



HEALTH

Freeing Our People: Getting Young People out of Nursing Homes

June 1, 2013 Mark Boatman

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The institutionalization of people with disabilities in nursing homes has long existed, but over the past decade the number of younger residents has increased significantly. According to the Centers for Medicare and Medicaid Services, the number of nursing home residents under 65 rose 22 percent in the past eight years. George Gallego, a 47-year-old para from New York, is troubled by this trend. His organization, Wheels of Progress, has made it their mission to help liberate young people from New York City nursing homes.



George Gallego: committed to getting young people out of nursing homes.

More than two decades ago, Gallego, a circulation manager for a New York City newspaper, had a promising career ahead of him. That all changed when he fell three stories at a Manhattan warehouse and became a paraplegic. The accident plunged Gallego into a deep depression and he ballooned to 350 pounds. Intimacy left his marriage after the accident, he eventually got divorced, and he struggled with being out of work. No New York City newspapers would hire him, and the inability to provide for his three small children made it difficult to embrace life again. “How could I be expected to embrace anything when everything seemed to be going downhill?” he says.



His wake-up call came after he saw a picture of his overweight body. He vowed then to get a grip on his life and get back into shape. Exercising helped him shed the extra pounds, and it also helped relieve his severe nerve pain and muscle spasms. “It didn’t erase the pain, but it made it manageable,” he says.

Now the self-professed workaholic desperately wanted to return to work. He realized that he’d probably need to reinvent himself to find new opportunities. He enrolled at Mercy College, just outside of New York City, to begin his pursuit of a bachelor’s degree in organizational management, followed by a master’s degree in organizational leadership.

Now on the right track, he began wanting to give back in some way. He had gone through difficult times following his injury, not having anyone to encourage him in his recovery. He decided he wanted to help mentor others with new spinal cord injuries. “I didn’t think it was necessary for other people to go through the struggles that I went through,” he says.



hospitals and rehabilitation centers. “The more I was able to go from one institution to another, the more I realized how widespread the problem of institutionalization was,” Gallego says. He had no idea that the experience with his first mentee would lead him to found the non-profit Wheels of Progress.

### Birth of Activism

Jonathan Gonzalez was hanging out with friends on Dec. 30, 2006 when he was held hostage after a drug deal turned bad. Fearing for his life, the 20-year-old decided to boldly scramble for freedom, but during his escape he was shot — the bullet ricocheted off his shoulder blade and went into his neck. He was rushed to a Harlem hospital, but his C2-4 vertebrae were irreparably damaged.

Gonzalez spent five months at New York’s Mount Sinai Hospital for rehabilitation, and that’s where he met Gallego. He received much needed encouragement and the two became friends over many visits. Gallego was there when the hospital social worker came to discuss discharge plans with Gonzalez.



Jonathan Gonzalez and his son spent time together in a nursing home.

Few options existed because of Gonzalez’s extensive needs and his mother’s apartment being inaccessible. The social worker sold the nursing home as a wonderful environment with other young people and nurses to take care of Gonzalez’s needs, Gallego says. Going home that evening, Gallego felt OK because he thought his new friend would be well cared for. He would soon realize how wrong he was.

On a spring day in 2007, an optimistic Gonzalez entered the Beth Abraham nursing home in the Bronx. “When you first get to the nursing home, it’s all great. There are many new people and it seemed like everything was going to be all right,” he says.

When Gallego visited his friend in the nursing home, the experience proved to be life changing. Rolling through the geriatric facility, Gallego was stunned by what he saw. Several residents were yelling for the attention of the nurses and aides, and the air was filled with the odor of urine and feces. In Gonzalez’s room a man in the next bed appeared to be on death’s door. “He had a bowel movement right in the bed and nobody was taking care of him,” Gallego says.

He spent several hours with Gonzalez on that first visit, and when he left he had tears streaming down his face. “That’s when I vowed that I’ll do whatever I can to come up with an alternate solution to warehousing young folks,” he says. The idea for Wheels of Progress was born.

### The Long Road to Progress

Gonzalez settled into life at Beth Abraham, but being trapped in an institution that wasn’t created to meet the needs of younger residents depressed him greatly. The bland, pre-cooked food didn’t help his mood, either. “The food was disgusting,” Gonzalez says. “I hated it.” He was given somewhat more appealing menu alternatives, but only after he fought for them.

