



Families are the Key to Innovative Housing Solutions

By Thomas Reinke

Families and individuals

with developmental disabilities are leading the way in establishing innovative housing options. They are creating homes with supportive services more tailored to specific individual needs. They are developing homes with physical environments that feel more like home, or are more therapeutic. And they are taking steps toward true community integration.

There are tremendous gaps in housing options for people with developmental disabilities, especially those whose only income is SSI. First, there's a lack of affordable rental homes and apartments. Second, the demand for low income housing through HUD programs such as Section 8 and 811 programs far outstrips the demand, and the priorities in those programs

are justifiably toward the homeless. Most importantly though, the Medicaid program is totally inadequate in the area of housing. For example, Medicaid HCBS waivers do not pay for rent and living expenses; they only provide supportive services to help people living in community settings. And they often restrict housing options to group homes of four or fewer people.

Around the country there are examples where families and individuals have stepped up in the right way, by taking greater responsibility, to establish better, long term, more appealing "homes," not "housing."

Benjamin House, Elizabeth City, North Carolina

One of these examples is a home founded by

Ann Parke Hughes in Elizabeth City, North Carolina. Ann and Lennie Hughes have three children. Their youngest, Benjamin, 31, is diagnosed with autism, cerebral palsy, and mild mental retardation.

"God put a dream in my heart that there would be a place for Benjamin when we are gone. I didn't know what that place would be, but I prayed every morning and gradually the vision came to me," said Ann.

In 1998 Ann set to make her vision of a non-denominational, faith-based group home for 12 people a reality. "When I started this I didn't know what I was doing - I had no idea of all of the regulations, financial issues, and obstacles I would encounter, but I knew I had to do something, and at each roadblock God brought good people forward to help me."

In 1999 a non-profit corporation was formed with a board comprised of parents, interested community residents, and representatives of local churches. Construction on Benjamin house started in 2004 and was completed in late 2005. Its residents moved in in February of 2006.

Ann and the board encountered and overcame the major obstacles that stymie most creative housing projects. The first was regulations related to the size of group homes that are funded through Medicaid waiver programs.

North Carolina's Community Alternatives Program (CAP) is the primary source of funding for services to people with developmental dis-

abilities. CAP is a Medicaid Home and Community Based Services (HCBS) waiver program. In North Carolina and many other states HCBS waiver programs restrict the number of people living in a group home to four or less. But Ann and her board felt that a small home would not be economically viable in providing a more supportive environment. With the support their state representative they were able to get an exception to have 12 people at Benjamin House.

The second major obstacle Benjamin House overcame was funding for construction. The 10,000 square foot house cost \$1.2 million dollars to build. Most innovative housing projects obtain capital funding from a variety of sources, including local fundraising, grants or corporate donations, and by tapping into state and federal sources. The primary sources for state funding are programs administered by state housing finance agencies. These agencies may provide low interest loans, low income housing tax credits and other development financing aimed at a variety of low income target populations.

Benjamin House received \$400,000 from the North Carolina Housing Finance Agency in the form of a low interest loan; \$400,000 was raised locally through charitable donations and events and \$300,000 came from a North Carolina Foundation. A local bank provided construction financing.

Benjamin House's monthly average expenses are about \$5,000 per individual.

Benjamin House is closely tied to many community organizations and churches. Ann said this came about because "I talked to everyone I could about what I wanted to do to see where I could get help. And gradually donations and other support started coming in from many different places."

This type of grass roots appeal is one of the most important steps to success in most innovative housing programs. Benjamin House's strong community ties have led to volunteer involvement, greater community acceptance for its residents and ongoing funding or support opportunities. The home's success is due in part because it has established a clear identity for itself; it is known for its strong faith-based underpinnings and focus.

The home is U shaped with common living areas at the bottom and each of the two arms

continued on page 22

A place where people care



Heartspring's commitment to realizing measurable outcomes is made possible through the dedication of determined specialists who believe that every child can learn. Heartspring team members use proven techniques, experience, creativity and personal insight to understand and develop the mind and body of each student. In education, like every other aspect of life at Heartspring, the program is made to fit the student, rather than fitting the student into the program.



www.heartspring.org

8700 East 29th Street North Wichita, Kansas 67226

1.800.835.1043

continued from page 21

having 6 bedrooms. The middle space is open and there are a lot of windows to allow in natural light. And there is a small chapel.

