

September 28, 2023
Legislative Days testimony
Senate Human Services Committee

Amy Fellows
Eugene, OR

I'm the parent of a 14 year old who has institutional trauma and betrayal from the medical, mental health and educational systems misunderstanding their complex needs as a Black Nonbinary late diagnosed Autistic child. This misunderstanding created and exasperated their mental health challenges.

They began experiencing very challenging distress behaviors when overstimulated around 18 months old. These were more than the typical toddler but as a first time parent I was not sure what was typical. By 4.5 after multiple daycare and preschool settings we were referred for an IFSP (early childhood IEP).

By 5.5 they had an inaccurate ADHD/ODD diagnosis and were sent on the stimulant med trials which made things worse. Medical racism often misdiagnosis Black Autistics as ODD. At the beginning of 1st grade when they were unable to handle the social dynamic in their Montessori school and was asked to leave I asked their Kaiser child psychiatrist for additional support. I said we needed wrap around services and she did not know what that was so she suggested a new medication which sent my child into 7 hours of manic aggressive behavior resulting in a 2 week hospitalization over my birthday, Halloween and their 7th birthday. This is my biggest regret in life. We were discharged into Intensive Community Treatment Services through Albertina Kerr and finally got 90 days of in home mental health supports.

It would take 4 more years and 3 full psych evaluations (costing me \$10k out of pocket with insurance) to finally get an accurate diagnosis of Autism and enter the DDS system.

If we had the option to get more in home supports sooner, maybe referred to a program like Psych under 21 through the IFSP process or by their child psychiatrist we could have avoided a traumatizing hospital stay that severely impacted our attachment and connection and we have had to work years to reestablish. Having access to PSW/DSP type in home supports would have given me a break and time to support my own mental health so I could better coregulate my child.

A further barrier to mental health supports was having commercial insurance. When we moved from Portland to Eugene (where we had family support) while in the Intensive Community Treatment Services period with private insurance I was unable to find any mental health professionals to support them. The only places that would support a child fresh from crisis only took OHP. This is an issue for many families and why this Psych Under 21 program could be so transformational for children in our state as we recover from the collective trauma of the pandemic.