

## LAW AMENDMENTS COMMITTEE – MARCH 6, 2020

Thank you for the opportunity to address the committee today and to share our concerns with the Financial Measures Act that has just passed second reading. We're here to talk about how this budget bill impacts Nova Scotians with disabilities and their right to live good lives in inclusive communities. Our observations on the recent budget will pertain to that.

I'm Wendy Lill and I'm chair of Community Homes Action Group. We've been around now for 10 years. CHAG is a group of concerned citizens, health care and social services and legal professionals, parents and advocates formed in 2010 to draw government's attention to the crisis in residential options for persons with disabilities. And to work with them to find solutions.

I'm also the mom of an amazing young man, who has a developmental disability and also lives a full and productive and "supported" happy life in a small group home in Dartmouth. Most aspects of my life have been informed by our journey together. Thanks Sam!

Because of the speed with which this bill is being processed, none of my colleagues were able to attend today – but they've sent some family stories to add to this presentation. At the end, I'll also invite you to another event in the community where you can meet and learn much more about the lives of the people we're talking about here.

First a bit of background; A moratorium on the creation of small community based homes for persons with developmental disabilities in the mid 1990's led to a critical and growing shortage of community options. At that time, there were still many hundreds of people living in large congregate facilities – at a time when provinces across the country were far ahead of Nova Scotia in terms of deinstitutionalization.

Since then, the shortage of supported community living capacity had grown throughout several governments and all political stripes.

From a wait list of many hundreds living in institutions and hundreds more living with aging families in the communities, the waitlists have now grown to nearly 1600.

In 2013, the current government adopted the Roadmap report, Choice Equality and Good Lives in Inclusive Communities. A 10-year time frame for significantly increasing community based supported living options while decreasing reliance on large institutions. So far however, the allocation of resources from government needed to create community capacity has been woefully inadequate.

The lack of political action on this file has had dire consequences on peoples' lives.

The Emerald Hall Human rights case last year found the government had clearly violated the human rights of three Nova Scotians for many years for failing to provide the resources necessary to allow them to live in community, not locked way.

In May, the UN Special Rapporteur on the Rights of Persons with Disabilities visited Canada (and Halifax) - I'm sure some of you had the opportunity to meet her –reported we still lag far behind in the implementation of its obligations under the UN Conventions on the Rights of Persons with Disabilities.

We too believe that a Home is a human right and there are many good people in our communities eager to move forward on this.

In April and October 2019, Autism Nova Scotia held a Supported Housing Summit where hundreds of family members, first voice, advocates, service deliverers, civil servants came together to share their knowledge, experience and commitment to creating the kinds of supported housing choices needed.

In January of this year, our group expressed our concerns about slow pace and waitlists to the Minister of Finance and called again for significant ongoing financial commitment towards meeting their commitments to implement the Roadmap.

Which brings us to the Budget 2020.

The two relevant items in the budget around these issues are the following:

7.4 million to begin transitioning residents out of ARCs (Adult Residential Centres) and RRCs (Regional Rehabilitation Centres) and 2.8 million to increase the Flex In-home program.

It is almost 7 years since government adopted the Roadmap report and a ten year time frame to significantly increasing community based living options and decrease reliance on institutions. Since then, the waitlists have gone steadily upward not down.

The budget announced they are going to begin moving 50 people out of RRCs and ARCS into Independent Living Supports in the community. Obviously we are hopeful that 50 people will finally be able to move out of institutions and take their rightful place in their communities. But our experience thus far makes us skeptical.

In 2017, the government announced they were going to open 8 small option homes in communities in Nova Scotia and to date, only 3 of these homes are fully operational, 3 more on the runway and two still in planning stages. How long will these 50 individuals have to wait?

In this budget there was no mention of addressing the hundreds of people on waitlists for small option homes and families everywhere in this province are devastated.

Despite the findings of the Human Rights Board of Inquiry and the warning about violating the human rights of our population, the system is still gridlocked. The choices are not there for families.

In the 2020 budget, the other addition to the DSP program targeted for our population is an amount of 2.8 million for the Flex In Home program. Again, while welcomed, this does not tackle the central issue of creating increased capacity of supported housing options.

In closing, there are hundreds of young adults now on waitlists living, waiting with aging parents - wanting to start their lives, take their rightful places in supported living options in their communities. - and they are no closer today than they were 7 years ago.

And the mental and physical health costs and the family break ups occurring from the stress of caring for loved ones with complex needs are very real. We need action now on clearing this waitlist and offering real choices for these vulnerable citizens.

We all respond to human stories.....much better than numbers. If I have time, I'd be glad to share some of these stories with you.

Dawn Leblanc, one of CHAG's members, who wanted to be here today, a social worker for over twenty years working with families and individuals with complex needs has shared some real life situations folks are facing.

Here are a few examples.

One mother in HRM has four children. Her oldest son, has Tourette's syndrome. His younger brother, Christopher, has Autism Spectrum Disorder. Christopher just turned 22. He still lives with his mother and father. Since her sons were diagnosed with their conditions, The mother has been unable to return to full-time work. The demands she needs to meet at home are too great.

"My role has just been to advocate for them, full time, non-stop, from morning to night,"  
"I'm getting older, my husband's getting older. We feel exhausted, not just physically but emotionally and mentally."

This past summer, they received a call from the Department of Community Services informing them that a place in a small option home had become available. But they felt it

wasn't the right fit for him and it would mean the end of all activities that Christopher was participating in.

"I know the perfect place isn't out there, but it's got to be right,"

But with a significant waitlist, the Department of Community Services told them it would likely be two years before Christopher's case would be revisited.

Another parent of an adult daughter with intellectual disability and autism spectrum disorder says her daughter has been on the waitlist for many years and will soon be 30 years old. She whispered that she is so frustrated and had contacted her MLA. These hushed tones are familiar when parents speak about their needs. Exposing one's situation and asking for more is threatening because people are fearful that speaking out might impact the services they are now receiving and somehow make the situation even worse.

And then there are the worst case scenarios.

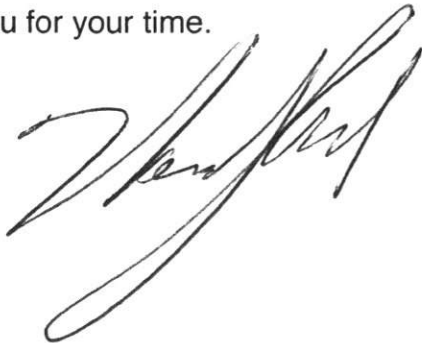
We also know of a young woman with physical disability who was hoping to move into a small option home which would meet the accessibility and care needs she had. She had been waiting for years for her dream home. She died waiting.

Ruth Strubank, another CHAG member and the ED of NSACL says that she is seeing families becoming more and more desperate. The only way for people to get anywhere, unfortunately, seems to be to break down, scream the loudest and then there may be a small-win. But no one is seeing a collective systemic change. The sad thing is that most folks don't have the lobbying skills... too tired, too exhausted and wrung out meeting the needs of their individuals.

But families on waitlists are beginning to speak out. In the weeks and months ahead, families will be visiting their MLAS to talk more about their struggles and dreams. And there will be a community meeting at Club Inclusion on April 7 for families to gather and talk about these issues and how to get real action for their loved ones. You are all welcome and will be getting invitations.

We hope to see you there.

Thank you for your time.

A handwritten signature in black ink, appearing to be 'Ruth Strubank', written in a cursive style.