

Submitter: Ezme Fern
On Behalf Of: Silverton
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB538

Dear Senator Patterson and members of the committee,

I am writing to you in support of SB 538, as a disabled parent who is raising a disabled child this bill if fully funded would be life changing for our family. Since the start of the ongoing pandemic we have been homebound in order to protect our child and myself.

We have strict illness mitigation protocols to ensure our child does not have breathing suppression and/or status seizures that require AMR support.

We have had an impossible time locating caregivers willing to wear N95 masks, and follow our doctor guidelines. In a few short months, we have had 4 caregivers in and out of our child's life. As society has moved on from Covid; our family is abandoned, forever stuck isolating at home.

In Fall 2022, we all caught Covid, and our already challenging medical caregiving became upended. Our child was turned away from emergency supports due to all pediatric hospitals being on triage.

We reached out to ODDS, to support us with a nurse, it was suggested that we "could place our child in medical foster care". No parent wants to place their child with strangers who do not have the skills to ensure their child's survival. The state was willing to institutionalize disabled children, and pay foster parents instead of supporting disabled families in times of crisis. We were terrified our child wouldn't pull through.

Immediately following this traumatic experience, my partner and I both caught serious cases of shingles. Mine developed into post herpetic neuralgia, a debilitating nerve pain that reemerges from stress. On top of that, I developed long covid.

My spouse was forced to give up his career in order to care for my child and myself. In order to be available for potential medical emergencies for our child or myself, he can only work a part time entry level job.

We are living check to check and do not have money to save for a wheelchair van to ensure my child's and my safety. My chronic pain and muscle weakness, make transporting our child dangerous and painful for me to do. There are no funding supports for this essential basic access. Thus, we rarely leave the house. Without

SNAPS and Medicaid we would not be able to make ends meet. I have been on the waitlist for SSI disability support for over a year.

If SB 538 were to pass, my spouse could get paid to support my child, and be able to be home with us when medical supports are needed for myself or our child.

Our child qualifies for 625 hours of caregiver support per month, 150 of those are 2 to 1 hours. The reality is we cannot fill the hours as there are not caregivers available. There has been an ongoing shortage for many years. The state knows there are not enough caregivers to support disabled families. Every week, I contact agencies and receive the same response; "we are still searching, but currently do not have caregivers available to fulfill your child's illness mitigations". Enable agency denied working with us, due to our Covid mitigations. They stated they could not require staff to follow the respiratory precautions we have in place to ensure our child's survival.

This is the game we play, constantly fighting against systems of oppression that are meant to support us, but prevent us from accessing basic supports.

We have 5 case managers, however the bulk of labor falls on myself. No matter how ill I am, I correct medical supply errors, coordinate care with neurology, nephrology, neurosurgery, and other clinics. Ongoing education providers about consent, about disability culture, about not objectifying my child and fighting for basic respiratory virus safety.

My time is spent fighting ableist, eugenics medical systems. Disabled families are fighting an uphill battle that is made more challenging by denying children's right to choose their caregiver. Please support the autonomy of disabled children by allowing them to choose their caregivers. Please fully support SB 538.

Regards,
Ezme Fern, they