

I work part time as a school counselor. Each day that I go to work, I wonder if this is going to be the last day or week that I'm able to work. I'm running on fumes fueled by fumes. My emotional and physical reserves are shot. Six months before the pandemic, my child was 2.5, and was diagnosed with type 1 diabetes. Six months after that, she was diagnosed as autistic. She requires around the clock medical care. One night last week I got up 10 times to treat her blood sugars, and then went to work the next morning. There has been one night in the last week that I was able to sleep from 11 pm - 6 am without getting up to care for her blood sugar. Our family relies on my part-time income to stay afloat, but if I was paid as her caregiver, both she and I would have a better quality of life. She qualifies for 168 hours of care per month, but she's 5 and wants to be with her Mom. Like most autistic individuals, she co-regulates off of her primary caregiver, and she thrives when we are together. She has a wonderful caregiver that is with her 20 hours/week, but more than that and she would be dysregulated and unhappy. We are a very middle class family and are barely getting by having to pay for all of her needs, medical supplies, etc. If we were allowed to be her caregivers, our quality of life (and most importantly HER QUALITY of life) would drastically increase. She is a bright rainbow star of a child who has so many wonderful gifts and insights to offer the world. She deserves the best care, just like any other child. Please allow parents to be paid caregivers for their children with disabilities.

Thank you for reading,

Theresa Jahangir

Parent of a wonderful 5 year old child with disabilities

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Theresa Jahangir

*she/her*