

balance

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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Meet Bob Gordon

BY BOB GORDON My 75th birthday will happen later this year. In 1953, I had my 20th birthday in Vancouver General Hospital in an iron lung. You wouldn't have found a single person who would bet I'd survive this long. It's been a great life regardless.

I spent my first 12 years on a dairy farm on Vancouver Island. Those were carefree years until my father died in 1946 and my family moved to Victoria. After graduating from high school, I moved to Vancouver to apprentice as a refrigeration mechanic. I learned fast and within a year was given a service truck and did repairs and small installations.

The polio epidemic caught up with me in 1953 which ended my career

as a mechanic. I was diagnosed in VGH where I spent a year and a half. A dedicated polio wing was built at George Pearson Centre in 1955, where I lived until 1969. During those years, I spent some time at GF Strong Rehab Centre, but there was little that they could do with a quadriplegic who had severe respiratory limitations.

I was fortunate to be given an opportunity to return to work with the refridgeration company. I bought a car and learned to drive.

During my final years at Pearson, a skilled rehabilitation nurse was able to teach me how to look after myself using mechanical aides and some creativity. I was able to move out with my respirator in 1969. I lived in the swinging West End on the 7th floor, with a view of Coal Harbour and Stanley Park. Life was good.

One thing led to another and I got married. When I discovered that I was going to be a father, I bought a small rancher on one acre in south Surrey near White Rock. I built a ramp for the house and a new accessible bathroom.

Fortunately, my working career progressed well, advancing to more challenging positions, finally becoming a major shareholder. But, my marriage failed and that led to a series of babysitters/housekeepers,

until my daughter reached her teenage years.

We are still living in the same place. I now have a 5-year-old grandson and I'm retired. Three years ago, my bronchitis got difficult to deal with and I had a tracheotomy installed. We have an annual back yard barbeque for the polio alumni from Pearson and graduates. I keep informed and stay connected by membership in PPASS, BCCPD, BCPA & BCITS (PROP).

If anyone wants to reminisce about old times, I can be contacted at bob-gordon2001@hotmail.com. Remember the good times. ●



Bob Gordon

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Peers and Mentors are Here for You

BY MARY MARGARET LAMBERT On June 12, 2008, a group of BCITS mentors met at Noble House to discuss the different roles of peer mentors, clients and members representing PROP and TIL. After much discussion, we identified five areas we felt were most important for peer mentors and members to provide support and service:

- Newcomers to BCITS
- Ongoing mentoring to BCITS
- Community education
- Family, friends and staff
- Government and funders

Newcomers to BCITS

People who are new to BCITS may be facing a significant life challenge, especially people asking about the PROP program. The same is true for people requesting assistance from TIL. People may be asking: What do I need? Where and how do I get it? And who will pay for it? Having someone to listen and be an understanding ear can make a world of difference.

Everyone experiences significant life challenges and it is easy to feel like you are the only one going through it. Talking to a peer mentor about their experiences and how they live their life can reassure and educate someone new to the programs. A

We are dedicated to making sure that our clients have access to the resources they need, whether it is equipment, training or friendship.

newcomer doesn't have to reinvent the wheel. Learning from someone who has already been through what they're going through can make a transition much easier.

Peer mentors can provide support by visiting a newcomer in hospital or at home, or talking on the phone with them. Mentors can also invite the newcomer to their home or workplace to see the technologies they use. This can be motivating and educational for someone considering what technologies would meet their needs.

Ongoing Mentoring

People who have been with BCITS for a while sometimes need support or need to learn something new. Knowing that there is someone out there living with some of the same challenges can be a great comfort and a great resource. Networking has many benefits, such as having a social connection, having strength in numbers, access to a wealth of knowledge and having a strong voice as an united group.

We understand that for some people it's difficult to be involved in a group—for many reasons. One of our challenges as an organization is to find ways to be available



Mary Margaret Lambert

to give support that best meets the needs of all of our members and clients. We respect everyone's right to privacy and their right to solitude. We also understand that loneliness is an epidemic for many people, not just people with disabilities. We are dedicated to making sure that our clients have access to the resources they need, whether it is equipment, training or friendship.

