

HOUSING

What are the Options for Housing and How Do I Find Them?

Finding the right residential option for a young adult with autism is certainly one of the most difficult parts of the transition process. There are different options to choose from, but several hurdles to get over before the individual is settled in the right place. The most important thing is to build the skills necessary for your young adult to live as independently as possible as an adult.



Start Early!

It is critical to be proactive when it comes to choosing the right residential option.

Think first about what's best for your child as an individual based on his or her needs, abilities, strengths, etc.

- Where would your child thrive?
- Where would he or she be happiest and feel safest?
- What type of setting would best help him or her achieve an independent, successful future?
- What supports does he or she need? What types of options can best provide those supports?
- What setting can help your young adult expand upon his or her strengths and abilities?

A great place to start is your school district. They can help, or they can tell you where you can go to get help. Check in with other families you know who have a family member with autism or other developmental disability. If you don't know any personally, you can most likely find some families through support groups, local autism organizations, etc. To find out about options in your area, contact state and local agencies to speak about residential options. This is hard work and will take time, but it is critical to uncover all possible options in your community and the surrounding area. The hard work will be worth it in the long run.

Once you find some good options, **ASK LOTS OF QUESTIONS!**



Some Questions to Ask

When reviewing housing options you may want to consider:

1. How much experience does the provider have in working with individuals with disabilities? Autism in particular?
2. How does the agency help transition the individual from his own home to the new residential facility? What do they do to smooth the process?
3. What kind of training does the staff receive? How often are they on duty?
4. What is the staff turnover rate? Staff to resident ratio?
5. How does the staff deal with emergencies?
6. How structured is the schedule? What does the schedule look like?
7. What activities take place both in and out of the home? Is there any interaction with the community at large?
8. How will my family be involved in the plan of services?
9. Can I talk to other families with experience in these facilities?
10. What clinical staff do you have?
11. What is the situation with day programs/vocational services/life skills training, etc?

Autism Residential Placement Options: ARCHWay – State Developmental Disabilities Agencies and Service: A Starting Point

Types of Housing Options

The issue of housing can be complicated. It is important to research all types of options, and continue to narrow down your list until you find the best fit. Each type of residential program is designed to provide a different level of support for the residents in the program. Below, we have provided information about residential program options as well as funding options as outlined in: *Opening Doors: A Discussion of Residential Options* produced by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center and Arizona State University.

www.autismcenter.org/documents/openingdoors_print_042610_001.pdf



Residential Program Options

Transitional Models

Transitional residential programs offer a relatively short-term (e.g. one month to two years) residential experience with the expressed goal of transitioning the individual back to their previous environment or a new residence upon completion of the program. Transitional programs generally fall into one of three categories: 1) programs providing intensive inpatient behavioral evaluation and intervention for individuals with severe behavior disorders; 2) programs providing an intensive life skills course of instruction for individuals who, upon completion of the program, are expected to live independently; and 3) college support programs.

Supported Living

Supported living programs provide residential services to adults with developmental disabilities who are able to live in self-owned or leased homes in the community. Among the core tenets of supporting living are that 1) everyone, independent of current skills sets, can benefit from supported living; 2) programming and instruction are directed by the consumer and not by the program; 3) to be effective, communities of support must be built around the person and promote their involvement, and; 4) smaller numbers result in greater levels of community integration. Supported living is designed to foster the individual's full membership in the community as they work toward their long-term personal goals.

Supervised Living

Supervised living is a residential model designed to provide services to individuals with ASDs with greater oversight and direction than might be provided in a supported living context, but less than group home living. In supervised living, the homes may be self-owned or leased. Although individual residences may be small (generally no more than one or two adults with autism per residence), there may be a number of such residences scattered throughout the apartment building or housing complex, allowing for greater staff accessibility and oversight.

Groups Homes (Supported and Supervised)

With the onset of de-institutionalization came the movement of individuals with ASDs and other developmental disabilities from large, congregate care facilities to smaller, more typical homes in the community. Group homes exist in every state. They are small, residential facilities (i.e. actual homes) located in the community and designed to serve children and adults with ASDs, intellectual disabilities or other chronic conditions. Typically, group homes have eight or fewer occupants and are staffed 24 hours a day by trained agency staff. Ownership of the house usually lies with the provider agency (as do staffing decisions) and not with the residents of the house. A primary goal of group home living is to promote increasingly greater levels of independence in the residents. As such, instruction in daily living and self help skills including meal preparation, laundry, housecleaning, home maintenance, money management, hygiene, showering, dressing and appropriate social interactions are provided by the agency staff.



