

October 1, 2016

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Ms. Vikki Wachino
Deputy Administrator and Director
Center for Medicaid and CHIP Services
U.S. Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Re: Public Comment on Oregon's 1115(a) Medicaid Demonstration Waiver Renewal Application

Dear Ms. Wachino,

Thank you for the opportunity to provide comment on Oregon's 1115(a) Medicaid Demonstration Waiver Renewal Application.

I am a private citizen, and a volunteer consumer advocate on behalf of individuals with autism and other disabilities. I volunteer my time independently, through an ad-hoc grass roots organization I created called "Autism Insurance for Oregon" which has approximately 750 participants; and through Autism Speaks, the Autism Society of Oregon, and other organizations. Over the past few years, I have written and passed several Oregon laws improving patient access to health care; helped expand mental health parity protections to all children with developmental disabilities in Oregon by administrative rule; and worked with the Oregon Health Authority and Health Evidence Review Commission to enhance Medicaid coverage. I have also assisted well over 100 individual consumers with various aspects of appeals related to both commercial insurance and Medicaid coverage, and have served as a consultant on several state and federal class action lawsuits over improper denials of care.

Please do NOT approve the extension of the Oregon Health Plan until several critical issues are fixed – regarding the EPSDT Waiver; consumer representation on the Health Evidence Review Commission (HERC); and Oregon's inadequate appeal and enforcement procedures.

These flaws with the waiver application violate the intent of the social security act, and do not promote its objectives, as required by Sec. 1115. [42 U.S.C. 1315] (a).

EPSDT Waiver:

Oregon's application seeks to renew the "EPSDT" clause in Oregon's existing waiver:¹

"6. 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 of services required to treat a condition identified during an EPSDT screening to the extent that the services are beyond the scope of the benefit package* available to the individual. The State must arrange for, and make available, all services within the scope of the benefit package available to the individual that are required for treatment of conditions identified as part of an EPSDT screening. (Applies to all Populations above.)" (*emphasis added*)

This directly contradicts the U.S. Department of Health and Human Services explanation of EPSDT:²

"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 follows³:

"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 opinion⁴ 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.⁵

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. Indeed, during

¹ OHP Special Terms, Conditions, and Accountability Plan, NUMBER: 21-W-00013/10 and 11-W-00160/10, page 5, section "6. Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)", <https://www.oregon.gov/oha/OHPB/Documents/special-terms-conditions-accountability-plan.pdf>

² <http://mchb.hrsa.gov/epsdt/overview.html#1>

³ <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>

⁴ Deanna Laidler, Sr. Assistant Attorney General, Oregon Department of Justice, to Darren Coffman, Director, Health Evidence Review Commission, "Mental Health Parity and Rehabilitative Therapies," March 9, 2016; attached as JUSTICE-#7133424-v2-Mental_Health_Parity_and_Rehab_Therapy.pdf

⁵ 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>

discussion in a recent (May 19, 2016) HERC Value-based Benefits Subcommittee hearing on rehabilitative care under EPSDT, members openly discussed their “purpose” to impose “limits” on care to save costs.

One recent example involves inpatient behavioral health care for self-injurious behavior. While HERC created a specific line (line 442, and guideline note 126) for “STEREOTYPY/HABIT DISORDER AND SELF-ABUSIVE BEHAVIOR DUE TO NEUROLOGICAL DYSFUNCTION” in response to testimony by Christie Riehl, a mother seeking coverage for her daughter, HERC neglected to include any in-patient treatment codes on this line. When Christie’s daughter, an EPSDT-eligible patient age 18, attempted to seek coverage under this line created in response to her mother’s testimony, she was denied coverage of life-saving inpatient behavioral health care, without regard to medical necessity and with no opportunity to appeal for coverage of “below the line” or unlisted treatment codes.⁶

Recommendation: The EPSDT clause in Oregon’s section 1115(a) waiver should be removed. Oregon should be required to comply fully with EPSDT, to ensure that all EPSDT-eligible children receive the medically necessary care that Congress intended, without rationing.

HERC Membership:

Membership of the Health Evidence Review Commission (HERC), which develops the prioritized list of healthcare services, lacks true consumer representation and has too much insurer / CCO representation. The clause on HERC membership should be tightened to ensure that Oregon truly provides the representation it has promised.

