

Continuum of care in the USA – organizational characteristics

A wide variety of formal, long term residential care arrangements in the US are available. These include supportive housing, residential care, assisted living, nursing homes, chronic care facilities, hospice care, retirement communities of various sorts, university-based retirement residences, Veterans' Affairs domiciliary care, etc. Ultimately, it is the individual and his or her family or personal caregiver network that is responsible for decision-making about long term residential care.

In 2009, about 1.4 million US residents lived in about 16,000 nursing homes, which must provide skilled nursing care. Average length of stay in nursing homes varies, but only about 25% stay more than 3 years with 20% residing in a nursing home less than 90 days. Length of stays in assisted living facilities average about 30 months. Regarding the size of facilities, nursing homes average about 90 residents or 108 beds. On average they have 114 employees. Nursing home occupancy rates were around 84% in 2009. Nursing home occupancies were nearly 100% in the 1970s and 1980s, but occupancy has dropped in recent years as more attractive alternatives to nursing homes have become available, in spite of the aging of the population. Also, states and the federal government have tightened their requirements to qualify for eligibility. Finally, the number of residents in nursing homes has declined because of the Supreme Court decision in 1999 which affirmed that individuals have the right to remain in their own home if they choose so that state Medicaid programs must provide home and community based service (HCBS) alternatives.

In addition to nursing homes, there are 6,440 intermediate care facilities for the developmentally disabled (ICF-DD) with about 114,000 beds. This number has declined rapidly

over the past two decades as states have developed home and community based service (HCBS) alternatives. In the US, there were over 131,000 licensed residential care facilities with 1,5 million beds reported in 2007. Of these facilities, there were 50,000 that served the aged and adults with 1 million beds, 53,000 facilities with 271,00 beds that served children, and 28,000 facilities with 197,000 beds for individuals with developmental disabilities and mental disabilities.. Residential care facilities for the elderly are often called assisted living facilities and are often given a separate licensing category by states and over 38,000 facilities are reported. Residential care facilities do not have to provide skilled nursing services but they must provide assistance and meals to residents.

Characteristics of patients in various long term residential care facilities are known. Most patients in nursing homes are over 75 years of age, largely female, and Caucasian. The average residents in assisted living facility is 87 years old . For the over 65 population in a nursing home, the average age is 82 . Women residents outnumber men by about 3 to 1 in assisted living facilities. About 77% of assisted living residents are widowed. 82% are Caucasian, 14% African American, and 5% Hispanic/Latino. About 60% had graduated from high school and 10% had a college degree. The average income was less than \$10,000 per year. More than half of nursing home residents were chair bound and nearly as many had dementia. Fewer than 3.5% had restraints. On average, residents received a total of 3 to 4 hours of care from staff each day. These staff include RNs, LPNs, and assistants.

US long term care facilities continue to be plagued with quality and safety problems. Less than 10% of nursing homes were free of any deficiencies in recent years with deficiencies being defined as poor food sanitation, professional standards, accidents infection control, pressure sores, and other various quality measures, etc. Because Medicare and Medicaid

payments structures offer hospitals a financial incentive to discharge early, even before appropriate plans for follow up care are in place, high rates of re-hospitalization result.

Coordination and integration of services in the US

From the point of view of the patient/consumer/client, the continuum of care is haphazard and fragmented. There is little systematic or organized attention to the patient's transition from one stage to another in terms of intensity of assistance required. This is regrettable because long term care is best if it is organized, with seamless transition across time, and the evolution of need for care. In the best situation, there is a case worker, nurse, social worker, or even an interdisciplinary team, that is trained to coordinate a patient's care across time. Case management involves assessment, planning, arranging for services, constantly monitoring the performance of providers, and making decisions in light of the patient's changing needs. Ideally, case management is undertaken by an individual or unit that has a fiduciary responsibility to the patients. In the US today, case management may be undertaken by a provider organization or a payer. In other situations, it is the untrained patient with the help of his or her family that struggles with the decisions that must be made.

