

To: Community Services Standing Committee, Legislative Assembly, Nova Scotia

From: Disability Rights Coalition

Re: Progress Update on Phasing out Adult Residential Centre and Regional Rehabilitation Centre Facilities

Date: September 6, 2022

Thank you for inviting the Disability Rights Coalition to speak to the topic before the Committee today entitled “Progress Update on Phasing out Adult Residential Centre and Regional Rehabilitation Centre Facilities.”

Fast Facts:

The institutions that serve to segregate and isolate persons with disabilities in congregate settings in this Province include not just the eight Adult Residential Centres and Regional Rehabilitation Centres being considered by this Committee, but dozens of Residential Care Facilities, nursing homes and psychiatric hospitals where on any given day hundreds of people with disabilities are forced to live because the government has failed to provide them with meaningful access to a comprehensive system of supports to live in the community.

In 1996, Nova Scotia closed the last institution for children with disabilities, after a decade of government reports recommending the deinstitutionalization of persons with disabilities. The closure of its institutions for adults with disabilities was supposed to follow but never happened.

In 2006, the United Nations passed the Convention on the Rights of Persons with Disabilities, ratified by Canada in 2010. In 2017, in reviewing Canada’s human rights record, the UN noted that Provinces such as Nova Scotia needed to establish timeframes to close institutions and replace them with a comprehensive system of support for independent living for persons with disabilities.

In 2008, Nova Scotia funded the creation of yet another new institution for adults with disabilities in Sackville, Nova Scotia.

In 2013, all parties of the Nova Scotia Legislature endorsed the recommendations of the [Roadmap](#), Choice, Equality and Good Lives in Inclusive Communities and the principle that “all persons can be supported to live in community.” All parties committed to the closure of institutions for persons with disabilities.

Since 2013, not a single institution has been closed in Nova Scotia and hundreds of persons with disabilities continue to face institutionalisation as their only option.

In 2020, the Disability Rights Coalition and others applauded the government’s announcement that it would close the Harbourside Adult Residential Centre in Yarmouth within the next 12-18 months and move 27 people to community based settings. Two years later, Harbourside remains open.

In 2021, the Nova Scotia Court of Appeal ruled that Nova Scotia has been systematically discriminating against persons with disabilities since 1998 by forcing them to reside in institutions where they do not need to be.

We know from decades of experience that the chief rationalizations for institutionalising people with disabilities for their “own good” to protect their health and safety have been proven over and over again to be manifestly false. Successive government reports and reviews of institutions where people are arbitrarily forced to live together in congregate settings demonstrate the abuse, neglect and significant health and safety risks and harms of congregate living. The impact and response to Covid 19 demonstrates both the increased risk and extreme restrictions imposed on residents of congregate care facilities that significantly impair their quality of life. Forcing people to live in institutions where they don’t need to be also has a significant negative impact on people’s mental health.

Despite public commitments to closing institutions, to our knowledge, successive governments have failed to provide to the public or this Legislature any kind of a comprehensive plan to close institutions for persons with disabilities, including timeframes and dates for closure and a comprehensive system of support for independent living to enable people to live in the community.

Conclusion:

Despite the clear human rights emergency in this Province as expressed by the Court of Appeal last year, there is still currently no plan being put before this Committee from the Nova Scotia government to close institutions for persons with disabilities.

There is no plan being put forward to this Committee to move persons with disabilities out of psychiatric hospitals or nursing homes where they don’t need to be.

The topic of today’s discussions is “phasing out” RRCs and ARCs not closure. Whose interests is this incremental approach to deinstitutionalization designed to protect? Certainly not the people whose rights are being violated and who will live and die in these institutions without experiencing equality and inclusion in our community.

Why is the topic restricted to RRCs and ARCs when we know that Nova Scotia funds dozens of other institutions? This creates the false impression that with a little tweaking the problem will be solved. Nova Scotia needs a comprehensive plan to close all institutions.

Despite its commitment on paper since 2013 that all persons can be supported to live in community, Nova Scotia has failed to close a single institution.

Our government can no longer claim ignorance of the discriminatory impacts of its practices and policies of institutionalising persons with disabilities.

People with disabilities in this Province have waited long enough. This Committee must demand a plan to close all the institutions – including not just the RRCs and the ARCs but also the RCFs and other institutional settings complete with timeframes and measurable outcomes.

That plan must include meaningful access to community based settings for those leaving the institutions and be adequately resourced by this Legislature in the next sitting.



Good morning, I am Karen McNeil, a family physician of 33 years. I work with adults with intellectual and developmental disability (IDD) from across the province at a consultant clinic within Dalhousie Family Medicine. I spoke to the Standing Committee last year with Wendy Lil, our CHAG Chair. At that time, we spoke of the need for more than bricks and mortar to address the housing crisis for people with IDD. Today I would like to expand on this need through an **equity, diversity and inclusion lens**.

People with intellectual and developmental disabilities are experiencing a tragic gap in adult services compared to the general population, this is the equity piece. We put funding and focus into early years and school years of children with IDD, (maybe not enough but we do fund this) and when these children become adults, they meet a “service cliff”. Basic Services such as OT, SLP, Psychology, are essentially absent for this population. If an adult with IDD in NS did not learn to communicate, toilet, do laundry or self-regulate in childhood, too bad, so sad, you missed the boat. This sounds flippant, because it is.

As a province, we do not seem to acknowledge that people with developmental disability, have just that, a developmental disability, not a developmental arrest. They continue to learn and develop as we all do. This tragic gap in services results in missed life opportunities, and stressful homes for adults with IDD, and their families and caregivers. We would not tolerate this inequity ourselves.

