January 7, 2021

Health Policy and Analytics Medicaid Waiver Renewal Team
Attn: Michelle Hatfield
Oregon Health Authority
500 Summer St. NE, E65
Salem, OR 97301

Re: Comments on Oregon Health Plan 1115 Demonstration Waiver Application for Renewal

Dear Ms. Hatfield:

We appreciate this opportunity to provide comments as the Oregon Health Plan (OHP) applies to the Centers for Medicare & Medicaid Services (CMS) for a new five-year Medicaid waiver, known as the 1115 Demonstration. We hope that the state will incorporate the perspectives of people with disabilities that disproportionately are impacted by the state's prioritized list of services by barring the use of the discriminatory quality-adjusted life year (QALY) as a consideration; by ensuring that individuals with disabilities and significant health conditions do not face discrimination in accessing suicide prevention services; and by discontinuing the EPSDT waiver that too often fails to give children the care they need.

As you know, in 1992, Oregon submitted a waiver application relying on the QALY to prioritize services for coverage that was denied by the U.S. Department of Health and Human Services as "discriminatory and inconsistent with the Americans with Disabilities Act."[1] The waiver was later approved in 1993, after committing to changes for ADA compliance. Despite ADA concerns, Oregon has reverted to an approach for prioritizing health services for coverage that factors cost effectiveness and the QALY. Officially, Oregon excluded the survey-based QALY data that triggered denial of its initial waiver application in 1992. Yet, the voting members of Oregon's Health Policy Commission have authority to

[1] https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html

override the results of non-QALY considerations, which they did in over 70% of the cases. The discriminatory outcome for how care is valued and prioritized is the same.[2]

Today, the Health Evidence Review Commission (HERC), which guides the Oregon Health Plan's benefit decisions, continues to use QALY-driven data and analysis in the formula for the prioritized list of services. As reconstructed in 2008, Oregon's revised prioritization framework emphasizes preventive services and chronic disease management in order to keep the "population healthy rather than waiting until an individual gets sick before higher cost services are offered to try to restore good health." This focus on preventative care for the healthy population has deprioritized – and in some cases defunded – coverage of health services for individuals living with disabilities, including mental health services for children. Although Oregon removed a direct and explicit reference to QALYs from its cost-effectiveness framework in 2017, it continues to rely upon the QALY-driven prioritization scores for condition-treatment pairs that were already established at that time. In addition, HERC continues to consider QALY-based analysis in evaluating other factors in the formula.[3]

The HERC does not routinely seek input from patients or individuals impacted by the health conditions in evaluating impact on healthy life or suffering. Instead, commissioners are frequently presented with QALY metrics calculated by entities such as the Institute for Clinical and Economic Review (ICER) as they vote. After a category is determined and weighting factors established, a total score is calculated and reviewed by the HERC, which reserves the right to manually override the scores to move services up or down the prioritized list. A few excluded services for people with disabilities include treatment for hearing impairment, Bell's Palsy, Spastic Diplegia, and certain personality disorders.[4]

Oregon also chooses to provide coverage for some services that aren't on the list at all. For instance, it is the policy of the state of Oregon to provide Medicaid coverage of physician-assisted suicide, including counseling and lethal prescriptions. It has been reported that OHP patients who have been denied coverage of potentially life-extending health services that were "below the line" have been advised by OHP that physician assisted suicide is a covered alternative.[5] This outcome – preference for assisted suicide over treatment – is the direct result of the state's discriminatory policies and is clearly unethical and in violation of disability and civil rights protections.

The ethical challenges of Oregon's use of discriminatory metrics to ration services it will cover are exacerbated for children. Oregon is the only state with an EPSDT waiver. In every other state, under Federal law, Medicaid includes a critical benefit for children and adolescents under the age of 21, called "Early and Periodic Screening, Diagnostic and Treatment" (EPSDT) to ensure that they receive "age-appropriate screening, preventive services, and treatment services that are medically necessary to correct or ameliorate any identified conditions – the right care to the right child at the right time in the right setting." Critically, the EPSDT provision requires comprehensive coverage of health services for children – *regardless of whether or not such services are otherwise covered* under the state

[2] https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Brief-History-Health-Services-Prioritization-Oregon.pdf
[3] https://www.oregon.gov/oha/HPA/DSI-HERC/Pages/Prioritization-Methodology.aspx
[4] https://www.oregon.gov/oha/HPA/DSI-HERC/Pages/Prioritized-List.aspx
[5] https://abcnews.go.com/Health/story?id=5517492&page=1

Medicaid plan for adults ages 21 and older – to make certain that rationing is not imposed for this vulnerable population.[6] Even still, Oregon's Section 1115 Medicaid waiver includes a provision authorizing it to withhold medically necessary care from children over the age of one if it is "below the line" on its "Prioritized List" of health services. A few examples include noncoverage of treatment for selective mutism, conduct disorder, recurrent ear infections, minor burns, and pica.

We believe it is time to end this failed experiment of relying on discrimination to ration care. Our specific recommendations are as follows:

1. **Full Compliance with EPSDT**
   The provision allowing Oregon to "[r]estrict coverage for treatment services identified during Early and Periodic Screening, Diagnosis and Treatment (EPSDT) to those services that are consistent with the prioritized list of health services for individuals above age one" should be removed. Oregon should comply fully with EPSDT, to ensure that all EPSDT-eligible children receive the medically necessary care that Congress intended, without rationing.

2. **Prohibit the Use of Discriminatory QALY Measures**
   The waiver should include a provision explicitly renouncing use of discriminatory measures such as QALYs, such as this:

   > "Prohibition on Reliance on Discriminatory Measures. The state shall not develop or utilize, directly or indirectly, in whole or in part, through a contracted entity or other third-party, a dollars-per- quality-adjusted life year or any similar measures or research in determining whether a particular health care treatment is cost-effective, recommended, the value of a treatment, or in determining coverage, reimbursement, appropriate payment amounts, cost-sharing, or incentive policies or programs."

3. **Non-discrimination in Suicide Prevention Services**
   The waiver should include a provision affirming that patients with disabilities who express a desire to harm or kill themselves in a medical setting, even when they qualify for lethal drugs under Oregon's "Death with Dignity Act," will be provided with the same harm and suicide prevention services[7] as the general public. No patient should ever be placed under pressure – intentional or otherwise – to die by suicide because of the subjective judgments on the value of their lives or an inability to find coverage for medically indicated care, treatments, or therapies.

[6] https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

[7] The term "harm and suicide prevention services" includes screening, diagnosis, psychiatric treatment, therapy, counseling, and other services whose purpose is the detection and treatment of suicidal ideation and tendencies and the causes thereof, including depression, mental disorders, and lack of access to rehabilitative and supportive care.

We appreciate the opportunity to comment.

Sincerely,

Disability Policy Consortium

Disability Rights California

Disability Rights Education and Defense Fund

Not Dead Yet

Patients Rights Action Fund

Partnership to Improve Patient Care

The Coelho Center for Disability Law, Policy, and Innovation