The Inappropriate Institutionalization of People with Mental Illness in Long Term Care Facilities: History & Recommendations

Nina Loewenstein, J.D., M.P.H.

nina.loewenstein1@gmail.com

Some Statistics:

- 26% of New York's adults and children are Medicaid recipients. (Kaiser Foundation, 2019)
- Four of nine New Yorkers with disabilities is a Medicaid recipient. (Kaiser Foundation, 2019)
- Five out of eight of New York's 89, 775 nursing home residents in 2019 were Medicaid recipients. (Kaiser Foundation, 2019)
- New York ranks second of all states in Medicaid institutional spending. It is eighth in Medicaid spending on home and community-based services. (AARP, 2018)
- Approximately one quarter of individuals admitted to a nursing home annually have psychiatric disability, and such individuals are most likely to be long stay residents. (Grabowski, 2009)
- Over 6,000 New Yorkers with psychiatric disability live in adult homes (according to adult home reports). (NY DOH, 2018)


316
EXIT

Nursing Homes – Growth 1950s &1960s – Medical Model

- History of long-term custodial care in private homes – 1930's response to almhouses.
- 1950s-60s: Federal building funds – hospital standards
- Medicaid & Medicare – 1965. States required to include nursing facility services under Medicaid. Fueled dramatic expansion and for-profit ownership.
- Substitute for housing, with some care, including for people leaving psychiatric centers between 1960 and 1970.

➢ By 1965, two-third of nursing home residents on Medicaid.

➢ By 1986, over 75% of U.S. nursing homes for-profit ownership.

➢ Pervasive problems with quality of care, staff training, numbers of staff. Federal and state standards develop, with lax enforcement. Reluctance to close homes.

(Hawes & Phillips, 1986; Institute of Medicine 1986)

Growth in Numbers of People with Psychiatric Disabilities in Nursing Homes:

- Transinsitutionalization: Closures of Psychiatric Hospitals 1960's & 70s:
  - Civil Commitment Criteria
  - Psychoactive Medications

Lost or undeveloped independent living skills. Rehabilitative services would not be offered under Medicaid until 1990's. (Bazelon Center, 2001) Nursing homes increasingly available.

New York State Adult Homes also accepting from psychiatric hospitals: "Impacted Adult Homes"

- Institutionalization: Entering nursing homes and adult homes from the community.

- Estimated 25% of increase in nursing home population between 1960 and 1970 attributed to the deinstitutionalization or diversion of individuals from mental institutions into nursing homes. Number of residents with psychiatric disabilities nearly doubled 1969-1974. (Zimmer, 1984)

- 1960-1980 – Over 100% increase in nursing home populations with psychiatric disability. (Rahman, 2013)

Nursing Homes: Abuse & Neglect of Residents with Psychiatric Disabilities – during and following growth in admissions

- Low numbers of staff & staff who are trained/educated in psychiatric rehabilitation

  - Overuse of anti-psychotic drugs, physical restraints
  - Highly inadequate treatment of mental illness, depression

(Institute of Medicine 1986; Rahman, 2013)

1984 Study (Zimmer, 1984): Upstate New York nursing homes:

- Failures to diagnose mental illness, refer for psychiatric evaluation
- Lack of recreational and social opportunities, psychosocial programming
- Staff identified two-thirds of 1100 residents surveyed as having "behavioral problems," restrained & medicated with psychotrophic drugs.

Nursing Home Reform Act: Medicaid Reform
(Omnibus Reconciliation Act of 1987)

- Effort to ensure quality of care – compliance tied to Medicaid/Medicare payments
- Effort to curb abuses in nursing homes, including physical & chemical restraint.
- Limit admissions of individuals who have mental illness and/or intellectual disability. Screening & assessment requirements.

"Preadmission & Resident Review (PASRR)" – independent of nursing home

- ✓ Identify and assess mental illness and/or intellectual disability
- ✓ Review necessity of nursing home care
- ✓ Evaluate for community alternatives
- ✓ Recommend "specialized services" for PASRR disability

Recovery Movement – Response to Psychiatric Institutionalization

- Self-Determination: Choices about Treatment
  Daily Life
  Companions
  Work, volunteer, housing, etc.

