

New Name
for BCCPD!

Persistent Stigma
Around Mental Illness

Growing up
with Deafness

transition

The Magazine of Disability Alliance BC (formerly BC Coalition of People with Disabilities)

Stigma.

When other people write your life story.



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editorial

BY SHELLEY HOURSTON

Many of us reach adulthood bearing the scars of stigma experienced in childhood—commonly known as bullying—only to discover that stigma is rampant in the adult world as well.

*Stigma: “a mark of disgrace associated with a particular circumstance, quality or person”**

While stigma may be a “social construct” or a “theoretical concept,” anyone who has experienced social isolation, verbal or physical assault or discrimination because of the assumptions of another person knows that stigma is a painful reality.

Many of us reach adulthood bearing the scars of stigma experienced in childhood—commonly

known as bullying—only to discover that stigma is rampant in the adult world as well.

We live in a society that holds up the ideal of authenticity—“Be yourself!”—unless of course you’ve been deemed defective or unworthy, in which case you should not be yourself.

Consequences of stigma are widespread, affecting education, employment, housing, access to healthcare and more. Perhaps even worse, internalized stigma, shame, low self-esteem and social isolation intensify mental and physical health problems.

In this TRANSITION, you’ll read about stigma in different guises and environments. Mental illness, physical disability, HIV, Hepatitis C, developmental disabilities, hearing disabilities and substance misuse are explored from the perspective of individuals, as well as organizations working to reduce the road-

blocks and pain stigma causes.

Reading stories about people facing similar challenges can give us ideas and make our journey feel less lonely. Connecting with organizations that increase awareness and understanding can provide an opportunity both to gain and to give support.

Sharing your experience of stigma will inspire others to live their own life stories too.

At Disability Alliance BC (formerly BC Coalition of People with Disabilities), we believe that everyone has the right to create and live their own life story. Standing up and taking control of your life story can be scary, but it helps to remember that everyone has something—an experience, a preference, a diagnosis or a belief or custom—that they feel would be condemned if shared.

What would taking control of your story look like? Everyone needs to find their own path, but rejecting the judgment of people who don’t even know you is a great first step.

* Oxford Dictionaries. <http://tinyurl.com/l28w9fj>

SHELLEY HOURSTON IS PROGRAM DIRECTOR OF DABC’S WELLNESS AND DISABILITY INITIATIVE. 

What's In a Name?

BCCPD is now Disability Alliance BC!

| BY PAT DANFORTH AND JANE DYSON

Yes, BC Coalition of People with Disabilities' name is now **Disability Alliance BC**. BCCPD members voted strongly in favour of the change at our Annual General Meeting (AGM) in June. Since then, we've been gradually transitioning over to using our new name.

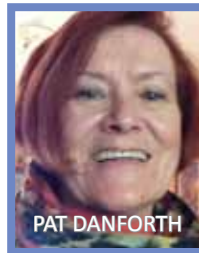
Organizations change their name. In fact, we changed ours 24 years ago. In 1977, our founding name was British Columbia Coalition of the Disabled. In 1990, we changed it to BC Coalition of People with Disabilities.

The change reflected the fact that people with disabilities are people who happen to have a disability, rather than being "the disabled."

So why change our name?

Two years ago, we decided it was time to update our logo. We connected with Spring Advertising who generously volunteered their time to help us develop one. They suggested we also look at our name. They asked us if it continued to reflect who we are and how we are changing, what we do and why we do it?

BC Coalition of People with Disabilities is a long name and, while it has served us well, Board and staff agreed it was time to update. A Board member suggested the word "Alliance"—we liked it because it expresses strength



PAT DANFORTH



JANE DYSON

and community. As a provincial organization, we also wanted to keep "BC" in our name. We serve people with disabilities and, while the experience of disability is unique to each person, we have many things in common that affect us. "Disability", of course, reflects this common ground.

So, Disability Alliance BC was born. We are very excited about this change and it is a landmark event for our organization. Now that we've decided on a new name, Spring Advertising is working on a logo and tag line which will be completed soon.

We hope you like our new name. Change can be challenging—and this is a big change—but it is *just* a name. Disability Alliance BC—or D-A-B-C for short—will be doing the same work for the disability community. That has not changed. **T**

ABOUT TRANSITION

Editorial Statement

The views and opinions expressed within the pages of TRANSITION are not necessarily those held by the total membership or Board of Directors. The material presented is meant to be thought-provoking and to promote dialogue.

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Stigma, Mental Health and Substance Use

Using the word stigma makes it seem different than racism, homophobia or sexism. It isn't.

| BY THE CANADIAN MENTAL HEALTH ASSOCIATION

About one in five people—over six and a half million Canadians—experience a mental illness or substance use problem in their lifetime. Unfortunately, many people don't ask for help because they feel ashamed or scared.

People may judge them and treat them negatively based on a mental health or substance use problem. Others have trouble finding a place to live, finding a job, maintaining relationships and other important parts of life. In fact, most people living with a mental illness say that stigma is worse than the symptoms they feel.

Stigma originally meant a physical mark of shame. Now, it's an invisible mark that sets you apart from others. The problem with the word "stigma" is that it puts the focus on the person's difference instead of on the people who are setting them apart.

Using the word stigma makes it seem different than racism, homophobia or sexism. It isn't. So it's time to talk about stigma for what it really is: prejudice and discrimination. Prejudice is holding negative attitudes or beliefs about people who are viewed as different. Discrimination is acting on these ideas or beliefs.

Layers of Stigma

Many people don't experience stigma for just one reason. They may experience discrimination based on many different prejudices, like sexual orientation, gender, culture or physical disability. Discrimination itself can lead to mental health or substance use problems. And people who already face discrimination for any reason may be even less able to find help for mental health or substance use problems or less able to find services that meet their needs.

Causes and Effects of Discrimination

Many factors lead to discrimination. Major examples include:

- **Fear:** Such as the fear of violence and the fear of the issues themselves because they affect our mind and behaviour. Some fears may be reinforced in the media.
- **Untrue beliefs:** Such as the belief that people can't recover or that people can't participate in their communities.
- **Blame and self-blame:** People may be blamed for their conditions or substance use and viewed as weak. People with mental illnesses or substance use problems, and their loved ones, may also deeply blame themselves.

Stigma
Stereotypes
Prejudice
Ignorance

Discrimination can prevent people from getting or having basic things most of us take for granted, like:

- Contributing to communities and feeling productive
- Feeling loved, needed and accepted by family and friends
- Feeling positive about ourselves
- Getting hired, promoted or keeping a job
- Finding or keeping a place to live in a safe community
- Getting proper health care
- Getting insurance
- Going to school
- Immigrating to another country

In many cultures, the entire family carries their loved one's stigma because they strongly identify as a group. As a result, family members may not confide in friends or others in their support network.

How Bad Is It?


Research shows that over half of people living with mental illnesses said they were embarrassed about their health problems, and over half felt like they had experienced

discrimination. In one recent Canadian study, researchers found that:

- Just under half of Canadians thought a mental illness was an excuse for poor behaviour
- Only about one in three Canadians would continue to be friends with someone with an alcohol use problem
- Only about one in four would continue to be friends with someone with a drug use problem

5 Ways to Make a Difference

- Tell someone who doesn't know my story of mental health or substance use, or help others tell their story
- Seek direct contact by volunteering for a mental health or addictions organization, or find personal stories of recovery
- Think about the words I use. Do I use people-centered language like, "A person living with..." or do I say, "A schizophrenic" or, "An alcoholic?"
- Think about how I personally support and treat people around me who are living with a mental health or substance use problem
- Speak up when I see discrimination or when I see a law or policy that unfairly excludes people

EXCERPTED WITH PERMISSION FROM THE CANADIAN MENTAL HEALTH ASSOCIATION PUBLICATION, 'STIGMA AND DISCRIMINATION AROUND MENTAL HEALTH AND SUBSTANCE USE PROBLEMS'. READ THE FULL INFORMATION SHEET AND OTHER RESOURCES ON STIGMA AND DISCRIMINATION AT WWW.HERETOHELP.BC.CA. 

