





# Autism Speaks<sup>®</sup> **FAMILY SERVICES**

Housing and Residential Supports Tool Kit







www.AutismSpeaks.org

## Housing and Residential Supports Tool Kit

### A tool kit to assist individuals and families as they identify and secure appropriate residential supports and services.

Please share your comments. We welcome any feedback or input that you would like to provide in order to make this kit as helpful as possible. Please email us at <u>Housing@autismspeaks.org</u>

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### Introduction

Moving out of the family home is one of the biggest milestones in a person's life. For those with autism spectrum disorders (ASDs), this can be a long and challenging process. Coordinating choices for the physical home as well as the necessary support services can be complicated, leaving families unsure of where to start. Our hope is that this tool kit will assist you and your family in planning for this important event and help you gain a better understanding of the housing and residential supports available to adults on the autism spectrum. The Autism Speaks Family Services Housing and



Residential Supports Tool Kit will enable you to understand the planning and decisions that may need to be made as you start planning for your loved ones to transition into their own homes.

#### **History of Housing and Residential Supports**

To understand the evolution of housing for people with autism and developmental disabilities, it is important to review the history. Less than a generation ago, most adults with autism and other developmental disabilities did not live with their families, but rather many were placed in large care facilities called **developmental centers**.

Beginning in the 1970s and 1980s, states began to serve more adults with developmental disabilities including autism in smaller settings through **community-based services**. During that time, **residential services** were increasingly delivered by **provider agencies**, many of them non-profit groups started and organized by parents. These agencies were often given a contract from the government to provide specific services and supports that were directly linked to their agency' housing; that is, in order to receive services, an individual had to move to a particular home or apartment where those particular supports were offered. Families had limited options, and there was no way for services and supports to follow the person if he or she needed to make a change. This model for residential services did not require the person or his or her family to help secure the house or fund the residential supports needed by the resident.

In recent years, there have been two major changes:

There has been a fundamental shift in how and where residential services and supports are planned and delivered. This new approach, sometimes called **self-directed services** or **person-centered services**, allows families and the individual to help plan the services separately from the housing itself. It gives families and individuals a bigger say in where the individual lives, what supports he or she receives and by whom those supports are provided. It can also give the family and individual more control over how money is allocated.

State and federal government funding – while still the *primary* source of funding – is now rarely the *sole* source of funding. Families and individuals are being challenged to identify a range of funding sources – both public and private – to help pay for housing and housing supports.

This new approach brings challenges as well as exciting opportunities for change. Individuals with autism and their families need information, expertise and support as they grapple with an avalanche of questions: Who buys the house? Who manages the property? Is a license required to start the home? How is staff hired? What role does my family play?

This tool kit provides information and resources needed by families as they explore housing and residential services for an adult with autism. It seeks to demystify complicated issues such as housing finance and rental subsidies.



### What Can I Expect from this Tool Kit?

#### The purpose of this tool kit is to:

- Provide an overview of housing options and the supports and services often needed by adults with autism.
- Describe options for funding capital costs, operating costs and residential services and supports.
- Create a structure to help families and, to the best extent possible, an individual with autism, consider and plan for the types of residential services and supports needed.
- Serve as a catalyst for expanding opportunities to meet the housing needs of people with autism.



"I cannot stress too much the importance of an individual moving out of his family home while his parents are still healthy enough and young enough to help in the transition process...while going through the process of finding housing is not for the faint of heart, there is no doubt that it is best for everyone."

> - Elaine, Mother of a 37 year-old man with autism who recently moved into his own home.



### **Success Stories**

Below are examples of individuals with autism living successfully in the community with supports:

Mitch became part of the Jay Nolan Supported Living Program in January 2006 at age 45. For the first time in his life, Mitch came to experience what it was like to have a home of his own. JNCS helped Mitch develop a support plan that would allow him to live in his own home and be part of his community as independently as possible with all of the necessary supports.





Nick shares a home in Northridge, California 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 and trying new things. He now exercises at a gym and loves to hike, bike and do almost anything physical.