- Community Integration: Social, Housing, Employment

- Social Model: Social Supports, Peer supports
  Strength-Based v. Deficits
  Empathy
  Person-centered treatments and planning

Peer Supports in Community Settings - Developing Goals, Supporting Participation in Activities of Choice

Kinship with Independent Living Movement: Living with Disabilities
Independence with Chosen Supports
Overcoming Stigma

Enactment of Americans With Disabilities Act 1990 (ADA)

Congress describes the isolation and segregation of individuals with disabilities as a serious and pervasive form of discrimination. 42 U.S.C. § 12101(a)(2), (3) & (5).

- Brings down barriers to inclusion in community
  - ✓ Extends civil rights protections – Anti-discrimination
  - ✓ Requires reasonable accommodations for disability in housing, employment, government and places of public accommodation.

"Community Integration Mandate" and the Supreme Court's *Olmstead* Decision

Community Integration Mandate: Requires state and local governments to "administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. 35.130(d).

"Most Integrated Setting:" Enables individual with disability to interact with non-disabled persons to fullest extent possible. 28 C.F.R. Part 35, Appendix A.

In *Olmstead v. L.C.*, 527 U.S. 581, 600 (1999), Supreme Court held that state violates the Americans with Disabilities Act of 1990 (ADA) if provides care to people with disabilities in institutional settings when they could be appropriately served in a community-based setting. Perpetuates unwarranted assumptions that people are incapable or unworthy of living in community.

Under *Olmstead,* state must show it has a plan for reducing reliance on institutions given limited resources. Following the passage of the ADA, and increasingly after *Olmstead*, states, including New York, begin to provide Medicaid coverage for psychiatric rehabilitative services to support independent living. Including:

- Residential supports to develop independent living skills
- Social skills development
- Case Management
- Assertive Community Treatment
- Peer supports

(Bazelon, 2001)

New York State Office of Mental Health begins supported housing program in 1990, and funds transitional community residences.

Continued Admissions of People with Psychiatric Disabilities into Nursing Homes. Why?

- Community housing & supports slow to develop. Supported housing not planned for New Yorkers in nursing homes or adult homes.
  - Medicaid Waivers for home & community-based services are optional: few state waivers for people with psychiatric disability who are nursing home eligible
- Siloed mental health & medical systems, incentive to discharge quickly from hospital
- Ineffective PASRR screening systems with broad exceptions, failures to follow individuals with PASRR disabilities "temporarily" admitted into nursing homes
- Incentives to fill NH beds; no enforcement of admissions & resident review req's

Nationally: In 2005, over 500,000 people with mental illness in nursing homes. (Grabowski, 2009)

Dept Health & Human Services Inspector General Reports (2001):

- People with schizophrenia tend to be admitted at younger ages and are more likely to end up being long-stay residents.
- Half of nursing home residents with major mental illness did not receive PASRR preadmissions screening.
- Nursing home services to treat psychiatric disorders are woefully inadequate.

New York: 1990's waves of admissions from psychiatric centers into locked units in New York City & New Jersey nursing homes.

- By 2004, New York was among the states with the highest number of long-stay residents with schizophrenia and bipolar disorder. More than half likely to stay beyond 90 days, twice the rate of residents without these disabilities. (Grabowski, 2009)

"Mentally Ill and Locked Up in Nursing Homes," Clifford Levy New York Times Investigation. October 6, 2002.

- Pataki administration approved waves of admissions from NYS psychiatric centers into NYC area nursing homes operating unlicensed, locked "neurobiological" units. OMH Commissioner James Stone called the units "excellent long-term housing."
- Nursing homes lacked trained staff, programming
- Hundreds of physically healthy individuals, many in 30's & 40's, "languishing"
- Isolated and segregated on units.
- Many wore "wanderguards"

"Broken Homes," Clifford Levy New York Times Investigation April 28-30, 2002.

NYC adult homes New York City adult homes housing thousands of adults with serious mental illness discharged from psychiatric hospitals beginning in 1960's.
Offer to provide independent living skills, reenter mainstream community.

- For profit, sparsely staffed with low-wage workers who lack training in mental health issues
- 200 to 400 bed homes, "devolved into places of misery and neglect," and violence
- Lightly regulated, no enforcement following state investigations – avoid closure
- Medicaid fraud, fraudulent record-keeping
- 15,000 people with serious mental illness in adult homes statewide, 12,000 in NYC area.

