

Housing and Residential Supports

One of the most difficult parts of the transition process is finding the right residential option for your child's future. Coordinating choices for the physical home, as well as the necessary support services can be complicated, often leaving families unsure of where to start. The information below, along with the [Autism Speaks Housing and Residential Supports Tool Kit](#), can help assist you and your family in planning for the future in the areas of housing and community living.

There are different options to choose from, but several hurdles to get over before your child is settled in the right place. The most important thing is to build the skills necessary for him or her to live as independently as possible as an adult. And remember - start early!

Where Do I Begin?

It is critical to be proactive when it comes to choosing the right residential option. Think first about what is best for your child as an individual based on his or her needs, abilities, strengths, challenges, etc. Some important questions to ask might be:

Where would your child thrive?

Where would he or she be happiest?

Where would he or she feel safest?

What type of setting would best help him or her achieve an independent and successful future?

What supports does he or she need and what types of options can best provide those supports?

What setting can help your child expand upon his or her strengths and abilities?

Many of these questions can be answered through the person-centered planning process which can help families and individuals with autism identify the right types of residential and support services based on the individual's goals and needs. More information about person-centered planning can be found in the Self-Advocacy section of this kit.

A great place to start is with your school district. They can help or 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 or local autism organizations. 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! Below are some you may want to consider when looking into a specific option or speaking to a housing agency:

What type of housing models do you offer?

How long have you been providing residential services?

What type of training does your staff receive to work with an adult with autism?

What level of support does the staff provide to the adults with autism? Is support available 24 hours a day?

Can I speak with other families who are using your service?

How do the residents spend their time during the day and on weekends?

How close is the local community and how often do you access community resources?

Who provides transportation during the week and on weekends?

How close are hospitals?

What is done in a medical and/or behavioral emergency?

What is done to support medical and/or behavioral needs?

What type of training do staff receive?

It is important when researching residential placement for your child, that you keep him or her as involved in the process as possible. Allow your child to contribute to the discussion in the best way he or she knows how. Though some young adults with autism may not be able to decide on their own what type of housing they'd like to live in for their future, do your best to keep your child's preferences and strengths in mind. This is likely one of the most important decisions your family will make, so it is critical to make sure everyone is on the same page and that an outcome is reached that everyone can be happy about, especially your child.

Most residential service providers that receive public support, including all providers that receive Medicaid, are regulated by state agencies. For Medicaid providers, the state agency conducts routine monitoring – often referred to as “survey and certification.” Before choosing to use any provider, ask to see the latest monitoring, survey or licensure reports conducted by the state. You can also contact the state regulatory agency to find out if any complaints of abuse and neglect have been filed against a provider or if the provider has violated any licensure or regulatory standard.



Models for Residential Support

There are many different community-based residential service options. Some of these options combine housing and support services, while others allow the housing and support services to be purchased and arranged separately. As you read these descriptions, bear in mind that states may use different terms to describe similar models:

Supported Living offers services to individuals with disabilities who are able to live independently in a home or an apartment. The services, typically minimal in nature, are based on the individual's specific support needs and are provided by caregivers working under the direction of the individual.

Supervised Living (semi-independent living) offers more direct and intensive structured supports available 24 hours a day, if needed. The individual may live in a house or apartment, either alone or with others. Functional life skills such as banking, shopping, cooking and going to doctor appointments can be taught or supported by staff.

Group Home Living has been the traditional model for residential services for individuals with developmental disabilities. In a group home, several unrelated people (all of whom have a disability) live together with onsite staff who are present 24 hours a day, 7 days a week. Instruction focuses on independent living skills and community activities. The house is owned and operated by a provider agency that also employs and supervises the staff. Typically group homes have eight or fewer residents.

Group Living/Ownership (co-op) is similar to group home living, except that the house is owned by a group of families or individuals who have formed a cooperative agreement. Caregivers hired by the cooperative, in some cases, by an agency contracted by the cooperative, provide support services.



Teaching Family Model/Foster Home Living offers family-style living with support services available 24/7 by professional teaching parents, usually a married couple. The individual may be the only person with a disability living in the home or there may be others with or without disabilities.

Farmstead Communities provide residential supports and services for a number of individuals within the context of a working farm. These models generally combine residential living arrangements with agriculture science and community-based employment.

Assisted Living Facilities/Intermediate Care Facilities (ICF) provide assistance with personal care and activities of daily living such as bathing, grooming, dressing and more. In some states, ICF programs also provide medication assistance and/or reminders. Each ICF is responsible for providing active treatment, consistent training and health support. Assisted living communities differ from nursing homes in that they don't offer complex medical services.

