

# institution watch

PEOPLE  
FIRST  
of CANADA



PERSONNES  
D'ABORD  
du CANADA



Canadian Association  
for Community Living  
Association canadienne pour  
l'intégration communautaire

Diversity includes. On se ressemble.

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Monitoring the progress toward a vision of full community living for *all* persons with intellectual disabilities.

*This is a newsletter written and produced by the People First of Canada CACL Joint Task Force on the Right to Live in Community. For more information, contact Don Gallant at (416) 661 9611 or Shelley Fletcher at (866) 854-8915.*

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## A MESSAGE FROM THE TASK FORCE

Laurie Larson and Shane Haddad, Co-Chairs



*"Just because everything is different doesn't mean anything has changed."  
- Irene Peter*

From one institution to another – that's the unfortunate path that some people with intellectual disabilities end up following in our country. Even as our large institutions close at a painfully slow pace, more and more people with intellectual disabilities are being placed in other inappropriate settings like nursing homes, hospitals, long-term care facilities, and other services with different names but all providing the same unacceptable outcome.

As a society, we have long ago recognized that institutions are just not good for people. From the stacks and stacks of research, to the history of asylums and institutions, to the present day ten-bed group homes and their problems, we already know that institutions don't allow people their full human rights, let alone anything that resembles 'a life.' Yet we continue to make them, even to fashion other facilities into institutions, and we continue to put people with intellectual disabilities in there.

In the past, we proudly put the names of respected people (often saints and politicians alike) on these institutions, and we briefly held them up as the best outcome for people with intellectual disabilities. In the face of what we know today, we had hoped to bury the names of these places and their purposes. We now use vague or distracting words like rehabilitation centres, residential centres, and the latest misnomer – centres of excellence. But in the end they are all the same thing – institutions. It might be smaller and prettier, but it is still an institution – a barrier to the life that exists outside its walls.

*continued on next page...*

**"An institution is any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise, control over their lives and their day to day decisions. An institution is not defined merely by its size."**

For a society that affirms and reaffirms our beliefs in the basics of human rights – things like the right to life and its necessities, freedom, equality, accessibility, inclusion, justice, and protection – we often do a poor job of showing these beliefs in the reality that exists beyond our paper philosophies. No matter how many documents we sign, agree with, or develop, we are not making it easy for people with intellectual disabilities to live in the community.

We are often willing to let numbers – be it hours of support, the empty beds in a facility, or an IQ assessment – dictate what supports a person can get to live in the community. And it's not just numbers that prevents people from getting out of institutions and facilities. In some places, there are stringent fire and safety regulations that reduce a person's ability to get housing, in other places, you have to announce yourself to your neighbours and see if they 'approve' of having you in their neighbourhood. By and large, we are not willing to look at the person and tailor supports to their lives; we let the numbers, policies, and rules do the work, and the person becomes secondary to the process.

Pat Worth, co-founder of People First of Canada, once said, "An institution is not just a place; it is the way people think."

We have to stop thinking that people with intellectual disabilities belong in institutions of any kind – from the large brick buildings to the nursing homes, the hospitals, and the residential centres. People with intellectual disabilities belong with everybody else – in the community.

This edition of *Institution Watch* looks at the inappropriate use of nursing homes, seniors' homes, hospitals, and other institutional residential settings for people with intellectual disabilities.

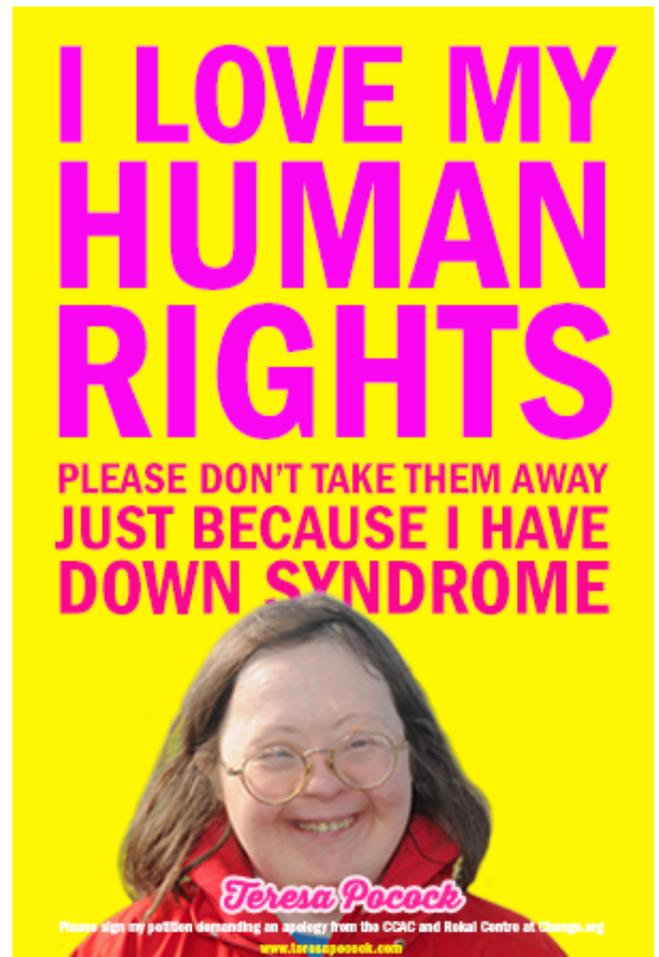
## HUMAN RIGHTS SHOULD NEVER BE DISABLED

