

balance

what it's all about

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A Larger World Through Technology

by cathy grant | I have a very limited range of motion in my hands and arms because of my CP, but I have equipment and assistive technology that has made my life easier.

My computer used to sit on a raised table, but it was difficult to use. My phone wasn't on the table, so if it rang, I didn't always make it in time to get the call.

TIL designed a new platform for me that fit a smaller keyboard, a trackball (which is easier for me to use than a regular mouse) and my phone.

This new set up has given me a lot more independence. Having these devices allows me to do more and make decisions in my home, so I don't have to rely so much on my caregivers. This is very empowering and I value being able to do things without my staff. This also means I have more privacy.

I use my computer to surf the web, to discover new ideas and informa-



Without my computer and other equipment, I would have much less independence and access to the broader world.

tion to help me understand life better.

Another piece of assistive technology I use is a DANA which is a large version of the old Palm Pilot.

Some day, I hope to own my own home. It's been a dream for many years. With the help of BCITS, Kinsmen and my best friend, I was able to purchase a new-to-me wheelchair accessible van, so I can go out of town for holidays and visit family and friends.

Without my computer and other equipment, I would have much less independence and access to the broader world.

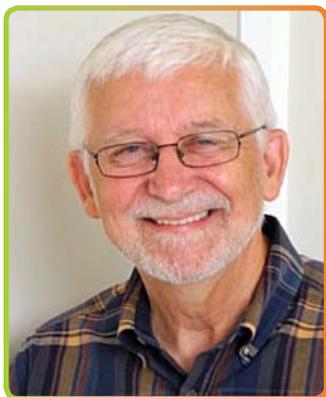
My first book, *The Journey*, is about my life experiences and lessons. I write to help people understand what I and other people with disabilities live through, including our humanity, gifts and talents.

I have another book in progress about how caregivers and service providers can care for us better. There will be some broader viewpoints, as well as my own.

You can find Cathy's book, *The Journey*, at www.Smashwords.Org.

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A Fireside Chat with Simon Cox

BY ANN VRLAK

“It turned out, the engineering was easy. It was the personal side that intrigued me. How did the person think about the tech they needed? How did that particular person want it to work? It was really interesting.”

In the 70s, a young engineer named Simon Cox worked at the UBC TRIUMF centre where experiments in physics were all in a day's work. The idea came to him that it would be interesting to do engineering in assistive technology (AT) for people who have a disability.

“It was rare to find a field that was new,” Simon said, “where the sky was the limit because not much work had been done yet. As a young man, I was excited at the prospect of using my ideas and starting from scratch.”

He applied for a Biomedical Electronic Technologist (BMET) position at the Kinsmen Foundation of BC in the Technical Aids department. Simon landed the job and, for over 30 years, has been an innovator and driving force in assistive technology.

The Technical Aids program at Kinsmen had started several years before Simon came on the scene. Kinsmen's Executive Director, Ed Sherwood, was from England and had experience with AT devices used to help people with disabilities to work. “He knew about sip and puff typewriters and remotes to help people control devices in their home, that kind of thing,” Simon said. “There wasn't anything like that in Canada back in the 70s.”

“I also worked with Margret Perry, a marvellous, knowledgeable Oc-

cupational Therapist from England that co-sponsored many Canadian AT conferences that placed BC as a leader in Assistive Technology,” he said.

So Kinsmen imported some of the technology and began to build their own for Kinsmen clients. “Before my time, there was a woman named Jo who had severe rheumatoid arthritis,” Simon said. “She lived at home with her husband and she was in bed virtually all day because of the pain. There was no medication at the time to help.” When her husband went to work, she was alone and couldn't do anything her self, like change the TV channel or dial the phone.

Simon said, “She apparently had a huge fear of fire and not being able to call for help. So, Kinsmen put together the first Patient Operated Selector Mechanism in Canada, a POSM, that controlled electronic devices in her home. It made a really big difference to her life.” This was the forerunner of the Environmental Control Systems now widely used by TIL.

