

TO: Senate Judiciary Committee **FROM:** Disability Rights Oregon (DRO)

DATE: March 3, 2021

RE: DRO 's Testimony in Opposition to Senate Bill 199 as drafted

Dear Chair, Vice-Chairs, and Members of the Committee:

Disability Rights Oregon submits this testimony in opposition of Senate Bill 199 as currently drafted as it requires potentially biased end-of-life decision making. The bill includes an entire section where an individual must weight their "quality of life" when deciding to elect life sustaining health care.

Problem: As Written, SB 199 Would Exacerbate Existing Disability Discrimination

The phrase "quality of life" is often a euphemism for stereotypes and prejudice about the lives of people with disabilities. Since the beginning of the COVID-19 pandemic, Disability Rights Oregon has received a steady stream of complaints about healthcare discrimination experienced by people with disabilities. These complaints include being denied care if individuals did not have a standing Physicians Order on Life Sustaining Treatment (POLST) or Do Not Resuscitate Order (DNR). These complaints have been widespread, coming from every corner of the State and from nearly every hospital system including the following:

- In March, Disability Rights Oregon investigated and substantiated a complaint about a
 person with an intellectual disability with COVID-19 being inappropriately influenced about
 regarding life sustaining medical treatment. The physician cited the "low quality of life" of
 the person with a disability.
- Sarah McSweeney was a 45-year-old woman who loved going out to coffee and taking trips with friends. She also loved getting her hair done, listening to music, and was looking for a job. On April 21, 2020, she went to the hospital with a slight fever. From the very first day of her hospital stay, hospital staff repeatedly pressed her guardian to sign a Do Not Resuscitate Order. It was clear to Sarah's guardian and care team that the hospital did not believe she lived a quality life based on her disabilities. When Sarah's team tried to explain to the hospital that Sarah lived a very full and promising life, the hospital staff replied in a sarcastic and surprised manner, "this girl?" Sarah died on May 10, 2020. See enclosure.

Solution: Remove Section (B) Pertaining to "Quality of Life

During the emergency summer session of 2020, SB 1606 was passed and provided a critical first step to addressing health based discrimination by prohibiting hospitals from requiringe a POLST or DNR as a prerequisite to treatment. Further, in December 2020, the Oregon Health Authority applied principles of non-discrimination and health equity when it modified the crisis care guidelines to exclude several factors when allocating scare resources including, "quality of life, which can lead to the systematical deprioritization of resources for individuals with developmental, intellectual, and other disabilities, older adults, and individuals from communities of color."

We similarly ask you to strip all language regarding "quality of life" from this bill.

Disability Rights Oregon (DRO)

For more than 40 years, DRO has served as Oregon's federally authorized and funded Protection & Advocacy System. DRO is committed to ensuring the civil rights of all people are protected and enforced, including youth in correctional settings.

If you have questions regarding the position of DRO please contact Meghan Moyer at 503-432-5777.