By Franke James, Ontario

My sister Teresa's happy and adventurous life today is in stark contrast to two years ago when she was declared "incapable" and forced into an Ontario nursing home at age 49. Against her will. Against my father's wishes. And despite the fact that I had offered in writing to take Teresa into my home.

But before I tell you about that tumultuous time, I want to share with you some of Teresa's achievements since she came to live with me and my husband on December 1, 2013. (We now live in Vancouver.)

For the first time in her life, Teresa has a Canadian Passport. She has accompanied us on some very special trips. She's danced in front of the White House in Washington, DC. She's enjoyed sightseeing in New York City. She's attended environmental conferences in Niagara Falls, Guelph, and Victoria. She's had coffee with David Suzuki and shaken his hand. She's been hugged by MP and Green Party Leader, Elizabeth May. She's sung "Girls Just Want to Have Fun!" onstage at Best Buddies' Karaoke events.



Teresa has tromped through the snow in Whistler and stood amongst the towering trees near China Beach. She's taken scores of photos of the "big boats" in the Strait of Juan de Fuca and the Burrard Inlet, carefully recording the names of the ships. She's currently taking dance classes with All Bodies Dance and making artworks at Gallery Gaget. Teresa's memory is so good she keeps our food shopping list in her head and has an eye for a bargain. She is thrilled when she spots sale prices on food items we regularly buy. She has an orange Compass card and is learning to take the Skytrain. Teresa is really "living it up" and enjoying her life. As she should.

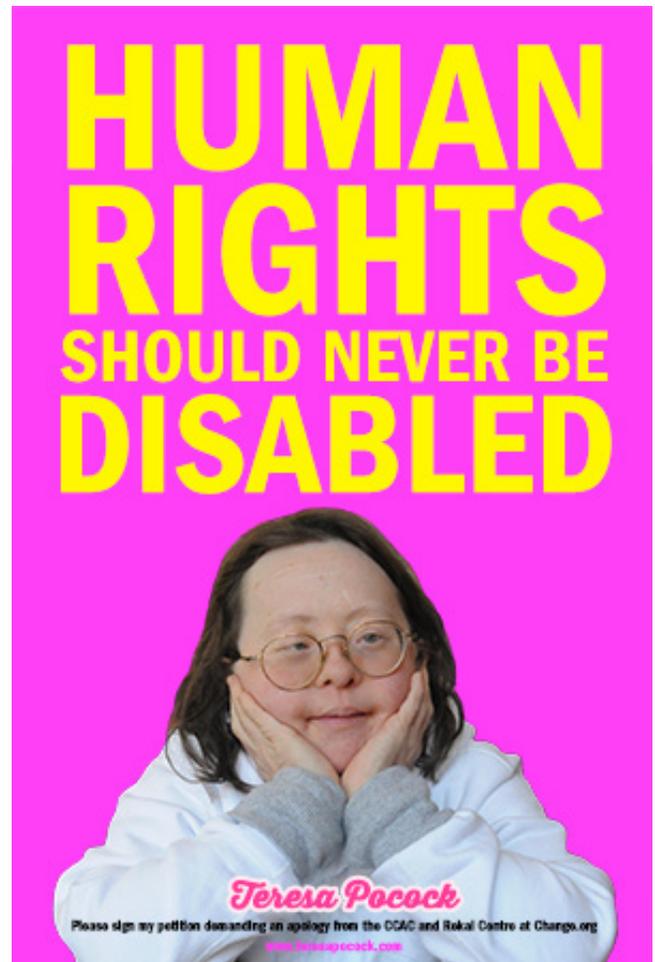
*Contrast her happiness and ability today in February 2016, with her supposed 'incapacity' back in November 2013.*

Declaring someone with Down syndrome incapable is frighteningly easy. With the stroke of a pen, Teresa's human right to decide where she lives was taken away. The capacity assessment stripped Teresa of her right to choose where she lives. But the test should never have taken place. I can say that with certainty because we recently filed Freedom of Information requests. We discovered that the capacity test was unlawfully conducted. Documents from the Ontario Ministry of Health show that the Community Care Access Centre (CCAC) ignored Teresa's directions in her 1995 Power of Attorney (POA) document. The POA clearly stated that only Teresa's own doctor could conduct a capacity test (or a doctor chosen by her POA, who was my father at that time).

