Bill: HB1053 DDA Self-Directed Services Parent Providers

Hearing date: Wednesday March 5th at 1pm

Name: Jamey and Stacy Cohen, parents of self-direction participant Caden Cohen (Caden is a 24-year-old young man who is profoundly autistic, completely non-verbal, and he also suffers from epilepsy)

I honestly can't imagine that anyone would be against parents being able to provide services for the recipients of self-directed services. As parents of a profoundly autistic and non-verbal 24-year-old son, there is no one in the world that knows his needs and cares about his well-being more than us, his parents. Being non-verbal, Caden has very little communication skills. He is unable to effectively use communication devices, so having extensive experience with Caden is truly the only means of understanding his wants and needs.

Caden also suffers from epilepsy and has 'drop-seizures' about 4-6 times a year. The seizures come with very little warning or signs and thus require immense experience with Caden to best identify the start of a seizure. Quick action to recognize the commencement of the seizure is the only way to prevent a fall and keep him safe.

Please ensure that parents can continue to provide services for their loved ones in the self-direction program. It is already tremendously challenging being the parents of a disabled child. Being forced to rely on strangers to keep Caden safe and happy would just add greatly to our already stressful lives. It would be truly unconscionable, in our opinion, to not allow this.