

Victoria Milburn
Testimony on HB 33
Supporting the DD Workforce
3/22/23

I am a single mother to a disabled child I am also the mother to a 15 yr old, 12 yr old, and 5 yr old. Due to the shortage of support I work for my daughter, so essentially I am nurse and mom 24 hrs a day. This takes a toll on me mentally, physically and emotionally, it also takes a toll on my children because why is Lily more important is what they ask. Can you explain to them why there isn't enough direct care support so their mom can be mom to them as well as to Lily and not just nurse all day. Imagine needing to use the restroom, I have to take camera monitors with me because Lily has experienced seizure in minutes while I was u loading the dishwasher. The only break I get is school which isn't a break at all because I still get called in to administer meds when the nurse isn't there, I have to make sure her e meds are in her backpack everyday as well as diapers at school, also tell me when I have time to attempt to potty train a non verbal 6 yr old who is failure to thrive and developmentally delayed. I have had to start counseling as well depression medications. Imagine meeting a man in which I was so lucky to have done but never be able to go on a date because #1 there is no one for Lily but me and Allen and Imagine everyone staring at you because all she can do is yell, my other children won't even attend dinner because of that. I am not ashamed of it but it shouldn't be a factor if there were enough support systems for these individuals. Imagine your child being on palliative care which means her illness will end her life prob before ours but cannot receive SSI disability for her because I went to nursing school and did something with my life so now she is denied SSI due to my income. Imagine trying to find sitters when she is admitted how hard that is because I can't leave her alone. We are not okay, we are just surviving in all aspects of life just to make it another day.