

Illinois Nursing Homes as Care Providers for Mentally Ill: How Did We Get Here?

There were nearly 125,000 young and middle-aged adults with mental illness living in nursing homes in the United States in 2008; that is up from 89,000 people in 2002.¹ Additionally, in a nationwide survey, only 20% of nursing facilities offered a performance quality review of their mental health care and patient outcomes, and 62% reported that they have run into significant challenges treating mentally ill individuals in a nursing home setting.² Mixing populations of mentally ill persons with the elderly and other physically disabled persons in nursing homes presents potential dangers to all concerned; significant strain is placed on the facility's ability to treat mental illness properly and to offer quality care to elderly and physically disabled nursing home residents.

Of the 125,000 young and middle-aged adults with mental illness living in nursing homes in our country, 12,736 of these individuals, or 10%, live in Illinois' facilities.³ Illinois cares for more persons with mental illness in nursing homes than any other state.⁴ In October of 2009, Illinois Governor Pat Quinn formed the Nursing Home Safety Task Force in response to reports of frequent violent episodes in Illinois nursing home facilities between mentally ill residents and physically confined residents.⁵ While mental illness and violence are not directly correlated, in many settings if serious psychiatric disorders are not properly treated, behavioral symptoms can become problematic.

In evaluating these conditions in nursing homes, it is important to take a step back and look at how nursing homes have become care providers for such a large proportion of the mentally ill population. Following is an historical assessment of how people with mental illness are cared for in the United States and factors that have contributed to Illinois' reliance on nursing homes to house younger individuals with mental illness.

Basic Background of Deinstitutionalization

Several primary factors have led to the shift in philosophy from providing care for persons with mental illness in mental institutions to that of providing mental health services to people in the community.

- **Advances in Psychotropic Drugs (1950s)**
 - Psychotropic drugs introduced: drugs did not cure psychosis, but enabled people to manage their psychotic symptoms.
 - The number of people with mental illness who were deemed eligible to live voluntarily on their own increased.⁶

- **Right to Treatment and Right to Liberty Litigation (1960-2000)**
 - During the 1960s and into the 1970s the underlying belief in legal circles was that patients with mental illness have "a right to treatment" which requires that mental health treatment be administered in the least restrictive manner.
 - Regardless of whether treatment is voluntary, which is preferred, or involuntary, specific criteria were established for acceptable treatment.⁷
 - Relevant court rulings include:
 - 1966 - *Rouse v. Cameron* (District of Columbia): The court ruled that the purpose of involuntary hospitalization is treatment, not punishment. If treatment was inadequate or otherwise inappropriate, conditional or unconditional release may be appropriate.
 - 1971 - *Wyatt v. Stickney* (Alabama): The court established the precedent for a right to treatment to be found within the 14th Amendment, denying imprisonment without due process. The case set forward several assertions: an individual's liberty is drastically curtailed as a part of civil commitment; an individual is committed without the procedural safeguards of the criminal process; due process requires that he/she receive such treatment as will give him/her a reasonable chance to be cured; and commitment without proper treatment is also considered cruel and unusual punishment.⁸
 - 1975 - *Youngberg v. Romeo* (U.S. Supreme Court): The Supreme Court held that an involuntarily hospitalized patient was only entitled to that amount of treatment required to assure his freedom from unnecessary restraint and preventable assault inside the institution.
 - 1999 - *Olmstead v. L.C. and E. W.* (U.S. Supreme Court): The Supreme Court ruled that under the Americans with Disabilities Act states should be required to place patients in the least restrictive setting; in this case, nursing homes were included. The ruling specifically advised that anyone who was willing and able to live in the community must have that option.⁹

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- **The Shift from State Funding of Mental Health Care to Shared State and Federal Responsibility**
 - 1965, “Medicaid IMD Exclusion” enacted a Medicaid law prohibiting federal financial participation for health services provided to individuals ages 16 to 64 who are patients of an institution of mental disease (IMD). Essentially this regulation made patients ineligible for Medicaid while residing in state mental institutions (IMD’s), even if the care that they received was related only to their physical health.
 - An IMD is defined as a hospital, nursing facility, or other institution of more than 16 beds that is primarily (over half) engaged in the treatment of persons with mental illness. This definition is meant to favor the establishment of small scale community facilities.¹⁰
 - Traditionally, care for persons with mental illness was a state responsibility, but as maintenance of state mental institutions became more and more costly and less frequently utilized, states began to dissolve their role in administering mental health care by reducing admissions to state hospitals and moving people who were not considered dangerous to themselves or others out of the facilities. This, in combination with the institution of the Medicaid IMD Exclusion, drastically changed the states’ role in provision of mental health services.
 - As part of this adjustment, states were divided into regional funding areas with central governance and funding structure supported by federal and state systems. This shift symbolized the beginning of a drastic move away from state-centered control for the care of the mentally ill to one that was shared in community settings between state, federal, county and local governments.¹¹
 - According to the IMD definition, nursing homes which maintain a patient base below the 50% mentally ill population threshold are able to accept mentally ill individuals and provide basic in-patient housing, health care, and mental health services, and receive payment for services with a federal Medicaid match. By keeping the percentage of nursing home patients with mental illness below 50%, the financial burden of caring for persons with mental illness is shared between the state and the federal government through Medicaid.¹²

