

Sheila Murphy Testimony

I live in Bismarck in the 47th District

Good Morning Madam Chairwoman Lee and members of the Senate Human Services Committee. I thank you kindly for this opportunity to speak today. My name is Sheila Murphy and I reside in Bismarck in the 47th District. I am for Senate Bill 2276. I am the legal guardian for my granddaughter Kelahni Walking Eagle who is almost 4 years old. Kelahni has spastic quadriplegia cerebral palsy & is a survivor of a traumatic brain injury. She is medically fragile & has developmental delays. She cannot eat like a normal child. She can barely swallow her own saliva without equipment & medication to control secretions & prevent choking. Her nourishment comes through her feeding tubes as do all her medications, her formula, & water for hydration. She needs assistance with all Activities of Daily Living. She is nonverbal. She has detached retinas in her eyes that prevent her from seeing the world properly. She has a port placed under her skin on her chest that will stay inside of her for years. This helps get medication and emergency nutrition into her body because getting a needle into her veins has been impossible. This port alone needs monthly maintenance to prevent infection. Kelahni must be watched at all times due to her inability to move her body herself. This includes positioning her head and hands correctly and stretching her arms & legs at every diaper change to prevent contractures.

Our day consists of 7 medication passes that begin at 5:30am with the last medication given at 10:00pm. She will always wear a diaper no matter how old she is. In our home when Kelahni wets a diaper we are having a good day because even her urinary system & bowels have been effected by her condition. To leave Kelahni in the care of others requires God's mercy of allowing me to have complete faith that a stranger will care for her as I would. Will my respite caregiver cheer Kelahni on after she goes number 2? Or will she wince in disgust because she has to change a messy diaper? When you have a child with a feeding tube remember this is all liquid going into her body and it is all liquid coming out. It is a tough job to find someone who is not bothered by this. I am struggling to say the least with keeping my full time job and finding & retaining adequate care for her. I feel I should be able to get paid to take care of her. Her care is a huge responsibility and it is around the clock with no breaks.

I miss countless days to months of employment. The shortest time being a few hours and the longest I've been gone from work has been 10 weeks. Kelahni's doctor recommended she go to school but do you know at her age she can only go half days? So I had to find a respite caregiver that was willing to work a split shift. My caregiver comes at 7:00am puts her on the bus at noon, leaves and

comes back at 4pm to get her off the bus. She then stays at my home until 7pm until I get home from work. It has been by sheer luck and God's mercy that I found a person to do this. A point to keep in mind is I only have the one caregiver. There is no back up person. The in home healthcare service I use has not been able to find a back up caregiver for Kelahni and it has been 7 months of searching. Please keep in mind my caregiver does have family emergencies & she does get sick herself. How ironic that my caregiver was supposed to be here today to help me and she called in sick. So I cannot go back to work this afternoon as planned. Keep in mind I am a single parent. There is no second income. I also have two teenagers at home to provide for.

There is a huge problem right now finding proper care for our disabled children with special needs. When I asked an in home daycare provider if she had an opening I was instantly denied due to Kelahni needing more attention then the daycare could provide. I knew then I was in for a fight if I wanted to keep working. I've had caregivers who did not follow what my wishes were & safety guidelines that put Kelahni in danger. For an example my motherly instinct told me to check on my granddaughter during my workday without calling first. When I did the caregiver had her in her stander with no orthotics on her feet. This could have caused broken ankles. Not to mention a lawsuit. Problems with a hired facility to do her cares that I have experienced are: people sleeping on the job, cares not being performed correctly, g tube tubing being taped on Kelahni's belly upside down against the natural flow of gravity, pressure sores on her heels because they did not move her, being on their cell phones when they are supposed to be reading her books and stimulating her mind, stretches not being done so her joints got more stiff, not washing their hands appropriately so she gets infections from them which lead to hospitalizations, watching tv and not interacting with her.

I've tried a residential living facility and it was not a pleasant experience. I'm back to utilizing a service that hires the caregiver for me and they keep track of the hours of staff. My hours are going to waste because they don't have the staff to fulfill the hours that we are granted every month. That means everyone is losing. Currently it costs the state \$28,000+ to pay for Kelahni to have a caregiver for 3 months. This is for 255 hours of care per month. We have our caregiver for 168 hours per month. That is a loss of 87 hours monthly. I've asked for care on the weekends but right now I can only receive care during the weekday so I can work not rest. My wages from my job are just slightly above this amount annually. And I have caregivers quitting without two weeks notice, quitting because they can't do the heavy work of lifting or it is too hard for them to do. We are dealing with a different working pool right now from which to choose from. If a potential employee doesn't like the work they just quit and are off to find something else. They don't think twice about switching to an easier job. This is a demanding job and for my granddaughter I have to trust who I am leaving her with. She is a

special child and Kelahni should be able to have who she trusts there to care for her and for me to be able to make a living without going broke or worse becoming homeless. I love North Dakota and I've lived here for most of my 50 years that I've been alive. But, if I have to move to Minnesota where I can get paid to care for my granddaughter it may be what it comes down to. I don't understand why I should have to move to get the golden standard of care when we are perfectly able to do that here in North Dakota. Please consider this help it just makes sense. Thank You!

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