control of the resources for their health.

This marked the beginning of a long struggle to obtain adequate funding, maintain a provincial rather than a regionalized delivery system, and enshrine consumer driven governance and operation into every element of the programs and policies of a Provincial Respiratory Outreach program. In practice this meant that the Consumer Working Group had to ward off efforts by respirologists, respiratory therapists and regional authorities to take over the program, lobby government representatives repeatedly, spend years in the wilderness of unanswered phoned calls and refusals to meet, all the while staying focused on their vision. This vision was articulated in an April 1999 paper that was developed by the Consumer Working Group and widely circulated in the community. This paper laid out the essential components of a provincial program and envisioned an autonomous Provincial Respiratory Outreach Centre with a steering committee made up of at least 50% consumers and operating with a values driven program that was accountable first and foremost to its users.

This Working Paper became the focus of all subsequent lobbying efforts and formed the basis of the opposition to the Kilshaw report, the first concrete proposal that the Ministry of Health put forward for a new provincial program. The Kilshaw Report recommended that a provincial program be housed at Vancouver Hospital and built on the remnants of the Pearson program. The Consumer Working Group prepared a detailed critique of the Kilshaw report and presented it to the Minister of Health. The Kilshaw report was shelved and a long period of silence followed which led the BC Coalition of People with Disabilities to issue a warning to the Deputy Minister of Health that any further jeopardy to the health and well-being of the consumers of the program as a result of the absence of a safe and effective respiratory outreach program would be his responsibility.

Finally, in 2000, the Ministry of Health announced that \$1.2 million annually would be made available through the administration of the Vancouver Coastal Health Authority to provide for a provincial respiratory outreach program. Despite the sense of exhilaration, there was little opportunity to celebrate because the announcement of a financial commitment meant that consumers needed to redouble their efforts to ensure that the program that was to be developed would stay true to their vision.

An Implementation Steering Committee was formed which included consumers, representatives from the ALS Society, the Muscular Dystrophy Association, the Post-polio association, the BC Coalition of People with Disabilities, representatives from Vancouver Hospital, Vancouver Coastal Health, as well as respirologists and respiratory therapists. This Committee was given full responsibility to design and implement a provincial program subject to the approval of the Ministry of Health.

The community groups and consumers coalesced around the ideal that the provincial respiratory outreach program should be community based but faced opposition from the hospital and health authority representatives who believed that it should be hospital based. A researcher was hired to investigate how the Pearson program had really operated and the results of the research confirmed the consumers' experience. It was demonstrated that the Pearson program had been barely functioning and had been stymied by hospital procedures and territoriality. This confirmed the importance of the community's position and the Implementation Committee became deadlocked. It appeared for a time that the authority of the hospital forces would win the day.

However the Consumer Working group came up with a plan. Many of the consumers had for many years used the Technology for Independent Living (TIL) program, which was housed at the Kinsmen Foundation and had just recently come under the administrative umbrella of the BC Paraplegic Association. TIL epitomized the kind of culture and responsiveness that was envisioned for the respiratory program and it possessed expertise and experience in managing equipment. With TIL's collaboration, a proposal was made by the community representatives on the Implementation Committee to house the provincial respiratory outreach program with TIL. This proposal faced an uphill battle that was finally won when the Vice-President of Vancouver Coastal Health threw his support behind it after a particularly tense series of negotiating meetings.

The implementation process went on for almost a year as every possible scenario was worked through while a business plan was being developed. There are no other examples in public policy making, apart from the implementation of British Columbia's adult guardianship laws, where consumers played such a pivotal role in every detail of the planning of the program. The Implementation Committee was the management committee and took the responsibility for overseeing the budget, staffing, the development of policies, procedures and evaluation criteria, negotiating contracts and working out the administrative role of the BCPA.

The unique history of the development of the Provincial Respiratory Outreach Program 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. Respiratory equipment and the supplies and therapy that accompany it are major resources for their health and these resources are, in essence, being held in trust by PROP/TIL. PROP and TIL has since formed its own non-profit organization BC Association of Individualized Technology and Supports for People with Disabilities (BCITS) April 1, 2006.