

**FINDING A HOME  
FOR ADULTS  
WITH DISABILITIES**

**in Harrisonburg,  
Rockingham County and Vicinity**



**Produced for the Lifespan Project  
of The Arc of Harrisonburg and  
Rockingham, Virginia**

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This guide is one of six developed for parents of children with intellectual disabilities under the auspices of The Arc of Harrisonburg and Rockingham. It focuses on key life decision points: receiving a diagnosis and having a child with a disability enter an early intervention program, starting school, transitioning out of the school system, securing employment, finding a place to live outside the caregiver's home, and aging with a disability.

All of the guides can be found at <http://www.hrarc.org>. The printed version of this guide is prepared periodically. As information changes, updated information and resources may be found on our website.

If you know of a resource that you would like to be added, please email the Executive Director of The Arc of Harrisonburg-Rockingham at [execdir@hrarc.org](mailto:execdir@hrarc.org) with your suggestion. The Executive Director maintains the discretion to accept or decline any suggestions pertaining to this resource. The most recent information will be posted on the web and will precede the publication in hardcopy.

If you found this guide to be helpful, please consider making a donation to The Arc of Harrisonburg and Rockingham so that we may continue to provide these valuable guides. Please make a note Guides in the memo line of your check.

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## INTRODUCTION TO LIFESPAN

Developmental Disabilities (DD) by definition last a lifetime, so caring for a loved one with DD is a lifelong responsibility. Because of the nature of these disabilities, caregivers must make crucial (and often very difficult) decisions throughout the lifespan of their loved one—where he or she will go to school, what they will do for recreation, where they will live, and how to ensure his or her financial security once the caregiver is no longer there.

While caregivers want to make the best choices for their loved one, research shows that many do not have the resources to do so. A national survey by The Arc found many families struggling to help their loved one with a developmental disability:

- 44% of families surveyed don't have enough money for needed care and almost half report having more care giving responsibilities than they can handle
- 71% can't find after school care, community services or summer activities for their loved one
- 91% report they don't have enough information to make good choices about housing options
- 92% report that they don't have enough help in planning for the future.
- 54% report that their adult family member with DD was not employed either full- or part-time
- 75% of families have no long-term care plan

### About LIFESPAN

Families need realistic, actionable information with which they can make a wide range of decisions as their child grows up. Providing this information is the mission of The Arc of Harrisonburg and Rockingham Virginia's Lifespan project.

Lifespan focuses on six key decision points in the lifetime of an individual with a developmental disability:

- Receiving a diagnosis and having a child enter an early intervention program

- Starting school and entering the special education system
- Transitioning out of the school system and into Adult services
- Entering the world of work
- Finding a home
- Aging with a disability

For each lifespan phase, we provide materials in both print and digital formats, online resources, and workshops.

The information found in this guide is applicable to all people with developmental disabilities and their families, although much of the contact information for resources are particular to the Harrisonburg and Rockingham area. To explore resources specific to your local community, contact the Community Services Board (CSB) in your region. You can find your local CSB in visiting Department of Behavioral Health and Developmental Services (DBHDS) at <http://www.dbhds.virginia.gov/community-services-boards-csbsor>. The CSB is the point-of-entry into the publicly-funded system of services for people with mental health, intellectual, and developmental disabilities. Also, visit The Arc of Virginia at <http://www.thearcova.org> to find the local Arc chapter in or near your community.

### Help for You, the Parent and/or Caregiver

As a first step in Lifespan, we have written six guides to address important issues that parents should consider at each of these important life stages. The guides are designed to help you recognize opportunities, weigh options, and work through decisions. Checklists, timelines, worksheets, and links to other resources are included wherever possible. Each document has also been reviewed by a task force of parents and professionals with relevant experience and expertise.

Although each guide addresses issues related to a specific phase of life, each repeats information parents and caregivers need to know whether their loved one is two, 22, or 62 years old: how to protect your loved

one's financial future, how to apply for benefits, and where to go for more help.

### **Your Rights and Responsibilities**

This is not a legal document and does not spell out your or your child's rights and responsibilities under the law. Every effort has been made to verify the information in the document, but please be aware that items such as program regulations, deadlines, fees, and contact information can change. Referrals to organizations and individuals are for informational purposes and do not constitute an endorsement of their services. Please send any comments to Heather Denman, [Execdir@hrarc.org](mailto:Execdir@hrarc.org) or to The Arc of Harrisonburg and Rockingham, 620 Simms Ave, Harrisonburg, VA 22802.

