

The Legacy of *Olmstead*: Life Outside the Nursing Home Walls

If Jane Koza gets her wish, she will be at Yankee Stadium on Sunday, August 11, throwing out the ceremonial first pitch and picking up an Anthony Volpe bobble head doll.



It wouldn't be her first time around a pitcher's mound. A lifetime ago — in the late 1970s and 1980 — she was a star pitcher for the Kean University softball team. And it certainly would not be her first time at Yankee Stadium, cheering on her favorite team and sporting a Yankees T-shirt with Aaron Judge's name and number on the back.

But we're getting ahead of ourselves. This story is not about ball games, nor is it just about Jane herself — it's about 4,400-plus New Jerseyans who, like Jane, left nursing homes to lead fuller lives in the community during the past decade and a half. And it's about thousands of other nursing home residents who might be able to do the same if state officials support a fundamental shift in policies and investment priorities.

This Saturday, June 22, marks 25 years since the U.S. Supreme Court ruled, in *Olmstead v. L.C. and E.W.*, that unnecessary institutionalization constitutes unlawful discrimination under the Americans with Disabilities Act.

The *Olmstead* decision, along with robust advocacy and follow-up litigation, enabled many individuals with mental illness or developmental disabilities to leave institutions for appropriate, home-like settings in the community. The ruling also benefited nursing home residents.

In response to the *Olmstead* decision, the U.S. Centers for Medicare and Medicaid Services (CMS) launched *Money Follows the Person*, a program that offers funding to states to help move eligible older adults and people with disabilities out of institutions and back into the community. The federal government gives states an enhanced Medicaid reimbursement for each person that moves home, generating savings that the state must reinvest in home- and community-based services.

The New Jersey Department of Human Services, which administers the state Medicaid program, began participating in 2008. The Office of the Long-Term Care Ombudsman (LTCO) joined the partnership — called *I Choose Home NJ* — in 2012.

Since 2008, *I Choose Home NJ* has helped more than 4,400 people move from nursing homes and development centers to the community. The program has generated more than \$45 million in savings — and growing — for New Jersey to invest in home- and community-based services.

"Nursing homes will be the next deinstitutionalization effort in New Jersey," said Long-Term Care Ombudsman Laurie Facciarossa Brewer. "Many nursing homes are laid out like hospitals and have an institutional feel. Of the 360 nursing homes we have in New Jersey, 80 percent

are licensed for 100 beds or more. Some are twice that size. Surveys show that people prefer to receive care in their homes or to live in smaller, more home-like long-term care settings. That is the direction we need to go."

A Linden native, Jane was quite an athlete back in the day. She played basketball and softball at Mother Seton Regional High School, a Catholic girls' school in nearby Clark, N.J., and then at Kean University. In 1979, her junior year at Kean, she pitched her way to an earned run average (ERA) of 0.64, which remains the school's single-season record.

After college, Jane moved to Florida. She lived in Key West for many years before returning to the mainland. During much of this time, she was a self-employed stained glass artist, making window and wall art, as well as reproductions of Tiffany lamps.

Her health issues began in the 2000s. Jane had difficulty walking and underwent knee surgery. She contracted an infectious disease that damaged her spinal cord and ultimately led to paralysis. Only in her 40s at the time, Jane ended up in a nursing home in Florida.

Jane credits her sister Lorraine with helping her through the hardest times and essentially saving her life — more than once. "If it wasn't for her, I wouldn't be here," Jane says.

In 2006, Lorraine and her husband brought Jane north to a nursing home in Linden. Jane made the best of her situation at the nursing home, which is now known as AristaCare at Parkside. She met a special friend, Stanley, and made friends among the staff members. She also served as president of the Resident Council.

However, she was miserable for much of the time. Her health deteriorated; eventually both her legs had to be amputated.

Jane says Jeannie Seals — a Certified Volunteer Advocate representing the LTCO who regularly visited the Linden nursing home — inspired Jane to start thinking about leaving the nursing home for a place of her own. Then, Kathleen Filippone, RN, a nurse liaison on the I Choose Home NJ team, was instrumental in helping her through the process.

After years on waiting lists to obtain affordable, accessible housing, Jane learned about a barrier-free building in Linden on the site of a vacant convent. She had a Section 8 voucher at the ready to hand over to secure new housing.

On the last day before her voucher expired, Jane got the call from Kathleen. She had her apartment. Jane moved in during the fall of 2019 and made a new life for herself. She recently upgraded to a two-bedroom place across the hall.

Brewer, the Long-Term Care Ombudsman, and her team are committed to changing the landscape of long-term care in New Jersey. Some people need the level of care that a nursing home can provide, she noted. But they could be better served in smaller, home-like spaces.

The New Jersey Task Force on Long-Term Care Quality and Safety issued its final report in the spring, recommending that New Jersey invest substantial public funds into home- and community-based services to prevent people from winding up in nursing homes in the first place. The report also recommended incentives for developing smaller nursing homes that are designed to provide person-centered care and a better resident experience.

Affordable and accessible housing is scarce in New Jersey, which can make it difficult to move people out of nursing homes, Brewer said. The state also needs more flexible and generous Medicaid rules so that more people can receive the care they need at home.

“We have a long road ahead of us,” Brewer said, “but we are headed in the right direction. And the *Olmstead* decision certainly helped to clear the way.”

“Many residents do not need or want to live in nursing homes,” Brewer continued. “They are capable of living in the community, with supportive services in place. And the bottom line is that it is cheaper to help people age in place at home rather than in an institutional setting.”



Jane zips around Linden — and beyond — like she’s on a mission.

On a recent Wednesday she set off in her motorized wheelchair toward the John T. Gregorio Center to meet her friend Barbra for a little bingo. The next day, she planned to go back to her old nursing home to visit a friend on the staff. The previous weekend, she went out to lunch with her sister. Recently, Jane and Barbra took the Access Link bus to Point Pleasant.

That level of freedom was impossible when she was at the nursing home. Jane says living independently also helped her get into a better frame of mind and become more spiritually involved in her artistic pursuits.

She produces vibrant, colorful works of art — with colored markers on heavy paper — that she displays and sells at arts and crafts fairs and other venues. Some pieces decorate her apartment, along with a few Tiffany lamp reproductions and a stained glass representation of a sailboat on the open sea with the message: “I can and I will.”

Jane is also taking a course on storytelling at the Gregorio Center to help her write a memoir.

Stanley, who now lives at a nursing home in Old Bridge, has a birthday coming up. Jane plans to surprise him with a visit.

Jane herself will turn 66 on July 28. Exactly two weeks later, on August 11, Jane hopes to be at Yankee Stadium, when the Yankees will give away bobble heads to celebrate their Gold Glove shortstop, Anthony Volpe.

So how does Jane plan to end up throwing out the first pitch? Well, she submitted the scenario to *Wish of a Lifetime*, a charitable affiliate of AARP that grants life-changing wishes to older adults and inspires people to redefine aging in America.

Jane's wish also involves a private suite, a well-stocked buffet, seats behind home plate, and her sister Lorraine by her side.

It's a longshot, for sure. But betting against Jane never seems like the smart play.

I Choose Home NJ helps eligible nursing home residents move back into the community with in-home services.

Nursing home residents who want to move to the community can receive assistance if they have lived in their facility for 60 days or more and are eligible for Medicaid.

More info: Visit <https://www.nj.gov/ooie/ichoose/> or call 1-855-HOME-005 (1-855-466-3005).

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