There was a split in the family about the care for my 91-year-old father and Teresa, who lived with him at the time. He expected that one of us would take Teresa, but the ones in charge had other plans. My father (a retired lawyer) told the CCAC that he would sue if they tried to put Teresa in long term care. By then the CCAC had already done the capacity test without my father's knowledge (and in direct violation of Teresa's directions in her 1995 POA) and the road was paved for Teresa to be put into long term care. Everything snowballed from that unlawful capacity test. The mistakes were then compounded again and again.

During the capacity assessment, the CCAC did not attempt to verify with an objective third party whether Teresa was telling the truth about her abilities. They just didn't believe her and assumed incapacity even before the test started. Teresa's health records show that her own statements of independence ("I can shower myself. I can dress myself") were not believed and were instead used against her bizarrely as evidence of "cognitive decline".

After Teresa was found "incapable", she was forced against her will into a nursing home. I will never forget seeing Teresa in the Toronto nursing home in November 2013. She was sitting on a single bed, with a thin sheet hanging between her and a roommate who could not walk, talk or feed herself. I was shocked at the cruelty of it all. Teresa was surrounded by people whose next stop was the grave. She was being robbed of her future and she had no way to fight back. It broke my heart.



A few days later, she was rescued by my 91-year-old father who was “adamant” he did not want his daughter living in a nursing home. But then, on December 4th, the nursing home called the police, in a shockingly callous and brutal effort to force her back. Fortunately the police interviewed Teresa and respected her wishes to live with me and my husband.

How did this injustice happen and why has no one apologized to Teresa?

Teresa’s health records show that the crisis list was manipulated to get her to the very top, and placed in the nursing home. Her profile contained false information which made her appear to need 24/7 care. In January 2014, I made a presentation with Teresa, to the MPP’s on the Ontario Government’s Select Committee : *Teresa’s story: Crisis, Capacity and Courage* . Christine Elliott, Vice Chair (and soon to be Patient Ombudsman in Ontario) described Teresa’s story as “truly shocking.” And it truly is.

But even more shocking is that Teresa is not alone in being placed in long term care. She is the tip of the iceberg. Two years ago, CBC Radio (September 2014, The Current) reported that 5,338 developmentally disabled people under 65 were put in Ontario long term care homes between 2008 - 2012. The Ontario Select Committee stated in their July 2014 report that, “Long term care homes are pressured to accommodate young and middle-aged people with developmental disabilities without any medical need for this type of care or any training to support this group of clients.”

Ryan Walker, a developmental service worker, testified to the Ontario Select Committee. On January 20, 2014, Walker said, “We have people with developmental disabilities being placed in psychiatric and long term care facilities. They are being placed there either just to get a placement or just to receive care. If I were to put this to a metaphor, it would be like going to your auto mechanic to file your taxes. It’s just not right. You’re not going to get any good work done with that, and it’s not going to help the situation at all either.”

You can help Teresa by signing her petition. It calls on the Ontario government to apologize to Teresa for violating her human rights and forcing her into a long term care home. 25,000 people have signed already but we need to double that number to show the government that this type of abuse of the developmentally disabled will not be swept under the rug.

We will not be silent. It is up to us, the ones who are strong enough to speak up to defend our loved ones who are defenseless. **Because Human Rights Should Never Be Disabled.**



Sign the petition at: <http://www.change.org/teresapocock>

# WAREHOUSED AT THE NOVA SCOTIA HOSPITAL FOR 10+ YEARS

By Robert DeVet, Nova Scotia  
<http://nsadvocate.org/>

KJIPUKTUK (Halifax) – Tracey Meisner, the mother of a 31-year-old man who has so far spent 12 miserable years in a locked-down unit at the Nova Scotia Hospital in Dartmouth, wants him out of that place.

Matthew lives with autism and severe mood disorders that make his behaviour unpredictable and at times aggressive. The aggression often turns inward, as he tends to self-harm.

No human being should have to suffer Matthew's fate at Emerald Hall, the Nova Scotia Hospital unit where he has spent almost half his life. He doesn't get outside much. No stimulation is offered. There are no incentives to explore. Matthew mostly just sits in his room, day after day after day.

"Matthew has limited ability to cope and so he's going to be what they call amped up a bit and then they throw a bunch of medication at him," says Meisner. "Then the next day I read a staff note saying he was slow and unfocused and hard to get going. Well, he's just taken the benzodiazepine medications, no wonder he is slow and unfocused."

