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Help people with disabilities live in the community

Unnecessary segregation in nursing homes 'has been linked to accelerated mental, emotional, and physical decline' when residents have little autonomy and little ability to engage in outside activities, a lawsuit says.

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For many people with disabilities, living in a nursing home is a last resort. Maybe they lost their housing after a lengthy hospital stay. Maybe their care needs became too much

for a spouse or child to handle. While some people need round-the-clock care, others may be able to live in the community — if they had more support.

A lawsuit filed in the US District Court in Boston last year by people with disabilities and their advocates, <u>David Marsters v. Maura Healey</u>, seeks to force the state's Executive Office of Health and Human Services to move more people with disabilities out of nursing homes and into community settings, with supportive services.

Simultaneously, the US Department of Justice is investigating whether state government is violating the Americans with Disabilities Act by not helping people with disabilities transition from institutions back to their communities. A Healey administration official said the state is cooperating with the investigation, which began in July 2022 and has not issued any findings.

The Healey administration entered mediation last week in an attempt to reach a settlement with the lawsuit's plaintiffs. Two similar suits, settled during former governor Deval Patrick's administration, resulted in the transition of thousands of people with brain injuries and intellectual and developmental disabilities from nursing homes into community settings, with enhanced support. A similar settlement covering all people with disabilities would be the right way to resolve the litigation and, more importantly, to provide quality care for people in the settings where they are most comfortable.

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"We want people to be able to have a choice of living in the community versus remaining in institutional care," said Carolyn Villers, executive director of Massachusetts Senior Action Council, an advocacy group for seniors which is also one of the plaintiffs.

A spokesperson for the Executive Office of Health and Human Services said the Healey administration is committed to serving residents with disabilities and complying with the Americans with Disabilities Act and continues "to make significant investments in homeand community-based services to help individuals live in the communities of their choice."

Other than the Massachusetts Senior Action Council, the plaintiffs are all people with disabilities — physical and mental — who are living in nursing homes but would prefer to live in a residential setting. All could potentially have their needs addressed in the community. Their attorneys, led by Steven Schwartz of the Center for Public Representation, an Easthampton-based public interest law firm, are seeking certification for a class action to represent all people with disabilities in nursing homes.

The plaintiffs' complaint argues that unnecessary segregation in nursing homes "has been linked to accelerated mental, emotional, and physical decline," when residents have little autonomy and little ability to engage in outside activities. Massachusetts has homeand community-based services that provide assistance to people in their homes, but the lawsuit argues that these are insufficient to help everyone who could benefit.

The plaintiffs say this violates the Americans with Disabilities Act as interpreted by a 1999 <u>US Supreme Court ruling</u>, which found that unnecessary institutionalization of individuals with disabilities constitutes discrimination.

When the Healey administration sought to have the case dismissed on procedural grounds, the US Department of Justice <u>weighed in</u> in favor of allowing the case to proceed. The Justice Department <u>recently sued</u> Colorado on similar grounds, arguing

that the state is violating the ADA by unnecessarily institutionalizing people with physical disabilities in nursing homes.

There are approximately 22,000 adults with disabilities on Medicaid in nursing homes, according to the Massachusetts lawsuit. Former state elder affairs secretary Paul Lanzikos, cofounder of Dignity Alliance Massachusetts, which advocates for community-based care for seniors, estimated that 15,000 to 17,000 of them have clinical needs that could be met in the community.

The state is making some efforts to offer these services. Massachusetts offers multiple home- and community-based care programs, each applying to a different population, like autistic children or frail elders. AARP ranked Massachusetts fourth nationwide for providing long-term services and supports. In 2021, the state committed to using \$500 million in American Rescue Plan Act money by 2024 to improve access to home- and community-based services, including developing the workforce, enhancing access, and improving technology. But, as is detailed in the lawsuit, programs are capped in how many people they can accept and there are gaps in services — for example, there is a need for case managers to work with nursing home residents to identify community-based housing options.

Disability rights advocates are hoping the lawsuit results in an expansion of the options counseling program, where caseworkers help people in nursing homes or at risk of entering nursing homes understand the range of services available to them and how to access them. Another goal is an expansion of community-based programs to serve more people and ensure equal accessibility statewide. A third is a commitment — similar to commitments made in the earlier two settlements — to move some number of people out of nursing homes each year.

Villers said she would like to see creative programs established, as has been done with the populations involved in the earlier settlements, like roommate programs, where two people with disabilities share an apartment and services or where a caregiver roommate provides evening assistance in exchange for free housing.

The time is ripe for Massachusetts to settle the lawsuit. Massachusetts just got approved to participate in a program that makes more federal Medicaid money available for initiatives that move people out of nursing homes with community supports. The federal ARPA money can bolster community-based services.

Any settlement probably would not involve an immediate sea change but instead a gradual expansion of services while moving a few hundred people a year out of nursing homes, if they choose to leave. Since community-based services tend to be less expensive than institutional care, that could potentially save money for the taxpayers who fund Medicaid while providing more fulfilling lives for people with disabilities.

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