

April 13, 2022

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Honorable Chiquita Brooks-LaSure  
Administrator  
Centers for Medicare and Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244

Re: Public Comment on Oregon's Section 1115 Medicaid Demonstration Waiver Renewal Application

Dear Administrator Brooks-LaSure,

I am writing as a member of the public, and as the father of two Medicaid-eligible children with disabilities, to provide comment on Oregon's planned Section 1115 Medicaid Demonstration Waiver Renewal Application.

There are three critical fixes that should be included in Oregon's next waiver: removing the obsolete EPSDT waiver provision, renouncing the use of discriminatory Quality Adjusted Life Year (QALY) metrics in ranking services on the prioritized list, and ensuring that individuals with disabilities and significant health conditions do not face discrimination in accessing suicide prevention services.

**Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Waiver:**

I welcome Oregon's decision to discontinue the existing EPSDT waiver, but urge CMS to require Oregon to rapidly come into full compliance.

To cap this critical issue, Oregon is currently the only state in the country that reserves the right to withhold medically necessary care from children on Medicaid for the sole purpose of saving money, through the EPSDT waiver clause, which reads:

**3. Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)  
Section 1902(a)(10)(A) and 1902(a)(43)(C)**

To allow the state to restrict coverage for treatment services identified during an EPSDT screening for individuals above age 1 to the extent that such services are not consistent with a prioritized list of conditions and treatments. (Applies to all Medicaid state plan populations, except population 23.)

This directly contradicts the U.S. Department of Health and Human Services explanation of EPSDT:<sup>1</sup>

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<sup>1</sup> <http://mchb.hrsa.gov/epsdt/overview.html#1>

“All medically necessary diagnostic and treatment services within the federal definition of Medicaid medical assistance must be covered, *regardless of whether or not such services are otherwise covered* under the state Medicaid plan for adults ages 21 and older.” (*emphasis added*)

The Center for Medicaid and CHIP Services has further described EPSDT as follows<sup>2</sup>:

“In 1967, Congress introduced the Medicaid benefit for children and adolescents, known as Early and Periodic Screening, Diagnostic and Treatment (EPSDT). The goal of this benefit is to ensure that children under the age of 21 who are enrolled in Medicaid 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. This broad scope supports a comprehensive, high-quality health benefit.”

The Oregon Department of Justice has published an opinion<sup>3</sup> asserting that this clause in the waiver permits Oregon to limit or exclude coverage of medically necessary care from children, even when those limits or exclusions specifically contradict CMS guidance, such as CMS guidance prohibiting “hard” limits on physical therapy visits for children.<sup>4</sup>

The State of Oregon has used this EPSDT clause to save money by withholding medically necessary care from needy children. Specifically, Oregon uses the prioritized list of health care services to determine which services are to be provided. Services that are “below the line” – or simply not recorded on the list at all – are withheld, regardless of individual determinations of medical necessity.

Over the past year, I have met with a number of physicians and families on OHP who have struggled to access medically necessary care for their patients and children to learn about the human impact of Oregon’s EPSDT waiver.

Here are some findings and observations:

- Many of the condition / treatment pairs that are “below the line” are debilitating but treatable, and denying coverage can lead to significant harm. Some examples:
  - Selective mutism: untreated children cannot fully participate in school or community. HERC found that treatment was highly effective, but excluded coverage anyway because of an erroneous belief that the condition was insignificant to patients.
  - Chronic otitis media: physicians have advised us that they must wait until a child suffers actual hearing loss before they can get coverage of this condition.
  - Conduct disorder: low-income children on Medicaid who exhibit disruptive behavior are denied access to psychotherapy for this DSM-5 condition, resulting in a higher chance of incarceration.

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<sup>2</sup> <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>

<sup>3</sup> Deanna Laidler, Sr. Assistant Attorney General, Oregon Department of Justice, to Darren Coffman, Director, Health Evidence Review Commission, “Mental Health Parity and Rehabilitative Therapies,” October 5, 2016

<sup>4</sup> CMS, EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents (“CMS EPSDT Guidance”), p.24, available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>

- Inpatient behavioral treatment for severe autism: while the prioritized list covers outpatient Applied Behavior Analysis (ABA) therapy as a treatment for autism, the list does NOT include any inpatient services. There are Oregon teens with severe autism who require much more intensive, inpatient treatment to address self-injurious to aggressive behaviors – which are excluded from the list without regard to medical necessity. Some nationally ranked hospitals have begun refusing Medicaid patients from Oregon because of Oregon’s notorious refusal to pay for behavioral health treatment, and no Oregon hospitals have the necessary capabilities.
- Many physicians resort to “code games” to work around the prioritized list
  - For instance, coding “selective mutism” as “anxiety” or “depression”
  - This bypasses the list – defeating any intent at cost savings – while increasing bureaucratic burden
  - Obscures a patient’s true condition by disguising it as a coverable condition, making a patient’s medical history harder for future medical providers to follow and treat
  - Exposes physicians to risk of prosecution for fraud
- Oregon’s prioritized list places a high priority on coverage of common services for otherwise healthy people (routine dental exams) while deprioritizing rarer or more serious conditions for patients with disabilities.
  - Any “rare” condition that simply hasn’t been considered by HERC is automatically excluded (below the line) with no opportunity for a successful appeal
  - Palliative care (and even assisted suicide) are given a higher starting category weight (65 points) than life saving care (40 points)
- Priorities are set on the list without direct input from patients and families on values and preferences, resulting in strange or inappropriate decisions
  - Selective mutism and Pika were both scored below the line because HERC believed that the conditions had minimal impact on patients or that there was no need for treatment

Please refer to the attached issue briefs from Disability Rights Oregon on “How the Oregon Health Plan Discriminates” and “Oregon’s Unique EPSDT Waiver Allows OHP to Deny Medically Necessary Care to Children to Save Money” for more information.