One way BCITS provides ongoing support and education is the "Show and Tell" gatherings where people share information and experiences. There is now a peer page on the BCITS website where information will be posted (<http://www.bcits.org>). We are looking for other ways to provide ongoing support to our members and clients. If you have any suggestions, please let us know.

Community Education

There is a need to educate people about "life after a ventilator." Some people think that when someone has to use a ventilator they are virtually dead. This could not be further from the truth.

There are various technologies that can give some people with disabilities the independence to stay active in the community and at home. It is important to have community

continued on opposite page

support for our organization to grow and to continue to provide these much-needed services. Talking to groups, schools and the media is another important part of the work that peer mentors are doing and will continue to do. If there is a group or event that you think would be a good opportunity for BCITS to make a presentation, please let us know.

Family, Friends and Staff

Often when a peer mentor meets with a newcomer, there are family members, friends and staff who also have questions and concerns. Family and friends can have a great impact on how a newcomer adjusts to change. Reassuring and educating family members, friends and staff can be just as important as picking the correct equipment to enable a person to maximize their independence. Fear for their loved one's safety and well-being can be clouded by misconceptions of how someone with an extreme disability lives and by a lack of knowledge about the resources available for them to live a life of their choosing.

PROP training is available free of charge to family members, friends and staff whose loved one uses a ventilator, as well as being available to the person using the vent. Peer mentors participate in the training sessions to introduce peer mentoring and to be available for questions.

Government and funders

Most people with disabilities have to deal with government agencies and organizations that provide funding for services and equipment that they need. BCITS also needs to have a good relationship with government, community organizations and individual donors for the continued financial success of our organization. As a client-driven organization, it is important that peer mentors actively participate in developing and maintaining strong working relationship with funders for BCITS.

BCITS is looking for clients who would like to be peer mentors. If you are interested, please contact us at our toll free number 1-866-326-1245 or email at info@bcits.org. ●

Speaking Through Art

A.J. Brown started to explore various arts in 1999 as a way to overcome personal fears. She had a brain injury during birth that caused her to become Deaf and to have a condition that resembles Cerebral Palsy. As a result, she has difficulty speaking and using sign language. She uses a Lightwriter, a portable communication device from TIL, which "speaks" for her when she types out words in written English.

You can see some of her art online at www.handsandpurrs.ca or at a solo art exhibit from November 4-November 16 at the Seymour Art Gallery in Deep Cove, North Vancouver, 4360 Gallant Avenue. ●



Q. My BiPap mask is hurting the bridge of my nose, what can I do?

A. If you see redness on the bridge of your nose, you can try loosening the straps of your face mask and see if that helps without causing leaks in your mask. If this does not help, then try putting a small band aid on your nose before you use your mask, or some opsite, duoderm or mole skin on your nose. This will act as a buffer between your nose and the mask and reduce the redness and soreness.

Q. How often should I clean my mask?

A. You should wipe it off every morning and then clean the cushion (silicone seal) every week. Wash it in warm, soapy water and then rinse it really well and let it dry. If you see any dirt or grease on your cushion, you may need to clean it more than once a week and that is what you should be watching for. You should wipe out the plastic frame of the mask with a damp cloth and wash it once a month.

Remember that if you wash your headgear it is going to take a while to dry because it has to be air dried and should not be put into the dryer. So, having a second headgear on hand is a good idea.

If you have a question for one of BCITS' Respiratory Therapist or Biomedical Engineer, send it to info@bcits.org.

