



December 29, 2021

Dana Hittle
Interim Deputy State Medicaid Director
500 Summer St. NE, E65
Salem, OR 97301

RE: Oregon 1115 Demonstration Waiver for the Oregon Health Program

Dear Deputy Director Hittle:

The National Multiple Sclerosis Society (the Society) appreciates the opportunity to submit comments on the Oregon 1115 Demonstration Waiver for the Oregon Health Program.

Nearly one million people are living with multiple sclerosis (MS) in the United States, more than twice the original estimate. MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling, to walking difficulties, fatigue, dizziness, pain, depression, blindness, and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS.

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families, and the Society is committed to ensuring that Medicaid provides adequate, affordable, and accessible healthcare coverage. The Society appreciates the focus that the Oregon Health Program has placed on equitable access to healthcare in the 1115 Demonstration Waiver. In addition, Oregon's request to provide multi-year continuous enrollment for all beneficiaries ages six and over will help to eliminate gaps in coverage.

Unfortunately, this waiver contains multiple proposals that undermine access to care for people living with MS. The Society is most concerned with the proposed closed formulary for adult beneficiaries, which will make it harder for people living with MS to access the medications they need to stay healthy. Additionally, we also see issues in Oregon's proposals to continue to limit retroactive coverage for nearly all Medicaid beneficiaries as this will continue to significantly jeopardize access to care for people living with MS.

The Society therefore offers the following comments and suggested changes to the 1115 Demonstration Waiver renewal for the Oregon Health Program.



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Continuous Eligibility

The Society supports the request for continuous enrollment for children under six and two-year continuous eligibility for beneficiaries over the age of six. Continuous eligibility reduces gaps in coverage that prevent patients from accessing the care that they need. Continuous eligibility increases equitable access to care, as studies show that children of color are more likely to be affected by gaps in coverage.ⁱ Research has also shown that individuals with disruptions in coverage during a year are more likely to delay care, receive less preventive care, refill prescriptions less often, and have more emergency department visits.ⁱⁱ For patients living with MS, delaying access to treatment will almost always result in increased disease activity, loss of function, and possible irreversible disability progression. Continuous eligibility will help reduce these negative health outcomes.

Closed Formulary

The Society is most concerned by the proposal to transition to a closed formulary for adult beneficiaries. A growing body of evidence indicates that early and ongoing treatment with a Food and Drug Administration (FDA) approved disease-modifying therapy (DMT) is the best way to manage the MS disease course, prevent accumulation of disability, and protect the brain from damage due to MS.

Fortunately, there are now over 20 FDA-approved DMTs for different forms of MS. The full range of MS DMTs represent various mechanisms of action and routes of administration with varying efficacy, side effects and safety profiles. No single agent is ‘best’ for all people living with MSⁱⁱⁱ. As MS presents differently in each individual, every person’s response to a DMT will be unique. In fact, it is critically important that payers, payment models, delivery systems, and the health care stakeholders at large recognize that despite similarities in their indications and usage, these medications are not therapeutically interchangeable. It is not uncommon for people to work their way through several of the medications as they find the one that stabilizes their disease, or as different medications stop working for them. Thus, a closed formulary limits the ability of MS providers and specialists to make key medical decisions for the care of their patients.

Closed formulary proposals also represent a significant departure from traditional Medicaid policy. A closed formulary requires Oregon waive the requirement of compliance with Section 1927 of the Social Security Act. It is through Section 1927 of the Social Security Act that Congress established the drug rebate program in which all pharmaceutical manufacturers must provide rebates or discounts on the price of drugs in the Medicaid program. Through this rebate program, state Medicaid programs receive the best price for covered drugs. In exchange for participation in the rebate program, Congress requires state Medicaid programs to cover almost all drugs produced by participating manufacturers. This means that the drug rebate program has the effect of not only guaranteeing low prices to states, but also ensuring broad access to crucial medications for low-income people. Under current law, states can use preferred drug lists and require prior authorization before coverage is granted, but they are not allowed to utilize closed formularies.



