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Starting life over

LAWSUIT HELPS MAN BACK INTO COMMUNITY

by Donna Boynton



Meaghan Belcher, left, of Douglas watches while Carol Maxwell kisses her son, Raymond Gould, 28, also of Douglas, while meeting with Mr. Gould's friends.



April Gould of Douglas kisses her brother Raymond during the welcoming party.

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DOUGLAS — Raymond Gould sat at the dining room table, pinching off pieces of a muffin top, his first meal in his home as he was surrounded by family and friends. Moments earlier, he had walked into his apartment at Hayward Landing, victoriously announcing, “I’m outta there!”

“There” was the nursing home the 28-year-old had been living in for more than a year as he recovered from a sinus infection that caused an abscess on his brain and later a stroke, leaving him in a coma for three months.

The illness left Mr. Gould with an acquired brain injury — those caused by internal medical events such as stroke or disease as opposed to traumatic brain injuries caused by a fall or accident. There have been few options for Mr. Gould in his recovery, outside of institutions and nursing homes. But a class action lawsuit, *Hutchinson v. Patrick*, settled in 2008, has made it possible for Mr. Gould to live in the community and receive the services he needs.

Mr. Gould is among the first people with acquired brain injuries who will move from a nursing home to the community as a result of the class action settlement. Yesterday, he moved out of the nursing home and into the home of two care providers.

Over the next three years, an estimated 300 people are expected to follow, according to Arlene

Korab, executive director of the Brain Injury Association of Massachusetts. She welcomed Mr. Gould home yesterday.

The Brain Injury Association — along with five plaintiffs who are survivors of brain injuries and the Stavros Center for Independent Living — charged the state was violating the Americans with Disabilities Act by failing to provide adequate community services that would allow those with brain injuries to live in the community. Without these services, some people have remained unnecessarily institutionalized.

As a result of the settlement, two community programs were established to assist people with brain injuries. One of them allows two Medicaid home and community-based waivers for which Mr. Gould was chosen through an electronic lottery. Those waivers will allow him to receive individual treatment under a personalized plan that identifies transitional and long-term services, Medicaid funded services and community-based support that will allow him to live in the community, not an institution.

“The Hutchinson settlement gives every brain injury patient a chance to survive,” said his mother, Carol Maxwell of Fitchburg. “It's been a long journey, but by the grace of God my son is here today. ... Raymond is a pioneer. My hope is that Raymond is truly going to pave the way for a lot of people who need help.”

Two years ago, doctors had given Mr. Gould a 2 percent chance of survival.

“They asked me to remove life support and the feeding tube,” Mrs. Maxwell recalled. “I said, ‘Absolutely not. That is your science talking. My God says differently.’ From that day forward he began to improve.”

In June, Mr. Gould walked her down the aisle on a sandy Misquamicut Beach in Rhode Island as she married Tobin Maxwell, and later that day the talented color guard coach for Douglas High School who once dreamed of competing on “So You Think You Can Dance?” danced with his mother.

“I have fought for two years so my son could get proper medical attention,” his mother said through tears about the frustrating journey she and her family have had until assistance was made available through the Hutchinson settlement.

From the day he fell ill, his mother was constantly at his bedside. As her prayers for healing turned to tireless advocacy for his care, Mrs. Maxwell lost her job and the one bright spot in her life — her 7-month-old grandson, Logan Gould, who was instrumental in inspiring Mr. Gould during his recovery, died from SIDS in September 2009.

Mrs. Maxwell toured more than 20 nursing homes before deciding to place Ray at St. Mary Health Care in Worcester, where he began to progress in his recovery. When Mr. Gould first arrived at St. Mary's he couldn't speak, he couldn't move and he was angry.

“He was a young guy. At 27, he is not your typical skilled nursing home placement,” Alison

Sleeper Ames, his occupational therapist and co-rehab director at St. Mary's, said.

Ms. Sleeper Ames, who worked with Carol Clouthier, physical therapy assistant and co-rehab director, said Mr. Gould progressed from shaking his head yes or no to initiating conversation with the staff. He would plateau and then make unexpected gains, which the staff called “Ray Leaps” — sitting up in bed by himself, putting his feet on the floor from the bed by himself, accomplishing the little things that come automatic for most everyone else.

“For Ray to leave here he would need a lot of services, but it would be a more enriching life,” Ms. Sleeper Ames said. “He has been making progress physically and socially, but emotionally, he turned 28 in June and he is with people who are 60 or older. It is easier to challenge yourself with people around your same age.”

Staying in the nursing home setting for much longer will begin to cause mental and emotional setbacks for Mr. Gould, as many of the elderly residents there that have been his support system are dying. And it was increasingly difficult for his friends to see him in that environment. Some stopped visiting. Now, Mr. Gould will be living in the apartment below his long-time friend, Megan Belcher.

“I think Ray is going to do amazing things. He is really limitless,” Ms. Sleeper Ames said. “I didn't realize how important this was and how many people could be served in a better way until we met Ray.”

Today, he can walk independently, he can get on an off an elevator and in and out of cars. Living in Douglas, he will now focus on activities of daily living — brushing his teeth, showering, redeveloping his routines with the homecare providers he has been placed with through Alternatives Unlimited.

“It's killing me as a mom to know that he is going into ‘foster care,’” Mrs. Maxwell said. “I've been a good mom. But it is all in God's plan. ... He was so sick I never knew he could get to this level, to live in this setting in the town where he was raised.”

Mrs. Maxwell and her husband are seeking a variance from the city of Fitchburg to renovate their home to allow Mr. Gould to visit and live with them.

“Everything he is doing is a miracle,” Mrs. Maxwell said, adding that she and her family will be celebrating the holidays for the first time in two years.

“We are looking forward to much needed joy and rest,” Mrs. Maxwell said. “I just want a happy holiday with my family.”