The Unacceptable Institutionalization of People with Psychiatric Disabilities in Nursing Homes

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Some Statistics:

- Medicaid is the primary payer for nursing home care, covering 62% of nursing home residents in the Unites States. (Kaiser Foundation, 2017)
- 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)
- People receiving Medicaid with diagnosis of schizophrenia enter nursing homes at younger ages than people without a psychiatric diagnosis. At ages 40-64, the nursing homes admissions risk for people with schizophrenia is nearly four times greater than those without a psychiatric diagnosis, even though people with schizophrenia in that age group have fewer medical and physical assistance needs. (Andrews, 2009)

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

- History of long-term custodial care in private homes – Social Security Act 1935
- 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 hospitals between 1960 and 1970.

- By 1965, two-thirds of nursing home residents on Medicaid.
- By 1986, over 75% of U.S. nursing homes have for-profit ownership.

Growth in Numbers of People with Psychiatric Disabilities in Nursing Homes

- Transinstitutionalization: Closures of Psychiatric Hospitals in the 1960s & 1970s:

  - Civil Commitment criteria, and increased focus on civil rights
  - Clinical research about community treatment
  - Markedly increased costs of hospital care
  - Development of more effective psychoactive medications

But people left hospitals with lost or undeveloped independent living skills, and inadequate planning. Increase in community health resources not enough - rehabilitative services would not be offered under Medicaid until 1990's. (Bazelon Center, 2001) Inadequate housing in community, whereas nursing homes increasingly available.

Growth in Numbers of People with Psychiatric Disabilities in Nursing Homes (cont'd)

- Institutionalization: Entering nursing 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 psychiatric 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)

- Efforts to move people with psychiatric disabilities out of psychiatric hospitals or out of nursing homes WILL NOT SUCCEED if sufficient community-based services of adequate quality are not available.

Abuse & Neglect of Nursing Home Residents with Psychiatric Disabilities

- Pervasive problems with quality of care overall, staff training, numbers of staff. Lax enforcement of standards, reluctance to close homes.

- Low numbers of staff & lack of training 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, and to refer for psychiatric evaluation
- Lack of recreational and social opportunities, psychosocial programming
- Staff identified two-thirds of 1100 residents as having "behavioral problems," restrained & medicated them with psychotropic drugs

Nursing Home Reform Act: Medicaid Reform

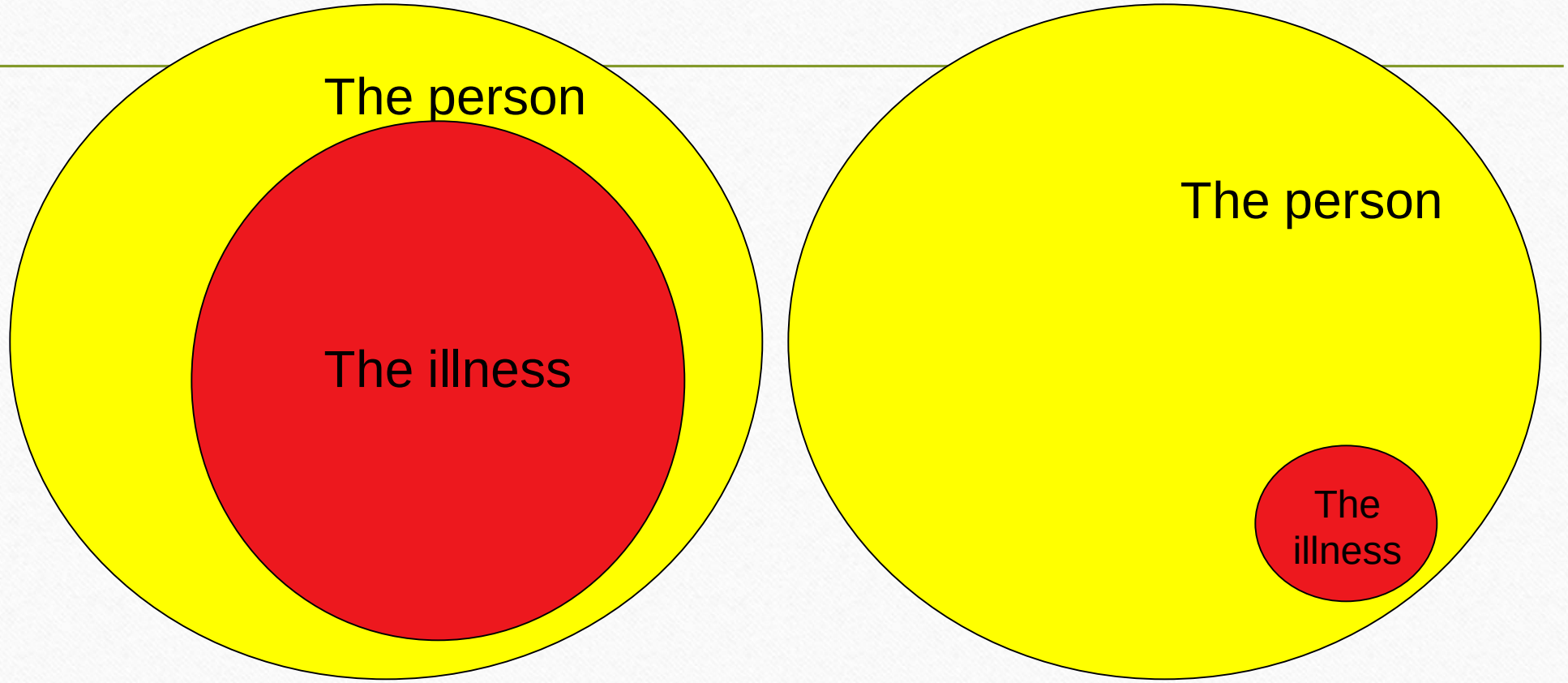
(Omnibus Budget Reconciliation Act of 1987, or OBRA 1987)

