

March 6, 2022

Senate Finance Committee

SB 868- Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act of 2022)

Health and Government Operations Committee

HB 1020- Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act of 2022)

We are testifying in support of Bill HB1020/SB868.

Our son Ade is 37 years old. He has Down syndrome, which primarily affects his cognitive abilities. He is limited in his ability to express himself and to understand what is communicated to him. His reading and writing abilities are at the grade school level. Nevertheless, he has many abilities that allow him to live a fulfilled life. Ade regularly participates in programs offered by Howard County Recreation and Parks, and he participates in athletics and bowling in Howard County Special Olympics. Ade has a personal trainer at the YMCA, where he also swims. He enjoys listening to music, going to the movies, going to summer camp, and traveling.

Ade has been living in his own apartment since December 2019, with support from his self-directed staff. Ade really likes the independence that this has given him. In his apartment, he helps his staff member with cooking and cleaning. He is very adept at using his computer, accessing apps on his Smart TV, and using his preprogrammed iPhone to call family members.

A priority for us is to provide a situation for Ade that will allow him to live as independently as possible when we are no longer here. Self-direction has been a godsend for Ade. If Ade could express the benefits that he has enjoyed since he joined self-direction, he would say:

- “It allows me to have more independence from my parents.”
- “It allows me to choose the activities that I want to participate in.”
- “It provides funds for activities I enjoy, such as summer camp.”

However, there are still many gaps in the ability of self-direction to support Ade’s independence. We support Bill HB1020/SB868 because it addresses several of these critical gaps. Ade would benefit from almost all the bill’s provisions, but we will just highlight two of them:

- Ade does not have the cognitive ability to make decisions about his self-directed services independently without support. We are working very hard to ensure that there is a team in place to support Ade when we are no longer here. It is critical that the self-direction competency requirements be removed in favor of team support in order for Ade to continue to enjoy the benefits of self-direction.

- It is critically important that someone provide coordination of Ade's support team, ensuring that the team is functioning to meet all his needs. Currently that is a role that we fill, but this will be an enormous gap when we are no longer here. We support the inclusion in self-direction services of administrative supports, such as a manager/coordinator of services.

Please vote to recommend passage of HB1020/SB868 out of committee. As the parents of someone with a developmental disability, we ask for your uncompromising support of our right to choose the types and intensity of supports and services our son receives, so that he and others with developmental disabilities have control over how they want to live their own lives.

Thank you!

Akinwale and Jacqueline Akinpelu