

Terry Rockstad Testimony

SB 2226 – Residential End-of-Life Facilities Senate Industry, Business & Labor February 1, 2021, 2:15pm

Chairman Klein and members of the committee, my name is Terry Rockstad, Founder of the Rockstad Foundation, and I am here to testify in support of SB 2226, which would add a new option for hospice patients by creating a licensure for residential end-of-life facilities.

Before me you have heard some compelling stories of how this facility will fill a needed gap in North Dakota. A residential end-of-life facility has been a dream of mine and the Rockstad Foundation since 2014. I have had many friends of all ages who have experienced hospice care. For some, it was a blessing to be able to provide hospice in their loved-one's home. However, I have seen first-hand many friends suffer from the stress and anxiety of becoming a loved one's primary caregiver; and the grief they experience each time they pass by the room in which their loved one died. I also know many people who struggle from the guilt of not being able to honor their loved one's wish of being in a home during end of life, and eventually pass in an institutional setting surrounded by strangers instead of family. This is especially evident during this COVID-19 pandemic. And finally, my heart breaks for those who simply do not have a family member or friend who is capable to provide the care needed when end of life is near.

Today I want to address: 1) What a residential end-of-life facility is, 2) Why it is needed, 3) Who it will benefit, and 4) Insight to our financial projections to make this a reality.

1) First, What a Residential End-Of-Life Facility Is. North Dakota's existing hospice provider licensure allows for facilities to be built and operated. However, if a for-profit or non-profit entity would like to build the facility only and partner with a provider or multiple providers, there is no licensure available. While exploring this concept, we visited with multiple employees from the Department of Health to find a fit under existing Century Code. We exhaustively searched under Basic Care, Home Health, Hospice and elsewhere without success. We then met with

employees from the Department of Human Services to find a fit under current laws of Nursing Homes, Assisted Living or Adult Foster Care without further success. Throughout all of our conversations, it became evident that we do not fit under any of these codes and need to be in an independent chapter under the Health Department. This proposed language defines a residential end-of-life facility licensure and subsequently establishes administrative rules that will detail the life safety requirements.

It is critical to understand that the Rockstad Foundation does not have a preference as to the specific language or the department of which this would be regulated. In fact, if your opinion is that this type of facility doesn't need to be licensed, we only would ask that law would be enacted to state that we can exist without licensure. Our only objective is to create confidence to the public that this is a safe facility for loved ones who are vulnerable adults.

To take you inside this proposed facility, individuals could receive hospice services from a licensed hospice provider of their choosing, and facility staff would collaborate with hospice providers to ensure the goals and priorities of the patients and families are met. The facility would specialize in providing 24-hour end-of-life care by qualified, dedicated staff and volunteers. These homes are staffed by RNs, LPNs, and CNAs who provide personalized supportive care 24 hours a day, seven days a week, with a significantly low guest to caregiver ratio – often 1 caregiver to every 3 or 4 guests.

Some comparable facilities across the nation are larger facilities with eight to 12 private rooms, while others are single family or twin homes with one or two individuals receiving care. There are often rooms available for families to stay while others have the capability for the family members to live with their loved one. The residential end-of-life facility employees and volunteers take care of the family members' caregiving tasks, cook meals and provide light cleaning, so families can solely focus on spending quality time and making lasting memories with their loved one.

2) Why Residential End-of-Life Facilities are Needed. I want to highlight some of the research our Foundation has done of why these facilities are needed:

1. North Dakota's population of 65 or older use hospice services the most. They are currently 22% of the state's population and that number will increase by 11% in the next 10-15 years. (CensusReporter.org.)
2. From 2016 through 2018, beneficiaries who received hospice care under Medicare Part A increased by 65% (Great Plains Quality Innovation Network).
3. There is currently no true home setting in North Dakota where 24-hour supportive care is provided for those who seek hospice services and are unable to receive care in their home.

3) Who Will Benefit from a Residential End-of-Life Facility? This type of home can fill gaps in the continuum of care. Those who will benefit include:

- People who need hospice services but have limiting factors which make it difficult or impossible to receive hospice services at home, and who wish to be in a home setting. This being said, it is not the intention to move or recruit an individual that is in a nursing home or assisted living who does not want to move.
- Families who want to honor a loved one's wish of being in a home during life's final season but are unable to provide that support in their loved one's home.
- Families who need relief care for longer than the five-day Medicare/Medicaid Hospice respite benefit. Five days just isn't long enough for some families; but if a loved one moves into a residential end-of-life facility, those families can get the relief they need.
- Hospice patients whose home is no longer a viable option but desire a home setting. It's a "home away from home."

