

June 22, 2020

To: Senate Human Services Committee

From: Gabrielle Guedon, Executive Director, Oregon Self Advocacy Coalition

**RE: Please support LC 52 Ensuring People with Disabilities Have Access to Healthcare.** Experience of Oregon Self Advocacy Coalition Members During the COVID-19 Crisis

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Chair Gelser and Members of the Committee:

The Oregon Self Advocacy Coalition (OSAC) is a statewide nonprofit organization made up of individual self-advocates and 18 local self-advocacy groups. We bring people with intellectual and developmental disabilities (IDD) together to speak with one voice about things that matter to them. OSAC's vision for people with disabilities is that they be as independent as possible and fit into their communities.

I have a medical condition that makes me at risk of serious complications if I get COVID-19. I had H1N1 and became very ill and had to spend time in the hospital. It took me six to nine months to recover. During my weeks in the hospital, my mother was able to stay by my side the whole time. She was able to help the hospital staff understand all my complicated, underlying conditions and explained all of the medications I was on at the time. Luckily, my mom was there to help advocate for me. The doctors wouldn't take the time to understand the symptoms that I was trying to explain to them, so they didn't realize that I also had a double ear infection. They kept giving me too much pain medication and not treating my ear infection until my mother was able to step in and explain. The doctors and nurses didn't have any experience with people who have IDD and I felt scared, confused and frustrated and really relieved to have my mom there to support me.

Everyone deserves to be able to have support making critical life saving decisions. People with IDD might not understand all of the consequences to the decisions they are making if they don't have someone they know and trust with them to help explain things like a ventilator and hospice care. People with IDD are more likely to just agree with whatever a doctor or nurse tells them to do, but that does not mean it is in their personal best interest. Also, we hope that most people have these conversations with family and providers before they get sick, so they go into the hospital knowing what they want. For people with IDD who have trouble communicating, family and providers need to be at the hospital to make sure everyone knows their wishes.

It is crucial to support LC 52 now and not in a few months because people with IDD are making plans to not go to the hospital, even if they really sick. People with IDD have heard that they will be forced to be alone and not allowed the support they need to understand their care or communicate their needs or in making decisions about their care. People with IDD are fearful that they will be mistreated and not get the care they deserve because they have a disability. People with IDD are afraid that they will die alone in the hospital. Two of our members have been to the hospital, they were not allowed to have support with them and did not feel like they were taken seriously and did not have the same level of care that they would have if they would have had support with them.

Thank you for the opportunity to submit this testimony. OSAC is excited to work with you to make sure that people with IDD are able to get the support they need when hospitalized for any reason.

Sincerely,

Gabrielle Guedon, Executive Director