"He hardly ever gets to go outside," says Meisner. "But if you're feeling kind of restless then it would be so nice to get out for a walk, it's nice to get fresh air."

## Proper support is lacking

"It's very frustrating. The hospital fails to promote appropriate levels of enrichment and this encourages behaviour that puts those patients at risk. (Residents) are essentially warehoused in those places. It makes me so angry."

Support by a behavioural specialist would make a big difference, Meisner says, but getting hospital staff and management to commit to that has been a struggle every step of the way.

Two years ago some out-of-province experts worked with Matthew and Emerald Hall staff and the changes were remarkable.

"He was doing so much better. He would come home, and we went swimming, and he loves to swim and we would have a lovely time. He didn't need medications," Meisner says. Then the therapist's contract was not renewed, Meisner's protests were ignored, and staff reverted to old routines.

"Instead of calming him down naturally, and be more therapeutic and helpful, they would just lock him up in his room again, and as a result the problem behaviour would escalate. And then staff would say it was too dangerous for him to go out," Meisner says.

## Concerns about abuse

Tracey Meisner also worries that Matthew may be mistreated.

Sometimes he will repeat phrases he has heard at an earlier time, which is not uncommon for people who live with autism. "He started saying things like oh I don't care you can stay in your pissy clothes all day long, and we're going to keep you locked up, you little c\*\*\*sucker, things like that," Meisner says.

Meisner doesn't feel that the Department of Health and Wellness, responsible for Matthew's well-being, is listening when she raises the alarm about her suspicions.

"We did file complaints but the department didn't even come to the unit to interview anybody about any of those things. Essentially they spoke to one of the managers at Emerald Hall and that's how they concluded that there was really nothing they can do," Meisner tells the *Nova Scotia Advocate*.

Two earlier allegations that her son was being abused by Emerald Hall staff were found to be justified, Meisner says.

Shortly after Matthews's arrival at Emerald Hall it was discovered that he had been hit by front line staff while being held.

If it wasn't for two courageous new workers reporting the physical abuse by their colleagues, nobody would have known. The case went to court and two workers lost their jobs, Meisner says.

There was also an instance in 2014 when a front line worker was found to have used excessive force. That worker, although no longer in charge of Matthew, still works at Emerald Hall.

"I see him there all the time, it's like a slap in the face. We'll come in and visit and we'll see him with another patient just a door up the hallway," Meisner says.

Abuse in institutions is notoriously difficult to prove. Residents are extremely vulnerable, and often lack even elementary communication skills. Yet abuse happens frequently. Last year the *Nova Scotia Advocate* found evidence that in a three-year period, on average one in twenty residents fell victim to abuse in institutions administered by the Department of Community Services.



## Province doesn't help, says mother

Neither the Department of Health and Wellness nor the Nova Scotia Hospital administration has offered much support, says Matthew's mother. Efforts to get proper care and therapeutic support for Matthew in a unit other than Emerald Hall are an uphill battle.

"It's absolutely awful. I'm angry a lot of the time. I'm angry because I am constantly trying to get some kind of reassurance from managers who aren't truthful. We spent all of last year having meetings with the directors of these programs, and they were very unproductive," Meisner says.

Late last year the Nova Scotia Hospital management finally promised to move Matthew to another unit that provides a more stimulating environment. But a space for Mathew has to be created there, and that will take time, Meisner is told.

"We'll see," is all Meisner will say.

## Nova Scotia Health Authority responds

In an emailed response to our questions, Everton McLean, spokesperson for the Nova Scotia Health Authority (NSHA), states that Emerald Hall offers a full suite of therapeutic support for its residents.

"Unfortunately, at times, clients admitted to Emerald Hall for stabilization have then subsequently not been able to be discharged back to community due to lack of appropriate placement options for them. Ideally, community placement options would exist to provide longer-term residential care to some of the more complex patients so that they would not have to stay for many years in an acute care hospital," McLean writes.

Based on admission dates of current patients, the average stay of patients at Emerald Hall is well over eight years, McLean tells the *Nova Scotia Advocate*.

"It is important to point out that prolonged stays in institutions can be harmful to a person's psychological, emotional and physical health and, hence, community placement is crucial," McLean adds. "The harmful effects of institutionalization can be significant and negative — and may further erode people's ability to eventually live in the community."

For privacy reasons the department is unable to speak about individual cases.

But abuse is consistently investigated as stipulated in the *Protection for Persons in Care Act*, and NSHA's *Abuse Prevention and Response* policy, says McLean.

## Community living remains ultimate goal, says mother

Getting Matthew moved out of Emerald Hall is only step one for Tracey Meisner.

