
Class Action Lawsuit Filed on Behalf of Persons with Brain Injuries

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Catherine Hutchinson says she's trapped—trapped by her disability, trapped in a nursing facility, and trapped in a system that for nine years has denied her rehabilitative services and shunned her desire to reclaim her life in the community.

This morning, advocates filed a class action lawsuit in US District Court in Springfield, charging that the Governor and other state officials of the Commonwealth of Massachusetts are violating federal law by failing to provide appropriate community-based services to Hutchinson and other individuals with serious brain injuries who are confined in nursing and rehabilitative facilities throughout the state.

"Their brain injuries are life-changing and profound, but they don't deserve or need to be relegated to a lifetime of institutional care," said Richard Johnston, a partner at Wilmer Cutler Pickering Hale and Dorr LLP, which represents the plaintiffs along with the Center for Public Representation.

At a press conference this morning at WilmerHale's Boston office, Hutchinson's guardian, Sandy Julien, read a statement that Hutchinson had written from the Middleboro Skilled Care Center, where she has lived for more than nine years.

"Sometimes I feel I am in prison for a crime I didn't commit," wrote Hutchinson, 54, who eleven years ago suffered a brainstem stroke that left her a mute quadriplegic. "I need to start living my life, instead of just existing in a wheelchair."

Hutchinson, a mother and grandmother who previously lived in Attleboro, operates her electric wheelchair by manipulating her head, and communicates through her eyes, utilizing a letter board and by email. She said that she has not been able to access necessary rehabilitative services that would assist her transition to the community. "We must find a way to allow people like me to live as independently as possible," she wrote. "I should not have to fight the system when each day I must already fight to communicate, to be understood, make choices and express my feelings."

Added co-counsel Steven Schwartz of the Center for Representation, "Like all of us, the plaintiffs want to, and are entitled to, live in their own homes and in their own communities. The Commonwealth can and must do better."

Named as defendants in the lawsuit are Governor Deval Patrick; JudyAnn Bigby, Secretary of the Executive Office of Health & Human Services; Leslie Kirwan, Secretary of the Executive Office of Administration & Finance; Thomas Dehner, Acting Director of MassHealth; and Elmer Bartels, Commissioner of the Massachusetts Rehabilitation Commission.

Schwartz said that the plaintiffs were forced to file the lawsuit because both the Romney and the Patrick Administrations rejected proposals to promote community integration for individuals with brain injuries. Schwartz said Bigby met with the plaintiffs only once. “Now it may take a lengthy and expensive legal battle to ensure that persons with brain injuries who are confined in institutions will finally have a chance to live ordinary lives in the community,” he said.

Institutional settings are all that plaintiff Glen Jones has known for the past 21 years. Jones, 57, has lived in three facilities since the 1986 motor vehicle accident that left him in a coma for three weeks. He lives at the Worcester Skilled Care Center, 60 miles from his family in Haverhill. His care providers and social workers echo Hutchinson’s treatment professionals: With appropriate services, they can live in the community, where they could enjoy the company of friends and family and benefit from integrated social interactions.

Other named plaintiffs seeking a return to community living are Nathaniel Wilson, 54, of Springfield, a resident at Wingate of Wilbraham Skilled Nursing Facility, who last year suffered a stroke that impacted the left side of his body, affecting his speech, mobility and hand and facial muscles; and Raymond Puchalski, 58, of Millers Falls, who resides far from home in the neurobehavioral unit at Kindred/Goddard Hospital in Stoughton. This is his second institutional placement since the driver of an oncoming vehicle fell asleep and crashed into his car four years ago.

According to Johnston, there are many hundreds, if not thousands, of nursing facility residents, who like these plaintiffs, are confined in nursing facilities contrary to their wishes and the recommendations of their treating professionals. These individuals are joined by the families and professionals who are members of the Brain Injury Association of Massachusetts (BIAMA), a Westborough-based statewide advocacy organization which serves 30,000 people annually. BIAMA also is a plaintiff in this case.

