

Submitter: Carie Pagan
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB1565

Hello,

Thank you for your time on SB1565

Our daughter Nina is 11 years old and has a genetic syndrome and autism. She suffers seizures, horrible gastrointestinal issues and severely violent behaviors. Mostly to herself but also to us and the other very few others who come into close contact with her with biting, scratching and hair pulling. We have sacrificed our life plans to care for her. And we will continue to do so. She continues to fight and so will we. She is a tenacious, resilient, affectionate young girl who deserves a chance to grow, learn and thrive. We are both unable to work full time and have had to further reduce our work availability as animals has gotten older; stronger and more strong willed. Our son had to move out of the house once he reached college age even though the value is only 30 min away and it's caused hardship for our family because Nina wakes at all hours of the night, breaks things, screams, runs around the house entering all rooms. Nina also needed a calm room with padding to keep her safe so our son's bedroom became that. We do not meet poverty guidelines but are not financially stable either and struggle to pay for utilities, student loan payments, gas and all of the extra expenses my Nina requires to stay in our home. I had to go down to half days at my dental office to be able to get Nina to school and her Dad has to miss every other Monday and continual unplanned missed hours and days when Nina has seizures, pain, explosive diarrhea or behavioral incidents, along with other appointments of hers.

SB 1565 will be a lifeline for vulnerable children like ours. Please follow the federal governments guidance and help give quality of life for our beloved children who have the most severe behaviors and health issues. We have gone back into debt since the temporary paid parent program ended. I don't believe we will be able to continue keeping Nina in her home without paid parent care giving. This bill simply fulfills what has already been deemed necessary for struggling families to keep their severely disabled children safe and in their homes.

The challenge to keep safe such a complex & high need child in a home setting is more then most people could even imagine. It's difficult to impossible to find attendant care for a child that bites, pulls hair, runs away, smears feces, tries to eat dangerous objects and chemicals, has seizures, non verbal but ear piercing screamsand we ALWAYS have to be available 24/7, to get her to school, pick her up from school, on-call during the school day, night and day, even if a care provider is there. Please let us keep Nina in her loving home where she can be safe with proper care and attention. This bill is the financially responsible and ethical choice.

Thank you,

Cari & Daniel Pagan