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NEW YORK SUPREME COURT
APPELLATE DIVISION, FOURTH DEPARTMENT

AINSWORTH M. BENNETT, Individually and on behalf
of the ESTATE OF VIRGINIA R. BENNETT
Plaintiff-Appellant,

-against-

ST. JOHN'S HOME and ST. JOHN'S HEALTH CARE CORPORATION
Defendants-Respondents.

BRIEF AMICI CURIAE OF AARP, LONG TERM CARE COMMUNITY COALITION, MFY LEGAL SERVICES, AND DISABILITY RIGHTS NEW YORK IN SUPPORT OF PLAINTIFF-APPELLANT

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INTRODUCTION

The right to self-determination and personal autonomy is naturally conferred on all adults, regardless of the person's age, disability, background, or economic status. This case is about respecting a person's right to personal autonomy as to where she will live and who she chooses as a caregiver. Mrs. Bennett expressed her clear choice to return to her own home with care provided by a combination of professional staff and informal family caregivers, and yet she continued to languish in Defendant's facility due to the Defendant's refusal to engage in discharge planning allowing Mrs. Bennett's husband to act as one of her caregivers. This refusal was based on an opaque and misguided appraisal of Mr. Bennett's capabilities. Defendant declared that Mrs. Bennett required "24-hour care," but failed to facilitate such an intensive level of care outside of an institution. The court below did not question Mrs. Bennett's ability to choose to live and receive care at home, but unjustifiably disregarded her clearly expressed desire to return home after her physical rehabilitation.

Federal and state policies enable people who need supports and services to fulfill their right to live in their own homes and communities. The legislative history of the statutes at issue in this case supports the right of a person like Mrs. Bennett to live her life in the community, not to be forced to languish in a nursing facility, and research highlights the positive outcomes for individuals who live in their own home or community as they age.

I. INTERESTS OF AMICI CURIAE

AARP is a nonprofit, nonpartisan organization with a membership that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse. Since its founding in 1958,

AARP has advocated for a system of Long-Term Services and Supports (LTSS) that are centered on the wants and needs of the individual. In particular, AARP advocates for people to have the right to decide on and direct the services and supports they receive. AARP also supports policies that enable family members to care for their loved ones, instead of supplanting family caregivers with nursing facility care.

The Long Term Care Community Coalition (LTCCC) is a U.S. nonprofit organization dedicated to improving the quality of life and quality of care for people who use and/or reside in nursing homes and other types of long term care (LTC) facilities in New York and nationally. The Coalition is comprised of a range of professional, civic, aging and disability organizations. It uses the perspectives gained from its members to identify the major issues affecting quality of care and quality of life for elderly and disabled LTC consumers, and undertakes studies and in-depth analyses of those issues in order to gain insights and develop meaningful recommendations for both policymakers and stakeholders. Nursing home resident rights and other legal, policy and regulatory issues related to nursing home care have been the focal point of LTCCC's work since the organization was incorporated in 1989.

MFY Legal Services, Inc. (MFY) envisions a society in which no one is denied justice because he or she cannot afford an attorney. To make this vision a reality, for over 50 years MFY has provided free legal assistance to residents of New York City on a wide range of civil legal issues, prioritizing services to vulnerable and under-served populations, while simultaneously working to end the root causes of inequities through impact litigation, law reform and policy advocacy. MFY provides advice and representation to more than 8,000 New Yorkers each year. MFY's Nursing Home Residents Project provides information and advocacy for nursing home residents and their families who are struggling with abuse, neglect, civil rights

violations, unfair consumer practices, and improper discharge planning. MFY also provides know-your-rights trainings and educational sessions to nursing home residents and family councils. Because of the far-reaching implications of this matter for its clients, MFY has a substantial interest in its outcome.

Disability Rights New York (DRNY) is the federally authorized Protection and Advocacy System and Client Assistance Program for people with disabilities in New York State. DRNY provides free legal and other advocacy services to advance and protect the rights of people with disabilities. DRNY advocates to ensure that its clients are free from abuse and neglect and from unlawful discrimination. DRNY provides these services under federal grant funded mandates that have been established by Congress to protect and advocate for the rights, safety, and autonomy of people with disabilities. Since 1989, DRNY has fought for the constitutional and statutory rights of New Yorkers with disabilities to live independently and enjoy equality of opportunity in their own communities. DRNY has succeeded in preventing or ending the needless institutionalization of many people with both mental and physical disabilities through individual representation, systemic litigation and advocating for policies that promote personal choice and dignity.

