

June 2, 2020

To: Senate Human Services Committee

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

RE: Experience of Oregon Self Advocacy Coalition Members During the COVID-19 Crisis

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. I have learned from this and am following my doctor's advice and staying home during the COVID-19 pandemic.

Staying home, however, has meant that I have lost much of my independence. I cannot do simple things like go to the grocery store. My friends still invite me places (with social distancing), but I have to say no. This is hard because my friends do not understand the risks for me or what it is like to have a medical condition.

For work, it was a huge adjustment for me to emotionally handle being isolated in my house. I felt like I was letting everyone down. I have lost hours and money because I cannot do the work I normally do. We have made plans for how OSAC would operate in case I get sick. I have a doctor's note saying I cannot travel. OSAC is a statewide organization that has

contracts requiring travel. I typically travel to our member groups and for our contract work, but now we have to figure out how do this work without travel for the foreseeable future. Remote connections do not always work for our member groups.

Isolation is something I have avoided all my life because isolation is not healthy. Yet, now I am isolated from my friends and community. A mental health provider has helped me handle this.

I have taken this time to contact many of our member groups to learn more about the experience of other people experiencing IDD. Here are a few of the major themes I heard:

1. Many of people with IDD are still waiting for stimulus checks. Some people don't even know what the stimulus checks are – they aren't being told about them.
2. For the most part, people with IDD are not accessing unemployment. They have been told that they cannot apply for unemployment because they are not working due to their health conditions, but their employer may still be open. People have also been told not to apply for unemployment because they are worried that they will lose their health and disability benefits if they apply. Neither of these things are true, but people do not know that.
3. People with IDD are making plans to not go to the hospital, even if they really should go to the hospital.
 - People with IDD are scared that hospitals will not allow them to have support they need to understand their care or communicate their needs. They are terrified of being without support when they need help communicating their needs or understanding and 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. 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.

4. Many people with IDD do not have technology to connect with doctors, providers, employers, friends, or family right now. This leads to more isolation.
 - If they do have access to technology, many people with IDD are not able to get the support they need to set up the technology or learn to use it.
 - We are grateful that the Office of Developmental Disability Services has made it easier to access technology, but the problem remains that people with IDD do not know about the policy change.
5. People are scared of losing their support if there are cuts to developmental disability services. These services are crucial to their independence and to keep their jobs as well as have a full life.

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 to be a part of their community and have full lives.