

Submitter: Adam Mueller

On Behalf Of:

Committee: Senate Committee On Health Care

Measure, Appointment or Topic: SB538

My son is profoundly autistic, nonverbal, and with high support needs. My wife had to leave her career to care for him full-time. We spent months on a waitlist for a DSP, only to be matched with a caregiver - an 18 year old right out of high school - who was woefully inadequate to handle our son's extreme behaviors and safety risks. It took almost a year to be matched with an appropriate DSP, but her availability is only a fraction of the hours that we need. It has not been enough to allow my wife to return to work. She has attempted multiple times to do work-from-home gigs, but our son's high needs have made even that impossible. Our family is not making ends meet on my single income. We frequently have to put groceries on credit cards. We feel trapped in poverty through no fault of our own. Allowing my wife to be our son's paid caregiver would be life-changing for our family. Nobody is more equipped to take care of our son than his mother. As a nonverbal individual, he is an extreme risk for being the victim of abuse by outside caretakers. We have experienced the heartbreak and worry of having him returned to us with unexplained bruises and welts and he has no ability to tell us how these injuries occurred. Once, on a day when his school was short-staffed, he managed to elope from campus and wander a busy parking lot unattended - this shows the high level of supervision he requires and how a shortage in caretakers could lead to a tragic outcome. No family should be put in this position. There is a massive shortage of appropriate care for children like ours, and we are suffering the consequences when we are more than willing to step-up and bridge the gap. Please pass SB538.