

# institution watch

PEOPLE  
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PERSONNES  
D'ABORD  
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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 Deinstitutionalization. For more information, contact Don Gallant at 416-661-9611 or Shelley Fletcher at 204-784-7362.*

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## A MESSAGE FROM THE TASK FORCE

Norm McLeod and Gordon Fletcher, Co-Chairs



Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) indicates that States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, Article 19 further states that this should be achieved by ensuring:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

While Canada ratified the CRPD more than 10 years ago (March 11, 2010), there remains significant work to do in this country to make the CRPD real and meaningful in the lives of Canadians with disabilities. Specifically related to Article 19, the Task Force contends that Canadians with disabilities are not yet able to fully and freely exercise their right to choose where and with whom they will live. All too routinely we witness persons with disabilities being placed in institutions when in fact their choice would be to remain in community. The continued existence and use of institutions as a residential option for persons with intellectual disabilities remains an obvious violation to the intent of Article 19 of the Convention.

In this edition we focus on the current situation in Nova Scotia.

“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.”

## Guest Editorial – Jean Coleman

### "Shame Shame Shame"

Shame on the Nova Scotia government for delaying what was promised to Nova Scotians with an intellectual disability who have been left in institutions for years.

Nova Scotia now has the shameful distinction of being one of the last provinces in Canada to close all of their institutions. There are over 500 people with disabilities being held in 8 institutions across Nova Scotia.

No need to go too far back to get an idea of how the government has dragged its feet. In 2013 a "Roadmap" was developed to increase community based living options and decrease reliance on institutions or, in other words, to bring people out of institutions into community. (see Wendy Lill's article) The feeling for families and individuals was that finally a plan was in place that was developed by government and community to bring people home. It was a sign of hope for the first time in a long time.

It is now 7 years later and hope has long faded. Families are increasingly frustrated by the lack of any progress. In 2017 (4 years later) the government committed to create just eight small option homes (less than 4 people) two years later only three have been created. At this rate, how many of the people the government promises to move out of institutions will be dead before living in the community is made available?

There are 1600 people in Nova Scotia with intellectual disabilities seeking alternatives to unacceptable living condition, they are on the "wait list". While some Nova Scotians continue to languish in disability institutions, others, living in their family homes, are pushed to their breaking point- particularly as parents age. Imagine having to leave the only home you have known for a place where your capacities are ignored, and your distress instead of being met with understanding, provoke use of physical or chemical restraints. For some institutional living is the reality of leaving home.

This is totally unacceptable and yet the government continues to say that they are working towards people moving into the community but it seems to be lip service. When are people with an intellectual disability going to have the same choices and rights to live in community as everybody else?

Shame on the Nova Scotia government for painfully prolonging deinstitutionalization.

## **STILL WAITING - Wendy Lill, Community Homes Action Group**

In the mid 1990s, the Nova Scotia government placed a moratorium on the creation of small community-based homes for persons with an intellectual disability, autism and other developmental disorders. At a time when other provinces were moving ahead with deinstitutionalization, Nova Scotia ground to a halt. Since then, the shortage of supported community living capacity has continued to grow. Today there are close to 1100 persons with disabilities living in large congregate care facilities and group homes in Nova Scotia.

In 2013, the disability community was encouraged to see the provincial government accept the recommendations of a joint Community-Government Advisory Committee - Choice Equality and Good Lives in Inclusive Communities – a Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program (Roadmap) as a five year action plan to significantly increase community based supported living options while decreasing reliance on large institutions. When government doubled the implementation time frame to ten years, there was disappointment with the extension. And since then mainly frustration at the glacial pace of change. The allocation of resources needed to create community capacity has been woefully inadequate. Waitlists for various supported community living options now exceed 1600.

The lack of political action on this file has had dire consequences on peoples' lives and has not gone unnoticed. In 2019, the Emerald Hall Human Rights case found the Nova Scotia government had clearly violated the human rights of three Nova Scotians for many years by failing to provide the resources necessary to allow them to live in community, not locked away. Last year as well, the UN Special Rapporteur on the Rights of Persons with Disabilities visited Canada and Nova Scotia and reported we still lag far behind in the implementation of our obligations under the UN Convention on the Rights of Persons with Disabilities.

In the recent 2020 budget, seven years after accepting the Roadmap, the government announced it would begin moving 50 people out of RRCs and ARCS into Independent Living Supports in communities. The question for many is what have they been waiting for? While we welcome the possibility that 50 people will finally be able to move out of institutions and take their rightful place in their communities, experience thus far makes us skeptical.