II. STATEMENT OF FACTS

AARP adopts and incorporates by reference the Statement of Facts articulated in Plaintiff-Appellant's brief.

III. ARGUMENT

A. Federal and State Policy Support the Individual's Right to Choose a Home or Community-Based Long-Term Care Setting.

Title II of the Americans with Disabilities Act (ADA) prohibits any exclusion from the "services, programs, or activities" of a public entity based on a person's disability. 42 U.S.C.

§ 12132 (2012). Federal regulations implementing Title II include an "integration mandate," which generally requires public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 CFR § 35.130(d). As the U.S. Department of Justice recently noted, one of Congress' primarily goals in passing the ADA was to "protect[] individuals with disabilities from the harm of unnecessary institutionalization." See Brief for the United States as Amicus Curiae Supporting Plaintiffs-Appellees at 14, Davis v. Shah, No. 14-543 (2d Cir. filed Feb. 24, 2014).

In 1999, the U.S. Supreme Court recognized that unjustified institutionalization of persons with disabilities constitutes a form of discrimination under Title II of the ADA. Specifically, the Court held that public entities must provide community-based services to persons with disabilities when community-based services are appropriate to the individual's needs, the individual does not oppose community-based treatment, and community-based services can be reasonably accommodated. See Olmstead v. L.C., 527 U.S. 581, 587 (1999). Olmstead addresses the ADA's explicit recognition that "historically, society has tended to isolate and segregate individuals with disabilities." 42 U.S.C. § 12101(a)(2) (2012).

In recognition of their obligations under the integration mandate, federal and state programs and policies are now designed to enable older adults to receive services in their own homes or in another community-based setting as an alternative to institutionalization, regardless of their age or functional status. For example, the federal Money Follows the Person (MFP) program provides supplemental services to individuals seeking to return to their home or the communities of their choice from a nursing facility. Deficit Reduction Act (DRA) of 2005, Pub. L. No. 109-171, § 6071, 120 Stat. 102, (2006), amended by Pub. L. No. 111-148, § 2403 (2010). The MFP program is intended to "to assure continued provision of home and community-based

long-term care services to eligible individuals who choose to transition from an institutional to a community setting." Id. New York is one of 44 states that participate in this program. See Ctrs. for Medicare and Medicaid Servs., Money Follows the Person, available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Money-Follows-the-Person.html.

Enacted in 2010, the Patient Protection and Affordable Care Act (ACA) offers funding to states and creates new programs that incentivize states to serve eligible individuals in community-based settings as an alternative to institutionalization. In addition to strengthening the MFP program, the ACA gives new incentives for states to offer home and community-based long-term services and supports (LTSS) as an alternative to institutional care. Among these programs is the "Balancing Incentive Program," which allocates $3 billion to states that would enable them to make structural changes to their systems of care away from institutions and toward community-based care. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 10202, 124 Stat. 923, Mar. 23, 2010. Another new program is the "Community First Choice Option," which provides increased Medicaid funds to states that choose to provide home and community-based attendant services to Medicaid beneficiaries who would otherwise require institutional care. Id. at § 2401, 124 Stat. 297.

New York has long recognized the need for availability of in-home support services for older adults. Through its Medicaid program, New York operates a program known as the "Nursing Home Transition and Diversion Waiver" (NHTD Waiver) that is intended to keep eligible individuals from entering or remaining in nursing facilities. In doing so, the program balances the right of older adults and adults with disabilities "to be in control of their lives, encounter and manage risks and learn from their experiences" with the need "to assure the

[individual's] health and welfare." N.Y. Dep't of Health, Section I: Introduction and Philosophy of the NHTD Waiver, available at https://www.health.ny.gov/facilities/long_term_care/waiver/nhtd_manual/section_01/index.htm. Services available under the NHTD Waiver include: in-person assistance with the individual's activities of daily living, such as dressing, bathing, and eating; assistive technology devices; home visits by medical personnel; home and vehicle modifications; and respite services to temporarily provide relief to unpaid family caregivers. See N.Y. Dep't of Health, Section VI: Waiver Services, available at https://www.health.ny.gov/facilities/long_term_care/waiver/nhtd_manual/section_06/index.htm.

