

Chairman Ruby and Members of the House Human Services Committee-

My name is Brittany Zappone, and I live in Bismarck, ND. I have two children, Kohner (10) and Kenadi (6). I am here today in support of SB2305 pertaining to the Family Paid Caregiver Service Pilot Project.

I come today with testimony that may be considered a rare example, but I assure you this is happening as we speak today. My family has not been a part of the pilot program as my son would not meet the criteria and my daughter, who was shaken at 2 months of age, passed away from her injuries in May 2023, shortly after the pilot program was established. She was medically complex and needed 24/7 care. We started with respite and quickly found the care provided was rarely quality.

Parents are expected to work to keep a roof over our family's heads and trust those who care for our children while we're away. However, I had caregivers that slept on the job, others that refused to care for her altogether, and she even incurred injuries on their watch. I, thankfully, kept cameras in my house so I was able to catch these things, but it shouldn't have happened to begin with.

If a respite provider we trusted was not available, we lost the hours. Essentially, someone else got them because I refused to place my daughter in harm's way. In the last year Kenadi was with us, we finally found one respite provider we trusted, and she stayed with us until my daughter passed away. We got lucky there.

Among other things, my daughter needed several medications administered daily, assistance with all ADLs, and she was visually impaired. She relied heavily on trusting a caregiver's voice to feel safe. She also had epilepsy and attended intense therapies 5 days a week. All in addition to a full school day. She was stubborn and determined to beat all the odds stacked against her. Her smile would brighten any room, and you knew when she felt safe.

I worked a job that was fairly flexible and very understanding; another area we got lucky. I went where my children needed me and my job knew that. If we had extended hospital stays, surgeries, appointments, etc. I attended them and did so without pay. It had a great financial impact, but my children are always my priority. I worked a lot of time after hours with my children nearby and often sacrificed family time because I needed to pay the bills. We made it because we had to. It is time we will never get back, but I will never regret putting them first.

My daughter transitioned to hospice, and I immediately put in leave, without pay. My daughter remained on hospice for 4 months and I spent every single moment with her, my son, and my family. My son is medically needy and has intense therapies as well, which have only gotten more intense since my daughter passed. He continues these today.

I realize many will think that we are just parents asking to be paid to be parents. We certainly are parents, but we are different. We do the extraordinary because, well, we aren't the ordinary. We don't fit in the box. We have many titles, and we do all of this for those that we love. For those who deserve to have someone care for them. Someone that truly cares.

These respite hours are already approved for these families. The workers are paid a good wage, ours was paid \$24/hour to care for my daughter. We did not use all our hours, but the dollar amount was more than what is being offered here in this program. Families do this 24/7 because it is needed and without any hesitation. Families will never do it for the money, but they are also expected to keep the rest of the family afloat and a roof over their heads. It is impossible to do both. These cares are extraordinary and are above and beyond what someone would do in the home for a child with "ordinary" cares.

I have friends that have their children in an institution as they cannot physically lift them any longer and there was no staff available to help them keep their loved one at home. Imagine being a child and being somewhere with strangers every day after spending so many years surrounded by a loving family. It breaks my heart every time I visit. The level of care is significantly worse than a loving parent would provide. People go there for a job, and unfortunately, not always because they love the kids. I have visited and provided care to some when I saw it was needed and not a single staff member would come to help. I would walk in and see children sitting in wheelchairs and having nothing but a screen to stare at with no caregiver in sight. It is truly heartbreaking and not a decision any of the families made easily. The care is not quality and, therefore, the children do not thrive.

Child caregivers are not asking for anything more than what adults are getting. I am also involved in a home health care business and see what services are provided to adults in their home. Why can adults receive this and not the children? What people do not see is what these children must go through just to get on these lists. The number of doctors, therapists, and specialists the children need to see for support as well as the extra time and dedication from their

caregivers shouldn't be overlooked.

I cannot stand here and tell you how this will affect my family as that opportunity is no longer an option. I can, however, tell you that I provided care for my children despite the challenges. I was the only one that knew my daughter and her needs in a way no one else could without spending the time with her and listening to her. I was there through all her medical appointments, emergency medical flights, therapies, her 27 surgeries and recovery, her time on hospice, and the only one with her as she took her last breath.

We as parents will always step up when needed. All we are asking here is that we are seen as an equal to the others and to be compensated. For others to truly know what it is like, they would have to experience it. I strongly believe no one would stand here and say that institutional care is best after that. Unfortunately, some had no other choice. I am positive everyone in this room has a story to tell. They all may be different, but they will all be tied together by the love and extraordinary care they provide for those who deserve it most.

I thank you for your time today and ask that you consider a do pass on this bill. The need is there, and it will be heard many times over today, we just need your help to get there.

Thank you for your time and consideration,

Brittany Zappone

Bismarck, ND

Brittany.Zappone1516@gmail.com