ON LIVING WITH MENTAL ILLNESS

Patrick

Many of us who are afflicted with mental illness try very hard to hide ourselves from the general public, so that we are not recognized as having a disability. We don't want other people to know that we're not "normal." We have worn masks throughout our lives and know which face to put on in which circumstances.

Kate


How have I come to understand the difference between looking healthy and actually being unwell? My perception of mental illness has changed because of my own experience of it. I used to have the stereotypical idea that people with mental illness appear "out of it," and were identifiable by their erratic behaviour and messy appearance. I realize now that I also believed mental illness was a character weakness.

Prejudice and stigma in our society about the appearance and behaviour of the mentally ill may stem from the fact that people do not receive adequate treatment until their condition and functioning deteriorates significantly past the point where they ought to receive intervention. The prejudice can be that of the person who is ill, their family, friends and coworkers or that of health care professionals.

Karen

Two years ago, when my son "Wayne" (not his real name) was 16, he was a handsome, wellrounded young man, destined for a healthy and productive adulthood.

It's hard to reconcile that image with the gaunt 18-year-old who now sits, day in and day out, in a darkened living room, motionless, with downcast vacant eyes, no longer capable of, or interested in, any sort of sustained conversation. This is mental illness.

When I think back to last summer and how the changes in Wayne's demeanor were reflected in the faces of our adult friends and neighbours, above all else, I recall their concern and kind words. People—many, complete strangers—just kept pulling up and dropping him off at our home. They'd find him wandering or standing gazing into their neighbours' yards, or maybe sitting motionless for hours in the long grass near the highway, and they'd offer him rides in their cars. "I'm so amazed at the scope of human kindness," I told my husband. "He looks odd and scary. You wouldn't think they'd pick him up." I was surprised to discover how many other families have been touched by mental illness. 

See details at <http://www.heretohelp.bc.ca>

Excerpted with permission from the Canadian Mental Health Association, BC Partners for Mental Health and Addictions Information.

everyday resilience | leaving the dark room of stigma | by shelley hourston

Researchers (and wise friends) can point to an array of effective resilience strategies to help us “bounce back” from life’s trials. Many of these techniques are simple, but when we’re backed into a corner we tend to be resistant to helpful suggestions.

Knowing how difficult it can be to implement resilience tools when we need them the most makes real life stories, like Elina’s, especially powerful.

Elina Chiu moved to Canada from Hong Kong at age 14. By the time she was 15, she was using drugs and living on the streets. In time, she would be diagnosed with HIV and Hepatitis C. PTSD (post-traumatic stress disorder) from violence at home worsened her isolation and downward spiral.

Today at 36, Elina speaks softly and confidently of the things she’s learned and the way she lives each day. Elina is one of those rare people whose presence creates a calm space for others to rest and find hope.

When I ask about her experience with stigma, Elina nods. She describes stigma as being “shut in a dark room.” When someone says something negative or labels her, she says, “I feel the darkness ...I give them the power to put me in a dark room again. To me it feels like a jail. I’ve been there thousands of times.”

She’s learned though that she is able to leave the jail. “There’s a

door...and the door doesn’t have a lock on it. You can definitely open it and walk out of it yourself. But we tend to pretend we don’t see it.”

Over the years, Elina has discovered she can change the way she reacts when someone does or says something that reminds her of the past. She doesn’t have to get angry, blow up and end up in the dark room.




“I still have problems from emotions and things, but I found that’s okay.” Using substances was a way of avoiding feeling her emotions. Now that she is no longer using, Elina says, “I finally understand that it’s okay to feel.”

“I believe a lot of time when people say things, it’s either because they don’t understand or they misunderstand or they shut down like what I used to do.” So they resort to labeling to “build a wall to

“I believe a lot of time when people say things, it’s either because they don’t understand or they misunderstand or they shut down like what I used to do.”

separate themselves from me. To deal with it, even though my feelings get hurt, I try to be truthful. Let’s be real and talk about it, if you have a problem with me.”

Listening to Elina talk about her life, it’s clear that her beliefs and values are key to the way she lives each day. She describes herself as a spiritual person and attends a First Nations spiritual group which she says has helped her enormously. She also volunteers at Vancouver Native Health Society’s (VNHS) Drop In Centre. “I’m very, very glad that I volunteer here! I’ve learned so much! I’ve learned to be kind to myself, I need to learn how to be kind to other people because it’s connected.”

In addition to her volunteer work, Elina attends the Downtown East Education Centre. As much as she loves her studies, her face transforms when she begins to talk about her art. “Art is my protection. It’s the biggest protection of my feelings. When I do a painting or a drawing... I put my emotion into it. I put it up on the wall in my bedroom. Every morning I open up my eyes and [my art] reminds me of what I’ve done and how far I’ve come. I have used my hands to make these things to build a home for myself, instead of just a space to go home and sleep.” 

SWING INTO SPRING WITH US IN 2015

We've set the date and location for our 2015 Swing Into Spring Fundraiser! Our last two fundraisers have been such a great success, thanks to your support and that of our wonderful sponsors, that next year we'll be celebrating the coming of spring in a bigger location: the Croatian Cultural Centre.

Swing Into Spring 2015 will be on **Thursday April 9th**. We are thrilled to have **Stephen Quinn**, of CBC's *On the Coast*, back as our charming host. And, the spectacular **David C. Jones** will once again be providing his special brand of entertainment. We'll let you know about our other special guests a bit closer to the event.

At the fundraiser, we'll be announcing our **2015 Outstanding Employer of the Year Award** winner and an Honourary Mention winner. If you're a person with a disability whose employer has gone the extra mile for you, why not nominate her or him for the award?

Please watch for our nomination forms which will be available on our website in September. If you have any questions about our Outstanding Employer of the Year Award, please email Val at feedback@disabilityalliancebc.org.

Join Us as an Honoured Sponsor

Are you interested in sponsoring Swing Into Spring 2015? Sponsorship packages range from \$500-\$6,000 and we have a special early bird offer. **If you become a sponsor by December 31st 2014, you'll receive a free ad in TRANSITION, in addition to any ads that are part of your sponsorship package!**

If you would like to join us, please contact Jody Lorenz at jody@disabilityalliancebc.org or phone her at 604-875-0188.

see YOU ON APRIL 9TH 2015!



DAVID C. JONES (LEFT) AND HIS UNIQUE BRAND OF AUDIENCE PARTICIPATION!



LAST YEAR'S EMPLOYER OF THE YEAR AWARD WINNER, STARBUCKS

Stigma



Sheryl's Story

I am 6 years old and listening to a teacher for the Deaf and Hard of Hearing tell my mother our move to a rural school means I will "be on the streets by the time I'm twelve." My mother purses her lips and says nothing. I can feel her anger and her fear.

Throughout my childhood, my mother's fear and resulting determination are palpable. She is determined I will not be another "hearing impaired" child who grows up uneducated and unemployed. She knows I face significant hurdles and attempts to mitigate these challenges, dedicating hours each day to teach me language and how to speak.

When she has exhausted her capabilities, I am sent to weekly speech therapy lessons for the next nine years. Evenings are devoted to helping with homework to compensate for the lessons I miss because I don't hear. I grow up convinced I must be stupid. Why else would I require so much assistance?

I am employed from an early age at my parent's fabric store in

Employment in a Hearing World

| BY SHERYL BURNS AND RUTH MCCANN

In my parents' store, I'm not aware of any barriers to employment, but my father witnesses conversations with the customers and worries.

Meacham, Saskatchewan. When my parents purchase the village grocery store and run the local post office, I work sorting mail, stocking grocery shelves and handling the cashier job.

In my parents' store, I'm not aware of any barriers to employment, but my father witnesses conversations with the customers and worries. He tells me I miss a lot because of my hearing. Despite his warnings, I don't comprehend the extent of my challenges. Everyone knows me. My lip reading skills are honed and I have learned to pretend to hear like everyone else.

