

SALN

Self Advocate Leadership Network

April 25, 2020

SALN COVID-19 News-sheet #6

This News-sheet is a public document. Information, quotes, and questions are invited to be shared and included outside of SALN.

The majority of SALN members are part of provincial self-advocacy and advisory groups. SALN is aware and interested in the BC self-advocate movement. All SALN members are well established and recognizable. All SALN members are from leading groups in the movement.

SALN Mission Statement:

To promote a good life through positive and informed: actions, networking, and advocacy.

1. SALN would like to share the following:

1. SALN supports Inclusion BC's call on the Government of BC and the Ministry of Health to immediately reinstate the position of the Medical Health Director and Consultancy.

SALN Information on the BC Medical Health Director and Consultancy

- This was a position the BC government had years ago but stopped it.
- **The role was a doctor who was available to help people, families and organizations get help from someone in the medical community to deal with health and medical issues for people with disabilities.**
- The doctor would assist and investigate health and medical issues, illness, deaths if people did not have one of these plans.
- **Years ago it was Dr. Plain. He was amazing and responded immediately to anyone needing help or guidance.**
- Dr. Plain was available to people, families, agencies – he was quick to respond, dealt with ethical issues, looked into a breach of rights, etc.
- Years ago, some people had “anticipatory health care plans” and some people did not.
 - **“Anticipatory Health Care Plan** was a plan/document that helped you make informed choice about how and where you want to be treated and supported with health and medical care in the future if you got sick or were dying. It required health care practitioners to work with people and their supporters to ensure the right thing is done at the right time by the right people (based on the person’s wishes) to achieve the best health outcome.”

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SALN Comment:

- "SALN encourages the BC government to reinstate the BC Medical Health Director and Consultancy during the crisis and ongoing after. The Medical Health Director and Consultancy provides individuals, families and community organizations who support individuals with diversabilities [developmental and intellectual disabilities] and complex health care needs essential expertise and support during critical health care situations. In addition, the position ensures equal access to quality health care when barriers within the system are faced."

Quotes from SALN members:

- "I think this service is essential."
- **"This position is absolutely needed in times like this."**
- "We need someone everyone can consult with and get help."
- **"We need a doctor who is available to help people advocate for and with people, families, service providers, supporters to ensure people are getting the health care treatment they want and need."**
- "Firsthand experience from a SALN supporter: "When my daughter was critically ill and I figured out why she was ill. Her daughter's family doctor would not agree with my theory. The doctor in this position at the time (after Dr. Plain) agreed with me and flew over from Victoria. He went with me to the family doctor to advocate for me and my daughter."
- "The doctor needs to be very accessible and quick to respond."
- "They need to be available to people, families, service providers."
- "They need to advocate for health care needs and address ethical issues and support people's rights."
- "When if people can't speak for themselves? They need someone like this to help. It is important to have this resource."
- **"This is not just necessary, it is essential. This needs to be in place, it must be in place. If not, things may go downhill instead of uphill."**
- "The health care system and everyone involved [would be] held responsible to provide the right health care treatment for everyone."
- "We want to make sure people are accountable."
- "A doctor should be available in BC that has knowledge of all aspects of disability."
- "I honestly would like to see more people having a person-centred approach when dealing with people. We are all people and we all deserve to have our share of the resources we need."
- "This position will support us to have our own voice and be heard."

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Quotes from SALN on the qualities of a new BC Medical Health Director and Consultancy

- “This doctor needs to know how to talk in plain language instead of doctor language.”
- “If this doctor is talking to both a self-advocate and a supporter, they need to ensure they first talk to the self-advocate and always involve the self-advocate. Sometimes doctors don’t do this. They forget to talk to me – they need to include me always.”
- “They need to be aware of all disability rights so they can actually talk to the person as a person – not just talk to other people.”
- “We need someone who will help advocate and help parents advocate for their children. Not all doctors listen.”
- **“The person needs to have a lot of disability knowledge and who can help break down barriers.”**

2. The Ministry of Health has issued an order that says if someone goes into hospital, they can have essential visits only. For example – if someone was at the end of their life a family member would be allowed to visit. The Essential Service order also includes allowing a caregiver to come in if the patient has feeding or mobility issues. CLBC is asking that the health order include allowing a caregiver or family member to come with a patient to the hospital if they need help with communication and decision making. The Ministry of Health is working to make sure this language is included in the policy and will bring that back as soon as it’s available to share.

Comment from SALN:

- **“SALN would like to thank the people involved that are working to ensure that people with diversabilities are able to have people they trust, know, and care about to support them if they need emergency health care. SALN would like to encourage the Ministry of Health to publish the policy as soon as possible.”**

Quotes from SALN members:

- “Thank you for thinking of all of us and we really appreciate it.”
- “Thank you to all the health care workers.”
- **“This will help all the staff in the hospitals to know how to help people and support them to understand their rights. It will relieve pressure on staff and be more efficient for hospital staff.”**

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3. Ariis Knight, a woman who did not use words to communicate and had complex care needs, passed without having care from anyone who knew how she communicated.

SALN Information on Ms. Ariis Knight

- [Peace Arch News Article](#) with content from UNITI CEO, Doug Tennant
 - “Tennant emphasized his concern isn’t with the “heroic” care that frontline workers at the Peace Arch Hospital have been providing during the pandemic. “They’ve always done fantastic work,” he said. “This is about a policy that needs to be changed.”

Comment from Comment:

- “SALN sends sympathy and call to action for Aiirs Knight. Now is the time for the Health Minister’s policy. We acknowledge that the BC government supports people, like Ariis Knight, in having an advocate by their side. Then it is critical that this policy is published and shared with health care workers so that they are informed.”

Quotes from SALN members:

- “We appreciate the plain language CLBC is putting out for this.”
- “It is important because if someone with a disability has to have someone to be there in the hospital to help them know everything will be ok – hospitals needs to know this is allowed.”
- “If you can’t reach the representative – it is important to find a friend, supporter or someone to help them understand so they get help immediately. Help people not feel scared. Have someone there with them.”
- “It’s not happening quickly enough. This needs to get off the desk and into policy.
- “UN Convention of Rights, self-determination, is part of this.”
- **“How do we figure out, in a positive and supportive way, to put a rush on it [the policy]?”**

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4. SALN and SAS social media campaign, #HowAreYouCoping

- SALN has published podcast #1, [Don't Forget About Us, #HowAreYouCoping](#)
 - This podcast is about #HowAreYouCoping during COVID-19
 - Facilitated by SALN member, Alexander Magnussen with SALN members Michael McLellan and Kara Anderson
- SALN and SAS have published [two videos on #HowAreYouCoping](#)
 - Please watch, share and add your own videos using #HowAreYouCoping
 - Your videos will be shared on the www.Facebook.com/SelfAdvocateSAS site
- This campaign has been funded as part of UNITI's efforts to support people with lived experience in increasing awareness and rights for people with diversabilities.

2. SALN would like to be informed of the following:

1. SALN would like to know a set date when the policy for people with diversabilities [developmental and intellectual disabilities] and complex health care needs who need support while in hospital care will be published.
2. What can SALN do to support BC in publishing the policy to allow advocates/support for people with diversabilities [developmental and intellectual disabilities] in hospital?
3. SALN would like to encourage self-advocacy groups, leaders/supervisor/managers/directors of programs and services, family groups, etc. to send their contact information to be added to SALN distribution list so that they can share SALN content during this crisis. There is no limit. Send contacts to j.glennie@shsbc.ca.

Please invite SALN to participate in creating and delivering solutions where it makes sense. Response can be sent to SALN support, Jillian Glennie, at sas@shsbc.ca.