Outside of the Medicaid program, New York also operates a program designed to provide some supportive services—including service coordination, health assessment and monitoring, and home delivered meals—in single-family homes located in neighborhoods with a large population of older adults. These programs are called Neighborhood Naturally Occurring Retirement Communities, or NNORCs. See N.Y.S. Off. for the Aging, Naturally Occurring Retirement Community Supportive Service Program (NORC-SSP) and Neighborhood NORC (NNORC), available at http://www.aging.ny.gov/NYSOFA/Programs/CommunityBased/NORC-NNORC.cfm. Three NNORCs operate in Monroe County. N.Y.S. Off. for the Aging, Neighborhood NORC Program Contact Information, available at http://www.aging.ny.gov/NYSOFA/Services/NNORCprogramcontacts.pdf.

Assistive technology enables many older adults to safely age in place without the need for constant in-person observation. These devices can perform a variety of tasks that enable the independence of adults with dementia, from monitoring for falls to providing verbal reminders to take medications. See, e.g., Weil Cornell Med. Coll., Home Safety—Virtual Home, available at http://www.thiscaringhome.org/virtual_home/default.aspx. Under a federal grant, New York

operates a program through which it supports adults in need of LTSS through assistive technology devices that monitor the individual's health and safety. Known as the Technology-Related Assistance for Individuals with Disabilities (TRAID) Program, this program funds twelve Regional TRAID Centers, where individuals receive information, training, device demonstration, device reuse, device exchange, and device loans. See New York Just. Ctr., Assistive Technology (TRAID) Program, available at http://www.justicecenter.ny.gov/services-supports/assistive-technology-traid.

Given the variety of resources potentially available to older New Yorkers who desire to live in the community, nursing facility staff should be able to identify a combination of services that would enable older adults to live at home with 24-hour assistance from different sources. In many cases, individuals find themselves stuck in nursing facilities because the burden is on the individual to "prove" their ability to leave, without any knowledge or information about available community-based services. Caregivers are likewise often tasked with "proving" their ability to provide care without knowing what tasks they would be expected to perform. To preserve the patient's right to her own autonomy and choice, any patient assessment should be uniformly applied and assume first that the patient can live in his or her own home with appropriate services and supports, and then identify any and all paid and unpaid, formal and informal, in-person and technology-based supports that would support the patient at home. When nursing facilities do not undertake their burden to prove a patient's inability to reside in the community or educate patients about their treatment options, their incentive to unnecessarily retain patients remains steadfast, at a steep cost to the patient's independence and, as discussed below, overall well-being.

B. The Legislative History of 2803-c and 2801-d Supports the Right to Age in Place.

The legislative history of the operative statutes in this case supports the right of an adult to age in place. N.Y. Pub. Health Laws § 2803-c and § 2801-d were adopted following a report from the Moreland Act Commission, convened by Governor Carey to "investigate a state-wide scandal regarding the licensing and approval of nursing homes and residential facilities in New York." Patrick J. Dellay, Note, Curbing Influence Peddling in Albany: The 1987 Ethics in Government Act, 53 Brook. L. Rev. 1051, 1058 n.20 (citing Exec. Order No. 2, Jan. 10, 1975, reprinted in State of New York, Public Papers of Hugh L. Carey, at 7367 (1982)).

The Moreland Commission endorsed both N.Y. Pub. Health Law § 2803-c, which describes the rights of patients of all health care facilities, and N.Y. Pub. Health Law § 2801-d, which provides a private right of action to a patient for any violation of their rights under state or federal law. During the Senate debates of both pieces of legislation, the legislature expressed a clear concern about individuals moving into nursing facilities, where they were "ceas[ing] to be a human being and a citizen, with all the rights that all of us have." Morisette v Terence Cardinal Cooke Health Care Ctr., 797 N.Y.S.2d 856, 861 (N.Y. Sup. Ct. 2005) (quoting N.Y. Sen. Transcript, May 13, 1975, at 4568-69)). As the New York Supreme Court in New York County recently articulated, the Patient's Bill of Rights was enacted by the legislature with "the right to receive adequate and appropriate medical care" in mind. Id. at 860.

Upon the signing of Pub. Health Laws § 2803-c and § 2801-d nearly 40 years ago, Governor Carey recognized that he was ratifying a "forceful bill of rights for patients in nursing homes which will guarantee them the dignity and privacy that is their due." 1975 N.Y. Sess. Laws 1764-65 (McKinney), Statement of Gov. Hugh L. Carey, Aug. 6, 1975 (emphasis added). According to the Governor, the bill was intended to "provid[e]...patients with basic rights, as

well as the right to have their grievances addressed." Id. The Governor likewise envisioned these statutes as "giv[ing] each patient the potential to act as his own ombudsman" responsible for monitoring the quality of her own care and services. Id. at 1764.

