



June 25, 2020

Dear Governor Brown; Senate President Peter Courtney, Senate Majority Leader Rob Wagner, Senate Republican Leader Fred Girod; House Speaker Tina Kotek, House Majority Leader Barbara Smith Warner, and House Republican Leader Christine Drazan,

CPAO (Community Providers Association of Oregon) and ORA (Oregon Resource Association) ask that you Introduce and Pass SB 1606 this Special Session: Guaranteeing Access to Appropriate Lifesaving Testing, Care and Treatment for Higher Risk Populations . These two, long-standing Associations represent Medicaid Provider Agencies that provide a wide range of individualized, professional care and support to children and adults who experience intellectual and developmental disabilities (IDD) across the state.

Over the years we have fought many a battle, with and on behalf of those we support, for equity in access to all viable medical treatment options. We have also fought, tirelessly, time and again, alongside individuals and guardians, to compel medical professionals that their patients with IDD, many of whom also experience medical disability, have rich, full lives; that they deserve, and have a legal right to be just as valued as any other patient in their care. The problem being addressed in this proposed legislation is a longstanding one of institutional discrimination, and it has been experienced statewide, in a multitude of hospital settings.

And today, the COVID-19 epidemic has grossly exacerbated this discrimination. We are hearing, *far* more frequently than is typical, stories from numerous members of denial of access to ADA accommodations, despite these being reinforced by two recent publications of the Oregon Health Authority's "COVID-19 Guidance on Screening and Visitation at Acute Health Care Facilities," (revisions dated April 23, 2020 and June 8, 2020). In some situations, these denials occur even when we are referencing these guidance documents. Some providers have found success after getting incredibly assertive, demanding to see a hospital administrator, and walking them through both the OHA document and the Disability Rights Oregon "Know Your Rights: COVID-19 & Reasonable Accommodations in Hospitals" publication. But not every individual, family member, or provider knows *to* demand this, or *how* to demand it. Nor should they have to. They deserve accommodation, and overall equity in treatment, without having to argue for it.

Further, we have seen significant increase in medical professionals pressuring individuals, families, guardians and their support teams to change the POLSTs (Physician's Orders for Life Sustaining Treatment) of Oregonians who experience IDD, once hospitalized, to indicate DNR (Do Not Resuscitate) and/or DNI (Do Not Intubate) orders, versus the life-saving measures specified previously; often citing lack of "quality of life" as their concern. This is absolutely unacceptable, and blatantly discriminatory. And yet, it persists, and it grows.

A statewide, macro-level systems FIX is clearly required, to mitigate these continued, massive civil rights violations; to end the inequities and to enforce the illegality of medical discrimination for Oregonians who experience disability. The Oregon State Legislature is appropriately positioned to address this problem head-on, systemically, via state mandated, enforceable policy. Consideration of this suggested law cannot wait. Every day, this under-abated discrimination puts lives and options at risk, and it is bound to intensify in a

second COVID “wave.” Further, even if COVID were to be fully eradicated tomorrow, discrimination in medical care has been a longstanding issue, and MUST be remedied before even more lives of Oregonians with IDD are unnecessarily and unjustly altered due to lack of full access to, or consideration of, ALL viable medical options. We are thrilled to see such a powerful legislative concept. It gives great hope.

Before closing, we’d like to emphasize our support of SB 1606’s enforcement of ADA access to support people in hospital settings, also called for in recent OHA and US Health and Human Services guidelines; assurance that Crisis Care Guidance does not allow for discrimination in who gets care and who does not based on disability; and its requirement that those for whom end of life care is being discussed have support from people they choose before making decisions.

In close, ORA and CPAO implore you to pass SB 1606 in the June 24th Special Session. Lives are at risk due to this discrimination every day, and even more so, during this crisis. Oregonians with IDD cannot afford for this inequity to continue. Their very lives are at stake.

We thank you for your consideration, and we are happy to help support this effort to achieve equitable treatment in medical care for people with disabilities.

In Tremendous Appreciation,

Loralei LaVoie, CPAO Board President; Lois Gibson, ORA Executive Director
Anna Keenan-Mudrick, CPAO Legislative Chair; Joanne Fuhrman ORA Legislative Chair