

Submitter: Calli Ross

On Behalf  
Of:

Committee: Joint Committee On Ways and Means Subcommittee On Human  
Services

Measure: HB5026

Co-chair Campos, Co-Chair Valderrama and Members of the Committee,

My name is Calli Ross and I am writing on behalf of my son, Tennyson Ross. Tens experiences medical, intellectual and developmental disabilities. However, Tens is more than capable of expressing his opinion and communicating with those that know him best.

In 2020 Tens experienced a pulmonary hypertensive crises and coded for 33 minutes. I watched my little boy die and then I watched him fight to live. He recovered to an extent after a prolonged hospital stay and was released home, with, what was assumed, well under a year to live. This time frame happened to coincide with minors experiencing disability being allowed to choose their parent as their paid caregiver. I was able to stay by Tens' side, provide support and continuity of care while still making sure my family didn't sink into poverty; a well known side effect of raising a child with disabilities. Over the course of this time period we did what no doctor thought possible, we achieved stability. Today Tens is as healthy as he ever has been, he's spent longer periods outside the hospital than before and he enjoys more community involvement than prior even to Covid. I will tell you, praising myself makes me uncomfortable- but I know, without a shred of doubt, nobody can or will keep my son as healthy or provide him the quality of life I will. Nobody can do this, as the state itself defines it, "job" better than myself. The care I provide my son, the care any parent with a child receiving Medicaid Home Services provides, far exceeds natural parent supports.

I support fully funding ODDS because my child's very quantity and quality of life depends on it. Tens needs programs like the paid parent initiative in order to stay in his community, healthy and happy. Without this resource, Oregon's disabled children will be the ones to bare the brunt of the cost. To me, this is a moral issue and Oregon needs to land on the right side of history.

I would like to end this testimony with Tens' own words using his eye gaze device:

"Tens, who do you want taking care of you?"

"Bandit. Bluey. Bingo. Bandit"

"Ok, what HUMAN do you want taking care of you?"

"MAMA. MAMA. MAMA."

“Why do you want Mama to take care of you?”  
“Games. Help. Hugs. Games. Nutella”

Thank you,  
Calli Ross