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Oregon State Legislature
Joint Ways and Means Subcommittee on Human Services
Chair Campos
900 Court Street NE
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Dear Committee Members,

Testimony in Support of Full Funding for Oregon's Medicaid Program

Thank you for taking the time to consider the public testimony regarding the 2025 Medicaid budget.

I strongly support the full funding of Oregon's Medicaid program, as my own life and the life of my son depend on it. Without Medicaid, we would not be alive today.

I was born and raised in Oregon, and like many families (pre-2008), we struggled to cover my escalating healthcare costs under private insurance due to the complexity of my medical condition. As a result, my family often delayed seeking medical care and postponed essential treatments because of financial constraints. We were not middle class. I was born with a genetic condition that didn't get diagnosed until I was 19 years old due to the cost to see specialists, I had to wait to qualify for Oregon Health Plan (OHP). At this point much of the medical care I already had received made my condition worse due to misdiagnosis. While I am incredibly grateful to have access to health coverage it comes with significant constraints that have limited my ability to access proper timely treatment.

In 2008, at the age of 18, I became eligible for both Social Security and the Oregon Health Plan (OHP). While my care has always been difficult to manage, the expanded coverage under the Affordable Care Act (ACA) (also commonly referred to as the Obama Health Plan) has significantly reduced my medical debt. In 2012, I also became eligible for Medicare, which provided dual coverage and theoretically improved my overall healthcare access with reduced out-of-pocket expenses. However, many medical providers began limiting the number of patients they would accept with dual coverage due to the extremely low reimbursement rates. (These rates are very similar to Medicaid)

For example, a leg CT was billed at \$168, Medicare paid \$39.
Psychiatric visit- billed \$235, paid \$62.74.
Echo needed for pre-op testing billed \$710, paid \$57.22.
Urgent care visit for a UTI- billed \$334, paid \$37.67.

For an inpatient hospital stay Medicare paid \$63,000 in 2024 for a four-level spinal fusion but only paid \$1847.90 out of \$16,998.95 of the surgeon's costs including time and equipment which he ultimately wrote off to give me a break. In the end I paid \$2800 as my co-pay for an out of state procedure (plus flight, lodging, transportation, food and prescriptions). If it wasn't for the kindness of my surgeon I don't know where I would be right now.

I am breaking this down because my condition is so complex there are limited physicians comfortable treating patients like me. There are less than 5 neurosurgeons in the world that perform the very specific cervical fusion that helped me regain functionality. Having access to care is only one piece if we cannot access the proper types of care, it becomes a wash spending year through revolving doors being shuffled from one doctor to the next. Oregon currently does not treat or recognize the treatments identified for Ehlers- Danlos Syndrome, our largest hospital system (OHSU) has openly stated they will not treat patients unless they fit within a specific subtype/parameters.

Imagine having a very specific break on your hand, and the specific procedure you need can only be performed by a handful of surgeons. Unfortunately, your insurance doesn't cover any of them, what do you do? As time goes on the disability becomes worse, perhaps creating a now chronic pain condition because you can't access the treatment. If you are like thousands of Oregonians, you figure out how to change your lifestyle until there are no more options. Now if you had the ability to get to the proper surgeon and have the surgery, suddenly you don't need all these additional services, lost wages etc. It's a different financial picture.

I know of patients right now who are homeless or living out of their car (as I once was), trying to save every penny to get access to the care they need so they can get back on their feet. Every day becomes a fight to survive and stay alive.

Over the years, Oregon has made tremendous progress in expanding healthcare coverage beyond traditional doctor visits and prescriptions. The state has focused on addressing critical issues that affect health outcomes, such as community health workers, housing instability, behavioral health services, and long-term care. These areas are essential for addressing healthcare at its root causes, and any reduction in services would have a devastating impact on the health and well-being of thousands of families across the state, including my son and me.

While I understand there are concerns about the current administration and federal funding for state programs, I urge this committee to reflect on the substantial strides Oregon has made in safeguarding its most vulnerable citizens. According to Elmaleh-Sachs et. Al. Dually eligible Medicare and Medicaid patients total over 12 million Americans and are among the poorest and sickest in the United States. We must continue to expand coverage and collaborate with our healthcare providers to address the challenges in accessing medical and behavioral care.

Throughout my adult life, I have worked tirelessly to stabilize my health so that I could contribute to society. But life has pushed me into advocating for changes at various levels to address the needs of patients with complex healthcare conditions. My value to society is no less than anyone who is healthy and able to work a full-time job—a concept I have only recently come to accept. For some of us, healthcare costs are greater than most people's annual salaries,

and we need more assistance from the state until our country has a stable healthcare system in place. In 2024 alone I spent over \$10,000 out of pocket in healthcare costs not covered by Medicare or Medicaid. I went to churches, non-profits and sought out any resource available to cover the mounting out-of-pocket expenses. This was a struggle, met only by a combination of incurring credit card debts, personal loans and exhausting my meager savings. If I didn't have access to this, I would not be a functional person right now. For years I have existed so far below the poverty line unable to afford personal care items, much less co-pays on prescriptions or decent food.

Medicaid isn't just a lifeline for me but it's also for my son who was born at 29 weeks. The ability to focus on my son and his progress without concerns of mounting debt or choosing between food and medical care is my traumatic life experience. It is vital to me as a mother that my 5-year-old son have an opportunity to grow up healthy and enjoy childhood. Being able to understand his healthcare needs allows him to circumvent the pitfalls I went through which pivoted the trajectory of my life towards advocacy. Due to the expanded healthcare coverage in Oregon, I was able to get through my pregnancy and access the care needed during that life changing ordeal. My son can access healthcare services and better coordinated care thanks to Oregon covering all kids. Providing this vital safety net early on gives him a greater chance at thriving in this lifetime.

