

**IN SUPPORT OF HB 1179 (SB 0959)**  
**House Health and Government Operations Committee**  
**Jean J. Weller 2-29-2020**



My son Paul Weller has been a participant in Self-Directed Services since its inception. He was born premature with multiple disabilities including Cerebral Palsy and Cortical Visual Impairment, and mild intellectual challenges. He is now 37 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. Still, he has a great sense of humor, loves music, and wants to go out every day even if it's just for a ride. 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 has been fairly often. There is no duplication of services.

With the New Waiver, DDA has proposed that participants like Paul should spend much of their time out of the house moving toward more Community Integration. It has removed the "Self" out of Self-Direction and replaced it with "DDA" -Directed Services. They have insisted that the only "Meaningful Day" is one in which the participant is working in the non-disabled community gaining skills for Integrated Employment. Paul takes PT and OT twice a week and Counseling once a week. He is only able to volunteer a few hours once a week at his Support Broker's office, but then, again nowhere with crowds or noisy children. His Cerebral Palsy makes it impossible for him to work independently.

Another change is that since my son requires an accessible van, which we own, the DDA will no longer cover a mileage reimbursement to the family for his travel to his non-medical activities. However, they will reimburse an employee who uses his or her own vehicle to transport SDS participants who do not require accessible vans for Transportation! This is discrimination against those participants in Self-Direction who need accessible transportation which they already have available to them.

DDA has been very unresponsive to questions about those in SDS who do not fit the profile of their "ideal" developmentally disabled participant who can improve him or herself to the point of Community Integration and maybe even earning a minimum wage job! There are plenty who want to live meaningful lives in SDS by choosing their own activities out in the community, whether they choose to be working or not. And it should be their choice to do so in Self-Direction. DDA's answer is to evaluate everyone to see if they are capable enough to self-direct! They have lost the Vision of the original Self-Direction Concept that anyone can self-direct with enough support! To sum up, **A Meaningful Life should not be determined by the State, but by the person living it.**