Developmental Centers are large residential facilities clustered on a campus-like setting where residents have intensive needs related to their developmental disabilities. Most states no longer run large developmental centers and some states that do are looking to shift people to more community-based settings and will only place a person in a developmental center on an emergency basis.

Funding Options

It can be challenging and confusing to navigate the funding streams for housing for your young adult with autism. Below is some information about options and programs for you to look into when finding the right housing fit for your child:

Self-Funded Housing

Self-funded housing is purchased by the family and/or the individual using private money and/or public dollars. The funds are secured and directed by your child and family, not an outside agency.

When exploring ways to pay for housing, you should consider all resources available to you and your child, including:

Donations

Income

Grants

Foundations

Banks

Community Development Financial Institutions (CDFI)

Credit unions

Private insurance

Special Needs Trusts

Individual Development Accounts (IDAs)

Pooled trusts

Tax credits

Individuals with autism and other disabilities are often eligible to participate in state and federal programs designed to provide funding to build and renovate houses. It is important to know that each program has distinct guidelines and that programs can often vary by state.

Most public funding for projects will be contingent on your child's ability to pay for rent/mortgage and a social-service plan that addresses health and safety. There are many public programs that offer assistance to people with disabilities and others with low and limited income.

Below we have highlighted programs that are more frequently used for people with disabilities. For a more comprehensive review of federal programs, visit the United States Department of Housing and Urban Development's (HUD) website at hud.gov.

HUD Section 811 provides interest-free capital advances to nonprofit sponsors to develop rental housing for low-income persons with disabilities. HUD Section 911 Housing Choice Vouchers (HCV) are dispersed directly by HUD to persons with disabilities to spend on the housing option of their choosing.

Low Income Housing Tax Credit (LIHTC) allows qualified for-profit and nonprofit developers to apply on a state-by-state basis 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% of area median income.

Home 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 Grants (CDBG) are grants to jurisdictions that can be used to support affordable housing through land acquisition and infrastructure development.

Federal Resources

The HUD programs above provide funding for families or groups of families to purchase or rent their own apartment, condominium, house, etc. for their family member with autism. It is important to note, however, that very often costs for the physical home and costs for the services provided within the home are kept separate.

You should discuss funding options with the state agency responsible for serving adults with developmental disabilities. Below is a list of some federal entitlements that can help with residential support costs and other services. You can find more information in the Legal Matters section of this kit:

Medicaid Benefits

In most states, individuals who need residential support will need to be eligible for Medicaid, a program designed to pay for intensive services. Medicaid pays for a wide array of services for people with disabilities, including long-term services and supports. To be eligible for Medicaid, a person must fit in a specific category of coverage and meet income and assets requirements.

Home and Community-Based Waiver Services

Through the use of Medicaid Home and Community-Based Services (HCBS) Waivers, people with autism and other disabilities can use Medicaid funds more flexibly. Waiver services are an option available to states to provide integrated community-based long term care services and supports to qualified Medicaid recipients. These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) and non-medical services (respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. The exact type of residential support included in an HCBS waiver as well as who is eligible for the program varies within and across states.



Supplemental Security Income (SSI)

SSI is a federal program through the Social Security Administration that provides cash benefits directly to recipients. In order to receive SSI, an individual must be disabled and have a limited income, including a maximum asset limit of \$2,000. In 40 states, individuals who qualify for SSI are automatically qualified for Medicaid. Learn more and determine if you qualify at ssa.gov/ssi.

Waiting Lists are Long – Plan Ahead!

Regardless of the funding mechanisms available, the most important thing when it comes to housing and residential supports is to plan ahead. Unfortunately, at this time there are many more people waiting for appropriate supported living settings than there are openings in these settings.

Although there are state-funded day services and/or vocational rehabilitation programs for young adults when they transition to adult life, many families are surprised to learn that there can be a waiting list of five, ten and even 15 years or more for residential services and supports that are funded with public dollars, specifically Medicaid HCBS waivers.

It is important to understand and monitor the waiting list in your state and stay vigilant in pursuit of accurate information. Begin planning as early as possible and take the time to research your state's funding structure for housing and supports to minimize waiting time.

Be sure to put your child's name on the HCBS waiver waiting list as soon as possible – it may be many years before he or she is offered services.



Conclusion

The thought of your child living outside your home at this point might seem very overwhelming. But regardless, it is never too early to start researching residential plans and the corresponding funding mechanisms, even if you aren't quite sure of when, if at all, you think might be the best time for the move. With diligent and proactive research and planning, you can help guarantee that whether his or her future home is down the hall from you, two blocks away or across the state border, your child will live in a place that will allow him or her to be as happy and as independent as possible.