### **FINDING A HOME FOR ADULTS WITH DISABILITIES: An Introduction**

We all need a safe, clean, comfortable place to live. If you're a person with a disability, or you are helping someone with a disability, you may have already discovered that finding such a place is difficult. Lack of physical housing, long waiting lists for waivers and affordable housing, and reduced government funding for rental subsidies all make finding a place outside the family home a challenge. Moreover, rents in Virginia can be relatively high, and many places have limited physical accessibility features.

These conditions require families to begin planning for their loved ones' housing earlier than ever, to begin talking with other families and friends, and to **be creative**. Families across the country are finding housing solutions for and with their family members who have disabilities. However, these options can take several years or more to develop and require ongoing support and coordination to sustain. Taking steps now can prevent the task from becoming overwhelming in the future.

#### What's In This Guide

To help you with this task, this document addresses the following issues:

#### **Who qualifies for government housing support.**

Your family member may be eligible for Supplementary Security Income (SSI) or Social Security Disability Income (SSDI) from the Social Security Administration; SSI benefits must be used

for food or housing-related needs, such as rent and utilities. Some adults with a developmental disability may be eligible for a Developmental Disabilities Medicaid Waiver, which would make them eligible for supports in certain housing programs.

**What publicly financed housing is available.** All localities have some publicly-supported programs for housing.

**How different options work.** Because not everyone qualifies for or can afford every option, at the end of every chapter we weigh the pros and cons of that choice.

**Whether support services can be integrated with housing.** For many people with disabilities, a home would not be a safe place to live unless supports are built into the housing model, or supports can be brought in. This guide provides information on how you can use a variety of support options in each housing model.

**Which steps to take now to protect your loved one's financial future.** As a parent, you need to have a Will as a way of protecting all your heirs, whether they have a disability or not. You also need to create a Special Needs Trust to protect any public benefits that your loved one with a disability receives or may receive.

#### A Brief History of Housing in Virginia

The civil rights of and social attitudes towards individuals with disabilities have evolved considerably over the last century. These changes are reflected in the Department of Justice Settlement Agreement that focuses on increasing community-based options for individuals with disabilities.

**From a Medical to an Inclusion Model<sup>1</sup>** Until the mid-1900s, public policy regarding individuals with disabilities was steeped in a **medical** model that viewed individuals with disabilities as sick or broken and doctors as the experts who could cure or fix them. However, as parents began to advocate for free, appropriate public education for their children with disabilities in the mid-1900s, the medical model gave way to an **educational** one—training individuals to perform basic adaptive living skills so they could fit better into the community.

The civil rights movement in the late 1960s continued the push for an end to discrimination, segregation, and isolation and called for equal treatment and equal access to goods and services in government, public accommodations, and housing. The Americans with Disabilities Act adopted these principles on behalf of people with disabilities in 1990, and the Fair Housing Act was amended in 1991 to prohibit discrimination against people with disabilities with regards to real estate.

These new laws were accompanied by changes to the federal Medicaid program in the late 1980s to early 1990s that permitted states to apply for Home- and Community-Based Waivers. The waivers allowed individuals to opt out of having Medicaid pay for care in skilled-nursing or intermediate-care facilities, and instead use those funds to pay for supportive services in community-based settings. This was the beginning of the **integration** model.

During the 1990s, the independent living movement for people with disabilities gained significant momentum. The movement's slogan was "nothing about us without us," and it emphasized principles of consumer choice and control over services and housing: a paradigm of **inclusion**.

### **Where We Are Now**

The principles of independence and consumer choice are reflected in the 2012 Department of Justice settlement with The Commonwealth of Virginia. The settlement requires Virginia to ensure that community-based supports are viable options for **all** people with DD. In response, the state decided to close four of its five training centers (institutional settings for people with DD) and move toward a community-for-all model.

As part of the Settlement Agreement, the Commonwealth has developed a Housing Plan to increase access to independent living options (such as homes or apartments) for **anyone with DD who is interested**, not just those leaving the training centers. The goals of the Housing Plan include expanding the inventory of affordable, accessible rental units for individuals with disabilities, increasing access to rental subsidies, and building awareness of the choices for independent living.

