

To Whom It May Concern,

I am Mom to 5-year old Charlee, my daughter with cerebral palsy who is non-verbal and non-mobile. It is incredibly difficult to find qualified caregivers who can do the daily work needed to support Charlee or who can stay on with our family when we have been in the hospital during any of our 5 neurosurgeries and recoveries. I have not been able to work since Charlee was born because I don't have reliable support to be able to have any semblance of a schedule for myself. Our family subsists on the income Charlee's dad makes at his restaurants. We have had to rely on WIC and SNAP to get by at times and it was agonizing when the pandemic hit and we had no idea what the next months held for his restaurants.

Being Charlee's paid caregiver has given our family stability for the first time since Charlee was born. Having finances to make our family work has opened up time and space for our family. In May of 2021, Charlee had a spinal fusion in Oakland, California. Charlee's dad was able to be with us through the surgery and recovery because we didn't have to worry about lost wages if he took the time away. Without the time and effort it takes to figure out how to make ends meet, I was able to devote myself to work with Charlee on PT post surgery. Since January of 2021, Charlee has been able to make choices using a communication device, which in the past I never had time or capacity to work with her on. It wasn't our plan for me not to work when I was pregnant with Charlee. We envisioned placing her in child care while I continued my career. Capable and reliable caregivers seem non-existent for the level of medical needs Charlee has. This temporary allowance has changed everything for our family. It will be crushing if it is taken away. I love Charlee so much and I want to be present for her without the anxiety and stress so I can give her the best support I can.

Please show your support for families like mine in demanding more action and more transparency from the Office of Developmental Disabilities Services.

Sincerely,

Lenore E. Eklund