



May 20, 2020

To: House Health Care Committee

From: Leslie Sutton, Oregon DD Coalition

RE: Hospital Visitors and Support for People Experiencing Intellectual and Developmental Disabilities

Dear Chair Salinas and Members of the Committee:

Thank you for your continued work on behalf of Oregonians in this challenging time of Coronavirus crisis. The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 36 organizations across Oregon that promote quality services, equality and community integration for Oregonians experiencing intellectual and developmental disabilities (IDD) and their families.¹ Thank you for exploring COVID-19 impacts on populations who are at particular risk.

We believe that we are all better off when we can access health care when we need it and have our care options presented in a way that we understand. Many people with IDD are at higher risk of developing serious complications to COVID-19 due to co-occurring conditions.² We believe that many people experiencing IDD will be hospitalized before the COVID-19 pandemic ends. The support family, friends and direct care staff provide while a person with IDD is hospitalized is critical to the person's ability to understand their care and treatment, communicate with staff, and handle behavior support needs which are personal, detailed and the hospital staff are not trained nor able to provide. This support is a reasonable accommodation that will help ensure people with IDD have an equal opportunity to benefit from treatment.

Yet, despite Oregon Health Authority (OHA) "[COVID-19 Visitation Guidance for Acute Care Facilities: April 23, 2020](#),"³ allowing people with IDD to have support while they are in the hospital, many of these supporters are denied access at the hospital because hospitals have not implemented the OHA

¹ DD Coalition members include a statewide coalition of people experiencing IDD, peer-based family support organizations, support services brokerages, advocacy organizations and service providers.

² Current CDC guidelines indicate that people with underlying conditions such as heart or lung conditions or diabetes are at particular risk for COVID-19 complications. People experiencing Autism are at greater risk of health complications including immune, metabolic and heart conditions. Croen L.A. *et al.* *Autism* Epub ahead of print (2015) **PubMed**, People with Cerebral Palsy are at risk for respiratory and cardiovascular diseases <https://www.cerebralpalsy.org/information/respiratory-health>, <https://cerebralpalsynewstoday.com/2018/10/01/cardiovascular-disease-is-more-prevalent-in-patients-with-cerebral-palsy/> 1 in 2 People with Down Syndrome are born with a heart defect <https://www.ndss.org/resources/the-heart-down-syndrome/>

³ Oregon Health Authority Hospital Visitor Guidance, April 23, 2020: <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf>



Hospital Visitor Guidance. **We ask that the OHA Hospital Visitor Guidance be enforced to ensure all Oregon hospitals change their visitor rules on relevant websites and community materials and train their hospital staff and associated medical office staff of the change in policy.**

The OHA guidance is critical for Oregon to implement the US Department of Health and Human Services guidance that requires that covered entities should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served by:

“Addressing the needs of individuals with disabilities, including individuals with mobility impairments, individuals who use assistive devices, auxiliary aids, or durable medical equipment, individuals with impaired sensory, manual, and speaking skills, and individuals with immunosuppressed conditions including HIV/AIDS in emergency planning;”⁴

A national letter, written by civil rights attorneys and signed by 89 disability organizations, stressed the need for reasonable accommodations to ensure a person with a disability will “have equal opportunity to benefit from treatment.”⁵ People with IDD need this support from family, friends and direct support professionals for equal opportunity to benefit from treatment.

Families and people with disabilities are making care decisions based upon their understanding of the various approaches that healthcare providers are choosing, including decisions about whether or not to seek care and where. With inconsistent application of the OHA guidance, many people are forced to take enormous risks of foregoing health care or going to the hospital without support from people who can help them understand their care options.

We continue to hear about people experiencing IDD who are not allowed to have support with them in the emergency room, during procedures or once they are admitted. These stories come from different parts of the state and involve different hospital systems. Further, we are also hearing that Oregonians experiencing IDD are being asked to sign documents when they do not have support from people who know them to understand what they are signing. These documents will seriously impact the level and type of care the person will receive.

It is imperative that hospitals implement the OHA Hospital Visitor Guidance allowing people with IDD to have friends, family and direct support professionals support them during their hospitalization. This reasonable accommodation will allow people with IDD can have an equal opportunity to benefit from hospital treatment during COVID-19.

⁴ Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

⁵ APPLYING HHS'S GUIDANCE FOR STATES AND HEALTH CARE PROVIDERS ON AVOIDING DISABILITY-BASED DISCRIMINATION IN TREATMENT RATIONING https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf