

March 7, 2022

**Health and Government Operations Committee
HB 1020- Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act of 2022)**

Position: Favorable

We would like to register our support for HB1020. While all of the stipulations in the bill are important, we would like to emphasize two of the stipulations that we feel are most critical. They are: 1) No prohibition to having family as staff per CMS rules, and 2) Remove competency requirements in favor of team support.

It would be a travesty to not allow parents (and other family members) to be hired as staff. Simply put, the family are the individuals that care most about the participant's happiness and wellbeing. They are also the individuals who know the participants the best and understand their needs, wishes, and health conditions.

We are the parents of Caden Cohen, 21, who is profoundly autistic and is completely non-verbal. He also has epilepsy and thus suffers from seizures. We can communicate with him and understand him better than anyone else. We can also identify signs that a seizure may be occurring and act promptly to keep him safe.

There are so many sacrifices involved in raising and caring for children with disabilities. And with adult children that have aged out of their school program, parents often find the available adult programs to be substandard. In order to provide the highest level of care that their children deserve, parents often have to give up their career to provide these services themselves. It would be unjust to not allow parents (and other family members) to be hired as staff.

Regarding the competency stipulation, it would add an unnecessary and unjust burden to require a competency requirement of the self-directed participant. In many cases, like ours, our son is unable to make his own decisions due to his level of ability and thus 'prove competency'. It should be up to his parents and his support team to decide if the self-directed program is appropriate.

Thank you for considering our testimony and please vote to recommend passage of this bill out of committee.

Very respectfully,



Jamey and Stacey Cohen