Arlene Korab, executive director of BIAMA knows firsthand “the critical difference between life in an institution and life in the community.” Her son, who suffered a traumatic brain injury, lives in a community residence with support staff. “We do not go to an institution to see him,” she said at the press conference. “We go to his home to spend time with him and he visits us at our home.”

An avid sports fan, her son attends local and professional sporting events. “He shops for his personal needs, plans his meals, shops for his groceries, even goes to the movies and restaurants,” said Korab. His life expands beyond the community residence. “He has friends and acquaintances who are not paid to live with him,” said Korab.

According to the Massachusetts Department of Public Health, 37,298 individuals went to the emergency departments with traumatic brain injuries in 2004. The Centers for Disease Control report that 5.3 million Americans are living with disabilities as a result of traumatic brain injuries

(TBI)—head injuries caused by external events, such as falls or accidents. Acquired brain injuries (ABI)—caused by internal medical events such as stroke, disease or poisoning—also are significantly prevalent: More than 700,000 Americans suffer new or recurrent strokes every year.

The majority of people with brain injuries spend weeks or months in acute care hospitals and rehabilitative facilities. Once the acute treatment ends, these individuals still need some level of assistance with personal care and activities of daily living rehabilitative care. However, as Johnston noted, there are few community-based options for continued rehabilitative care, and as a result, individuals with brain injuries have no choice but to be admitted to nursing and rehabilitative facilities to have their basic needs met.

As many as a quarter of the estimated 8,200 individuals with brain injuries currently in nursing and rehabilitative facilities in Massachusetts could successfully transition to integrated community settings if services were available, Johnston said.

The lawsuit charges that Massachusetts has not engaged in any meaningful efforts to create community alternatives for individuals with brain injuries. The plaintiffs also allege that the state has failed to provide these individuals with medically necessary services, including speech, occupational and physical therapy—all of which are Medicaid-covered services.

Schwartz said that the Commonwealth has ignored federal directives and Supreme Court decisions that require states to develop and implement plans to move people with brain injuries from institutional to community settings. In addition, he said that unlike other states, Massachusetts did not even apply for federal funding to transition people with disabilities from nursing facilities to the community, while New Jersey will receive \$30-million over five years for this program.

He called upon the Commonwealth to commit to creating community programs for people with brain injuries—programs it already has created for individuals with psychiatric disabilities and with mental retardation. “Massachusetts knows better,” he said.

There is no state agency in Massachusetts designated to serve people with brain injuries. The Massachusetts Rehabilitation Commission administers the Brain Injury and Statewide Specialized Community Services Program that is restricted to people with traumatic brain injury. Individuals such as Hutchinson and Wilson, who have acquired brain injury, are not eligible for BISSCS program. Yet even those with TBI wait years for services. The program, according to its own website, served only 867 of the 2,048 people with TBI deemed eligible for services in 2005. In 2006, the numbers did not improve: The program served only 967 of the 2,262 eligible recipients.

Massachusetts Rehabilitation Commission also administers the Brain Injury Waiver but that too is a finite program that serves only those with TBI, and is capped at 100 people. In fact, even though this program is funded in significant part by the federal government, the Commonwealth recently cut it in half, so today there are even fewer federally-funded community placements than when the program was started in 2003.

The plaintiffs allege that the state is violating the Americans with Disabilities Act and other federal laws, including the Rehabilitation Act and the Social Security Act, which governs Medicaid

regulations. The lawsuit calls upon the state to inform residents of nursing and rehabilitative facilities about state and federally-funded programs that provide community-based services to all persons with brain injuries; to assess them for such services; to provide these services, regardless of the type and severity of their brain injuries. The suit seeks an order compelling the state to develop a comprehensive plan that provides integrated community settings and supports to facility residents with brain injuries and to provide them with Medicaid-covered rehabilitative services as long as medically necessary.

Johnston pointed out that many of these services already are available in the community, but not in sufficient capacity or intensity to meet the level of need.

As Korab of BIAMA observed, “Brain injuries don’t institutionalize people. States do.”