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On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB646

I am one of the parent caregivers who was able to be paid during the COVID public health emergency. We were invited to join the program because my son has had severe behavioral issues for many years, and profound communication deficits.

For context, he has been allotted 296 hours per month of attendant care since 2016, but most of that time there were no caregivers for us, so I was left to work those hours – almost two full time jobs worth of extra hours, month after month, year after year - while struggling to make ends meet in my spare time.

With the temporary paid parent caregiver program, I used the opportunity to focus exclusively on my son's communication deficits, because his behavior specialist advised me that there was undoubtedly a connection between the behavior and the communication problems. In coordination with my son's speech therapist, we devised a plan to use his communication device out in the community, across all settings, all day every day.

Soon, the challenging behaviors dwindled to zero. Within a few months, he was able to manage his behavior in more and more challenging situations. Then, we were able to get – and keep! – another caregiver for attendant care, because his behaviors weren't getting in the way. Now, he is attending a day program, going out into the community with his peers.

None of this would have been possible before. He was headed for an adulthood lived in increasingly restrictive non-community settings, because under the current rules, he kept falling through all the cracks. The attendant care hours had been assigned, but there was no way for us to make use of them, so we did without. Only the extraordinary flexibility of the temporary program allowed our family to find a path toward a life lived in community for my son.

What families need for better outcomes is for parents to be able to direct the use of the money set aside to support our kids, and to be able to choose the supports that serve the kids best. For us, that was accomplished through the paid parent caregiving opportunity that the COVID health emergency provided; and extending the program permanently, as inclusively to all families as possible, seems like the most straightforward solution to our current caregiver shortage.

Whichever bill we choose going forward, I believe we need fewer restrictive rules for parents, not more of them; and if families are not using their allotted supports, month

after month and year after year, we need to view that as a failure of the system to adequately support the child rather than a money-saving opportunity for the state at the family's expense.