

Chairman Weisz, Vice-Chair Representative Rohr, and members of the House Human Services Committee, thank you for allowing me to speak on behalf of SB2145 regarding access to LTC facilities by Essential Caregivers.

My name is Beth Sanford. I am a Master's-Prepared Registered Nurse, born and raised in North Dakota. I got my start in nursing working in my local LTC facility at age 15. I was a nurse's aide for seven years before obtaining my BSN and then MSN from UND. My specialty is working with vulnerable populations, which includes a two-year stint in LTC and a memory care unit as a staff nurse and then nurse manager. For the last five and half years I have been employed as an assistant professor at a local university. Among the courses and content that I teach are public health, leadership, disaster-preparedness, and ethics. I am also a Doctor of Nursing Practice student specializing in Public Health and Policy. In addition, specifically related to this bill, I am former member of the Reuniting Residents and Families taskforce set up by DHS and a co-founder of the family-led organization, North Dakota Advocacy for Residents in Long Term Care.

Over the last year, I spent considerable hours reviewing and investigating the policies handed down from CMS, scrutinizing the recently rescinded Executive Order 2020.22-1 and the VP3 team guidance. The EO and VP3 team guidance impacted approximately 8,000 residents in Assisted Living Rental Properties, Basic Care and Skilled Nursing facilities, countless family members and staff—upward estimate of 100,000 North Dakotans.

I believe the visitation restrictions that violated the rights of the resident stem not solely from the federal CMS guidelines, which is what families are told, but primarily from the EO and the interpretations of the CMS guidelines by the DHS VP3 taskforce and individual facilities. **The fine print in the VP3 taskforce interpretations authorized facilities to enforce further restrictions above and beyond the executive order and federal guidelines at their own discretion.** Three additional areas confounded visitation attempts:

- Reported data collection inconsistencies.
- Quality control issues within the NDDOH and ND State lab leading to high false positivity rates; and
- An important retesting protocol aiding in eliminating false positives that restricted visitation was discontinued.

**The unintended consequences of these policies have caused a lot of unnecessary suffering.**

I testify before you today not only as a 25Y seasoned healthcare professional, but as a daughter of North Dakota whose family has been deeply impacted by EO and its interpretation and application.

In December of 2019, our 93Y Grandmother moved from an assisted living rental property to the skilled nursing side of her facility. Recent renovation of the facility had cut off her independent access to activities, chapel and her life-long friends on the skilled nursing side. Other than the fact that she is legally blind and walks with a walker, she is very healthy. Like every family, the visitor restrictions while residing in LTC began to take its toll on her wellbeing and quality of life including her cognition, physical & emotional health. She became unable to operate her phone isolating her further from her only living child and daily visitor, our mother. At one point she asked me if my mother was in jail. Her

conversational ability strikingly declined, and she was unable to talk about anything but the weather. She also began to complain about increased pain; likely from the hours and hours of sitting isolated alone in her room. Our mother visited her daily at the window, but it was thick-paned glass that was difficult for my grandmother to hear through in addition to her visual impairment.

In July 2020, after an incident where our family was refused a valid compassionate care visit, we removed my grandmother from the LTC facility. She is now being cared for by my mother and a local woman we have hired as there is no homecare in our county. Our family has a beautiful end to our story, our grandmother came back to life. At the age of 93, she regained her cognitive function, her emotional health, mobility and then some. She now sings, dances, laughs, tells jokes, lifts weights, exercises, walks three times per day, attends church and bible study and participates in all family events. She is truly living her best life.

However, there was only one problem. We couldn't sleep at night knowing that 8,000 other North Dakotans and their families and overworked staff were still suffering excessive visitation restrictions. Not everyone has the means or ability to bring their loved one home. Families kept contacting us from all over the state.

In September of 2020, tired of the months of run around and passing the buck from agency to agency unreturned emails and calls from state media, it was clear there was no help for residents and families in ND. The legislature was our last resort. Four resident family members and I looked to our hometown Senator, Dale Patten for help. We shared our story and informed him of the devastating unintended consequences of EO and the VP3 and facility interpretations of the CMS guidelines. Thank you to Senator Patten and Senator Roers and the other members of the Senate Human Services committee for speaking out about the excessive restrictions on LTC thus ending the media freeze on the issue. The family led organization, North Dakota Advocacy for Residents in Long Term Care was created at this time as an effort to bring families together for emotional support, inform residents and families of their rights under the 1987 Nursing Home Reform Act, and as a venue to discuss state and facility overreach. To date, over 16,000 North Dakotans have accessed information from our group and page, a confirmation that we are not the only family with a resident that required advocacy during COVID overreach. At that time, we began to discuss with Senator Roers the need to follow other states who had enacted Designated Caregiver Laws such as Colorado and Arizona. That brings us to today.

However, Lingering questions remain unanswered. We have the following requests:

- Follow up with the dozens, if not hundreds, of complaints of abuse and neglect, use of chemical and physical restraints that were referred to the Reuniting Residents and Families Taskforce Chairman, state ombudsman's office and to the department of health and human services.
- Reevaluate the policy of not retesting residents in LTC facilities after an asymptomatic positive.

Further comments:

- Regarding county positivity rates: The map with the color coding of counties is not accessible to residents and families. It should be easily accessible for families on the front page of the NDDOH website and the NDLTCA website and facility website to communicate with families.
- The state lab publicly reported issues with software malfunctions and quality control problems leading to high false positivity rates in November and December of 2020. These quality control

issues led to unnecessary restrictions in visitation in LTC not allowing many residents to see family over the holidays.

In Summary, CMS Visitation Guidelines:

Failure to facilitate visitation, without adequate reason related to clinical necessity or resident safety, would constitute a potential violation of 42 CFR 483.10(f)(4), and the facility would be subject to citation and enforcement actions.

SB2145 is urgently needed. Managing LTC is a delicate balance that needs to include the holistic care for the resident including visitation of essential caregivers. Every year, there are facilities that are in violation of CMS codes that protect the rights of the resident. In fact, we have counties that are in green without one positive case in the facility that were still not allowing visitation as of last week. There are people who had not seen or touched their loved one since March 2020 before the EO was rescinded. This is an unacceptable violation of human rights and is in direct violation of the 1987 Nursing Home Reform Act Resident Bill of Rights.

The hearts of thousands of North Dakotans: residents, family, friends and staff are broken. This law is imperative not just for the days of COVID, but for all time to protect visitation freedoms of our loved ones in LTC.

Please vote in favor of SB2145.

Thank you for your time and consideration.