

TO: Senate Human Services Committee, Committee Hearing January 24, 2023

RE: SB 2276,

Senator Lee and committee members:

My name is **Sam Johnson** and I reside in Grand Forks, ND, legislative **District 17**.

I am testifying in **SUPPORT of Senate Bill No. 2276** for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

I am the oldest brother, and since the passing of our parents, now the legal guardian of Robert Johnson, who is a 50-yr. old man with Down Syndrome, Type II Diabetes, and Early-Onset Dementia.

Since moving with us to Grand Forks ten years ago, Robert has been trying to live a full and complete life as (in his own words) “An Independent Man.”

But in order for this to happen, in order for Robert to be an active, tax-paying citizen in the community, it is necessary for him to have **support services for his work, his day program, and most importantly, residential living.**

And for awhile, Robert had all these things in place with proper supports ...

— Robert had a **part-time job** at SamsClub with appropriate Vocational supports, where he earned a good paycheck from which taxes, etc. were deducted;

— he received **valuable day supports** for the hours during which he was not working at SamsClub;

— and he had **good residential staff support** while living in 2-bd room condo with a housemate, both of them being supported with evening and over-night in-home staff supports **as their needs required.**

Then in 2018, DD implemented the “new payment methodology.” These new provider payment changes came with a required “redetermination” for Robert and individuals like him, using new SIS and ICAP assessment tools, which ended up **negatively impacting his support services, and actually resulted in a serious cutback of staff supported service hours for Robert** from 60 hrs. to an impossible 34 hrs. per week!

This was disastrous! The most significant result for Robert, and others like him who were receiving similar residential support services, was that he now had to go into a larger group living situation to live with more client-housemates in order to “pool their reduced hours of service” and be served by fewer support staff in order to meet these support service reductions! **This has been a very poor situation indeed** that didn’t, and still often doesn’t, provide the goals of person-centered support “maximizing **independence, and self-sufficiency, to prevent institutionalization..**” In fact, in the view of many, this resulted in a step backwards toward group institutional living!

For almost half a year while trying to find a group living place for Robert, my wife and I took turns spending the evenings and nights with Robert in order to fill the gaps left by the loss of his much needed residential support staff. And since Robert has a close-knit family that includes 4 other siblings and a number of college-aged nieces and nephews, several of them also took turns staying with Robert as caregivers.

In fact, to our DD case manager we suggested hiring of one or more family members, who were very willing to be live-in residential support staff caregivers for Robert. But financial support from the state for family employment was not possible, and there was no parent/guardian caregiver compensation available at that time.

In the end, sadly, Robert had to move away from us, out of Grand Forks, relocating to Devils Lake to live in a group home with 3 other individuals and shared staff spread so thin that his individual needs are sometimes not met.

It’s with this situation in mind then, that **I ask you to vote YES in support of Senate Bill 2276** that could provide for family caregiver compensation, making it possible for family members themselves to provide much needed and better residential live-in support that would be more personal and individualized, and actually lead to a higher quality of care with better outcomes, more social and community involvement, and a greater degree of independence.

On behalf of families like ours who would wish to provide more personal care for their loved one with special needs, and who need state support in order to provide this caregiving, I say **THANK YOU** for supporting SB 2276!

Sincerely, Sam Johnson — 701-350-1590. — samjohnson58201@gmail.com