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Brain-injured plaintiffs living fuller lives after class action lawsuit

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Staff photo by John Suchocki

Raymond J. Puchalski was among four brain-injured plaintiffs who sued the state in 2007 for community-based care. He is pictured here at his friend's on Old Bay Road in Belchertown.
BELCHERTOWN - It was a clear day in June. Roads were dry. There wasn’t a single reason a car should have swerved into Raymond Puchalski’s lane as he drove on a straight-away in Erving. But it did.

Puchalski wasn’t supposed to live through the night following the 2003 accident. Then, he wasn’t expected to come out of a monthlong coma, or to ever walk or talk again. But he did.

Credit serendipity or the mysterious ability the body has to heal itself. However, Puchalski’s severe brain injuries and resulting cognitive disabilities left his loved ones, and the state Medicaid system, struggling with how best to care for him with so much life left. After dismal stints in a nursing home in Northampton and a long-term care facility in Stoughton, Puchalski, now 63, was among four brain-injured plaintiffs who in 2007 sued the state for community-based, individual care.

“I ask you: Is this a man who needs to be locked up? It was the hardest thing I ever had to do - to sign those papers. But I wanted him safe,” said Puchalski’s longtime love and legal guardian, Nickie Chandler, 61, of Belchertown. “He would ask me: ’Nickie, how long do I have to live here?’ And I would tell him, ’Ray, I’m doing my best. I’m doing my best.’”

With the help of the Center for Public Representation in Northampton, which has long advocated for community placements for various disabled groups, Chandler’s best resulted in the lawsuit that settled swiftly in 2008. The settlement yielded a vow from the state to place 100 brain-injured residents in less restrictive environments each year for three years: 300 total.

For Puchalski, that means weekdays at a newly built group home in Westfield run by the Berkshire County Arc, which offer community services to the brain-injured and those with developmental disabilities. The facility houses four men with brain injuries and offers round-the-clock care, plus outings and a host of personal choices of which Puchalski was deprived in other placements.

The simple pleasures of choosing what he wants for breakfast, or cooking his own dinner, or being able to attend the occasional Red Sox game are now available to him, while in previous placements “outings” may have consisted of once-weekly trips to the cafeteria. Chandler said Puchalski would take huge gulps of air on the rare occasions he made it outside.

“I love it outdoors. I love sports. I love fishing. I love hunting,” said Puchalski, who has marked short-term memory loss as a result of the accident, but remembers the girl who sat behind him in seventh grade and the 1966 Mustang he drove as a young man.

Pamela M. Bush, spokeswoman for the Brain Injury Association of Massachusetts, said the brain-injured were historically a smaller, more neglected group of disabled than, say, the mentally disabled, thousands of whom won their own way out of locked facilities and state schools with lawsuits decades before.

Massachusetts was the first state to settle successfully with brain-injured plaintiffs with Catherine Hutchinson v. Gov. Deval Patrick, et al.

Those covered under the lawsuit include those with brain injuries from accidents, stroke, sinus infections and any other “acquired or traumatic” brain injuries. Along with Puchalski,
53 brain-injury survivors have been placed in group homes, foster homes or independent settings since the lawsuit settled, with 60 more in the process.

“It sounds slow, but you have to find a place for them to go and you have to find the proper services,” Bush said. “You can’t just open the doors and wish them well.”

With the average annual cost of caring for a patient in a nursing home between $80,000 and $100,000, moving these patients out to the community - even to newly built facilities - is cost neutral, according to Bush.

She added that although there was a swell of enthusiasm surrounding the lawsuit and its successful settlement, the number of applicants has been smaller than advocates expected.

“Survivors and family members can get anxious. It’s scary to make the move. But, with the right care, as we know, the brain has plasticity and improvements can be remarkable,” Bush said.

Medicaid hosts biannual open enrollments for so-called Hutchinson/ABI (acquired brain injury) Waivers, with one upcoming in the spring. Marketing for the two-week enrollment periods is limited and the injured and their loved ones may be put off by the prospect of a long application, but Bush said the process is relatively simple. More information is available at www.biama.org and help is available through the agency.

For Puchalski, the new placement means being able to take up photography, revisit his days as an antiques “picker,” and go to dinner and the theater for his birthday with “his sweetheart,” Chandler, who remembers their first date dancing to a country band.

“I thought he might never live long enough at his age to enjoy living outside those institutions,” Chandler said. “But I also thought at least if I could save one person having to live where they didn’t belong, it would be worth it.”