"Matthew arrived at Emerald Hall when he was 19, and now he is 31," says Meisner. "His biggest problem right now is that he is where he is, it's been such a horror.

"We're just fighting for him to have a better life. He could do well in the community, with the proper supports. So let's start working towards getting him those supports. We'll cross the community thing when we come to it."

*Photo contributed by Tracey Meisner*

**In a previous issue we asked: “Why do you think people are still being placed in institutions, nursing homes and other long term care facilities rather than having more appropriate supports found for them in their community”?**

**Here’s some of what we heard...**

- **Perhaps a lack of affordable care options being offered by agencies. Government has concerns about people being housed in independent settings because of the potential liability. There may be many more reasons that I am not currently aware of.**
- **Community supports need to be built and can be costly depending on the needs of the individual. With so many competing interests for government and other funding, this is an easy solution even though it isn’t the right one.**
- **Many times there is not enough support. There is no home and family to help them so they go into institutions after their parents get old or die. They end up living in institutions because they do not have money to buy their own home and there is not enough Government housing and funding to get them to live in the community. We need better support for people to live in the community.**

## **DEAR FRIENDS, FAMILIES, AND ALLIES...**

**By John Cox, Nova Scotia**

I once asked my friend, Michael Bach, that question, “Why do you think people are still being placed in institutions, nursing homes and other long term care facilities rather than having more appropriate supports found for them in their community?” And his response was that we were seen as less than human. It’s something that’s stuck with me for a while. It’s why governments can justify institutions, it’s why people live in poverty, it’s why policies are created to make it increasingly hard to survive. I remember a time when my check would run out 5-6 days at the end of the month. Now it’s gone within the first few days. And there’s still an effort to decrease the rates of social assistance in Nova Scotia.

It’s time to change our approach in what we do when it comes to government.

On Dec. 3, 2015, the Community Homes Action Group released a report card on services in Nova Scotia ([nsacl.wordpress.ca](http://nsacl.wordpress.ca)). If you look at the report card, some of the comments are around waiting for 20 years to get services - my son died while waiting for services, or committed suicide. This is unacceptable. “The longer we play nice, the longer we try not to offend, the worse it becomes”. The Nova Scotia government is looking to



redesign the system and there has been nothing I've seen that suggests that my life will be better because of these changes to come.

There has been a movement to cut funding to organizations such as People First and ACLs across this country. Stephen Harper said government shouldn't fund organizations that advocate against them. The Minister of Community Services in Nova Scotia, Joanne Bernard, suggested the same as she cut NSACL and NS People First funding by 30% (*Editors note: As of April 1, 2016, NS People First and NSACL have had their full funding reinstated.*)

But the reality is, in my opinion, is that the #1 abusers of people with disabilities in this country is our government, both Federal and Provincial. If they start creating services that are responsive and effective to create programs and services that are needed, then maybe we can stop criticizing our politicians and bureaucrats and use People First and ACLs differently.

In the last year, three different people at three different times said the Nova Scotia government is either waiting for me to collect CPP at 65 or die. I'm 54-years-old and know I won't make it to 65. Even though I am OK with this, it still bothers me that there are people who will be happy to see me go because it will save them \$574 a month. It bothers me that people are led to suicide because it's a more preferred option.

In the paper a couple of weeks ago, there was an article about refugees coming to Nova Scotia. And that Halifax was going to provide bus passes and memberships to recreation facilities for a year. I'm not saying this isn't great, but no one has offered this for people with disabilities. I had to get a doctor's note to get a bus pass. Passes cost \$78 a month. I get \$40. I was talking to a woman last week who only gets \$20. Another man was asked why he needed a bus pass. Workers are making decisions on transportation that are independent from policy, and it seems like funding is decided on an individual basis.

Why is this city deciding to provide transportation to foreigners but making it increasing hard for Canadians with disabilities to be able to get around? It's because I am seen as less than human. Personally, sometimes I cannot walk two blocks without difficulty. I was in the hospital twice last month because my body shut down. A bus pass is very important for me to just get around.

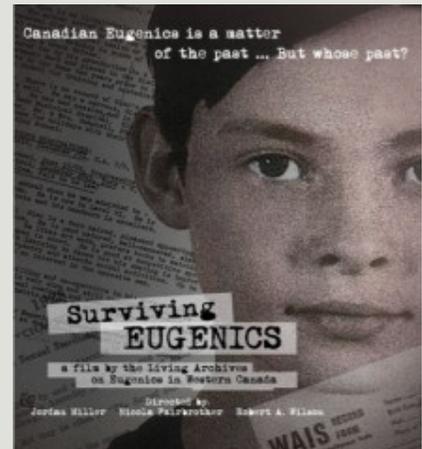
I think of every time I see my friend David Weremy. His message is the same whenever he talks about institutions. 'Burn them down.' We can no longer afford to be nice. We need to be radical and more aggressive in our message. Don't get me wrong, I don't mean storming Parliament Hill with pitchforks and screaming in anger. But we can no longer afford to be nice. We need to stop worrying about offending the powers that be and stop pussy footing around and say it's not OK to lock me away from my community. It's not OK to force me to live in poverty. And it's not OK to treat me as less than human.