N.Y. Pub. Health Law § 2801-d was enacted with the express acknowledgment that nursing facilities "control[] virtually...the entire existence [of their patients]," and, as a result, many nursing facility patients remain "helpless and isolated." 1975 N.Y. Sess. Laws 1685 (McKinney), Memorandum of State Executive Department (emphasis added). In recognition of these facts, § 2801-d provides a clear disincentive for facilities to violate the personal rights of their patients. The legislature explicitly recognized that many patients cannot afford attorneys that would enable them to assert their rights, further adding to their vulnerability. Id. To remedy this problem, § 2801-d created a broad recovery structure designed to incentivize private attorneys to accept these cases on an individual or class basis. Id. The empowerment of private attorneys to accept claims arising out of this statute provides a clear incentive, albeit a purely financial one, for facilities to abide by the personal rights of their patients.

New York courts continue to support a broad application of both statutes. An action under N.Y. Pub. Health Law § 2801-d is available independent of whether the plaintiff has asserted a claim in negligence and medical malpractice. Marshall v. Leppard, 851 N.Y.S.2d 58 (N.Y. Sup. Ct. 2007). An action under N.Y. Pub. Health Law § 2801-d is also independent of the merits of any related claim for malpractice. Kash v. Jewish Home & Infirmary of Rochester, 873 N.Y.S.2d 819, 821 (N.Y. App. Div. 2009).

The "rights" originally described by the Governor and legislature have evolved since 1975. However, at the time it was passed, both the Governor and the legislature intended § 2803-c and § 2801-d to become a shield against the intrusion of personal rights by nursing

facilities. Their recognition of the control that long-term care facilities exert over patients and concern for preserving patient dignity and privacy indicate a desire to protect patients, not only from substandard facility-based care, but also from unnecessary facility-based care.

C. Living an Integrated Life in the Community Results in Positive Outcomes for Older Adults.

America's population age 65 and older increased by nearly ten million between 2002 and 2012, and is projected to more than double by 2060. Admin. on Aging, U.S. Dep't of Health and Human Servs., A Profile of Older Americans: 2013, at 3, available at http://www.aoa.gov/Aging_Statistics/Profile/2013/docs/2013_Profile.pdf. As the population of older adults continues to increase, so too will the demand for LTSS. An estimated 70% of individuals who reach the age of 65 will need some form of LTSS at some point in their lives. Robert Wood Johnson Found., Long-Term Care: What Are the Issues?, at 2, available at http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2014/rwjf410654.

Now with ample supports in place, it is essential that stakeholders respect the right of older adults to receive high-quality LTSS in the most integrated setting appropriate for the needs of the individual, as well as their right to have choices as to who provides and where they receive these services. The vast majority of Americans prefer to remain in their own homes as they age. See, e.g., AARP Pub. Pol'y Inst., Home and Community Preferences of the 45+ Population, November 2010, available at http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf. By contrast, "few people agree to go to a nursing home if they think they have any choice in the matter." Robert L. Kane & Joan C. West, It Shouldn't Be This Way: The Failure of Long Term Care (2005). Mrs. Bennett's clearly expressed desire to reside at home with services and supports "is not just an idiosyncratic choice" of a person faced with the possibility of living in a nursing facility, but instead "represents a real heartfelt need [to] continue[] the arc of life,

which...is not yet completed." Lawrence A. Frolik, Housing Choices and Older Clients: Dealing with Issues of Identity and Quality of Life, 24 Pa. Law. 26 (2002).

When a nursing facility respects an individual's choice to reside at home, and then makes all appropriate efforts to facilitate that choice, that person often experiences better health outcomes. Researchers recently evaluated an "Age in Place" (AIP) program in Missouri that provided an array of community-based services pursuant to a care plan developed and supervised by nursing staff.[1] Researchers found that the program's participants—approximately 2,000 non-disabled elderly Medicare beneficiaries who were hospitalized within the preceding six months—experienced significantly better outcomes than those who resided in a local nursing facility. Karen Dorman Marek et al., Clinical Outcomes of Aging in Place, 54 Nursing Research 202, 202–11 (2005). Specifically, participants in the AIP program experienced more improved cognition and lower rates of depression than their nursing facility counterparts. Id.

