

2023

LONG TERM CARE
in ILLINOIS

A Guide for Illinois Attorneys



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BIOGRAPHY



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For the past 40 years, Dr. Steven Fox has focused his practice on the care and treatment of older adults and disabled individuals. His expertise in Alzheimer's disease and dementing illnesses began with his Master's degree research conducted in 1977. He received his Bachelor's degree from Northwestern University in 1975 and graduated from Chicago College of Osteopathic Medicine in 1981.

Dr. Fox has conducted forensic examinations and provided expert testimony in criminal and civil elder abuse and financial exploitation trials. He is a recognized court-appointed expert in guardianship, undue influence in probate proceedings.

Since 1999, he has served as Medical Director of Wellspring Personal Care an IDPH licensed Home Nursing Agency. He is the Chair of the Medical Advisory Committee of the Home Care Association of America.

For the past 30 years he has provided expert testimony in nursing home, assisted living, home care and personal injury litigation. Dr. Fox has taught and published on the topics of decisional capacity, guardianship, brain injury, personality disorder, nursing home care and litigation.

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LONG TERM CARE in ILLINOIS

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2023 Post Pandemic Care

The Covid pandemic has been disastrous for long-term care nationally and in Illinois. One out of three coronavirus deaths in the United States have been residents or employees of nursing facilities. Prior to the pandemic, nursing facility understaffing was commonplace and directly correlated with poor quality of care. It is alarming that long-term care facilities have lost over 400,000 employees from February 2020 to March 2022. Despite offering the highest wage increases compared to any other healthcare sector, job growth has stalled. The nursing home workforce has not been this low since 1994. The Bureau of Labor Statistics projects that it will not return to pre-pandemic levels until 2027.

This crisis in the long-term care industry will continue to worsen. The lack of staff has resulted in a historically low occupancy rate of 72% which threatens the financial viability of up to half of all nursing facilities. According to a study done by the American Health Care Association, 61% of nursing facilities have been forced to limit new admissions due to the inability to provide staff.

Clinical and nonclinical staff shortages in nursing homes have effected hospitals, emergency rooms and home care. Fewer available nursing home beds results in hospitals being unable to discharge their patients. This has increased hospital length of stay and stressed their entire system. Compared to 2019, data from

Strata Decision Technology found that one out of four hospital discharges were delayed.

The inability to discharge inpatients results in beds being unavailable for newly admitted emergency room patients. Emergency rooms then must keep patients in the department or “board” them on gurneys in hallways and waiting rooms. In November, the American College of Emergency Physicians with 32 other national healthcare organizations sent a letter to President Biden documenting the problem and asking him to address it, stating, “Boarding has become its own public health emergency.”

In Illinois, licensed Home Nursing and Home Services agencies have also been disrupted by this unprecedented shortage of trained and qualified caregivers. It is particularly difficult for Home Nursing agencies that are required to employ Certified Nursing Assistant (CNAs) who perform their duties under the supervision of a Registered Nurse (RN). Many home care providers are unable to meet the immediate and growing need for in-home care.

In 2023 and extending into the near future, the entire continuum of care will be challenged by the lack of a long-term care workforce. Prior to the pandemic, the primary question regarding long-term care was the ability to pay for care.

Now, the question of the availability and existence of quality care has become a first consideration.

The cost and availability of quality long-term care should be of interest and importance to an attorney. The need for informed representation and advocacy for clients who are injured, disabled or elderly has never been greater. Personal injury attorneys need an accurate current cost of care to negotiate and achieve a settlement that will provide quality care for the remainder of the injured individuals life. An accurate long-term prognosis and cost of care is necessary for Probate Court determinations of “the least restrictive setting” for a ward. Elder care and estate planning attorneys need to have the knowledge and confidence to advise their clients about the greatest threat to their financial well-being, the cost of long-term care.





Long Term Care Defined

Long-term care consists of the services provided to an individual with an illness or disability that is chronic and prevents independent living. The health and personal care needs of long-term care patients are primarily based upon cognitive and functional impairments.