- 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 psychiatric and/or intellectual disability through screening & assessment requirements.

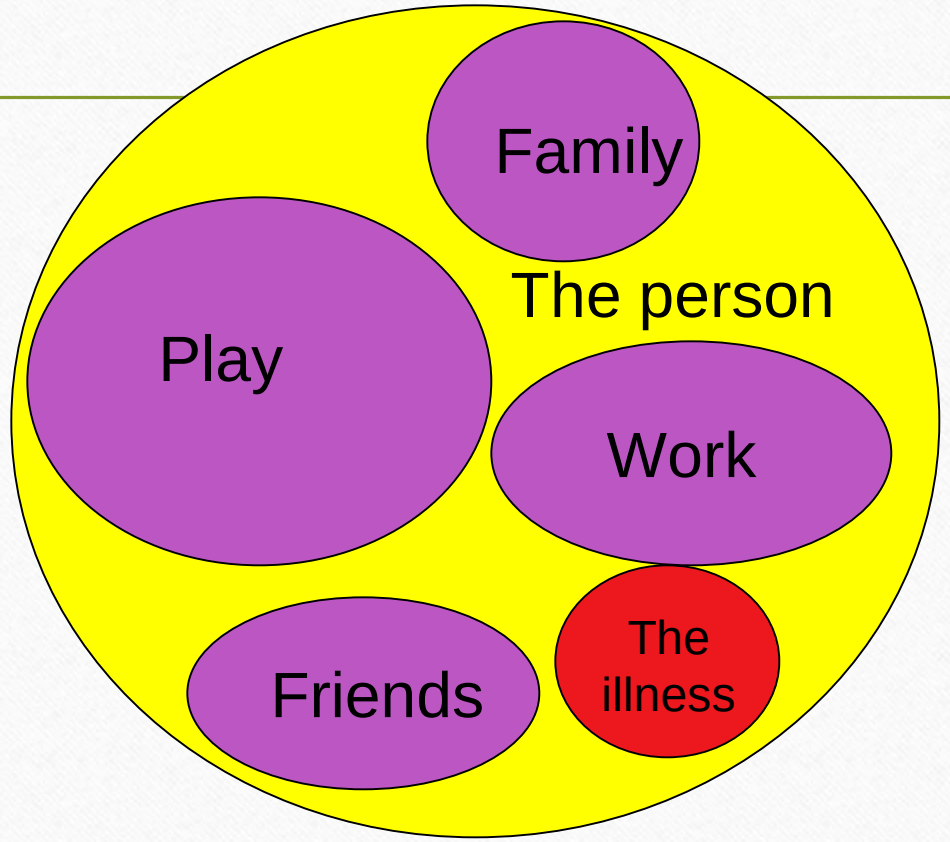
"Preadmission Screening & Resident Review (PASRR)" – independent evaluator