The last Federal election has for the first time in years given me hope. I believe that Justin Trudeau will at least start listening to us. Now is the time for the Joint Task Force to ask Mr. Trudeau to sign the optional protocol of the *UN Convention on the Rights of People with Disabilities*. Say we need a national deinstitutionalization strategy. Start working with provinces to close institutions and create policies and resources to better support people to not live in poverty. My experience has been that provinces cannot or will not do this on their own. And I believe that in order to create a better society, we need to all work together to build a better Canada.

## SURVIVING EUGENICS Documentary

*Surviving Eugenics* is a documentary about the history and ongoing significance of eugenics. Anchored by survivor narratives from the province of Alberta, *Surviving Eugenics* provides a unique insiders' view of life in institutions for the "feeble-minded", and raises broader questions about disability, human variation, and contemporary social policies.

For more information about this powerful documentary see: <http://eugenicsarchives.ca/film/>



## LOSING ONE'S IDENTITY

By Ann Wheatley, PEI

Three recent, powerful stories have highlighted the precarious situation in which many Prince Edward Island men and women with intellectual disabilities live and how an admission to the hospital for a relatively straightforward health issue can, with frightening ease, lead to the loss of one's legal identity.

**Jake** was taken to the hospital with flu symptoms, which cleared up within 24 hours. Then, after being given a test that he did not consent to, it was decided that he required more care than could be provided in the community care facility where he had been living. Without any attempt to find appropriate housing in the community he was transferred to the psychiatric hospital, where he stayed for 3½ years. During that time, Jake's advocate, Pat, with the support of PEI Citizen Advocacy, invited some of Jake's friends to form a support circle. Members of the circle helped Jake to make a plan, which included living in an apartment with a friend. Jake was deeply unhappy and wanted to leave



the hospital, but his doctor decided that he could not go back to the community and convinced Health PEI to apply to the courts to have the Public Guardian appointed as Jake's decision-maker. The Public Guardian, upon meeting Jake, disagreed that a guardian was needed and considered Jake's plan to be a good one. The hospital still did not want Jake to leave. But when a new psychiatrist entered the scene, Jake's plan to live in the community was approved.

**Lloyd** says when he landed in the hospital it was because of mental health issues. He needed, and received treatment. But a year later, it felt like incarceration more than anything else. He, too, had been sent to the psychiatric hospital. There were long periods when he was on his own, because his doctor decided not to allow his supporters and friends to visit him. He was told he needed to be in community care, although he had been living on his own for years, most recently with his wife, Debbie. The hospital tried to get guardianship. Lloyd was finally able to connect with Citizen Advocacy, which organized a planning session with friends from the community and his church, People First members and community mental health workers. At this session a two year plan was created for Lloyd. The Public Guardian agreed that the plan was a good one, and the application for guardianship was dropped. Lloyd eventually decided to move into a community care facility until he got back on his feet.



**Debbie** is married to Lloyd. She ended up in the hospital at the same time as he did, as a result of medical problems. Although her medical issues cleared up within months, she ended up being stuck in the hospital for over a year and a half. She steadfastly refused to go to a nursing home, which is what the hospital social worker wanted. So, Health PEI went to court again, this time to have the Public Guardian appointed for Debbie. Once again, Citizen Advocacy and People First rallied, this time drawing in the local residential agency, and friends from Debbie's church and community. A place was found for Debbie, where she could receive all the help she needed, and a plan was made. Still the hospital didn't agree. Debbie was forced to go to court. The judge looked at the plan and agreed that Debbie should be allowed to try it out. Debbie's new home suits her well. Although she and Lloyd live apart, they have a long-term plan to live together again.

It has been over five years since Canada ratified the *UN Convention on the Rights of People with Disabilities*, which obliges Canada (and Prince Edward Island) to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, to promote respect for their inherent dignity", and to "advance their full and effective participation and inclusion in society", providing access to supports "they may require in exercising their legal capacity", ensuring that they "enjoy the right to liberty and security of the person" on an equal basis with others.

