Senate Finance Committee
May 28, 2019
Chairman Matt Dolan
Ranking Member Vernon Sykes

**Written Testimony Given by Kimberly Woody**

I am submitting this written testimony in support of the Informed Choice Amendment.

My husband and I as stepmom, have a 49 year old handicapped son. Due to an unfortunate delivery, he has been handicapped since birth and deemed mentally incompetent.

He went into his first group home in January, 2007. It was not the best scenario for him due to a lack of training on behalf of the staff. Three years later, he went into a shared living home with a caregiver from the group home and his family. He remained with the family until June, 2018.

We discovered that he had been abused and neglected. His placement in a private home had not allowed us the opportunity to monitor his care at our discretion. Major health conditions had gone without continued medical treatment. Necessary medical equipment had disappeared. He had numerous broken bones, kidney stones, uncontrolled blood pressure, left ventricle hypertrophy, bleeding retina and the list goes on.

He was placed in a Respite facility only to be neglected and abused again. We began to take care of Steven ourselves.

Several months later, we secured a fulltime caregiver with the DODD to care for Steven in an apartment that we rented for him. After 3 months, we discovered that his care was greatly compromised and the caregiver was taking advantage of Steven. A bakery business was being run out of the apartment that we secured for Steven. For use of his apartment, Steven was told by the caregiver that he was being paid in baked goods. Steven was told that he was the office manager of the business. The caregiver was let go. We took over Steven’s care once again. It was reinforced to us by the DODD, that he would be a hard placement due to his needs.

As aging parents, we knew that we could not meet all of the medical needs that Steven had. We told the DODD that we needed help with his situation. We were able to secure 8 hours a day coverage with a DODD caregiving business. It gave us a break, but it was not the answer.

His medical needs far exceeded the training of the DODD caregivers. He refused lifesaving medications, showers, fluids and other essentials that were necessary to his quality of life. The caregivers told us that it would be an invasion of Steven’s civil rights, if they were to make Steven take something that he refused, even prescribed medication and fluids.

As we were struggling to improve his quality of life. It became clear the care situation was not conducive to his medical requirements. The DODD informed us again, that he would be a hard placement due to his medical conditions. We were extremely confused how the DODD specialized in the care of the disabled, yet could not secure medical help for Steven’s needs. We needed answers.

The DODD sent us via Gmail, a minimal list of facilities to contact at our own discretion. Upon investigation, the listings were ICF. We had never heard the term, understood what an ICF entailed or that it was ever an option for Steven. We did not understand why it took five failed community placements, including abuse and neglect, before we were informed of the ICF option.

We secured placement for him at the Brookside Extended Care, ICF just nine miles from our home. Brookside has the medical expertise that Steven requires. The care is totally inclusive of all needed services. His quality of life has improved tremendously. We are able to monitor him and his medical care at our own discretion. We have entrance to the facility at any time without prior notice. He is part of a community of people that treat him with dignity.

We are troubled that no information had ever been offered that held the answers to his long term medical needs. Why would families not be informed about ICFs at the same time they are informed about waiver services? How and when is it determined who gets the information about ICFs? It is not being responsible to manage a service system that does not uphold the dignity of life or quality of life of individuals that cannot fend for themselves.

Steven has endured abuse, neglect, his health permanently compromised and taken advantage of as a disabled individual. The ICF option being offered from the beginning, would have given us the answer to his medical care far sooner. The harmful experiences Steven endured should never have happened and it has been very painful to witness as parents.

The ICF has given us an inner peace that he will be taken care of and treated with dignity should something happen to us. We are grateful for the answer to a very significant need within our family.

Thank you for allowing me to give my written testimony.