

# Testimony in Support of Amended HB 1513 A More Inclusive Amendment Senate Human Finance and Taxation Committee

March 14, 2023 • 9:15 a.m. • Fort Totten Kilee Harmon kilee@thegaiahome.org • cell: 701.226.4546

Chairman Kannianen and members of the committee, my name is Kilee Harmon, and I am the Executive Director of Gaia Home, which is a nonprofit based in Bismarck that is working to create one of the first Residential End-of-Life Facility communities of its kind in the state. Today I am here to submit testimony and respectfully ask for a "Do Pass" recommendation to the amended version of House Bill 1513, which if enacted, will include Residential End-of-Life Facilities as an eligible facility in addition to a hospice care facility owned by a hospice provider, to receive the proposed sales and use tax exemption for tangible personal property used to construct, expand, or upgrade a facility.

I support the amendment for the following reasons:

- 1. Gaia Home's mission is to bring comfort, compassion, and dignity to all persons and their loved ones, as we nurture the human spirit through the end-of-life journey.
  - a. Since November of 2020, we have lived our mission by collaborating with hospice providers to fill a current gap in end-of-life care services in our community, region, and state with the creation of Residential End-of-Life Facilities.
  - During the 2021 legislative session, it was Gaia Home leadership that brought forth the legislation that created NDCC 23.17.7 which established the Residential End-of-Life Facilities licensure.
  - c. On March 7 of this year the Administrative Rules Committee adopted the administrative rules for Residential End-of-Life Facilities that were developed through a stakeholder group organized by ND Health and Human Services and was comprised of individuals from Gaia Home Leadership, the Health Division of Facilities, Division of Life Safety & Construction, and Hospice programs from across the state.
- Residential End-of-Life Facilities have a similar purpose to that of a hospice care
  facility owned by a hospice provider hospice services are provided in both, and the
  facilities are dedicated to offering the best end-of-life care to patients and their
  families.
  - a. The vision for Gaia Home is to build and operate a neighborhood of residential units and community spaces for families and their loved ones to move into, receive hospice services from a hospice provider of their



choosing, and Gaia Home's caregiving staff who specialize in end-of-life care, will provide 24-hour personalized care to the hospice patient and their family, taking the caregiving role off of the family members' shoulders, giving them all the chance to truly treasure their precious time together during the final season of life.

- 3. Gaia Home's leadership is currently working to bring the vision to life.
  - a. At this moment Gaia Home is in the leadership phase of a \$12 million capital campaign. We have just over \$4 million in pledges committed and are continuing our fundraising efforts with a goal to begin construction in 2024.
  - b. As a non-profit working to bring this solution to those who want a homier option for their end-of-life care, any and all dollars we can save during construction through this exemption will only further support our mission going forward.

That concludes my testimony. I thank you again for your time and attention, and I will happily stand for any questions you may have.

#### For Reference Only

Video explaining what Residential End-of-Life Facilities are: Introduction of Gaia Home

Who will Residential End-of-Life Facilities Like Gaia Home Be a Solution For? Today, there is no place in North Dakota that specializes in end-of-life care in a true home setting, which is an option in many other states, but currently does not exist here.

For families and their loved ones facing the final season of life, in-home hospice care is the most desirable option. However, whether due to medical or other concerns, in-home hospice is just not feasible for many, and the current option is to spend the final journey in a non-home, unfamiliar setting. Gaia Home will provide a comfortable, homey solution for:

- People requiring hospice care who have limiting factors which make it difficult or impossible to receive services at their home.
- Families with loved ones who wish to remain in a comfortable home setting during the end-of-life journey but are unable to provide the home-based 24-hour caregiving needed.
- People needing compassionate end-of-life care who live outside of a hospice service.
- Family members currently acting as primary caregivers to their loved ones who need support in administering care or managing grief.
- Hospice patients whose home is no longer a viable option for their required care but do not wish to spend their final season in a non-home setting.



 Terminally ill individuals who are discharged from the hospital but have no housing to live out their final journey.

#### How Residential End-of-Life Facilities Like Gaia Home Are Different

- Gaia Home intends to open its residential units and community spaces to licensed hospice providers so they can offer this true home setting with 24-hour supportive care to their patients.
- Gaia Guests can receive hospice services from licensed hospice providers, and Gaia caregivers will collaborate with hospice providers to ensure the goals and priorities of the patients and families are met.
- Every Gaia Guest will receive personalized care 24 hours a day, seven days a week, with a significantly low guest to caregiver ratio. Family members can live with their loved one in a private home setting and spend quality time making lasting memories as Gaia caregivers relieve families of the many difficult caretaking tasks.