In 2017, the government announced the opening of eight small option homes in the province and to date, only three of these homes are fully operational, three more on the runway and two still in planning stages. How long will these 50 individuals have to wait? And what about all of the other hundreds living in congregate facilities?

One thing has become tragically clear throughout the first wave of the Covid 19 pandemic: housing vulnerable people in congregated settings with shared bedrooms and washroom facilities is a recipe for disaster.

Let us hope that going forward, deinstitutionalization and the creation of small supported housing options will finally, truly become a key government and public health priority.

## **Fighting for Deinstitutionalization in Nova Scotia: Emerald Hall Human Rights Case – Sheila Wildeman, Dalhousie University**

Those who have not been following the human rights complaint, *MacLean v Nova Scotia*, should start paying attention now. The case will be heard at the Nova Scotia Court of Appeal in November. People First Canada, CACL and the Council of Canadians with Disabilities will intervene.

At stake is whether institutionalization counts as discrimination – and what, if anything, human rights can do to respond.

Beth MacLean, Joey Delaney and Sheila Livingstone, all persons labeled with intellectual disabilities, brought the complaint to the Nova Scotia human rights commission in 2014. The Disability Rights Coalition [DRC] joined in the complaint.

MacLean, Delaney and Livingstone each lived for many years in a locked hospital ward reserved for people labeled with intellectual and mental health disabilities (Emerald Hall). MacLean lived there for over 15 years, the others for about a decade.

MacLean testified to the human rights tribunal last year that Emerald Hall was a noisy, chaotic, highly distressing place. She hated it and wanted to leave. There was no medical reason for her to stay. But she, like Delaney and Livingstone, hadn't the funds to purchase community living supports. And the province's disability support program offered them no alternatives.

This, the complainants argued, was discrimination on the basis of disability and poverty ("source of income"). When people who are not disabled need social assistance, they get a basic allowance to access community-based housing. In contrast, the complainants, like many others with disabilities who are poor, had to choose between institutionalization and situations in which their basic needs would go unmet.

The DRC joined with the complainants to produce thousands of pages of evidence showing that the province's disability supports program has, through a toxic combination of decades-long wait lists and rigid institutional "options", created a second-class system of social assistance -- one that systematically devalues persons with disabilities.

This is what Catherine Frazee, in testimony to the tribunal, referred to as ableism. Ableism involves systemic discrimination: segregating, excluding, and otherwise disrespecting persons with disabilities in ways so deeply baked into social policies and practices that those who are more privileged may not even notice that there is a problem. As Frazee made clear – or, it turns out, she made it clear to everyone but the human rights tribunal -- warehousing people with disabilities in conditions that would not be tolerated were the victims non-disabled is ableism, pure and simple. Doing so while failing to adopt models of community living well established

throughout Canada and the world is a gross failure of social and moral, and arguably legal, responsibility.

In a March 2019 decision, Nova Scotia's human rights tribunal agreed that the province had discriminated against the three individuals. However, the tribunal fundamentally misunderstood the discrimination in issue. For the tribunal, the problem was that the complainants, warehoused for so long at Emerald Hall, were denied meaningful access to the provincial disability support services that other persons with disabilities enjoyed. They did not have acute psychiatric diagnoses; they had been put in the wrong place.

This is "separate but equal" reasoning. It says that people with disabilities should have equal access to the services provided them as a class. What it does not do is examine whether the services in question are systematically inferior to the services (in this case, social assistance) available to others.

This led to a second major flaw. The tribunal rejected the DRC's argument that the province's twenty-year moratorium on small options homes and continued reliance on large institutions constitutes systemic discrimination. It held that those working inside the system meant well, and that it was thus unfair to argue systemic discrimination.

This showed a failure to grasp what systemic discrimination means. As Frazee stated, systemic discrimination is all about business as usual: the ways that institutions and policies systematically favour some over others. Good intentions are irrelevant.

A final flaw related to remedies. Importantly, the tribunal ordered that the two surviving complainants (Livingstone died before the complaint was heard) must be moved to "a community living facility suited to their capacities and needs." Beyond this, they each received \$100,000; a smaller sum flowed to Livingstone's estate. Given that the complainants endured jail-like conditions for a decade or more, they expected higher damages, comparable to those granted to persons wrongly convicted and incarcerated.

Worse still, the tribunal's awards reflected a discriminatory appraisal of the lives and capacities of persons with disabilities. It wrote: "Joey Delaney is so disabled that payment to him of a very large sum will not have a greater impact on his life than a moderate sum." And: "Beth MacLean does have capacity, but the potential benefit to her of a very large damage award is limited." To this, the tribunal added it was "mindful" that "the people of Nova Scotia, through their government and their servants, kept the Complainants safe, clean, warm, fed, clothed and healthy" over their lives.