Intermediate Care Facility – Mental Retardation (ICF-MR) (Institutional) (most intensive)

The ICF-MR is a residential program that was established in 1971 by the Federal government as an optional Medicaid service. The funding for this facility-based program, which includes both the facility and the support services, stays with the facility, not the person. Programs range from large congregate settings to those which are community-based and sized much like a group home. The underlying philosophy is that individuals with developmental disabilities can continue to learn and develop skills when supported by adequate programs and services tailored to their individual strengths and needs. Each ICF-MR is responsible for providing active treatment, consistent training and health support allowing individuals to maximize their independence. Currently, all 50 states have at least one ICF-MR facility. The ICF-MR has traditionally served individuals with complex needs and who are medically fragile and multi-challenged. There has been a shift away from the development of new ICF-MR facilities and a transition to more person-centric funding models.

Agricultural Autism Community/Farmstead Programs (Supported and Supervised)

Agricultural autism community, or farmstead programs, are proven hybrid models that generally combine residential living arrangements, typically in several single family homes or individual apartments in multi-unit dwellings located on site or in nearby locations, with stable agricultural science and community-based employment. A few of the communities are residential only. Most offer day programs, job training and employment both on- and off-site for adults with autism who live with their families in nearby areas.

Funding Options

It can be challenging and confusing to navigate the funding streams for housing for your young adult with autism. Each state has varying programs and guidelines, so you will need to research funding options specific to your state. The state page of the Autism Speaks Resource Guide will provide you with some of the contacts necessary to begin this process. The following list outlines some of the national programs that provide funding for services such as housing:

Federal Entitlements

Medicaid – Title 19 – for medical necessity, paid directly to the service provider, not specific to housing. This is not specific to housing services, but is based upon the services delivered. A person must qualify for Developmental Disability Services in their state. States have a required match which can be used for room and board.

Supplemental Security Income (SSI) – paid directly to recipients. This is income to cover everything except medical care. An individual must be disabled and have a limited income.



Other Funding Options

Large donor/charitable organization (simplest model) – a single donor or multiple donors contribute the construction/acquisition funding through a 501(c)(3) organization that serves the developmentally disabled population.

Private pay (can be families together with other families) – Families with resources pay for all services and the facilities together with other families.

Low income housing (greatest single source of funding) – Federal and state funds are granted to construction housing for low-income and special needs populations.

HUD Section 811- This program provides interest-free capital advances to nonprofit sponsors to develop rental housing for low-income persons with disabilities.

Low Income Housing Tax Credit (LIHTC) – This program allows qualified for-profit and nonprofit developers to apply, on a state-by-state program, for federal tax credits that they can sell to investors and use the proceeds as equity for the development of apartment complexes for persons below 60 percent area median income.

HUD Section 202 – Similar to 811, this program is available only to nonprofit organizations that target both low-income seniors and frail elderly by providing capital advances to finance the construction, rehabilitation or acquisition of structures and also provides rent subsidies for projects to help make them more affordable.

Home Program – This program provides formula grants and loans to state and local participating jurisdictions to expand housing opportunities for low and moderate income individuals and households.

Community Development Block Grant (CDBG) – CDBG's are grants to jurisdictions which can be used to support affordable housing through land acquisition and infrastructure development.

HUD Section 811 Housing Choice Vouchers (HCV) – These vouchers are dispersed directly by HUD to persons with disabilities to spend on the housing option of their choosing.

HUD Section 8 HCV – This voucher program is for individuals with below 60% of the area median income, including disabled persons.

Home and Community Based Waivers (HCBS) – Some states may offer a variety of services to consumers under an HCBS waiver program. These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management and/or environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications.



One of the challenges of some residential options is that often the housing unit and the services within the home are provided by one agency. Because the services are tied to the housing, if a young adult or adult with autism is unsatisfied with the services in the home, in many cases he or she will need to leave the home.

Skills to consider for Independent Living

Some skills that individuals may need to master in order to live more independently include:

- Safety Skills
- Phone Skills
- Cleaning and maintaining a home
- Laundry and Clothing care
- Budgeting
- Nutrition and Cooking
- Grocery Shopping

It may be helpful to have these skills included in your young adult's IEP so that there can be a focus on these skills prior to adulthood.