Perhaps 30 years ago there was some policy justification for rationing care to low income children by withholding medically necessary care from them to save money – but not now. America has come a very long way since then in providing universal access to health care, especially for children, with a substantial expansion in Medicaid funding under the Affordable Care Act. It’s time for Oregon to catch up to the rest of the nation – and comply fully with EPSDT’s requirement to provide “all medically necessary diagnostic and treatment services ... regardless of whether or not such services are otherwise covered ... for adults ages 21 and older”.

From my conversations with the State of Oregon, I understand that Oregon plans to request a lengthy transition period before full implementation of EPSDT. While it may take time for Oregon to adjust its prioritized list process to enhance access to critical EPSDT services, Oregon must immediately allow

EPSDT-eligible children to appeal denials of “below the line” services on the basis of medical necessity – with an impartial process, such as an External Medical Review process under 42 CFR 438.402.

**Recommendation:** 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 and promptly with EPSDT, to ensure that all EPSDT-eligible children receive the medically necessary care that Congress intended, without rationing.

Oregon should be required to immediately allow EPSDT-eligible children to appeal denials of “below the line” services on grounds of medical necessity with an impartial process, such as an External Medical Review process under 42 CFR 438.402.

### **Quality Adjusted Life Year (QALY) Metrics:**

Oregon’s initial Medicaid waiver application was denied in 1992 on grounds that “Oregon’s plan in substantial part values the life of a person with a disability less than the life of a person without a disability. This premise is discriminatory and inconsistent with the Americans with Disabilities Act.” (See attached letter from HHS to Oregon).

Nevertheless, Oregon has consistently used discriminatory “Quality Adjusted Life Year” (QALY) metrics as a factor in ranking services on the prioritized list. QALY is a tool that estimates the value of a treatment according to years of additional life – discounted by the level of disability. This approach places a lower value on years of life for those with disabilities – such as my children – than on years of life for people without disabilities – and is inherently discriminatory.

Over the past six months, I have studied the Oregon Health Plan’s use of QALY metrics in detail, and have met with senior OHA leadership for input. Here are my initial observations:

- Oregon Health Authority records show that when the US Department of Health and Human Services directed Oregon NOT to use the QALY metric in 1992, on grounds that it violated the Americans with Disabilities Act, the HRC simply worked around this by voting to adopt essentially the same discriminatory results derived from the QALY-based formula.<sup>5</sup>
- Despite Federal guidance to the contrary, Oregon continued to use the QALY as an explicit input in the “cost effectiveness” factor in the prioritization formula until 2017
  - Most of the condition-treatment pairs now on the list continue to be ranked using the old QALY-based factor
- HERC continues to rely upon QALY-based cost effectiveness reports from ICER, NICE, and other organizations. When staff prepare summaries of those reports for the commissioners, they

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<sup>5</sup> Bob DiPrete and Darren Coffman, “A Brief History of Health Services Prioritization in Oregon,” Oregon Health Authority, March 2007. <https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Brief-History-Health-Services-Prioritization-Oregon.pdf>

frequently cite and call attention to the QALY scores, as is clearly documented in meeting materials

- Other factors in the formula, such as “Impact on Health Life” closely resemble the QALY concept. When HERC commissioners vote on these factors, they do so immediately after reviewing staff briefings and reports with QALY scores

When the Oregon Health Plan ranks services on the prioritized list, using QALYs in any way, it engages in discrimination against individuals in violation of the Americans with Disabilities Act and contrary to the mission of the Oregon Health Policy Board to promote health equity.

Recommendation: The Waiver should include a provision explicitly renouncing use of discriminatory measures such as QALYs, with a provision 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.”

### **Non-discrimination in Suicide Prevention Services**

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.<sup>6</sup> OHP patients who have been denied coverage of potentially life-saving health services that were “below the line” have been advised by OHP that physician assisted suicide is a covered alternative to life saving care.<sup>7</sup> This sends a message to patients with disabilities or serious illness that they are not worth treating – but Oregon will pay to expedite their death.

It is ethically essential to ensure that any patients with disabilities or serious illness continue to receive full suicide prevention services, especially if they have been confronted with a denial of life-saving care due to the prioritized list. Physicians and CCOs should NOT assume that a disabled patient who has been denied access to care is making a “rationale” or reasonable choice to hasten the end of their lives without first providing the same range of suicide prevention services that any other member of the general public would receive.

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<sup>6</sup> Oregon Health Authority, “Prioritized List of Health Services,” 2/1/2021, P. SI-1, “STATEMENT OF INTENT 2: DEATH WITH DIGNITY ACT.”

<sup>7</sup> Susan Donaldson James, “Death Drugs Cause Uproar in Oregon. Oregon woman denied drugs for lung cancer, but offered assisted-death drugs.” ABC News, 8/6/2008. (<https://abcnews.go.com/Health/story?id=5517492>)

Recommendation:

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<sup>8</sup> 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.

Sincerely,

/s

Paul Terdal

Attachments:

- HHS Letter to Oregon 1992: letter and press release from US Department of Health and Human Services to Oregon, in 1992, denying initial waiver application for violating civil rights of individuals with disabilities
- DRO Issue Brief: Oregon's Unique EPSDT Waiver Allows OHP to Deny Medically Necessary Care to Children to Save Money
- DRO Issue Brief: How the Oregon Health Plan Discriminates

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<sup>8</sup> 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.