

Submitter: Misty Faye

On Behalf Of:

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

Measure, Appointment or Topic: SB5547

To whom it may concern,

I am the mother of a child with significant intellectual and developmental disabilities (ID/DD). Every day of my life is centered around my child's care—not just in the typical ways parents support their children, but in every moment, every breath, and every action. I am my child's full-time nurse, teacher, protector, therapist, and advocate. My son qualifies for maximum hours but no caregiver is willing to take on his level of care.

My child requires constant supervision due to severe cognitive delays and a high risk of elopement. I cannot leave the room, let alone the house, without risking their safety. Bathing, eating, sleeping—nothing is simple. There are no days off, no shifts to hand over, and no time to rest. My child does not understand danger, cannot be left unattended, and depends on me for their most basic needs—emotionally, physically, and cognitively.

I have asked, applied, and waited—systems are either overwhelmed, underfunded, or simply not designed for kids like mine. Even programs that exist on paper often don't result in real, consistent, human help.

I am also a nurse. I care for others professionally, and yet there is no system that cares for me while I carry this 24/7 responsibility. My skills do not exempt me from exhaustion. My love for my child does not protect me from burnout. I live in a constant state of hyper-vigilance—exhausted, isolated, grieving a “normal” life while fiercely fighting for the safety and dignity of the one I was given.

The emotional toll is deep. I rarely sleep. I cry often. I worry about the future—who will care for my child if something happens to me? How will they survive in a system that barely sees them now? And still, every day, I get up and do it again.

I am sharing this not for sympathy, but for change. Families like mine fall through the cracks. Children like mine deserve care. Parents like me deserve support. Without it, we are breaking. Quietly, invisibly, and far too often, alone.

Sincerely,

Misty Faye BSN RN CCM.