

February 21, 2023

Re: Support for HF 716

Mr. Chair and committee members,

We are Dennis and Susan Kane, parents of Hannah Kane.

Having grown up in the 1960's and being peripherally aware of state institutions, one of the many fears we had upon realizing the gravity of our daughter Hannah's disability was, like all parents, where and how would she live after we were no longer able to care for her?

This concern was supplanted by many, many more pressing and immediate concerns as she, and we, negotiated the doctors, therapy and educational systems and so many other challenges as she grew to become the vibrant outgoing young lady we know today.

Many hurdles, both expected and unforeseen, have been encountered and dealt with, but now we find ourselves facing head on and in very real time, that initial fear of what is to become of her after we are gone.

One of, if not our biggest concern, we thought was dealt with for now, is housing. Hannah lives in a home of her own. We planned and worked hard to save and pay for this home. She has staff that come in to assist her with essential life functions and assure she is safe. To accomplish this staffing, we were forced to switch from the DD waiver using CDCS waiver to DD waiver using IHS supports. One of the unintended consequences of that change is the reason for bringing this to the attention of the Legislature.

We have discovered, that according to the current state statute, Hannah cannot get the support staff she needs if she vacations out of state.

Previous to this change she was able to bring staff with her when she traveled and she was free to travel with staff, with or without her family. We always paid for her and her staff travel expenses. The waiver paid wages for staff, via CDCS, the same as they would if she was simply sitting on her own couch in her home.

We request the statute to be amended. Our wish is for Hannah to be able to travel to visit her many cousins and friends that we have fostered relationships

with throughout her life now, and in the future. When we are no longer living it is our goal to have these relationships (cousins) to help give her added natural supports, only achievable by being able to travel.

It seems obvious the IHS program was missed as most all of the other DD waiver programs allow out of state travel (CDCS, TBI, CADI and more). Frankly the way the ruling is worded IHS disallows Hannah to go to Wisconsin for lunch with her staff which is 10 minutes from her Minnesota home.

In short, our fear, and our greatest concern, will be that she is trapped in her own home, just as in previous generations, she may have been trapped in an institution!

We do not believe that was the intent of the law when it was written and indeed contradicts the freedom to travel freely that we all take for granted. Instead, it discriminates against people with disabilities living in their own homes, to travel with the supports they need. We respectfully request the law be amended so that Hannah and all of her peers can live the life they deserve, travel if they wish with support staff, and not be restricted by any of the waiver programs.

Respectfully submitted,

Dennis and Susan Kane, parents and guardians of Hannah Kane

Lake Elmo, Minnesota