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SPRING 2020



Fulfilling the dream of family 26

For people with MS, adoption can be the answer.

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At home with **MS**

Affordable, accessible apartments designed just for people with MS make life easier for them.

by Matt Alderton



Harmon Apartments in Boston is a supportive, independent community of 36 accessible, affordable apartments.

PHOTOS COURTESY OF HARMON APARTMENTS



Accessible apartments often have community rooms where support groups are offered.

The year was 2006 and Susan Stellmacher was loving life. Although she'd had a rough go of things a few years before — she'd divorced, lost her job and was having multiple sclerosis flare-ups again after years of remission — things were finally looking up. In good health once more, the 51-year-old Minnesotan had moved back to her home state from Maryland, had a job she loved recruiting donors for a local blood bank, drove a zippy Chrysler PT Cruiser and lived independently in a beautiful apartment with a wood-burning fireplace that she adored.

Then came an MS relapse so bad that it literally knocked her down.

“I awakened one morning, and it felt like somebody had stabbed my left eye with a knife,” recalls Stellmacher, now 65. “When I went to stand up and get out of bed, I fell on the floor. After that, I eventually ended up in a wheelchair.”

After her physical fall came an existential one: Because she could no longer drive or work, Stellmacher had to give up her car, her job and, ultimately, her apartment, which because of her new permanent



For many people with MS, supportive housing is appealing for the sense of community it fosters.

disability was no longer affordable or practical.

“When I got sick, I couldn't afford the rent anymore,” Stellmacher says. “Plus, it wasn't a safe environment for me at all. My bathroom, for example, had a combination shower/bathtub, so you had to step over the tub to get into the shower. There were no grab bars. So if you lost your balance, guess what?”

Although she still recalls with sadness everything she lost back then, Stellmacher also beams with joy at what she gained soon thereafter: a new two-bedroom apartment at Kingsley Commons, one of the nation's first apartment buildings designed to provide independent living exclusively for people with MS. Located in Minneapolis, it offers 25 accessible, affordable apartments with wheelchair-friendly features like roll-under countertops, roll-in showers with folding seats and safety bars, wide doors and low cabinets, just to name a few.

“It has served me well and will always continue to do so — whether I'm walking or not,” says Stellmacher, who moved into Kingsley Commons when it opened in 2007 and has recently begun walking again after years

of using a wheelchair.

For people such as Stellmacher, communities like Kingsley Commons are unicorns: as magical as they are rare. As their numbers slowly grow, however, they're proving that people with MS can live as independently as they can happily. All they need is a safe place to do it.

Building independence

Kingsley Commons was developed jointly by nonprofit housing developer CommonBond Communities and local partner the Powderhorn Community Council, who teamed up to build the \$2.9 million project using a combination of public and private funds.

Although not everyone celebrated it — critics decried Kingsley Commons for segregating people with disabilities and said developers should build blended residences instead—many people who got wind of the concept loved it. Among them: Ken Regan, vice president of Regan Development Corp., an Ardsley, New York-based developer of affordable housing. After being diagnosed with MS himself in 2003, he began researching the MS community and discovered what he believed was a major housing gap.

“There are a lot of people out there who have physical and cognitive disabilities that arise out of their MS, but they're not so disabled that they need to be in a nursing home,” Regan says. “I had the idea to create specialized housing for those people to enable them to thrive in a more independent setting.”

Regan visited Kingsley Commons for inspiration and research, and subsequently has built six communities in New Jersey and Connecticut that are reserved either

wholly or in part for people with MS.

Regan's first MS-focused development was Kershaw Commons in Freehold, New Jersey, which opened in 2011 and has 30 fully accessible one- and two-bedroom apartments designed and built for people with MS.

“We took the state's existing affordable housing development funds and secured private investment on top of that to create what in effect is a community of



Kershaw Commons in New Jersey has 30 fully accessible one- and two-bedroom apartments that were designed for people with MS.

PHOTO COURTESY OF KERSHAW COMMONS

people where almost everyone is living with disabilities that at varying degrees are a result of MS,” Regan explains. “In some cases we have older people who were previously in a nursing home because there really were no alternatives to that for them, and in other cases we have young people in their 20s and 30s who thought they were going to have to live in an institutional setting for the rest of their lives but now have a place where they can live independently.”

5 ways to make your home more accessible

People living with MS can make their homes safer, more comfortable and easier to navigate with a few simple changes.

Remove area rugs - Rugs can be a tripping hazard for everyone, so avoid them in high traffic areas or use carpet tape to secure them to hard floors.

Install a raised toilet - Toilet safety frames are available at most home improvement stores and offer a low-cost way to increase bathroom safety.

Pick the right appliances - Consider a front control range, side-by-side refrigerator and front-loading washers and dryers to make household chores easier.

