

Submitter: Lisa Tschudi  
On Behalf Of: Oriana Rochlen  
Committee: Joint Committee On Ways and Means  
Measure, Appointment or Topic: HB5006

I request that you remove the ban on paying parents as care workers so that very high needs children with disabilities can access the Medicaid services they are already entitled to.

The only reason Tensy's Law, SB 538, is considered to have an additional cost is because of the state's failure to provide a functional home care system. By refusing to recognize parents of minors as part of the home care workforce, the state is making it harder for children to get the support they need.

I am a parent of a wonderful young lady with IDD. Had the ACA expansion and Tensy's Law been in place when she was young, I could have provided her more stable housing and more opportunities of many sorts. As it was, we moved frequently, creating a lot of upheaval in her life to follow one parent's career due to the other parent(me!) being unpaid while providing extensive disability related support. That support included: preparing ketogenic diet where all meals were measured out for each ingredient to match a plan to the nearest gram, scheduling, providing transportation for and meaningfully participating in at least once weekly medical appointments, and sometimes daily, following at home plans developed by medical professionals regarding mobility and speech, assisting with bathing, toileting and all other activities of daily living (and what was very unusual is that this continued to be necessary for a teen), and so much more. There were no nonparental DSPs to hire for many of the DSP hours she was offered by the state, though we hired whenever we could and as parents we remained the on-call backstop when there were frequently no shows, making it impossible for both of us parents to predictably attend another job. And my daughter was fortunate to have both parents with her and actively engaged, which some kids do not.

Without adequate in-home support, families face the heartbreaking decision of placing their child in an institution or struggling without adequate support. Many parents are left with no choice but to quit their jobs, take unpaid leave, or forgo sleep to meet their child's needs. Tensy's Law provides an immediate, no-cost workforce solution by allowing parents—who are already trained, qualified, and committed—to provide this essential care. I firmly believe that one of the things that keeps vulnerable kids more safe is the widest possible choice, when practically and sustainably available. Paying parent caregivers is one very important component of these choices.