

From: [Wendy Chan](#)
To: [1115 Waiver Renewal](#)
Subject: Letter of Support
Date: Wednesday, January 5, 2022 8:15:08 AM

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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

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

Dear Ms. Hatfield:

Thank you for 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.

My 14 year old son Blake is autistic. This year, Blake grew 10 inches and 70 lbs and became adult sized. Blake can be aggressive. This fall we had to call 911 multiple times, Blake has lived in the ER for two 1 week periods, he has had two 2 month stays in psych wards in UCLA and now at Unity where they wanted to discharge Blake last week even though he attacked staff where they were left bleeding (and Blake was bleeding), multiple times in the 48 hours prior to discharge. When I refused to pick up Blake, they called DHA.

Multiple agencies are involved now and trying to help but the bottom line is that Oregon has no place for Blake – neither from a medical treatment facility nor a residential or therapeutic facility. I am left desperately searching for a placement where Blake can be safe and those are out of state.

Blake needs inpatient ABA and there is no place he can receive this in Oregon. This urgent and required care should be covered by his Medicaid insurance. We are trying our best to take care of our son and other siblings, but Oregon as a state has failed in supporting Blake. We have no where to turn and need to go out of state for his continued care. Blake spent 2 months at UCLA Resnick Psychiatric Hospital this summer.

Blake does not want to do any of these harmful behaviors. He is completely remorseful and feels terrible whenever he is in a rage. He pleads with me to ask me when this behavior will stop. It's heartbreaking. But he feels a compulsion to do it, or he cannot control his rage when some small random thing does not go as he expected.

Also, medical companies have refused to transport Blake because of a new Oregon law that comes into effect today - SB 710. So even if Blake gets into these out of state facilities, I don't know how I will transport him there.

To this end, I recommend 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 services⁷ 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,
Wendy K Chan