Jay Nolan Community Services (JNCS) strongly supports the belief that people with developmental disabilities have the right to access assistance and supports and the ability to contribute to their respective communities. Support is specific for each individual's needs, interests, and desires. Visit the <u>Jay Nolan</u> website for additional information.

Below are examples of individuals supported through Autism Living And Working, Inc. (ALAW) located in Pennsylvania:

Rebecca and staff member Stacy get ready for a party at her three bedroom end-row home that she shares with her housemate Elisha (not pictured). They moved in nearly ten years ago in early 2002. The two families used a Limited Liability Corporation (LLC) model for this home.





Mike & Mike hanging outside their home. They moved in during the summer of 2000 and share their 3-bedroom twin brick home with another housemate, Matt (not pictured). The three families used the LLC model for this home as well.

A Limited Liability Company (LLC) is a business structure allowed by state statute. LLCs are popular because, similar to a corporation, owners have limited personal liability for the debts and actions of the LLC. LLCs are more like a partnership, providing management flexibility and the benefit of pass-through taxation. <u>IRS.gov</u>

Please see the <u>Autism Living And Working</u> website for additional information.

### Entitlement for Services vs. Eligibility and Availability for Services

Families of loved ones with autism are often surprised to learn that the services provided through the public school system do not continue after graduation or when their adult child ages out of the educational system. There are several fundamental changes that occur in terms of service provision. The following section explains these changes in more detail.

**The Individuals with Disabilities Education Act (IDEA)** allocates federal funding to state and local school districts to provide special education services to eligible students with disabilities. Under IDEA, a child is *entitled* to special education services (defined as a free and appropriate education in the least restrictive environment) from threethrough 21 (in most states).

Once the child leaves the school system, whether at age 18 or age 21, the educational entitlements of IDEA are no longer in place. Some refer to this scenario as when "the school bus stops coming to the home." We are emphasizing the shift to adult services in this tool kit so that individuals and families are very aware of the difference in an entitlement to services system such as public education, versus the adult service system, which is based on the availability of resources and the eligibility to receive specific services. Because there is a limited amount of resources in adult services, there are often waiting lists for these services. To better understand the transition from school to adult life, please refer to the <u>Autism Speaks Transition Tool Kit</u>.

### Waiting Lists

Although there are state-funded day services and/or vocational rehabilitation programs for adults when they transition from school to adult life, many families are surprised to learn that there can be a waiting list of five, ten and even fifteen years or more for residential services and supports that are funded with public dollars, specifically Medicaid Home and Communitybased Waivers\*. Families should be sure they understand the waiting list in their state and stay vigilant in pursuit of accurate information. They should begin planning as early as age 16 and take the time to research their state's funding structure for



housing and supports to minimize the waiting time. Information in this tool kit will help you to understand what the waiting list is and what you can do to learn more about your state's process and specific guidelines. You can find more state specific information in the Autism Speaks Resource Guide.

\*For more information, visit the Kaiser Family Foundation Commission on Medicaid here.

### What Rights are Afforded to Adults with Autism?

There are a number of laws that protect individuals with disabilities. To review these rights, click on the specific links below or click <u>here</u> to view a full list.

**The Rehabilitation Act** includes a variety of provisions focused on rights, advocacy and protections for individuals with disabilities. Section 504 of this act is a civil rights law that protects people with disabilities from discrimination related to services, employment and public accommodations. Section 504 applies to any institution that receives federal funds such as schools, public colleges, hospitals, non-profit agencies and public housing. Click <u>here</u> to learn more.

The Americans with Disabilities Act (ADA) is a federal law that prohibits discrimination against people with disabilities in employment, and mandates that these individuals have the right to public accommodations, as well as access to programs of public agencies. The ADA protects against discrimination only if the individual could participate in the program or perform the job with "reasonable accommodations." Without the accommodations, the individual must be "otherwise qualified." It is important to note that after high school, the accommodations accessed



through ADA or Section 504 are not provided automatically, but must be requested by you or your young adult with autism. Click <u>here</u> to learn more.

**Olmstead Decision** is the result of a 1999 United States Supreme Court decision. The Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity. Click <u>here</u> to learn more.