People with IDD are neurodiverse; do we understand and embrace their neurodiversity? I don't think we do. We spend hundreds of thousands of dollars, doing the same thing over and over, 1:1, 2:1 care, replacing furniture, walls, electronics that are destroyed and caregivers who are sadly injured. It is also sad that we medically restrain people with IDD because we do not have the resources to understand what they are communicating, how to meet their sensory needs or how to help them process their trauma.

We see these spending and prescribing practices largely because the neurodiverse needs of this population are not recognized or met. People with IDD are not supported in their continued development **and** families and caregivers are left to navigate, complex communication, sensory, and trauma needs **that most** SLP's, OT's, BT's and psychologists could not do without specialized training.

We have knowledge and skills in our province, but we need to grow them, with a province wide, life span approach. It is time to do something different. The present government is looking at health care delivery with fresh eyes. Can we also do this in our provision of services for people with IDD? I believe we can. Embracing neurodiversity, will allow us to work alongside people with IDD to create real homes where they can be independent, productive and happy.

The final part of the EDI lens is inclusion. Simon will help you understand how we are missing out here.



My name is Simon Snyder, I am a member of CHAG, People First NS, and My Home My Rights.

I lived in an institution for 7 years: the Nova Scotia Youth Training Centre in Bible Hill. There was physical and mental abuse, some of the residents were sexually abused. Sexual abuse never happened to me, but the other kinds of abuse did. In a lot of institutions, the same thing happens.

What are you here to say government should do?

You need to create more small option homes and other choices for community living. You need to close the large institutions without more stalling. Put your money where your mouth is.

Tell us more about what living in an institution is like.

Apart from physical, mental and sexual abuse, they treat you like you are an inmate in a prison. You can't come and go as you want, you've got to ask permission.

I live independently now. I can just lock the door and go up to Robin's and get a coffee. In an institution you have to get permission to go get a coffee. It is none of their damn business if you want to get a coffee.

Other things are none of their business too. When I went to school you weren't allowed to have relationships: no matter if it was two guys two girls or a guy and a girl. If you had a relationship you'd get the strap.

Tell us more about that if you can, Simon

The strap it was about 2 inches thick, 4 inches wide, and 18 inches long. And it was leather. I remember one night, me and this guy were sharing a room, and he was getting his pyjamas on for bed, and his back from his shoulders right down to his waist was bright red like a fire

truck. He took his pants and underwear off to put his PJ pants on and his butt was fire engine red as well. He lay on his bed and cried softly. He lay on his stomach for a while but every time he turned over from his stomach to his back he started crying again.

That is what it was like and I never want to see that again.

What was it like when you left the institution?

When I came out of the institution I drank every day. But I had the support of family and friends and I turned my life around. Some people don't have family and friends. But people can have good lives if they are given the right supports.

What moved you to speak up about this today Simon?

I have the benefit of being able to express myself. I don't read and write so well but I can tell you what I think. Many people who live in institutions have many needs, but no voice.

People First has a saying: We speak for the people who can't speak for themselves. We also say: Nothing about us, without us.

It brings up bad memories to tell my story. But if it helps just one person then it was worth it.

Do you have a last message for government?

As you build up community supports you have to make sure everyone is involved, and has a voice. Especially the people living in institutions you ignored for so long.

I have two main messages:

1 – Nothing about us, without us.

2 - Move faster and put your money where your mouth is.



I'm Sheila Wildeman, I am a law professor at Dalhousie. With Dr Karen McNeil and Simon Snyder I speak on behalf of the Community Homes Action Group, or CHAG. CHAG members have worked for deinstitutionalization and responsive community supports for decades.

Over the last twenty years, we have contributed to many reports on system transformation. In 2013, Government committed to the principles of Choice, Equality and Good Lives in Community (also known as the Roadmap). This was ten years ago yet today, **hundreds** of people are still living in institutions and over a thousand more are living in other settings with pressing unmet support needs.

Now the province has been told by the Court of Appeal that it is illegally denying disabled people supports for community inclusion. We agree with the DRC that what is needed for government to meet its obligations are **transparent, enforceable goals and standards, anchored in human rights and the voices of persons with disabilities.**

We propose three key ingredients to disability supports transformation.

First, **transparency.** I recently asked Diverse Abilities, the largest institutional service providers, for their restraint and seclusion policies and was refused. Deinstitutionalization means rooting out deep institutional preferences for secrecy and control. We need regular public reporting on system transformation. We need to know how government is meeting its commitment to provide individualized supports based on person-directed plans, including through access to allied social and health care and self-advocacy networks. Those who have lived in institutions most of their lives will need dedicated support to recover from that trauma. We need to know **how these and other support needs are being met so people are not set up to fail.**

Second, a transformed system requires **accountability in light of rights-based standards.** The Disability Support system has long been rooted in a charity model marked by untrammelled discretion. System transformation requires legislated standards centring the Convention on the Rights of Persons with Disabilities and disability rights-holders. It requires independent, accessible complaints and review systems and advocacy supports. It requires, too, that disability-related income amounts **are indexed to inflation as a matter of law** – and that **support staff wages are fair.**

Third, deinstitutionalization requires **rights-centred education and capacity-building** to facilitate the cultural shift from old reflexes of control to responsive supports. **Karen and Simon will speak more on your responsibility to ACT NOW to build a culture of disability supports out of the legacy of institutionalized control.**