Refusing to cover medications also interferes with the healthcare provider's ability to exercise discretion and identify a personalized approach for the person they are treating. This personalized approach is key in successful management of chronic conditions like MS. In addition, impeding healthcare providers' ability to prescribe the right treatment for a person with MS could potentially drive-up costs for the state, because when a person with MS receives the wrong treatment, they may end up needing more intensive and costly services down the road. In fact, there is evidence to this effect that closed formularies are unhelpful as cost-cutting measures. Reviews of more than 90 recent studies demonstrate that formulary restrictions are a lose-lose proposition: they are harmful to people's health, *and* they do not save money.^{iv} The Society appreciates the states intention of cost control in Medicaid system overall, but the real, demonstrable harms to people living with MS and other chronic conditions that could result from a close formulary is clear, while the savings are not.

The Society also highlights that Oregon's proposal does not include an appeals process for patients to access non-formulary medications. However, even an appeals process or exemptions for certain classes drugs would not eliminate the barriers to care which patients would face with a closed formulary.

The Society asks the Oregon Health Program to amend the 1115 demonstration waiver to incorporate the changes recommended above to ensure Oregonians can continue to access the medications they and their health care providers agree is the most beneficial for the person living with MS. We ask that the waiver renewal application be amended to so Oregonians continue to benefit from a robust, open formulary which allows people living with MS and other chronic diseases to access the full range of medications available.

Retroactive Coverage

The Society is lastly concerned by the proposal to continue to eliminate retroactive coverage for nearly all beneficiaries, excluding the aged, blind, and disabled. Retroactive eligibility in Medicaid prevents gaps in coverage by covering individuals for a set amount of time prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame. It is common that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Eligible applicants may also delay necessary healthcare until the Medicaid enrollment process is complete, which can increase their health risks and exacerbate any health conditions that they may have.

Retroactive eligibility allows patients who have been diagnosed with a serious illness, such as MS, to begin treatment without being burdened by medical debt prior to their official eligibility determination. In Indiana, Medicaid recipients were responsible for an average of \$1,561 in medical costs with the elimination of retroactive eligibility.^v Without retroactive eligibility, Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy.

Patients with underlying health conditions who are unable to access regular care are often forced to go to emergency rooms and hospitals if their conditions worsen, leading health systems to provide more uncompensated care. For example, when Ohio was considering a similar provision in 2016, a consulting



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firm advised the state that hospitals could accrue as much as \$2.5 billion more in uncompensated care as a result of the waiver.^{vi} Increased uncompensated care costs are especially concerning as safety net hospitals and other providers continue to deal with limited resources and capacity during the COVID-19 pandemic. Limiting retroactive coverage increases the financial hardships to rural hospitals that absorb uncompensated care costs. The Society opposes the continued limitations to retroactive coverage and encourages the state to expand retroactive and presumptive coverage to include all Medicaid beneficiaries.

Thank you for the opportunity to provide comments.

Sincerely,

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ⁱ Osorio, Aubrianna. Alker, Joan, “Gaps in Coverage: A Look at Child Health Insurance Trends”, Center for Children & Families (CCF) of the Georgetown University Health Policy Institute, November 21, 2021. [Gaps in Coverage: A Look at Child Health Insurance Trends – Center For Children and Families \(georgetown.edu\)](https://www.georgetown.edu/sites/georgetown.edu/files/2021-11/Gaps_in_Coverage_A_Look_at_Child_Health_Insurance_Trends_-_Center_for_Children_and_Families_(georgetown.edu).pdf)

ⁱⁱ <https://aspe.hhs.gov/sites/default/files/private/pdf/265366/medicaid-churning-ib.pdf>.

ⁱⁱⁱ MS Coalition. The Use of Disease Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence. http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color. Accessed December 26, 2018.

^{iv} Yujin Park et al., The Effect of Formulary Restrictions on Patient and Payer Outcomes: A Systematic Literature Review 23 J. Managed Care & Specialty Pharm. 893, 898 (2017) and Laura E. Happe et al., A Systematic Literature Review Assessing the Directional Impact of Managed Care Formulary Restrictions on Medication Adherence, Clinical outcomes, Economic outcomes, and Health Care Resource Utilization 20 J. Managed Care & Specialty Pharm. 677, 681 (2014)

^v Healthy Indiana Plan 2.0 CMS Redetermination Letter. July 29, 2016. Available at: <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-lockouts-redetermination-07292016.pdf>

^{vi} Virgil Dickson, “Ohio Medicaid waiver could cost hospitals \$2.5 billion”, Modern Healthcare, April 22, 2016. (<http://www.modernhealthcare.com/article/20160422/NEWS/160429965>)