

Chair Schultz and Committee. Thank you for the opportunity to testify. My name is Jessica Neil.

Who better to care for their child than the parent?

We have the honor of caring for our 7 children with special needs. Although there is nothing greater than being their parents their needs do not end, we want to take a break, need to step away, care for another one of their individual needs, or simply make a meal.

The opportunity to have PCAs and caregiver staff over the years used to be a given without taking much time to find and hire them. However, over the last 18 plus months it has been nearly impossible. We have lost three of our PCA's to higher paying jobs that offer benefits.

For nine weeks, during the peacetime emergency period when parents of minors were allowed to work more than 40 hours, our entire family felt a weight lifted as we were able to care for our children and provide financially as well. Unfortunately, that 9 weeks ended and we are now back to a 40 hour cap for parents of minors. This 40 hour cap applies for the entire household, even if both parents are providing care. Now, down to one very part time staff, we have made the hard decision to have my husband Jason leave his job and stay home to care for the children. This is a very stressful decision for our family given the financial impacts it has for our family.. I work from home and on average miss about 4 hours of work a week to help care for the kiddos during the day.

When the 40 hour weekly cap was temporary waived we had a lightening of the financial stress our family faces in our efforts to provide disability care for our children in our own home. The ability to have both my husband and me providing disability services for our children has proven to meet their needs in a way that we could have not imagined, given the current workforce shortage.

Too often our children are defined and controlled by what their diagnoses demand in one way or another. Let me introduce my children:

Takoda (5)- born addicted to meth, has a central line, feeding tube, immune issues, language/speech delays, chronic lung disease, severe eczema. Qualifies for 13 hours of PCA care and nursing.

Josephine (11) – born 7 ½ wks early due to bio mom's alcohol and drug use, significant behavioral issues in school, community, and home. Requires constant supervision. Qualifies for 6.5 hours a day of PCA care.

Emmanuel (14) – born in the bush in Liberia, Africa, deprived of oxygen at birth resulting in Cerebral Palsy. Declared a “bad omen” he was hidden away by a village elder for safety. Epilepsy and microcephaly in addition. Qualifies for 12 hours a day of PCA

Tyler (16) – born addicted and taken away at 2 days old and placed with us and three bio sibs. Fetal Alcohol Syndrome, conduct disorder, anxiety, depression, attachment disorder, autism. Qualifies for 6.75 hours a day of PCA.

Garmen (17) – sex slave survivor from Liberia, Africa, PTSD, RAD, depression, major cognitive delays. Qualifies for 6.5 hours a day of PCA.

Malachi (18)- Fetal Alcohol Syndrome, Autism, Hypogammaglobulinemia (autoimmune disorder), May Thurners Syndrome, Asthma, gastroparesis. Qualifies for 12 hours a day of PCA.

Miriam (18)- Fetal Alcohol Syndrome, Anxiety, Depression, Language processing disorder, Hypogammaglobulinemia, asthma. Qualifies for 6.5 hours a day of PCA.

After the names of our beautiful children are a hefty list of diagnoses and labels. However, the sheer fact that I get to write this today is that they are conquerors defined by their strengths and ability to beat all odds. That fact is what matters! That fact is why we must meet their needs with excellence.

Allowing the 40-hour limit cap to be lifted for parents of minors and spouses affirms the fact that our children and so many others deserve to be given the best, the chance to shine in the ways we know they can.

When told we matter, we succeed!

Please support House File 3199, and allow families like mine to decide who can provide care for their children, especially while we continue to navigate the pandemic and the workforce shortage crisis.

Thank you.