But what Debbie, Lloyd and Jake experienced was a complete denial of their human rights as guaranteed by the Convention. In each case, they were assumed by healthcare professionals to have no capacity to make or understand the consequences of their decisions. In each case the same personnel put barriers in the way of



the people Debbie, Jake and Lloyd had indicated they wanted to support them and in fact even failed to ask if they wanted support. Instead of finding ways to ensure each individual was supported to express their preferences, the system took the direct route of applying to the courts for the appointment of the Public Guardian who they hoped would make decisions that supported their (the system's) view of what was best for Debbie, Lloyd and Jake.

It is important to note that in each case, it was the community that came together to develop support networks and create plans. As difficult as it was for Debbie, Lloyd and Jake, they did have the benefit of community connections and of knowing where to turn.

There are far too many people who are much more isolated, without the kind of support they need to ensure that their voices are heard and their rights are respected.

These stories show us that the balance has not swung far enough to community living, despite our best efforts. Institutionalization is not simply a bleak chapter in our social history books. It exists still, robbing individuals of their dignity and their right to personhood.

The experiences of Debbie, Jake and Lloyd clearly demonstrate the need for effective Supported Decision-Making legislation and education, and the absolute necessity of strong advocacy and support networks.

*Editor's note – While PEI still does not have supported decision making legislation, Citizen Advocacy PEI has facilitated these three supported decision making circles. They were developed as part of the planning process to show that there is an alternative to guardianship. Also Debbie has now been in her supported living arrangement for three months and is 'doing great'.*

## **THIS IS NO PLACE FOR YOUNG PEOPLE**

**NICOLE BÉRUBÉ SHARES HER STORY**

**By the New Brunswick Association for Community Living**

Imagine you are 47 years old and living in your own apartment. You have a disability and use a wheelchair, but you are living independently with some supports. You come and go as you please, make your own decisions, visit friends, go shopping, manage your own finances, and enjoy activities like knitting and crafts. Your apartment is full of objects that bring you joy and pleasure. Then you become ill. You have pneumonia. While you are in hospital, your support workers - who are paid for their time - must move on to other jobs. You eventually lose your home and all of your belongings and are told you have no other choice but to live in a nursing home for seniors. This is what happened to Nicole Bérubé of Bathurst, New Brunswick.

Now 49 years old, Nicole has been living at a Bathurst nursing home for the past year and a half. I visited her in the facility to talk to her about her experience. Accompanying me is Dianne Cormier Northrup, President of the New Brunswick Association for Community Living (NBACL), a non-profit organization that works on behalf of children and adults with an intellectual disability. NBACL Social Inclusion Facilitator, July Synott is also with me. We enter the facility. It is clean and modern. The colours are muted – the walls and floors a dull terracotta. The cafeteria and common rooms are expansive and there are very few smaller seating areas for more intimate gatherings. It does not feel like a home. It feels, looks and smells like a hospital. Nicole’s room is located in what is called the “Angel” wing.



It’s bingo day at the facility. While we wait for the game to finish, we talk to a nurse through a glass window to ask if there is a room where we can speak privately with Nicole. The nurse is friendly and tries to accommodate us, but no room is available. We resort to a corner of an empty cafeteria where we pull up some chairs to speak. Nicole greets us. She is clutching her purse with one hand, a can of soda with the other. She is wearing brightly coloured bracelets and a sad expression on her face. She wants to share her story with us.

*Please Note: The following interview reflects Nicole’s personal views on her experience living as a young person in a senior’s home.*

### **How did you come to live here?**

**Nicole:** I got sick. I had double pneumonia. I was in the hospital for four months. When I got better after about three or four weeks, I was discharged from the hospital. But when I tried to get new workers from the Red Cross and the other care company they told me they didn’t have anyone right now. I would have to wait. Two months into my hospital stay, my sister closed down my apartment and got rid of all of my things. I don’t know what happened to them and I didn’t even get any money for anything that came out of my apartment. I had no place to live so they made me live here. But, I don’t want to live here. This is not a place for young people.

### **What was your life like before you came to the facility?**

**Nicole:** I was living in my own home. I had support workers who came in the day and I had a lifeline at night. Sometimes my brother would stay with me. I could come and go when I wanted. I could go and do my own stuff. I could get my own groceries and take care of my own money. I had friends all around my neighborhood that I could go visit. I would go to the mall. I would go through the Tim Hortons drive through with my chair. I was very active. I would just get up in the morning and go.

### **What is your life like here?**

**Nicole:** It feels like I'm in a prison - worse than a prison. When I lived in my own apartment, I was independent. I could do what I wanted. I could eat what and when I wanted, visit my friends, manage my own money. But, when I was placed here, they pulled the plug on my life. That's how I feel. I feel like giving up.

In my own place, I could transfer myself from my chair to the bathroom. After I got out of the hospital, I couldn't transfer myself anymore. Now I have a catheter and an adult diaper - not by choice! They make me wear it, because I need a lift for transfers and the staff don't have time.

