Chairman Bob Hackett Vice Chair Cecil Thomas

Testimony Given by Kimberly Woody

I am testifying 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 and the list goes on.

His medical needs far exceeded the training of the DODD caregivers. He refused lifesaving medications, showers, fluids and other major components that were necessary to his quality of life. The caregivers were not permitted to get him to do what was medically needed, because it was an invasion of his civil rights.

We were struggling to improve his quality of life and this situation was not conducive to his medical needs. We wanted answers. The DODD informed us that he would be a hard placement due to his medical conditions.

We were finally given a minimal list of facilities to contact at our own discretion. Upon investigation, the listings were ICF facilities. We had never heard the term, understood what an ICF facility entailed or that it was ever an option for him.

We placed him in an ICF facility. They have the medical expertise that he requires, it is totally inclusive and his quality of life has improved. 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 care. Why would families not be informed about ICF facilities as an option of care for their loved one? How and when is it determined who gets the information? A person with disabilities should not have to be exposed to abuse, neglect and their health permanently compromised to learn of an ICF facility. It is not being responsible to manage a service system that does not uphold the dignity of life or quality of life for individuals that cannot fend for themselves.

The ICF facility 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.