SB 909

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From 'Yes' to Silence: The Unfulfilled Promises of Oregon's Culture of Yes

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The Culture of Yes was not only a powerful piece of legislation, it brought hope to thousands of families like mine that the tides of change were on the horizon; that dignity, respect, understanding, collaboration, disability affirming care, and a seat at the table would soon become our reality. That unfortunately, has not been the case.

Senate Bill 909 is a fourth attempt at realizing the promise Oregon made to children experiencing serious emotional disturbances (SED) 12 years ago. First was the State Plan, which explicitly called out providing home and community based services (HCBS) to individuals who meet the level of care of “institution providing psychiatric services for individuals under age 21” (Psych Under 21 Benefit). However, no level of care criteria or assessment was produced, leaving families without desperately needed care- care they don’t even know they are entitled to. Second came Senate Bill 820 in 2023, which failed to be scheduled in Ways and Means. This simple bill would have required the Oregon Health Authority (OHA) to begin services for these children, with eligibility criteria required by January 1st, 2025. Third was Senate Bill 1557 in 2024, The Culture of Yes, which brought everything from Senate Bill 820 together with beautiful values, cross-agency collaboration requirements, and mandates for access to care. **A year after Senate Bill 1557 was passed into law, families and their children still have little hope of receiving the services they are entitled to**

Properly supporting children with severe mental health needs is deeply personal to me. Over four generations, I have witnessed firsthand how Oregon has failed to adequately support vulnerable populations. This failure led me to dedicate hundreds of hours over the past three years to research, advocacy, and policy and service improvement. **These three years were not just a test on an advocate's patience, resolve, and grit; it was also a test on how the state would respond to needed change. The results, unfortunately, have been heartbreaking.**

The Oregon Health Authority's own core values state *We communicate honestly and openly, and our actions are upfront and visible. We provide open access to information and meaningful opportunities to provide input and participate in our decision-making.* The Culture of Yes added additional values for the implementation of services to children and youth with serious emotional disturbances including *Children, youth and their families are the experts on their lives and needs and must be meaningfully included in all decisions about their individual services and supports and be meaningfully included in policy making and service design.* The lived reality of the past year reflects none of these values.

First, OHA contracted with the University of Connecticut (UConn) for $135,000 to report data on current services, recommendations, and implementation requirements. The report was contracted to outline the time, resources, and practical steps needed to bring these recommendations to fruition, including statutory, state plan, and policy changes, as well as infrastructure development. Additionally, UConn was tasked with recommending clinical criteria for the Psych Under 21 Benefit. To furnish this report, UConn was required to collaborate with families and youth with lived experience. Despite informing OHA ahead of time that I wished to be involved and expressing concerns that independent advocates might be excluded, OHA failed to invite me to any of the group sessions. After multiple requests, OHA staff provided an opportunity for my input, which consisted of verbally answering a three-question "feedback survey." It is also worth noting that the number of participants included in the reported engagement sessions included paid staff members.

The preliminary report, completed in October 2024, simply reiterated what we already know: the services Oregon provides to other populations and the services Oregon does NOT provide to children and youth with SED. The report also outlines the services that would be helpful for families and youth with SED. This raises an important question—Medicaid outlines which services states are eligible to provide, and the state decides which ones to offer. **So why does Oregon need convincing to provide services it is already mandated to offer?** The final report and clinical criteria recommendations were due by January 31, 2025, yet OHA has not furnished either document in response to public records requests.

Additionally, OHA launched a website for SB 1557 Implementation, which is not accessible from their homepage. This website includes a July 2024 memo to behavioral health systems regarding the prohibition of denying mental health services to youth with Intellectual and Developmental Disabilities, as required by SB 1557. However, there is no evidence of any additional work being done to enforce this prohibition. The website also lists monthly progress reports on SB 1557 implementation.

The first report, from June 2024, provides a timeline on implementation of HCBS with the "roll out" not scheduled until 2029! Further, the website contains a section for "Engagement Opportunities," which remains blank, despite reports stating that engagements are ongoing.

