TO: THE LAW AMENDMENTS COMMITTEE RE: BILL 16, The Adult Capacity and Decision-Making Act

Monday, October 16, 2017

Presentation by: Wendy Lill

It is an honour to be here today to speak to your committee on Bill 16, The Adult Capacity and Decision-Making Act. It is an important bill and I believe the cornerstone of legislation guiding our treatment and care of persons with disabilities as well as those who may be experiencing limitations to their abilities at times in their lives.

I am here as a member of Community Homes Action Group, a group of concerned citizens, health care professionals, parents and advocates who have come together to draw attention to the crisis in residential options for persons with disabilities and to work with government to find solutions. I'm also here as the mother of a young adult with a developmental disability. I've been thinking about the issues of capacity and independence and quality of life for persons with disabilities for a long time. I've been asking the questions - how do we make sure the people we love and also the ones we don't love – or don't even know – are able to live independently and make choices and decisions on their own? How do we accommodate them? The goal is not to take over their decision making but to assist with it. The fact is it's often much easier and more efficient to just take charge of things, just get it done, make decisions for someone, instead of taking the time to really try to discern someone's wishes. It's a constant struggle to figure all this out. Are we controlling lives or enabling people to live to their potential? That is surely what the concept of human rights is all about. That is what Bill 16 must be about.

From 1997 to 2004, while the Member of Parliament for Dartmouth, I was on the Disabilities Sub-committee in the House of Commons. I had the opportunity to interact with many individuals and organizations from across the country working to strengthen federal legislation, programs and services for persons with disabilities. The duty to accommodate persons with disabilities was a central issue we addressed at the federal level. It was a red letter day in 2010, when the United Nations Convention on the Rights of Persons with Disabilities was ratified by Canada - with the full support of the Government of Nova Scotia - to ensure people have access to the supports and accommodations they need to enhance and exercise their decision- making capacity.

In 2013, I was co-chair the Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities Program. We were "the Roadmap Committee." Our committee was mandated by the Minister of Community Services to develop a roadmap for transformation of the Nova Scotia Services to Persons with Disabilities Program - guided by the United Nations Convention on the Rights of Persons with Disabilities.

In our work, we found many people with significant intellectual, cognitive and mental health disabilities were being restricted in abilities to make decisions – *to a much greater degree than necessary*. Service provision in the disability and older adult sectors was/is often based on an assumption that because people need supports and care, others should make decisions on their behalf. As people age and their cognitive functioning declines, family, community member, and service providers often respond by restricting the scope of a person's decision making even further.

The Roadmap committee reported that Nova Scotia needed a much more robust legal framework for supported decision making that would provide individuals and families a means to enhance capacity to make decisions and thereby maximize opportunities for supported living.

We recommended legislative reform immediately - to ensure compliance with the UN CRPD on several pieces of legislation - in particular, reforms to the *Incompetent Persons Act* and the *Adult Protection Act*. And we recommended the establishment of a legal and regulatory framework for making supported decision-making arrangements.

That was 2013. It is now 2017. It has been extremely frustrating to see the sluggish pace of change on all of these important pieces of legislation. Fortunately, in 2016, the Nova Scotia Supreme struck down the *Incompetent Persons Act* calling on the government to address the human rights violations in the law - thereby kick starting the important change needed. Which brings us here today to Bill 16 – The Adult Capacity and Decision-making Act.

There are concerns about Bill 16 that need to be addressed before it becomes law. But I believe there exists the will and the expertise to bring that about.

I have read some of the excellent speeches in the Legislature after second reading of the bill. I've read the submissions and concerns presented by Professor Archie Kaiser, School of Law and Department of Psychiatry, Dalhousie University as well as the brief submitted by Nova Scotia Association of Community Living (NSACL) and Canadian Association of Community Living (CACL).

There are legal and human rights experts in this room today who will provide you with chapter and verse as to what areas it this legislation need work and I hope also, some clear recommendations on how to fix the bill. I will leave the heavy lifting to them.

But I would like to address a couple of things. I've heard the argument that this bill as it stands now is "a start." It's better than the last bill. It doesn't have to be perfect. We should just get the thing out the door and we'll smooth the edges later.

That's absolutely the wrong view. From our work on the Roadmap Committee we know there are several interrelated acts that guide the lives and welfare of persons with disabilities. It's like laying a foundation for a house. Each piece needs to fit together. You can't have a solid house if flaws exist in the foundation.

People and organizations I respect say the building blocks are flawed. If this Act is flawed, then the other acts also attached to it can't help also but be flawed and we will be building a structure which won't stand the test of time nor the strong and inevitable winds of a legal challenge in the future.

I've also heard the comment Bill 16 isn't really central to anything. That it won't really impact the lives of many Nova Scotians. In fact, the opposite is that case. I would say this Act is foundational for all of us in the future. For moms of 32 year old sons with disabilities, or 32 month old sons, to your mothers and fathers or spouses who may find themselves with diminished capacity at some point in their lives. We may all at some point in our lives be subjected to this law – and let's hope it's a good one. We need to get this right.

The Canadian Association of Community Living and its provincial branch – Nova Scotia Association of Community Living have stated Bill 16 neither meets the Court's challenge to clear up its human rights violations nor the requirement in the UN Convention on the Rights of Persons with Disabilities to ensure people have access to the supports and accommodations they need to enhance and exercise their decision-making capacity.

At present, Bill 16 is mute when it comes to the actual mechanisms by which supported decisions will take place - and what role and responsibility the state has to make that happen. Article 12.3 of the UN CRPD states "parties to the Convention have an obligation to ensure people have access to the supports they need to exercise their legal capacity." Bill 16 as it presently stands, recognizes no such obligation - the absence of which leaves such grandiose phrases as "promoting dignity, autonomy and freedom of decision making" empty indeed. So we need to correct this.

Before closing, I'd like to address one more refrain I've heard circulating about Bill 16 and that is "it's too late to do more now. The deadline placed by the Supreme Court can't be changed. The bill *must* be passed now."

To that I would simply say – if the Supreme Court is made aware that the drafters of the Bill need more time to work – in conjunction with legal and human rights representatives within the community to meet the stated goals set by the court, to correct the human rights violations within the act, why on earth would it not be wiling to grant an extension? Why on earth would the court not accommodate this request?

There are areas of concern within the bill that need to be addressed before it becomes law. I urge people of good faith – from government and community – to come together quickly and effectively to make this happen on behalf of our citizens with disabilities.

Thank you for your attention and interest in creating quality legislation for the province of Nova Scotia.

end