

February 7, 2024

To: Sen Patterson, Chair, Senate Committee On Health Care

From: Oregon Developmental Disabilities Coalition

RE: Support for SB 1508, prohibiting the use of quality of life measures in state medical assistance program decisions

Chair Patterson and Members of the Committee:

The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 40 organizations and individuals across Oregon that come together to advocate for the services to further the values outlined in ORS 427.007: to support people with intellectual or developmental disabilities (IDD) to exercise self-determination, living and working in the most integrated community settings, and providing services for families to raise their children at home. Our members represent advocacy groups (including self-advocacy organizations), family peer supports, DD residential providers, DD supported employment providers, and Support Services Brokerages.

We believe that all human life is equally valuable. People should have equal access to life-improving and sustaining medical opportunities and resources. The concept of Quality Adjusted Life Years (QALY) or the use of "quality of life in general measures" is wholly at odds with these values. As SB 1508 defines, "Quality of life in general measure" means an assessment of the value, effective-ness or cost-effectiveness of a treatment that gives greater value to a year of life lived in perfect health than the value given to a year of life lived in less than perfect health."

The lives and perspectives of people with intellectual and developmental disabilities are too often left unconsidered in our society. Oregon's DD Coalition works alongside them to elevate and amplify their perspectives and ensure that people with intellectual and developmental disabilities are a part of every decision that affects them.

The Oregon DD Coalition supports SB 1508, which would severely restrict the use of quality of life measures in Oregon's decision-making processes for the state's medical assistance program. The bill takes several important steps:

Section 1: Prohibits OHA from using quality measures or data derived from their use Sections 2-3: Bars the HERC from the use of quality of life measures in determining a service's value, in weighing a service's cost effectiveness, or in recommending a service



Advancing Opportunities

Section 4: Makes further adjustments to the process and standards for data used to inform HERC processes Section 5: Adds a definition for "quality of life in general measure"

These elements combine to steer our decision-making bodies toward fundamental equity. They direct the use of high ethical standards for the data and research that informs their work. We celebrate this bill as a positive path forward for our state.

Oregon is full of communities where people with disabilities are important members. Their lives are valued. We urge you to support SB 1508 and reject medical discrimination in Oregon.