The plan emphasizes decoupling housing and services. In this way, an individual's choice about where he or she lives is a separate decision from where he or she obtains services (which is currently not the case for those living in group homes).

### **Fair Housing Act**

The federal Fair Housing Act prohibits discrimination in the sale or rental of housing based upon race, color, national origin, religion, sex, familial status, or disability. Discrimination includes refusing to rent or sell, setting different terms or conditions on rentals or sales, and denying that housing is available.

If you rent a home, your landlord may not refuse to let you make reasonable modifications to the home to make it accessible for you. However, they do not have to pay for these modifications and may mandate that the home be returned to its original condition when you leave.

**If you think your rights have been violated** because of your disability, contact the office of Housing and Urban Development (HUD) at (888) 799-2085 or go online at <http://www.hud.gov/complaints/housediscrim.cfm>. You only have one year to file a complaint after you feel your rights have been violated.

VA Fair Housing Office:

(804) 367-8530

(888) 551-3247

<http://www.dpor.virginia.gov/FairHousing/>

### **The Key to Funding:**

Housing vs. Residential Services

Many individuals with developmental disabilities will need both housing and residential support services to be able to live in the community. It's important to understand the difference between these two in order to understand your child's options.

**Housing** is the physical place where one lives, or refers to the rental assistance to pay to stay in the physical home. Housing could be your family home, an apartment, a rented room, or a home purchased for your child (group homes are not housing in this sense; see below). The cost of the housing itself (rent or

mortgage, property taxes) are the responsibility of the property owner/renter.

Because many individuals with disabilities cannot afford the high rents in this area, there are public programs to help with rent (housing choice vouchers, State Rental Assistance Program [SRAP], public housing, and below-market rate units). However, in reality **the waiting lists for these programs in Central Virginia are often long and/or closed, with the exception of SRAP which is currently accepting referrals.**

**Residential Services** refers to the support and supervision provided by caregivers hired by individuals or through an agency. Residential services may be available for individuals living in the family home, apartments or rented rooms, if they qualify for public funding of residential services (have a waiver), or can pay privately for someone to come in. In this case, the services would go wherever the individual goes; for example, they could switch apartments and the supports would follow.

However, for residential programs such as group homes, the physical housing and the residential services are tied together; the **housing is considered a residential service rather than housing. Because the cost of these programs is so high, only persons with Medicaid waivers typically can afford them.** Even with a waiver, the individual still has to pay a residential fee, typically a portion of their SSI/income.

#### Some Creative Alternatives

Because access to public housing and group home-type options is very limited, parents and housing advocates are working to develop alternatives. This guide discusses some of these alternatives, including microboards and life estates (see section **Finding a Home: Privately Financed Options**).

The Arc of Northern Virginia maintains a Google group housing listserv. If you would like to join this group, request to join here:  
<https://groups.google.com/forum/?hl=en#!forum/arc-nova-housing-resource-forum>

## DEVELOPING A PLAN FOR HOUSING: Seven Issues to Consider

At present, families have two possible ways to finance housing for a family member with a disability. The first would be to have most of the cost of both physical housing and services supported by public funds (Medicaid Waiver and Social Security).

The second would be to have the physical housing such as an apartment or house supported by private funds (or rental assistance), and services partly or totally paid for with public funds (such as with Medicaid Waiver, CSB funding, or the like).

Whatever the source of funding, you and your family need a concrete idea of when your adult child with a disability will want or need to move out of the family home, what their requirements are, and what housing is actually available to you.

