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On Behalf Of:  
Committee: Senate Committee On Human Services  
Measure: SB91

I've been a mother to special needs children the whole time I've been a mother. Since I was 15 yrs old

My daughter will be 40 this year she was born with severe heart lung problems, deaf in one ear and blind in one eye, multiple issues.

Then my next son has developmental disabilities and severe seizures. Being a special needs mother is not easy... I struggled when my kids were young. For a long time we survived on grilled cheese sandwiches and koolaid it was always a struggle for me.... I can imagine if I was a mother that had gone to college and had a career and a wonderful job and then had my children I would have lost everything.... I did work a few times when they were little I can't tell you how many lunch breaks that I spent the whole time on the phone for my kids doctors, ssi, pharmacy, whatever there is always someone you need to be calling when you have special needs kids... My son still lives with me he's an adult, he's 38 and I get paid to take care of him. That would have made life so much easier when my kids were little... we went without a lot, the amount of phone calls you have to make in order to make an appointment, get a prescription, get a referral, then you need to call the insurance companies..It takes a lot of time. This in addition to all the daily care and appointment you have to drive to, many times that appointment is a 4 hr drive from your home.... And then you're doing it without sleep, because your child's had a severe seizure and you have to stay up all night watching them. If I had worked regularly at a job I can already tell you I would have been fired from them. I do not understand why our state thinks that it's better to pay strangers to take care of children that doctors make sure survive, and then expect these people to go out and live a normal life and have a job and just be like everything's good !!!! it's not like that. I've been doing this long enough that I can tell you people aren't showing up at my door with dinners when I'm tired, they're not paying my bills, they're not talking to all these people that want something from you, and all you're trying to do is survive. I'm not sure what I could say to make you understand how severely this is needed. Back when my daughter was a year old they sent her home to die, they didn't send her home on a ventilator, but she was on oxygen. There's just so many things that I don't even know how to put them in a letter. Another issue I want to bring up is these parents that are raising the severely disabled children, when the severely disabled children pass away the parents again will be left with nothing, I'm lucky that my child being an adult I have a retirement that I pay into every year and I don't know if that's being offered to these young parents but I think it should be. I think everything that would be offered to a government entity (strangers) to care for this child should be offered to the parent. I think if doctors are

going to save them, they need to account for the fact that these children are going to need care for the rest of their lives.

Thank you