

Hello, my name is Kimberly Burgess. I am writing in support of SB646.

I am writing on behalf of my family and most importantly, my son, Bryson. Bryson is 6 years old. At the age of one and a half years, he was diagnosed with congenital muscular dystrophy muscle eye brain disease (CMD MEB). This is a rare and progressive disease with fewer than 50 cases worldwide.

Bryson needs help and is totally reliant on others for all his daily needs. He is nonverbal, nonmobile and fed through a gtube. He needs help with hygiene, feeding, bathroom needs, dressing, sitting, repositioning throughout the day and night just to name a few.

The temporary order of allowing myself and other parents to be paid to care for our medically fragile children has been a blessing. Before, we were reliant on agencies to be staffed, find someone who fit and cared for Bryson and wasn't just here for a paycheck, and someone who would actually show up. If they didn't, I was, and his approved hours were going unfilled. Bryson qualifies for over 300 hours of attendant care each month and those all went unfilled for years because no one was willing to work. I am. I have been. I always will.

Being that Bryson requires help with some of the most vulnerable and private moments of being a person, having me as a caregiver allows him the dignity and privacy he deserves. Agencies have a high turn over rate, and it was a constant revolving door of new people bringing their germs into our home and more of a meet and greet than true care. Kids need routine and stability. Since the pandemic began, Bryson has had no hospitalizations and only 1 ER trip which is down significantly from years prior.

I understand that the passing of a bill is mostly about money. But allowing our kids to be cared for by their parents in their safe place is going to be a lower price tag compared to the cost of hospitalizations, institutions, etc. Being a paid parent caregiver for Bryson has allowed our family to thrive. We weren't forced to choose groceries or the gas bill.

I am already here, I know what makes Bryson smile, laugh, dance. I know that he doesn't like his feet touched. Parents know their children best. Why put these vulnerable fragile children in the hands of others who must be trained by us, the parents. Why not choose to allow the parents the right to be paid for a fraction of the time they are already doing the work.

Please consider the passing of SB646. Thank you for your time.