# Why Residential End-of-Life Facilities Like Gaia Home Are Needed Now

The need for Gaia Home and its placement in Bismarck – which is often referred to as the healthcare hub for Central and Western North Dakota – is evident because of: the increase in the 65+ aging population (the group that is most likely to utilize hospice services), the overall population growth expectations for the region, current hospice utilization, and the lack of services in the region.

- According to the Rural Health Information Hub (ruralhealthinfo.org):
  - o In North Dakota's non-metro areas 16.9% of its population is 65 or older, and in its metro areas 13.7% is 65 or older.
  - o 16.2% of Burleigh County's population is 65+
  - There are five counties in the state in which 29.8% or more of the population is 65 or older. Four of these counties (i.e., Sheridan, McIntosh, Grant, and Emmons) are within 120 miles of Bismarck.
  - Burleigh's neighboring counties (that are also part of Region VII West Central Human Service Center) of Sheridan, Grant, Emmons, Oliver, McClean, Kidder, Mercer, Morton and Sioux have a 65+ aging population equal to 32%, 29.8%, 28.7%, 24%, 23.4%, 20%, 16.4% and 8%, respectively.
- According to the ND Census Office Population Projections of the State, Region, and Counties 2016:
  - o From 2020 to 2030, North Dakota's population of 65 or older is expected to grow 25% from 122,120 to 152,818.
  - From 2020 to 2030, the population in North Dakota's Western four regions combined is anticipated to grow from 402,853 to 468,512, a 16.3% increase.



- In the expected migration scenario, the Western four combined economic regions (Williston, Minot, Dickinson, and Bismarck) reach a population surpassing the four combined Eastern regions (Devils Lake, Grand Forks, Jamestown, and Fargo) of the state between 2025 and 2030.
- According to local hospice providers, and out-of-state providers who operate
  facilities similar to Gaia Home on a daily basis, 10-30% of people on hospice services
  may need a place like Gaia Home. The average daily census of people on hospice
  services in the Bismarck-Mandan and surrounding communities is roughly 92
  people, which means anywhere from 9 to 28 individuals each day could possibly
  benefit from Gaia Home.
- According to the NDHHS hospice locator, in North Dakota's Western four regions
  there is a total of 28 counties and four of those countries currently have no hospice
  services; and nine of those counties have only one hospice provider to choose from.
  People needing compassionate end-of-life care who live outside of a hospice service
  area or have too few hospice providers to choose from could benefit from Gaia
  Home.

Why is hospice utilization so low in ND, and what can be done? According to Figure 4: Hospice utilization by state (percentage) in the NHPCO Facts and Figures 2022 Edition, the proportion of North Dakota Medicare decedents enrolled in hospice at the time of death in 2020 was 31.6%, which makes ND ranked 49<sup>th</sup> out of all 52 states, territories and District of Columbia. Essentially, this indicates that the Medicare hospice benefit is not being fully utilized in North Dakota. This can be due to not having access to hospice services, and people not fully understanding what the hospice benefit all includes and can offer them. One way to increase hospice utilization is by increasing access to hospice services and homey facilities in which people can receive hospice services when in-home hospice care is not an option and they want to be in a home environment. Gaia Home and residential end-of-life facilities will support this effort.





What type of hospice care will hospice providers be able to provide within Gaia Home?

There are four levels of hospice care provided by the Medicare hospice benefit. They are routine home care, continuous home care, respite care, and general inpatient.

#### 1. Routine Home Care

a. It is the most utilized level of hospice care. According to Table 5: Percent of Days by Level of Care in the NHPCO Facts and Figures 2022 Edition, in 2020, 98.7% of the days of care were under Routine Home Care. That is when the hospice program's interdisciplinary team (i.e., Patient and family, Physician including