New York "*Olmstead*" lawsuits: Brought on behalf of individuals with serious mental illness both in large New York City adult homes (*O'Toole* class) and in nursing homes statewide (*Joseph S. v. Hogan*):

1. Adult Homes case filed in 2003, refiled as class action (*O'Toole v. Cuomo)* following trial and dismissal on appeal on technical grounds. U.S. DOJ intervention. Ongoing transitions of 4,000 class members to supported housing in community through settlement.
   - Extensive trial court opinion finding the adult homes were institutions segregating people with serious mental illness; State is subject to Olmstead obligations even though the homes are privately operated; and adult home residents with serious mental illness were capable of living in community integrated setting of supported housing.

At time of *O'Toole* settlement:

- State regulation limits census of residents with serious mental illness in homes of eighty or more beds, "Transitional adult homes." OMH psychiatric centers cannot discharge patients into TAH's.
- Growth in Assisted Living Program (ALP) beds. State invites TAH's to develop ALP beds – Medicaid funded.
  - Eligible for nursing home due to the lack of a home or a suitable home environment in which to live and safely receive services; (18 NYCRR 494.4(d)(1))
  - Adult home approves admissions and reviews need for ALP;
  - NYS Commission on Quality of Care found exaggerated needs for ALP in 2007
  - Many *O'Toole* class members moved into ALP beds. In sample, some were signed up for services they did not need, moved into community without need for home care or home care that could be provided in community.

2. *Joseph S. v. Hogan*: Nursing Home *Olmstead* case

- Olmstead and PASRR claims on behalf of individuals with serious mental illness who been discharged from psychiatric centers into New York State and out of state nursing homes.
  - Capable of living in community integrated settings with supports
  - PASRR evaluation failed to consider community-based alternatives.

- Office of Mental Health stopped large numbers of discharges from psychiatric centers into nursing homes.

- PASRR Evaluation altered to consider community-based alternatives.

- Settlement before trial: Transitions began late 2012, by 2016 eighty residents moved to community through process.

Have these cases brought needed change to New York State? Are there reforms underway to reduce needless institutionalization of people with psychiatric disabilities in nursing homes and adult homes? Continued admissions into many adult homes and transinstitutionalization between nursing homes and adult homes.

- The Olmstead cases serve(d) classes of individuals in segregated settings and did not address systemic reforms for people outside the classes. Not "risk of institutionalization" cases. Compare: https://www.justice.gov/opa/pr/justice-department-reaches-major-olmstead-settlement-agreement-north-dakota

- Fewer discharges from psychiatric centers to nursing homes and discharges prohibited from psychiatric centers to transitional adult homes. Increase in supported housing with transition supports, including peer supports, from psychiatric centers. OMH skilled nursing facility transition supports program may serve some discharged from psychiatric centers to the community.

- Most PASRR nursing home admission/review deficiencies not addressed by *Joseph S*. E.g., still failure to track people with PASRR disability who enter homes for convalescent care.

- Promising efforts to integrate mental health and home health services, increase mobile outreach through demonstration projects (Geriatric Mental Health Act) have not yet had statewide impact. Limited by lack of access to personal care assistants & home care. OMH analysis: more than half of the residents across its housing programs were adults age 50 or older and that many of them were likely to benefit from receiving long-term services and supports (LTSS). It is not yet clear if/how OMH will adapt its existing housing programs. Lack of sufficient accessible, affordable housing. (Interagency Council Reports 2018 & 2019; Geriatric Mental Health Alliance, 2008)

- Medicare-eligible Medicaid recipients are not eligible for the most intensive community mental health supports and care coordination. Medicaid managed care health home care coordinators stretched thin.

- Empire State Supported Housing Initiative (ESSHI) may house people with psychiatric disability who are homeless, would otherwise enter NH's & AH's. Despite devastation from COVID, October 2020 RFP for 1200 units people in nursing homes are not eligible unless homeless prior to admission. Adult home residents not eligible. https://omh.ny.gov/omhweb/rfp/2020/esshi/index.html

- Eligibility for personal care services under Medicaid is limited to needs for physical assistance with ADL's because of physical conditions. People who have other kinds of conditions, including psychiatric disability, may require supervisory or cueing assistance with ADL's.

