



Getting Creative: Models for Filling the Housing Gap

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Previous installments of this three-part series have examined the [scope and causes of the housing crisis](#) faced by people with disabilities, as well as [government programs designed to address it](#). This final article explores models being used by nonprofits, families and private industry-often with the help of government subsidies-to develop residential options.

In California alone, approximately 175,000 people with developmental disabilities live with family members, many of whom are aging. When their caregivers pass away, where will they live?

Mary Eble, executive director of the North Bay Housing Coalition, is committed to finding accessible and affordable answers for them. One of the programs that she administers uses state and federal grants to purchase and renovate property to be used as homes for individuals with special needs. A [video on her agency’s website](#) describes one such project, which enabled a young man who lived at Sonoma Developmental Center to move into an attractive townhouse near his family, who had been relocated due to Hurricane Katrina.

Many nonprofits throughout the nation undertake similar initiatives, refurbishing apartments or single family homes and often providing wraparound support services. They sometimes partner with private developers, helping them obtain government funding and advising them on accessible design. Such arrangements may include “set-asides,” agreements that developers will make a specified number of units within a large complex available for the exclusive use of individuals with disabilities.

But waiting lists for such housing can be “years long” and, as a result, frustrated families have begun developing alternatives.

The Mission Project

In 2004, three families launched a nonprofit known as The Mission Project, a program through which individuals with developmental disabilities are supported in apartments spread throughout the community of Mission, Kansas.

The vision of The Mission Project is “to establish and maintain support structures for persons with developmental disabilities to enable them to live independently in a safe environment with the opportunity to engage in meaningful work, social interaction with

peers, educational opportunities, physical activities, training and recreation.” The goal is to foster and promote independence and self-governance of the participants, with the oversight of parents and guardians to provide assistance and direction when needed. Think of it as a parent group, dedicated to providing a safe environment where their children can live independently, with support, and providing educational opportunities, fitness activities, and an active and varied social life.

A steering committee of parents and guardians works with a board of directors to organize multiple activities to support participants’ growing independence and active involvement in community activities. Case management, job coaching, group problem solving meetings and a 24-hour support line staffed by parents all help the participants accomplish their goals and live as independently as possible. Plenty of social activities are planned and the participants are encouraged, but not required, to attend. A van service provides transportation to jobs. The program does not serve individuals requiring 24-hour support; the participants must be able to function moderately autonomously. Participants are responsible for their own rent, food, and independent living and job supports, paid for with SSI/SSD, Medicaid waiver funds, special needs trusts, job earnings and family resources. Fundraising events, grants and private donations cover the organization’s operating expenses.

The success of The Mission Project is building. There are now two independent Mission Projects in operation. The original program has 18 participants, and a second group of 9 participants is located nearby. Plans are to establish additional groups based on the same model and with help from the parent organization. More information on The Mission Project can be found at their website, www.themissionproject.org.

Camphill

[Camphill](#), comprised of 100 locations in 22 countries, has a very different model. Communities consist of up to 20 households, generally consisting of two to 12 persons each. In a few cases, individuals live alone, by choice.

Camphill stresses “mutual exchange,” through which everyone in the community shares responsibility for its upkeep. Many of the communities maintain gardens and orchards, and raise farm animals for food. Staff members and their families live alongside individuals with disabilities, and while medical, therapeutic, educational and employment coaching services are available, the program’s website claims that communities don’t view themselves as “service providers with clients.” There are no fees to residents, with all expenses covered by government programs, state contracts and private philanthropy.

Sweetwater Spectrum

In 2007, families banded with professionals and community leaders to establish a first-of-its kind residential community in Sonoma, California, for adults with autism. The three-acre property accommodates four homes, a community center, therapy pool, greenhouse and garden. Every house has four residents, each with a separate bedroom and bathroom. Serving the full range of spectrum disorders, it's designed to meet needs that are largely unaddressed by other residential options: sensory issues and social isolation.

"Our architectural design has been described as creating a serene environment," explains Carolyn Klebanoff, one of the founders and mother of a resident. In addition to overall accessibility, much attention has been paid to acoustics and privacy. "In each home, as well as the community building, there are spaces so that an individual can observe the rest of the group without necessarily being in their midst. Each bedroom unit is configured so that you can't hear what's going on next door."

Klebanoff explains that, given deficits in social skills, special attention must be taken to prevent individuals with autism from becoming isolated—even when living with others. Community activities include working in Sweetwater's organic gardens and a wide range of classes.