As part of his new job, Simon went out to meet people who needed AT. He went into their homes and listened to what they needed. “It turned out, the engineering was easy. It was the personal side that intrigued me,” Simon said. “How did

the person think about the tech they needed? How did that particular person want it to work? It was really interesting.”

One of Simon's first clients was a woman who left the TV on all night because she couldn't turn it on or off. “I knew I could fix that easily,” he said. “I took a straw and hooked it up to a remote control, and she could control the volume and channels. It was such a small thing for me, but she was so delighted it was incredible.”

“We knew from the beginning that our clients were the innovators and we were just the contractors,” said Simon. “They'd tell us their assistive device needs and we would just translate that design idea with the technology of the time.”

Simon and the other BMETs in the program developed different types of switches for different disabilities and technology, like sip and puff, and infrared controls. “And we made special touch switches for people who couldn't use joysticks on their wheelchairs. They weren't strictly legal according to Health Canada because the Canadian Standards Association hadn't caught up with AT yet. But we used them anyway.”

The program started to grow as the staff found they could help people with a range of disabilities, such as spinal cord injury, cerebral palsy,

muscular dystrophy, multiple sclerosis, amyotrophic lateral sclerosis, and others. Word began to spread about the program and the devices that were giving people with high levels of disability much more freedom in their homes and in the community.

"We were always about customization," said Simon. "We knew cookie-cutter devices weren't going to work. Even people with the same disability had different abilities, different preferences. That's always what drove us: the right device for each person." And seeing what people needed, gave Simon more ideas for new and better gadgets.

Simon also saw how small things make big changes for people with disabilities. "Many people think the big, flashy things are important, but it's actually the less glamorous things that make a difference," He said. "People don't need a hi-tech robot, they need a way to open their front door on their own."

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That mindset is one of the biggest obstacles to finding funding, Simon said. "But funders and especially governments want to support the flashy things." This is one of the ongoing challenges, he says, to convince the public and funders of the importance and power of these small changes.

"We have a joke," he said. "It's not important whether it works, it's important how it looks.' Unfortunately, that's often true, as far as funding goes."

It was funding challenges that led to the Technical Aids program "moving out" from Kinsmen in 1999 to the BC Paraplegic Association (now Spinal Cord Injury BC). As time went on, the program staff felt the best long-term plan was to form a new organization that served people with severe levels of disability. So, the newly-named Technology for Independent Living program partnered with the Provincial Respiratory Outreach Program and created BC Association for Individualized Technology for People with Disabilities in 2006.

"We had a great core group," said Simon. "Kirsty Dickinson, Seka Bojbasa (then Jovanovic), Stephen Hendradjaja, and Rodel Mangahis. And they're all still here, except for Kirsty who we really miss."

Under the BCITS umbrella, TIL has had a chance to refine its mission and services to meet the individual needs of its clients. The program has grown to 655 clients throughout BC and was the home of the groundbreaking Equipment and Assistive Devices Initiative (EATI) that put

AT into the hands of hundreds of people with disabilities who were seeking volunteer and paid work.

"I think EATI contributed to some changes in attitudes about assistive technology," said Simon. "If I were asked, I'd say the three things people with severe disability need to live independently are housing, attendant care and assistive devices. Not having these means people can't be independent or participate."

Though attitudes in the community are changing, government attitudes are slower to change. "It's the simple solutions issue again; most government staff can't see how life-changing the small changes are."

And the effects of an investment in AT on other program expenditures can be hard to convey. "Government sees how much an AT program might cost and thinks, 'Oh, that's too expensive.' But those investments can mean less money's needed for health care, employment programs and other services. That connection doesn't seem to get across."

TIL's commitment to its clients hasn't dimmed over the years. And though Simon is in "retirement," he is still involved in TIL and PROP, and in the upcoming redevelopment of the George Pearson Centre.

