

Submitter: Oriana Horneck  
On Behalf Of:  
Committee: Senate Committee On Human Services  
Measure: SB91

My name is Oriana Horneck and my son, Avery, has a rare condition called KCNA2 epileptic encephalopathy. We have been able to access the current temporary paid parent caregiver program under the PHE and it has been the best thing for Avery and his health.

I am in support of a paid parent caregiver bill. I believe that any child who is assessed at needing more care than their typical peers should have the option for their parents to be their paid caregiver. SB 646 accomplishes that, which I support, but if we need to find a middle ground, here are some things to consider.

#1 Remove the 30% cap on agencies. A system with this in place will result in waitlists for parents to get established with agencies. If you feel the need to regulate agencies, do it another way that does not negatively impact the families trying to use the program.

#2 In the coming years with the transition to using ONA scores with significantly reduced hours across the board, the program (SB 646 & 91) will both cost significantly less than has been claimed. It won't be as expensive as it sounds.

#3 You need to know that no matter if any bill is passed or not, all of the children we're talking about have hours that can be filled by support workers. Whether it is me, as my child's mother, filling those hours, or it's someone outside the home, these hours are billed to Medicaid. The only reason the current system (without paid parents) sounds cheaper is because there is such a huge workforce shortage that families like ours are unable to fill the hours our child needs with consistent, quality care.

Finally, please remember... We have a temporary program that has shown in multiple ways that allowing parents to be their child's paid caregiver is the best option for these kids. They are happier, healthier and more involved in their community.