| n 2020, the vast majority of Med   |           |             |       |           |          |
|--|-----------|-------------|-------|-----------|----------|
| are (RHC) level with a slight inc<br>GIP) level saw a slight decrease                |           |             |       | eneral in | patient  |
| an y rate, sait a signic accrease  | 110111201 | 7 (1.2 00 1 | .0).  |           |          |
| Table 4: Spending by Leve  | l of Ca   | re          |       |           |          |
| Percent of Days by Spending  |           |             |       |           |          |
| Routine Home Care (RHC)  |           |             | 92.7% |           |          |
| General Inpatient Care (GIP) Inpatient Respite Care (IRC) Continuous Home Care (CHC) |           |             | 5.6%  |           |          |
|  |           |             | 0.6%  | -         |          |
|  |           |             |       |           |          |
| ource: Hospice Analytics   |           |             |       |           |          |
| able 5: Percent of Days b  | v l ava   | of Car      |       |           |          |
| CONTRACTOR OF THE  | , Leve    | or car      |       |           | X COLUMN |
| Percent of Days by Level of Care   | 2016      | 2017        | 2018  | 2019      | 2020     |
| Routine home care  | 98.0%     | 98.0%       | 98.2% | 98.3%     | 98.7%    |
|  | 1.6%      | 1.3%        | 1.2%  | 1.2%      | 1.0%     |
| General inpatient care   |           | 0.3%        | 0.3%  | 0.3%      | 0.2%     |
|  | 0.3%      |             |       |           |          |
| General inpatient care  Inpatient respite care  Continuous home care                 | 0.3%      | 0.2%        | 0.2%  | 0.2%      | 0.2%     |

the medical director and attending physician, Registered nurse, Medical social worker, trained volunteers, providers of special services including a spiritual counselor, a registered pharmacist, a registered dietitian, or professional in the field of mental health may be included in the hospice care team as determined appropriate by the hospice program) creates the patient's plan of care, sets up the durable medical equipment needed wherever the patient calls home, organizes the medication schedule, trains the patient's caregivers on how to provide care per the plan, and more. The hospice program is not with the patient 24/7, and the caregiver role falls onto family and friends.

#### 2. Continuous Home Care (CHC)

a. It is care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services, and are intended to maintain the terminally ill patient at home during a pain or symptom crisis. In 2020, .2% of days of care were CHC.



## 3. Inpatient Respite Care (IRC)

- a. This level of care provides temporary relief to the patient's primary caregiver by moving the patient into a facility for 5-days. The facility's room and board is covered by the Medicare benefit for those 5-days. However, two consecutive 5-day stays are not allowed, so on the 6<sup>th</sup> and any consecutive day thereafter, the patient is responsible for room and board.
- b. Respite care can be provided in CMS certified facilities such as a hospital, hospice inpatient facility, or a long-term care facility.
- c. In 2020, .2% of days of care were IRC.
- d. Even though hospice programs would not be able to offer IRC in Gaia Home's Residential End-of-Life Facility, they could offer "relief care" in which people can stay longer than the 5-day respite benefit. The patient and/or family would be responsible for the room and board fees for "relief care" at Gaia Home and more than likely at other Residential End-of-Life Facilities. However, Gaia Home's goal is to substantially grow our endowment fund so we can subsidize 5-days (and possibly more) of patients' room and board fees for those who do not have an ability to pay.

## 4. Lastly, General Inpatient Care (GIP)

- a. This level of care is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility that has registered nursing available 24 hours a day to provide direct patient care.
- b. In 2020, 1% of days of care were GIP.
- c. Hospice programs would not be able to offer GIP in Residential End-of-Life Facilities.

Even though all levels of hospice care cannot be offered in Residential End-of-Life Facilities, routine home care – the most utilized level of care – and continuous home care can be offered.

## What services are offered in a Residential End-of-Life Facility?

Based upon the recently passed Administrative Rules for Residential End-of-Life Facilities they will be able to offer the following:

 Hospice Services by having an agreement with one or more hospice programs licensed under North Dakota Century Code chapter 23-17.4 to provide hospice services.



- 2. Residential services, which means intermittent, nonpersonal care tasks, such as housekeeping, laundry, shopping, and arranging for transportation.
- 3. Support services, which includes responsibility for patient health and safety, assistance with activities of daily living and instrumental activities of daily living, provision of leisure, recreational, and therapeutic activities, supervision of nutritional needs, and medication administration.
- 4. Volunteer services, which means the services provided by individuals, voluntarily and without remuneration, who have successfully completed a training program implemented by the facility.

## What about employment and the shortage of nursing personnel?

We fully understand there is a nursing shortage on a national level and state level. Our hope is to help supplement the staffing with qualified volunteers which is what you will see in other similar places. However, even with that being the case, we do not foresee the nursing shortage as a reason to not be more inclusive of Residential End-of-Life Facilities in the language for the proposed bill.

# If a hospice patient revokes from the hospice agency, are they still able to live in a Residential End-of-Life Facility?

If they choose to be a hospice patient of a different hospice program that provides services in the Residential End-of-Life Facility, a hospice patient would be able to stay.

If they are not a hospice patient, the patient will no longer be able to stay in a Residential End-of-Life Facility.