In August 2024, OHA contracted with Oregon Family Support Network (OFSN) for $460,000 to conduct additional engagement and reporting. The first report published in December 2024 recounts the stories from 21 parents and 12 youth, of crisis and failed support. While these stories are important to tell, no one at OFSN or OHA have been able to provide details on how these stories will be used to implement SB 1557. After all, the state is required to implement and provide HCBS for children and youth with SED. **Continuing to ask for traumatic stories of system failure without a direct line to implementation only reinforces the feeling of being heard but not listened to.**

Additionally, The OFSN contract deliverables by November 2024 included *developing leadership for ongoing convening of a group of families to provide feedback and recommendations to Medicaid* and *provide informational sessions with diverse families and youth to ensure they understand the intentions of SB 1557, know how youth and family engagement is envisioned as part of the work, and build the foundation for informed and meaningful engagement in the implementation.* Further, the contract includes *covenings to record and synthesize recommendations for the March 2025 legislative report* and *engaging with parents and youth on the level of care tool.* In the six months of contracted work, OFSN has only provided the December report and a listing of engagements in the January 2025 progress report. Despite direct inquiries, there is no information provided on how these engagement sessions move forward the implementation of HCBS nor how the public can engage directly.

Advocates know that the departments, agencies, and organizations- those doing the "work" (and getting paid for it)- hold all the power. Our involvement is only allowed when it is invited, on their terms, and when we remain dispassionate. The Culture of Yes set to change that status quo. However, I have yet to see a culture shift. Instead, I see OHA shifting responsibility to other organizations, failing to provide clear direction or demonstrate progress towards implementation, and even unable to disclose how many positions have been dedicated to this work. I see organizations working through intermediaries to selectively interview families, rather than openly involving all stakeholders- many of whom have been advocating alongside me for years. **I see massive contracts, spanning half a million dollars, with little to show and no accountability.**

SB 909 is desperately needed to keep the implementation of Home and Community Based Services for children with Serious Emotional Disturbances moving in the right direction. We are far past advocating for care, we already codified that access into law. It is time to implement. It is time to bring the most passionate advocates and family members to the decision making table.

It is time to turn the 'Culture of Yes' from the 'Culture of if I feel like it' to the 'CULTURE OF NOW.'

Medicaid Access Beyond Parental Income

Parental disregard of income is critical for ensuring that every child, regardless of their family's financial situation, can access the vital care they need. In Oregon, children with intellectual and developmental disabilities already benefit from parental income disregard under Medicaid, but extending this policy to include those with hospital level care needs and serious emotional disturbances is an essential next step. **A robust federal Medicaid match incentivizes states to invest in better care, making expanded coverage both practical and sustainable.**

Medicaid provides a crucial safety net for children with disabilities, ensuring access to essential healthcare services. Many families raising disabled children are unable to access full insurance coverage, making it difficult to afford essential health services such as counseling, psychiatric care, medications, and medical equipment. By expanding Medicaid eligibility through income disregard, more children can receive the care they need without their families facing financial hardship.

Expanding parental income disregard is especially important when considering the comprehensive support that home and community-based services (HCBS) provide. **These services not only help children avoid the isolation and disruption of hospital or inpatient care but also enable them to thrive in their home environments. Ensuring access to HCBS can significantly improve quality of life and long term outcomes for children with serious medical and emotional needs.**

Additionally, School Medicaid services ensure that children receive the support necessary to succeed academically and socially. Accessing School Medicaid services brings additional federal dollars into our schools, allowing for counseling services, one-to-one nursing, and physical and occupational therapy. These services create a holistic support system that benefits both families and communities.

Ultimately, disregarding parental income for Medicaid eligibility paves the way for more equitable access to care. By including children with hospital level needs and those with serious emotional disturbances, we can harness the federal match to boost state investment and ensure that every child has the support they need to lead a healthy, productive life.