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Home Sweet Home

By Lila Hanif, Staff Reporter

North Coast Community Homes offers shelter, independence to adults with mental disabilities.

They often refer to themselves as “ALAP’s”; they are the aging parents who have chosen to care for their adult children with mental retardation and developmental disabilities (MR/DD) at home for “As Long As Possible.”

They belong to a remarkable generation of parents whose mentally disabled children were born in the boom years (between 1946 and 1964), at a time when professionals routinely encouraged parents to put their children with MR/DD into state-run institutions.

Professionals viewed children with MR/DD as incapable of learning or development. They probably wouldn’t live to adulthood, let alone become independent was the accepted theory.

This generation of parents rejected the experts’ advice. They questioned the need for institutionalization, advocated for more humane and helpful treatment for their institutionalized children, and removed their children entirely from these institutions when the means.

Collectively, they pioneered “the first real system of home and community-based services, educational and work programs, and recreational opportunities,” according to a study from the Scripps Gerontology Center at Miami University.

You’ll find many parents of this generation on the board of North Coast Community Homes (NCCH), the oldest and most respected nonsectarian, nonprofit agency to develop homes for adults with MR/DD in Ohio. Many of the agency’s devoted board members, donors and volunteers first learned of NCCH when their own intellectually or cognitively impaired adult children were ready to live independently. (Note: In many circles, “intellectual or cognitive impairment” has become the preferred term for “mental retardation.”

To avoid confusion, we are using the terms mental retardation and developmental delay because that’s the official terminology the state of Ohio uses.)



Housemates Donna, left, and Lorraine make cookies. NCCH residents divide household chores in independent settings



NCCH homes, renovated for clients’ unique needs, become permanent homes where peers, from left, Tyrone, Mike and Raynelle develop lifelong friendships.

Deinstitutionalization

NCCH began in 1984, when the state bowed to pressure to close the Ohio Developmental Centers, says Gary Shamis, managing partner of SS & G Financial and president of the boards of both NCCH and the CJN. Institutions were closing, but there was nowhere for the residents to go, so NCCH developed 54 group homes for people with MR/DD in Cuyahoga County.

Like many of NCCH's volunteers and donors, Shamis had a family member with developmental delays in his late brother David. Thankfully, says Shamis, David grew up in a "very good" group home, not a state developmental center. David's positive experiences subsequently inspired Shamis to take up the cause of appropriate housing for people with MR/DD.

Ron Gross, vice president of Moskal Gross Orchosky and secretary/treasurer of the NCCH board, also has a brother with mental retardation. "Jimmy was in a bad institution before, and it's never going to happen again," he says with a shudder. Jimmy has lived happily in a NCCH home on Bagley Road for the past 20 years.

Currently, NCCH houses a total of 908 residents in 182 properties in Cuyahoga, Lake, Stark and Summit Counties. But there have never been enough homes to meet the demand. In Cuyahoga County alone, 2,400 people with mental disabilities are on the residential waiting list kept by the County Board of Mental Retardation and Developmental Disabilities.

"There are always enormous waiting lists," says Barbara Rosenthal, vice president of resource development at NCCH. "There are 400 people on the 'active list' of people ready to move into housing right away, and 30 to 40 people on the 'emergency' list, which means they need to be placed somewhere in the next 30 days.

"How do we deal with those numbers?" Rosenthal asks rhetorically. NCCH develops an average three to four additional homes a year that provide spaces for a total of 12 to 16 more people.

Furthermore, demand will only increase. More than 60% of adult Ohioans with MR/DD live at home, and at least 22,000 of them live with parents who are 60 or older, according to the Scripps Gerontology Center. For the first time in history, adults with MR/DD are outliving their parents. When today's adults with MR/DD were born, a person with Down syndrome was expected to die in adolescence; today the life expectancy of people with Down syndrome is 55, with many living into their 60s and 70's.

NCCH makes a house a home

NCCH recognizes that the generation of parents who worked so hard to improve the quality of their children's lives is now faced with the problem of keeping these children out of large group homes (defined as a home with 6 or more residents) and placing them in small, private residential homes of the kind NCCH develops.

