

Submitter: Carie Pagan

On Behalf Of:

Committee: Senate Committee On Human Services

Measure: SB646

I was unable to attend hearing due to the care needs of our 10 year old daughter. Nina has refractory epilepsy, genetic mutation on deaf 1 gene, Lennox Gastaut syndrome, autism, PICA and is non verbal. Nina is a fierce, resilient, beautiful girl who suffers greatly from her disabilities. Nina requires supervision every moment of the night and day due to seizures, self injurious behaviors, inability to discern what is safe and what is not. Nina will eat non food items, run into a busy street, jump into a pool of water.....she is unafraid, sensory seeking, strong and fast! We've had to install countless safety locks, guards, pads, alarms, cameras, specialized fencing, specialized car seats.....the list goes on. Nina is getting bigger and often times it takes two of us to manage her behaviors safely. Nina takes 110% of our time, energy and existence to keep her existing safely and with quality of life. Even before the pandemic we struggled to find adequate care giving help. Now it is simply non existent. It is a stressful, unpredictable, frightening and difficult job emotionally and physically and historically has low pay. It takes a special person to do this job and do it with care, respect and diligence. No one cares more then us, Nina's parents. We absolutely want qualified caregiving help but even if/when there are competent, willing people to help it is often the parents who can give the best care. Being paid caregivers has alleviated a great burden as we easily lose 1/3 of our wages needing to leave work for Nina's medical and behavioral needs. Since becoming paid caregivers Nina has avoided any ED visits and has become toilet trained during the day. Nina's quality of life and progression of skills has markedly improved and our family has stayed out of crisis. Please support and pass this bill. SB 91 would also provide help much needed for families but the cap on hours would have a seriously negative impact. As well as parents who have multiple children with disabilities. It would make the most sense for us to all work together to find a solution or compromise within the two bills. Children like Nina who are utilizing hospitals less and families being financially independent of state welfare services should be considered in cost. I do believe school systems are relevant also as many kids, like Nina are forced to have shortened days. Nina was given less and less hours at school until she was forced down to only one hour per day despite her legal right to have access to education.

The impact of not allowing parents to continue to be paid caregivers their children with beyond typical medical and behavioral needs will be dangerous for families as there presently is no other qualified caregivers to meet these needs that the state itself has already deemed necessary and promised to provide.

Thank you

Cari Pagan