Tuesday, May 5, 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 RE: Essential Support Person(s) for Patients with Disabilities

We are writing regarding the urgent need for a clear and consistent provincial policy to ensure the rights of people with disabilities to the presence of a family member, friend, or paid worker to provide essential support in health care settings. These statutory, constitutional, and human rights are conferred by provincial, federal, and international law, and any infringement results in discrimination.

Many hospitals and other health care settings have placed a variety of restrictions on patient visitors as important virus prevention measures during the COVID-19 pandemic. However, these restrictions have been a significant source of fear for the disability community, as many people with disabilities require the presence of essential support person(s) in order to equitably access health care services.

These fears were realized in the tragic death of Ariis Knight at Peace Arch Hospital. Ariis communicated using non-verbal methods, including eye movements, facial expressions, and breathing. Her unique communications took months, if not years, to learn to understand. However, she was denied the presence of an essential support person who knew and understood her methods of communication. She died alone and unable to effectively communicate with her health care providers.

Following Ariis' death, Dr. Bonnie Henry stated that it was her expectation that hospitals make exceptions to restrictions to accommodate people with disabilities. However, this is not consistently happening: since Ariis' death we continue to hear of situations in which people with disabilities have been denied their essential support person(s) or had to advocate at various levels for it. This patchwork approach is creating unnecessary barriers for people with disabilities in accessing health care during an already frightening and potentially life-threatening time.

In an April 29, 2020 statement, the Office of the United Nations High Commissioner for Human Rights observed that "persons with disabilities face even greater inequalities in accessing health care during the pandemic due to inaccessible health information and environments, as well as selective medical guidelines and protocols that may magnify the discrimination persons with disabilities face in health care provision. These protocols at times reveal medical bias against persons with disabilities concerning their quality of life and social value."

While we understand the need for restrictive visitation policies during the pandemic, there is a significant difference between a visitor and an essential support person. People with a variety of psychosocial or physical disabilities, intellectual disabilities, communication barriers, and atypical behaviour will often require the presence of someone else to provide the accommodations necessary to act as a partner in care. They can reduce anxiety, support patient safety, and enable communication and health care decision-making. For Indigenous patients, essential support person(s) may also facilitate access to traditional and culturally specific care. Where support is required because of a disability, the *Canadian Charter of Rights and Freedoms*, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and BC's legislation guarantee patients the right to that accommodation.

Legal Framework

The UNCRPD, to which Canada is a signatory, requires states to recognize that persons with disabilities have legal capacity on an equal basis with others in all aspects of life and to provide access by persons with disabilities to the support they may require in exercising their legal capacity (Article 12).

The *Canadian Charter of Rights and Freedoms* protects the rights to life, liberty to make fundamental life choices like health care treatment, and security of the person to ensure our bodily integrity is respected (s. 7). It guarantees the right to equal benefit of the law without discrimination based on physical or mental disability (s. 15). The BC *Human Rights Code* similarly guarantees that people with disabilities have the right to accommodation when accessing public services like health care (s. 8)

The *Health Care (Consent) and Care Facility (Admission) Act* establishes broad health care consent rights for adults in British Columbia. It sets out that health care providers are not permitted to provide health care without obtaining consent (s. 5, subject to certain emergency exceptions). Consent is only valid if health care providers communicate with patients to ensure the following elements are met:

- it is specific to the proposed health care,
- it is given voluntarily, without fraud or misrepresentation,
- the health care provider gives the adult the information required to understand the proposed health care and to make a decision, including information about:
    - (i) the condition for which the health care is proposed,
    - (ii) the nature of the proposed health care,
    - (iii) the risks and benefits of the proposed health care, and
    - (iv) alternative courses of health care, and
- the adult has an opportunity to ask questions and receive answers about the proposed health care (s. 6).

The *Act* sets out that if a patient is assessed as incapable of giving or refusing consent to proposed health care because of an illness, injury, or disability, health care providers must seek consent from a supported or substitute decision maker like a representative (ss. 11, 16). The way an adult communicates is not grounds for deciding that he or she is incapable of understanding health care decisions, an important acknowledgement that people communicate in many different ways (s. 3). Health care providers have a duty to communicate with adults in a manner appropriate to the adult's skills and abilities, and expressly acknowledges the role that close relatives and friends can play in assisting adults in understanding or to demonstrate an understanding with respect to health care consent decisions (s. 8).

People with disabilities may require support and services, such as the presence of essential support person(s) who are familiar with their methods of communication, in order to enable the communication and decision-making necessary to provide consent to health care. People with disabilities may appoint representatives to help them with health care consent decisions by making a representation agreement under the *Representation Agreement Act*.

In *Eldridge v. British Columbia (Attorney General)*, [1997] 3 SCR 624, the Supreme Court of Canada found that “effective communication is an indispensable component of the delivery of a medical service”. The case presented evidence that the absence of sign language interpreters could impair deaf people’s ability to communicate with their health care providers, and thus increases the risk of misdiagnosis and ineffective treatment. The Supreme Court of Canada held that the *Canadian Charter of Rights and Freedoms* required sign language interpreters be provided in medical settings to ensure that deaf people could benefit equally from health care services offered to everyone. The same principle applies to other disabilities: people are constitutionally entitled to the support and services they need to communicate effectively with health care providers.

Policy Recommendation

We request clear provincial policy to provide direction and consistency in ensuring that patients with disabilities are entitled to the support they need to access health care. This will ensure equitable access to health care services for people with disabilities.

Health care providers are working tirelessly under extraordinarily challenging circumstances. They too deserve the support and guidance that a clear provincial policy can bring.

We recommend that the provincial policy address the following key points:

- People with disabilities have the right to essential support person(s) in health care settings where such support is a necessary accommodation because of a disability;

- Essential support person(s) may be a family member, friend, paid worker, or other service provider knowledgeable with the patient and their communication methods, values, wishes, preferences, beliefs, behaviour, spiritual or cultural connections, and history of care;

- Patients and their essential support person(s) should be fully informed of any limitations on their ability to support the patient at the time of admission (e.g. limited access to other areas of the hospital and/or restrictions on re-entry); and

- Essential support person(s) should be provided with Personal Protective Equipment when health care providers consider it a necessary precaution.

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

Sincerely,

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)

And the following organizations:

dabc disability alliance bc | we are all connected

FAMILY SUPPORT Institute of BC *families supporting families*

vela

uniti
together we're stronger

individualized FUNDING resource centre

HEALTH JUSTICE

BCCEO
SOCIAL SERVICE LEADERSHIP NETWORK

S A L N
Self Advocate Leadership Network British Columbia

PLAN
PLANNED LIFETIME ADVOCACY NETWORK

BACi Burnaby Association for Community Inclusion

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