The mission of NCCH says Shamis, is driven "by the understanding that parents won't live forever, and men and women with disabilities have the right to live in an environment that is safe and comfortable and that will allow them maximum independence.

Creating the right home for a person with MR/DD is a long, complex, and ultimately expensive undertaking. NCCH has become widely recognized for developing the gold standard of community housing for people with special needs.

An NCCH home usually starts when the County Board of MR/DD matches three or four people who are compatible and have “the same level of disabilities,” Rosenthal explains. From that point on, the residents are involved in every aspect of the process. They look at potential houses and neighborhoods, and when they find one that suits, NCCH buys it.

“We believe in the empowerment of the individuals to the greatest extent possible,” says Rosenthal.

The houses are then rehabbed to meet the specific needs of the people who will live in them, taking into account their disabilities, strengths and preferences. People with mobility issues, for example, will obviously need a house that is wheelchair accessible.



NCCH renovates its homes to fit each resident’s unique accessibility and safety needs, usually an extensive and expensive project.

Meeting the challenge

“Challenging” behaviors of the kind that might keep someone out of other kinds of housing are also taken into account and adjustments made. “Every client is uniquely handled,” says Shamis. “A group of ‘runners’ (people who wander away from home) won’t be housed on (busy) Cedar Road, for example.”

One NCCH house is home to three people with Prader-Willi syndrome, a genetic disorder associated with poor muscle tone and an insatiable appetite, which can lead to life-threatening obesity. Unique adaptations were made for those tenants, Rosenthal explains. “The kitchen is kept locked, and there has to be a room for exercise equipment.”

For an autistic tenant who habitually knocked holes in the wall with her head, “we spent a lot of time and money coming up with a wall material” that she couldn’t harm and that couldn’t harm her, says Rosenthal. “We have one tenant who likes to break windows. We found a coating that makes the window unbreakable.”

Another factor that sets NCCH apart from other housing providers is its commitment to parity. A smoke detector provides a certain level of protection from fire for most of the population, but to achieve that same level of safety for people with disabilities requires extra measures, like installing a sprinkler system.

“Government funds do not pay for sprinkler systems for folks in wheelchairs,” says Rosenthal. “They don’t pay for the tempering valves NCCH puts on hot water heaters to prevent scalding. They also don’t pay for overhead track lifts that allow mobility-impaired residents to get out of bed in case of fire, which cost about \$17,000.”

Finding the funding

Keeping houses affordable and inviting for tenants is a crucial part of NCCH’s mission. Its tenants are “some of the most underprivileged people in our society,” Shamis says. The average income of

NCCH's tenants is \$8,800 a year, most of which is federal SSI (Supplemental Security Income).

To keep costs down, NCCH buys its properties outright to avoid debt service that could drive up rents. While that saves money, it also requires a good bit of operating capital, Rosenthal explains.

NCCH gets some of its funding from government sources, but there's always a gap between what the government will pay for and what clients need.

There's "a significant shortfall in day-to-day operations," Shamis admits. To make up that shortfall and to build its operating capital, NCCH turns to the private sector, including foundations, corporations and individuals.

Next week NCCH is holding its first-ever benefit at Beau Ravine Farm in Waite Hill.

Raising awareness

"We've never had a benefit before," notes Rosenthal. "I'm hoping to raise awareness among a new population who hasn't been involved with us in the past."

As charitable causes go, NCCH is not "sexy" or "high-profile," says Gross. But "we do a lot of good work for a population that really needs the service. My family has been a pretty large beneficiary of the program," he says. "We know my brother Jimmy is in a safe environment, that he gets good care, and that they don't misuse the funds."

If families are appreciative, NCCH tenants themselves are ecstatic about living independently in their own homes. Barbara Goldstein, whose 47-year-old daughter Elise has lived in an NCCH residence in University Heights for the past four years, says her daughter is "very happy. She's with her own peers, and she likes to be there. When she's away from her home, she can't wait to get back."

Elise, who has cerebral palsy, sometimes tells her mother, "You can't tell me what to do anymore. I'm independent!" For many "as long as possible" parents, that's music to their ears.