Residents are actively encouraged to develop relationships with their housemates, campus neighbors and others within Sonoma at large. "People aren't 'assigned' to Sweetwater," she observes, "they choose the other members of their household. Sweetwater provides an environment where they can develop true, reciprocal friends," she claims. "In an ideal world, that should be possible anywhere, but especially for individuals with severe autism, that's often not the case."

Rent is affordable, based on Social Security standards, and subsidies are available for the community fee. Residents are individually responsible for any independent living services they require. At present, private philanthropy covers all capital costs, although Sweetwater hopes eventually to receive grants from the government and large foundations.

"Replicating this pilot is a frequent topic of conversation," says Klebanoff. "The house/campus/town model works and could certainly be implemented for people with a wide range of disabilities. The key is choice. Right now, there are too few options."

Legacy Homes

Eble's North Bay Housing Coalition is also working with people who want to enable a person with disabilities to remain in the family home once parents have passed away by donating it to a nonprofit. "The key point," she says, "is to begin the conversation about the future before a crisis hits the family." She advises involving adult children in such decision-making to ensure that they prefer such an arrangement. Pointing out that an individual may

wish to move elsewhere at some future time, she and her colleagues are working to develop a network whereby individuals can choose to move anywhere in California.

She emphasizes that she doesn't automatically accept any house that's on offer. "I develop a 30-year preservation plan to determine feasibility," she explains. "Is there a mortgage involved? Will it need a new roof? It's essential that we have the means to maintain the property."

Purchase through a Special Needs Trust

When there are considerable funds being held by a third party or estate planning special needs trust (SNT), some families opt for buying a home for their loved one. It is generally best that the home is owned by the third party SNT for a number of reasons. First, if the home is owned by the beneficiary, upon the individual's death, the home may be subject to a Medicaid lien for any Medicaid the beneficiary has used after the age of 55. If the home is owned by the third party SNT, there is no lien. Secondly, if the home is owned by the trust and must, for some reason, be sold, the funds will go back to the trust to continue to provide support for the beneficiary without interruption of the beneficiary's benefits. Lastly, if the home is held in the third party SNT, the home will not be subject to the beneficiary's creditors.

If the family is considering purchasing a home within a third party special needs trust, it is recommended that they discuss with their SNT attorney how the proposed purchase may affect the beneficiary's benefit eligibility. For instance, if the beneficiary is receiving SSI (Supplemental Security Income) and the home has a mortgage, the mortgage payments will be counted as income, reducing SSI, dollar for dollar, for the amount of the mortgage payment, capped at \$260.34 in 2014. For families considering this option, this slight reduction in SSI payments is an acceptable sacrifice balanced against the benefit of having their loved ones living in a solid residence. If, on the other hand, the beneficiary is receiving SSDI or childhood disability benefits, payment of the mortgage does not interfere with their benefits.

If bought using a first party SNT (established using the beneficiary's own funds, often from an inheritance or personal injury settlement) and held within the trust, upon the individual's death, the property will be subject to claims by Medicaid for reimbursement of services during the beneficiary's lifetime. Some states allow the home to be held outside of the trust, which can lessen the lien to Medicaid usage after the age of 55. Once again, it is highly recommended that families consult an attorney about specific rules in their state before the home is purchased.

In addition, maintenance costs can drain an SNT, so this is a decision that should be considered with care. For more detail, see “[Buying a House for a Special Needs Beneficiary: Proceed with Care!](#)” and “Special Needs Trusts and Home Ownership: A Trustee’s Concerns.”

Differing Opinions

Although creative approaches are being tested throughout the country, reproducing them in sufficient numbers poses a serious challenge, and opinions diverge concerning the type of housing that best serves the needs of people with disabilities. How large should a household be? In California, it’s difficult to get funding for projects in which more than six individuals with special needs live together.

North Bay Housing Coalition values the separation of housing from services. “Without that division,” Eble explains, “a person who’s dissatisfied with their support services can’t make a change without moving. Given the housing shortage, they’re essentially locked in.”

And how do you define “inclusion”? In addressing charges that Sweetwater is another form of “congregate, institutional living,” Klebanoff points out that residents are very involved with the surrounding town, working, attending classes or participating in local activities on a daily basis.

Some advocates passionately believe that certain models are “best” or to be avoided “at all costs.” Their positions, fueled by genuine concerns for quality of life, reverberate with the outrage that finally closed some of the nation’s most egregious institutions.

But the debate continues, further complicating the task of professional and family developers alike in developing solutions to this critical problem. Success will depend on developing more choices designed to meet the individual needs of a very diverse population.

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