

balance

what it's all about

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Accessibility Isn't Our Only Need

BY CATHY GRANT | So, last month I checked out an accessible apartment that I could have moved into if it met with my approval—it didn't.

It was accessible, and the property manager was willing to make it more so, but the issues that made it inappropriate for me went far beyond a single issue.

This experience got me thinking. What are some of the other things that are just as important as accessibility in a living space for someone using a wheelchair?

Besides accessibility, the single most important feature of an apartment for someone in a wheelchair is storage space! This isn't a gender issue, although I do have a lot of clothes. Simply put, people in wheelchairs have more stuff that needs to be stored.

In my case, there is a hoist to get me from my bed into the chair, its recharger, the recharger for my electric wheelchair, my manual chair, incontinent pads, extra towels and face cloths, extra pants, and a host of other little things. All of this needs to be stored away, so it's not underfoot.

Another important need is to be near a transit stop, preferably a main bus line or Skytrain station that provides easy access for my support staff. Given how much they are paid, and how expensive housing is today,

This experience got me thinking about the other things that are just as important in a living space as accessibility for someone using a wheelchair.

most of my staff live East of Burnaby, so they commute for an hour every day to and from work.

If their commute time is increased by half an hour or more, the chances of holding on to my staff for any length of time starts to decrease rapidly.

Finally, there is the issue that someone in a wheelchair needs more room. Let's face it I have a lot of stuff! I also need a certain amount of furniture for my roommate, staff and guests, and I need space to maneuver my wheelchair around it.

Then, of course, there's the bedroom. Not only does this room need enough space for both my bed and wheelchair, but also enough space

continued on next page

inside

- 1 | [Accessibility Isn't Our Only Need by Cathy Grant](#)
- 3 | [TIL is Ready to Help, Virtually!](#)
- 3 | [BCITS Welcomes Ean Price](#)
- 4 | [The Sound of Approval by Nancy Lear](#)
- 5 | [A Big Thank you to airG by Ruth Marzetti](#)
- 6 | [Podcast Reviews](#)
- 7 | [Help Us Fulfill Our Vision](#)
- 7 | [Pathways to Independence by Nancy Lear](#)
- 8 | [Opinion Piece: CSIL and BC's Minimum Wage by A. J.](#)



in memoriam

Cathy Grant

1959 - 2019

While circling Cathy, she challenged us to take risks alongside her, to be as brave as her, to be as rebellious as her. Sometimes we took those risks, sometimes we didn't.

Jupiter is the planet with the most powerful gravitational pull because it has the largest mass. That's how it works in space. But that can't be how it works here on earth.

The power of pull cannot only be linked to mass here on earth because Cathy Grant was a tiny woman who had immense pull. Once in Cathy's orbit, there was no getting out, not really. And as we mourn her passing and reflect on her life, we are so thankful that she pulled us in and kept us in her orbit.

While circling Cathy, she pulled at our values, pushed at our actions, and challenged us to think and act in ways we had never considered before.

While circling Cathy, she challenged us to take risks alongside her, to be as brave as her, to be as rebellious as her. Sometimes we took those risks, sometimes we didn't. Sometimes we were brave, sometimes we weren't. Sometimes we joined her rebellion and sometimes we watched from the sidelines.

But always we circled her. Always we stayed in her orbit. Always we were guided by her powerful pull.

We'll miss Cathy. We feel blessed to have been in her orbit. We'll forever feel the pull.

FROM CATHY'S FRIENDS AT BURNABY ASSOCIATION FOR COMMUNITY INCLUSION (BACI)

Accessibility, cont'd from p. 1

for my staff to transfer me safely from the bed to the wheelchair and vice versa.

Without enough space for either me or my staff, both of us could be injured doing something that's absolutely necessary.

And I'm lucky I have an overhead track system. It has always been a source of wonder to me how people deal with a mobile hoist or a hospital bed within an already cramped apartment.

Without enough space for either me or my staff, both of us could be injured doing something that's absolutely necessary.

All of these things are important considerations for those who develop accessible housing. Today, it's no longer enough to claim "accessibility" by having outlets raised off the floor and a walk-in shower.