Because aging in place preserves individual choice and autonomy, adults who age in place are less likely to rely on emergency rooms and other forms of expensive medical services. In a study of a program in Pittsburgh, PA, that combined subsidized housing with community-based services, participants in the program were less likely to use local emergency rooms and transfer to nursing homes than those who did not participate in the program. Nicholas Castle & Neil Resnick, Service-Enriched Housing: The Staying at Home Program, J. Applied Gerontology, at 1-21 (2014). Program participants were also more likely to participate in

[1] "Aging in place" generally refers to the ability of older adults "to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level." Nat'l Conf. of State Legislatures & AARP Pub. Pol'y Inst., Aging in Place: A State Survey of Livability Policies and Practices, at 1 (2011) (emphasis added), available at http://assets.aarp.org/rgcenter/ppi/liv-com/aging-in-place-2011-full.pdf. It is a concept that represents the common-sense desire of older adults to remain in familiar settings surrounded by friends and family despite whatever obstacles they might face as they age.

physical activities and report greater overall satisfaction with their services than non-participants. Id.

Better patient outcomes can also be seen in individuals who "age in place" with the support of national programs, such as Medicare. A recent study compared health outcomes for Medicare beneficiaries six months after a hospital discharge between those who used home health care services and those who did not. Although the study noted that individuals receiving home health care services tend to report a worse health status and have higher rates of chronic conditions, the health status of home health users improved at a greater rate than those who did not use home health services. Jack Hadley et al., Posthospitalization Home Health Care Use and Changes in Functional Status in a Medicare Population, 38 Med. Care 494, 494 (2000).

The fact that older adults who remain in familiar settings surrounded by familiar people are less likely to experience depression cannot be a surprise to anyone who has cared for their loved ones at home. In contrast, the consequences of an unnecessarily prolonged nursing facility placement are particularly severe. According to a recent study of nursing facility residents in the Netherlands, the rates of depression among nursing facility residents are three to four times higher than individuals who receive supports and services in a community-based setting. K. Jongelis et al., Prevalence and Risk Indicators of Depression in Elderly Nursing Home Patients: The AGED Study, 83 J. Affective Disorders 135, 135-42(2004).

Nursing facility residents are generally less likely to receive constant care and supervision than individuals who reside in their own home. According to a recent study by Families for Better Care, the quality of care in New York's nursing facilities received a failing grade, ranking 45th overall amongst the states. Families for Better Care, Nursing Home Report Cards: New York, available at http://nursinghomereportcards.com/state/ny/. In particular, the

study noted chronic understaffing of New York's nursing facilities, as well as a high rate of patient complaints verified by the state long-term care ombudsman. Id.

Nursing facilities must promptly care for the individual's short-term needs and begin planning for discharge to services at home or in the community because the longer a resident stays in a nursing facility, the less likely she will ever leave. Knowing this correlation, many nursing facilities see it as an incentive to give incomplete or inaccurate assessments of an individual's ability to be cared for at home. The risk of people becoming "stuck" in a nursing facility without any means of ever returning to their homes is especially high in New York. According to a recent nationwide survey of LTSS services by the SCAN Foundation and AARP, only 6.4% of nursing facility residents in New York with stays of 90 days or more ever return to the community, ranking 42nd nationwide. Susan C. Reinhard et al., Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers 89 (2d ed. 2014), available at http://www.longtermscorecard.org/~/media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf. 25.9% of new nursing home stays in New York last 100 days or more, ranking 48th nationwide. Id.

This case exemplifies the conduct—such as the lack of transparency in assessing an individual's ability to reside at home, placing the burden on the individual or their family to "prove" their ability to reside at home or provide care, and failing to consider a broad array of support services in discharge planning efforts—that enables nursing facilities to unnecessarily retain patients against their will and in violation of their civil rights. In accordance with the policies clearly expressed in federal and state law, New York's nursing facilities must respect the

individual's right to reside in their own home with the caregivers, paid and unpaid, of their own choosing.

CONCLUSION

For all of the foregoing reasons, amici curiae respectfully urge this Court to reverse the decision below.

Dated: 13th day of October 2014

Respectfully submitted,

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CERTIFICATE OF SERVICE

STATE OF NEW YORK)

COUNTY OF MONROE) ss:

ANDREW B. STRICKLAND, being duly sworn, deposes and says:

On this 13th day of October, 2014, I served a true copy of the Brief Amici Curiae of AARP, Long Term Care Community Coalition, MFY Legal Services, and Disability Rights New York in support of plaintiff-appellant by mailing the same in a sealed envelope via fedex mail addressed to the last known addressee(s) as indicated below:

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