

Parent Testimony Before Robert Bethell Committee

April 20, 2022

Sarah Watkins Mace

Parent of Luke Mace, Recipient of I/DD Waiver

Andover, KS, Butler County

I wanted to speak with you for a few moments about the issue of parent pay and the wages available to direct support workers of individuals on the IDD waiver. My 14 year-old son, diagnosed with Autism, ID, epilepsy, Disruptive Mood Dysregulation Disorder and a host of other disabilities, is fortunate enough to receive the IDD waiver. He can be aggressive at times, which requires that his workers have more specialized skills to help keep him safe and happy. We are self-directed and have to select our own workers. Since the pandemic started, wages have increased in every other sector except for those receiving wages controlled by the IDD waiver. The last worker we were able to find quit unexpectedly one day in October and never returned, only after she stole my credit card information and stole from our family. The wages that are available for the direct support workers are not ones that would attract reliable honest individuals to work with some of the most vulnerable members of our society. They are also not enough to provide a living wage. If we want individuals who work with individuals with IDD to provide safe and secure care, then the wages need to be increased. Further, I have had to reduce my hours at work because we are unable to find anyone willing to work with our son at the current wages and also due to the overall labor shortage. My family and I have had to endure a loss of wages in my job so that I can care for our son. Consequently, the opportunity for parent pay has become even more critical. Without the parent pay that has been available during the pandemic, I am not sure that we would have enough money to cover all of our expenses, many of which we incur due to the requirements of providing for our special needs children, who are not currently able to receive SSI or other funds since our family's income is more than the requirements. We recently received word that retention and recruitment bonuses would be available. That is a wonderful opportunity, but it is difficult to offer bonuses to either recruit or retain workers when we cannot find any workers who can only receive the present wages since the present wages are not enough to provide a living wage. I would ask that your committee strongly consider, pass on recommendations that will allow the direct support workers who work for families who self-direct to earn competitive wages with a 20% rider and cost of living rider so that only 20% can be consumed by the FMS providers and other increased wages would not require an act of the legislature and Kansas families would be suffering as a result. Also I would ask that you would consider doing what is necessary to help continue parent pay. Bills/legislative acts need to quickly be put before the legislature before the end of the legislative session so that the suffering of recipients of the IDD waiver and the Kansas families who love them would be alleviated.