Beth MacLean, removed from her parents at age 10 because she was difficult to manage at school, and forced to live, from age 15 to 24, in a 100+ bed facility for adults with communal bedrooms and bathrooms until she was moved to the still-worse Emerald Hall, might have something to say about that.

In short, the very compensation awarded to the individual complainants was infected by ableism – and a fundamental lack of imagination about the nature and value of supports for community inclusion.

Finally, in keeping with the tribunal's refusal to recognize systemic discrimination, it limited its award to the individuals before it. It refused to grant systemic remedies requiring government to adopt a more responsive, person-directed system of supported community living. The message is that the approximately 1500 people stuck on Nova Scotia's wait lists for appropriate community living, many languishing in large congregate facilities, will have to bring their own human rights challenges.

At the province's court of appeal this fall, some of Canada's top disability rights lawyers – including Vince Calderhead for the individual complainants and Claire McNeil for the DRC – will argue against the flawed reasoning of the tribunal. This is an opportunity for human rights law to recognize that institutionalization is discrimination, not just against a few who can prove they deserved something better, but against all who are given no support options beyond segregated, congregate facilities.

Are human rights up to the job? We shall see.

## Leta's Story - Leta Jarvis

My name is Leta Jarvis and I was born in Halifax, Nova Scotia. I come from a combined family of eighteen siblings. My Brother Paul and I were the two youngest. I barely remember Paul, as he was a baby when I was sent to my first institution at seven years of age.

The next time I saw Paul was at the NSYTC when I was about 12. He had been living there a while but I was not allowed to talk to him because the boys and girls were not allowed to talk to each other. If they did they were punished. I lived there for six years and barely had a chance to speak with him. I snuck into the hall way in school sometimes and talked quickly to him a few times to see how he was.

I moved to another institution when I was eighteen and did not find my brother again until he was visiting my niece in Halifax in mid 2000 and I went to visit. He was living in an institution in Halifax and was visiting her there for the day. I started contacting him at the institution. He was moved to Kings Rehab about ten years ago and was closer to me then, as I lived in Windsor. He used to come visit me and sometimes stay for the weekend. We became quite close and spent lots of time together on our visits. His visits stopped for about a year when he had some troubles but I kept visiting him at Kings Rehab. He started day visits for a couple of hours every month after that.

Our contact changed when I moved to Truro about 3 ½ years ago. The first year Paul was coming for regular visits every month. I had several moves after that and so we did not have visits for about a year. We always talked on the phone every couple of days. Kings Rehab started his visits

again about two years ago when I found a nice apartment. About a year ago the institution started having staff problems and Paul did not get up for a visit for almost five months. He was up to see me twice last winter just before Covid-19 hit our province.

I have been talking to his workers at Kings for most of the year about making a plan for Paul to move to my community and live in a small options home so I can see him more and spend time with him. I think it would be good for him and me, as we are both getting older and we both have health problems. I met with some case managers in early March to start talking about a plan for my brother. Then Covid -19 hit our province. I hope to hear from the government about a plan for my brother to have him move closer to me so we can spend quality family time together.

Government must do better at making life better for citizens who have been labelled with an intellectual disability and work on moving citizens out of institutions and into their communities where they belong!

## **My Life in Northwood - Shannon Sweet**

I am forty-seven years old and was raised in Windsor.

My move to Northwood was not by choice. Every time I had to have my wheelchair adjusted I needed to come to Halifax. I also could not get funding for an electric wheelchair if I stayed in Windsor. I had to move to Halifax to get the funding so I needed a place where they could meet my care needs. There were roughly 700 people living at Northwood in the Manor and Tower.

I moved to Northwood in 2016. I have had my own room because I need space for my electric chair. If I did not have my chair I would probably have had a roommate or two. There were only 1 or 2 private rooms on each of the nine floors and some rooms had three beds. My floor had many seniors with dementia. There were two younger women that I associated with – one in her forties and other in her early fifties.