### Checklist For Housing

- Think about timing and the need for housing
- Identify loved one's housing needs and preferences
- Review financial resources that could possibly be applied toward housing
- Discuss "social assets," such as family and friends.
- Consider building or reinforcing your circle of support
- Apply for waivers, SSI/SSDI, Medicaid and get on housing waiting lists, if you haven't already
- Explore housing options in your community
- Make a housing budget

### 1. Consider Timing

Thinking about having a loved one with a disability move out of the family home is extremely difficult for many parents. But it behooves parents at the very least to have a plan in place. First, even if your adult child

is ready to move, finding appropriate housing can take years. Second, if the time arrives when you are unable to care for your adult child, a plan can guide future caregivers in providing the type of life (and home) that you and your son or daughter have envisioned. Issues to consider in looking for housing, and the timing for your search, include:

- Best estimate of when your loved one would be interested/need a new housing situation (one year, 3 years, five years)
- Your age and the age of your spouse
- The age of your adult child's siblings
- How far away siblings and other family members live from you
- Changes in your health status
- Changes in the health status of your loved one with a disability
- Any expressed desire by your family member to move and/or be more independent
- Desire to have them settled before you are no longer able to support them in your home

## 2. Identify Housing Needs and Preferences

When discussing housing needs and preferences, consider:

- Proximity to family members
- Need for familiar surroundings (such as being in same neighborhood as childhood home)
- Walking distance to public and/or accessible transportation
- Proximity to employment, recreation activities, doctor/health care, shopping and banking
- Preference for private bedroom and bath
- Need for room for live-in caregiver or guests

- Amount of staff support needed (full-time live in, rotating throughout day, or drop-in support)
- Need/desire for social contact within the home: live alone, with one or more roommates, or in a group environment
- Level of social interaction wanted/needed outside the home

For assistance in defining and clarifying your support needs and preferences, visit the online toolkit at <https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/home-toolbox/>, for an example of a **Support and Housing Needs Assessment** and a **Housing Needs Profile**.

### 3. Review Financial Resources

In developing a financial plan for housing, you need to think about funding for two separate items: the cost of securing a physical space to live (down payment, mortgage, or rent), and secondly, the cost of support services (payment for people who provide supervision, caregiving, and similar services) for the individual.

**For those with a Medicaid Developmental Disabilities Waiver:** A Family-Support or Building-Independence Waiver can pay for the cost of support services (in certain approved settings) but the cost of rent is separate and must be paid for by the individual with a DD. A Community-Living Waiver pays for a congregate setting or group home and the person's income pays for the rent there.

**For those without a Medicaid Developmental Disabilities Waiver:** For those who do not have a waiver, it will be necessary to find resources to pay for the physical housing and support services (if needed by the individual).

To fund housing, consider assets such as current savings and investments, real estate, income from benefits such as SSI, and potential inheritances. Although funds from a Special Needs Trust may be used to support housing, doing so will reduce SSI benefits. The CCC (Commonwealth Coordinated Care) Plus Waiver may be used to fund limited supports.

#### 4. Identify Social Assets and Build Support Networks

Not all assets are financial. As you start to think about how to move towards a long-term plan for housing and supports, think about the social assets you have—your support network. The most important resource your loved one will ever have is the community of people who will care about—and care for—him or her. This community is often termed a **Circle of Support**.

A **circle of support** is a group of people who are willing to help create and carry out a plan focused on the physical, emotional, and financial well-being of your family member with a disability.

This network may include family members, teachers, doctors, family friends, neighbors, lawyers, realtors, financial planners, co-workers, and anyone who would like to help. Some members of your loved one's circle of support will be long-term participants, while others may be invited to join for a limited period of time in order to accomplish specific tasks or goals of the individual with a disability.

In deciding on housing for your adult child with a disability, people in your loved one's circle of support could help with such things as developing a budget, applying for programs, accompanying on visits to potential group homes, and helping to interview roommates.

#### Developing a Circle of Support

A Circle of Support begins with members of the immediate family and then radiates out to include people who volunteer their time and energy to support your loved one, as well as paid professionals and service providers.

#### The Parts of the Circle

Circles of support should be as diverse as possible to address the needs of your loved one. However, you can count on change: individual members of the circle may drop out of the circle for a while, switch roles, or move on and be replaced. The important thing is to maintain a balance of the types of people in the circle beyond family, including but not limited to:

- Your loved one's friends

- Other same-aged peers (such as from work, church choir, or an art class)
- Family friends
- Neighbors
- Co-workers of siblings or other family members
- Coaches, adaptive recreation staff
- Religious personnel
- Current or former teachers
- Doctors, therapists
- Employers/supervisors
- Day program staff
- Aides, attendants, or companions
- Lawyers, realtors, financial planners
- Caseworker in local human services agency
- Staff at local advocacy organizations, such as The Arc
- Residential services staff

Everyone has someone who could participate in the Circle of Support, even where there are no siblings or other close relatives. Many people don't feel comfortable taking on the whole plan, but most people are happy to lend advice and some time and effort.