The Office of Fair Housing and Equal Opportunity (FHEO) administers and enforces <u>federal</u> <u>laws</u> and establishes policies that make sure all Americans have equal access to the housing of their choice. Click <u>here</u> to learn more.

**The National Disability Rights Network (NDRN)** is a nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the P&A/CAP network is the largest provider of legally-based advocacy services to people with disabilities in the United States. Click <u>here</u> to learn more.

### How Do I Begin the Housing Search?

When planning for the housing and residential support needs for an individual with autism, it is often best to begin by asking some basic questions about the specific types of supports and services the individual may need, and by considering his or her abilities, interests and preferences.

### **Questions to Consider:**

#### Supports and Services Needed

- Can I live alone safely?
- Can I take care of my personal hygiene needs?
- Can I organize and pay my own bills?
- Can I go grocery shopping?
- Can I cook?
- Do I need behavioral supports?
- Can I manage my own medication?

#### <u>Location</u>

- Do I need public transportation?
- Do I want to be able to walk to recreation areas, shopping and other community activities?
- Do I want to live near a hospital, movie theatre or family members?
- Do I need to be near my job or volunteer site?
- How close do I want my neighbors to be?
- Do I want a back yard?

#### Interests and Preferences

- Do I want to live alone or with a housemate? Does it matter?
- Do I want a dog, cat or other pet?
- Do I want my own bathroom?
- Do I want to be able to cook my own meals?
- Do I want the freedom to come and go as I please?
- Do I want to live with people of the same sex, opposite sex or both?

#### **Financial Considerations**

- What are the sources of my monthly income? How will this change over time?
- What are my monthly expenses?
- Do I have a special needs trust? How can those funds be used?

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The data suggests that the demand for housing across the country has significantly outpaced the supply with approximately 270,000\* people with developmental disabilities on a waiting list for housing. \*Click here for more information

### Putting the Pieces Together: Options for Housing & Models for Residential Supports

When planning for residential services and supports for an individual with autism, there are three aspects of housing that should be considered:

- 1) The housing itself and the costs associated with it, whether owned or rented.
- 2) Ongoing expenses such as utilities, water, heating, trash collection, cable, phone, etc.
- 3) Specialized services and support.

Depending on the individual's choices and preferences, all three aspects of housing can be combined, such as in the case of an agency-operated group home, or a home purchased and arranged separately.

### **Housing Options**

Generally speaking, housing options – sometimes referred to as "bricks and mortar" – are often the same as for any person looking for a place to live. These options include:

- A single family, stand-alone home
- Duplex, townhouse, or condo
- Apartment
- Room rental in a home

In addition, as part of the planning process, a family will want to consider the best option for securing housing:

- Ownership
- Rental
- Lease
- Со-ор



### 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.

### Services in the Community:

• **Supported Living** offers services to individuals with disabilities who are able to live 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.

\*As long as the supports are personalized, anyone can benefit from the supported living model, including those with the most significant support needs.

- 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.



- Group Living/Ownership (Co-op) is similar to group home living, except that the house itself is owned by a group of families or individuals who have formed a cooperative agreement. Caregivers hired by the cooperative, and 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 maybe others with or without disabilities.

- **Farmstead Communities** provide residential supports and services for a number of individuals within the context of a working farm.
- 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. Assisted living communities differ from nursing homes in that they don't offer complex medical services. Click here for more information on Assisted Living.



#### Services in Institutional Settings:

- Nursing Homes can be used to provide housing and support services to those who are more medically fragile or aged.
- 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. Some states that operate developmental centers are looking to shift people to more community-based settings and will only place a person in a developmental center on an emergency basis.

A decision to pursue separate housing and support services means the individual and the family will also have to decide if they want to plan and coordinate services on their own, or with the help of an agency.

"Ultimately, it is the people in the life of an individual with ASD that create a real home. However, the home itself, the physical environment, plays a critical role in promoting independence and improving the quality of an individual's life. A supportive and appropriate physical environment can shift the balance in favor of the person living a life in their home with the ability to make meaningful choices and experience greater control over their lives."