Long-term care is provided in different places by a range of caregivers and health-care professionals. Most long-term care is provided at home by unpaid family mem-

bers and friends. In Illinois, paid or formal care in the home is provided by Home Services and Home Nursing Agencies which are licensed and regulated by the Illinois Department of Public Health.

If certified by a physician, individuals can also receive home care and hospice benefits from Medicare-Certified agencies. The services are considered "intermittent" and limited by the number of visits and a 30-day period of care.

Long-term care is also provided in Medicare- Certified and State Licensed; skilled nursing facilities, intermediate care facilities, rehabilitation facilities, behavioral health facilities and long -term chronic care hospitals.

Long Term Care 50 +1

Where is Illinois?

There is no uniform availability, cost or quality of care in the United States for long term care services. In Connecticut the median annual cost of nursing home care is approximately \$150,000 and in Texas \$55,000.

Variability by state continues across the continuum including assisted-living, home care, and adult daycare.

To compare all 50 states and Washington DC, medicareguide.com used 27 relevant metrics to determine a composite ranking based on cost, access to care and quality of care.

Best and Worst States for Long Term Care 2022

STATE	QUALITY	ACCESS	COST	50+1 RANK	TOTAL SCORE
California	23.55	21.84	26.51	1	73.69
Texas	15.75	19.13	27.57	4	62.45
New York	20.90	18.29	22.19	5	61.38
Wisconsin	24.16	20.35	15.09	6	59.60
Pennsylvania	15.42	22.31	21.70	7	59.42
Ohio	14.68	19.23	21.62	13	55.52
ILLINOIS	13.71	12.69	24.06	28	50.46
Indiana	13.00	15.11	17.78	36	45.90

SOURCE: www.medicare-guide.com



ILLINOIS (HB246)
**Nursing Home Reform Long Overdue
and Potentially Positive**

Thank you, Governor Pritzker. Last year he signed this law that will make Illinois the first day to implement a major reform in nursing home care. For the first time there will be a direct tie between funding for the nursing home industry and quality measures which will address quality hiring and staffing. The law will also provide accountability by creating transparency as to who owns nursing homes, how much they profit and where the profits go.

Poor nursing home staffing ratios contributed to this and Illinois was the worst in the country for the percentage of nursing home residents who are assessed and provided the pneumococcal vaccine.

The quality of care and deficiencies of Illinois nursing homes were highlighted in the Families for Better Care 2019 Nursing Home Report Card. Illinois was ranked 49th and received a grade of F. Illinois was described as being at the “bottom of the barrel” with other low- ranking states.

The Centers for Medicare and Medicaid services CMS five- star quality rating system for nursing homes consistently demonstrates that Illinois is below in the national average for 4 and 5 Star ratings. Illinois facilities average a 2 star rating. The February 2023 CMS report on the Special Facility Focus (SFF) Program, identifies 30 Illinois facilities. The SSF program is intended to identify nursing homes that have a history of serious quality issues



Illinois is
28th overall
and **42nd** in the
quality of care.

Illinois Nursing Homes

Medicare to Private Pay to Medicaid

There were 771 facilities in Illinois licensed to provide Skilled Nursing, in 2021. They accounted for 81,415 Medicare Certified Beds. There are only 14 facilities licensed solely as Intermediate Care Facilities. The vast majority of facilities are licensed as both SNF and ICF. Any confusion over this dual licensing is understandable but unwarranted.

The terms “Skilled Nursing” and “Intermediate Care” refer to the people who provide the care and not the physical facility. These terms are used to define who has the ability and authorization to provide specific services to a designated resident. Significantly, they also establish who pays for the services: Medicare, Medicaid, private insurance or out-of-pocket.

For any Medicare beneficiary to receive Skilled Nursing in a long-term care facility or in a rehabilitation facility, a completed and signed Physician’s Certification must be obtained. While there are no specific procedures or required forms for certification, the documentation must contain the following information:

- + The individual needs skilled nursing care (furnished directly by or requiring the supervision of skilled nursing personnel) or other skilled rehabilitation services.
- + Services are required daily.
- + Services can only be provided in a SNF or swing-bed on an inpatient basis.
- + Services are for an ongoing condition for which the individual received inpatient care in a hospital, or for a new condition that arose while the individual was receiving care in the SNF for a condition which she received inpatient care in a participating qualified hospital.
- + A dated signature of a certifying physician or physician extender (nurse practitioner, clinical nurse specialist or a physician assistant). The physician extender may not have a direct or indirect employment relationship with the facility and must be working in collaboration with the physician.