In the summer after my first year in university, I find work at a grocery store that sells ice cream cones. I struggle to hear ice cream orders as teams of chattering customers crowd the counter. I must continuously ask them to repeat themselves. The owner becomes frustrated and fires me saying, "You're too slow. You can't hear and the customers don't want to wait." I return to work in my parents' store for the rest of the summer. I feel defeated and ashamed.

Because of the stigma around deafness, challenges related to employment have continued throughout my life. Thirteen years ago, I applied for a job similar to employment I already held. I was well respected in my field. A year

after getting the job, I learned discussion regarding my ability to perform the duties of the job had occurred as a result of my hearing.

The questioning of my abilities continues to this day. Even colleagues who have worked with me for years sometimes fall into stigmatizing me because of my deafness. At one of my work sites, I learned a long-time colleague articulated her doubts saying, "I don't think she can do the job, she misses too much." This statement was made in spite of my efforts to ensure I could do the job. For example, colleagues agreed to stand when speaking to help me identify speakers and lip read.

For people with hearing disabilities, it is exhausting to hear in employment and social settings. This exhaustion, compounded by the frustration and stigma, makes employment challenging. People with hearing challenges are acutely aware of scrutiny of their abilities. We feel we must outperform and work harder than our "hearing" counterparts to be seen as capable and worthy of employment.

I'd like to dedicate this article to my parents, Penny and Garry Joynt, because they believed and never stopped trying.

SHERYL IS VICE-PRESIDENT AND LEAD GRIEVANCE OFFICER OF CUPE LOCAL 1936. SHE IS A DISABILITY RIGHTS ACTIVIST WITHIN THE CANADIAN UNION OF PUBLIC EMPLOYEES.

Ruth's Story

If I had to label myself, I would say that I'm deaf. When I tell people this, they automatically assume I can't hear anything at all, use sign language and am not able to speak. Then they are pretty shocked that I can speak and hear.

It's the same in the deaf community. If you can hear, use hearing aids and speak, then you're not really considered deaf. Experiencing these two reactions throughout my life made me feel like I don't belong—not in the hearing community nor in the deaf community. That makes me feel quite lonely and sometimes isolated from others.

I was 3 years old when my grandmother discovered that I couldn't hear. She thought something was wrong and decided to test the theory out by dropping a biscuit tin on a tile floor! My parents took me to be fitted for hearing aids and were told I'd have no life and should be sent to Dublin to a deaf school. Growing up in a rural area in Ireland was hard. I was singled out more than most because I was the only deaf child in elementary and high school.


I decided to enter the world of employment at the age of 16, but most of the responses were negative—I didn't have any experience or I wasn't able to work because of my hearing difficulties. I studied History and Archaeology at University College Dublin, Ireland. The dean told me I had to have a supervisor at all times because I was a liability on archaeology field trips—because of my hearing. I have a Masters Degree in Library Science from London, but could

I was 3 years old when my grandmother discovered that I couldn't hear. She thought something was wrong and decided to test the theory out by dropping a biscuit tin on a tile floor!

not find any form of employment other than volunteer work in Ireland or the UK.

My biggest recent challenge with stigma was with the government of Ireland. I wanted to take part in an employment program called the JobBridge Scheme. Successful applicants would do a 6 to 9-month internship with a company or organization, while being on job welfare. I was on disability benefits and was told that I wasn't eligible because of my disability. In spite of letters from my parents, I wasn't able to be part of the program.

Since moving to Canada, I've found that, while some people still have narrow attitudes about disability, my experience has been mostly good. I was surprised to learn there are many non-profit organizations for deaf people in Vancouver. At home, there is only one nationwide organization. I've also managed to secure employment working on-call for the library at Vancouver Community College. I'm hopeful this means more positive changes are coming.

RUTH MCCANN MOVED FROM IRELAND TO CANADA IN FEBRUARY OF 2014 FOR A NEW EXPERIENCE AND ADVENTURE. SHE KEEPS IN TOUCH WITH FRIENDS AND FAMILY BACK HOME THROUGH HER BLOG AT [HTTP://RUTHMCCANN45.WORDPRESS.COM/](http://ruthmccann45.wordpress.com/). 

HEARING LOSS, EDUCATION AND EMPLOYMENT



"Hearing loss is considered the fastest growing disability in the world. In North America, one in 10 people is thought to have some degree of hearing loss, ranging from mild loss to profound deafness; for those aged 65 and over, the percentage rises to 50%. It is a rare business that has no employees with hearing loss, and most organizations can expect hearing issues to become increasingly common among its workers."

(Working with Hearing Loss: A Guide for Employees, Employers and Entrepreneurs. Canadian Hard of Hearing Association, 2008. Available: <http://tinyurl.com/n55l4qu>).

Statistics Canada's national survey in 2006 revealed the following about Canadians with hearing limitations:

- 50.2% reported their educational attainment as high school or below
- 20.1% had a college degree or diploma below a bachelor's degree
- 7.5% had a bachelor's degree
- 18.5% had a trade or apprentice certificate
- 47.3% reported "being employed"
- 33.2% of those employed said that their hearing limitation "limited the amount or kind of work they could perform"
- 32.3% of those employed said their hearing limitation made it difficult to advance or change jobs

(Facts on Hearing Limitations. Statistics Canada, 2006, rev. 2009.)

See more at <http://tinyurl.com/k9b99qu>

People with Disabilities Waiting for the LNG Ship to Come In

BY JOAN RUSH



People with disabilities are drowning, while they wait for BC's Liquid Natural Gas (LNG) ship to come in.

I wonder how BC civil servants or a health services union, for example, would respond if the province only offered to increase wages if they could be financed by economic growth—perhaps through the proposed liquefied natural gas (LNG) trade?

Not happily, I am guessing. However, that is exactly what the BC government has proposed for BC citizens who receive disability assistance.

When the government released its Accessibility 2014 Strategy in June 2014, Premier Christy Clark commented that a raise in disability assistance will be considered when it is “affordable” through provincial economic growth, suggesting LNG as a solution to growing our economy.

So, the Premier hinted, people with disabilities may get a raise in disability assistance when, and if, our LNG ship comes in. In the meantime, it seems disability assistance will remain at the same level it has been at since 2007.

Many people agree with Premier Clark that provincial services must be affordable. However, we also know that when children with disabilities become adults they begin to suffer the indignities of grinding poverty and lack of access to necessary care.

Since 2007, the cost of living, especially housing, has soared. However, the monthly disability benefit (PWD) of \$906 has not increased and some services to this group have decreased. After the economic downturn of 2009, dental services were cut from the already deficient PWD dental plan, and some have never been replaced, despite the turnaround in the economy. Coverage under the provincial pharmaceutical plan has also been cut.

The union that supports BC adults with developmental disabilities won a small wage increase this past year, but was only allowed to fund the increase through savings from the programs they run. The only place to find these “savings” is through cuts to services or cuts to maintenance of group homes.

Are we all willing to leave people with disabilities living in these impoverished and, from a medical and dental perspective, imperilled conditions, while we wait for

So, the Premier hinted, people with disabilities may get a raise in disability assistance when, and if, our LNG ship comes in. In the meantime, it seems disability assistance will remain at the same level it has been at since 2007.

economic improvement, possibly through LNG profits that might not come our way for five or ten years, if ever? If we truly believe in inclusion and equity, we would try to ensure that we improve services to the disability community in step with the increases granted to the other members of our civil service.

Government decision-makers should realize that people with severe disabilities are living poor and sometimes wretched lives, while the province optimistically hopes for LNG profits to materialize. The government should recognize its obligation to ensure BC citizens with disabilities have enough money to live dignified lives. The province should provide increases to disability assistance at the same rate that BC civil servants, including unionized and non-unionized workers, win increases. We should not leave the most vulnerable and challenged among us to be the only members of our society who desperately need that LNG ship to come in.

JOAN L. RUSH, LL.B., LL.M. (HEALTH LAW AND ETHICS), IS A RETIRED LAWYER IN VANCOUVER WHO ADVOCATES FOR ADULTS WITH DEVELOPMENTAL DISABILITIES. **T**

did you have POLIO?