- New York's Nursing Home Transition Diversion Medicaid Waiver for people who are nursing home eligible is not easily combined with OMH supportive housing. This waiver program is not oriented to people with psychiatric disabilities and often requires backup supports.

*Social Security Act 1915(c) Waiver Services: Permits states to waive certain Medicaid requirements in order to offer array of home and community-based services that promote community living and thereby avoid institutionalization. Relatively few states have waivers targeting mental health services, and those waivers are designed to avoid psychiatric hospitalization, including New York. (Exception: Colorado's Community Mental Health Supports Waiver)

- "Open Doors Transition Program" (Money Follow the Person) needs expansion to enable more inreach into nursing homes to work with more individuals to transition to the community, and also to assist those at risk of nursing home placement.

**Money Follows the Person: Federal Medicaid program funding grants to states to assist with transitions from NH's.

It's your choice.

If you want to transition to home and community-based services, we'll work together to determine the best options for you.
Call Open Doors today at 1.844.545.7108.

OpenDoors

State Money Follow the Person Program Contacts:

https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/list-of-money-follows-person-grantees/index.html

Protection and Advocacy Systems by State

(National Empowerment Center link)

Each state has a designated protection and advocacy system that offers advocacy and assistance with legal and civil rights issues pertaining to disability. Click here to find your state's protection and advocacy system.

- Disability Rights New York: http://www.drny.org

References:

1. David Grabowski et al., "Quality of Mental Health Care for Nursing Home Residents: A Literature Review," Medical Care Research & Review, 67(6):627-656 (December 2010).
2. Kaiser Family Foundation: Medicaid in New York (October 2019); Medicaid's Role in Nursing Home Care (June 2017); Total Number of Residents in Certified Nursing Facilities (2019)
3. AARP: Across the States (August 2018).
4. Catherine Hawes & Charles Philips, "The Changing Structure of the Nursing Home Industry and the Impact o Ownership on Quality, Cost and Access," in For-Profit Enterprise in Healthcare, Institute of Medicine Committee on Implications of For-Profit Enterprise in Health Care (1986).
5. Improving the Quality of Care in Nursing Homes, Institute of Medicine Committee on Nursing Home Regulation (1986). Appendix A: History of Federal Nursing Home Regulation
6. James Zimmer et al., "Behavioral Problems Among Patients in Skilled Nursing Facilities," *American Journal of Public Health* 74: 1118-1121 (1984).
7. Bazelon Center for Mental Health Law, "Recovery in the Community: Funding Mental Health Rehabilitative Approaches Under Medicaid" (2001).
8. Momotazur Rahman et al., "Serious Mental Illness & Nursing Home Quality of Care," *Health Services Research* 48:4, 1279-1298 (August 2013).

References, cont'd:

9. Larry Davidson, "The Recovery Movement: Implications for Mental Health Care and Enabling People to Participate Fully in Life," *Health Affairs* 35: No.6: 1091-1097 (2016).
10. PASRR Technical Assistance Center National Reports 2012-2016.
11. U.S. Department of Health & Human Services Office of Inspector General, "Younger Nursing Facility Residents: An Unidentified Population" (2001).
12. U.S. Department of Health & Human Services Office of Inspector General, "Younger Nursing Facility Residents with Mental Illness: Preadmission Screening and Resident Review (PASRR) Implementation and Oversight" (2001).
13. David Grabowski et al., "Mental Illness in Nursing Homes: Variations Across States," *Health Affairs* 28(3): 689-700 (2009).
14. Helena Temin-Greener et al., "Are Post-Acute Patients with Behavioral Health Disorders Admitted to Lower Quality Nursing Homes?" *American Journal of Geriatric Psychiatry* 26:6, 643-654 (June 2018).
15. Interagency Geriatric Mental Health & Chemical Dependence Planning Council Reports 2018 and 2019 Annual Reports to the Governor &Legislature of New York State on Geriatric Mental Health & Chemical Dependence.
16. Geriatric Mental Health Alliance of New York, "Housing in the Mental Health System for Aging People with Serious Psychiatric Disabilities" (Consensus Workgroup) (January 2008).
17. Photo credit: Elizabeth Jones.