I would much rather be investing my time in living a life outside of constant advocacy—fighting for basic health coverage, filling out countless forms, and struggling to keep up with the ever-changing regulations that dictate which services I am eligible for. These administrative burdens ultimately impact my daily ability to function. I am fully dependent on IV fluids through a port in my chest. I require assistance with long term care services due to going through over 33 surgeries and being without family support. My only option in this lifetime was to fight with every ounce of my being from falling through the existing cracks of our current healthcare system or allow my health to take me. I want to live, and I deserve to exist outside of the constant state of survival mode. (See appendix A to see national disability healthcare related expenses).

Oregon must continue to protect and strengthen its healthcare system. This is the foundation we Oregonians all rely on. Without health, nothing else is possible. Please understand: the more complex the care need, the more help we need -- not less. The more fragmented our care becomes it places a massive burden to exist day to day. The rate of unemployment for disabled people is 80% (Bureau of Labor and Statistics) (See Appendix B), those are folks unable to find accessible employment or able to keep their health stable enough to sustain gainful employment. Every single one of those folks is reliant on some type of welfare program to stay alive. We deserve a chance to exist beyond survival.

I am asking the committee to focus on the following:

- 1. Strengthen our current healthcare system by ensuring adequate funding and improving reimbursement rates for healthcare providers.** Support our providers by giving them the tools necessary to care for our patient population. (Costs of caring: AHA 2024)

2. **Explore ways to fund our healthcare system without relying solely on federal dollars**, so that we can maintain and expand access to critical services for all Oregonians.

3. **Focus on improving access to medical providers by improving reimbursement rates and decrease the paperwork burden placed on clinics and medical professionals.** Time and money is wasted arguing with insurance companies to get the coverage needed.

4. **Focus on improving complex patient care with more coordinated efforts and expanded access beyond the doctor's office.** (A small study published by The American Journal of Managed Care found that A complex care management program for high-need, high-cost Medicaid patients reduced total medical expenditures by 37% and inpatient utilization by 59%).

Please understand that I want to be doing so much more with my life, but this is where I believe God has placed me. Our system needs improvements and only when we focus on supporting the most fragile among us fully, will we finally grow as a better society.

I thank each one of you for your time and consideration of my plea for help.

Citations

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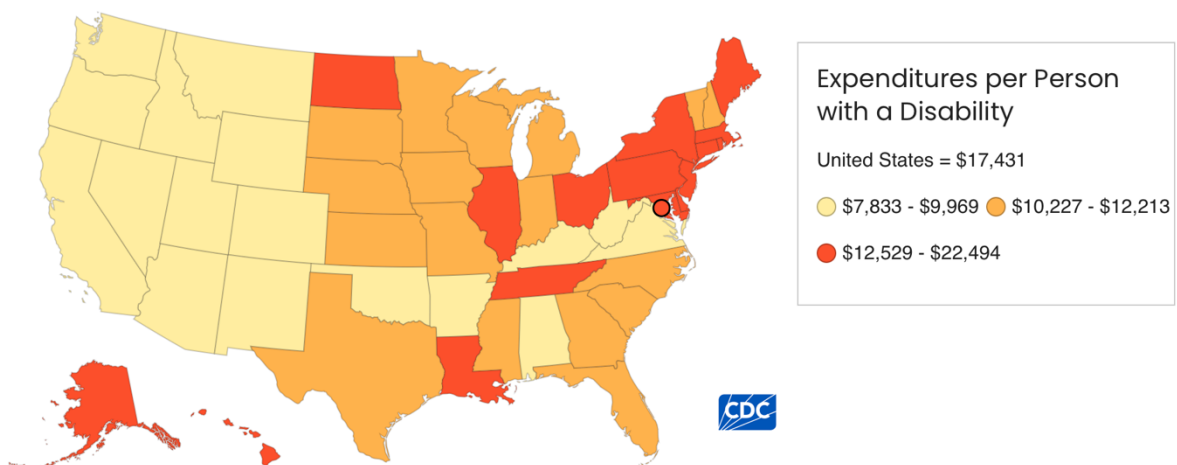
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Appendix

- In 2015, disability-associated healthcare expenditures accounted for 36% of all healthcare expenditures for adults residing in the United States, totaling \$868 billion, with state expenditures ranging from \$1.4 billion in Wyoming to \$102.8 billion in California. Of the national total
 - Medicare paid \$324.7 billion.
 - Medicaid paid \$277.2 billion.
 - Non-public sources paid \$266.1 billion.
- Healthcare spending for people with disabilities is determined by the cost of health-related services and the number of services used. Both vary across states and over time, which contributes to differences in healthcare spending across states.

For information on your state's total disability-associated healthcare expenditures, please review your [state's profile](#).

Estimated Mean Disability-Associated Healthcare Expenditures per Person with a Disability



Appendix A. 2015 estimated mean disability-associated healthcare costs per person with a disability in the United States.

Appendix B.

Disability employment in the US in 2018 and 2023⁴

	2018	2023
Total population of persons with disabilities	29.9 million	33.9 million
Persons of working age with disabilities (16-64 years)	15.1 million (51%)	17 million (50%)
Persons of working age with disabilities who are employed	4.4 million (29%)	6.3 million (37%)

Appendix B. Disability Employment in the US in 2018 and 2023. Looking at the Rate of Disability in the United States Compared to Rate of People Employed. Accenture. "The Disability Inclusion Imperative." Accenture, 2023, <https://www.accenture.com/content/dam/accenture/final/accenture-com/document-2/Disability-Inclusion-Report-Business-Imperative.pdf>