Program for brain injured expands worlds

HOLLISTON — Chris Currier doesn’t remember his one-car accident in Framingham at age 31 on the evening of July 17, 1993. Nor does he recall anything during the month he remained hospitalized in a coma with a brain injury at the University of Massachusetts Medical Center in Worcester.

However, Currier, now 50, has an important message to share. He does so from his wheelchair, using the index finger of his left hand to type each letter on the keypad of a communication device, which then reads his words aloud:

“My life was entirely centered around my love of alcohol. I was sober for a while, and then that fateful night, I had had just about enough of everything. I was just going to get drunk one more time,” he said, but “the powers that be had other plans for me.”

While still in a coma, Currier was moved to Braintree Rehabilitation Hospital, where he remained for 18 months before being transferred to a rehab center in Worcester. He lived there for 17 years, until he moved into his own handicapped-accessible apartment in Holliston on June 14, 2011.

The transfer was made possible through a state and federal waiver program for individuals with an acquired brain injury who wish to reintegrate from a nursing facility, chronic care, or rehabilitation hospital into the community.
The program is the result of the landmark Hutchinson v. Patrick settlement on June 2, 2008, in which lead plaintiff Cathy Hutchinson fought for her right to move out of the nursing home in which she had lived for more than a decade because of a brain injury. She now lives in a group home in Taunton with four other women who benefited from the case.

Their class-action lawsuit was based on a requirement in the federal Americans with Disabilities Act that individuals with disabilities must receive support services in the most integrated setting appropriate to their needs.

According to the state Department of Public Health, more than 8,000 people living in nursing homes with brain injuries may be eligible for the waiver program.

As of March, 134 individuals had transitioned to independent living or been approved for the move. The program will be capped at 300 clients for the first three years, with additional opportunities anticipated in the future, according to the Brain Injury Association of Massachusetts, a private, nonprofit organization based in Westborough that is implementing the program.

Funding for the services will continue for the participant’s lifetime, said Arlene Korab, the association’s executive director.

“The process doesn’t happen overnight, and it can be scary to make a change, but we haven’t had one person come back and say, ‘I shouldn’t have left the nursing home,’” said Korab, who was a member of the group that initiated the lawsuit. She refused to put her son, Kevin, in a nursing home after he suffered a brain injury 30 years ago as a 17-year-old freshman at Northeastern University.

“When your loved one walks out the door and doesn’t come home the same person, it’s devastating,” she said, noting that the best place may indeed be a nursing home for a period of time. “For people whose improvement has stagnated, or who are depressed, there has to be something better — and that is the opportunity to live independently in the community.”

While Currier never doubted his decision, he pointed to his sister, Kim Cleverdon of Mendon, who admitted to worrying about all the logistics necessary for him to thrive outside the rehabilitation facility. Waiver participants are assigned an individual service plan and a case manager to provide referrals, continually monitor those services, and make changes when necessary.

Praising her brother’s continuing progress, Cleverdon said she understands how he yearned for more independence, despite the professionalism and compassion of the rehabilitation center staff. The second youngest of five children, Currier loves trivia, music, being outside, and shopping for clothes, baseball hats, and Nike shoes — so much that his niece decorated the bottom of his 50th birthday cake on April 30 in orange fondant shaped like a Nike shoe box.

Today, Currier benefits from modifications in his apartment, such as an electric opener for his front door, receives physical therapy at a day program, and has personal care assistants while he is home. He proudly shows off his defined abs and biceps, which he sculpted religiously at a local gym where he worked out free of charge until it closed a few weeks ago.
He recently achieved his goal of getting out of his hospital-style bed and into his wheelchair without assistance, and is working toward getting himself into a standing position.

“Chris needed the services, but he didn’t like the feel of a nursing home,” Cleverdon said. “As good as they are there, he had to go to the cafeteria and eat whatever they were serving that day. He had to go to bed when they wanted him to go to bed. He had to share a room with someone else.”

For Currier, however, the limitations went beyond personal preferences. He still gets emotional when recalling the names and contributions of his various therapists, but said, “I was around people who were convinced that they were as well as they were ever going to get. I decided that was not for me.”

Although Korab said the average move date is six months after acceptance into the Acquired Brain Injury Waiver Program, it took 13 months for Currier to leave his rehabilitation facility. While the process of finding the right fit in terms of living space, services, and providers was lengthy, Currier smiled, nodded, and gave a thumbs up to indicate the effort was worthwhile.

That was precisely the motivation for Wayland resident Louise Rijk. In October 2010, a staph infection triggered endocarditis and a stroke in her son, Johan, then a senior at Framingham State College. After three or four weeks at Brigham and Women’s Hospital and another month at Spaulding Rehabilitation Hospital in Boston, he transferred to a nursing home in Lexington.

While the facility offered the complex rehabilitation services he needed, Rijk said, her son became bored and despondent. Self-conscious about his right-side weakness and aphasia speech disorder, his reluctance to socialize turned to refusal after he was reprimanded by elderly female residents for taking their usual seats in the cafeteria.

“It was very nice there,” Rijk said, “but it just wasn’t appropriate for a 23-year-old.” Through the waiver program, she moved her son back home last summer.

Now Johan receives outpatient speech and occupational therapy, attends a conversation group and film study class for young people with aphasia, uses an iPad with specialized software donated by the Easter Seals organization, and goes to the library, the Museum of Science in Boston, and other outings with a companion provided by the waiver program two days a week.

Rijk provides many of Johan’s personal-care needs, and her 27-year-old son, Matt, assists by driving him to his many therapy and doctor appointments.

“We’re thankful Johan is still around, and we’re happy to do it,” Rijk said, “but it can be a challenge to find the right support.”

Stroke survivor Joanne Susi of Walpole said she is grateful that the waiver program enabled her to move after three “long” years from a Dedham rehabilitation center into a handicapped-accessible apartment in March 2011. A life coach and motivational speaker whose stroke affected her left side but not her speech, the 62-year-old is doing well and anxious to enroll in Braintree Rehabilitation Hospital’s driving rehabilitation program.
Susi likens the client-centric nature of the Acquired Brain Injury Waiver Program to the saying that when life gives you lemons, make lemonade. “It not only has the recipe,” she said, “but all the ingredients to tweak the sweetness to your liking.”

Susi continues to receive help with cleaning, laundry, and personal care in the mornings and evenings, but loves exercising at home and cooking for her family and friends. While she accepted needing to be at the rehabilitation center at the time, Susi said, living independently with support has brought “great relief” to her and her three children.

“I’ve gone from surviving to thriving.”

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