

March 20th, 2023

Members of the Minnesota House Human Services Finance Committee:

I apologize that I am not able to be there in person before you today to provide testimony on HF2087. I have previously provided testimony before committees in both chambers - including this one - on similar bills. Its passage is of critical importance to the most vulnerable Minnesotans and their families.

My name is Jason Bennett, and I am the father of Ashlyn, a (recently turned) 18-year-old young woman, who has severe disabilities. My fiancée and I - and our blended family of four children from ages 11-22 – live in North Mankato. We are Ashlyn’s legal guardians. I work as a detective for a police department, and my fiancée works in state government. I have a Bachelor’s Degree in Law Enforcement and a Master’s in Public Administration. I also serve on the Minnesota Board of Peace Officer Standards and Training, having been appointed by Gov. Walz in 2019. We are a family of public servants.

Ashlyn is currently a Junior at Mankato East High School. In 2008, she was diagnosed with Rett Syndrome, which is caused by a genetic mutation on the X-chromosome. She cannot walk or talk, effectively communicate with others, or interact with her environment. She is completely dependent on others for everything. The list of her treatments, medications, and daily cares is significant, but in short, Ashlyn requires an advanced hospital level of care, 24 hours a day, 7 days a week, just to remain at home. She is authorized to receive 24-hour a day, complex nursing care at home, but due to the nursing staffing crisis, she does not receive the care she needs.

To provide an example of how deeply this crisis affects our family:

- Since January 1st, it has been about 11 weeks, or 77 days, or 1856 hours
- During that time, the nursing company was able to fill about 968 of those hours
- That is a fill rate of just over 50%. Ashlyn is barely getting a nurse half of the amount of time she needs.
- This is an *average* of nearly 80 hours per week where there was no nurse to care for Ashlyn...One week was nearly 100 hours, and another week was over 110 hours – hours that WE are having to cover. That’s the equivalent of between two and three full-time nursing positions that we don’t have.
- This is not an anomaly...this is now our “normal”

This leaves my fiancée and I to try to fill in as Ashlyn’s nurse – which we are not. We are essentially both working two full-time jobs. We work our day jobs, and then often come home and immediately have to take over care of Ashlyn at 5pm, and may have to cover until the nurse returns 14 hours later at 7am. I have almost no leave time left (vacation or sick) due to the shortage, and I must save all I can in the event of another missed nursing shift or an inevitable hospitalization.

When there is no nurse, we have no choice – there is nothing that can take priority over Ashlyn’s care. We must forego vacations, dates together, social activities, sleep, and frequently even our jobs, just to cover the shifts. We’ve even had discussions about whether one of us should leave our job to provide the care that Ashlyn needs. This would mean not only a loss of income, but a loss of insurance coverage, and a loss of a public servant to the community.

Pediatric Home Service (PHS) provides Ashlyn's in-home nursing care. They are an amazing company, both to work with as a parent, and from what I've heard from the nurses that work there. But I know that because of the low payment rates, home care companies like PHS cannot pay the nurses that provide care for people like Ashlyn wages that are competitive. Over the years, we have lost many nurses to better paying hospital jobs; very few stay to work in home care for longer than a couple of years.

And why would nurses want to work in home care instead of a hospital? In home care, there is uncertainty in the environment they will be working in. They are the only medical staff on-site, and if something goes wrong, the only "backup" they may have is a family member to help them. If a home care nurse takes a day off, or calls out sick, there is often no one to cover. These aren't concerns in a hospital setting...And for all the additional uncertainty and stress that comes with being a homecare nurse, they make significantly less money – tens of thousands of dollars less – than nurses in a hospital. The bottom line is the pay gap for home care nurses *must* be closed for families that rely on home care to even have a shot at getting their loved ones the care they need. This bill's 55% increase in payment rates makes a significant dent in that gap, but most certainly does not close it completely. But without it, the home care nursing shortage will only get worse – and I cannot fathom what "worse" would look like for our family, or how we would possibly manage it.

As I indicated previously, if nothing is done, one or both of us may have to leave our jobs, to provide just the basic day-to-day medical care that Ashlyn needs to keep her alive. We will not be able to be Ashlyn's parents, we will be her nurses. We will no longer be able to provide insurance coverage for our family. We have three other children who we will not be able to devote the necessary time and attention to. We will have no time to be a family; there will be no quality of life to speak of for Ashlyn, or our entire family. All our time, energy and resources will be dedicated to *attempting* to provide the level of medical care that Ashlyn needs – care that we are not qualified to provide, which will likely lead to more hospitalizations, and very poor health outcomes for Ashlyn.

It doesn't have to be this way.

I know that this bill will not solve all the problems of the home care nursing shortage. But it is a step in the right direction, and the time to act is now. This cannot wait any longer, and there can be no half-measures. Things are only getting worse, and if we haven't reached it already, a breaking point is inevitable.

This bill is a significant step towards helping families like ours, by paying home care nurses a competitive wage that is commensurate with the critical care they provide. It will help Ashlyn, and persons like her, to be healthy and remain at home, to receive the quality medical care they need, and allow families like ours to continue to work in and contribute to our communities. It will let us be parents to our medically fragile children.

I am happy to help in any way possible. Thank you for your time.

Jason Bennett
North Mankato, MN