

Submitter: Claire Watson  
On Behalf Of: SB 646  
Committee: Senate Committee On Human Services  
Measure: SB646

To the person reading this I hope you take this seriously.

Hello I am a sister to a special needs brother. My brother has a very complicated genetic disease that he was diagnosed with at age two. This disease is called MPS type two or hunter syndrome. This affects his everyday life like hearing and communicating with others. He is hard of hearing and handicapped. I hope that you think this through and know that passing this law will be the best choice and here are some reasons why.

My brother doesn't know how to communicate well and has his own way of doing things. It's hard to figure out how to understand him at first and without knowing what he's trying to say or tell you, many things can go wrong. My mom is his personal PSW, and the best PSW for him. She is better than any other random person that hasn't been with him since his diagnosis. One of these examples of communication is banging his hand on a hard surface like a wall, door, or table. When he does this it means that he wants something and that's how he tells us this. Someone that doesn't know this could think that he is just doing it to be annoying or to make random sound which neither of those is what he means. With my mom or dad being his PSW they would know exactly what he is trying to tell us and what it is he wants so he doesn't have to feel negative about this situation that he has no control of.

Another reason that hopefully will help you make up your mind about this decision that could affect so many families' lives. My brother had a stem cell transplant in Minnesota in 2019 right before Covid. The reason for this transplant was to see if it could help freeze or at least help my brother's hunter syndrome cells and DNA that contains it. The aftermath of this transplant was that he lost all communication and still hasn't gained ability to control his bladder. In the aftermath of this he can not be potty trained (but is working on it) or tell us that he needs to be changed or use the potty. If he gets a stranger to be his PSW he may not be treated ideally like wiping his chronic runny noses or changing his diaper or pants. We don't know if they would just not be comfortable doing this or just won't pay attention to him and his needs, but with my mom being his PSW he is able to get his hygienic needs dealt with and not ignored because as a mother of five she can see when he needs to be changed and obviously his nose wiped.

With these two reasons, I hope you can take this into consideration and make a choice that will help people with disabilities and those families with their family members with the disability. Thank you for your time.

Sincerely  
Claire Watson