

**IN SUPPORT OF HB 1020 The Self Direction Act of 2022**  
**Written Testimony by Jean J. Weller**

**Favorable**

My son Paul Weller has been a participant in Self-Directed Services since its inception. He was born premature and injured at birth by an incompetent 1<sup>st</sup> year Resident. He was diagnosed with multiple disabilities including Cerebral Palsy(x4), Cortical Visual Impairment, Mild Intellectual challenges, and Auditory Processing difficulties. He is now 39 years old, very verbal, and uses a power wheelchair to get around. He developed Type I Diabetes in 2006 and has REM nursing 12 hours/day because he is not able to manage his Insulin Pump or care for himself physically. Still, he loves to go out into the Community every day and wants to entertain people by telling Jokes. However, Paul has an anxiety disorder which can become acute in crowded areas where there are a lot of children. If he goes to the Mall, he needs to sit in a quiet area. He needs Personal Support to manage his Diabetes diet for his meals, drive him to his various Dr.'s appointments and therapies and outings, and to be there for Personal Care when one of our nurses doesn't show up which happens fairly often. There is no duplication of services.

Paul takes PT every week and Counseling. He goes to Spirit Club, where he exercises his upper extremities to increase his strength in using his walker. He and his nurse and his Direct Support Professional shop for groceries every week. Paul volunteers a few hours a week at his Support Broker's office preparing folders, making the coffee, and shredding documents but then, again not where there are crowds or noisy children. He also loves to go to church. (see attached profile of Paul)! When DDA created the new Waiver in 2020, it decided that it would **no longer reimburse** Self-Directed Service participants for their mileage used during their approved daily activities **if** they used their medically necessary personal accessible vans owned by their parents!

Participants like Paul cannot safely ride in standard vehicles because they require the seating assistance of a specially designed wheelchair which requires an accessible van often purchased by the families at great expense. However, DDA will reimburse an employee who uses his or her own vehicle to transport those SDS participants who do not require accessible vans for Transportation! This is discrimination against those participants who have more physical challenges because they need accessible transportation. Of course, DDA provides accessible transportation for all participants in their Traditional Group facilities.

DDA was very unresponsive to questions about those in SDS who needed accessible transportation. They have refused to allow transportation funds to be allocated to reimburse parents even when it was medically necessary for the participant's safety and well-being. DDA tried to force applicants for new Fiscal Management Services to agree that they would evaluate participants to see if they were "competent enough" to be able to "self-direct", suggesting that a participant with fewer intellectual abilities might be excluded from Self-Directed Services. Not one FMS applicant was willing to evaluate participants. DDA has proven that it has no understanding of Self-Directed Services' main premise that "all participants can be successful in Self-Direction if they are provided with the necessary supports."

Please pass HB 1020 out of Committee, so DDA cannot continue to reduce the choices and services that Self-Directed Services was created to provide for the best Self-Determination that all persons with Intellectual and Developmental Disabilities deserve.