

Submitter: Emily Dayton

On Behalf Of:

Committee: Senate Committee On Human Services

Measure: SB91

Dear Senate Committee on Human Services,

As a parent to a child who has disabilities and chronic, complex medical conditions, I support the importance of passing SB 91 in order to support my child's decision to be cared for and supported by her parents. However, there are huge discrepancies within SB 91 that must be addressed in order to have equitable access and support for all parents and children with disabilities.

The 30% cap of hours will exclude certain families, and make it challenging to support a child's autonomy of care. The bill was not created in collaboration with disabled parents and parents of children with disabilities to establish a program that is fully supportive and inclusive.

As an individual who has disabilities and is caring for a child who has disabilities, I can attest to the challenges with locating a qualified and loving caregiver for my child. We had 12 caregivers in 2 years rotating in and out of our child's life; which increased illness transmission, hospitalizations, and our families' concerns for our child's safety.

The impact of passing an inclusive bill that supports all parent caregivers to be paid to care for their disabled child will save the states millions in hospital emergencies and medical foster care.

I would like to see legislators working directly with parents and children with disabilities to establish supports that are equitable and impactful. As it stands SB 91 is exclusive and adds extra barriers to parents and disabled children. The added barriers regarding "acceptable activities" appears controlling and burdensome. Please include those of us who are impacted in this decision-making process.

Kind Regards,

Emily Fern Dayton, MS (She/They)
Anti-ableism activist/ Parent