

Submitter: Trevor Brooks  
On Behalf Of:  
Committee: Joint Committee On Ways and Means  
Measure, Appointment or Topic: HB5006

I have been a live-in DSP for a child with autism, sensory processing disorder, and some other diagnoses for almost 5 years now. Some days (mostly summer / weekends) I am on the clock between 12 and 14 hours straight. While I appreciate the opportunity to be well paid for this important work, it has been really great since my client's parent got selected in the CEN lottery late last year. Not only am I now able to sleep in the morning which means I will have more energy for the child throughout the day, but the mother can get paid for doing things that parents of neurotypical children definitely are not expected to be doing for their 13 year old children every school day morning or when I have my own out of the house things to do like appointments. I.E. removing his dirty diaper, cleaning him off, possibly all the bedding, taking the diaper out to the trash, showering him, dressing him, getting his backpack ready, etc. This morning process usually takes at least an hour total leading up to when he gets on the bus (a time which is the most likely time of the day for him to have a violent tantrum). After that comes a time consuming but less gross process with his older brother who also has autism. So by the time she has been up for two hours she has already done more 1 on 1 work with the children combined than most parents of teenagers have to do in an entire day, or potentially an entire week depending on how they are. Does she do it with grace and without complaint? Yes. She understands that it is her role as a parent to take care of her children, regardless of what that entails. HOWEVER, these are things most parents get to stop doing every morning after about ten years, or less. Neither child has a full school day, so it isn't like she could go get a 9-5 job, or really any job that isn't work from home. And how is she supposed to work from home when I am not on the clock? With two disabled children in the house who can barely even pour their own drink, much less make a meal.

I don't think that parents of severely disabled children wanting to claim 40 hours a week is a stretch at all. In fact, it has always boggled my mind that the state isn't clamoring for these parents to get paid for their above and beyond efforts. Would the state rather have strangers coming into the house and taking care of the children, many strangers whose biggest motivator for being there is to get money? Or should they rather the person(s) who love and care about them the most be managing their needs. I say this because from a monetary standpoint, hurt children cost OHP a LOT of money. A PSW or DSP might be distracted by something from outside of the house, easily overriding their attention to their client and the client runs out of the house, gets hit by a car, mauled by a dog, falls into a river, etc. How much are the associated medical bills going to cost the state? Tens of thousands? Hundreds of thousands? Wages for police / fire / ambulance responding to a call that never should

have happened in the first place? One absent minded mistake by a worker who doesn't actually LOVE or have a vested interest in the client could easily cost the state multiple years worth parent care-giver wages. PSWs and DSPs are not inherently bad people, or wasted positions but most any parent would readily attest that no one will love their child as much as they do, regardless of disabilities.

Lawmakers can have whatever opinions they want about families with disabled children but from a numbers standpoint it seems obvious to me that parents of disabled children SHOULD NOT be considered natural support in regards to being able to claim hours or not taking care of their children. Someone is going to be getting paid anyways. The dollars are already earmarked for the clients so why can't it be the most loving provider claiming some of those hours? I haven't heard what I consider to be a truly valid response in the years that I have been part of this community.