Medicare Physician’s Certification

Provider Type	Who Signs Certification	Certification Timeframe	Recertification
Hospital Inpatient	Attending physician or by another physician with knowledge of the case with authorization from attending physician or by a member of hospital’s medical staff with knowledge of the case.	No later than the 12th day of hospitalization	Interval between recertifications not to exceed 30 days
SNF	Attending physician or physician on staff at SNF with knowledge of case, or physician extender	Obtain at time of admission or shortly thereafter	First recertification no later than the 14th day of inpatient extended care services. Subsequent at intervals not exceeding 30 days.
HHA	Attending physician	Obtain at time POC is established or shortly thereafter	Physician must recertify at least once every 60 days
Hospice	For initial 90-day period, must obtain written certification statements from medical director of hospice or physician member of the hospice interdisciplinary group and the attending physician.	If written certification is not obtained within 2 calendar days of the initiation of hospice care, a verbal certification must be obtained.	Must be obtained for each period of hospice care; written certification by hospice medical director or physician member of interdisciplinary group.

There are specific requirements for the timing of the certifications and recertifications for Medicare covered services. While Medicare requests that certification be completed at the time of admission, this generally does not occur. Unfortunately, Medicare gives considerable time for physician visits. The physician must see the resident within the first 30 days. Doctors are also given the leeway of another 10 days for the visit to be considered as timely. In practice, if any new skilled nursing patient is not visited by the attending physician within 72 hours of admission that is a red flag for questionable quality of care.

The initial certification for Medicare Skilled Nursing is essential for the patient’s successful rehabilitation and preservation of their best cognitive and functional ability. Working collaboratively with the attending physician can help in determining whether a skilled nursing facility, rehabilitation facility or home care is the best option for a good outcome.



The terms “Skilled Nursing” and “Intermediate Care” refer to the people who provide the care and not the physical facility.

Skilled Nursing vs Custodial Care

The defining issue.

Skilled Care refers to a patient's need for care or treatment that can only be performed by licensed nurses, RNs, Registered Nurse or LPNs, Licensed Practical Nurse. Skilled care is medically necessary when provided to improve the quality of health care of patients or to maintain or slow decompensation of a patient's condition. Palliative and hospice care are also skilled care services. Skilled care plans often include physical therapy, occupational therapy, speech therapy, and wound care.

