NEW MOBILITY

HEALTH

Escaping the Nursing Home

May 1, 2008 Richard Holicky

People end up in nursing homes for a variety of reasons, the biggest four being they have nowhere else to go or can't find accessible housing, they're unable to secure reliable and affordable home health services, they are shipped to nursing homes to convalesce from surgery and never leave, or they lack the necessary family support. And it's not just poor people, the uninsured or the uninformed who end up in confinement.

Photo by Ray Ng

Devoe Mack was the first in his family to graduate from college. In 1993 Mack was working in the Philadelphia business sector when a neighborhood teen came to his home, robbed him and then shot him through the door after leaving. Mack, 40, spent three and half months in Thomas Jefferson rehab recovering from a complete C5 injury. Despite limited use of his arms, he was discharged in a manual chair. Divorced, living alone and with no place to go upon discharge, his best option was to move back to Memphis and live with his mother.

"I got to Memphis and didn't know anyone," he says. "I started out with home health seven days a week but they kept cutting back, first to five, then down to three days a week. When my mother passed away in '97, my brother took over the house, and I lived with him and his wife."

Life in general wasn't exactly rosy.

"I had to rely on my brothers to take me anywhere and when I did get out, there wasn't much in the city that was accessible. I had no idea there was an entire community of people with disabilities there. I was isolated and thought I was the only disabled person in Memphis. I spent most of my time in my room, feeling sort of ashamed and not wanting people to see me in a chair."

His home health care disintegrated in both frequency and reliability, dwindling from the needed three or four visits a day to two a day, twice a week. Eventually his situation became untenable and Mack entered a Memphis nursing home in August 2003.

Those in nursing homes face an uphill battle to regain their independence. Finding accessible and affordable housing presents a can of worms big enough to meet the needs of a boatload of fishermen. Not many people have heard of independent living centers prior to disability, and few are aware of the details of SSI, Medicaid, Section 8 housing or personal care assistance programs until they need them.

Many people get daily help from either family members or a personal attendant, but not everyone comes from a family with the closeness, time, resources and skill sets necessary to provide home health care.
Few insurance policies pay for such services, and the vast majority of public funding is held in a death grip by the nursing home industry, which receives 98 percent of all state funding for long term care in Tennessee. Paying out of pocket is out of reach for most.

Health care providers, especially those having minimum experience with people with disabilities, all too frequently err on the side of the "safety" that controlled environments provide. Once confined to a nursing facility, even if only to recover from surgery, many people become physically and mentally overly-dependent on staff and services. And politicians seem joined at the hip with the industry's lobby and the prevailing attitude that "these people" require assistance 24/7. The challenge, as one CIL worker put it, is to convince health care professionals and politicians alike that people have "the right to risk."

The Underground Railroad

When Devoe Mack landed in a nursing home 10 years after being shot, he tried not to give up hope, but it was difficult. "It was scary and felt like I might be there forever," he says. "The only positive thing was being around other disabled people, so I didn't feel so isolated. I had no idea that it was possible to get out."

Randy Alexander does all he can to transition people from nursing homes back into the community.

It was Mack's good fortune that an old high school friend visiting Memphis learned of Mack's accident and came to see him at the home. "He told me I had to get out. He surfed the net, found the Memphis Center for Independent Living, and I decided to check it out. I had no idea people with disabilities could work and function and have good attitudes and make changes."

When Mack got to MCIL, he saw all these disabled people working and doing good things. "That was so exciting! I got to working on getting out, but I couldn't find a place to live." There were only 24 subsidized accessible units in the entire Memphis area.

"Then this guy Darrell came to MCIL from Denver talking about the "Underground Railroad" and how I could get the necessary care I needed and have a life in Denver," says Mack. "I was always kind of adventuresome and thought, 'I'm 50 years old, what do I have to lose?' and I began doing what I had to do to make it happen."

MCIL's Randy Alexander guided Mack through the process of contacting Social Security and Medicaid to let them know of his impending move. He also connected Mack with Barry Rosenberg, who runs a home health agency in Denver.

"Barry told me he would help me with most everything — a place to stay, getting food stamps, covering me for home health care until Medicaid in Colorado kicked in. MCIL said they would pay my airfare, give me money for food and a couple hundred dollars for incidentals. It was all really happening." But just before moving, Mack got a little concerned about whether this would all work out or if it was just some scam. "It seemed too good to be true," he says. "But Darrel assured me again, so I went ahead."

A friend from Laramie met him at the airport and they took a cab to the apartment, where Rosenberg, a nurse and a CNA were all waiting. "When I woke the next day, an aide was here to do my care. It was all so smooth and organized, the care was excellent and people were showing up when they're supposed to. It was new and exciting,

Mack's apartment is one in 12 that Rosenberg owns and rents to his clients, who share personal care assistants. Mack sees aides three times a day for a total of four hours per day.

