HB1053

DDA Self Directed Services Parent Providers

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Lisa VanRoekel

I would like to introduce myself; My name is Lisa VanRoekel. I am the mother of Collin, a 25 year old young man, who has autism. He has been self-directing his DDA waiver services for over two years. I have been serving as a paid provider by helping Collin with personal supports. This model works so well for Collin and our family. Life is very hectic as a caregiver of someone who has autism and significant developmental disabilities. It is a situation of perpetual work as I am constantly providing the type of care that is provided to a young child. It helps so much to be paid for this work that I provide. Because of Collin's significant needs, I am not able to work full time outside the home, so it helps our family so much that I am paid for his care. Collin and I have a close relationship, and he prefers my help with personal care tasks such as bathing, grooming, and other personal self-care needs. He wouldn't want a stranger helping him with these personal tasks and it would be cumbersome to hire someone to work around our ever-changing daily schedule and come in for just a few hours per day. It would be very difficult to find an individual willing to come to our house to be paid for just a few hours of work in the morning and again at night. Please don't eliminate parents as providers of services for our children. We know our children best and understand the type of care that they need. We love our children, and our children with disabilities want us, their parents, to be providing this type of personal care for them.

The experience of self-direction has been wonderful for him. It allows him to choose the activities to include in his Person Centered Plan which are the most meaningful for him. Collin exhibits extreme hyperactivity which limits his engagement and participation in many activities. He is not able to sustain his attention to participate in activities which require him to sit at a table for extended periods of time, nor does he find these types of activities interesting. Through self-direction Collin has been able to choose activities which fit his needs such as participating in a program at Wheaton Park Stables. He is able to move and run outside, (which meets his sensory needs), as he completes his work at the stables. He truly enjoys interacting with the horses and other individuals with and without disabilities who also work there. He feels happy in having a place to go where his work is valued. Collin participates in other activities in the community such as attending classes at a gym. These activities, Wheaton Park Stables and the gym, are included in IFDGS. If IFDGS is eliminated, Collin no longer has access to participate in these wonderful programs. Collin enjoys being a part of the community. Please don't take away his ability to participate in these activities which he truly enjoys. As his mother, it makes me so happy to see him participating in life in a meaningful way.