Q&A
Ask the RT

balance

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Content Kirsty Dickinson, Simon Cox
Balance Coordinator Seka Jovanovic
Editor | Designer Ann Vrlak
Publication Coordination
 BC Coalition of People with Disabilities

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Mailing Address

9007 Shaughnessy Street,
 Vancouver BC V6P 6R9

TIL Phone 604-326-0175

PROP Phone 1-866-326-1245

Fax 604-326-0176

Email info@bcits.org

Web site www.bcits.org

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Getting to Know your Ventilator Battery

1. Disconnect the ventilator completely from the wheelchair or any other back up power sources.
2. Plug the ventilator power cord into a wall outlet and charge overnight.
3. Rubber Glove and Circuit Set-up: take the rubber glove and secure it to the end of the circuit hose with a rubber band.
4. Unplug the ventilator from the wall outlet or any other battery source and run the ventilator on its internal battery. Note the start time.
5. Run the ventilator until the low power alarm begins to sound (the battery meter shows 20% on Legendair). Make a note of the end time. The difference between the end time and start time is the current life of your internal battery.
6. Recharge the ventilator immediately.

can then compare the internal battery time with previous months so you will know if the batteries are in good condition.

2. Ensure the ventilator is completely disconnected from any battery source (wheelchair, etc.) before charging the ventilator in a wall outlet; otherwise, it could damage the internal battery of the ventilator over time.
3. When the ventilator is connected to the wheelchair battery, charging the wheelchair does not charge the internal vent battery.

For Legendair Ventilator

1. The meter that shows the internal battery capacity will come on only when the unit is running off the internal battery.
2. Please plug your Legendair in to AC power when the battery meter shows 20%.

Please make sure you charge your external battery source overnight. ●

How to Charge the Internal Battery

1. Disconnect the ventilator completely from the wheelchair battery or any other battery source.
2. Plug the ventilator directly into the wall outlet.
3. The AC power indicator on the front display should be on.

Charge the battery every day overnight.

Note

1. To ensure the internal battery is always in good condition, please do the charging and discharging procedure once a month. You

Staff update

We would like to welcome two new BCITS staff.



Carol Mullen, a Respiratory Therapist, who will be working in the Interior of BC.

BioMed Technician, **Samiko Guest**, will be covering for Joanne Bengert while she is on maternity leave starting in November 2008.



Opinion

by Paul Caune

Too many public problems are debated without the benefit of hindsight, without keeping in mind the context that gave birth to the problems. The housing, care and services for people with disabilities is no exception.

In 1870s British Columbia, there was no place for the “insane,” but jails which caused a scandal at the time. So, for the protection of the public, the government created an institution called Woodlands School which expanded over the next hundred years. Thousands of children and adults passed through Woodlands and other institutions, until their authoritarianism and abuse created a backlash. In the late 1970s, a public campaign led by parents of children with disabilities called for “de-institutionalization”: closing down the cruel institutions and moving people with disabilities into their own homes in the community.

The parents were no doubt desperate to get or keep their children out of what were horrific conditions. But, they made a fatal error. They placed their children on a path that came full circle to what they were trying to escape from: institutions. Not the giant institutions of the bygone era, but small ones called group homes run by so-called service providers.

The service providers (non-profit government contractors) made parents’ dream of community living real. But, in my opinion, the service providers have become just as heartless and out of touch as those who

ran the old institutions. While they have received millions of dollars in government money for 30 years, the disabled community as a whole is not much better off.

I’ve found that managers of service providers tend to be condescending and self-righteous. Why are they like this? The system the service providers evolved away from was worse, but they seemed over time to start making the same mistakes. Like using a business model in an attempt to make group homes appear “viable” and “innovative” to government. But, business is a special interest that’s about making a profit, short term and nothing else.

Service providers don’t seem to understand that their “business” of providing services to us doesn’t belong in the for-profit business world. This won’t improve our quality of life. And, I think this approach started attracting more and more people who can’t think outside this model.

The managers aggressively deter everyone, including Board members, from debating any subject of importance. Whenever the debate is going in a direction that challenges the management, they invoke the Privacy Act or confidentiality or assure us “that they’re working on it.” Because there is no rigorous debate—the best method humans have invented to discover error and thereby improve themselves—bad decisions are made over and over again.