An example of supported living from Jay Nolan Community Services can be found below http://jaynolan.org/nick_essay.php

One look at the smile on Nick Anderson's face and you get a sense of just how fun loving and personable this young man is. Whether he is talking about his businesses—he has two—his love of the outdoors, his affinity for animals or his obsession with pizza, Nick is a delight. He is also an adult living with autism.

Nick's journey with Jay Nolan Community Services began at age 11 when he began attending JNCS Saturday Program. It was there that he learned about riding public transportation, interacting with community members, and trying new and different things. Later as a teenager, he again broadened his horizons spending two summers at JNCS' summer camp.

However, it was not until 2007 after graduating high school that Nick would experience his most dramatic successes. As part of his support plan, JNCS has helped Nick start two ventures—a dog walking and a vending machine business. Nick's support staff keeps him organized and teaches him business basics (i.e., keeping up with billing, stocking, customer service, etc.). Every day after walking his five canine friends, Nick returns home to hand write his customer invoices. Once a week, he and a support staff member stop by his soda vending machine at JNCS to collect the change and check on the stock.

Nick shares a Northridge home with Evan, one of his former one-on-one aides and his wife, Nadia. Since moving into supported living, Nick is more open to change...to trying new things. He now exercises at a gym, and loves to hike, bike and do almost anything physical. His affinity for pizza hasn't wavered though. If he could, he would eat it for breakfast, lunch and dinner. One of his favorite places is Marcelino's Italian Kitchen. Marcelino has become a family friend and lets Nick behind the counter to make his favorite pizza—meatballs, onions and mushrooms. Likes being around other people—and his family, friends, and support staff provide just that.



Some parents may feel guilty about moving their child out of their home. But, "In some situations, the family may decide that a professional setting might be better able to provide the amount of structure and support this child or adult needs to continue to grow. Others feel that it is time for the adult to move from the shelter of his family and experience the independence that supervised living can provide. Families must understand that moving an adult into a residential program is not signing them over to the state or an agency and then losing their parental rights. This decision can be reversed at any time the family decides the placement is not meeting the child's or adult's needs."

- *Guiding Your Teenager with Special Needs through the Transition from School to Adult Life: Tools for Parents*
by Mary Korpi

Unfortunately, at this time there are many more people waiting for appropriate supported living settings than there are openings in these settings.

Waiting lists are long – so start the process early!

It is important for parents to work with the Service Coordinator at the Developmental Disabilities Office in their area as soon as possible to complete and submit residential applications to the appropriate adult service agencies. You may even want to add your child's name to the waiting list even if you are not yet ready to consider this move. Completing an application places your child in a 'waiting pool' from which appropriate individuals are selected depending on the opening. After an individual is selected, there is an interview process, discussions, etc.

Long-term planning is the best way to avoid crisis situations.

Involving your Young Adult in the Moving Process

Although housing options can be difficult to find it is important to involve your young adult in as much of the process as possible. This can include:

- Choosing the home
- Deciding on the décor – especially in personal spaces such as bedrooms
- Interviewing staff (if appropriate)
- Organizing their belongings
- Shopping for groceries

A new home for your young adult will be a change for both of you. The transition will be easier if you work together to plan out the new space and involve your young adult to the best of their ability. You may want to consider visiting the home several times before the move in date and take pictures or video of the space. This will assist your young adult in familiarizing themselves with their new surroundings. If there are other residents in the home you may want to consider having your young adult spend time with them both in the home and community before they move in.



Housing Resources

Opening Doors: A Discussion of Residential Options

Produced by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center and Arizona State University

www.autismcenter.org/openingdoors.aspx

Homes for Autism

www.homesforautism.org/housing.html

Housing Choices Coalition

www.housingchoices.com

Autism Residential Placement Options

www.child-autism-parent-cafe.com/residential-placement.html

Community Development Block Grant Program

www.hud.gov/offices/cpd/communitydevelopment/programs

The Disability Opportunity Fund

thedof.org

Foundation for Autism Support and Training: ARCHWay

www.foundationforautismsupportandtraining.org/archway.html

Autism Links: Service Provider Directory

www.autismlink.com/services

U.S. Department of Health and Human Services Administration on Developmental Disabilities

www.acf.hhs.gov/programs/add

U.S. Department of Housing and Urban Development (HUD)

<http://portal.hud.gov/portal/page/portal/HUD>

Supplemental Security Income

www.ssa.gov/ssi

Medicaid Title XIX

www.ssa.gov/OP_Home/ssact/title19/1900.htm

To search for some residential options in your area, visit the Autism Speaks Resource Guide (AutismSpeaks.org/community/resources), and search for "Residential Services."



