

January 7, 2022

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Health Policy and Analytics Medicaid Waiver Renewal Team
Attn: Michelle Hatfield
Oregon Health Authority
500 Summer St. NE, E65
Salem, OR 97301
By email: 1115Waiver.Renewal@dhsosha.state.or.us

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

Dear Ms. Hatfield,

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:

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: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*)

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

The Center for Medicaid and CHIP Services has further described EPSDT as follows²:

“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 opinion³ 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.⁴

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 few months, 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.
 - 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

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

³ 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

⁴ 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>

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”.

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

Quality Adjusted Life Year (QALY) Metrics:

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.⁵
- 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 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.”

⁵ 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>

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.⁶ 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.⁷ 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.

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 services⁸ 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:

- 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

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

⁷ 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>)

⁸ 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.

Oregon's Unique EPSDT Waiver Allows OHP to Deny Medically Necessary Care to Children to Save Money

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 Medicaid plan for adults ages 21 and older – to make certain that rationing is not imposed for this vulnerable population.

Except in Oregon.

Oregon's Section 1115 Medicaid waiver includes a provision authorizing it to withhold medically necessary care from children over the age of 1 if it is “below the line” on its “Prioritized List” of health services:

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.) [Centers For Medicare & Medicaid Services Amended Waiver List and Expenditure Authority; Number: 21-W-00013/10 and 11-W-00160/10 Title: Oregon Health Plan \(OHP\)](#)

Effective January 1, 2020, Oregon Health Plan covers [Prioritized List](#) lines 1 through 471. Any service that is “below the line” – numbered higher than 471 – is automatically excluded from coverage regardless of need, as is any service that isn't included anywhere on the list at all.

The Oregon Department of Justice has published an opinion 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. [Meeting Packet, April, 2016](#)

The purpose of the waiver – and of this EPSDT clause – is to save money by withholding medically necessary care from needy children. Some services for children that have been excluded because they fall below the line include: Selective Mutism – Medical / Psychotherapy (line 473), Conduct Disorder, Age 18 or Under (Line 479), Chronic Otitis Media (line 475).

Selective Mutism fell below the line and is excluded even though it scored high on effectiveness (4 out of 5), and even though Oregon's Health Evidence Review Commission (HERC) concluded that 80% of affected individuals would need care – because the category weight in [HERC's methodology](#) was low (Non Fatal condition = 20), and because HERC staff concluded that the “impact on healthy life” for a child unable to speak was very low (1 out of 10); that the impact on suffering was low (1 out of 5); and there was no impact to the general population for a child who is unable to communicate.

Conduct Disorder fell below the line and is excluded because the category weight is low (Non Fatal condition = 20) and because HERC staff rated effectiveness low (1 on a 0 to 5 scale). As a result, children and adolescents in Oregon with a conduct disorder who might have a chance of benefiting from professional counseling or psychotherapy are denied care and placed at much higher risk of incarceration in the juvenile justice system.

Chronic Otitis Media (recurrent ear infection) fell below the line and is excluded even though it scored medium on effectiveness (3 out of 5), and even though Oregon’s Health Evidence Review Commission (HERC) concluded that 80% of affected individuals would need care – because the category weight was low (Non Fatal condition = 20), and because HERC staff concluded that “impact on healthy life” for a child with chronic otitis media was low (2 out of 10), even though it can result in [severe complications](#) if left untreated, including permanent hearing loss and problems with speech and language development.

Prioritization of Selective Mutism, Conduct Disorder, and Chronic Otitis Media with [HERC Methodology](#):

Factor:	Selective Mutism (line 473)	Conduct Disorder (line 479)	Chronic Otitis Media (line 475)	Range:
Category Weight	20*	20*	20*	1 to 100
Impact on Healthy Life:	1	5	2	0 to 10
Impact on Suffering:	1	3	1	0 to 5
Population Effects:	0	2	0	0 to 5
Vulnerable Population:	0	2	0	0 to 5
Tertiary Prevention:	1	1	1	0 to 5
Effectiveness:	4	1	3	0 to 5
% Need for Service:	80%	70%	80%	0% to 100%
Total Score:	192	182	192	

* Nonfatal Conditions, Where Treatment is Aimed at Disease Modification or Cure

For children whose families can afford commercial insurance plans, coverage of all three conditions is required under Oregon and Federal law as an “Essential Health Benefit” – insurers would face severe civil penalties for refusing to provide coverage.

Oregon’s vulnerable youth deserve better. It is time to end this failed experiment relying on discrimination to ration care.

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.

