

Submitter: Angela Fleming
On Behalf Of: SB 538
Committee: Joint Committee On Ways and Means
Measure, Appointment or Topic: HB5006

My name is Angela Fleming, and I am writing to express my strong support for Senate Bill 538. This issue is urgent and requires our immediate focus. It is essential that every parent has the opportunity to act as a caregiver for their minor children who qualify under the criteria established by SB 91. We must address the current shortcomings in our system.

As a grandmother, I feel compelled to share my deep concerns. I am fortunate to have two remarkable grandsons, both of whom are eligible for the CEN waiver. While one grandson has successfully enrolled in the program, the other is still waiting, currently sitting at number 548 on the list. Both boys encounter a range of medical difficulties, including Autism, Down syndrome, atrioventricular septal defect (AVSD), ventricular septal defect (VSD) that necessitated open-heart surgery, airway collapse issues, food protein-induced enterocolitis syndrome (FPIES), various autoimmune disorders, type 1 juvenile diabetes, severe protein allergies, hypothyroidism, Crohn's disease, and colitis. One grandson has begun receiving biological home infusions, leaving his immune system weakened and fragile. During flu season, he cannot be exposed to illness, which makes it imperative for all visitors to be in good health.

It is vital that both of my grandsons are provided with a nurturing environment that prioritizes their health and safety, as detailed in the support programs established for them. They require a stable, calm, and predictable atmosphere to flourish, especially considering their unique and complex needs. The choice for parents to leave their children in the care of others is never straightforward, particularly when those children have such serious medical conditions. My daughter-in-law has had to leave her job entirely to care for the boys, while my son continues to work to support the family.

I have seen firsthand the challenges my son and daughter-in-law face in securing reliable care. The available workforce is insufficient, and often does not provide the level of care that my grandsons urgently need. They deserve caregivers who are not only committed but also fully qualified to care for them and ensure their safety and well-being. Living in a rural area has drastically limited my grandsons' access to attendant care services, making the option for a paid parent caregiver absolutely essential. I strongly urge you to consider providing equitable funding for each child on the waitlist, ensuring they receive 40 hours per week of paid parent home and community-based services (HCBS) tailored to their specific needs. My son has had to utilize numerous Family and Medical Leave Act (FMLA) days due to the extraordinary demands of caring for his children.

With over 35 years of experience supporting individuals with disabilities, my husband and I have dedicated our lives to this mission. We have attended countless state and national conferences advocating for the rights and needs of those with disabilities. Additionally, we have been actively involved in assisting individuals transition from institutional settings to community-based living arrangements, including managing group homes and running our own foster home for the past 12 years.

Drawing from my extensive experience, I can confidently assert that when a parent is able to provide care for their child, it is unequivocally the best option. The movement towards home and community-based services aims to ensure that every individual can thrive in the least restrictive living environment possible, and this principle should extend to children as well. We must consider the children—please address the systemic barriers that hinder my grandsons from accessing the most qualified caregivers: their parents, who are filled with love and dedication to their well-being. Please support SB 538 and prioritize these children in this legislative session.

Thank you for your attention to this vital issue.

Sincerely,
Angela Fleming
Roseburg, Or