"I'm living, not just existing," he says. "My attitude is so much better now. I'm in school, I got a girlfriend, a van. Part of life is feeling like you can contribute, and I hope to be looking for work soon." Now he says he wants to give something back.

"I shouldn't have to leave my birthplace and family in order to live," he says. "The mentality in Tennessee is different than here. Race is always a factor, but there disability and money were the bottom line. People were saying it's just too expensive to make things accessible. There should be more places like this. I thank God for people like Barry and Randy and MCIL. They all try and get the system to work."

CIL Freedom Fighters

The Underground Railroad from Tennessee to Colorado is a modern version of the system that facilitated escape from slavery. Its origins date back to the early '90s, when workers at MCIL, frustrated with the near total lack of services in Tennessee, hooked up with CIL workers in Colorado, where people could actually count on reliable and funded home care. Working together, activists at MCIL and Atlantis CIL in Denver helped Latonya Reeves, who is legally blind and has CP, become the first Underground Railroad passenger.

Latonya Reeves' main duties involve transitioning others out of nursing homes.

"I was living with my godparents, and they were no longer able to provide the care I needed," Reeves recalls. "I couldn't get daily care and was looking at having to go back to a nursing home. That's when I called MCIL. I knew people in Denver from ADAPT actions, so it wasn't that scary. [ADAPT founder] Wade Blank met me at the airport and I've been working for Atlantis in Denver ever since." Appropriately, Reeves' main duties now involve transitioning others out of nursing homes.

James Chapman

James Chapman was running a successful small painting business and had contracts with the city of Denver, the state of Colorado and a large public transportation company. Then, at 39, he broke his back in a violent fall down a flight of steps. After a 30-day stay in a Denver hospital where he received no rehab save for learning transfers, he was sent home.

"The hospital's patient rep helped me with Medicaid, checked out my home and said I was ready for discharge, even though I had five steps to get in to my house. I didn't know anything about bowel or bladder management. I did know I had a big contract at Invesco Field (where the Broncos play) and had to get back to work."

If he hadn't run into a CIL worker he knew, James Chapman might still be residing in a nursing home.

Getting around the work site in an ATV, Chapman's skin broke down quickly, sending him back to the hospital for surgery. Once healed, he had no place to go, and the hospital discharged him to a local nursing home. In six short months he'd lost his health, his wife, his house and his business.

"The first thing I heard from the nursing home personnel was how this was it, that if I wanted to stay healthy I needed to be there. But the staff wasn't knowledgeable about SCI and did a poor job of keeping the surgery site clean. It wasn't a very young person-friendly place and had little connection to the outside world. People were two to a room with only a curtain for privacy, so it was uncomfortable for

money."

As nursing homes go, Chapman could have done worse. This place was located in Denver, the residents' average age was 50, and many were there hoping to recover from stroke, TBI, heart attacks or mental health problems. But once there, some were abandoned by their families. Others went there to heal and had lost their housing.

"No one there ever told me about my options, about CILs or private charities," says Chapman. "I kept thinking about how to find the resources I needed to get out, but I might still be there if I hadn't run into Bill."

Bill Bass works for the Disability Center for Independent Living in Denver and was doing some outreach at Chapman's nursing home. The two recognized each other from Bass's painting days at Chapman's job site. They immediately began working together to find housing and get food stamps and assistance for utilities and rent. Bass connected him with local charitable organizations and the food bank and got Chapman a referral to Craig Hospital to receive some world class rehab: bowel and bladder training, wheelchair skills, recreational therapy, driver's training — the whole nine yards.

Bill Bass hooks up people moving from nursing homes with everything they need.

Nine months later Chapman moved into a Section 8 two-bedroom accessible apartment and began living independently from a wheelchair.

"At first it was like being a baby. I'd never been out of the nursing home for more than half a day, so everything was an adjustment. I was unsure about all the obstacles and didn't know what I could do, like playing with my kids, camping and stuff."

Five years later, Chapman's got the hang of it, and his life's on the upswing. He's renting to buy, volunteering with several youth organizations and serves on the Living Center's board. He has also gained full custody of his son, 11, and visits often with his daughter, 16. He's working with Voc Rehab toward self-employment to sell his line of wheelchair accessories and market himself as an ADA accessibility consultant. In the meantime he supplements SSI by making customized buttons, stickers and T-shirts as "The Button Man."

Ryan Loosemore

Ryan Loosemore broke his neck in a BMX biking accident in Hartford, Conn., when he was 16. Following months of acute care and rehab — he's a C1-3 with C5 function – he was ready for discharge. Only one catch: because his parents' home was totally inaccessible, a nursing home was his only option.

