Chair Patterson, Vice-Chair Hayden, and Members of the Committee,

Thank you for the opportunity to submit written testimony in support of Senate Bill 538.

My name is Lisa Ledson, and I am here today not just as a registered nurse and an advocate with Advocates for Disability Supports but as a mother—Hannah's mother. Hannah is my bright, funny, and determined daughter, who happens to live with quadriplegic cerebral palsy, hypoxic-ischemic encephalopathy (HIE), cortical visual impairment (CVI), intractable epilepsy, and is G-tube dependent. Hannah is a primary wheelchair user whose needs are complex. Still, her joy is simple—she loves connecting with her friends and family on her iPad using Kids Messenger, dancing to music, swimming, swinging, and traveling!

Hannah's Story: The Beginning On May 26, 2012, during Labor Day weekend, I was 32 weeks and 3 days pregnant with twin girls. I slept on the couch because my bed was no longer comfortable. As I rolled over, I felt my water break. My contractions intensified, and I immediately went to the hospital, where I was admitted due to being in active labor.

It was clear to me that a baby was trying to make her way out, and I repeatedly asked if I could push. I pleaded for more pain medication, but the nurse continued to say, "I am waiting for the doctor to respond." For 2.5 agonizing hours, one nurse struggled to capture all three of our heart rates. Finally, the dayshift operating room staff and a doctor arrived, and I was taken for a C-section due to Baby B being breech.

As I lay on the operating table, the nurse began placing a catheter, only to discover that Hannah's umbilical cord had prolapsed. This had gone undetected, and the situation suddenly became an emergency. When the doctors opened my abdomen, they found that Hannah's head had already entered the birth canal. The OBGYN stated to me in the recovery area, "I had to pull hard to get her out." When Hannah was born, she was not alive.

Hannah spent a month in the NICU, and my gut told me something was wrong. I asked countless questions, only to be met with gaslighting and blame placed on her premature birth, and "She's just premature." Eventually, after discharge, I could push for the testing I knew she needed with a doctor who would listen. It was then confirmed—that Hannah had suffered an anoxic brain injury during delivery, along with Hypoxic-Ischemic Encephalopathy and an intraventricular hemorrhagic brain bleed. None of these diagnoses were detected while she was in the NICU. I firmly believe that all of these injuries were preventable.

After years of reflection and conversations with the medical team that cared for us, one fact remains clear: **lack of adequate staffing** was the primary reason my daughter suffered her brain injuries that morning. Her disabilities are not her fault. Despite this, after years of therapy and immense gratitude that she survived and is thriving, I am left with one lingering question: **Why do families leave the NICU with no real access to in-home and community-based services, despite the medical and disability community knowing these children will need lifelong support?**

How can we, as a society, claim to believe in equal access to in-home and community-based support, yet families like mine are left to fend for themselves? No one offered help to my daughter—I had to fight for every resource, ask every question, and figure out how to make people listen to what she needed. And for years, until the pandemic arrived, we were barely staying afloat.

Why This Bill Matters for My Family For years, I have been Hannah's mom and one of her primary caregivers. Despite her significant medical and behavioral support needs, she is a child who deserves to grow up in a stable, loving, and familiar environment and have access to her community and a robust education. The ability to **be paid as Hannah's caregiver** ensures that she receives the highest level of support—support that no rotating workforce of strangers can replicate.

Hannah requires **24/7 monitoring and medication administration** due to her intractable epilepsy. She relies on her G-tube for nutrition, making daily routines complex and medically intensive. She requires a patient support provider who understands her autistic tendencies and can ensure that her sensory needs are considered regularly. These are not tasks that can be handed off to anyone; they require skill, experience, and an intimate understanding of her needs.

Without the ability to be her paid caregiver, I would be forced to navigate an impossible choice: **leave her care in the hands of an undertrained workforce or forgo financial stability.**

The Daily Impact of Parent Caregiving By being compensated for the care I already provide, I can:

- **Ensure stability in her daily routine**: Hannah thrives on predictability. With a rotating door of caregivers, she becomes anxious and unsettled.
- **Prevent unnecessary hospitalizations**: Studies, including those from Colorado, show that **paid parent caregiving reduces ER visits and hospital stays**, ultimately saving the state money.
- **Promote her independence**: Because I know her abilities intimately, I can encourage her growth and help her navigate the world in ways unfamiliar caregivers simply cannot.
- **Provide consistency in communication and advocacy**: I am not just her caregiver; I am her advocate at medical appointments, IEP meetings, and therapy sessions. A hired caregiver may be unable to fill that role with the same depth of knowledge and commitment.

The Fiscal Reality: A Small Investment for Full Inclusion The **Office of Developmental Disabilities Services (ODDS)** has reported the fiscal impact of fully funding the **Children's Extraordinary Needs (CEN) Program**. Their analysis shows that for the **25-27 biennium**, the General Fund cost of implementing SB 538 would be **$32.8 million**, and for the **27-29 biennium**, it would be **$55.9 million**.

While these figures may sound significant, let's put them into perspective: this is **a minimal amount of money compared to the cost of institutional care or emergency medical interventions** that occur when children do not have access to adequate home care. **This funding ensures community access and in-home support, making it an ethical and fiscally responsible choice.**

The **CEN program currently serves only 155 children** despite a **waitlist of approximately 1,600 children** who also qualify. The funding for this program is currently capped, **preventing hundreds of children with the most complex medical and behavioral support needs from accessing the services they need to thrive.** SB 538 ensures that these children are not left behind.

A More Cost-Effective, Family-Centered Approach Oregon costs significantly **less** to support **home-based care** than institutional care. By passing SB 538 and maximizing federal matching funds, the state can allocate resources **more efficiently**, ensuring children like Hannah get the support they need without adding financial strain to families or the healthcare system.

Conclusion Senate Bill 538 is not just about compensation—it is about ensuring that children with high medical and behavioral support needs **receive the best, most stable, and most effective care possible**. Oregon has an opportunity to lead the way in recognizing the value of parent caregiving. I urge this committee to pass SB 538 and give families like mine the support to keep our children safe, thriving, and at home where they belong.

Thank you for your time and consideration. Please pass SB 538 and support Oregon's most medically and behaviorally complex children and their families.

Sincerely, Lisa Ledson