National Consequences: Mentally Ill Turn to Nursing Homes with Increasing Frequency

- Beginning in the 1960’s, mental hospitals began downsizing drastically. By 2000, 115 of the 350 state mental hospitals nationally had been closed.¹³
- As a consequence of the changing standards in treatment in mental hospitals many sought admission to nursing homes over mental hospitals. Most, if not all, older mentally ill patients who were not able to live independently were transferred to nursing homes.¹⁴
- By 1974, approximately 85,000 individuals had been directly transferred from mental hospitals to nursing homes. In 1977, approximately half of the 1.3 million nursing home residents across the country had a primary psychiatric diagnosis. By 1978, the number of mentally ill persons confined in nursing homes exceeded the number of mentally ill in mental hospitals.¹⁵
- The deinstitutionalization of mental hospital residents to nursing homes represents movement from one institution to another; trans-institutionalization.

National Reform Laws Concerning Persons with Mental Illness Receiving Care in Nursing Homes

- In 1966, 90% of nursing home administrators said that they would accept depressed, confused, withdrawn or disoriented patients, even if they could not feed or dress themselves. Concerns grew as to whether these facilities were equipped to provide an adequate level of mental health care for such patients because nursing homes frequently sent unmanageable patients with mental illness back to mental hospitals.¹⁶
- Several studies completed in the late 1960s revealed inadequate staffing levels and inappropriate levels of mental health assistance in many nursing home facilities.¹⁷

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- In 1977, as a response to mental health inadequacies that arose due to deinstitutionalization, the National Institute of Mental Health launched its Community Support Programs (CSP). Highlights of the CSP mission included: helping states and communities move resources from institutions to the community; collaborating with other Federal agencies to affect knowledge dissemination and systems change; and establishing community support systems (a network of services and supports focusing on empowerment and leading to recovery).¹⁸
- In 1986, the Institute of Medicine (IOM) produced a study entitled “Improving Quality of Care in Nursing Homes” which specifically addressed issues amongst mentally ill nursing home residents.
 - The report alluded to safety concerns for the overall nursing home resident population.
 - Notably, the report acknowledged the strong effect that Medicaid payment policies have on the provision of mental health care in nursing homes.
 - The report also emphasized the importance of encouraging proper training and staffing levels for those treating mentally ill patients in nursing homes.¹⁹
- In 1987, the IOM report triggered the enactment of the Omnibus Budget Reconciliation Act of 1987, which identified steps towards significant reform in nursing homes. Under this law, Congress created a Pre-Admission Screening and Annual Resident Review (PASARR) program, a set of regulations that officially went into effect January 29, 1993.
 - The regulations required preadmission mental health screenings for new residents of nursing homes; an annual review of resident mental health and nursing home treatment of mentally ill; prohibited use of physical restraints for discipline or convenience; a reduction in the over-use of antipsychotic medications; and made recommendations related to increased availability and training of nursing staff.
 - A 1996 amendment no longer required the Annual Resident Review, but required Resident Review in the case of significant mental or physical health changes. The resulting Pre-Admission Screening and Resident Review (PASRR) program is the current federal mandate.²⁰
- Recently, the effectiveness of the PASRR screening requirements has been evaluated and critiqued:
 - A 2006 survey conducted in all 50 states and the District of Columbia indicated varying levels of compliance with PASRR screening requirements within states.
 - Further, the PASRR process does not ensure that nursing home residents, once admitted, receive proper mental health attention; this is considered to be the nursing facility’s responsibility. With Medicaid often covering only basic psychiatric services and staffing capacity limited, many mentally ill patients struggle to receive care despite PASRR requirements.²¹

Illinois: Concern for Nursing Homes as Primary Care Providers for Persons with Mental Illness

