

Marla Whitmore
Testimony on HB 33
Supporting the DD Workforce

My name is Marla Whitmore and my husband and I are parents to a young lady with global developmental disability due to a congenital disease called Pontocerebellar Hypoplasia. It is a progressive disease that has left her wheelchair bound, g/j fed, on a vent, non-verbal, with uncontrolled seizures- to name a few of her diagnoses.

We are ABSOLUTELY CRUSHED from not enough home health nurses to take care of Cassidy. We have one nurse- she does 24 hours one week, 36 the next. Cassidy requires 24/7 care. My husband and I take turns every night all night getting up with her. We are exhausted. My husband then goes to his full time job and I'm often alone to care for Cassidy no matter how little sleep I've had- I'm averaging 3-4 hours a night. We live in Carroll County- hardly any home health nurses will come to our rural area. One health care provider informed me Carroll County is considered a "health care desert".

When I researched and found out how little home health nurses are paid, I was mortified. Caring for someone as complex and needing total care like Cassidy- these nurses need paid a competitive wage!!! There's people making a lot more in restaurants! Home Health agencies need to offer incentives to potential nurses!! Meanwhile, families like mine are desperate and there is a lot of us. We are exhausted, hurting, scared, & hopeless. Yet we will absolutely not relinquish care of our beloved children to a facility. We need help and we needed it yesterday. We've been asking-more like begging- for help for years. It seems that no one cares.