To:Representative Lisa Reynolds and members of the committeeFrom:Gwen Whelton, family member of a person supportedDate:2/8/23Subject:HB 2457

House Committee On Early Childhood and Human Services committee chair and committee. I am Gwen Whelton and mother to a wonderful man Christopher. Christopher has Cerebral palsy, a seizure disorder, cortical blindness Christopher doesn't walk or talk, and requires full assistance for bathing, dressing, and feeding. He has a g-tube but can enjoy food still. I have lived with Christopher for 25 of his years. I contracted with an agency to provide in home services when I injured myself and could no longer lift him. That agency served us in our home for approximately 3 -4 years. During the pandemic, I lost that home care. The agency did not have enough employees to serve Christopher's needs. You cannot imagine my fear that I was not going to have someone to feed, lift, change, visit take him for walks. I was panicked. I was lucky enough to have Christopher move into a home of a 24-hour provider. His staff whom I had contracted with was affiliated with that agency and they agreed to stay working with him. It is important to me for you to understand the level of care my son needs. He has feedings that are required through the g-tube, at specific times during the day. He has seizures that are managed with medication and diligent observation. His thalamus doesn't work so he cannot regulate his body heat. So he must be monitored. If he gets a fever he will begin seizing at 101. He cannot tell you when he is hurting. He doesn't have formal language you just have to watch his expressions... all nuance. You need to know how to make his food and what he likes and needs to eat to maintain his health. You need to know what makes him happy. The DSP's know him, understand him...took time to learn about him. And he has thrived. What I thought would be a terrible transition has turned out to be the best thing for Christopher - he is happy. Thanks to DSP's who provide needed care, keep him safe, and provide something that is most important the interaction. I can come to the home anytime and see him happily watching his favorite movie (Hairspray) or having one of his favorite meals. The DSP's maintain his body weight, provide care that keeps Christopher out of the hospital, lift, move, bathe him, and change him...all things that are undervalued and are desperately needed for his health and safety.

I am 65 my time of caregiving has passed. I know I cannot do this. But if we do not pay people a liveable wage there will not be people who can take care of people like my son. DSPs do things and provide care that most folks cannot imagine. My son did not ask to be born this way. I adopted Christopher knowing that his life would be full of challenges and as a nation that is supposed to be progressive and supports the most vulnerable among us. We take into consideration the people who do need additional health and safety, people like my son. But what about the population who have the calling to do this type of work? They need to have a wage where they can provide for their families, have time off, and not have to work additional

hours or jobs to supplement their income. What will we do when there is no one to do this work? I Cannot imagine what would happen to Christopher without them. Stability is an important thing. People leave this work not because they want to but because they have to choose between doing what they love and feeding their families. That instability is the problem..those are the things that cause people like my son, not to thrive—not knowing who will be there in the morning, not being able to trust that the person that knows him and understands his needs will be there. Please support a liveable wage for DSP's and for my son.

Thank you for your time, Gwen Whelton