The quality of care promised by the social worker was non-existent because the nursing home staff was stretched thin. “They really have no time to sit and really take their time with their care,” Gonzalez says. He would often wait hours to get changed or get needed assistance.

While in Mount Sinai, Gonzalez had developed a pressure sore. It healed in the hospital but reopened after he went to the nursing home and wouldn’t heal. He had to remain on his side for long periods. He eventually saw a specialist at Mount Sinai and found out the sore was infected. After a week back in the hospital, he returned to the nursing home with medications, but they wouldn’t refill them. Gonzalez surmises it was because they were too expensive. He doesn’t understand why the nursing home would risk his health. “Would they rather I almost die of infection or actually treat the wound and get it over with?” The sore finally healed after a couple of years.

Gonzalez persisted and Gallego kept supporting his young friend as he initially pushed for his freedom. It wasn’t easy, but a ray of hope emerged when Gallego helped his family find an accessible three-bedroom apartment. This would help solve the housing problem, but not the need for considerable caregiving. Gonzalez applied for care



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out.”

As Gallego got more involved with mentoring, he became a familiar face in area medical facilities and institutions. Soon agencies began calling him to see if he could place their at-risk clients in accessible housing. He was totally flabbergasted. “Are you kidding me? Here’s a housing agency calling a guy that doesn’t even own property or housing for people with disabilities,” says Gallego. “And they’re asking me if I can place them?”

Gallego began thinking about what model would work best for liberating people with disabilities. He decided to try to partner with developers, building managers and property owners to see if they would be willing to set aside vacant accessible units for people who were transitioning back into the community.

But housing was only half of the equation. Appropriate services and supports were also needed. Then in 2008, New York State implemented the Nursing Home Transition and Diversion Medicaid waiver, which provided assistance for those wanting to reintegrate back into the community or for those at risk of institutionalization.

The waiver provides numerous services, such as rental assistance, counseling, independent living skills, moving assistance and peer mentoring. The waiver also provides funds for housing modifications, assistive technology and basic home furnishings.

In 2009 the pieces of the puzzle started coming together for Gallego, and he officially began Wheels of Progress with a mission of providing transformative environments for people with disabilities in institutions or those who may be headed to one. In 2011, his new organization got a major shot in the arm when the Craig H. Nielsen Foundation donated \$100,000 to help transition 10 people back into the community. Gallego hopes to eventually secure a dependable funding stream, but in the meantime he’s using one of his passions to draw attention to his organization.

Gallego is a professional triathlete and a former member of the U.S. triathlon team. These competitions of endurance used to feed his need for adrenaline, but now they have become a platform to raise funding and awareness for his organization. He says it his goal in each race to raise enough money to liberate one person from a nursing home.



In the beginning, Wheels of Progress contacted other agencies to play a role in coordinating transition services, but most agencies weren’t capable of handling the needs of those with significant mobility impairments. Several agencies denied clients because their cases were too complex. It wasn’t long until Wheels of Progress decided to become a waiver provider.

Becoming a provider wasn’t easy — taking over a year to go through the entire process. Now the organization has easier access to valuable resources, but Gallego says he’s frustrated that many people in institutions and property owners don’t know the waiver exists. It’s now his mission to make sure this changes.

### Free at Last

While progress continued at a snail’s pace, Gonzalez refused to give up. Beth Abraham wasn’t supportive of his quest for freedom, and he says this is most likely because of the handsome monthly fee they were getting for his care.

Gallego, who had connections at Independence Care System, contacted them about services for Gonzalez. The agency sent out a nurse and social worker to assess his needs. He was told he qualified for 24/7 care. Getting to this stage required a voluminous amount of paperwork and phone calls.

It took nearly four years of struggle, but on Nov. 4, 2011, a triumphant Gonzalez left Beth Abraham nursing home to move into an apartment in uptown Manhattan with his mom and two young siblings. “It was like heaven,” he says. “Like getting 20 years in jail and finally getting out.”

The world of the geriatric institution can’t come close to life on the outside. Today Gonzalez says he feels more peaceful at home because he’s free to do as he pleases. He no longer has to wait a long time for help, ask for permission to leave the institution or follow numerous rules and regulations.



Wheels of Progress because of all the support they've given him.

Gonzalez wakes up with a smile more often these days. He could be bitter about his four-year nursing home incarceration, but instead he chooses to remain optimistic. "Being in a nursing home is not the best experience, but it's a learning one, and it makes it way better when you come home."

