

Thursday, May 7, 2020

Dr. Bonnie Henry
Provincial Health Officer
4th Floor, 1515 Blanshard Street
Victoria, BC V8W 9P4

Hon. Adrian Dix
Minister of Health
Room 337 Parliament Buildings
Victoria, BC V8V 1X4

Hon. Judy Darcy
Minister of Mental Health and Addictions
Room 346 Parliament Buildings
Victoria, BC V8V 1X4

Hon. Shane Simpson
Minister of Social Development and Poverty
Reduction
Room 247 Parliament Buildings
Victoria, BC V8V 1X4

OPEN LETTER

Essential Support Person(s) for Patients with Disabilities (plain language version of May 5, 2020 letter)

Dear Ministers, Dr. Henry and Dr. Behn Smith,

We are writing this letter to ensure that we, as people with disabilities, can have a support person(s) with us to help us in health care settings like hospitals, doctors' offices or other places we get medical help. A support person can be a family member, friend, sign language interpreter, or paid worker. Having support people with us in health care settings is our human right, and not allowing us to have them with us, is discrimination.

During the COVID-19 pandemic, support person(s) may not be allowed into the health care setting. This is a problem for people with disabilities, as many of us require the help of a support person(s). Support people can help us feel calmer, help us stay safe, and help us communicate our needs, decisions and experiences.

Sadly, a woman with a disability named Ariis Knight died at Peace Arch Hospital in Surrey, BC. Ariis did not use words to communicate. If you didn't know how she communicated, it was hard to understand what she was saying. Because of the dangers of spreading COVID-19, Ariis was not allowed to have a support person with her to help her communicate with her doctors and nurses, and she died alone.

After Ariis' died, Dr. Bonnie Henry, the Provincial Health Officer for British Columbia, said that hospitals need to accommodate people with disabilities, but this is not always happening. We have heard about other people with disabilities who have not been allowed to have support people with them at health care settings, and this is making it hard for us to get the health care we need during a scary and dangerous time. The Human Rights office at the United Nations has provided information showing that it is harder for people with disabilities to get the medical care that they need during a crisis like the COVID-19 pandemic.

For those of us who are Indigenous, support people can also help us receive health care that respects our culture and traditions.

The following laws protect our rights as people living with disabilities in Canada:

The United Nations Convention on the Rights of Persons with Disabilities (**UNCRPD**), says that governments in Canada must respect that people with disabilities have equal legal rights and should be able to have support people when we need them. (Article 12).

The **Canadian Charter of Rights and Freedoms** protects our right to life, and our choices for things like health care treatment. The Charter also makes clear that we are equal to all Canadians and should not be treated unfairly because of our disability, and that we have the right to stay safe and that our bodies be respected (Section 7).

The **BC Human Rights Code** says that people with disabilities must have the right to accommodation when using public services like health care (Section 8)

The **Health Care (Consent) and Care Facility (Admission) Act** talks about consent for health care for adults in British Columbia (BC). In BC, health care providers are not allowed to provide health care without getting our consent (Section 5, subject to certain emergency exceptions).

Consent means that:

- the healthcare providers explain what kind of care I will receive.
- I agree to care. No one is pushing me to say, “yes.”
- the health care provider gives me the information I need to understand the care I will receive so I can make a decision about:
 - (i) why I need help,
 - (ii) what kind of care I will receive,
 - (iii) the positives and the negatives of the care I will receive, and
 - (iv) the other types of care are available to me, and
- as an adult, I can ask questions and receive answers about the care I might receive.

The *Act* mentioned above says that if I am not able to give or refuse consent, health care providers must ask for consent from my substitute decision-maker (Sections 11, 16). Health care providers must communicate with me in a way that I can best understand. If I have trouble understanding, health care providers must talk with my support person(s) and get consent before making decisions about my care. In BC, People with disabilities can decide who can make health care decisions for them by making an agreement under the *Representation Agreement Act*.

Policy Recommendation

We are asking for a policy that helps to make sure that patients with disabilities have the support they need when they are getting health care. This will mean people with disabilities get the same quality of health care as other Canadians.

We know that health care providers are working very hard right now because of COVID-19, and we believe this kind of policy could also help them understand how they can better help people with disabilities.

We recommend that BC has a policy that makes sure:

- People with disabilities have the right to support person(s) in health care settings when we need accommodations;
- Support person(s) may be a family member, friend, sign language interpreter, a paid worker, or another service provider who knows how we communicate, as well as knows our values, needs, wishes, likes and dislikes, beliefs, behaviour, spiritual or cultural connections, and history of care;
- Patients and their support person(s) should be told if they cannot have their support person with them in certain parts of the health care setting.
- Support person(s) should be provided with Personal Protective Equipment (e.g. gloves and masks) when health care providers think it is necessary for everyone's safety.

Thank you for your attention to this important matter. We welcome the opportunity to discuss this with you further.

Sincerely,

Michael McLellan	Alexander Magnussen	Barb Goode	Teresa Pocock
Paul Gauthier	Chris Hofley	Kirsteen Main	Bryce Shaufelberger
Dave Sheritt	Jo-Anne Gauthier	Kara Anderson	Krista Milne
Lori Sheritt	Manjeet Ghangass	Franke James (Teresa's Sister)	Michael Wittman
David Knight (Ariis's brother)	Jane Holland (Bobby's Mom)	Cathy Anthony (Josh's Mom)	Stefan Wittman (Michael's Brother)
Al Etmanski (Liz's Dad)	Brenda Lenahan (Cole's Mom)	Norah Flaherty (Adam's Mom)	Bob Kashyap (Roshni's Dad)
Angela Clancy (Alan's Sister)	Angie Meyer	Carolyn Main (Kirsteen's Mom)	

And the following organizations:



cc:
Dr. Danièle Behn Smith, Deputy Provincial Health Officer
Kasari Govender, BC Human Rights Commissioner

Note: This is a mirrored, plain language version of the letter that was sent to Minister Dix, Minister Darcy, Minister Simpson, and Dr. Henry and Dr. Behn Smith on May 5, 2020. Full version available at www.plan.ca.

Glossary:

Accommodation: A change made that helps a person with a disability have equal human rights.

Consent: When you give permission for something to happen or agree to do something.

COVID-19 pandemic: A new illness spreading around the world that is spread by coughing, sneezing, touching someone or something with the illness on it and then touching your mouth, nose or eye. To stay safe from getting the virus, we need to stay at home and restrict the number of people that we are physically close to.

Discrimination: When someone is treated unfairly or differently because of physical and mental disability, age, race, gender, orientation, source of income, religious belief, family status and marital status.

Health Care Setting: Places where you receive health care like hospitals, the doctor's office, nursing homes, urgent care centres, outpatient clinics or home healthcare

Health Care Provider: People who provide health care like a doctor, nurse, dentist, psychologist or social worker.