

March 13, 2026

To Whom It May Concern:

I wish to convey my strong support for HB1593—a bill that requires the Deputy Secretary for Developmental Disabilities to provide notice to the public and consider comment on proposed changes before making changes to the Self-Directed Services Manual.

Our family uses Self-Directed Services (SDS) to provide supports for my son Jason. Jason is 24 and has an autism diagnosis. SDS provides invaluable staff and services to help Jason have a meaningful, engaging life experience. However, even under the best of circumstances, this "safety net" is fragile. Staff members come and go; day programs frequently cancel services and Jason's physical and mental condition can change without warning.

It's a delicate balance, but a productive one. Despite these challenges, Jason is thriving with SDS, and we are deeply grateful for its support. However, when DDA unexpectedly changes provisions in the service manual, this balance is broken and our family is thrown into a tailspin. In the recent past, DDA has reduced the acceptable wage rates for staff without any warning. Our family learned of the change by word-of-mouth. Then we had to wade through DDA's impenetrable website to identify the new pay scale. In the meantime, we scrambled to contact Jason's staff, inform them of the wage reduction and urge them to stay.

At the beginning of the budget year, Jason had allocated the bulk of his budget to staff wages. Now a large portion of this allocation was unusable. Technically, Jason was eligible to apply for a budget modification, but developing the budget mod request takes time, and once completed, is subject to DDA approval, which can take a LONG time. This situation caused untold stress and anxiety for our family.

In essence, DDA's unexpected wage action generated a pile of "dead money" in Jason's budget—funds locked in an allocation we could no longer use. Funds that we might have been able to put to some use had we received more notice. But, more importantly, it increased the anxiety level in our household tremendously. One staff member has already left Jason. The others are hanging in there, for now. But our family remains in a precarious position. HB1593 would have given our family the notice and opportunity to plan that we desperately needed.

Thank you for considering my thoughts on this important piece of legislation. If you wish to discuss them further, please feel free to contact me.

Sincerely,

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