Real livable space for people in wheelchairs requires people to, not only think outside of the box, but also to think big.

The need for more space for storage and to move around is, unfortunately, running counter to the current trends of housing and condo design in the Lower Mainland.

Unfortunately, this might be one of the hidden reasons why so many "accessible" apartments have been rented by people who do not need these accessibility features. ●



TIL is Ready to Help, Virtually!

TIL clients have been asking for more technical support solutions, and we're listening!

We are happy to be rolling out three new ways to contact the TIL technical support team for virtual appointments—Skype, Apple Facetime and Google Hangouts.

Here's how to reach us:

Skype "TIL BMED" (from any computer or smart device)

Apple Facetime "til@bcits.org" (from any Mac computer or iOS device)

Google Hangouts "TIL BMED" (from any computer or smart device)

To ensure you reach technical support when you use any of these platforms, email or call us beforehand to make sure a technologist is available for your desired appointment time.

Disclaimer: Skype, Facetime, and Hangouts are third-party services. You must agree to their terms and conditions before using their services. During your virtual appointment with TIL technical services, privacy data might be stored on servers outside of Canada. Should you wish not to utilize these services to receive TIL technical support, traditional technical support solutions by phone, email and home visits are still available. ●

BCITS Welcomes Ean Price

We'd like to welcome Ean Price, our new Innovation Strategist. Ean is well known to many of us. He has been active in the community for many years, including sitting on the BCITS board as well as volunteering for the Tetra Society, the Neil Squire Society and Muscular Dystrophy Canada.

At the last BCITS AGM, Ean had an epiphany. As he circled the room, he saw possible improvements that could be made to people's wheelchairs and realized he had much to offer. And, he realized his vocation was not working for an IT company, but researching current and new assistive devices and home automation.

When we heard this, BCITS was thrilled to invite him to our staff team. Ean's primary role as Innovation Strategist is to look to the horizon and let our BioMeds know about emerging technology and whether it might be useful to BCITS clients.

Since coming on board, Ean has been building up his contacts. He has attended a couple of tech conferences in Vancouver, and is getting to know researchers and developers and the equipment they have to offer. He has been testing various pieces of technology to see if it could be a fit for our membership.

With Ean's skills in technology and his passion to keep himself abreast of new developments, we are confident that our biomedical team are going to continue offering cutting edge equipment so our clients can live at home as independently and comfortably as possible.



Ean's primary role as Innovation Strategist is to look to the horizon and let our BioMeds know about emerging technology and whether it can be useful to BCITS clients.

Ean enjoys living in Kelowna. When he is not working for BCITS, he can be found sailing. In 2016, he was elected President of Kelowna's Disabled Sailing Association of BC.

Another current pastime is to test a piece of technology which is measuring his brain activity. The long-term goal is to use this technology to interact with his thoughts and close doors, turn on the TV and automate his home environment!

If you would like to reach out to Ean Price, check out his bio on our website and email us at info@bcits.org with specific questions, thoughts or ideas for Ean. ●



The Sound of Approval

BY NANCY LEAR | Everybody has noises they want or need to respond to, so I want to discuss the countless “beeps” in our lives.

There is the beep from the microwave, the beep when the elevator arrives, the annoying horn beeping from an impatient driver or the acknowledging beep that says “Hi, I’m the neighbour.”

In my life, however, some beeps take on a different connotation.

I have had respiratory concerns for the past ten years, so there are additional beeps that are now part of my life. Three months ago, I received a new ventilator and had to relearn the “beeps” in my life. The following is a demonstration of what happens when these beeps don’t happen.

On Saturday, November 13, 2000, I was in the bathroom when my care attendant cried out from the bedroom, “Nancy, I don’t hear the beep!”

She was preparing my wheelchair and ventilator for the day, unplugging the battery chargers and plugging in my ventilator to the wheelchair battery.

“Oh, right. I blew a fuse in the battery last night,” I replied.

A long silent pause, “Ok. I need to figure out your new set up!”

I was in the bathroom, breathing comfortably on my own and chose not to be stressed by this. I heard scurrying in the bedroom as she removed the battery case.

“So, how did this happen, Nancy?” my caregiver asked.