"TIL will be involved from the ground up, putting in the most cutting edge AT for people who are living at Pearson. We're really excited about that." ●

balance

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Consumers Front and Centre at Ventilation Conference

by esther khor | Bonjour! My name is Esther and I am one of the Respiratory Therapists at PROP.

Recently, I had the wonderful opportunity to attend the 14th International Home Ventilation Conference in Lyon, France. This conference is exciting because it's devoted only to home ventilation. Many attendees were ventilator users and their caregivers which added to the uniqueness of this medical conference.

In Canada, the home ventilation population is small compared to France, Italy or the United Kingdom. Among the 16 European countries, there are over 450 identified home ventilation centers.

During the conference, many groups come together to discuss their successes and challenges with home ventilation in their country.

New models of respiratory equipment were on display at the conference exhibits. There was a good mix of ventilator users, caregivers and health care professionals who asked the exhibitors questions.

Among the new home ventilators, one model is already integrated into PROP's equipment pool: the Trilogy. Before equipment is purchased by PROP, it is presented to the BCITS Purchasing Committee which is made up of PROP clients.

From the conference, it is apparent that home ventilation is growing in all parts of the world. PROP grows at a rate of 50-60 new clients every year. For us, this means there are



Many attendees were ventilator users and their caregivers which added to the uniqueness of this medical conference.

more people choosing to stay home and directing their care with support.

With those numbers, medical equipment manufacturers and physicians are paying more attention to consumers who are experts in their own care. This shift in consumer involvement is powerful.

As a PROP client, your involvement and direction in your care is powerful, too. If you are interested in the various roles at BCITS that are held by clients, please call us.

With your input, let's keep growing in the best possible ways. ●

Check Out Our Videos

We're developing quite a video collection at <https://www.youtube.com/user/BCITS>. BCITS has produced videos for vent users, bilevel users and other general videos. Take a look and let us know if you have ideas for future videos.



TIL? Who's That? What Do They Do?

BY WAYNE POGUE, BMET

We would like to take this opportunity to thank everyone who completed our BCITS client survey. The information we collected was, and will continue to be, very helpful in shaping our programs.

Also, we loved the "Dream TIL" section! You had some great suggestions and it's fun to imagine what's possible, either now or in the future.

Overall, you gave us great feedback. However, there seemed to be an overwhelming number of clients who don't know about TIL and the services we offer. So, I'd like to tell you a bit about TIL.

BCITS has two programs: the Provincial Respiratory Outreach Program (PROP) and Technology for Independent Living (TIL). If you're a client of PROP, you'll of course know it. TIL is somewhat hidden in the background of our clients' day-to-day life.

TIL is a program that allows people with severe physical disabilities to access more of their home independently. For example, working with a client's care team, we set up technology that allows our clients to do things like access their TV, phone, door openers, lights, and attendant call...just to name a few. The great thing is TIL equipment and services are provided at no cost to clients who do not have another payer, such as WCB or ICBC.

Here are some current TIL services:

Scanning Remotes We set up a customized "scanning" universal remote which can be controlled by a variety of simple switches, depending on

your unique needs. This remote can be mounted to your wheelchair, at your bedside or in other locations, and can be set up to control:

- TV, Cable, DVD, Blu-Ray, etc.
- Stereo, sound system
- Lamps, fans other simple devices
- Speakerphones and door openers (see below)

Smartphone/Tablet Control We can mount your smart device to your wheelchair, and provide "scanning" switch access (see photo).

Scanning Speakerphones This phone can be programmed with your frequently called numbers, so you can call any of your contacts with just a few presses of a button.

Attendant Call We can set up a device that will let someone in your home know you need assistance.

Door Openers We can install remote access door openers to your house or suite, or we can adapt any door opener remote you already have, but have difficulty using. Please see information on the door opener program on page 7.