Are you experiencing symptoms such as:

- **excessive fatigue** not related to activity or relieved by rest
- **increased weakness** in unaffected and / or previously affected or paralyzed areas
- **muscle and joint pain**
- **reduced endurance**
- **sensitivity to cold**
- **difficulty sleeping**
- **problems breathing and swallowing**
- **sensitivity to anaesthetics and medication**

If you are having difficulty with one or more of these symptoms and you had polio previously, you may have Post Polio Syndrome.

It is important to inform yourself about this condition. Tell your doctor.

For more information contact our office:

**Post Polio Awareness and
Support Society of British Columbia**

Phone: 1-250-655-8849

Fax: 1-250-655-8859

E-mail: ppass@ppassbc.com

www.ppassbc.com



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Sherly Burns

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Ruth McCann

Alexandra Niblock

Gudrun Langoff, Council of Senior Citizens Organizations

overcoming the stigma of the developmental disability label

| BY JASLEEN ARORA, ARDEN DUNCAN BONOKOSKI AND TAMARA HURTADO

As early as infancy, when an individual is diagnosed with the label of developmental disability, the only certainty is they will be stigmatized by low expectations about their capabilities and will live marginalized lives without strong advocacy on their behalf.

This means people with developmental disabilities are more likely to experience violence, live in poverty, receive low quality education and health services, and live isolated lonely lives.

This reality is what led some families in BC to come together to answer the question, “What can I do to ensure that my son or daughter with a developmental disability will lead a full life within their community?” These families were instrumental in changing the school system to have their sons and daughters included in the mainstream K12 school system. They realized their advocacy experience would again be needed to ensure inclusive opportunities were available after high school.

STEPS Forward is Born

STEPS Forward is a family-driven initiative rooted in the belief that inclusion in post-secondary education has the potential to be an important pathway to adulthood and a meaningful life.

Since 2001, STEPS Forward collaborated with colleges and universities to include young adults, who could not meet the entry requirements because of their disability, to complete an under-graduate education in the same ways and in the same classes as any other student.

Many of these students have now completed 4 years of non-credit studies in a field of their choice. They have also participated in all aspects of in-class learning. They have completed modified exams and assignments, and convoked alongside their peers earning degrees in the same concentrations of studies. Level of ability and prior academic achievement are not criteria for acceptance, nor indicators of success—the individual’s desire to learn and to be a student are.

The Same Goals and Opportunities

The goals of students with developmental disabilities are the same as any university student. They have found work in positions that have given them a sense of identity, used their skills and abilities, and allowed them to contribute to something they are passionate about.

The social life of campus has also been a significant part of their learning and students have participated in the diverse range of experiences and relationships that make up the typical university

Stigma
Preconceptions
Judgements
Isolation

community. Inclusion facilitators support students, faculty, campus staff and peers to build a dynamic inclusive community.

Inclusive post-secondary education has now been in place for more than 13 years in British Columbia. There are students with developmental disabilities studying at six post-secondary institutions across the province: University of BC, Emily Carr University of Art and Design, Simon Fraser University, UBC-Okanagan, Nicola Valley Institute of Technology and the University of Victoria.

While it makes perfect sense that the opportunities that exist for children, youth and young adults to be successful would also be important for people who have developmental disabilities, they have largely been denied these opportunities.

The executive director of STEPS Forward, Tamara Hurtado, has had a unique perspective on this at every life stage of her twin daughters—one of whom has the label of Down Syndrome. She has seen

Once a child has the label of disability, segregation and reduced access to typical opportunities is the rule rather than the exception.

how one of the twins has been systematically stigmatized, starting as early as registering for infant day care. She describes how one twin was automatically accepted into childcare, while the other was rejected and stewarded toward a separate program for infants with disabilities.

Hurtado finds it beyond comprehension, "that there was a need to separate babies given that all babies require a high level of attentive care. There was no existing medical issue for either twin and, therefore, no need for specialized care requiring the separation of 10-month-old twins."

Once a child has the label of disability, segregation and reduced access to typical opportunities is the rule rather than the exception. This segregation is often promoted as being in their best interest.

Overcoming Segregation

Students with developmental disabilities in the K12 system, in particular during high school, are singled out. They are told they cannot learn in the same places as other students and need to focus on skills, before being afforded the opportunity to share experiences with their peers, learn interesting subjects or to participate on sports teams.


Hurtado believes "the real message students receive is they are not valued learners, they cannot do things for themselves without

specialized support workers, and cannot aspire to learn the same things, in the same places as their siblings and peers because they are deficient in a significant way. They are constantly confronting rejection and a culture of reduced learning expectations and opportunities...it becomes a self-fulfilling prophecy."

Having the opportunities to have shared experience with others means they will learn as much as they can which is often more than anyone can predict.

It is crucial to see that particular individuals may not be able to complete work to the same standards, but they are nonetheless competent and interested learners who participate in many valuable ways. This has become evident as students who had been labeled as unemployable have had support to build an inclusive life, to study at university, make friends, and successfully hold interesting jobs and contribute to their community.

It comes as no surprise that post-secondary education, which has been pivotal for any young adult to a life pathway of higher expectations and opportunities, affords the same outcomes to young adults with developmental disabilities.

JASLEEN ARORA IS SENIOR FACILITATOR, SFU CAMPUSES, ARDEN DUNCAN BONOKOSKI IS COMMUNITY LIAISON AND TAMARA HURTADO IS EXECUTIVE DIRECTOR OF STEPS FORWARD AT [HTTP://TINYURL.COM/LKQY8WM](http://tinyurl.com/LKQY8WM). 

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The ADHD Catch 22

| BY PETE QUILY

“My family physician had little empathy or understanding of ADHD and how it affects my life. If my physician doesn’t understand, how can I expect my employer or colleagues to understand?” Person with ADHD

In 2009, the BC Medical Association released an Attention Deficit Hyperactivity Disorder (ADHD) white paper, “Your Attention Please—Improving Access for ADHD Patients.” The result? BC’s Liberal government has done nothing, nor has the BC NDP demanded it.

Few services for BC’s adults and children with ADHD exist, and few medical professionals are properly trained on ADHD. Media and politicians often tell me, for more resources, ADDers (people with ADHD) must speak out.

However, ADDers don’t. Most fear going public to demand proper diagnosis and treatment. But diagnosis and treatment won’t improve until more ADDers “come out” about their condition. That’s the Catch-22.

The stigma around ADHD has to be reduced. People with ADHD need to go public, demand resources and give a counter-narrative to prevailing myths.

Myths that Stigmatize

Denying ADHD. You may have heard: “ADHD doesn’t exist,” “ADHD is a big pharma conspiracy” or “My doctor doesn’t believe in ADHD.” ADHD is not a matter of belief or theology. It’s a matter of science and evidence. There are thousands of medical scans and clinical studies showing ADHD is real. Every major medical, psychiatric and psychological association says that ADHD exists and causes real impairments.¹

“I have often heard people describe ADHD as nonsense. It took me until the age of 24 to finally get diagnosed because I started to believe what I was hearing from others.”

Minimizing the number of people with ADHD. “It’s over-diagnosed” or “let boys be boys.” According to scientific evidence however, ADHD is sometimes over-diagnosed, often misdiagnosed, but most often under-diagnosed—90% of adults with ADHD are undiagnosed.² All three outcomes show the need to properly train medical professionals in BC on ADHD.

Pretending “expertise” on ADHD. “Don’t drug your kid” or “ADHD meds will make you a zombie.” ADHD medications have undergone hundreds, if not thousands, of studies. We don’t call a treatment for asthma “drugging your lungs?” Why are these statements acceptable for ADHD?

Making it about personal failure.

“You just need to try harder” or “You just need to focus.” Or for parents of ADHD children: “Take away sugar and food dyes” or “He just needs more discipline.” For children, these misguided approaches lead to a high rate of grade failure, dropouts and suicides. Adults struggle at work and relationships, have higher rates of addiction, divorce, crime, unemployment and suicide.

Making it about success. “You can’t have ADHD, you did well in school/work.” Many of us have problems in school, others don’t or have problems elsewhere. There are PhDs with ADHD, an ADHD MENSA group with over 600 members and three billionaires are public with their ADHD.