I ignored the question at first because I didn’t want my caregiver to be more upset than she was already. I knew full well it was my fault.

“Damn!” she said. “I dropped the fuse between the battery case and the battery.”

I calmly said, “I’ve got to get in my chair now. I can breathe on the internal battery, and we can deal with all this later.”

“Ok, we’ve got to hurry and get you breathing again.”

“Help or hinder,” I said with a giggle.

“Now stop!” she blurted.

Soon I was in my wheelchair, breathing comfortably and finishing my morning routine.

I went to the well-lit kitchen, so we could finish fixing the battery together.

“Ok, here we go. I’m taking the vent off now. It’ll be fine on the kitchen chair unless you move,” my caregiver joked.

“Oh, I’m not moving, don’t worry!” I concentrated on my breathing in silence.

Three months ago, I received a new ventilator and had to relearn the “beeps” in my life. The following is a demonstration of what happens when these beeps don’t happen.

“Geez, I still can’t reach the fuse. I know what! I’ll dump the battery out,” she said.

“Great idea.”

“This battery is heavy!” she moaned.

My caregiver tipped the battery upside down, but it wasn’t as easy to get the fuse out as we thought. But eventually, “Ah ha! I have it!” In a matter of minutes, the new fuse was installed and the battery returned to its case. There was a big sigh of relief from both of us.

“Great work, hon!” My caregiver hooked up the external power source and heard the beautiful beep of approval.

“Now you know, Nancy, I need to hear that beep!”

“Oh, don’t I know it! It’s the sound of approval that all is well and in good working order.”

The situation was under control. We were off to the mall to see a movie, do some shopping and enjoy a meal together.

All in a morning’s work! ●

balance

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We are pleased to have content from Balance reprinted in other publications. Contact us with your request and please cite BCITS, Balance and the edition date when reprinting.

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A Big Thank You to airG | by Ruth Marzetti

The Technology for Independent Living program gratefully received a generous donation from the staff at tech company airG. Last year, the staff chose BCITS as their charity to raise funds for, and raise funds they did! They had bingo nights and auctions, and presented us with a donation for assistive devices and home automation for our TIL members.

One happy TIL member said, "I spoke to Rodel (TIL Logistics Manager) yesterday and told him about the problem with my hoses. The new ones came today. I live in Summerland, so that blows my mind!

"And, if there's problem with my BiPAP, your staff fix it over the phone

or send me a new one. Rodel has given me a spare which I rotate. It's just amazing.

"Roger (BCITS BioMed) came for a home visit a while ago, and I asked him about Google Home and Alexa. He said he had a unit in the van, so he set me up. It's wonderful! Not only that, he gave me four light bulbs I needed. I am so pleased.

"Your team helps so much, in so many ways. Please know how much I appreciate you!"

Thank you airG for helping us be there for our clients!

For more information on airG, visit their website: <https://corp.airg.com/> ●

BCITS and airG staff members





Podcast Reviews

There are many podcasts covering disability issues. Here are three recent ones that aired this spring.

CBC's *White Coat Black Art* : Life with MS: Challenges, losses, but also purpose and "deep joy."
POSTED FEBRUARY 8.

CBC's Dr Brian Goldman interviews Elizabeth Rathbun who has lived for many years with MS.

Elizabeth eloquently describes the shocking diagnosis she received as an active, young mother with a responsible full-time job. Over the years, her life has been turned around.

In this thoughtful account of the challenges, her optimism continually shines through: "My relationships with my caregivers are filled with joy. I am enormously loyal to them. They are smart, intelligent, kind, resourceful, reliable... It is a relationship that's a gift, and it's a gift I would not have had without this disease."

To read or listen to the podcast, go to the CBC website: <https://www.cbc.ca/radio/whitecoat/life-with-ms-challenges-losses-but-also-purpose-and-deep-joy-1.5011270>

BBC *Woman's Hour*: Melanie Reid, interviewed by Jane Garvey.
POSTED MARCH 2018

Jane Garvey, presenter of the BBC *Woman's Hour* spoke with guest Melanie Reid, columnist of "Spinal Column" in the UK Saturday Times Magazine.