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

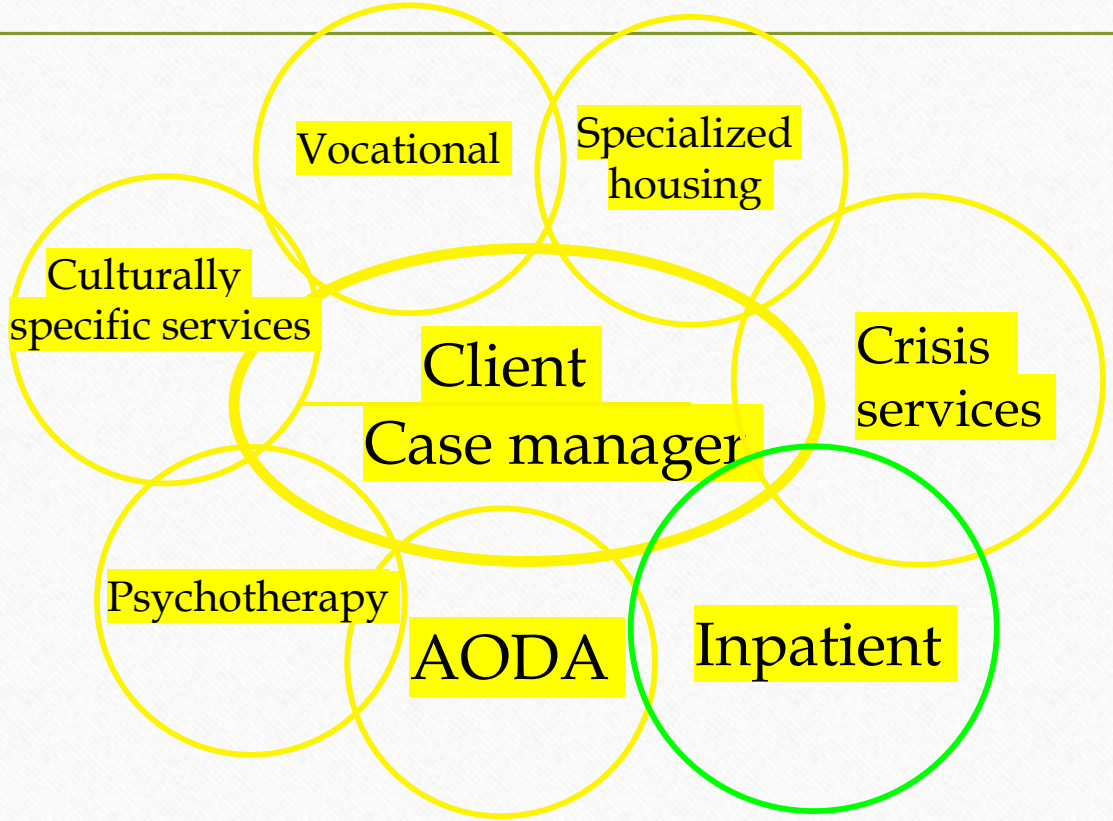
The process of recovery



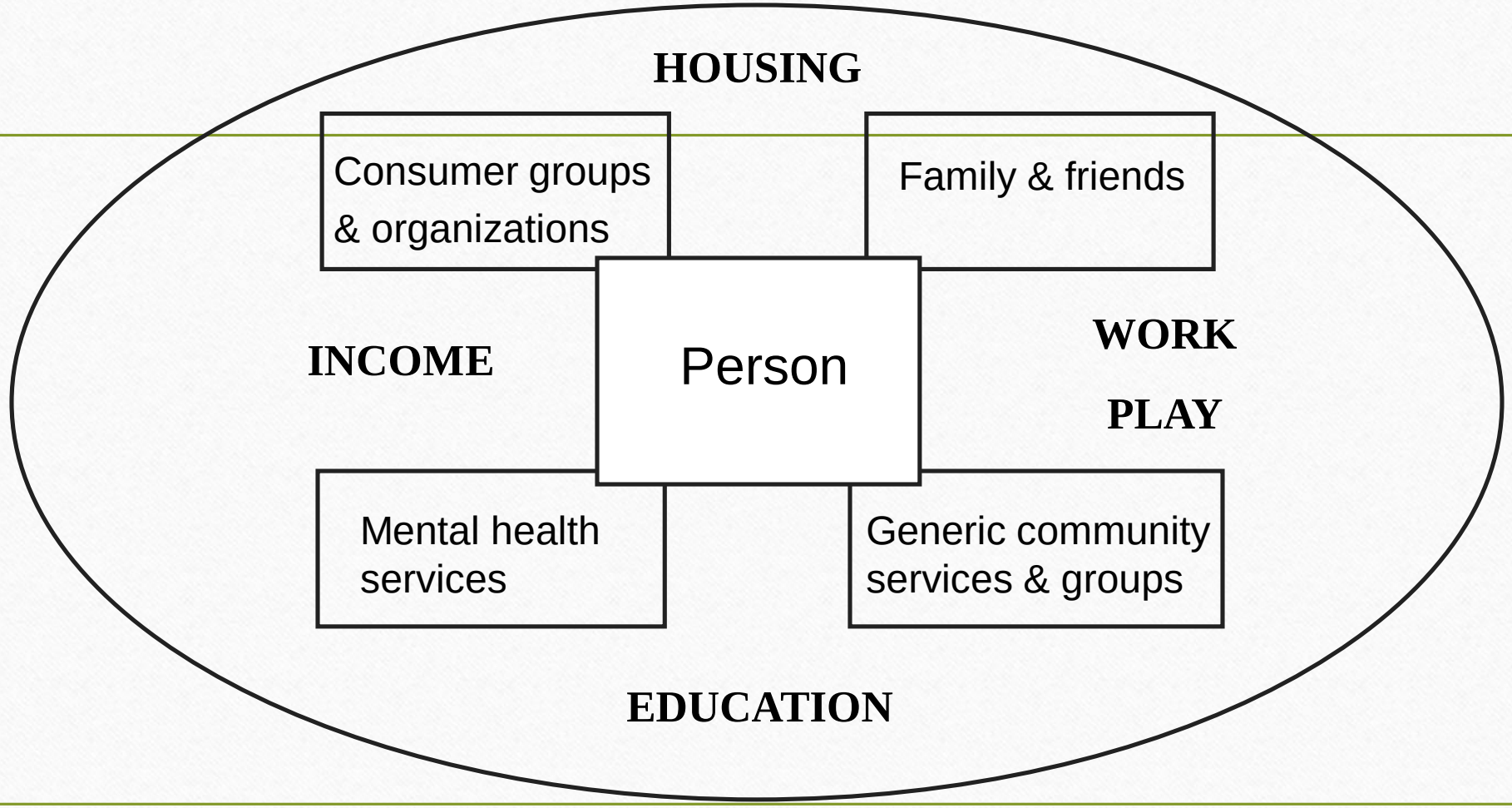
The process of recovery



Traditional approach *swaddles* the client with services and is deficits-based



Recovery-oriented system *supports* but does not surround the client and is strengths-based (Trainor, 1993)



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). Amended in 2008 to broaden coverage.

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

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

Community Integration Mandate: State and local governments must "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.

Olmstead v. L.C., 527 U.S. 581, 600 (1999): State violates the ADA if provides care to people with disabilities in institutional settings when they could be appropriately served in a community-based setting (as determined by treatment professionals). Perpetuates unwarranted assumptions that people are incapable or unworthy of living in community.

Courts have applied Olmstead to all state and Medicaid-funded institutions. Under *Olmstead,* state must show it has a plan for reducing reliance on institutions. Increasingly after the *Olmstead* decision + Surgeon General's Report (1999), which helped to mainstream recovery principles, state Medicaid programs have covered 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)

Yet despite these developments - admissions continue into nursing homes, and it is difficult to leave.

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 NH residents.
- Half of residents with major mental illness did not receive PASRR pre-screening.
- Nursing home services to treat psychiatric disorders are woefully inadequate.

