



Housing: A Big Piece of Puzzle for Ensuring Your Loved One's Future

By Desiree Kameka, [Autism Housing Network](#)

As the project leader for the Autism Housing Network, I have visited over 100 residential options and social enterprises across our country. I have seen the great, the good, the bad, and the “I thought this was a good idea.” Abraham Maslow was right when he listed “shelter” as one of the foundational elements for his [Hierarchy of Human Needs and Dimensions](#), along with air, water, food, sleep (another big one!) and clothing. A home determines physical and mental health, access to opportunities and quality of life for an individual. Housing is the anchor for a stable life.

When thinking about the future of your loved one with intellectual/developmental disabilities, you probably ask yourself if you should be focusing on finding the right service provider, building relationships, seeking employment, etc. We can invest enormous amounts of energy in pursuit of those important goals. But all that may be lost if rising rents force someone on an extremely low, fixed income, or their host family, to relocate. Or if the group home they live in must close. The greatest investment we make to ensure life stability is a home. Even when all other plans fail, loved ones still have their home.

To help families plan and understand their choices, Madison House Autism Foundation created a five-part video series called the AHN Virtual Tour of Housing and Support Options, which describes the benefits and considerations of 18 different housing and service delivery options, from traditional to emerging models. The video series will explain examples in depth, but there are four major categories to consider for legal and financial planning:

Rely 100 percent on government support

Options include:

- An Intermediate Care Facility (ICF-ID), through which housing and support services are provided to eligible persons needing an institutional level of support;
- Placing in a host family home, adult foster care or group home, with rent paid to the service provider using Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), and support services paid for through a Medicaid waiver;

- Securing an affordable housing voucher/unit, with a Medicaid waiver paying for support services in one's home.

The availability of these options is extremely limited and can fluctuate, depending on government policy and budgets. This is where members of the Special Needs Alliance can be of great help, since public assistance is often “means-tested,” and it is important to be vigilant to ensure that one remains eligible. The AHN Resource Directory has a filter for ‘Finding Public Assistance’ that can lead you to helpful links.

Invest privately in housing and access Medicaid for support services and/or arrange supportive housemates

This disconnects one's service provider from their housing and provides the most control over one's home. One could continue living in their family home, or could move into a tiny home/accessory dwelling on the same property, or another home purchased for them elsewhere. Some families combine resources in order to buy a home together. Others may purchase a home/unit in an intentionally neurodiverse cohousing or planned community. A Medicaid waiver would then be needed to pay for everyday assistance and support. Under these circumstances, one can change service providers as needed without being forced to relocate. This separation of housing and service provider is generally referred to as “consumer-controlled” housing. Renting to roommates can offer an additional income stream to help pay for living expenses, as well as offering unpaid support.

100% private pay, tuition-based residential

This can be a single apartment in a big city or a campus-based setting, where one has home, work and recreational options. Tuition includes one's housing, coordination of daily in-person support, meals, planned activities, transportation and other services. This is an option only if you can afford tuition that starts at \$38,000 a year for the individual's lifespan. It is important to think about whether or not the provider will be around for the duration of your loved one's life or what would happen if their support needs change. You can find a list of these in the AHN Housing Directory by clicking “Private Pay” under the “Payment Options” filter.

Transitional or post-secondary programs

This is not a permanent solution. Instead, it's a private pay program that intensely teaches life skills, with the goal of giving someone the training needed to live more independently in the future. It is an investment of at least \$2,500 a month for the duration of the program. These can also be found in the AHN Housing Directory.

I encourage families to explore options, and instead of trying to find the box to squeeze into, think of how supports can be based around the person. This will help determine the type of setting to call home and the people or places needed to maintain a happy lifestyle. This is called “person-centered planning” and, when at all possible, your loved one should be included in these discussions.

I hope this has been a helpful introduction and has persuaded you to prioritize housing when planning for the future. Please visit the Autism Housing Network for more information.

Desiree Kameka is the Director of Community Engagement and Housing Networks for the [Madison House Autism Foundation \(MHAF\)](#).

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