Dealing with Stigma

“I still feel embarrassed and ashamed by it, even if I know it’s not my fault. The stigmas are still there.” Person with ADHD

Many of my adult ADHD coaching clients self-stigmatize. They’ve heard ADHD myths repeated often, and they believe, repeat and perpetuate the stigma.

Learn more about ADHD. By knowing more, you can explain or refute myths. Learn ADHD’s facts and neurobiology to respond more effectively. Don’t suffer in silence and don’t overreact.

Stigma Shame Doubt

Learn about the myths of ADHD.

Learn about the common ways non-ADDERs and ADDERs who have experienced denial or shame stigmatize us.

Learn to explain ADHD and counter stigma. Find different responses for media, health and education professionals, coworkers or family and friends. Choose statements you feel comfortable with; practice your delivery to be calm and confident; and aim to persuade and educate, not to attack.

Call out stigma. Use facts. When appropriate, and depending on your confidence, comfort and the situation, explain why stigmas are myth. If you're open to it, your personal ADHD story can be much more powerful than facts. It's often harder to demonize a person you know.

Build support among family and friends. ADHD is 80% genetic—your parent(s) may have it. Your family lives with it. Start building support with “*ADD and Loving It!*?”—two actors interviewing ADHD experts in the best video on adult ADHD out there.³

Think the long game. Make small personal victories. Build pressure for change that will help others.

To learn more about ADHD stigma from the eyes of ADDERs, visit my website.

PETE QUILY IS AN ADULT ADHD COACH WHO HAS ADHD AND LEADS THE VANCOUVER ADULT ADD SUPPORT GROUP. HE IS ON THE BOARD OF CHADD VANCOUVER.



NOT ALL DISABILITIES ARE VISIBLE.

A growing number of Canadians suffer from **invisible** disabilities, such as addictions and mental health issues. In fact, one in five Canadians will experience some form of mental illness during their lifetime.

But did you know that:

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- People with disabilities have the right to work in an environment free of harassment and discrimination?
- People with disabilities have the right to accommodation and accessibility?

The Hospital Employees' Union advocates for the rights of health care workers with disabilities. And we're proud to support the work of the BC Coalition of People with Disabilities (soon to be Disability Alliance BC).



www.disabilityalliancebc.org

www.heu.org



Footnotes

¹ addcoach4u.com/doesaddreallyexist.html

² Dr. Russell Barkley, *Monitor on Psychology*, March 2012, p. 70

³ ADD and Loving It!? is available from totallyadd.com. <http://totallyaddshop.com/products/add-loving-it#.U7JFo41dWmU>

Online

Pete's online ADHD resources: addcoach4u.com

What would it take to go public with ADHD? adultaddstrengths.com/category/what-would-it-take-to-go-public-with-adhd/

Groups

There are two ADHD Support groups in BC:

- Vancouver Adult ADD Support Group addcoach4u.com/adultadd.html
- CHADD Vancouver (Children & Adults with ADHD) vcn.bc.ca/chaddvan? Vancouver ADHD Parent Program. (Must live in Vancouver) vch.ca/find_services/find_services/?&program_id=130 

resources

Reducing Personal prejudices

"Reducing prejudices needs to be a personal goal for each of us." Psychologist Dr. Jim Cole talks about examining our own stereotypes and prejudices. For example:

- Acknowledge you have learned prejudicial information about other people
- Confront without guilt or blame the stereotypes you have learned
- Become aware of your own "self-talk" about other groups of people

http://www.beyondprejudice.com/reduce_your.html

The Game of Fear, Blame and Shame


"Chelsea was born with HIV. I had been her doctor since she was five years old. Chelsea had a great sense of humor. She knew it too and dreamed of becoming a standup comedian. But behind her laughter was a broken heart. Chelsea's own family made her feel dirty because of her illness. They kept her dishes separate from their own and sanitized the places and spaces where she sat or touched."

Read Chelsea's full story at <http://tinyurl.com/l9ej7hr>

Positive Women: Exposing Injustice

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<http://www.positivewomenthemovie.org/video.html> 



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When Health Care Stigmatizes

| BY DEB SCHMITZ

Researchers have found that stigma related to hepatitis C is grounded in both fear of communicable disease and the association with drug use and addiction which carry their own tremendous stigma burden.

These attitudes are found widely in society and, very particularly and to great impact, in the health care system. As a caveat, many people speak also to the kindness, caring and excellent care they have received for their hepatitis C.

This article speaks to the pervasive and persistent hepatitis C stigma and discrimination that is interpersonal, structural and systemic and must be spoken of if it is to be fixed.

The Role of the PHCN

Since 2007, the mission of the Pacific Hepatitis C Network (PHCN) has been to bring together and support all those working on the complex issues that underlie health equity, access and quality of life issues experienced by people living with hepatitis C in British Columbia.

A number of PHCN publications give voice to the experience of people living with hepatitis C and the force of stigma and discrimination in their lives.

While stigma and discrimination occur across social and family networks, people living with hepatitis C speak most often to the very negative experiences they have had in relation to the health care system and health care providers.

How People Experience Stigma

PHCN's *Hepatitis C Response through Network Engagement: Stakeholder Survey Report (2014)* documents that stigmatization and discrimination remain key issues for people living with hepatitis C, regardless of the source of their infection or current lifestyle. The report describes how stigma and discrimination affect the way that people living with hepatitis C access services, how they negatively impact interactions between caregivers and care recipients, and lead to increased feelings of isolation for some people living with hepatitis C. This is true for people living in urban, and more rural and remote communities.

The survey report also points out that all strategies for decreasing isolation, improving access to services, and filling in service gaps must take into account the sources, effects and means to decrease stigma and discrimination.

One person described how, when asked about how hepatitis C has affected social connections, "emergency personnel treat me well until they find out I have hepatitis C." This is echoed by a speaker in the 2011 video *Living with Hepatitis C* talking about her experience with stigma and health care. "Now if I go in and say I have a liver disease, say in emergency, I'm treated with kindness and

| continued on next page

ABOUT HEP C

Hepatitis C is a disease of the liver caused by the hepatitis C virus. It can cause symptoms such as severe fatigue and brain fog, and can lead to liver disease, cirrhosis, liver cancer and End Stage Liver Disease (EDSL).

Hepatitis C is the leading cause of liver transplantation in Canada.

Hepatitis C is passed on by blood-blood contact with infected blood. Poor public policy and stigma related to addiction and illicit drug use continue to feed high rates of hepatitis C among people who use injection and inhalation drugs. Most new infections are within this group.

Some 63,000 people live with hepatitis C in British Columbia (BC Centre for Disease Control).

Forty thousand—two thirds—are baby boomers (born between 1945—1965, living with the virus for over 10 years and not generally onward transmitters of the virus).

Experts estimate a further 15,000—30,000 undiagnosed baby boomers in the province.

When Health Care Stigmatizes, continued from previous page

what you'd expect in an emergency room. If I say I have the C hepatitis on the other hand, I'm automatically assumed to be an addict and I'm seeking drugs."

The following comments are also from three different speakers in the *Living with Hepatitis* video. The theme of stigma came up in every interview, without prompting.

"...even people who are supposed to know about it, have this unwarranted fear that is not grounded in the first place and their ignorance creates an atmosphere of paranoia." "...it feels like people with hep C or people in the margins are basically worthless." "...I think that it's really unfortunate, that this should be a basis to deny people the ability to get healthy."

These responses hint at the depth of the stigmatization of people living with hepatitis C. Because systems and structural contexts are made by people, PHCN believes these experiences suggest an urgent need, as more people become ill with liver disease due to hepatitis C, to improve education and understanding about hepatitis C among health care providers and, as always, the community and general public.

DEB SCHMITZ HAS WORKED IN COMMUNITY-BASED HEALTH PROMOTION AND COMMUNITY DEVELOPMENT RELATED TO HEPATITIS C FOR THE PAST 15 YEARS. VISIT: WWW.PACIFICHEPC.ORG OR EMAIL DEB@PACIFICHEPC.ORG. 

