

Thursday, June 2, 2022

Dear Senate Interim Committee on Human Services, Mental Health and Recovery,

I am writing to you as a mother of a 6-year-old boy who has a smile that lights up the room, but also has multiple severe disabilities. This testimony is in support of paying parents as support professionals for their minor child. My son is entirely dependent on others for all daily living needs 24/7, he is nonverbal, tube-fed, has severe orthopedic impairments, and a multitude of other medical complexities. As you can imagine, it is a full-time job to care for him, which my husband and I have switched off doing since he was born. Even now that he is in kindergarten, it is impossible for me to hold my prior job as an elementary school teacher. He is frequently absent due to illnesses, appointments, therapy sessions, and periodic procedures and surgeries. No school would allow me to have the flexibility I need to be on call for my son's needs when they unexpectedly arise. Additionally, no PSW or DSP is available "on call" for these times, nor do they have the expertise I have in knowing how best to care for my child in these critical situations.

There is another very important reason that makes it incredibly hard to replace my caregiving with that of other hired workers. My son's medical complexities express themselves in a way that makes every single day unpredictable and different. Some days his muscle tone is incredibly high making it uncomfortable for him to be in certain positions. Some days that high tone plays out with increased vomiting and difficulty managing his secretions. Some days he is having hundreds of mini seizures all day long. Some days it is a mix of all of these. And the reasons behind each of these changes is far from known. It's a constant guessing game with a lot of trial and error in order to get our son to a place of comfort in his body and mind. Even then, positive changes only last temporarily until some other challenge arises.

Because of the amount of unknown predictors causing these changes, it takes a very close watch and documentation to observe patterns in order to make appropriate adjustments to his medical and physical care. If I were to pass off all of my son's 400+ hours of caregiver support to someone outside our home and hold a full-time job myself, I would be unable to track my son's daily medical changes appropriately and to the degree necessary for his best quality of life. Sure, I can train support workers to help manage how each of these situations plays out, but they do not have the expertise or experience with my son to be able to observe these changes over time. I feel that I would be doing a disservice to my son if I were to pass off his care to a handful of others, who are not going to provide the quality of care that I can. My son would be far sicker, less happy, and more irritable if the majority of his care were in the hands of others.

I strongly urge you to put yourselves in my shoes for a moment and think about the care you would want for your own child, grandchild, niece, or nephew if they were as medically complex as my son. If I were able to continue getting paid as my son's professional caregiver, he would be getting the best possible care and the care he deserves to be a healthy, happy, 6-year-old boy. If not, I will still choose to care for my son full-time, but because it is uncompensated, our family will go back to just scraping by on one income, and the State reaps the benefits of my unpaid labor.

Thank you for taking the time to read this and consider my family's position.

Sincerely,
Oriana Horneck