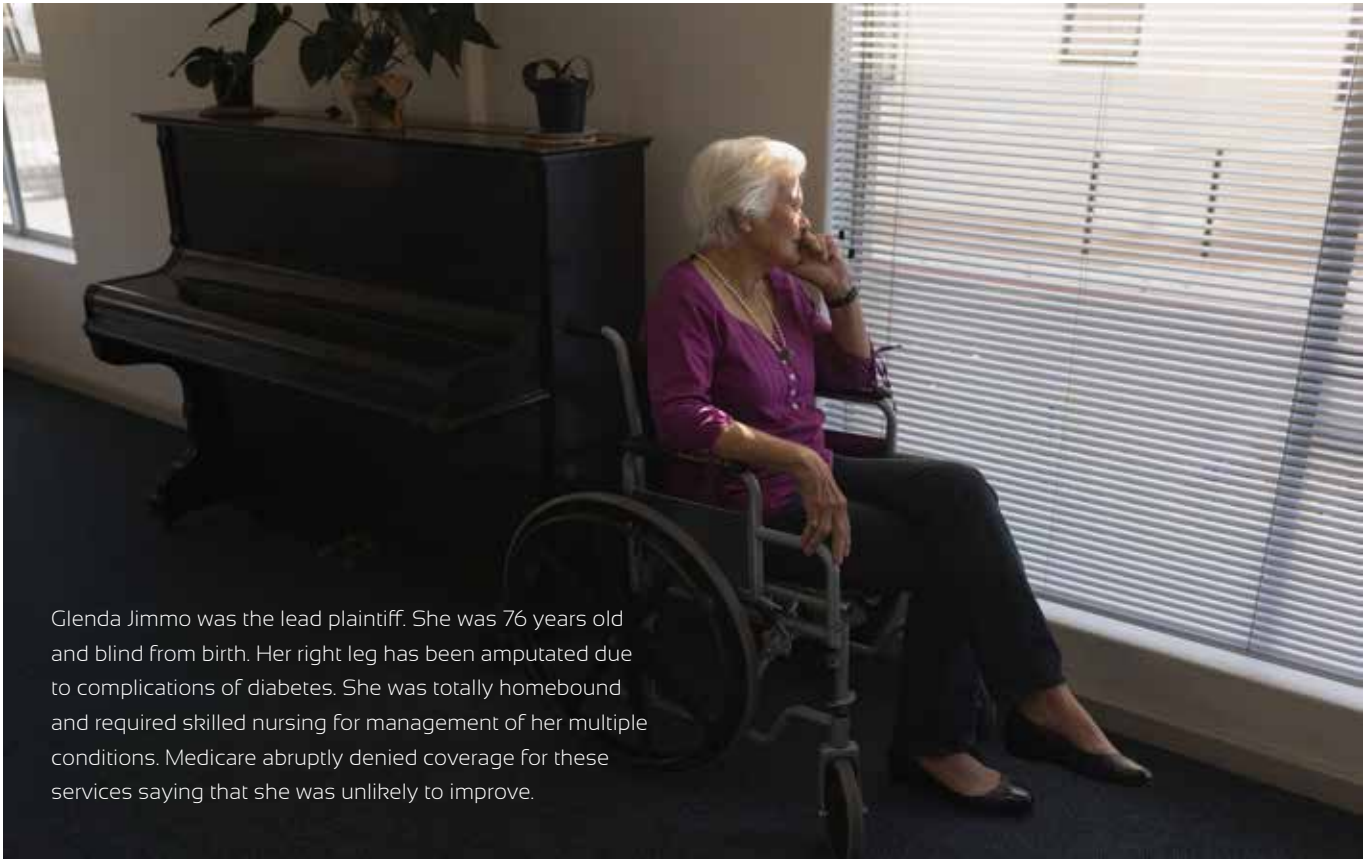
Custodial Care is the provision of services and supplies that can be given safely and reasonably by individuals who are neither skilled nor licensed medical personnel.

Certified Nursing Aids CNAs provide most of the custodial care in nursing facilities, rehabilitation facilities and Medicare home care.

Custodial care is about the individual's daily needs and not their medical needs. The primary reason people require any type of assistance is not medical but functional. They need help with the things that most of us do every day both physically and mentally with little consideration or difficulty.

Understanding, obtaining and benefiting from long-term care begins with seeing and addressing the loss of a person's activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include things a person does related to his or her own body such as getting up out of a chair, bathing, dressing, eating, etc. IADLs include activities a person does to take care of themselves that are outside of their body. In human development these are the cognitive and functional skills that we master in late adolescence and early adulthood. They are the abilities that we often defined as human, reading, learning, social comportment, managing finances, driving, shopping, meal preparation and maintenance of our living environment.

Human disability and dependence progress as a mirror image of child, adolescent and adult development. Except for traumatic brain injury, chronic physical and mental illness proceeds with the loss of the higher IADLs initially followed by the ADLs. The primary reason people need long-term institutional care is the loss of ADLs and memory.



Glenda Jimmo was the lead plaintiff. She was 76 years old and blind from birth. Her right leg has been amputated due to complications of diabetes. She was totally homebound and required skilled nursing for management of her multiple conditions. Medicare abruptly denied coverage for these services saying that she was unlikely to improve.