Stigma in Cultural Communities

| BY RAVNEET KAUR AND JAGDEEP GREWAL



JAGDEEP GREWAL



RAVNEET KAUR

According to the Canadian Mental Health Association, one in five adult Canadians will suffer a mental disorder in their lives. This means that one of our friends, family members and a member of our community can be affected. Mental illness can take various forms such as depression, anxiety, schizophrenia and more.

Across the globe, many individuals are stigmatized for their illness and become the target of discrimination. Although stigma and barriers to mental health and illness vary across different communities, ethnicities and cultures, such labelling often seems to be more prevalent among certain communities.

In the South Asian community, shame and guilt often surround mental illness. Seeking professional help is frowned upon which

leaves those who live with mental illness feeling reluctant and embarrassed to find help. Since the South Asian community is tightly connected to their family, the social stigma not only affects the individual, but their families and friends as well.

Facing challenges and barriers from family, friends and society, people who battle mental illness are afraid of being misunderstood, and their desire to feel accepted in the community is a continuous struggle.

One of the main reasons stigma is attached to mental illness is because mainstream society tends to hold misconceptions, including the assumption that mentally ill individuals aren't able to make valid decisions, take responsibility and build social relationships. The

community ostracizes the person and the more isolated the individual becomes, the more alienated he or she feels.

Unfortunately, this is a cycle which turns into a self-fulfilling prophecy—the more the individual is labelled with negative characteristics, the person internalizes it and then it eventually manifests into reality. With that, the person disengages from society and is unlikely to get a job, do volunteer work or connect with community resources.


With this in mind, there is a pressing need for more programs aimed at the reduction of stigma and barriers. More awareness and implementation of educational strategies are necessary to help reduce stigma faced by those who

In the South Asian community, shame and guilt often surround mental health illness. Seeking professional help is frowned upon which leaves those who live with mental health feeling reluctant and embarrassed to find help.

struggle with mental illness. To educate the public on these issues, it is important to start various outreach programs, focus groups, workshops and community gatherings that cater to all segments of society.

For those who live with mental illness, empowerment groups would be helpful since they would be provided with safe space and a welcoming environment to talk about the various struggles they face. This would allow them to feel supported since they would realize that they're not alone in facing challenges associated with mental illness.

It's important for our communities and our society to raise awareness and change their perspective on mental health and illness, which in turn, will begin to change their behaviour. As a community, we need to be more understanding of those who struggle with mental illnesses and provide them with opportunities for growth and space to feel included as an essential part of our communities.

RAVNEET KAUR BA, PSYCHOLOGY AND JAGDEEP GREWAL BA, HUMAN RESOURCES WORK WITH PROGRESSIVE INTERCULTURAL COMMUNITY SERVICES SOCIETY. CONTACT PICS AT PICS.BC.CA OR PHONE 604-324-7733. 



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HOUSING MATTERS

Ageism Could Cost You an Eye | BY GUDRUN LANGOLF

You might expect a dramatic story, after such a dramatic title. Well, it was a transformative one for me, that's for sure.

A while back, not "once upon a time" because this is no benign fairy tale, I travelled from Vancouver to Sechelt on the Sunshine Coast. Public transit to the Horse-shoe Bay ferry is still excellent and I struck up a conversation with a fellow rider who was returning home to Cumberland. Had she been to visit friends or relatives or shop in the big city? No, she had a medical appointment with a cancer specialist, an oncologist. The news was not good: she was about to lose her eye.

My seat mate told me she had a relatively rare melanoma of the eye. I was curious about how she had discovered the cancer, did it hurt, how it affected her, and so on.

She said her eyesight began changing about a year ago. It appeared to be failing gradually. She was 64 years old, nearing retirement age and so rationalized her failing eyesight as something that happens as we get older.

The "conventional" wisdom is that, as you age, your body will fail you in various ways and eyesight is just one of them.

Stigma

How ironic, that we are beginning to see an unfolding of the life cycle for a huge portion of our population (aka Boomers) when we continue to have embedded in our culture a fear of growing old.

I could tell you much more about this delightful woman who was still working full-time and happy to have a union job with benefits, the kind of art she creates, that she lives on her own and many other interesting facets of her life. I will only pass along her potentially life-saving message: ageism can hurt you, particularly if you buy into the stereotypical horse manure!

If your body, or its beautiful parts, don't feel right, don't assume it is due to the natural aging process. Get it checked out! My new friend on the bus wished she had sought medical advice sooner. For her, it could have saved her eye!

For a long time, I have ranted against the anti-wrinkles advertising we see everywhere. They imply that getting old must be bad. Seniors are more often than not looked upon as "not-abled", decrepit and in need of care. "Isms" keep us apart from each other: ableism, racism, ageism, sexism, etc. These labels and the prejudices that fuel them keep us from working together respectfully and spawn industries that profit from the situation. And yes, they can hurt us!

Too often, we buy into the stereotypes ourselves without being

aware of it, like my fellow traveller. Of course, we don't want to hurt each other, but because we live in a society that is surrounded by subtle, as well as outright prejudiced notions, it is easy not to question.

How ironic, that we are beginning to see an unfolding of the life cycle for a huge portion of our population (aka Boomers) when we continue to have embedded in our culture a fear of growing old. We see this fear in the negative stereotypes and the language that belittles growing old—its complexity and tremendous variability. Perversely and falsely, seniors are now even portrayed as the population which will bankrupt pension funds and destroy the health care system—the very institutions we helped to build.

This article first appeared in the COSCO News. The Council of Senior Citizens Organizations of BC is a federation of 84 seniors' organizations with a combined membership of over 100,000 seniors. Visit www.coscobc.ca.

GUDRUN LANGOLF IS FIRST VICE-PRESIDENT OF COSCO. SHE IS AN ACTIVE CITIZEN IN THE MARPOLE COMMUNITY OF VANCOUVER. **T**





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ABOUT US

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THANK YOU FOR YOUR INVALUABLE SUPPORT

Canadian Thalidomiders Ask the Government to Fulfill Its Promise

| BY ALEXANDRA NIBLOCK, MA (POLI SCI)

Virtually everyone knows that pregnant women are advised not to take drugs—whether prescription or nonprescription, but few are aware of the events that led to this recommendation. These events are the start of our story.

We are Canadian thalidomide survivors. Along with thalidomide survivors the world over, we are the embodiment of what can happen when pregnant women take improperly tested drugs.

Thalidomide is the infamous sedative advertised as “so safe that even pregnant women could take it.” It was prescribed to pregnant women in the late 50s and early 60s to treat morning sickness. The result was tens of thousands of babies around the globe born with severe birth defects, including missing limbs, missing organs, blindness, deafness and cognitive deficiencies. Many thousands of these babies died at or near birth because of the severity of their deformities.

Approved for sale in spring 1961, thalidomide was on the market in

Canada for less than a year. Despite its short run on the Canadian pharmaceutical market, hundreds of thalidomide births are believed to have resulted. Approximately 110 thalidomide babies survived to adulthood in Canada. The deformities suffered by Canadian thalidomiders could have been avoided had a government office properly fulfilled its responsibilities.

Canadian thalidomiders live each day with the catastrophic consequences of a decision taken by officials in the Health Protection Branch allowing thalidomide on the Canadian market, regardless of growing concern around the world about its safety.

The thalidomide tragedy did not occur in the United States, despite applications to market thalidomide made by the same licensee in both countries at the same time. Thalidomide was never formally approved for sale in the US because of concerns being raised in Europe about its safety and whether sufficient testing of it had been done by Chemie Grunenthal—the company that developed thalidomide—and the drug’s licensees.

The Honourable J. Waldo Mon-
tieth, Minister of Health and Wel-
fare, on January 29th, 1963, made
a promise to Canadians regarding
the Canadian thalidomide babies:

“It is our job to ensure that those
thalidomide victims are cared for
in the best possible manner, that
their needs are met to the full-

est extent we can devise, and to
ensure, as much as possible, that
a similar tragedy will never occur
again.”