#### Finding a Role

It takes a true community to secure the health, safety, and emotional and spiritual well-being of a human being. Members of your loved one's support system need to share various roles, and each person gives what they feel comfortable contributing. This, in turn, may depend on that person's:

- **Current relationship with the family member with a disability.** Siblings, family members or

friends who know and understand your loved one with a disability.

- **Comfort level with handling personal details of someone's life.** Taking on the job of trustee or conservator, for example, means being Comfortable making financial decisions for/with someone else. Those with full guardianship will also be helping make medical and even social decisions.
- **Current and anticipated time commitments around family and career.** Discuss how much time (and supervision) would actually be involved in a particular role and whether you could realistically perform that commitment on a consistent basis
- **Professional or personal expertise and interests.** Nothing is better than having cousins who like baseball, biking or baking if your loved one does too! Matching the needs and desires of your son or daughter with the interests and abilities of the Circle of Support is a win-win for everyone.

Consider **all** the ways a person could participate in the life of the individual with a disability. For example, people in the Circle of Support may help by

- Lending emotional support and serving as a sounding board
- Helping advocate for the person with a disability on the job, in the community, or in a residential setting
- Teaching a life skill like cooking or using a cell phone
- Arranging outings in the community, including attendance at religious services if desired
- Ensuring birthdays, graduations and anniversaries are recognized and celebrated
- Providing property management or maintenance services

- Giving logistical help, like offering rides, respite care or providing meals
- Planning vacations or summer camp experiences
- Serving as a travel companion or arranging for one
- Acting as drop-in eyes and ears on a job
- Advising on legal, financial, educational, or medical issues (depending on their expertise)
- Referring the family to resources
- Volunteering to be a caregiver in an emergency or a companion while the person is in the hospital
- Acting as guardian, trustee, or representative payee (these have specific duties)

#### Starting with the Family Circle

An essential first step would be to hold a family meeting. Make this first meeting low-key, maybe a family picnic or a get-together over dessert. This is an opportunity to discuss all the issues and ramifications of various roles:

- Make a list of the various caregiving and decision-making roles that will need to be assumed once you are no longer the caregiver
- Begin honest discussions about what each role entails in terms of time, energy, and knowledge. Assign someone to do research if necessary so that the duties of a particular role are clearly spelled out
- Brainstorm about anyone and everyone who might be included in a Circle of Support. Have the family member with a disability talk about who they like to spend time with (and who they don't)

Utilize the **Circle of Support Chart** found in our online toolkit to help you sort out who might play what roles.

<https://thearcofnova.org/programs/transition/findi ng-home-adults-disabilities/home-toolbox/>

## Getting the Circle Together

The next step would be to reach out to possible members of the Circle of Support and set up a meeting (in person if at all possible). Don't discount those who may live out of town; they can always participate using Skype, Facetime, or email.

Be clear about why you want them to come and that there's no commitment to participate in this first get-together. It's also a good idea to choose someone to facilitate the meeting and to draft an agenda so that everyone knows what's going to be discussed (and how long the meeting may last).

For more information on setting up and running a Circle of Support, see

<http://www.iidc.indiana.edu/?pageId=411>

Some families may want to consider a more formalized version of a Circle of Support, called a Microboard. Microboards are discussed in more detail later on.

### 5. Apply for Benefits

See the sections in this guide on **Applying for Social Security Disability Benefits** and **Applying for Medicaid Waivers** for information on eligibility and application requirements.

### 6. Explore Housing Options

This section discusses housing options that may be available in the Harrisonburg and Rockingham area.

### 7. Make a Housing Budget

To make a budget, take into account all of your assets and all of the costs. Sources of income include public benefits that could be used for housing and/or support services in a residence, Medicaid Waivers, and Supplementary Security Income (SSI) payments.

Private funds for housing and support services may come from earnings of the individual with a disability, his or her special needs trust funds, military benefits, insurance payouts, or from parents or other family members.