Service providers don’t seem to understand that their “business” of providing services to us doesn’t belong in the for-profit business world.



Also, the managers get more and more out of touch with reality. Instead of free speech, there are displays of consulting the wishes of “stakeholders” (the disabled clients) that everyone discovers are meaningless.

When we do try to speak up, complain or point out things that aren’t working, service providers use various means to stifle discussion. Our complaints are called “inappropriate” or “harassment” and our “perspective.” Which means: it’s “inappropriate” for you to “harass” us by pointing out what’s wrong and, anyway, that’s just your “perspective.”

This kind of approach to the people they’re supposed to be serving tells me that service providers are “devolving” to the type of institutions families were fighting so hard to change forty years ago.

People with disabilities must never forget, to paraphrase Lord Palmerston, “The disabled have no permanent friends or permanent enemies, but permanent interests” and act accordingly. ●

TIL Works with Clients and Therapists



BY JOANNE BENGERT

After our first issue of **BALANCE**, we had a few clients asking who we are and why you haven't seen us

around. I'd like to tell you a bit about how we are working in your community, even if we are working behind the scenes.

Technology for Independent Living (TIL) is a non-profit provincial program that provides environmental controls and communication aids for people throughout BC. In order to connect with clients all over the province, we work in conjunction with your community Occupational Therapists (OTs) and Speech and Language Pathologists (SLPs). Your local therapists work with you to assess your needs and apply to TIL for a long-term equipment loan.

If you are applying to TIL for environmental controls, such as TV or telephone access, someone from TIL will typically travel to your home to set up the equipment and train you and your family, caregivers and/or OT on how the equipment works. There are times, however, when you or your OT may want to get started on your own, so we will ship our equipment to the OT with some instructions and they will get the equipment set up. We will follow up with you on our next visit to your area.

There are also some community programs that provide great support to their clients and will often

I'd like to tell you a bit about how we are working in your community, even if we are working behind the scenes.

contact TIL on your behalf if there are equipment problems or follow-up questions. A good example is the Regional Resources for Adults with Disabilities (RRAD) program in Victoria. TIL still comes to your home and sets up the equipment, but the OT is often the liaison between you and our program.

Whether or not there's a "middle man," you are always welcome to contact TIL directly with questions or problems. If you feel more comfortable contacting us through your community therapist, please continue to do so; the choice is yours.

If you are applying to TIL for a communication aid, we usually order the device that you and your SLP have tested and selected. The SLP will then use their expertise to adjust the device to your specific needs. TIL will mount the system on your wheelchair or in your home, but if mounting is not required you may not see our smiling faces. If you have any problems with the communication aid, you can contact us directly and we can advise you on troubleshooting and repairs.

So what happens if you are a community therapist who is just learning about TIL? Well, give us a call. We try to provide education to community therapists in a couple of ways.

We provide In-Service Education to groups of therapists around the

province. We have recently spoken to groups in Kamloops as well as Penticton. If you are a community therapist and feel an In-Service session would be helpful to the therapists in your area, feel free to contact us. We are also happy to have a community therapist join us for an initial appointment with one of our mutual clients. We also attend the Master of Occupational Therapy degree program at UBC once a year, along with the Assistive Technology and Seating Services (ATSS) team from GF Strong, to tell students about us and about environmental control systems so they are aware before they head out into the community.

Whether you are a client or therapist, if you have any questions for TIL staff, please give us a ring at 604-326-0175. Otherwise we will see you out in the community. ●

Privacy Statement

BC Association for Individualized Technology and Supports for People with Disabilities (BCITS) respects and upholds an individual's right to privacy and the protection of their personal information. BCITS is committed to ensuring compliance with British Columbia's Personal Information and Protection of Privacy Act (PIPA). BCITS will inform people what personal information it collects about people and why. It will store information securely and identify who has access to the information it collects. It will inform people what information will be shared, with whom, and why. BCITS Privacy Officer: Clara Chalifour, info@bcits.org, 604-326-0175.

