

Lindsey Sodano  
Testimony on HB 33  
Supporting the DD Workforce

My daughter, age 14, has an Individual Options waiver with the highest funding range in the state. This is due to her intense physical needs and extreme behaviors. The pay rate for HPC providers for her includes the behavioral add-on, meant to reimburse providers a little extra for having to deal with difficult behaviors. Even with all this, she can't get a single provider. Her behaviors are too challenging, she tends to do a lot of damage (e.g., she has done thousands worth of damage to our car in the past two years), and "nanny" jobs in our town (Mason, OH) pay far, far higher and are quite frankly far, far easier jobs. I had to give up my career to take care of her full time, and my husband was laid off from his job (we think he was chosen because he misses so much work to take care of her), so now we are both taking care of her full-time. We did the math. She spends 17% of her time at school and 87% of her time with one or both of us providing hands-on care and full-time supervision at all times. We also have two other children, one of whom has a disability (but not a waiver). In November, the Appendix K winding down period will end and we will stop being paid, since our daughter will only be 15 at the time. Our entire family will then have to go three years with no income, no health insurance, no benefits, and no break, while still doing all the same work, until she turns 18 and we are allowed to be her paid providers again.