4) Insight to the Financial Costs of Making a Residential End-of-Life Facility

Finally, I want to share a bit of how we see this facility through a financial lens. The intent of the Rockstad Foundation is to create a separate non-profit entity and to build a 100% privately funded and licensed end-of-life facility that is opened to ND Hospice providers so they can offer this true home setting with 24-hour supportive care to their patients. You may be asking why not just become licensed and become another hospice service provider? The answer is simple: Our interest is not to encroach upon established hospice programs that provide wonderful hospice care—

our interest is to supplement with a facility and let the service providers do what they do best.

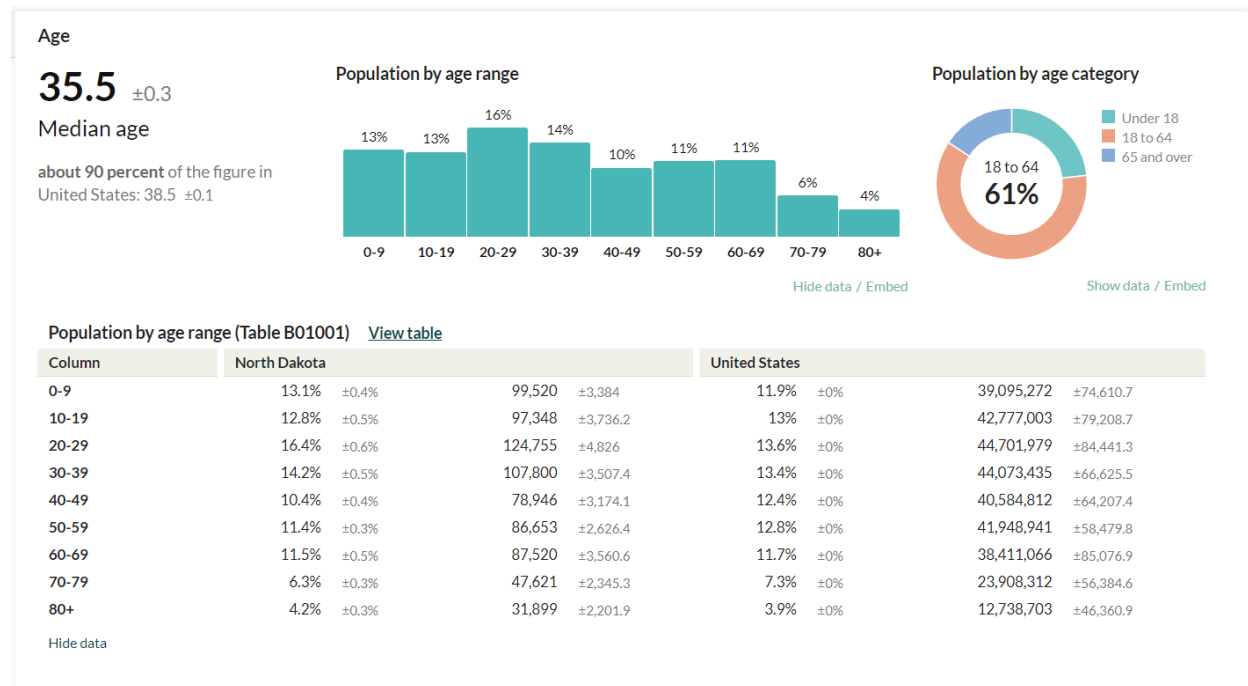
It is currently estimated that a \$35 million campaign is needed to build the 12 twin-home facility in Bismarck, fund initial operations, and to begin an endowment that will provide compassionate care funds for those who can't afford private pay. Currently, \$3.5 million has been committed thus far. Once legislation is passed, a capital campaign would kick off and construction would begin when the funds have been secured.

Based upon a successful campaign and initial projections, the facility would open in 2025 and 35% of the guests, or 84-139 people on an annual basis could have 100% of the costs defrayed in year one, and for the next 13 years without ANY additional donations. An initial business plan currently details that private funds will aim to subsidize the cost of the care, so the private pay component is only \$500 per day, which is the market rate for comparable facilities in other states. According to 2018 data, the median length-of-stay for individuals on hospice care in the Bismarck region is 11 days, therefore a family could expect an estimated cost of up to \$5,500. However, the overall goal is to grow the endowment to continue to push down the costs so eventually all guests are fully fund.

Finally, I want to leave you with what I have learned throughout this journey of researching and learning about hospice care. It is not the last step before dying—it is about giving individuals and families the ability to have dignity in the last phases of life —and we want to be part of making the last days comfortable and easier. I will show a short video of our vision. Thank you and I will stand for any questions after the video.

For Reference Only

Video explaining Residential End-of-Life Facilities: <https://youtu.be/nADQydzNI1I>



<https://censusreporter.org/profiles/04000US38-north-dakota/>