"It was hell," he recalls. "There were like a 100 people there, mostly old people needing care because of diabetes, strokes and stuff. Some were drunks, some had kidney problems, most of them were in wheelchairs. The only open bed was on the vent floor, so that's where they put me. I was the only young person there."

The facility offered few rehabilitation services and gave up on Loosemore quickly, saying it took him too long to regain any movement. They provided no organized activities, not even phones in the rooms.

Loosemore had to make his calls from the front desk, where conversations were time-limited and offered little privacy. Extremely depressed and with little to do, he stayed in bed for months. When he finally started getting up, it was to watch television or play video games.

"It was all a shock. Here I was, 17 and in a nursing home and away from my family and all. I just stuck to myself."

Eventually Loosemore remembered meeting the local CIL guy, Rick Famiglietti, while in rehab. Famiglietti had told him that he could live independently, a subject the nursing facility staff had never raised with him despite repeated inquiries. Loosemore's high school contacted Famiglietti once he turned 18 and the CIL worker then began visiting

"The nursing home never gave any information about getting out or living on my own and they didn't like that I kept asking about leaving. One administrator threatened to put me in front of a hearing and have me examined by the psychiatric staff. She basically said she'd take all my rights away if I kept talking to her staff about getting out."

Independence, he quickly found out, came with a steep learning curve: making sure SSI and Medicaid were in place, finding housing, getting utilities and phone set up, applying for a personal care assistance waiver and then locating PCAs. During this time, Loosemore was finishing up a full two years of high school, and upon completion began taking college courses.

"He has a pretty remarkable story," Famiglietti recalls, "because he's a quad with C5 function and needs help with a lot of things."

In all, Loosemore spent nearly three years in nursing facilities. He calls his transition both welcome and easy.

"I live alone and it's pretty much what I expected, mostly common sense, really. Now I've got a lot of peace and quiet with no one on my case. My PCAs come three times a day to help me in and out of bed, with dressing and for meals. Voc Rehab modified my van and my friends drive me around. Mostly I'm either doing school (three classes at school nearby) or hanging with my friends. It's more freedom and responsibility. It's good."

Mike Taylor

Mike Taylor is a poster child for what's wrong with rehabilitation and health care in America. An uninsured small businessman, Taylor spent months in a general hospital after breaking his back in November 2004. He received little SCI rehab and was discharged without ever learning any basic self-care, like bowel and bladder management. A skin sore he developed in the hospital flared up quickly and sent him back for surgery within weeks.

Once healed, but still lacking much rehab, he needed help with most everything. But in Tennessee, about the only place to find reliable personal assistance care was in a nursing facility. That's where Taylor was shipped.

"Once you're in there, man, it's a rut and it's very hard to get any information unless you find someone who knows something. Your stuff gets stolen and they don't do nothing about it. I didn't know anything about getting out and figured I was stuck there."

Surely the nursing home personnel would answer questions about regaining independence.

"Hell no! They don't tell you jack and just put it all back on the family. The state ombudsman isn't much help, either. Lucky for me, I met this other guy there, Devoe, who told me about Randy Alexander and MCIL. I went there and signed up to get out."

Taylor returned to the nursing home with a long list of homework assignments. He began with basics such as a valid ID, birth certificate and Social Security card and application. From there it was on to securing SSI, Medicaid, applying for food stamps, learning public transportation, applying for housing, finding out about utilities and all the rest. Under the best of circumstances, it's an arduous process.
From a nursing home, it's much worse. In the meantime, due to lousy care, Taylor's skin broke down again. Back to the hospital he went.

"The hospital tried to discharge me after 10 days, saying I was a troublemaker," says Taylor. "They couldn't find another nursing home and were going to ship me out of state. I called Randy and the whole center showed up in wheelchairs and blocked the doorways. They called the news media and helped me fight to stay close to home."

Eventually Taylor was discharged to a second nursing home about 200 miles away, near Nashville. The transition process was in motion but Taylor spent another nine months in that second facility, much of it simply waiting for accessible housing and working through all his homework. Finally, after more than two and half years in nursing facilities, Taylor wheeled out of the nursing facility last fall, this time to live on his own in Memphis.

"It was scary. I'd become real dependent on staff in the nursing home and didn't have any help for a couple of months," he says. "I needed help with moving and getting furniture and stuff. The Center can only do so much and you can't keep asking family for help with everything or you begin to wonder if you're gonna make it. I've had this skin wound for so long and needed help caring for it. I went through five home health agencies because the people they send want you to be totally dependent and let them run your life. I had problems finding doctors to prescribe the meds I need, docs who accept TennCare.

"Once you're in one of those places you might as well be in prison," he says. "But at least in prison you can get legal aide easier. In the nursing home you got no money, no way to learn how to take better care of yourself in the chair, no protection from having your stuff stolen, no way to get any information about getting out unless you find someone who knows something. Randy knows stuff … all the stuff."

