Submitter:	Stephanie Burns
On Behalf Of:	
Committee:	Senate Committee On Human Services
Measure:	SB646

Keep parents as DSP workers permanently
Support for SB 646

As I write this testimony I am sitting in a hospital with my son. He had two surgeries yesterday. We will be here, so he can recover, the rest of this week. I wish I could say this is our first rodeo but in his short 3 years of life we have spent a lot of time in all kinds of medical facilities and hospitals.Our son, son, Clay, was born with a brain malformation and diagnosed with intractable epilepsy at birth. His prognosis was unclear at best, but we knew he would need brain surgery for sure by the time he was 2 years old. His seizures were so out of control they planned to remove the portion of his brain that they all stemmed from. What we didn't know is that things would become so out of control but by the time he was 6 months old that his surgery plan would be moved up. So at 6 months old are little baby boy had 10% of his upper brain removed. It was supposed to be a cure, and they expected that he would be seizure free and medication free but permanently disabled with cerebral palsy, possible learning disabilities and an unclear future regarding walking talking and all the normal milestones. His surgery was not a cure for him and he continues to have seizures.Not too soon after his brain surgery it became clear that Clay did not just have one medical condition. The epilepsy and seizures had taken center stage but the vomiting issue that we thought was caused by convulsions proved us to be wrong. Our baby boy has been projectile vomiting day and night since he was 3 months old and every doctor we saw expected this to clear up as soon as his seizures went away. But his brain surgery came and went and our son was still vomiting in his sleep and wearing a pulse ox every time we laid him down. It took firing several pediatricians, being treated like I was a crazy mother and so much more to finally get to the right specialist who would listen to me. Our son was diagnosed with a rare autoimmune condition called eosinophilic esophagitis. It is characterized by vomiting and reflux and other digestive issues along with severe allergic reactions. So even though we had went over one medical hurdle and thought that we had received a miracle within a couple of months of him surviving his brain surgery we had a new chronic illness to manage.
Our son was paralyzed on the right side of his body following his brain surgery and has the expected outcome of cerebral palsy. It was a necessity to save his life as the seizures were so out of control, but he will need ongoing care throughout his life. Occupational therapy, speech therapy, feeding therapy, GI specialists, Neurologist, Allergists, Physical therapy to name a few. Also because of complications early on, our son does not eat through his mouth. He has been a 100% g tube fed. And as I have mentioned we are in the hospital currently because he just had a surgery on his

esophagus, stomach, and bowel. Our son's future is unclear. But what is clear is he needs an extraordinary amount of care. As parents the last two years have been very hard. During quarantine we didn't feel safe to expose our fragile son to a scary pandemic. Then when we were ready to branch out we found one worker, but she could never meet the hours we needed. And now we have no personal service worker for our son and although we have reached out to several agencies we have yet to find a worker. And our family continues to suffer financially as I have to stay home to meet our son's needs. What I am asking is that so many families similar to ours be given the choice to use their hours through DDS to their liking. I believe that parents are the best caregivers and we know best for our children. My hope is that all families, no matter how many care hours they are given, have the opportunity to care for their disabled children and also earn a much deserved and necessary income.
Thank you,
Stephanie Burns