

Dear Chair Schultz and Members of the Human Services Finance and Policy Committee,

I write in support of HF 1159.

Our son, William has cerebral palsy and epilepsy. He's five years old.

Will needs a lot more attention than your typical five-year-old. I quit my job when Will was injured in 2016. I tried to care for him, his younger brother and manage our household for two years. But it became too much for me to handle on my own.

We employed a personal care assistant (PCA) for a brief time, but when we went looking for PCA service that could give Will the time and care he required, we couldn't find it.

We had already altered our lives and were unsure as to what the next step would be, but his grandmother stepped in. She quit her job and received training to become a "direct support professional" so she could be compensated for her time and took a large pay cut in the process.

Our story is not unique, as grandparents and other older relatives often play a crucial role of support when it comes to raising children (whether they have a disability or not), but during the pandemic, I know many families who've lost these connections.

We've been lucky in this sense, but I also know that as Will gets older, he may need additional help in ways we can't anticipate.

Raising a child who has a disability can be hard in the best of times. There are many difficult decisions you have to make. All we're looking for is the flexibility to help us do what we're already doing. In a perfect world, I wouldn't have had to quit my job to care for my son and his grandmother wouldn't have had to do the same. But that's not the world we live in.

Our family is doing well for now and we'll continue to figure things out as we always have done.

But to know that if things changed for us, I could take over as my son's PCA and be compensated accordingly, would be a tremendous comfort to me and countless other parents and families. I hope this is something you'll consider as you make your decision regarding HF 1159.

Thank you,

Jessica Merchant,

*Farmington, Minnesota*