PROP Report Card from Clients

The BCITS 2008 Client Satisfaction Survey report is a "report card" on how well we are doing. It summarizes the responses gathered in the questionnaires we distributed to clients in July 2008. We're glad to see that it reflects some extremely positive results.

There are many important components of our service offerings including: delivering respiratory service, respiratory supplies, respiratory equipment and providing ongoing education and support in order to ensure clients' comfort and independence.

Our clients are telling us that there are areas of these services that need improvement and further attention. We are committed to using the survey information to change and improve our services to meet your changing needs.

Survey Highlights

- People from all 5 of BC's Health Regions responded to the survey.
- One-hundred percent of respondents awarded a rating of very satisfied, satisfied or neutral for satisfaction with PROP staff availability and understanding, delivering respiratory service, respiratory supplies, respiratory equipment and providing on going education and support in order to ensure clients' comfort and independence.
- PROP services overall were rated as very important, important or neutral.

We are committed to using the survey information to change and improve our services to meet your changing needs.

Clients would also like to see improvements in these areas, in this order of importance:

- Selection of respiratory equipment and supplies
- Provision of information on use and maintenance of equipment
- Services provided by the after-hours Respiratory Therapist
- Provision of information on what to do if equipment needs service
- Offering the vent and trach classes outside the Lower Mainland
- PROP staff availability
- Condition of PROP equipment
- Emergency planning with Respiratory Therapist

- Time required to deliver equipment
- The information provided on respiratory care during the Respiratory Therapist visit

Our sincere thanks to all of you who took the time to answer our survey. You have provided us with vital information we need to serve you better.

Your overall positive evaluation does not mean we will stop looking for ways to improve. We take our mandate of "client-centred" services to heart, and this survey gives us a wide range of comments and suggestions to use to refine and expand our services. Thank you again to all of you who answered the survey. ●

OUR THANKS TO BC REHAB FOUNDATION • BCITS Executive Director Simon Cox receives a cheque from BC Rehab Foundation Chair Kathy Scalzo.



The funding will support TIL's new environmental control system—Willow—that helps people with severe disabilities to wirelessly operate electronic devices within a care facility.

2008 Peer Show and Tell

On August 27th, the BCITS Peer Group hosted a Show and Tell at George Pearson Centre in Vancouver. PROP's RT Andre and TIL's Bio-Med Joanne were on hand to answer questions, and talk about the programs, new equipment and supplies.

People were particularly interested in Joanne's presentation on adapted cell phone access—cell phones that can be activated with a single button or a "sip'n puff" switch.

Simon Cox emceed a quiz on what clients know about the programs and winners went home with a BCITS key chain. Fifty clients, family/caregivers and friends attended the event. There were door prizes to be won and a lovely buffet supper that



was enjoyed by all. If you are interested in becoming involved with the Peer Group, please give us a call at 1-866-326-1245. We are particularly keen to involve clients who live outside the Lower Mainland. If you

are interested in talking to a Peer about any issue or concern you may have, please contact Kirsty or Seka at BCITS and a peer mentor will get back to you as soon as possible. ~ Jeanette & Heather ●

Gadgets

Foot Power

I like this one! Go to the website below to check out the WEZA, a Swahili word meaning power. It has an external battery (similar to a small car battery) that can be charged by pushing on the foot pedal in 5 second intervals. It is useful to operate any 12-volt device for emergency preparedness or when the power goes out for short periods of time. It can operate devices that can plug in your car cigarette lighter. More information is available at <http://www.freeplayenergy.com/product/weza>. The cost for this device is about \$200 to \$300.

The Tank

Wow! I think we all need one of these. I contacted the folks in Phoenix Arizona about this machine. It is



a chair that can conquer all terrains (sand, sun, snow and gravel) and climb inclines up to 45 degrees. The treads are made of rubber with lightweight aluminum struts. You can see more about this product at <http://www.tankchair.com>. Cost: about \$18,000 US. ~ Simon ●