

Submitter: Advocates For Disability Supports
On Behalf Of: Katie Zinno
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB538

ATTN: Legislators I am asking for your support of TENSY'S LAW (SB 538). Although parents of disabled adults can be paid caregivers, this option isn't available for children, leaving many young families with impossible choices. Tensy's Law would increase access to Oregon's Children's Extraordinary Needs (CEN) waiver; allow parents of minors to be personal support workers; and ensure this compensation comes from already-obligated funding. I am a single parent to an autistic child with serious health issues and he does not current qualify for the waiver due to his status being right below the cut off. What that means for us is that I must rely on welfare programs for housing, food, diapers and other necessities to allow us to survive. My son just started pre-k this year and due to illness has missed 15 out of 52 days since the start of the school year. This count doesn't include the early pick ups due to medical emergency or behavioral concerns. He has missed nearly 30% of the school year unable to get back up childcare which means that I must be on call 24/7. As you can imagine there are no employers willing to work with a parent in my situation requiring a flexible start/stop time, part time hours, remote work option that would pay enough to cover our support needs and therapies, co-pays and special diet foods. I am currently going back to school in attempts to find a pathway through this but also preparing for my child requiring to be homeschooled due to his sensory needs. Without the ability to get paid to care for my son even partially we are at risk of being homeless and reliant on welfare programs that are currently under attack with the current administration leaving us in uncertain waters. I lay awake at night scared for our future as I am also disabled with serious health issues navigating this system for both of us. My child doesn't sleep through the night at 5 years old that means I live chronically sleep deprived and my only respite is finding qualified care providers to offer overnights occasionally. I am the best advocate for my son but I am constantly torn between giving him the attention and focus he needs and wading through countless agencies and Medical Center's paperwork, phone calls, emails. It is literally a full-time job just to stay on top of it. This month alone we lost over \$400 in food stamps with no changes to our circumstances because the policy director has been auditing most accounts due to the recent fines imposed from the federal government for overpayments. Without the very specific supports my son needs he becomes violent, withdrawn and aggressive. On the flip side he is incredibly intelligent, compassionate and will thrive under the right circumstances. I am doing everything I can to prevent institutionalizing my child and giving him the tools he needs to succeed. Oregon has a legal and moral obligation to ensure that children with disabilities receive the care they are entitled to. The state already assesses the number of care hours a child needs, yet it consistently fails to meet these obligations due to workforce shortages. Tensy's Law is a simple solution: allow parents to be

paid caregivers, ensuring that children receive the care they are entitled to while keeping them in the homes they know and love. With regards, Katie Zinno Katie zinno