> George W. Braddock is the stepfather of a man with an ASD living independently, and the Founder of <u>Creative Housing Solutions, LLC</u>

### Funding for Housing

Once a family has considered the type of housing they are planning, they must next consider how it will be funded. There are a number of options:

#### **Agency-Owned Housing**

Provider agencies own and operate housing that is linked to specific support services. The Autism Speaks Family Services <u>Resource Guide</u> can help you locate residential service providers in your area. Agencies can have a variety of housing models, so calling them to discuss options and availability is critical to decision-making.



When working with an agency, families and/or individuals should ask:

- 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 that 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?
- Do residents have a choice if they want a roommate and what type of roommate they would like?

Agencies that have contracts with their state for residential services may also have funding contracts for day services. Because of the shift toward more self-directed services, an individual may live in a home operated by one agency and receive day services from a different agency, if that is his or her preference.

#### **Self-Funded Housing**

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

In order to pursue home ownership, families first need to determine if they can afford to purchase a house or



condominium, or if they will need to access public financing. To give you a better understanding of what buying a home entails and resources through the federal government through Disability.gov, click <u>here</u>.

For help to determine if you can afford a mortgage, click <u>here</u>.

When exploring ways to pay for housing, families should consider all resources available to them and the individual with autism 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.

Most public funding for projects is contingent on the individual'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. For a general overview of federal programs, visit the Housing and Urban Development's (HUD) website <u>here</u>.



There are too many programs to review in this tool kit, but we have highlighted several here that are more frequently used for people with disabilities. For a more comprehensive review of HUD programs, click <u>here</u>.

#### **Examples of HUD programs:**

- Low Income Housing Tax Credit (LIHTC) 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 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 which can be used to support affordable housing through land acquisition and infrastructure development.

### Other Funding Options Other than Low-Income Eligibility

**Large donor/charitable organization** – A single donor or multiple donors contribute the construction/acquisition funding through a 501(c) (3) organization that serves people with developmental disabilities.

**Private pay** – Families with resources pay for all services and the facilities together with other families.

### **Building a Team**

Housing can be arranged for a single person, or for several people. If you are planning to start a housing initiative for more than just your family member, it is important to have a **development team** working with you to add expertise on issues such as funding, design, and property management. A development team may include a property manager, an architect, a developer or contractor, social service agency, lawyer, and a banker. Most development projects use a combination of local, state and federal funding options.



### Funding for Operating Expenses

The individual with autism must be able to pay for room and board costs. Because adults on the spectrum have a disability and may have limited earned income and assets, they can usually qualify for generic resources for people with low income.

**Supplemental Security Income (SSI)** is paid directly to recipients. This is income to cover everything except medical care. An individual must be disabled and have a limited income including a maximum asset limit of \$2,000. SSI can be used to pay for room and board. Additional income from a job or private funds can be used as well. To determine if you qualify for social security resources, click <u>here</u>.

Families should also explore the use of 'generic' programs designed to help those with low incomes. There are programs to help pay for utilities, food, transportation and other costs associated with running a household. Visit <u>Disability.gov/benefits</u> to review assistance afforded to individuals with disabilities.

The Other Assistance Programs section includes information about programs that can help children and families with food, cash assistance and other needs. Visit <u>Benefits.gov</u> to find out about other federal and state programs.

- Family Assistance Programs
- Food & Nutrition
- Home Energy
- Prescription Drugs

### Funding for Residential Support Services

Most families cannot afford to privately support an adult with significant behavioral and/or medical needs. Therefore, it is critical to consider the support services that the individual will need to determine if appropriate and sufficient funding is available.

Families should discuss funding options with the state agency responsible for serving adults with developmental disabilities. In most states, individuals who need residential support will need to be eligible for **Medicaid** – a program designed to pay for intensive services. In the past, Medicaid funding was limited to those who lived in certain types of facilities. But now, through the use of **Medicaid Home and Community-Based Waivers**, people with autism and other disabilities can use these funds more flexibly. For more information on Medicaid and Medicaid Waivers, click <u>here</u>.

