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On Behalf Of: Oriana Rochlen
Committee: Joint Committee On Ways and Means
Measure, Appointment or Topic: HB5006

I urge you to provide full funding for children with extraordinary care needs. Please prioritize SB 538 for funding. Had this bill been around when my daughter was young, it would have dramatically improved my child's health and wellbeing, as well as that of our entire family.

My daughter has significant disabilities that require extensive care, over two full time jobs' worth, even now that she is an adult. We have never found enough non-parental caregivers for all of the hours she needs, and her dad and I are on call regardless when other caregivers miss their scheduled shifts for any reason. It continues to be impossible for my husband and I to both work other conventional jobs while our daughter lives in our home where she prefers and is safe, thriving and content. When she was young, we were all dependent on one income stream from my husband's work. With pay as DSPs now that she is an adult, we can confidently afford the home she lives in rather than being unstable in our housing. We would have also used part of our pay when she was younger on additional therapies not covered by insurance and extra expenses for the neurologist prescribed ketogenic diet, also not covered. She has consistently been very clear that she prefers to live in our home and for my husband and I to be her caregivers. We family members are and have always been the 'community' behind 'community based services' for people with disabilities. With your support, we can provide an even higher quality of consistent, stable care.

Kids with disabilities have enough challenges. They do not need the extra burden of being raised in poverty, financial instability, housing instability or the risk of sub-par care so that their parents can work other jobs. SB 538 ensures that more kids can remain safely and well cared for in their family homes. In fact, without such pay to parent providers that SB 538 will provide, the state is likely to incur greater expense since more families will be forced to seek placement for their child in foster care.