Issue Brief: How the Oregon Health Plan Discriminates

The Oregon Health Plan (OHP) delivers Medicaid and EPSDT under a Section 1115 demonstration waiver ranking health care services in a prioritized list from most to least important. Only services over a certain line are funded regardless of individual determinations of medical necessity.

In 1992, Oregon submitted a waiver application relying on the quality-adjusted life year (QALY) to prioritize services for coverage that was denied by the U.S. Department of Health and Human Services as violating the Americans with Disabilities Act (ADA):

“Our principal concern is 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.” [New York Times, HHS Secretary Louis W. Sullivan, M.D.](#)

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 quality-adjusted life year (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 override the results of non-QALY considerations, which they did in over 70% of the cases. The outcome for how care is valued and prioritized is the same:

“Because most objective measures representing health outcomes were not allowed, the subjective collective judgment of the Commissioners became more of a factor. As a result, many of the public values on health that had been expressed through the community meetings, the telephone survey, and in public testimony were reflected through the application of Commissioner judgment in the final prioritization process.” [Bob DiPrete and Darren Coffman, A Brief History Of Health Services Prioritization In Oregon.](#)

Today, the Health Evidence Review Commission (HERC) website explicitly describes the use of QALYs in its cost effectiveness framework, and it is embedded in the prioritization formula.

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. The process uses QALYs both explicitly – as a direct part of the formula – and implicitly, through QALY-based analyses of factors within the formula:

$$Score = \left(\begin{matrix} \text{Category} \\ \text{Weight} \end{matrix} \right) \times \left[\begin{matrix} \text{Impact on Healthy Life} \\ + \text{Impact on Suffering} \\ + \text{Population Effects} \\ + \text{Vulnerability of Population} \\ + \text{Tertiary Prevention} \end{matrix} \right] \times Effectiveness \times \left(\begin{matrix} \% \text{ Need for} \\ \text{Medical} \\ \text{Services} \end{matrix} \right)$$

Under this category weighting scheme, preventative services start with a category weighting multiplier of 95 – more than double that of care to cure a fatal illness, with a weight of just 40, and nearly 5 times the weight of services for nonfatal conditions. As an example, a routine dental exam is considered preventative, so it has a weight of 95 – while an appendectomy to treat appendicitis, or surgery to remove a treatable cancer would have a weight of just 40.

After the category weight, five population and individual impact measures are summed together - Impact on Healthy Life (sometimes referred to as Impact on Health Life Years and reflecting QALY inputs); Impact on Suffering Population Effects; Vulnerability of Population Affected; and Tertiary Prevention. The scores for these five factors are proposed by the HERC Medical Director and confirmed or amended by a vote of HERC's Value-based Benefits Subcommittee. 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 the Institute for Clinical and Economic Review (ICER) as they vote.

The final two factors in the formula – effectiveness and need for medical services – are multiplied together into an “effectiveness” score. The “effectiveness” score is proposed by the HERC Medical Director based on a review of medical evidence and factoring in QALY-based cost effectiveness analyses and confirmed or amended by the HERC Evidence-based Guidelines Subcommittee with this QALY-based framework:

“The cost of a technology will be considered according to the grading scale below, with “A” representing compelling evidence for adoption, “B” representing strong evidence for adoption, “C” representing moderate evidence for adoption, “D” representing weak evidence for adoption and “E” being compelling evidence for rejection:

- *A = more effective and cheaper than existing technology*
- *B = more effective and costs < \$25,000/LYS or QALY > existing technology*
- *C = more effective and costs \$25,000 to \$125,000/LYS or QALY > existing technology*
- *D = more effective and costs > \$125,000/LYS or QALY > existing technology*
- *E = less or equally as effective and more costly than existing technology”*

[Prioritization of Health Services: A Report to the Governor, 2013](#), p. 24. (**Emphasis** added)

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.

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. 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. (See for instance [“Death Drugs Cause Uproar in Oregon. Oregon woman denied drugs for lung cancer, but offered assisted-death drugs,”](#) ABC News, 2008)

Below the line – examples of excluded services for disabilities:

- Selective Mutism (psychotherapy recommended)
- Otosclerosis (hearing aid, cochlear implant or surgery options)
- Bell's Palsy (facial palsy, medication and physical therapy often recommended)
- Spastic Diplegia (form of cerebral palsy, physical therapy recommended)
- Personality Disorders Excluding Borderline and Schizotypal (psychotherapy recommended)

[Prioritized List of Health Services](#), Oregon Health Authority website.

Oregonians deserve better. It is time to end this failed, discriminatory experiment.

Disability Rights Oregon (DRO)

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