As stated earlier in this tool kit, many families are surprised to learn that the adult service system is not one of entitlement, but rather eligibility for services. Unlike special education services under the Individuals with Disabilities Education Act (IDEA), Medicaid Waiver services allow states to keep a waiting list, and allow states to limit the number of people served.

To find out about your state's Medicaid Home and Community-Based Waivers, click <u>here</u>, or contact your state's <u>disability services agency</u>.

### **Medicaid Benefits**

Individuals who qualify for SSI are eligible to receive Medicaid. Medicaid pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports, including institutional care in nursing facilities and, in some cases, non-specialized placements for people with disabilities.

To be eligible for Medicaid, a person must fit in a specific category of

coverage (i.e. age 65 or above, blindness, disabilities), and meet income and assets requirements.

### Medicaid Home and Community-Based Waiver Services

Waiver services are an option available to states to provide integrated community-based longterm care services and supports to qualified Medicaid recipients. The programs "waive" some of the rules of Medicaid to serve children and adults otherwise requiring an institutional level of care who can instead be served at home or in the community. Medicaid is a state-administered program and each state sets its own guidelines.

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These programs may provide a combination of both traditional medical services (i.e. dental services, skilled nursing services) as well as non-medical services (i.e. respite care, case management and/or environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. For more information, click <u>here</u>.

#### **Other Funding Methods for Support Services**

There are other methods of funding services that do not require a Medicaid Waiver, but the available funds are limited and usually unable to support the full scope of services that an adult with autism needs.

These include:

- Family support dollars
- Private funding
- Private health insurance
- State-only funding
- Local funding
- Grants and foundations



Regardless of the funding mechanisms available, planning is crucial.



### **Planning Tool: Needs and Priorities**

One of the first choices families face is how to structure support services. Families can work with an agency, or they can manage services independently. Use this form to explore what is important to you in each area. The blank spaces are for you to fill in

other things that matter to you and will be important considerations. The first box has been filled in as an example.

Considerations	Our Needs and Priorities	
Budgeting	It is important that we have control over the budget and can	
	choose how David's budget is spent.	
Flexibility		
Staff Hiring, Training		
and Supervision		
Budgeting		
Portability		
Emergency Supports		
Self-Direction		
Service Management		
& Coordination		
Behavioral Supports		
Paperwork		

### While You Wait: Securing Family Support Services

If an individual wants to remain at home, or is waiting for residential support services, the family may be eligible for some type of family support services. Although these services vary by state, family support services can include inhome respite care, out-of home respite care, short-term nursing services, cash subsidies, voucher services and environmental adaptations and modifications. For individuals experiencing behavioral crises, most states provide short-term, temporary out-of-home residential services designed to support an individual and his or her family through challenging times, while creating behavior plans once the individual returns home.



Family support is designed to give unpaid caregivers temporary relief from the tasks associated with care giving.

To see if your state has a formal state respite coalition, click here.

To review a state-by-state resource guide developed by the Family Caregiver Alliance, click <u>here</u>.

To access the Autism Speaks Family Services website and tool kits, click here.

In addition to funding options, there are resources for people with disabilities that can be used for a person to live more independently through traditional disability services. A helpful website is <u>Disability.gov</u>, which has links for the following specific information:

- Personal assistance services
- Independent living resources
- Sports and recreation
- Travel tips
- Guidelines on accessibility
- Volunteer opportunities
- State specific information

### **Planning Tool: Funding Options**

The following form can help you identify and document ways to help pay for services. For each arrangement you are considering, use this tool to explore options that can be used to pay for the three main areas needed.