Jimmo v. Sebelius 2013

The LANDMARK SETTLEMENT That EVERYONE is Supposed to Know About

Over 10 years ago, The Center for Medicare Advocacy and Vermont Legal Aid brought the Jimmo v. Sebelius class action lawsuit on behalf of beneficiaries who were being denied Medicare coverage for skilled care on the basis that they were not improving. In 2013, the federal District Court approved a settlement agreement that confirmed Medicare coverage should be determined by a beneficiaries need for care and not the individual's potential for improvement. Medicare would be required from that point on to pay for skilled care that was necessary to maintain an individual's condition or slow their decline. This settlement represented a huge victory for beneficiaries with long-standing and chronic disabling conditions.

Unfortunately, in 2023 skilled nursing facility, rehabilitation and home care patients are still being informed that their Medicare services are terminated due to their failure to improve. The initial settlement required the Centers for Medicare and Medicaid Services (CMS) to conduct a national educational campaign to inform providers and decision-makers about the ruling on coverage for beneficiaries.

In February 2017, Judge Christiana Reiss of the U.S. District Court in Vermont ordered CMS to comply with a corrective action plan due to their failure to conduct the educational campaign. CMS did create a webpage dedicated to the Jimmo case and a posting for Frequently Asked Questions (FAQs). However, 22 months later in October 2018 70% of providers remained

unaware of the Jimmo case and the educational campaign. Dr. William Cabin at Temple University completed research in 2020 that found:

Results indicate nurses believe they had little to no knowledge of the Jimmo case; there was limited communication about the case from their agencies; they lacked guidance on the implications of the case on intake and eligibility decisions; they receive no guidance on the impact of the case and documentation; and their lack of knowledge and guidance had adversus impacts on patients.

Fortunately, toolkits for challenging denials of coverage are available on the Medicare advocacy.org Jimmo v. Sebelius website.

Regarding patient discharge:

“no order can be carried out, no policy observed, and no regulation imposed without the physicians ascent... the physician is therefore de facto a moral accomplice and whatever is done for good or ill to patients.”

AMA Report of the Council on Ethical and Judicial Affairs

CEJA Report 5-A-12,2012

Hospital Discharge

Being on the precipice.

Most decisions about long-term care are made on short notice of a hospital discharge and with no knowledge about available options for the best and most appropriate type of care.

For older adults, and unfortunately those who experience an emergency hospitalization for the first time, a short hospitalization can result in a tremendous challenge to their future well-being and independence.

A 2020 research report in the Journal of Gerontology found that even those with good functioning and health were at great risk for adverse health outcomes. Approximately one out of three patients experienced a significant decline in their functional ability with post discharge mortality rates as high as 16%. Within three months of discharge, one third were hospitalized again.

Hospitals and the physician who signs the discharge order are jointly responsible for ensuring a safe and appropriate discharge. This is a mutual and non-delegatable responsibility.

AMA Code of Medical Ethics 1.1.8

To meet this obligation the physician must be satisfied that the discharge plan appropriately meets the individual’s medical needs. The patient’s health should not be expected to deteriorate solely due to inadequate resources or the inability to meet the standard of care at the discharge destination.

The AMA 2012 Report of the Council on Ethical and Judicial Affairs (CEJA Report 5-A-12) also states that “Physicians should actively seek the input of the patient’s future caretakers and respect their concerns when possible.” The report directly acknowledges that “Many healthcare institutions incentivize reducing the patient’s length of stay, for instance in an effort to constrain costs.” It warns “Physicians should be wary and avoid the influence of non-clinical elements during the discharge planning, because nonclinical factors can compromise the safety of patients.”

The hospital’s conditions of participation under Medicare and the Standard of Care require that the discharging physician and the institution’s staff work in a timely and collaborative manner to establish an appropriate and safe discharge plan.

The hospital's discharging process must be timely and identify any changes in the patient's condition that would require modification of the discharge. For any patient who is to receive post -acute home health or skilled nursing, a list of providers who participate in Medicare within the geographic area must be presented to the patient or their representative. The hospital must disclose any financial interest it may have in a provider.

At or near admission, the hospital must give the patient a Medicare specifically worded document An Important Message from Medicare which gives them information about their discharge and appeal rights. Two days before discharge the hospital must give the patient another copy. Presentation to and receipt by the patient or their representative must be documented in the medical record.