And – people with psychiatric conditions more likely to be in nursing homes with lower quality of care and less staffing. (Temkin-Greener, 2018)

Nationally: Continued overuse of anti-psychotic medications:

2011 DHHS OIG audit found nearly one in seven NH residents, majority with dementia (88%), received powerful anti-psychotics. High risk of harm/mortality for residents with dementia. CMS response cites concern of contractual arrangements that result in inappropriate over-prescribing practices.

CMS begins to require reporting use of anti-psychotic drugs (2012), but does not require facilities to report its use for residents with certain conditions, including schizophrenia.

- No incentive to curb anti-psychotic drug prescriptions for these conditions
- False labelling of schizophrenia and other disorders exempt from reporting (NYT, "Phony Diagnoses Hide High Rates of Drugging in Nursing Homes, Sept. 11, 2021).

Dramatic increase of anti-psychotic and other psychotropic drug use during COVID pandemic. (JAMA, March 2021)

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 New York 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 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."

Why the continued high admissions of people with psychiatric disabilities to nursing homes??

- Affordable community-based housing & supports slow to develop & insufficient.
- Lack of accessible supportive housing & coordinated mental health & medical supports
- Ineffective PASRR screening systems, individuals with PASRR disabilities "temporarily" admitted into nursing homes and not reviewed
- Pressure to discharge quickly from hospitals, NH $$ incentives to fill beds

Reasons for Admissions/Long Stays in Nursing Homes cont'd:

- Lack of family/personal support systems
- Difficult to return to community once housing is lost
- Effects of "institutionalization" on the behavior and motivation of NH residents
- Personal care supports may not be covered by Medicaid if needed because of cognitive decline or reasons related psychiatric disability, rather than physical disability.

- Home and community-based services to avoid institutionalization (more intensive "Medicaid Waiver" services) rarely designed for people with psychiatric disability who are nursing home eligible.

- "Money Follows the Person," federally funded state community transition programs begins in 2008, but in early years programs provides limited assistance to people with primarily psychiatric disability living in nursing homes.

Olmstead Cases: California, Connecticut, Illinois, Louisiana, New York, New Hampshire

- *Laguna Honda Hospital*, California case: Settlement (2004) of class action brought by California P&A:

  1) implemented targeted case management for class members in 1,000 bed nursing home to provide assessment and discharge planning, determine most integrated setting, for class members seeking HCBS services;

  2) improved PASRR statewide to consider:
     - individual's goals and preferences
     - community supports and services as alternatives to NH admission.

New York: *Joseph S. v. Hogan*, amended complaint filed in 2007:

- 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.

Settled in 2011, requiring independent assessments of remedy members and offer of community-based housing & services to those determined able and willing to move to community.

- PASRR Evaluation altered to consider community-based alternatives.
- Settlement does not require monitor or remedial expert.
- By 2016, eighty residents out of several hundred assessed moved to community.

Illinois: *Colbert v. Blagojevich,* class of plaintiffs with disabilities in Cook County nursing homes. Amended complaint filed in 2007, parties entered into consent decree in 2011, revised plan filed 2018. Monitoring (court-appointed monitor) is ongoing.

- "Class Members with Mental Illness" (primary, defined as serious mental illness under state law) and "Class Members with Physical Disabilities."
- Plan to transition class members, developed by parties and monitor, must be cost neutral.
- Targets for numbers of interested class members to receive evaluations by qualified professionals for community-based services. Determines level of need and eligibility. Right to appeal, and to reevaluations.
- State must develop community capacity; qualified professionals develop service plans with & for each class member.

Illinois, cont'd:

- Revised Cost Neutral Plan filed in 2018. States expenditures were 35% less for class members transitioned to community but are higher in first year of transition.

- State must develop community capacity; qualified professional develops service plans with and for each class member.

2019 Monitor's report to Court identifies areas of non-compliance: lack of committed & accountable leadership, plummeting performance in transition numbers; lack of data-driven community-based services and housing development strategy; and unaddressed pipeline impediments that delay or prevent transitions.

- 2,417 class members transitioned from 2013-2019, out of 20,278 residents.

United States Department of Justice (DOJ) Civil Rights Division enforces the ADA & its integration mandate. Investigated New Hampshire nursing home with "specialized services" for individuals with serious mental illness:

- DOJ findings (2011): Prolonged stays at NH because discharge & transition planning are insufficient, and community housing, supports, and services are in short supply. People with more complex physical and mental health conditions remain institutionalized because more intensive protections, services, and supports are not available in the community mental health system. Separate class action complaint (*Amanda v. Hassan*), brought by P&A and co-counsel, joined actions.