Melanie started the column after a riding accident nine years ago. The column is described by a listener as "beautifully written, funny and as blunt as hell." Melanie Reid's recent book, "The World I Fell Out Of," is reviewed in the interview.

In the podcast, Melanie gives a blisteringly honest account of living with a spinal cord injury. She talks about the initial injury and moves on to living with a spinal cord injury including bowel management, her relationship with her partner Dave, and the difficulty some women living with disabilities have in finding a partner.

To listen to the podcast, go to the BBC *Woman's Hour* website: <https://www.bbc.co.uk/sounds/play/m0002z36>

CBC's *Now Or Never*: People with Disabilities are Hot. POSTED MARCH 8.

Andrew Gurzy, a 34-year-old with Cerebral Palsy, knows he is hot!

He created the viral hashtag #DisabledPeopleAreHot. It all began when he searched "DisabledPeopleAreHot" on Twitter and got nothing. He was surprised to find it had never been used.

He created the hashtag, made some posts and, by the next morning, it had exploded. Thousands of positive happy tweets came in from people with disabilities posting images of themselves looking hot!

In the podcast, Andrew also talks about people who disagree with his views and express it in jokes or even sometimes in aggression. He believes some non-disabled people are not ready to see people with disabilities as attractive.

This hashtag is about people living with disabilities and being proud of who they are, sometimes hot, sometimes sexy. Even if you are not having your best day, he encourages you to post!

For more information go to the CBC *Now or Never* Website: <https://www.cbc.ca/radio/nowornever/how-do-you-feel-about-your-body-1.5042773/disabledpeoplearehot-viral-hashtag-sparks-conversation-about-sexuality-and-disability-1.5042776> ●



Pathways to Independence

BY NANCY LEAR | Pathways to Independence is a collaborative peer group organized by BCITS and the Individualized Funding Resource Centre (IFRC).

The main goals are to bring people with disabilities together to discuss current topics relating to independent living and for individual Peers to take a lead role in the discussion and choice of topics.

Accessible housing, the CSIL Program, TIL and employee benefits are just some of the topics discussed in the monthly workshops so far.

Each workshop is three hours with snacks and beverages to enjoy while mingling, making new friends, listening to guest speakers and asking questions.

The workshops take place at Sunset Community Centre at 6810 Main Street. Please contact BCITS or IFRC for the upcoming schedule.

If you are already registered for Pathways to Independence and have enjoyed these workshops, please continue to do so.

If you're not registered and wish to be notified of upcoming Pathways to Independence workshops, please contact Ruth Marzetti, ED at BCITS (rmarzetti@bcits.org) or Paul Gauthier, ED at IFRC (CSILPeers@IFRCSociety.org). •

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 all 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 have enclosed a cheque for \$ _____.
- ☐ I will make a donation by credit card through CanadaHelps.org.
[Donate in minutes by clicking on the DONATE button on our home page at www.bcits.org.]
- ☐ I would like to donate directly by VISA. I will call you 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

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 



OPINION PIECE

CSIL and BC's Minimum Wage

BY A.J. | CSIL employers' need to address the imminent minimum-wage increases.

I don't think I'm exaggerating when I say that caregivers are already difficult to find or that CSIL employers, including myself, are paying a wage just a dollar or two more than the current minimum wage.

The CSIL hourly allotment, though it may appear generous at first, does not appear so generous when all facts are considered. It does not reflect how many hours a day are actually required to assist CSIL clients in their daily needs. Furthermore, we need to manage emergency needs, staff training, EI and CPP, and more.

So, CSIL employers are lucky if they can pay \$15 an hour to their employees. Soon, that \$15 won't be enough to pay for experienced, educated and skilled caregivers. When people can do unskilled work for the minimum wage, with far fewer

responsibilities than a caregiver, how can CSIL employers realistically compete?

I'm sure I'm not alone in working hard to create a future for myself. I'm sure there are many of you, working to further your education and your skills, and reach other goals. We're working hard to make big contributions, not just soaking up taxpayer funds.

We need to be proactive. We are a highly motivated, productive and inspiring element of society.

We need some kind of minimum-wage and inflation-adjusted rate to allow us to continue to live and prosper.

Thank you for your attention.

These comments do not necessarily reflect the opinion of BCITS. ●