Today unfortunately, "Discharge Planning" is often an oxymoron and not an effective process with safe outcomes. Very few hospital physicians have an understanding of the patient's preadmission condition, level of functioning, support system and ability to live in the community.

A mild cognitive impairment prior to admission or a hospital delirium may be viewed as a progressive dementia with reduced expectations for full recovery.

The discharging physician may place their emphasis on the acute condition that required hospitalization without assessment or consideration of the patient's chronic medical conditions.

Physicians rarely participate in interdisciplinary discharge planning with the patient and their family.

From the hospital's perspective, there is little immediate risk or penalty to an individual being discharged too early or inappropriately. They are penalized for 30 day readmissions at up to 3% of a payment for a diagnostic category.

The true impact of penalties on hospital administrative policies and clinical practice is questionable. There has been progress in the past 20 years. Readmission rates which exceeded 20% nationally are now 15% in 2022. The implementation and success of readmission reduction programs at Illinois Hospitals remains variable and uncertain.

The hospital must have a registered nurse, a social worker or other qualified personnel who must respond to a request for a discharge plan. The request should be made to the physician and the hospital as early as possible after admission. Concerns about a written discharge plan can and should be addressed with the doctor and discharge staff.

The discharge plan should consider an address the following:

- + Patient's cognitive status
- + Patient activity level and functional status
- + Availability of family or companion support
- + Ability to obtain medication and supplies
- + Availability of transportation from the hospital to Home and for a follow- up visits
- + Availability of informal or paid services to assist to assist with ongoing care and supervision
- + Status of the patient's current residence and suitability for its condition (eg, stairs, cleanliness, safety)

DISCHARGE PLANNING FOR YOUR CLIENT

Start at Admission

Be proactive ask the physician to help

Upon the request of a patient's physician, the hospital must arrange for the development and initial implementation of a discharge plan for the patient. 42 CFR§ 482.43 (a)(4).

Get All Your Options

The hospital must not specify or otherwise limit the quality providers or suppliers that are available to the patient. 42 CFR § 482.43 (c) (2).

Get Proof of the Original Signed "IM"

The "IM" or "An Important Message From Medicare About Your Rights" is the threshold document for challenging hospital discharge. It must be provided to the patient and signed near admission and again prior to any discharge.

Beware of "Observational Status"

With billions of Medicare dollars at stake hospitals are designating more inpatient and emergency room episodes as "observational stays." To avoid re-admission penalties on a recently discharged patient, this status is used to classify the episode as outpatient care unfortunately, this means the patient is responsible for more of the bill and makes them ineligible for Medicare paid rehab or skilled nursing services. It is important to confirm and challenge your status if you are returning to the hospital for care.

Post-Acute Care

A Decision With Consequences

Approximately half of all Medicare beneficiaries will receive some form of post-acute care after hospital discharge. The University of Pennsylvania study published in JAMA Internal Medicine March, 2019 examined the outcome for 17 million Medicare hospitalizations. Approximately 60% of patients were discharged to a skilled nursing facility versus home health care. There was no difference in terms of improved functional status or 30-day mortality rate. There was a 5.6% higher 30-day readmission rate for home health care. However, despite this re-admission the total cost for initial hospitalization and post-acute care in the first 60 days after discharge was significantly lower (an average savings of \$5,385 per beneficiary).

In 2023, there remains a significant disparity between patient's preferences and hospital discharge. A Morning Consult National poll conducted in 2021 found that 94% of Medicare beneficiaries would prefer to receive post-hospital short-term healthcare at home. Only 3% would prefer a nursing home.

A viable explanation for this continued discrepancy would be the number of hospital systems that focus on payment and utilization review to the detriment of the complex and necessary work that is necessary for a safe and appropriate discharge. In those settings the quickest, easiest default option is discharge to a nursing home.

Medicare Home health care

When you consider the patient's preference, outcome and cost to the healthcare system, being discharged to home with Medicare-paid services is perhaps the best hospital discharge option.

