Submitter: Advocates For Disability Supports

On Behalf Of: Gwendolyn G Edde

Committee: Senate Committee On Health Care

Measure, Appointment or Topic: SB538

Dear Honorable Lawmakers, I am asking for your support of TENSY'S LAW (SB 538). I believe this can both save money efficiently and provide for better care in the long run. When I was growing up a child in my neighborhood had a medical episode that put him in this category - I can see how it's virtually impossible for both parents to work under such situations and he could not go to school, so the situation is above and beyond what the care of neurotypical kids is, and helping with this difference would be useful. Although parents of disabled adults can be paid caregivers, this option isn't available for children, leaving many young families with impossible choices. SB 538 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. Caring for a child with complex medical needs is a full-time job, yet many families are forced to live in poverty because the state refuses to compensate them for this labor. A staggering 75% of these families rely on public assistance, even though two-thirds say they could leave at least one assistance program if they were enrolled into CEN. 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. Thank you for your consideration. Gwendolyn G Edde