The other nice thing about TIL is there is always room for more services. This is why we want to hear from you! If you have something in your home you'd like to control, but you don't see it in this article, please let us know about it. We love doing odd projects and there may be other clients that could benefit from the same solution we find. If we are unable to take on your project, we may know of another program that could help you.



With changes in technology, we predict our services are going to expand quickly in coming years. Because we want to have the most up-to-date services for our clients, we want to keep you informed on developments and new services.

We will be doing this in a variety of ways over the next few months, especially by updating the TIL portion of our website. This section will be updated when new services or equipment become available to our clients.

If you have any questions about the services TIL offers, please contact us—and keep dreaming TIL! ●

Wayne Pogue is a Biomedical Technologist with BCITS.



An Important Notice for Medical Professionals



The technology and services we provide through our PROP and TIL programs are always changing. One of our goals is to keep medical professionals informed of these changes in a timely manner to serve you and your clients better.

If you are an interested OT, PT, RT, GP or any other medical professional, we would like to hear from you so we can update our contact list.

For those of you who provided contact information in the past, please send us any changed information.

For those who are interested in being added to our list, please send us all your contact information and we will mail our publications to you.

Please email us at info@bcits.org.

Contact Us

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help us fulfill our vision

BCITS, proud home of PROP and TIL, is a registered non-profit and charitable organization. The funds to operate these programs come from the Ministry of Health, through the Vancouver Coastal Health region. We are very grateful for this generous support.

However, this funding does not cover the costs to provide equipment to TIL clients. For example, a special telephone for a person with a high level disability can cost as much as \$1000 and an automatic door opener can cost \$3000.

We provide many devices like these to adults—at no cost—to fulfill our vision of people living in the community as independently as possible.

You can help us continue this work through your donation. Any contribution large or small will be gratefully accepted. 100% of your donation will go toward equipment and assistive devices.

Charitable Registration Number 807477070RR0001

I would like to support TIL's equipment program.

- I enclose a cheque for \$ _____.
- I will make a donation by credit card through CanadaHelps.org.
[Donate in minutes by clicking on the CanadaHelps button on our home page at www.bcits.org.]
- I would like to donate directly by VISA. I will call Clara Chalifour at 604-326-0175.

Please be sure to fill in all your contact details, so we can send your tax receipt (for donations of \$10 or more).

NAME _____

ADDRESS _____

CITY & PROVINCE _____ POSTAL CODE _____

PHONE _____

EMAIL _____

Please return form to: BCITS, #103-366 E. Kent Ave S., Vancouver, BC V5X 4N6

thank you for your support



A Proud Moment for BCITS

BY LILY CHEUNG

Each year, Respiratory Therapists come together to share knowledge and exchange ideas at the national Canadian Society of Respiratory Therapy Conference. This year PROP was invited to speak about the Home Ventilation Program in BC and more specifically how client participation is integrated into the program on a day-to-day basis. The panel speakers included: Walt Lawrence (BCITS client), Wayne Pogue (Biomedical Engineering Technologist) Esther Khor (Respiratory Therapist), and myself, Lily (Respiratory Therapist). During the panel interview, we reflected on how client engagement remains constitutional to BCITS; clients are involved throughout the organization as Board of Directors members, participants in the Ventilator Selection Committee, Peer Mentors and Mentees, as well as being the primary consumers and advocates of the services from PROP and TIL. The panel highlighted the possibilities for clients inside a medical model that involved them inclusively. In a room full of health care providers adapted to the ways of a traditional medical model, the discussion shifted the audience's mindset. Instead of patients receiving care from their providers, we encouraged providers to empower clients to improve their quality of life by actively participating and making meaningful decisions about their individualized health care needs. The client participation message resonated amongst the crowd and definitely settled into a palpable impression. Many audience members approached us after

the talk, expressing how inspired and moved they were by the clients themselves.