Take a seat - Adding a chair to the area where you get ready can help you combat fatigue and balance challenges.

Rethink your doorknobs - Lever style doorknobs and keypad locks are a good solution for people with dexterity challenges.

Keeping people with MS out of institutions benefits the social safety net as much as it does individuals, according to Fran Murphy, chief financial officer at The Boston Home, a skilled nursing facility in Boston that specializes in residential care for people with MS. In May 2019, The Boston Home opened Harmon Apartments, a supportive, independent community of 36 accessible, affordable apartments for people with disabilities — including people with MS, who occupy about 15 of the apartments.

“Nursing-home care is not adequately funded by the government. It’s a very difficult cost structure, so we began looking for ways to facilitate a lower-cost housing model that’s supportive of people with progressive diseases and mobility impairments,” Murphy says. “We looked at the work that was being done by others, including Kingsley Commons and Regan Development, and decided that their model made a lot of sense. If you can build homes that are flexible enough to continue supporting people with progressive diseases as they decline, they can stay in those homes longer.”

But accessible housing developments don’t just keep people with MS out of institutions. They also keep them out of homes in which they’re uncomfortable, unsafe and isolated.

“In many cases you’re taking people from a negative housing situation — they might live in a second-floor walk-up, for instance, where they can’t get in and out easily — and you’re giving them an opportunity to thrive,” Regan says. “That’s life-changing.”

Home sweet home

To comprehend just how life-changing supportive housing can be for people with MS, one need only look at the apartments themselves, which often exceed Americans with Disabilities Act (ADA) standards.

At Kershaw Commons and other Regan properties, for example, residents have: automatic door openers for the building and each apartment entry door; 42-inch doors that are wide enough for wheelchairs; hardwood and ceramic tile floors instead of carpeting for easy mobility; custom horizontal sliding windows that are easy to open from a seated position; linen closets



J.R. Hardenburgh lives at the Harmon Apartments with his companion dog, Gilly.

PHOTO COURTESY OF J.R. HARDENBURGH

“

The best part about living at Ojakian Commons is we all ‘get’ each other.”

—DIANE E. KEENEY

with slide-out cantilever shelving trays; accessible light and thermostat controls; bathrooms with roll-in showers, accessible mirrors and grab bars; kitchens with accessible cabinets that have roll-under access and slide-out cantilever shelving trays, front-control cooking ranges, side-by-side accessible refrigerators and countertop microwaves; and common areas with wide hallways, railings and automatic entry doors. There even are trash chutes with automatic openers so residents won't have difficulty pulling open doors to empty their garbage.

At Harmon Apartments, technology is set to play a major role. Apartments already feature secure keyless entry, for example — residents open their doors by swiping an RFID card and pushing a button — and eventually will be equipped with a smart home system that allows residents to control lighting, temperature and window shades from their mobile device.

What sound like amenities are so much more than that. At Kingsley Commons, for example, Stellmacher raves about her accessible bathroom. “There’s a nice pull-down seated bench in the shower with extra-long shower attachments,” she says. “I did not have that at my previous apartment at a time when I really needed it, which caused me to fall and so severely sprain my right ankle that I had to be in a boot cast for eight weeks.”

Falls also are a concern for J.R. Hardenburgh, a 64-year-old resident at Harmon Apartments. “My MS has progressed to the point where balance, gait and fatigue affect me every minute of every day,” says Hardenburgh, who five years ago began using a scooter to avoid falls. At that time, the father of three grown children decided to sell his longtime home — which



PHOTO COURTESY OF DIANE E. KEENEY

Diane E. Keeney, a resident of Ojakian Commons, enjoys gardening and socializing within her community.

had stairs in it — and move into a handicap-accessible apartment with his wife. When they subsequently divorced, he spent a year living with a friend, then couch surfed for two months before finally moving into a brand-new, fully accessible apartment at Harmon with his companion dog, Gilly.

“It’s got everything you could possibly want in an apartment as a handicapped person,” Hardenburgh says of his one-bedroom home, which he calls “nirvana.” “I’m never leaving.”

Creating community

For many residents, supportive housing is appealing not only because of the activities they can enjoy inside

their apartment, but also because of those they can enjoy outside of it.

Take Kershaw Commons. For residents there, it provides educational programming, a self-help group and yoga classes, including chair yoga for people who use wheelchairs or scooters.

Similar programs exist at Kingsley Commons and Harmon Apartments. The former offers adaptive yoga classes, adaptive boxing, a monthly MS support group and a large community room while the latter enjoys proximity to The Boston Home, where there's a Wheelchair Enhancement Center that provides customized enhancements to wheelchairs to make them more comfortable and functional. Both communities also have onsite social workers to help residents coordinate social services.

"Everyone here has a neurological disease. Some are far worse off than I am, some are a little bit better off, but we're all in the same boat," Hardenburgh says. "It's nice being surrounded by people who understand the challenges you face on a daily basis."