#### Housing and Support Option: \_\_\_\_\_

Housing Mortgage and Finance Agency (HMFA)		
John Doe		
732-555-1555		
jdoe@autismspeaks.org		
www.autismspeaks.org		
\$50,000		
Must be within HUD guidelines		
Call John on 12/2/11 at 3 p.m.		
Medicaid Home and		
Community-Based Waiver		
Susan Doe		
609-555-1234		
sdoe@autismspeaks.org		
www.autismspeaks.org		
\$100,000		
Must be within the state's Medicaid Waiver Guidelines		
Call case manager		
	Agency (HMFA)John Doe732-555-1555jdoe@autismspeaks.orgwww.autismspeaks.org\$50,000Must be within HUD guidelinesCall John on 12/2/11 at 3 p.m.Medicaid Home and Community-Based WaiverSusan Doe609-555-1234sdoe@autismspeaks.orgwww.autismspeaks.org\$100,000Must be within the state's Medicaid Waiver Guidelines	Agency (HMFA)John Doe732-555-1555jdoe@autismspeaks.orgwww.autismspeaks.org\$50,000Must be within HUD guidelinesCall John on 12/2/11 at 3 p.m.Medicaid Home and Community-Based WaiverSusan Doe609-555-1234sdoe@autismspeaks.orgwww.autismspeaks.org\$100,000Must be within the state's Medicaid Waiver Guidelines

Federal Resources	Social Security, Supplemental		
for Operating Funds	Security Income (SSI)		
Name of Contact	Matt Doe		
Phone Number	732-555-1234		
Email Address	mdoe@autismspeaks.org		
Website	www.autismspeaks.org		
Funding Amount	\$600 per month		
Restrictions	Within SSI guidelines		
Follow-up Needed	Social security office		
State Resources for			
Capital Funding			
Name of Contact			
Phone Number			
Email Address			
Website			
Funding Amount			
Restrictions			
Follow-up Needed			
State Resources for			
Support Services			
Name of Contact			
Phone Number			
Email Address			
Website			
μ	1	L	1

Funding Amount			
Restrictions			
Follow-up Needed			
State Resources for			
<b>Operating Funds</b>			
Name of Contact			
Phone Number			
Email Address			
Website			
Funding Amount			
Restrictions			
Follow-up Needed			
Local Resources for Capital Funding			
Name of Contact			
Phone Number			
Email Address			
Website			
Funding Amount			
Restrictions			
Follow-up Needed			
Local Resources for			
Support Services			
Name of Contact			
Phone Number			
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Email Address		
Website		
Funding Amount		
Restrictions		
Restrictions		
Follow-up Needed		
Local Resources for		
Operating Funds		
Name of Contact		
Phone Number		
Email Address		
Mahaita		
Website		
Funding Amount		
Restrictions		
Follow-up Needed		
Private Resources		
for Capital Funds		
Name of Contact		
Phone Number		
Email Address		
Website		
Funding Amount		
Restrictions		
Follow-up Needed		

Private Resources		
for Support Services		
Name of Contact		
Phone Number		
Email Address		
Website		
Funding Amount		
Restrictions		
Follow-up Needed		
Private Resources		
for Operating Funds		
Name of Contact		
Phone Number		
Email Address		
Website		
Funding Amount		
Restrictions		
Follow-up Needed		



### Additional Resources

### **The Corporation for Supportive Housing**

CSH is a national non-profit organization that helps communities create permanent housing with services to prevent and end homelessness.

### The Technical Assistance Collaborative Inc.

TAC is a national non-profit organization that works to achieve positive outcomes on behalf of people with disabilities, people who are homeless, and people with other special needs by providing state-of-the-art information, capacity building, and technical expertise to organizations and policymakers in the areas of mental health, substance abuse, human services, and affordable housing.

### **Creative Housing Solutions LLC**

Creative Housing Solutions provides consulting, technical support, planning and ownership advice, architectural support services, and education in support of the design of environments that support people with varying abilities, interests and lifestyles.

### Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders

The Opening Doors report is a collaborative study by the Urban Land Institute (ULI) Arizona, Southwest Autism Research & Resource Center (SARRC), the Arizona State University (ASU) Stardust Center for Affordable Homes and the Family and the ASU Herberger Institute School of Architecture and Landscape Architecture.

### The National Council on Disability - The State of Housing in America in the 21st Century: A Disability Perspective

This report looks at the state of housing for people with disabilities with the intent to provide recommendations that can improve housing opportunities. The research contained in this report provides a comprehensive overview of the state of housing in the 21st century and answers important questions about the current housing needs and options for people with disabilities living in the United States.