If:

1. The home is a suitable & safe environment
2. There is an available and accountable support system ie. Spouse, significant other, immediate or extended family members. Committed friends or neighbors.

And/Or

3. Illinois Licensed Home Nursing or Home Services staff.

For patients who require intermittent RN assessment and care in addition to speech, physical or occupational therapy to regain their baseline level of functioning care in the home is the best option.

Home Health Care in Illinois

Home care in Illinois is regulated and licensed by the Illinois Department of Public Health at three levels.

Home Health is equivalent to Medicare licensed home health care agencies. Public Health, Section 245.200.

Home Nursing Agencies provide skilled nursing services and home health aid (CNA) services under the supervision of a registered nurse.

Care is provided in accordance with a plan of treatment approved by the patient's health care professional under the supervision of the agency's registered nurse. Public Health, Section 245.205.

Home Services Agencies provide non-medical services that are intended to assist clients with activities of daily living. Personal care, housekeeping, laundry, cooking shopping can be provided. Public Health Section 245.210.

As of February 6, 2023, there were 949 Licensed Home Services Agencies versus 269 License Home Nursing Agencies in Illinois. A critical distinction is that Home Services agencies are prohibited from performing any services that would be directed by or fall under a licensed Registered Nurse, RN.

A recent change in the Nurse Practice Act (225 ILCS 657) permits a Certified Nurse's Aide CNA employed by a Home Nursing agency at the direction and under the supervision of a registered nurse to administer medication's including injections such as insulin to patients in a "Community-Based Setting." This would include assisted living facilities, apartments and homes.

To date, very few Home Nursing Agencies have established programs and training to provide "Nurse Delegation." However, the overwhelming need and demand for this service will clearly expand the availability for older adults in Illinois.

Assisted Living Facilities

Assisted living facilities provide a range of services that allow for levels of independence. There are options to increase care as needed over time. Formal contracts are required to move into a facility and receive care. Individual living spaces are provided, a variety of community spaces and social opportunities are available for residents.

There are over 400 assisted living communities in Illinois representing approximately 31,000 licensed beds. 55% of the residents are over the age of 85. Nationally, about 71% of residents have memory impairments and memory care is 20 to 30% more expensive than basic assisted living.

Assisted living is generally not the right option for individuals under 60, and those who need assistance with two or more activities of daily living. The ability to ambulate independently and communicate are also considerations. If a resident's physical or a medical condition deteriorates, they may be forced to leave the facility.

2023 Cost of Long-term Care in Illinois

The Genworth study of 2021 is the latest available data on the cost of care nationally and in Illinois. The inflationary impact on healthcare in 2022 will be reflected in the next report.

Due to the pandemic and staffing shortages all costs have risen significantly. For example, hourly rates for home health aids and Certified Nursing Aids CNAs in have increased by 20 to 25% to over \$30.00 per hour. The cost of live-in, 24 hour care, if it is even available is \$300-400 per day.

DISCHARGED "SICKER and QUICKER"

In 2023, hospital patients are much older, with multiple chronic diseases, cognitive impairment and physical disability.

HOSPITAL LENGTH OF STAY

1980	7.3 days
2023	4.5 days

The average monthly cost for assisted living in the 2021 reporting by Genworth was approximately \$4,500 per month. However, a brief survey of suburban Chicago facilities indicated a monthly cost in the range of \$6,000-10,000 per month. In 2021 a private room in a nursing facility in Illinois cost about \$7,200. Depending on the facility and need for care cost can easily exceed \$9,000 per month.

Summary and Conclusion

In 2023, finding and paying for long-term care is a greater challenge than ever before. Yet, there are some hopeful signs for improvement in Illinois.

The passage and implementation of (HB246) is a great step forward. Few things are more important than the genuine respect and appropriate compensation for the caregivers at the bedside. Illinois can also no longer remain a state where investment in a nursing home is a lucrative and unaccountable business decision.

The potential for "Nurse Delegation" for medication administration has the potential to address the estimated needs of 400,000 older adults living in Illinois.

In reality, as all students and practitioners of the law know, a settlement, administrative rule, law or regulation are all meaningless without attorney's and advocate's knowledge, validation and action.



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