SALN

Self Advocate Leadership Network

April 22, 2020

SALN COVID-19 News-sheet #5

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. People with developmental disabilities, who need necessary support, need to have someone in the hospital with them who is either family, their representative or a supporter/support staff so that they have an advocate who will directly support them in hospital.

SALN Comment:

- "People with diversabilities, intellectual and developmental disabilities, need to have an advocate with them in the hospital."
- "People with disabilities need to be able to have one person with them. Someone to help people communicate, with their physical supports, understanding, and decision making."
- "Hospitals need to know that people have a representation agreement and who their representative/contact is and understand they are the only people who can make health care decisions on behalf of the person."
- "If people have a representation agreement they should bring a copy if they have to go to the hospital."

Quotes from SALN members:

- "If people have a representation agreement, they need to be the person with them in the hospital and make decisions with them if they can be there."
- "It is very critical at this time to have family, representative or support workers to be in the hospital with you. It is a traumatic experience. The less trauma people experience the better."
- "It is important people have support when they are in the hospital."
- "If we don't have a voice in the hospital some pretty scary things can happen. Our voice not being heard and being denied the medical care that we need can easily happen."
- "I feel it is essential that people have somebody with them. But we need to make sure support workers do not take over. Doctors' need to talk to the patient if they can, not the support worker. We need to ensure people are not drowned out."

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- "I was in the hospital once and was a bit nervous going. A support staff came with me in the ambulance which helped me feel safe. It was important that my feelings were thought of and that I was comfortable in a situation I was not aware of."
- "People need to make sure they have a representation agreement in place to ensure the person they have chosen is helping to make decisions."

2. SALN Answers: Why should people with diversabilities, intellectual and developmental disabilities, get support in the hospital and not other people?

Quotes from SALN members:

- "It's not "we want", it's "we need" someone to advocate for us, speak for us if we can't speak for ourselves. We don't have power, other people have power and credibility and need to support us with supported decision making."
- "If somebody cannot speak for themselves it needs to be automatic someone is there. This shouldn't even be a question. A support person should be there if they need help with things in their life."

3. SALN Answers: What kind of people should be there for you, be that someone in the hospital with you who is either family, a representative or a supporter/support staff so that you have an advocate who will directly support you in hospital?

Quotes from SALN members:

- "People I trust. A trusting relationship."
- "Someone who is a strong support system."
- "Someone I know well, and they know me well."
- "Someone who loves and cares about us."
- "Someone who understands how we communicate."
- "Someone who knows what is important to me what matters to me."
- "Someone who will help me make important decisions and include me."
- "Someone who will ensure I am fully involved in what happens in my life."
- "Someone who knows exactly what they are doing. Someone who has the resources and knows the system."
- "Someone who connects with the person on a much deeper level."
- "It is really important you have the RIGHT person beside you and with you in the hospital."
- "We want someone we trust, that is credible, that knows the system, and who is not scared to stand up for us."

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4. There is a concern that triage guidelines will deny people with disabilities care and medical treatment.

Quotes from SALN members:

- "It is a human right to receive care, and just because I have a disability I should not be bumped to the bottom of the line. Having a disability should not be even being considered. It's not about better care it's about equal access."
- "I think it is essential that there is equality especially now. It is imperative that we are going into the hospital as an equal. Disability should not be an issue we are a person first. Our disability should not even be part of the health care decision.
- "You need to have people there with you to ensure you are not being discriminated against."

5. Government of BC Mental Health Supports During COVID-19, To support British Columbians of all ages during the COVID-19 pandemic, the Province is expanding existing mental health programs and launching new services.

Media Links:

April 21, 2020 Link: Government of BC Virtual Mental Health Supports During COVID-19

April 21, 2020 Link: Canadian Mental Health Association: British Columbia Division, COVID-19

SALN Comment:

"When you get on the Canadian Mental Health Association: British Columbia Division, CODIV-19 website, it is clearly laid out and easy to navigate. The layout made it easy to use and showed resources that SALN feels are important. SALN hopes everyone looks at the site and goes to the Government of BC Virtual Mental Health Supports during COVID-19 so that they can learn about resources like the Canadian Mental Health Association: British Columbia Division, COVID-19."

Quotes from SALN members:

- "The Government of BC website helps people get to the Canadian Mental Health Association: British Columbia Division, COVID-19 website page."
- "I plan to sign up for Bounce Back tonight." [This is one of the services available.]
- "When you use the Government of BC link, stay on that page to find information on mental health. I didn't do that the first time, I clicked one of the COVID-19 links at the top, and I ended up somewhere else."

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.