### US Department of Housing and Urban Development (HUD)

HUD Section 811 Program Resource Center

### Autism in the Workplace

This page on the Autism Speaks website highlights individuals with autism who are working as well as testimonies from their employers.

#### National Association of Residential Providers for Adults with Autism

NARPAA is an organization that works to assure the availability of residential services and other supports for adults with autism throughout their lives.

#### **The National Service Inclusion Project**

NSIP is a Corporation for National and Community Service (CNCS) training and technical assistance provider. Through comprehensive training, technical assistance, and product dissemination, NSIP strives to ensure meaningful service experiences for all Americans, regardless of their abilities. Most services are free of charge.

#### How to Get Assistive Technology

AT refers to any device, piece of equipment, product or a system that helps people with disabilities fully participate in school, the workforce or in their communities.

#### Advancing Futures for Adults with Autism

AFAA is a national consortium of organizations working together, led by the vision of individuals with autism and their families, to promote a collaborative spirit and develop both public and private sector support that improve the lives of adults living with autism.

#### National Association of Residential Providers for Adults with Autism

NARPAA is an organization that works to assure the availability of residential services and other supports for adults with autism throughout their lives.

#### **Disability Opportunity Fund**

The Disability Opportunity Fund is a non-profit banking institution which provides creative financing solutions for people with disabilities and their families. The DOF provides capital and double bottom line returns to its investors.

#### **Hello Housing**

We do more than develop affordable housing for underserved communities. We help transform lives. By bringing together a unique mix of partners and resources, we turn compelling ideas into meaningful solutions.

Legal Guidelines, prepared by Goodwin Procter, LLP for Autism Speaks

### **Glossary of Terms**

Apartment: a self-contained unit that is part of a larger building. It is rented not owned.

**Community based services**: support services for an adult with autism or other developmental disability that is provided in a setting that anyone in the public would use.

**Condo:** a housing structure that is a part of a bigger unit or building. The owner owns only the interiors of the condo.

**Co-op**: a mutual agreement to buy a home or unit with more than one owner.

**Development Team**: a group of experts in a particular area of housing services and supports that work together to secure property, build a residence, maintain the property, and provide the support services for adults with autism or other developmental disability.

Lease: renting a home or unit from the owner.

**Ownership**: the tenant or their family owns the home.

**Provider agencies:** a non-profit and/or private provider of a particular service to an adult with autism or other developmental disability that may include respite care, day habilitation, job coaching, etc. In housing services, the provider agency may own the residence; just provide the support service or both.

**Rental:** the tenant rents a home or unit but does not have ownership rights.

**Residential services:** services through a contracted provider that supports an individual with autism or other developmental disability to live in a residential setting rather than a nursing home or developmental center.

Room Rental in a Home: the resident is renting a bedroom in a traditional house.

**Self-directed** or **person-centered services:** a process by which the delivery of service is directed by the consumer (the individual receiving the service) that includes directing the budget,

possibly hiring and firing staff, etc.

**Single family, stand-alone home**: a traditional house that occupies one family.

**Supplemental Security Income (SSI**): A program funded by the Federal Government to provide cash benefits to disabled adults and children who have limited income and resources.

**Townhouse:** a style of housing where a row of independent and identical houses share walls.



The owner owns the land as well as the interiors, plus any yard or deck, and generally pays a fee for maintenance.



### **Autism Speaks Housing Committee**

Curtis Arledge, Chair*	Ilene Lainer
Peter Bell	Leslie Long
Ramsey Frank	John Maltby
Mike Glenn*	Jack Manning
Lisa Goring	Kevin Murray*
Charles Hammerman	Peter Olberg
Nicholas Hegarty	Denise Resnik
Adrian Jones*	James Schwab
Brian Kelly*	Mike Vranos

\*denotes Autism Speaks Board Member



### **Our Mission**

At Autism Speaks, our goal is to change the future for all who struggle with autism spectrum disorders.

We are dedicated to finding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.



www.AutismSpeaks.org