To add further confidence to the BCITS vehicle, we quickly realized how fortunate PROP is to work in such close proximity to their Biomedical Engineering Technologists counterparts. Across Canada, biomedical tech service can be rather limited. Clients may wait up to 18 months before services such as custom wiring for wheelchairs can be made available. For example, a wheelchair battery can be wired to another device to extend the battery life of attached devices. Ventilators have an internal battery that can last about 6 hours; however, when wired to a wheelchair, ventilators can last for many more hours. This extension provides a convenience to ventilator dependent individuals and broadens their scope of independence on a daily basis. Access to biomedical technologists is such a privilege in other parts of the country that even customized environmental control systems is considered a luxury. Our clients benefit directly from these services.

Our experience at the conference illustrated a symbiosis between client and provider, in essence, BCITS itself. The organization comprised of both PROP and TIL has forged a sustainable model supporting clients living at home. We left this conference feeling elated with the impressions made. As a client inspiring the work we do together, your ongoing participation is what makes this organization such a success! ●

Do You Need a Door Opener?

If you cannot open the door to your own home without assistance, you may be a candidate for the BCITS Open Door Program that provides automatic door openers.

You can apply to the program by using the form on our website at <http://bcits.org/becomeclient.htm>. You'll see that you also need to apply for our TIL program, if you aren't already a client.

The application will review your eligibility for the opener program, but please be aware we will usually provide openers to those who demonstrate the greatest need.

This service is available throughout BC, so do not hesitate to apply if you live outside the lower mainland.

BCITS has worked with organizations such as the BC Rehab Society, Provincial Gaming and the Kinsmen Rehabilitation Foundation to support the program through grants and fundraising activities, such as the BCITS/Kinsmen annual golf tournament.

See a video on this program, "Opening Doors to Independence," at <http://bcits.org/videosother.htm>.

We encourage you to apply as soon as you can, and we will do our best to help. ●

Yes, I Accept Your Invitation to Join BCITS

The BC Association for Individualized Technology and Supports for People with Disabilities (BCITS) Home of Provincial Respiratory Outreach Program (PROP) & Technology for Independent Living (TIL)

Name: _____

Address: _____

City/Prov: _____ Postal Code: _____

Telephone: _____ Email: _____

**Please mail this form along with any applicable membership fees to BCITS:
#103-366 E. Kent Ave S., Vancouver, BC V5X 4N6. Thank you.**

Please Check One

- Membership for Registered BCITS Clients** Please mail completed form to BCITS (the cost of postage constitutes your membership fee)
- Non-client Membership** Please mail completed form along with \$20 annual membership fee payable to BCITS.

BCITS  technology for living 

Take Care of Yourself This Flu Season

BY PATRICK CHO, RRT

Every year, we go through what we call the “flu season.” The flu is a severe upper respiratory tract infection caused by an influenza virus. This virus is highly adaptable and changes from year to year.

For this reason, the timing and severity of a flu epidemic is unpredictable. The season can start as early as October and last until May, but often it peaks in the winter months. If left untreated, influenza can lead to further complications like pneumonia and respiratory failure. Influenza symptoms can include headache, fever, loss of appetite, muscle pain, runny nose and tiredness. The flu can linger for a week to 10 days.

The virus is easily passed from person to person through direct contact such as coughing and sneezing, or being exposed to droplets left on objects and surfaces. If you do get sick, please see your doctor for antiviral drugs, rest at home and stay hydrated.

So how do you protect yourself and loved ones? The easiest way is to have the flu shot every year. The vaccine is now available and it targets the strain of influenza that is predicted for this season. Vaccination is especially important for PROP clients who are already at risk due to their compromised respiratory status. Family members and caregivers taking care of our clients are also highly encouraged to take the flu shot. If your caregiver is sick, they should take some time off to recover before working with you.

Other advice for reducing the risk of flu transmission is practicing good infection control. Cover your face if you cough or sneeze. Wash your hands frequently. Have hand sanitizer near supplies and equipment.

For your safety, most BCITS staff who provide home visits are vaccinated; those who are not, wear a mask. If you have any questions, please contact PROP. ●