Costs include rent or mortgage payments, utilities, real estate taxes, home repairs, and staff support costs, among others. Use the chart below to start calculating

what may be affordable. The income must be greater than monthly costs. Also consider having some money set aside for emergencies or unexpected expenses. Once you have this sheet completed, you can start to consider the options that may fit your budget.

For assistance in developing a **Household Spending Plan**, as well as a **Budget for Moving Expenses**, utilize the forms found at our online at

<https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/home-toolbox/>.

Options created by families often have the advantage of more closely matching the individual's needs and preferences, as well as having built-in monitoring- and quality-assurance mechanisms.

**A note about staff support costs.** Remember that unless personal care support is being funded through a Medicaid Waiver, you may need to factor the cost of support staff into your monthly budget. Think about how often you need staff and whether or not you can share staff with housemates. Also, consider having a caregiver live in the home of the person with a disability in exchange for free or reduced rent.

Currently the CCC Plus Medicaid Waiver pays \$9.87/hour for Consumer-Directed staff

[http://www.dmas.virginia.gov/files/links/5331/CCC+%20Waiver%20Web%20file%2003\\_24\\_2020.pdf](http://www.dmas.virginia.gov/files/links/5331/CCC+%20Waiver%20Web%20file%2003_24_2020.pdf).

Many families report having a great deal of trouble finding a well-qualified person willing to work for that salary. It is important to note that if you're using a waiver to hire staff, you may not legally supplement their rate of pay. For more information, see:

<http://www.dmas.virginia.gov>

However, you may pay for activities that the waiver doesn't cover. If you're hiring someone **privately** to serve as a staff attendant, you may need to consider offering more money for staff in order to find the right person for the job. Also, keep in mind the support they will need to provide. If you require someone who has a lot of experience with medical care, who can manage challenging behaviors, or someone who will have to provide a lot of lifting and physical care, you may need to spend more money.

### Your Housing Budget

Income Source	Costs
Social Security Benefits:	Rent/Mortgage (including property insurance, reserve funds, HOA/condo fees, and real estate taxes):
Wages:	Utilities:
Housing Supplement:	Property Manager:
Energy Assistance:	Home Maintenance:
Supplemental Nutrition Assistance Program Benefits:	Phone/Internet:
Checking/Savings Account:	Trash/Recycling:
Special Needs Trust:	Food:
Insurance Payouts:	Recreation:
Military Benefits:	Medical Supplies/Co-Pays:
Other Income:	Support Staff:
<b>TOTAL:</b>	<b>TOTAL:</b>

#### **APPLYING FOR BENEFITS: Social Security Disability Programs**

You may begin the application process for Social Security benefits on your child’s 18th birthday. The first step is to **determine eligibility** for any benefit program; the Social Security Administration (SSA) will decide which program is appropriate.

#### **SSI and SSDI**

For both Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), **a person must meet SSA’s definition of disability**. Disability is defined as the inability to engage in Substantial Gainful Activity (SGA) by reason of any medical (physical and/or mental or blind) impairment. The disability must have lasted or be expected to last for a continuous period of not less than 12 months or result in death. For 2020, the wage limit for the SGA is \$2,110 gross income/month for blindness and \$1260 gross income/month for those without blindness.

**SSI.** SSI is a cash assistance program for those with limited income AND are either 65 years old or older, or blind, or have a disability. Adult SSI beneficiaries must have limited income and resources, (\$2,000 in assets). Parents’ income does not count for adult

applicants. You do not need to have any work history. Monthly benefit payments are determined by the current benefit rate (\$783 a month in 2020), minus any **countable income**. If eligible for SSI, you will also be eligible for Medicaid.

**SSDI.** While SSI is a needs-based program, SSDI is an insurance program with benefits dependent on previous payments into the system. In other words, SSDI beneficiaries must have worked enough (or their parents or spouses must have worked long enough) to have made contributions into Federal Insurance Contributions Act (FICA). Monthly benefit payments are based on the worker’s lifetime average earnings covered by Social Security.