I usually eat breakfast in bed because the staff are too busy to get me up. I have to lie there and wait for someone to transfer me into my wheelchair.

I can leave here when I want, but it's not close to anything except for the hospital and buildings like that. It's in the middle of nowhere. It's far to go to the mall and it's really hard to get the wheelchair bus to bring me to town.

About a week ago, they came into my room and took everything out - my makeup, my shampoo, my puzzle books, everything, even my family album. I used to knit, but they took that away too. There are rules when you are in a nursing home. My room was decorated. I had pictures on my walls, but we're only allowed four pictures on our walls. The inspectors told the staff there was too much on the walls. And we're only allowed three things on the window sill and only one night table. The patients were given a warning to take everything down, but I had no one to help me to do that and to store my things. They came into my room. I asked what they were doing. They said, "We're cleaning out your room." I felt like it was like a drug bust. I was upset and crying and they made me leave my room and took everything out. I was violated. That's how I feel.

*Nicole suddenly stops talking. A staff member from the facility walks up to the nearby ice machine. Nicole waits for her to leave before continuing her story.*

I know I can live on my own. It's not that long ago. I was punished because I got pneumonia. That's how I feel. And my CPAP machine that was on a table on the right side of my bed was moved to the night table on the left so I haven't used my CPAP for about a week now. I told them I needed it on my right because that's the side I'm used to using it, but no one listens to me.

Capacité NB is working with me to try to get me out of here. I want to stay in Bathurst, because it's my home.

*It is time to leave. NBACL's Social Inclusion Facilitator, July, promises to help Nicole. She begins with a small step. July leaves the room to speak with the director of the facility and arrangements are made to have her CPAP machine placed on the right side of her bed. Arrangements are also made for Nicole to sort through the personal items that have been put into storage and pick out items she wants to keep with her. July shares this news with Nicole, who weeps with relief. Her eyes express hope. She points to July and says, "You're hired!" We all laugh. "This is the first time I have laughed in weeks," says Nicole. "It feels good."*

## An Historical Perspective

The William F. Roberts Hospital School, a large institution for people with an intellectual and other disabilities has been closed since 1985s. Yet today, approximately 350 people under the age of 65 are living in institutional settings such as nursing homes throughout New Brunswick.

## IN TRIBUTE

*It is with much sadness that we advise of the passing of two individuals who are featured in this edition of Institution Watch.*

It is with great sadness that we announce the passing of *Leilani Marietta Muir (O'Malley)* at her home in Devon, Alberta, on March 14, 2016. She was 72 years old. She is survived by her beloved dog Peggy Sue, and her friends and family. She had no children.

Leilani is featured prominently in the *Surviving Eugenics* documentary (see page 10 of this newsletter). As a child, Leilani lived at the Provincial Training School for Mental Defectives (PTS) in Red Deer after years of abuse from her mother. Despite many traumatic early experiences, she grew to become an extraordinary person who made a significant contribution to human rights in Alberta.

In 1995 she won a lawsuit against the Alberta government for wrongful sterilization while at the PTS. Her case opened the door to class action lawsuits for many other sterilization survivors. She kept her story alive in film, public speaking engagements and her 2014 book *A Whisper Past: Childless After Eugenic Sterilization in Alberta*. As part of the Living Archives on Eugenics in Western Canada project, she worked to collect data on the province's eugenic history. She was designated a "Game Changer" by CBC's *The Current* program and was the focus of the 1996 NFB documentary, *The Sterilization of Leilani Muir*, and the 2012 play, *The Invisible Child*. Leilani knew the power of her personal story, but suffered each time she told it, a price she paid for the betterment of future generations. Leilani was the living embodiment of kindness. She was deeply committed to the safety of children and animals. Despite the terrible treatment she received from her mother, she was able to forgive and see how her mother too had been shaped by adversity. In doing so, Leilani remained true to her own heart.

It is with great sadness that we announce the passing of *Jake Knockwood* (see story on page 10) who passed away on April 11, 2016 from congestive heart failure. He was a member of People First for well over 20 years, and never shy about speaking up for his rights. He had lived on and off at Hillsborough Hospital, but was always passionately defending his right to live in the community. He was well-loved. As part of the process of moving into the apartment where he last lived, a circle of friends was convened to support him. The long, hard fight to get out of the hospital, retain his decision-making rights and live in the community led to the realization of some big dreams - as short-lived as they turned out to be. Among other things, he was left a small amount of money and last Fall was able to use it to pay for a trip to Montréal for himself and a friend to see a Montreal Canadiens game - it was his team, the team he absolutely loved. He will be deeply missed by friends and family, and People First movement.