Coordination of care is difficult in the US today also because so many entities may be involved in the care of a single patient. Different providers and diverse payers have various rules for reporting and billing. Electronic medical records (EMR) can provide for the continuity of care for an individual across time and the various institutions administering care. EMR for long term residential care is uncommon in the US, though Medicare and the health care reform bill, ACA, have set in place strong incentives for movement in this direction.

Sources of payment across the Continuum of long term residential care

There are several sources of payment for long term residential care across the continuum of care. Medicare, Medicaid, the Veterans' Affairs, Long Term Care commercial insurance, and private pay are the most significant sources. Medicare and Medicaid pay the majority of long term residential costs (more than 65%). Medicare offers only short-term assistance because individuals have to be deemed in need of "skilled care", rather than "custodial care", in order to qualify. Custodial care is what many of those seeking long term care need – i.e. help with daily activities of life including eating, dressing, bathing, housework etc. Medicaid covers long term care for those without other resources to pay for it. Rules vary by state, but in most states to qualify for Medicaid coverage in a long term residential facility, an individual with savings must first "spend down" most of their assets. Generally, spouses are entitled to keep some of the assets, however.

Federal certification for Medicare and Medicaid payments is separate and not all nursing homes in a state may seek federal certification for such payments. About 95% of nursing home beds in the US are in facilities that are dual-certified. Residential care and assisted living facilities are not eligible for Medicare funds and generally do not receive Medicaid payments, except under special state HCBS waiver programs, so all payments for those services are private pay. The cost of nursing home care is about \$110,000 per year, the cost of assisted living is about \$70,000-80,000 per year, while small residential care facilities have much lower costs. Individuals must use their social security and/or supplemental security income (SSI) (for low income persons) to pay for care, and if they are poor, Medicaid will pay for the additional costs for nursing home care but not residential care. Assisted living is generally only private pay but some residential care facilities will accept social security and SSI as payment.

Private long term care insurance plays a minor role in the US – less than 10% of the total long term care is covered by private policies. Long term care insurance products are sold on the private market to individuals – both through employers and individually – and usually cover nursing homes, assisted living facilities, or home care for those who require help.

Who makes the rules and the policies?

Nursing homes that are certified for Medicare and Medicaid in order to receive federal funds must meet extensive uniform federal regulatory requirements. They are surveyed by state agencies, using the federal government regulations, every 12-15 months. In addition to federal standards, states can establish additional standards that nursing homes are required to meet. Where states have lower standards, those only apply to licensed and uncertified facilities.

Residential care and assisted living facilities are not paid by Medicare and Medicaid and therefore have no federal oversight. States set all the licensing standards for residential care and assisted living and in most states, these standards are minimal. ~~This~~This too contributes to the fact that regulatory standards are diverse, confused, and disorganized. States have widely differing resources, commitments, and policies to carry out state and federal oversight. State Medicaid programs establish financial eligibility standards for the Medicaid program that vary by state, although nursing home services are a mandatory service and HCBS are optional programs, so that states may establish waiting lists for HCBS but not for nursing home care. States also set the need criteria ~~or eligibility~~or eligibility to receive services for nursing homes and HCBS. Most states require that an individual has limitations in 2 or more activities of daily living in order to receive nursing home or HCBS. Since residential care is considered a private pay services, need criteria generally are not established by states. As a result, inequities are

common between those residing in different types of facilities and in different states. This limits access to quality long term HCBS in the US.

Conclusion

Long term residential care is piecemeal rather than integrated in the US. Dozens of different pieces of legislation govern long term residential care facilities in the US. Regulations that define how laws should be carried out at both the state and federal level are complex and difficult to reconcile. The formal long term resident care system in the US fails many extremely vulnerable people who desperately need it. Overall, it is no surprise that individuals who are unable to take care of themselves end up receiving informal, rather than formal care, carried out by family and friends.