Surge in aging disability population unlocks the door to innovative housing

Editor's note: This article highlights a service provider's leadership in finding solutions to a growing community issue.

The current generation of aging caregivers never imagined that their children with a developmental disability would outlive them -- but many are, thanks to advances in medical technology. Today, close to 3 million adults with intellectual and physical disabilities live with caregivers who are over age 55, and that number is expected to double by 2030. One study found that close to 90 percent of adults with disabilities live at home with aging parents.

Organizations are opening their doors to serve this aging population. Today, Marc Center of Mesa, Inc. serves more than 200 persons with developmental, physical, and mental disabilities who are over the age of 60; in 1975, the organization served only one person over the age of 50.

Behind these statistics are human faces -- faces reflecting the many challenges that confront adults with developmental disabilities and their aging caregivers. As parents become increasingly frail and immobile, they not only require more help for themselves, they also need more support for their adult children who cannot care for themselves. Yet family and social networks often collapse or become inactive as all family members grow older.

Kenny is a 52-year-old who needs assistance to make a sandwich, bathe, shave, or dress. His mother had cared for him since he was born. To provide respite for his mother, Marc Center had provided day services for Kenny for more than eighteen years.

Eventually, day services and his mother’s care were not enough to
sustain Kenny. As dementia and fragility overtook Kenny's mother, she was unable to clean, cook, launder, or be sure Kenny took his medication. With deteriorating sanitation in the home and no heating or air conditioning, Kenny's health was at risk. The state's Division of Developmental Disabilities was forced to remove Kenny from his mother's home and find a placement for him.

Initially, the closest available placement for Kenny was a group home 50 miles away. However, Kenny's mother was no longer able to drive, and the group home was rarely able to transport Kenny to see his mother.

An alternative solution was sought. Marc Center made room for Kenny in one of its group homes five miles from his mother's home. The organization also helped his mother apply to live in a nearby assisted living care facility.

Kenny's story and hundreds like his are prompting organizations to find creative housing solutions.

Marc Center proposed building The Village at Oasis Park as a HUD project designed to keep families like Kenny's intact. The project will allow senior, caregiving parents to live on the same campus alongside their adult children with disabilities. In addition to in-home care, the project's community center will provide a day program for both aging parents and adult children who need it.

Securing outside funding for The Village was the easy part. However, convincing HUD to allow this innovative project to move forward took Marc Center three years. Despite hurdles, this HUD project submission scored among the highest in the country because of the project's effectiveness, sustainability, efficiency, and long-term cost savings. Several HUD policies needed to be modified during the project's development:

- For years, HUD prohibited elderly persons in public housing to live within one mile of other HUD projects, no matter the population served. HUD believed that housing for both elderly persons and individuals with disabilities in the same location would create disability ghettos and devalue surrounding properties.

  Marc Center successfully argued that older persons and their
adult children with disabilities should not be separated, and they can thrive if they live side by side and receive the right kinds of support.

- HUD requires developers to maintain a modest design -- that is, construction with no-frills materials, such as laminated plastic countertops, indoor/outdoor carpets, pressboard kitchen cabinets, plastic faucets, and standard toilets that only last a few years.

In contrast, The Village will use countertop materials, such as granite or Corian®, which will not be damaged by a knife blade or hot pot. The project’s polished stone and glass walkways, well-constructed cabinetry, and higher grade fixtures will last for a long time.

Accommodations for populations that are aging and disabled will be built into The Village. Individuals with dexterity issues can easily manipulate the touch faucets. Kitchens will include features for persons with visual impairments. Flooring with zero-clearance thresholds can be easily maneuvered by persons using wheelchairs and will withstand heavy traffic. Countertops will be within reach of a person using a wheelchair.

Although these construction materials are more costly, Marc Center was able to demonstrate to HUD that their durability made them more economical in the long run than frequent repairs and replacements of less permanent materials.

- HUD typically approves a block-like, institutional appearance to represent the agency's bare-bones taxpayer underwriting.

In contrast, The Village will be aesthetically pleasing, indoors and out, and a place people will be proud to call home. The design features tree-lined walking paths, benches, and eye-pleasing (yet conservation-minded) desert landscaping, and the architecture blends well with the neighborhood. To enable an attractive exterior design, which HUD would not underwrite, Marc Center enlisted landscape design help from students at the nearby Arizona State University in Tempe.

The Village's supported living arrangement will enhance residents’ ability to live as independently as possible. The Marc Center’s most recent CARF survey report noted this exemplary: "Marc Center has attained a high level of integrity and continuity of services while balancing the expectations of the persons served and other stakeholders. The leadership is progressive in planning for the future needs of the persons served as exemplified by the development of various types of community living options and the health and wellness
program."

"The Village at Oasis Park campus answers the question of how people can live and play together and build a community," said Kay Moore, Marc Center’s chief operating officer. "This project was founded on a belief that persons with disabilities and their parents/caregivers can live independently on the same campus."

Phase 1 of The Village at Oasis Park, serving 28 residents, is scheduled to open in late summer 2012. When additional phases are completed, the campus will house 68 adults with disabilities and their aging caregivers.

Kenny and his mother are on the waiting list for housing at The Village so that they can again live close to each other.

For more information, please write Kay Moore, chief operating officer of Marc Center of Mesa, Inc., Kay.Moore@marccenter.com, or visit the organization’s website at www.marccenter.com. The organization provides educational, therapeutic, rehabilitation, counseling, and social services to persons with disabilities who live in Arizona.

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