A typical day before the virus involved breakfast at 9, pills and then staring at the walls until nurses had time to come and help with personal care – usually around eleven. Then a little more tidying, lunch and activities for the day. If it was a work day I put on my work vest and name tag and worked the Front desk on Mondays and Fridays. My duties included providing directions to visitors (Like a Walmart Greeter!) and responding to finding residents who were lost, fallen or sick. I was given a cell phone to reach the front desk to respond to these needs. My title was a “Northwood Ambassador”. On Tuesdays I worked with a Volunteer Coordinator. On Wednesdays and Thursdays I helped with the Laundry room – picking up and stacking coat hangers and stacking placemats. I worked with the launderer and would take materials from the different floors to the laundry room and coat hangers to Central Laundry. I often carried labels from where the seamstress worked and delivered labels to different floors, usually three times a day. On Saturdays and Sundays I would often leave the building to do my own thing – go to

Walmart, the waterfront or a farmer's market. I went back to my room for supper, unless I wanted to eat at the restaurant in the building. I usually did that 2-3 times a week as it was a nice option. In the evenings there was a bar area open on the main floor 2-3 times a week and I could go for a drink. There was Bingo available in the "Shirley Bernstein Room" on Monday and Saturday evenings. I could also hang around the main floor (I was on 11th floor and would go to 1st). I would talk to security and other residents. Visitors could come to my room and my family visited usually twice a month.

Since the virus - no visitors - and I have not seen parents in three months. Father dropped a package off at the front desk and was told to put it in the mail. I have to stay in my own room - used to be able to move around the floor a bit but people from Health services came in and stopped that. I used to go out and look out the window in the cafeteria and watch the city. I can't now. There are no activities or social events for anyone right now.


I was on the 11th floor but got moved to the 6th for three weeks, then the 10th. All of my personal belongings got packed up quickly - I was not given much notice and no help to pack things I wanted to take with me. All of my craft and scrapbooking materials are packed up somewhere and no one has time to get them out for me. I had associated with some ladies on the eleventh floor but they did not get moved. There is no one to talk to on my current floor. The staff are all new to me. A lot of the staff I was familiar with I have not seen since I was moved. The smokers in the building used to smoke outside but can not anymore. I know that at least one smoking room on one floor has been closed.

There is less privacy, although privacy has always been an issue. Staff would walk in when visitors were there. There is no recreational or social activities to do, nothing in my room and staff do not ask if I want something to do. When I ask about my craft and scrapbooking that was packed up, the staff say they are too busy to look for that stuff now. I am not allowed to have much of own things in my room because of space and staff time. It takes days to get mail or packages because there is a lack of staff and volunteers to do these things. My bath time was changed from Saturday morning to Saturday evening with no consultation or advising me. It is once a week -virus or no virus. Staff help with personal care through the week.

All of these changes and moves made me feel like a pinball in a machine - bounced and flung around. I do not feel safe as there are lots of people, including staff, who are coughing and sneezing. This was the case even before the virus. There are so many risks living in a nursing home or long term care facility - its like an institution! Whether it is contamination, sickness, illness, seniors with alzheimers doing things they are not aware of, or lack of sanitizing. There were often sick residents showing up at Bingo and coughing. There are a lot of smokers here and tobacco makes me sick.

I am still in contact with my family and friends through my iPad and phone. I text or phone my parents several times a week and get calls from my brother out west. I also stay in touch with facebook but the WIFI is not good here. I find I can get a good reception by the doorway for about five minutes. I facetime with my parents.





All day I am in my room looking out the window and watching TV. When I was moved to 6th floor we were allowed to move around a bit – in the dining room and common area. We were restricted to our rooms after visitors from infectious diseases checked our floor. People were still eating in the dining room but that stopped after my second week there. I do not see my social worker often. Sometimes staff or nurses will get needed items from stores and drugstores for me and other residents.

If there is another outbreak there should be more advanced notice to residents on changes. I should be allowed to take my personal belongings with me if I am moved and staff should help pack these items. For residents who understand social distancing - they should be allowed to move around on their own floor with a mask and gloves. Family and friends should be allowed to leave care packages at the door and residents should get them same day. There should be options for one to one and volunteer help – have masks and gloves for this purpose. There needs to be more access to the supplies residents need - hygiene items, snacks, juice packs, food. ONLY ONE PERSON PER ROOM. I ask question after question and never get answers – there should be answers to resident's questions.

As far as what the government did right with this virus – I would say not too much. They did get this facility cleaned thoroughly now – every “Nook and Cranny”. But they should have been doing that from day one.

*Northwood is the largest not-for-profit continuing care organization in Atlantic Canada. Nova Scotia has had 1067 cases of Covid 19 – 345 have occurred in Northwood. There were 99 staff affected, all of whom have recovered. There were 246 residents affected, with 193 recoveries and 53 deaths. Of the 63 deaths in Nova Scotia 53 occurred at Northwood.*