The community health benefits are what attracted resident Andrea Novak to Kershaw Commons when

she moved there in 2011.

"I saw an ad for Kershaw Commons, and I wanted the programs, support group, exercise classes, not to mention having an MS Center in my backyard," Novak says. "In short, I wanted to learn how to live well with MS."

And she is. "I didn't know much about MS [when I was diagnosed]," Novak continues. "Meeting people here and sharing our experiences with MS has been helpful."

Diane E. Keeney can relate. A resident of Ojakian Commons — a Regan development in Simsbury, Connecticut, that has 48 apartments, 40 of which are reserved for people with disabilities — she finds solace in her neighbors. "The best part about living at Ojakian Commons is we all 'get' each other," Keeney says. "Everyone has their own symptoms, as well as good days and bad days, but for the most part, we can relate and empathize with one another on what we are going through."

A new 'lease' on life

The people who live in communities like Ojakian Commons say social support is crucial to their well-being. But so-called "supportive housing" is only truly supportive if it's also affordable, Regan argues. "The key with this kind of housing is to make sure that we provide not only the accessibility features that people need, but also the financial structure that makes them economically secure," he says. "Especially with MS, situations change. If you move into a community and you're working, then your disability status changes and you can't work anymore, you shouldn't have to worry that you won't have enough money to pay your rent."

Although each has its own financial structure, most supportive housing communities for people with MS accept housing choice vouchers from low-income tenants. In some cases, tenants obtain from local public housing agencies their own vouchers that allow them to choose their own housing. In other cases, public housing agencies grant project-based vouchers that are attached to individual communities. In both cases, tenants typically pay 30% of their monthly income toward rent; the government-funded vouchers



PHOTO BY ROBERT BENSON PHOTOGRAPHY

Residents of Harmon Apartments have access to a Wheelchair Enhancement Center that provides customized improvements to wheelchairs to make them more comfortable and functional. (Pictured, from left: Tara Mizrahi, vice president of Affirmative Investments; David Ennis, president of Affirmative Investments; and residents Theresa Norwood Hart and Loretta Martin.

cover the balance of their rent.

At both Kershaw Commons and Ojakian Commons, Regan Development Corp. obtained project-based vouchers for each of its apartments. The same is true at Kingsley Commons, where residents have an average annual income of \$18,800. For Harmon Apartments, on the other hand, The Boston Home only received project-based vouchers for roughly a quarter of its apartments and rents the remaining affordable apartments out at a discount but accepts housing choice vouchers from tenants who have them.

For residents like Stellmacher, the assistance she receives is a lifeline. “Without it, there wouldn’t be a place for me to live,” she says. “I would be homeless.”

No place like home

If you ask the people who build, manage and live in them, supportive housing communities have only one major flaw: There aren’t enough of them.

“[The National MS Society] gets a lot of calls from community members, and one of the biggest reasons they call is that they’re looking for affordable, accessible housing,” says Erin Poznanski, vice president of the Society’s MS Navigator Services. “Those two words together — affordable and accessible — are really, really hard to come by.”

According to the Society, there are currently about 15 listings in Connecticut, Kansas, Massachusetts, Minnesota, New Jersey, Ohio and Pennsylvania. Of course, low supply means high demand. As a result, communities often have long wait lists. Residents who get an apartment typically rely on a mix of luck and need. When she applied for residency at Kingsley Commons, for example, Stellmacher says apartments were awarded on a first-come, first-served basis. Novak says the same was true for her at Kershaw Commons. For Harmon Apartments, on the other hand, The Boston Home held a lottery; applicants with disabilities were given priority and moved to the top of the list

along with Boston residents, and those who were chosen had to complete an interview and supply a doctor’s note attesting to their physical needs.

Newer communities like Harmon Apartments are a sign that Regan’s vision is alive and well. “It’s been a thrilling experience talking to residents who live at

Harmon Apartments and seeing how their lives have changed because of it,” says Marva Serotkin, former CEO of The Boston Home. “When people need accessible space and don’t have it, their lives are defined by inaccessibility. But now the windows are open and the doors are open, and they can come and go as they please. It just gives people a lot more options in their lives.” ■

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—J.R. HARDENBURGH

Matt Alderton is a Chicago-based writer and editor.



For information on accessible housing, contact an MS Navigator by calling 1-800-344-4867, emailing ContactUsNMSS@nmss.org, or online at nationalMSSociety.org/navigator.

Check out the National Multiple Sclerosis Society’s Guide to Accessible Housing at ntlms.org/AccessibleHousing or contact an MS Navigator at 1-800-344-4867 or email contactusnmss@nmss.org to receive a copy.

For additional information about locating accessible housing and legal issues related to accessible housing, visit nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Documents/Housing-Challenges.pdf.

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