



## Home Improvement

# Living Independently in a Home and Community of Choice: How?

By Gail Braswell, Linda Ritter,  
and Mary Jane Sufficool.....

In the March 2009 issue of *EP*, readers learned about a unique organization, Niche, Inc., which helps those with disabilities know the joy of neighborhood connection through cohousing communities. In this article, readers are introduced to *how* cohousing communities work and *why* they are such a vital resource in the ongoing challenge of offering those with disabilities the same human rights—like safe, cost effective, stable, and chosen home environments—that are afforded those without disabilities.

**Residents** in a group home, supported apartment, or intermediate care facility for the mentally retarded (ICF/MR) are not guaranteed a place for life. Neither are they guaranteed they won't have to move if their provider needs to "rearrange" clients. What happens when the support doesn't match the client's needs? A home becomes a house of cards, causing emotional and/or physical distress for many individuals challenged with disabilities.

In Virginia, our home state, support services and residential services are combined and state regulations only mandate

10 days notice for termination of services. Imagine if ordinary landlords had that kind of power!

The vast majority of individuals residing "in the community" live in residences owned and controlled by someone else. Choice is not an option when housemates are at the mercy of "majority rules." If three out of four residents want to go to a movie one night and only one person really, really wants to go to a dance, guess who sacrifices a little independence? That isn't the way everyone else lives, so why is it okay that those with disabilities have to live that way?

Separating residence from support gives an individual control over the most basic decisions regarding where they live, with whom they live, the level of the assistance they receive, and how they spend their time. Niche Inc. was created to promote home ownership as the compelling alternative to the agency controlled approach to housing and assistance services.

The most common housing options available to those with intellectual disabilities are:

- institutional care,
- intermediate care facilities for the mentally retarded (ICF/MR),
- group homes,
- adult foster care,
- supervised apartments in community settings, and
- living at home with family support.

Independent living does not mean doing everything alone, not needing anybody, or living in isolation. It is about having the same choices as everyone else. Accordingly, a person with a disability should have the option to own a home. That said, it is no small feat for a person with low income and assistance services to navigate the labyrinth of purchasing a home. Niche has researched the following strategies, and we'll explain briefly the advantages and disadvantages of each.

### How can a person with an intellectual disability live in his own home?

- A family member might allow an individual to live in a home they own. The family member can decide whether or not to charge the individual a rental fee. Living in a home owned by a family member can be a good solution, but the value of food or shelter that someone gives or the amount of money someone gives to help pay for them is counted as income, which can reduce the individual's SSI (Social Security Income) entitlement. Also, when the property owner dies, the house becomes part of

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their estate. When the estate is settled, either the individual with a disability needs a new home or there could be liability and/or tax issues imposed on that individual as the new owner.

- A family member might “donate” a home to a non-profit organization. The non-profit organization can decide whether or not to charge the individual a rental fee. Food, clothing, shelter, or home energy assistance provided free or at a reduced rate by private nonprofit organizations are not counted as income. Even if a family member donates a home to a non-profit, there is no guarantee that the individual will be able to stay in that particular home. When assistance services are associated with housing, if you lose one, you also lose the other. Equally important, if an individual is unhappy with either, the individual would have to move in order to secure both the housing and services needed.

- The individual can own a home. If the home is legally in the name of the individual, a family member may be assisting with maintenance costs or mortgage payments. Owning a home is not counted against the \$2000 limit in assets owned in the individual’s eligibility for entitlements, but again unfortunately, the value of food or shelter that someone gives or the amount of money someone gives to help pay for them is counted as income, which in turn reduces the entitlement.

- A corporation can own the property on behalf of the individual. The corporation can decide whether or not to charge the individual a rental fee. Working closely with an attorney and forming a small corporation can title property for the sole purpose of an individual with disabilities. Mortgage funding to purchase housing can be secured from housing and development authorities, banks, and other lending institutions. Legally, the individual is a tenant and with a reasonable rental fee charged, the individual’s entitlements are

not jeopardized. All of the property related expenses belong to the corporation, so they are not counted as income for the individual. To insure that the focus of the corporation remains on the individual for whom it was intended, family members, advocates, and friends should comprise the corporate board.

The last option mentioned above is a new and innovative approach to residential stability. This is the approach that Niche advocates and supports. Even an individual with very serious disabilities can have property owned and managed by a corporation. There are many other functions that the corporation can take on, if it is deemed appropriate for the individual. The corporation can:

- Accept Section 8 (housing choice) vouchers. If the individual receives a housing choice voucher, it could subsidize rental fees for the amount up to one-third of the individual’s income.
- Become an “employer of record.” Only an employer of record can receive Medicaid Waiver entitlement benefits directly, which means that assistance services for the individual can be contracted directly by the corporation.

- Act as a microboard for the individual. In the United States, microboards are a legal entity composed of family and friends who meet regularly to discuss the needs and desires of the individual, and how the microboard can satisfy them. Microboards are created to provide a continuation of care after the death of that individual’s parents.

Individuals with disabilities of all types and degrees can and do live successfully and independently in communities of their own choice when appropriate services and supports are available to them. •

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Gail Braswell, Linda Ritter, and Mary Jane Sufficool live in Virginia Beach, VA and are parents of children with disabilities and active advocates for independence. Gail’s son, Neal Pergerson (18), has Down syndrome and currently lives at home while finishing high school. Linda’s daughter, Kimberly (46), has cerebral palsy, severe mental retardation, seizures, autistic characteristics, and is non-verbal. She and a caregiver live in her home, purchased for her by a corporation her family created. Mary Jane’s son, Bart (29), has succinic semialdehyde dehydrogenase deficiency and lives in his own apartment supported by 24-hour caregivers. Gail, Linda, and Mary Jane are members of the Niche Inc. Board of Directors. All have served and continue to serve with other disability advocacy groups.

## For More Information

Financially sound choices should be considered in an effort to ensure protection of the person’s entitlements. Without supports such as rent subsidies, personal assistance, day programs, vocational training, transportation, and medical care, the person with disabilities may not be able to live successfully in the community.

Disclaimer: This article is not about what disability entitlements exist, what they are, or how they work. For information on these subjects go to:

- ◆ SSI and SSDI — [www.ssa.gov](http://www.ssa.gov)
- ◆ Medicaid Waiver — Call your local office for people with intellectual disabilities.
- ◆ Section 8 (Housing Choice Vouchers) — [www.hud.gov/renting](http://www.hud.gov/renting)
- ◆ Food Stamps — [www.fns.usda.gov](http://www.fns.usda.gov)