"I thought it was important to include some of the touches of home life, and one of those things in our family was always using cloth napkins. And so at every evening meal, we help make things like home by having real napkins," said Ann.

Bittersweet Farms, Whitehouse Ohio

An equally innovative, but entirely different housing innovation is Bittersweet Farms in Whitehouse, Ohio. This is a working farmstead that provides a home and vocational opportunities for 20 people with autism. There are three separate residences on the farm. The farm's programs and operations are designed to meet the intense service needs and requirements for a therapeutic environment of people with autism.

Bittersweet Farms opened in 1983, as a result of the dedication Bettye Ruth Kay, a special education teacher whose students were adolescents with autism. Her vision was that they would achieve their highest potential in a specially tailored program.

"The original idea was to have a working farm to make the farm more self sufficient. Later the concept expanded to create products that could be sold in the market place," said Vicki Obee-Hilty, the executive director. "Today, in addition to animals there's a woodshop, ceramics, an art studio and weaving."

Bittersweet Farms' identity in Whitehouse and its national reputation are derived from its 26-year history as a model for therapies and programs for people with autism. "We have great acceptance for autism in this small community," says Vicki. We are active in the community and we are a service provider in the community. We employ about 150 people and that gives us recognition as an important member of the business community."

Bittersweet Farms operating funds come primarily from the Medicaid ICF-MR program. ICF-MR programs are often incorrectly called an "institutional" program but in this case and many others, ICF-MRs are community based residences. ICF-MR funding cov-

ers items that are not included in Medicaid HCBS waiver programs. For example, ICF-MR pays housing expenses, but in Ohio, and other states, HCBS waivers do not pay for housing. Bittersweet Farms is an excellent example of a community based non-institutional program funded by the ICF-MR program. There are examples in other states.

The annual operating budget at the Farm is about \$5 million. In 2009 over \$450,000 came from fundraising—primarily grants and charitable donations. Grants from government agencies and programs have been particularly important, including such things as a van from the department of transportation, and renovation funds from block grants.

Bittersweet Farms is a non-profit membership organization, meaning that people who want to support its mission can join by making an annual membership contribution. Members elect the board of directors and 20 percent of the board is comprised on family members of the participants.

Bittersweet Farms also operates a second housing program under the HUD Section 811 Supportive Housing for Persons with Disabilities program. There are two buildings with 12 apartments for low-income individuals with autism. The HUD program provided construction financing and it provides ongoing rent subsidies.

Bittersweet Farms is also a community services provider to people covered by HCBS waivers and it is starting a consulting business to assist families and organizations across the country who are interested in

Key Elements

Successful innovative housing initiatives frequently have the following characteristics:

A motivated leader with a vision, and drive to success – A true leader is needed to overcome significant obstacles. And in situations where families band together it is common for turnover to occur as families clarify their own goals and choose new directions. In many cases this leader is a parent of person with disabilities.

Grass roots community organizing – the leaders, parents, families and board members are active members of community civic organizations, and advocate strongly for their programs.

Small size – innovative programs tend to be small organizations with a small number of clients, which allows them to tailor their services and simplifies community integration.

Tap other resources - Innovative housing programs tap into funding sources beyond categorical programs such as Medicaid waivers. Innovative programs frequently pair up with low income housing developers who know their way around state housing finance agencies, or they tap into other state funding sources.

replicating its model. "Autism programs are growing rapidly and we have 26 years of program experience to help them reduce their learning curves," said Obee-Hilty.

Innovative Strategies

Innovative housing projects such these two share a number of unique characteristics that differentiate them from housing programs operated by provider organizations. One of those differences is in community integration. In traditional provider agencies the focus is to integrate the residents into the community, through outings and trips into the community. While community outings are a part of innovative programs, leading programs pursue integration in other ways. One idea is to do it 180 degrees differently and integrate the community into the home. "At Bittersweet Farms we have a 'reverse' integration program called "Fall on the Farm." The community is invited to come out and spend a day with us," says Obee-Hilty. "There are tours, hay rides and demonstrations in our vocational workshops."

Benjamin House has a small chapel and several times a week ministers from different denominations come in to conduct services. In addition, a Girl Scout troop maintains a garden at the house. •

Thomas Reinke, MA, of Wallingford, Pennsylvania is a health care journalist, and parent of Mary Beth who has intellectual and motor disabilities. He is an Associate in the School of Population Health at Thomas Jefferson University and has served on the board of several disabilities advocacy organizations.