### Others Freed From Nursing Homes

Since Gallego began Wheels of Progress, he has helped free nearly 20 people from institutions. These liberations have been deeply rewarding, but he says he can't take sole credit. He has collaborated with Wheeling Forward CEO Alex Elegudin and has worked hand-in-hand with him to free people. Gallego's persistence paid off with getting Gonzalez out of Beth Abraham nursing home and back into the community, but it is also evident in the stories of others that Wheels of Progress has freed.

Jermaine Fairweather was in his early 20s when he became a C4-5 quadriplegic. He went to a nursing home after his family couldn't provide care for him and grew depressed. He felt it was like a modern-day prison for people in wheelchairs and wanted out. So he visited a social worker, but he says she wasn't interested in helping him.

Gallego got involved and helped Fairweather navigate the system and find supports through the nursing home transition waiver. After nearly four years, Fairweather was freed. "It was very liberating when I walked out that door," he says. "I'm never coming back here." It took a few days to adjust, but now he's making up for lost time.

Fairweather is seeking a degree in business administration and hopes someday to open his own business.



Jermaine Fairweather

John Ramirez, a C4-5 quad, resided at the Franklin nursing home for over one year because he didn't want to burden his family after he was shot in 2004. Overwhelmed by institutional life, he says the food was awful and there wasn't any continuity of caregivers. He learned to be assertive early on. "If you're not on top of these people, they don't go out of their way for you," he says. "If you let them do whatever they want, they will do whatever they want."

Gallego helped Ramirez find a new home. "He helped me find a place that we were able to purchase and I was able to remodel," Ramirez says. It took a year to arrange his moving into his Queens apartment. It was scary to move out, but Ramirez says he has been blessed to find good attendants and have strong family support. He also says Gallego has been amazing and supportive and is a friend he can count on.

Being in a nursing home is the worst thing Terrell Ellis has ever experienced. He was shot point-blank in the neck on December 20, 2007 and spent the next three years being bounced around nursing homes. Ellis says he had little freedom in the institution and the care was bad. He says aides would hide or ignore his needs. "I could be lying in feces and have a urine accident and the call bell was on for an hour and a half," he says.

Ellis had no clue about community options until he met Gallego, who helped him secure caregiving supports and a one-bedroom apartment in Flushing, N.Y. Getting out of the nursing home was like completing a long prison sentence for Ellis.

He says has a good life now, but he's deeply thankful for Gallego. "If it wasn't for me meeting George and him getting me into this program, I feel like ultimately I would have died."

### We Must Do It Ourselves

The biggest barrier to freedom, says Gallego, is paperwork. "It's a labyrinth and somebody can easily get lost," he says. A typical client needs several hours of assistance just to complete the initial 26-page service plan, and filling out paperwork is only the beginning. Next it must be submitted and followed-up on because if it isn't reviewed before a strict deadline, the process starts over.

been marginalized and forced to remain silent,” he says. Seeing the faces every day of young people desperate to get out of a nursing home is enough to keep him pushing ahead.

Last March Gallego was given the prestigious Paul G. Hearne Leadership Award for his work with Wheels of Progress. The award humbled him. “I have to say that was an amazing experience and an amazing honor,” he says. Having his work recognized by the American Association for People with Disabilities not only gave him a renewed burst of energy, but he says it will allow him to take his organization to the next level.

Gallego has come a long way with Wheels of Progress, but he has ambitious plans for the future. His dream is to build a building so he can transition people in greater numbers. He’s adamant that he doesn’t want it to become another institution. The building will implement universal design and have apartments for both nondisabled people and those with disabilities.

When he began addressing the institutionalization of young people, he thought the issue was just about housing, but he learned it was much more than that. “I see us collaborating with major organizations in order to be able to continue to provide not only housing but transformative environments for people, not just in New York, but throughout the country,” he says.

Gallego’s efforts to help young people escape the confines of the nursing home have given him the purpose he was looking for after his spinal cord injury. He has made this cause his life’s work, but says he can’t do it without the heavy involvement of others with disabilities. “I think it’s important for people within our community to realize that no one else can make a difference for us,” he says. “We really have to step up to the plate and make a difference for ourselves and other folks in our community.”

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George Gallego. I'll remember this name. You are making a difference in this life... helping young people get out of these poorly-run nursing homes. Kudos!

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