Like others who are grateful to have their freedom, now Taylor volunteers at MCIL.

"It's a good place," he says. "Being on my own is hard, but I'd rather die than go back to a nursing home."

Heroes of the Underground Railroad

The real heroes are those working in the CILs who devote their time and energy to liberating people from nursing homes and making the Supreme Court Olmstead decision's "living in the most integrated setting possible" a reality. Randy Alexander, Rick Famiglietti and Bill Bass all follow a similar game plan of doing outreach. Each guides their consumers with a general outline of the process, ranging from a two-page checklist to an eight-page guide to Connecticut's wire-bound 32-page transition guide.

Rick Famiglietti is one of a growing number of CIL workers who spring people from nursing homes.

Outreach is often a combination of fliers, in-services, referrals, word of mouth, hanging out at nursing homes and leaving bright yellow index cards with brief but valuable transition information.

"When we're working with someone in a nursing home, we try to talk really loud," MCIL's Alexander says with a smile. "That way other people can hear us. Sometimes the nursing facility social worker will give us a referral because they're looking to get rid of people with 'bad attitudes.'"

The process isn't always easy, and resistance from nursing home personnel looking to protect their revenue stream is fairly common. "It all depends on the facility's social worker," says Famiglietti. "Some are hostile, some are neutral and will let us provide information, and some are very helpful and supportive."

Once they find people, freedom fighters do a general self-assessment of the interested person. "We start by having people do a self-assessment," says Famiglietti, who works in West Haven, Conn. "Our intent is to get the individual involved and thinking right away about things like their support system, their resources, what kind of help with ADLs or monitoring of meds they'll need."

Following the assessment, basics must be in order — birth certificate, a picture ID, a Social Security card, landlord references, verification of disability, verification of income, a credit history, maybe a criminal background or clearing back utility bills. Not just clerical work, the entire process calls for CIL workers to do counseling all along the way.

"We have to help people get past their fear, help them let go of the safety net of the nursing home. Sometimes they need help understanding that living on their own won't be easy," offers Bill Bass of Denver's Disability Center for Independent Living. "Not everyone knows about how to set spending priorities, do shopping, cook, tend to personal recreation or even do personal hygiene."

Preparation

Preliminaries out of the way, the hard slog begins — finding housing (including applying for Section 8), securing food stamps, Medicaid, and other social services. It also often entails securing personal assistance services, learning about public transportation, looking into and initiating social recreation, such as church, friends, peer support, and independent living classes, if necessary.

Universally, housing is by far the biggest challenge. Denver often has as much as a five-year waiting list for subsidized housing. Most other areas in the country are no better. Reliable personal assistance is also a huge problem for people who pay out of pocket — and even more so for those who rely on Medicaid.

As actual transition approaches, people need to be sure they have everything they need — furniture, bed linen, kitchen stuff, medical supplies, utilities, etc. For those who have been in nursing homes for years and have had all these things taken care of for them, the level of responsibility can be daunting.

“We beg, borrow, steal, deal, do whatever it takes to get everything in place, often relying on donations from different organizations for cash and furniture,” Alexander says.

Follow-Up

All the workers closely monitor their people for several months following transition to ensure adjustment and to help with problems. Longer nursing home stays produce more problems. Some remember repeated cold showers and have trouble with hygiene; others struggle with money management, setting priorities or remembering to take medications; some can’t keep home health care or stay healthy.

“Most of the problems are similar to those that people have upon discharge from rehab,” Alexander says, “problems with health, transportation, recreation, finding and managing attendant care, isolation.”

“I can spend 10 to 15 hours a week checking on people those first couple of weeks,” Familgietti says, “and for at least six months total or until I’m confident they’re stable. It’s a hard process for some because nursing facilities can make people overly dependent.”

Other Heroes

Not all Underground Railroad Heroes work at CILs. Barry Rosenberg, like others who are committed to helping people transition from nursing homes to independence, often does more than his job description entails. His PASCO company has been integral to the Underground Railroad. He’s the real deal, in the business for years with home health agency clients who speak of him in hallowed terms. He’s worked with MCIL to transition about 10 people from Tennessee to Colorado.

“The consumer will call us, usually with someone from MCIL on the line with them,” he says. “MCIL does most of the coordinating from their end, but sometimes we’ll fly down to Memphis to explain the benefits process and talk about potential problems with moving here. We’ll apply for Medicare right away, as it often takes several months to get everything in place. Housing’s always a problem, so we’ll subsidize people until they get Section 8 and can usually work something out with a local pharmacy to cover meds until there’s coverage.”

Sometimes people have trouble adjusting. “Some don’t manage money well and have cable but no toilet paper,” says Rosenberg. “People lose some independence skills while in a nursing home, but we’ve only had one person go back to Tennessee. The rest are doing well here and are pretty happy.”