- Consent decree includes requirements for expanded community resources, inreach, person-centered transition planning, and independent monitor. Adds supported housing and community settings to meet the needs of people at NF who cannot be served in supported housing, and plan for residential supports.

- Most recent monitor's report (2021) recommended improved inreach, and improved access to waivers, subsidies, community providers, and to small scale community residential programs. 20 transitioned so far from NH.

Olmstead cases, cont'd:

DOJ complaint, Louisiana (2016): Louisiana has one of the highest percentages (14.5%) of adults with serious mental illnesses living in nursing homes (3,800 people).

"Individuals with serious mental illness in nursing facilities in Louisiana who express a desire to leave the facility and return to their own communities routinely receive little or no assistance to do so."

Detailed Louisiana settlement (2018) concerns Medicaid-eligible adults with serious mental illness resident in nursing facilities or who are referred for PASRR evaluation for NF placement.

DOJ settlement in Louisiana includes following requirements:

- State must develop and implement a plan to divert further NH admissions, and agree on implementation plan with DOJ with timeframes for transitions
- All screenings & evals, as well as transition planning, must presume that person can live in community
- PASRR improvements
- Transition planning, support and coordination that is person-centered and strength-based
- Support for informed choice, peer support; opportunities to visit community settings

DOJ Louisiana Settlement cont'd:

- Assess nursing facility residents during outreach
- Case management post-discharge to help maintain community placement and avoid re-institutionalization
- Community support services: crisis system, including mobile crisis response & telephone system
- Substance use recovery services
- Assertive Community Treatment expansion
- Seek Medicaid waivers necessary to ensure individuals needing help with activities of daily living have sufficient services
- Integrated day activities, including supported employment
- Expand Supportive housing, add tenancy supports

Office of Protection and Advocacy for Persons with Disabilities v. State of Connecticut:

Connecticut P&A filed action with co-counsel & settled case in 2014 on behalf of individuals with serious mental illness (PASRR defined) who can live in community with supports and services. Defendants determine who is eligible for class. Defendants must:

- Educate class members about community-based services and opportunities to visit settings
- Move all eligible class members who choose to move (w/in 18 mos)
- Determine most appropriate integrated setting through person-centered planning process
- Court-ordered settlement with remedial expert

Issue: many class members have conservator, who must also agree to plan before class member may transition.

Issues for settlements include:

- Guardian refusals to transition
- Insufficient housing
- Lack of leadership
- Coordinating services – “pipeline issues”
- Supporting and informing decision-making and supporting transitions
- Post-discharge supports
- Cost neutrality if short-term

Helpful to include strong inreach and supports, including peers; presumption to live in community; independent monitor

Federal initiatives supporting states to rebalance services in favor of community living for people who have psychiatric and medical conditions:

- Some states are now proposing more mental health services through the temporary availability of additional federal matching funds for HCBS under American Rescue Plan Act (10% bump). At least some (e.g., NY, MA) will enhance community-based supports for older adults with psychiatric conditions, improve diversion from nursing home admissions, with ARPA HCBS funds. Funding available through March 2024.

- Money Follow the Person (MFP) Federal Medicaid program has funded grants to states to assist with community transitions from NH's and intermediate care facilities since 2008. Increasing number of states (though less than half of 44 with MFP programs) transitioned people with psychiatric conditions from nursing homes 2010-2015. (Kaiser 2015) The Consolidated Appropriations Act (CAA) of 2021 extended funding for the MFP program through 2023 – 33 programs remain.

What more is available for your community under Medicaid and through supportive housing systems?

- How well integrated are medical and mental health services? Well adapted and available for older population?
- Sufficiently accessible and available supportive housing?
- Services such as personal care?
- Transportation, telehealth?

Example: New York State Geriatric Mental Health Alliance recommendations:

https://www.vibrant.org/what-we-do/advocacy-policy-education/geriatric-mental-health-alliance/

https://behavioralhealthnews.org/aging-in-supportive-housing-one-fall-away-from-institutionalization/

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