SB 2316 - Testimony by Dustin Gawrylow, as a private citizen (corrected version)

Madam Chairwoman and Members of the Committee,

For the record my name is Dustin Gawrylow, and on this particular bill I am speaking as a private citizen and not behalf of any organization.

I would like to thank Senator Mathern for prime sponsoring this bill, as well as you Madam Chairwoman for co-sponsoring. As well as the other co-sponsors: Senator Cleary, Representative Johnston and Representative Hendrix. Some may notice that this is an unusually diverse coalition, which was my goal to help generate more attention to the issue.

Personal Background and Interest In This Issue

My interest, understanding, and frustration on this issue has developed over the last year due to a situation involving my mother's healthcare situation.

I will try to minimize the personal and emotional aspects of this issue, but to give some context: my 70 year old mother broke her leg last March, and due to complications during/after surgery suffered from aspiration, which led to a collapsed lung due to over-suctioning, which has led to her being ventilator dependent at night and intermittently during the days.

After four weeks in ICU, my mother was transferred to Vibra in Mandan. After 100 days, the Medicare coverage window ran out, and three attempts to appeal to Medicare were denied.

From this point, I have learned the hard way just how broken the system is.

I learned about how facilities like Vibra are called "Long Term Acute Care Hospitals" but "long term" does not mean what people think it means. They either cannot receive or do not accept Medicaid as they are not actually meant to be "long term" like a nursing home.

In mid-July 2024, after the 100 days lapsed, my family went into frantic panic because we were told the only option was for her to be sent away to a facility in Provo, Utah because no skilled nursing home near by would accept a patient on a ventilator and North Dakota Medicaid.

Research and Investigation

I did not believe this to be true, so I spent two days straight calling facilities in North Dakota, Minnesota, South Dakota, Montana, and Wyoming - simply trying to find a facility that would take her that was also within a reasonable driving distance.

I personally contacted over 15 facilities in these states.

I learned that the last facility in North Dakota that accepted ventilator patients and took Medicaid was in Fargo, but they ceased to accept those patients in 2022, and that they would have stopped earlier but COVID kept the demand up to justify the program.

I learned that in Minnesota, there are only two facilities in the Twin Cities that accept ventilator patients and have reciprocity with North Dakota Medicaid - and those two facilities only have 40 beds between them in the ventilator units. But both stated the waiting list was 2-5 years, as the only way beds are opened up is when a resident/patient dies.

I was able to get the most information about the business supply/demand dynamics after spending two hours speaking to the admissions coordinator at the Advanced Care Hospital of Montana in Billings. She explained that the upper midwest is a desert when it comes to these services. They accept Medicare but do not accept North Dakota Medicaid, and that they too send the patients they cannot handle to a facility in Provo, Utah.

When we realized there were no facilities within a reasonable range of Bismarck, and that the only option was to send my mother to a facility 1,000 miles away to be alone and probably die alone, I decided something needed to be done.

That was the inspiration for this bill.

Which is more of a placeholder bill, that needs the details filled in.

The following is the concept language that I sent to a few legislators to explain the issue.

Bill Intent:

To protect and prevent North Dakota residents from being transferred out of state due to a lack of skilled nursing care for patients partially or completely dependent on ventilators.

Reason:

As of July 1st, 2024 there were no skilled nursing home facilities in North Dakota that would service patients with ventilator needs.

Objective:

Mandate and fully fund at least one skilled nursing to facilitate inside the boundaries of North Dakota to provide ventilator care to North Dakota residents - both private pay and those covered by North Dakota Medicaid.

If no skilled nursing home in North Dakota is willing to provide ventilator care, then the state of North Dakota will cover the associated costs of such care at any certified LTAC (Long Term Acute Care) facilities until an appropriate alternative is found.

Furthermore:

The state of North Dakota will work with neighboring states like South Dakota, Montana, and Wyoming to accommodate similar patients at the cost of their states to develop a critical mass of demand for ventilator services.

Funding:

All costs will be covered that are not otherwise covered by existing programs.

Retroactivity:

Any nursing home or LTAC that can document patients that were cared for without guaranteed payment by other programs in the last two calendar years shall be eligible for reimbursement based on a case by case audit of such deficiencies.

In developing this guidance, I was communicating with Scott Schneider of the Mandan Vibra facility. I have attached the communications between him and myself just on this particular bill concept.

Organizing A Fix

This issue mirrors that of the "rural doctor fix" we often hear about at the national level when it comes to Medicaid funding in general.

It is my understanding that Medicare and Medicaid reimburse facilities upward of \$1,800 per day for these patients, and that that amount is not enough to justify having permanent staff to take care of such patients. There is a "critical mass" issue. Of the two facilities in Minnesota that do accept these patients, one has 16-beds and the other has 24-bed. Which appears to be the level required to cover the costs of permanent staff.

From the time Medicare cut off authorization on July 12th until we found an apartment here in Bismarck AND lined up minimal in-home care on December 2nd, my mother was staying at the Mandan Vibra facility basically as a squatter incurring a \$1,800/day charge that she can never pay as she receives \$1,335/month from Social Security.

Taxpayers Do Not Actually Have A Safety Net

During this whole fiasco, it became apparent that families that are productive taxpayers (like my parents) and pay into the Medicare and Medicaid system really do not have a safety net when it comes to be their time to need help.

Conclusions

I would like to ask this committee to craft a bill that would create mechanisms and funding needed to create a situation where North Dakota taxpaying citizens can know that when it is their time to need extensive medical care, they can receive it in North Dakota and not be shipped out of the state.

While the fiscal note on this fix will likely be large - do we really want to be a state that cannot ensure its citizens have medical treatment and long term care inside the state?

This issue connects to other major issues the state is dealing with - like workforce development - how can we keep working families in North Dakota if their family members have to be sent a 1,000 miles away?

Keeping our elderly relatives close to us here in North Dakota should be as big of an issue as childcare and workforce development because it is "Standard of Living" issue.

I urge you to craft this bill to find a way to at least create pilot programs to start the processes of fixing this problem.

Thank you for your consideration.

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