It is true that in response to the
thalidomide tragedy, the Canadian
federal government changed the
protocol for bringing new pharma-
ceuticals to the market, develop-
ing a comprehensive and multi-
tiered system of testing before a
new drug would be approved for
sale. However, while the Canadian
government acted, as promised,
to “as much as possible” prevent
a similar tragedy occurring in Can-
ada, its promise to help Canadian
thalidomiders and their families,
went largely unfulfilled.

Around the world in the late 60s
and early 70s, thalidomiders and
their families, primarily through
class action suits, sought and
obtained compensation from their
governments and from the rele-
vant pharmaceutical firms respon-
sible for the sale of thalidomide.
Such was not the case in Canada,
where no class action legislation
existed until the early 1990s.

Unable to bring a class action
suit against the North American
licensees, and usually subject to
“gag” provisions in any agreed
upon settlement, each family and
their legal representatives had to
reinvent the wheel when dealing
with the pharmaceutical compa-
nies. As a result, settlements in
Canada were very uneven. For
example, one Canadian thalido-
mider with no arms could have
received an annuity that paid



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Canadian thalidomiders are asking the Government of Canada to follow the lead of the Great Britain, German, and other national governments in accepting their responsibility for thalidomide births in their jurisdictions.

approximately \$700.00 per month for his/her lifetime, while another thalidomider with all four limbs affected and confined to a wheelchair for life might have received a total lifetime settlement of only \$10,000.00. There was no way for families to work together and no help from any government body in dealing with the pharmaceutical companies.

As thalidomiders, we are known for our determination and drive for independence, no matter how severely we were affected by the drug. However, with our increasing age, we are forced by significant physical deterioration to accept help in even the most mundane of daily tasks. While we greatly value our independence, it is gradually being stolen from us, just as our limbs were stolen.

Our rapid physical deterioration in the last decade is universal amongst thalidomiders. More than 50 years of using and abusing our bodies in ways they were not meant to be used has had a serious and detrimental impact on them.

Canadian thalidomiders, with the critical assistance of the War Amputees of Canada, received from the federal government a "compassionate grant" of approximately \$75,000 in the early 90s. We

greatly appreciated these funds, but they were barely a drop in the bucket compared to the expense of living with our thalidomide-damaged bodies. Our continuing and increasing costs far exceed the dollars we received twenty years ago.

Canadian thalidomiders are asking the Government of Canada to follow the lead of the Great Britain, German, and other national governments in accepting their responsibility for thalidomide births in their jurisdictions. We are asking our government to show Canadian thalidomiders the respect we are due by acknowledging its role in the thalidomide debacle in Canada and to fulfill its promise of more than 50 years ago by ensuring our "...needs are met to the fullest extent [the Government of Canada] can devise..."

We are asking the Government of Canada to provide financial compensation sufficient to allow us to live the remainder of our lives with dignity and independence. We are asking our fellow Canadians to support us in our efforts to right this wrong.

For more information, please contact Alex at amniblock@shaw.ca. 

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THANK YOU!

Finding the Right Activities for You

In the last TRANSITION, we published some interviews about fitness and people with disabilities in the article *Open Gym is a Welcoming Space*. This is Part Two of the interviews conducted by Laura McCracken, Megan Hamm, Yoonjae Kim and Kevin Chuang from UBC's School of Kinesiology. We asked them to interview and write stories about people living with disability/chronic illness and their experiences with physical activity.

Mark

Mark is a 26-year-old man living in Steveston, BC who is in a new chapter of his life.

Five years ago, Mark saw a demonstration of power wheelchair soccer at a seminar at Riley Park Community Centre and was keen to try it out. He has been playing on Sundays at Killarney Community Centre ever since. His favourite part of the soccer program is when the drills are done and the game begins! It's a great way for him to burn excess energy and make friends.

Some of the other players are Mark's childhood friends from Easter Seals Camp, so the game is also a good way to see friends. He looks forward to competing in a two-day power wheelchair soccer tournament every year in Penticton, where his team plays four games over the weekend.

There are some other activities that Mark is interested in trying, for example wheelchair rugby, but he doesn't have the level of physical mobility required to push himself in a manual wheelchair. He says it is like his body is slower than his brain which can be frus-

trating at times. But he's found a sport he loves and he stays positive by focusing on what he can do, having fun and not worrying about comparing himself to anyone else.

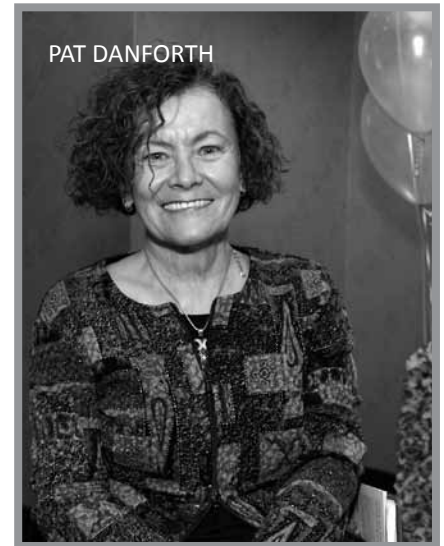
Mark's advice for someone who is hesitant about physical activity is, "Just try it!" There's nothing to lose. That's what Mark did and it worked out for him. He says, if you like sports, then power wheelchair soccer is a great option.

Pat

Pat is in her mid-60s and lives in Victoria, BC. She had a lower thoracic spinal cord injury in 1970, including a spinal fusion which limits the mobility of her back and repetitive strain injuries that have developed from many years of using a wheelchair.

Despite these limitations, Pat has been trying to be active since her injury. Before moving to Victoria in 2001, she lived in Regina, Saskatchewan where she used a gym with adaptive equipment and tracks for wheelchairs.

In Victoria, Pat had a hard time finding an accessible gym, but eventually found one with a piece of adaptive equipment donated



by a Paralympian. Pat exercised at this gym for 6 months, but unfortunately she pulled her biceps.

She was disappointed by the staff's lack of knowledge and training in working with people with disabilities, and feels this may have contributed to her injury.

Last November, Pat found a non-profit organization in Victoria called MOVE Adapted Fitness and Rehabilitation Society of BC. The MOVE gym had adaptive equipment, well-trained staff and student volunteers who supervised and developed fitness programs for people with disabilities and conditions requiring assistance or specialized equipment.

Pat has been going to the gym two to three times a week and she's noticed positive changes, including improvements in agility, strength and flexibility. This makes daily activities easier for Pat, for example, she no longer has to use tongs to remove clothing from her washer.

She also finds that physical activity has improved her posture and helps to reduce the "crunchy"

feeling in her back from arthritis. People around her, including her doctor, tell Pat that she looks better and healthier. Most importantly, Pat feels happy and knows she is stronger.

Pat's best strategy for staying active is to tell people around her she is working out, so that when people ask about her training, she is motivated to keep going. She has used a gym buddy in the past and finds it also works well—accountability to someone else helps!

When she doesn't want to work out, Pat talks herself into getting to the gym which is the hardest part for her. She says that "as long as you show up, that's half the battle."

The \$50/month cost of the gym membership is reasonable, but it is an additional cost when on a limited income. Pat discovered she could use the cost as a medical expense on her income tax return, if she has a physician's note confirming she needs structured physical activity programs for maintenance of physical well-being.

Pat's first activity goal was to regain the strength and mobility she lost after a wrist surgery a few years ago. Now that she has gained even more strength and mobility than before the surgery, her new goal is to be consistently active for a long time. **T**

INACTIVITY RELATED TO CHRONIC DISEASE IN ADULTS WITH DISABILITIES

Working age adults with disabilities who do not get any aerobic physical activity are 50 percent more likely than their active peers to have a chronic disease such as cancer, diabetes, stroke or heart disease, according to a 2014 Vital Signs report released by the US Centers for Disease Control and Prevention (CDC).

Nearly half (47 percent) of adults with disabilities who are able to do aerobic physical activity do not get any. An additional 22 percent are not active enough. Yet only about 44 percent of adults with disabilities who saw a doctor in the past year got a recommendation for physical activity.