Oregon’s application seeks to renew the existing description of the Health Evidence Review Commission (HERC) in the waiver as follows:⁷

“The Health Evidence Review Commission (HERC) prioritizes health services for the Oregon Health Plan. The HERC is administered through the Office for Oregon Health Policy and Research. The Commission consists of thirteen members appointed by the Governor, and includes five physicians, *two health consumers*, one dentist, one behavioral health representative, one complementary and alternative medicine representative, *one insurance industry representative*, one retail pharmacist and one public health nurse.”
(*emphasis added*)

In practice, HERC has several insurance industry representatives, and no bonafide consumer representatives.

⁶ “Oregon Woman Assails 'Alarming Gaps' in Care Coordination Between OHA and Other State Agencies,” The Lund Report, <https://www.thelundreport.org/content/oregon-woman-assails-alarming-gaps-care-coordination-between-oha-and-other-state-agencies>

⁷ OHP Special Terms, Conditions, and Accountability Plan, NUMBER: 21-W-00013/10 and 11-W-00160/10, page 21, IV. THE OREGON HEALTH PLAN / 18. Overview of the Oregon Health Plan (OHP) / f. Prioritized List of Health Services / i. Oversight / 1. The Health Evidence Review Commission (HERC), <https://www.oregon.gov/oha/OHPB/Documents/special-terms-conditions-accountability-plan.pdf>

Of the current membership, the following three are executives, employees, or board members of insurance companies or CCOs:

- Holly Jo Hodges, MD, Medical Director for WVP Health Authority, working with the Willamette Community Health Coordinated Care Organization, officially serves as the “Industry Representative” on HERC
- Dr. Wiley Chan, Director of Guidelines and Evidence-based Medicine for Kaiser Permanente Northwest, a health care services contractor (health insurer) and CCO; officially serves as a “Physician” on HERC.
- Chris Labhart, board member of Eastern Oregon Coordinated Care Organization, a CCO; officially serves on HERC as a “Consumer Representative”

The two official “consumer representatives” are:

- Mark Gibson, Director of the OHSU Center for Evidence-based Policy in Portland, holds a major consulting contract for HERC, and advises other Medicaid agencies and CCOs about coverage policy.
- Chris Labhart, a Grant County Commissioner – but is also a board member of Eastern Oregon Coordinated Care Organization, a CCO.

Both Mark Gibson and Chris Labhart clearly have significant contributions to make, but neither are bonafide consumer representatives – Mr. Gibson is a paid consultant to OHP and other state Medicaid agencies, and Mr. Labhart is a CCO board member.

Membership on HERC’s subcommittees is even further skewed towards the health insurers and CCOs, with major decisions being made by subcommittees in which industry representatives actually have a majority vote.

Recommendation: The HERC membership clause in Oregon’s section 1115(a) waiver should be clarified to specify:

- No more than one HERC member may be an executive, employee, or board member of an insurance company or CCO
- Consumer Representatives must be bonafide consumer representatives who are either (a) Medicaid recipients, or the parents or guardians of Medicaid recipients; or (b) representatives of non-profit advocacy organizations representing the needs of Medicaid consumers

Oregon’s Inadequate Appeal and Enforcement Procedures

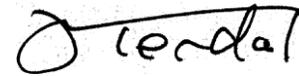
Recently, dozens of children with autism have been arbitrarily denied coverage of Applied Behavior Analysis therapy by the CCOs, despite the fact that this treatment is specifically included on the “prioritized list.” CCOs have been imposing unreasonable coverage criteria that directly contradict the list: while the list has two separate “lines” for ABA therapy – an autism line and a separate line for self-injurious behavior – the CCOs have been denying all therapy unless patients have BOTH autism and self-injurious behavior.

Once patients are denied coverage by the CCO and exhaust their internal appeal, the only remaining option is to appeal to an administrative law judge, in which the unrepresented Medicaid enrollee is pitted against a CCO attorney in a court proceeding. There are no provisions for Independent Medical Review.

Further, the Oregon Health Authority has advised me directly that while it is aware that the CCO's denials of autism coverage appear to violate the terms of the prioritized list, but that it lacks any enforcement authority to require compliance.

Recommendation: As a condition for approval of the waiver, Oregon should be directed to improve its appeal processes, to include Independent Medical Review; and to provide direct enforcement authority through a state government agency.

Sincerely,

A handwritten signature in black ink that reads "P. Terdal". The signature is written in a cursive, slightly slanted style.

Paul Terdal