

Submitter: Robin Burgess
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB492

My name is Robin Burgess, and I am writing to you as a disabled person who is concerned with how SB 492 may put other disabled people in my community at risk. This bill includes some propositions that appear to be aimed at prioritizing the needs of folks with disabilities and chronic illnesses, such as research review requirements. While these are potentially good steps to take, I urge you not to pass this bill in its current form, as it also has the potential to cut off disabled people from vital care. In particular, several sections of this bill include the addition of language to multiple laws that would prohibit the OHA and the Health Evidence Review Commission from taking into account measures of “quality of life” when making decisions, including when determining the cost efficacy and value of a service, or whether a service is recommended. I take this to mean that in the interest of cost efficacy, the Commission is to prioritize treatments that it deems “medically necessary” over that which is regarded as “quality of life” care.

This may seem straightforward to those who do not live with a disability, but let’s take a second to consider what is often considered “medically unnecessary”, “quality of life” care by insurers: assistive technology that people need to be able to live independently, including some mobility devices. In-home healthcare and caregiving, which allows immunocompromised disabled people to receive care and assistance with basic activities of daily life (ADLs) such as showering and dressing without the risk of exposure to disease. Mental health services, which will be the difference between life and death for so many people in our statewide mental health crisis. Pain management, which is what allows many disabled folks with long term incurable conditions (cancer, rheumatoid arthritis, spinal cord injuries, long COVID, etc.) to live a “functional” life at all. Comprehensive pain care is what allows many people to complete basic ADLs independently, and to maintain the concentration required to do something as simple as make doctor’s appointments, let alone go to school or work. Untreated chronic pain often leads to further health complications, and loss of access to pain care has consistently been found to force people to seek more dangerous alternatives (remember that we are also dealing with an increase in overdose deaths). Studies have consistently found a link between chronic pain and elevated suicide risk. A large study done by CDC researchers in 2018 found that 1 in 10 suicide deaths in the United States over 11 years included evidence of chronic pain. I have had multiple friends tell me that they would die if it weren’t for their medicines. One of my friends is fearful for how this bill will impact his future because his healthcare consists almost entirely of “quality of life” care, and his disability prevents him from working and gaining access to private insurance.

I understand that the state is scrambling to make a single payer plan work as the federal government ends emergency Medicaid funds, but there is a human cost to narrowing what can be considered for coverage, and most of those humans are poor and disabled. In Canada, disabled activists are fighting to keep physician-assisted suicide from becoming a genocidal alternative to quality of life care for people who can't pay their medical bills, and with this new bill I am concerned that we will need to prepare for the same fight in Oregon. "Quality of life measures" are life or death measures for disabled and chronically ill people in Oregon. Please do not pass SB 492 until it has been stripped of all references to taking "quality of life measures" out of consideration for determining provision of services.