"Physical activity is the closest thing we have to a wonder drug," said CDC Director Tom Frieden, MD, MPH "Unfortunately, many adults with disabilities don't get regular physical activity. That can change if doctors and other health care providers take a more active role helping their patients with disabilities develop a physical fitness plan that's right for them."

Some of the benefits from regular aerobic physical activity include increased heart and lung function; better performance in daily living activities; greater independence; decreased chances of developing chronic diseases; and, improved mental health.

Other key findings include:

- Inactive adults with disabilities were 50 percent more likely to report at least one chronic disease than were active adults with disabilities.
- Adults with disabilities were 82 percent more likely to be physically active if their doctor recommended it.

The *Physical Activity Guidelines for Americans* recommend that all adults, including those with disabilities, get at least 150 minutes of moderate-intensity aerobic physical activity each week. If meeting these guidelines is not possible, adults with disabilities should start physical activity slowly based on their abilities and fitness level.

See the full Centers for Disease Control and Prevention medical release at <http://tinyurl.com/lkqy8wm>.

Living with Developmental Disability and HIV | BY MELANIE MONDS AND NANCY CODY

We live and practice in a small northern community. There are many benefits to living in a small community, but if you are living with HIV, there are also many challenges. These challenges range from accessing a specialist to maintaining confidentiality.

Stigma is the greatest challenge a person living with HIV faces, but the challenge is even greater for an HIV-positive person who also has developmental delays (DD). In this article, we share the story of one such person in our community who is living with HIV who also has a developmental delay.

Positive Living North (PLN), a well-accessed program, has a drop-in that is open to the general community. Some of the drop-in patrons are or become infected with HIV and/or HCV. This is a short interview of one such person, June (not her real name), who accessed services at PLN before she was diagnosed with HIV.

Currently, June does not have a place to live. She had not received services for children with DD when she was young and now receives some support from Community Living BC (CLBC). There are other HIV-positive community members who have similar challenges, but are not doing as well as June. Unlike June, they have immense challenges in initiating or maintaining a regular medication regimen or even understanding the fact that they are living with HIV.

What's it like living with HIV in our small community?

No one knows that I am HIV positive just some staff of places, some family and a couple of people who are living with HIV. I feel comfortable with these people knowing. I don't want people to know because I worry about my safety. I fear they may threaten me with violence. I am worried about some particular people. Right now I have a one-to-one worker and she has a book of different things to work on: finances, boundaries, how to say no and don't give in. Being homeless right now is really hard. I am running from shelter to people's homes, couch surfing and I find myself sleeping in the bush.

You have been doing really well in taking the medication. How do you do this?

I have a disease that I have to live with for the rest of my life. I've gone through a lot of x-rays, CT scans and blood work. Since I been HIV-positive, lots of people have been asking me where I got it from and now I know, and he's gone. I can't do anything about it just keep taking my medications. I use protection, I always have a condom in my bag.

I see you have your CD player. Is music important to you?


Music is my life. I take the words in the music. I can sing and dance along with it.

What is needed?

There is a profound need for appropriate and effective supports, information and resources for adults with developmental delay who are living with HIV/AIDS.

Perhaps the greatest and most important challenge to address is homelessness. Local care providers have found that we are more successful in moving forward, if we collaborate across sectors and create a "wraparound" support for the individual.

We are calling on others in the province and across the country to share their stories, especially stories of success where adults with DD are living with HIV and have moved from homelessness to being supported, having a home and being active and contributing members of their community.

MELANIE MONDS IS ONSITE MANAGER, POSITIVE LIVING NORTH AND NANCY CODY IS A PUBLIC HEALTH NURSE. 



Congratulations to Simon Cox | BY JIM WATSON

The presentation of the Hal Rogers Fellow (HRF) Award was made to Simon Cox, on May 27, 2014 at the Annual Kinsmen Conference, held in Summerland, BC. Simon is the Executive Director of BC Association for Individualized Technology and Supports for People with Disabilities—the home of the Provincial Respiratory Outreach Program and the Technology for Independent Living program.

Simon was very surprised by the award and, in usual Simon Cox fashion, was shy about receiving this well-earned recognition of his work. He immediately started to suggest many others deserved it more than he did.

Keynote Speaker, Joanne Brekkas, was one of the first recipients of an assistive device from the Kinsmen Foundation of BC and from the Technology for Independent Living Department, then managed by Simon Cox.

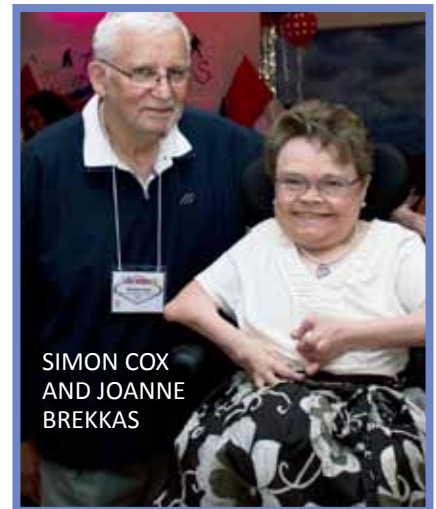
The Hal Rogers Fellow is the highest award given by the Kin Canada Foundation. This prestigious program recognizes individual Kin, Association Members, Kin Alumni and non-Kin who have made a sig-

nificant contribution to the community and to Canada. Each new Fellow receives a commemorative certificate, pin and medallion.

Proceeds from this program, named after Kin Canada's Founder Hal Rogers, assist in the creation of a permanent endowment fund that continues to support the work of Kin Canada and its Foundation.

Some notable recipients of this award include entertainer Celine Dion, past Governor General of Canada Michaëlle Jean, hockey legend Wayne Gretzky, football legend Michael "Pinball" Clemens, Rick Hansen and retired General Rick Hillier. Recipients are not chosen for who they are or what they do for a living. They are nominated and chosen for what they give back to Canada and its citizens.


Simon Cox worked with the Kinsmen Foundation of British Columbia for many years, and continues to support the Foundation and people with disabilities through his work with BCITS. His efforts have made a major impact on the lives of thousands of people in British Columbia.



SIMON COX
AND JOANNE
BREKKAS

Kinsmen honoured Simon several years ago by creating a District Award in his name for support of the Kinsmen Foundation and people with disabilities. The Simon Cox Award is given out each year to the Kin Club that demonstrates strong support of the Foundation and people with disabilities.

Simon was in attendance at this year's conference to present the Simon Cox award. What he didn't know was he was being honoured as a fellow.

We salute Simon on winning this much-deserved award. 

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Thank You to the Shoppers Drug Mart Life Foundation!

The Disability Alliance of BC (DABC) (formerly BC Coalition of People with Disabilities) would like to thank Shoppers Drug Mart Life Foundation for their generous donation of \$2,000 to support DABC's Women with Disabilities Networking for Health and Wellness sessions.

We are very grateful for the support of the Foundation. With their assistance, we will be providing peer support and health education sessions for women with disabilities on sexual health, menopause, food (in)security and physical activity.

On behalf of the DABC Board, staff and volunteers, we thank the Shoppers Drug Mart Foundation. **T**

FOLLOW US



Find and follow DABC at www.disabilityalliancebc.org/followus.htm.

You can also sign up for Our Voice, the DABC e-newsletter that will keep you up-to-date on important and interesting disability news between TRANSITION editions.



We couldn't do it without you.

Thank you to these organizations, government departments and companies who support our work on behalf of people with disabilities.

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Help Us Find Next Year's Employers of the Year

In 2014, Disability Alliance BC (formerly BC Coalition of People with Disabilities) held its inaugural Outstanding Employer of the Year awards. Employers were nominated by employees who have a disability and winners selected by a DABC committee of Board members, staff and volunteers.

The 2014 Employer of the Year winner was Starbucks Coffee Company (1500 W. 2nd Avenue, Vancouver store) and the Honourable Mention went to Progressive Intercultural Community Services.

Please see the article inside—Swing Into Spring With Us in 2015—to learn how you can nominate an Employer of the Year for 2015!

Thank you to the Province of BC for their continuing support.