- Since 1980, Illinois has closed seven state run mental hospitals, significantly contributing to the large numbers of mentally ill Illinois residents residing in nursing homes. Currently, Illinois has only 1,480 public hospital beds dedicated to serving persons with severe mental illness; for many, nursing homes serve as the only care alternative.²²
- In 2009, Illinois nursing homes provided care for the most mentally ill individuals under the age 65 of any US state; in total, 12,736 mentally ill persons.²³
- In 2005 Illinois ranked first in the nation for admitting the most severely mentally ill out of total new nursing home admissions at 3.7% of admissions; with California (3.5%), Louisiana (3.4%), and Missouri (3.4%) closely following.²⁴
- According to data compiled by the Illinois Department of Public Health in conjunction with the U.S. Center for Medicare and Medicaid Services, people with a primary diagnosis of mental illness now comprise more than 15 percent of the state's 92,225 nursing home residents.²⁵
- Because of several recent incidents that have drawn statewide and national attention, some Illinois nursing homes have become known for disruptive behavior and violence among residents. There are a total of 3,000 convicted felons in Illinois nursing homes—including 82 convicted murderers, 179 sex offenders and 185 armed robbers.²⁶

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- Criticism continues as Illinois now faces a class action lawsuit, *Williams v. Blagojevich*, alleging that housing mentally ill in IMD nursing homes is a violation of the Americans with Disabilities Act because individuals with mental illness are unnecessarily confined to IMDs, without adequate access to community-living options.²⁷
 - The plaintiffs are represented by Equip for Equality, Access Living, the ACLU of Illinois, the Bazelon Center for Mental Health Law, and the law firm Kirkland & Ellis.
- Beginning July 1, 2002, subpart S was included in the 77 Ill. Adm. Code 300: Skilled Nursing and Intermediate Care Facilities, “Providing Services to Persons with Serious Mental Illness”.²⁸ Subpart S addresses the assessment, reassessment, treatment plan, requirements of facilities, psychiatric rehabilitative services, discharge plans, work programs, community based rehabilitation programs and personnel involved with care of persons with mental illness in nursing homes.
- In 2005, the state initiated Illinois code 89 Ill. Adm. Code 145 establishing a demonstration project among nursing care facilities that primarily serve persons with severe mental illness.
 - The intent of the demonstration project was to allow nursing facilities to specialize in the treatment of mentally ill patients and focus their resources on providing psychiatric rehabilitation services instead of focusing on catering their services to avoid being classified as an IMD, and thus losing federally matched Medicaid funding.²⁹
 - The project tracked and assessed the number of mentally ill patients in nursing facilities throughout the state and assessed when nursing centers exceeded the IMD threshold. Through the course of the project, if a nursing facility qualified as an IMD, the state reimbursed the facility to continue the mental health services it was once providing, eliminating the fear of losing Medicaid funding. The demonstration project concluded on June 30, 2007 at the end of the grant period.³⁰
- To continue the state’s effort to focus on care for the mentally ill, the Illinois Department of Human Services reported that it is continuing its 2008 Mental Health Initiative to ensure quality services and settings for the care of persons with mental illness.³¹ The Initiative included several new components:
 - Ensuring correct coding and documentation of services provided under the new payment rules for nursing facilities, including those components connected to the provision of services to people with serious mental illness.
 - Working with the Division of Mental Health to plan and implement the mental health components of the Money Follows the Person Demonstration project, a project to reduce institution-based care.

Conclusion

Illinois’ reliance on caring for persons with mental illness in nursing homes stems from a complicated history of deinstitutionalization, mental health systems changes, and law suits at the state and national levels. Although originally designed to care for persons with physical health needs, nursing homes care for persons with mental health needs, too. Illinois has the responsibility to assure a safe environment in which nursing home residents can live, and where rehabilitation services for both physical and mental health needs are available to each resident. Violence, disorder and abuse are unacceptable and all the more disturbing when caring for vulnerable populations. Through the Nursing Home Safety Task Force, Governor Quinn has taken the first steps towards evaluating what is necessary to assure that people who live in nursing homes are safe. As the state moves forward in addressing the needs and safety concerns of nursing home residents, it is essential to approach the situation systematically and implement evidence-based solutions. Illinois is working towards reforming its long-term care system to provide more home and community based service options for all populations, including people with mental illness. However, we must also ensure that people with mental illness who choose or require institutionalization in settings such as nursing homes are not only safe but receive quality mental health services, oversight, and care.

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