Submitter: Hannah Grist
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB1565

Hello, I am writing this testimony with my disabled child on my lap. He’s plugged into his feeding pump getting his lunch. He’s on my lap because he has cerebral palsy and lacks almost all ability for voluntary movement. This means that during meal time, as food is pumped straight into his belly, when he gets uncomfortable and needs to burp he canno make that happen for himself. I am his mom and I do this for him. At each meal, four times a day, every day of the week, and every day of the year. Without burping it is very likely that he will become disregulated and vomit the entire contents of his newly filled stomach setting us back to square one.

After five years of life with my son I know his cues. I can get the burps out and prevent almost every single vomit.

This is one aspect of the daily care my son requires. Most of his needs are met by me or his dad. We get occasional help from family or professional caregivers but each helping hand requires supervision and expert support by one of us.

This high level of demand has set us up to receive 240 hours of attendant care a month. That’s 60 hours a week of professional support to help Henry in his daily activities of life. We have never been able to fill that number of attendant care hours with outside support. The maximum we have ever been able to fill with non-parent caregivers is 25 hours a week, or 100 hours a month. The result is that my husband and I take unpaid leave from work to perform the caregiving duties, unable to bill for the attendees care hours allocated to my son.

For a brief period of time during the tail end of the pandemic emergency declaration my husband was able to provide paid support to Henry. Being able to fully use Henry’s attendant care hours made up 40% of our monthly household income. When the Covid emergency “ended” our income dropped by 40% while the level of care and people performing the care, us parents, remained the same.

Please pass legislation that allows kids like Henry to use every single attendant care hour allocated to him. We are suffering, families are suffering. Help us in this already challenging life of severe disability l, make ends meet and avoid family breakdown.