#### **Applying for Benefits**

The steps for applying are:

Start with a disability report. Go to the website at <http://www.socialsecurity.gov/pgm/ssi.htm> and click on Disability Report for Adults. (You may also call 1-800-772-1213 or go to a Social Security Field Office.) Fill in as much information here as you can prior to your appointment at the local office. The application asks for names, addresses and telephone numbers of doctors and therapists who have treated your child and

information on any hospitalizations. More descriptive medical records—such as a letter explaining a diagnosis or evaluations by therapists or schools—can be brought to the intake meeting. **Always make copies of applications and supporting documentation and keep them on file.**

You may also complete the application at the appointment at the local SSA office, although this means taking all your medical records with you and considerably more time with the interviewer. If you do not have access to a computer, you can request an application be mailed to you when you call the 800 number.

**Call Social Security.** To make an appointment, call **1-800-772-1213** (TTY **1-800-325-0778**) between 7:00 am and 7:00 pm, Monday through Friday or contact your local Social Security office. It is best to call the 800 number rather than the local office as field offices are understaffed and the hold times can be very long. You will be greeted by an automated message system, which will prompt you to state why you are calling; say “Apply for SSI.”

The automated message system will ask for you to say or key in your child’s Social Security number. You will then be directed to a representative. During the phone interview, the representative will take information and enter it into a computer, which will secure the date of the application.

- Paperwork will be mailed to you. Fill it out and return within the allotted timeline.
- The document generated during the phone interview will also be mailed, to be signed for accuracy.
- Before mailing anything back to the agency, be sure to make copies.

**Set up a screening interview.** During the phone interview, the representative will set up a screening, which continues the application process, at your local Social Security of office.

Harrisonburg Local Office  
1241 N. Main Street  
Harrisonburg, VA 22802  
(800) 772-1213

**SSA Office Hours:**

Monday, Tuesday, Thursday, Friday 9:00 - 4:00  
Wednesday 9:00 - 12:00, closed on Saturdays, Sundays, and Federal Holidays.

**Go to the screening interview.** Bring any and all information to prove your child’s age, citizenship, disability, assets, and resources:

- Original birth certificate (or other proof of age and citizenship) and Social Security card
- Documentation to verify your address
- Copy of special needs trust, guardianship or conservator order
- Individual Education Plan (IEP)
- Income slips if your child has income
- Information on any assets your child owns like a savings account, investments, title to a car or life insurance. **These cannot total more than \$2,000 for SSI benefits** (unless held in a Special Needs Trust). Note that for programs with income limits, SSA considers parents’ income and assets up until your child turns 18 (individuals over 18 years of age are considered independent households).
- If you have **not** completed the application online, bring the required medical records and contact information to the screening
- Checkbook or other papers that show a bank account number to have benefits deposited directly into a bank account or a Representative Payee account if using
- A signed rent agreement between parent and child (to receive the full benefit)

**Wait for eligibility determination.** The agency will send your Disability Report Form and medical history to the Disability Determination Service (DDS). DDS may or may not request more information, such as work history, when the disability began, and what treatment has been given. DDS may also request, on

behalf of SSA, a medical or psychological exam (SSA pays for the exam by a physician chosen by SSA).

A decision is made in approximately 60 days about eligibility for benefits. If denied, you have 60 days to appeal.

For help with understanding how Social Security works for people who are working or want to work, contact Marilyn Morrison at Community Work Incentives Coordinator, (571) 339-1305 or [mmorrison@vaaccses.org](mailto:mmorrison@vaaccses.org)

### **Set up a Representative Payee account if needed.**

Once your child receives benefits, you will need to set up a Representative Payee account; be sure to title the account correctly (SSA has suggested wording).

### **Automatic deposit of benefits is required.**

Housing and SSI Benefits

**SSI is intended to cover living expenses like rent, food, and utilities.** For example, it is recommended that you charge your adult child rent if he or she lives in the family home. Rent charged must be at least 30% of the current federal benefit amount (\$783/month for 2020) to get the maximum SSI benefit. Be aware that SSI benefits may be reduced under the following circumstances:

In general, about one-third of your SSI benefit is assumed to be paying for housing expenses (rent or mortgage, utilities, property insurance/renter's insurance) and the other two-thirds for other eligible expenses like food and clothing.

If monies from a Special Needs Trust are used to purchase a home with a mortgage, and the **trust makes monthly mortgage payments**, then the beneficiary's SSI payments will be reduced by about one-third each month (the portion of SSI associated with housing). Benefits will not be reduced if utilizing funds from an ABLE Account. For more information on utilizing ABLE, visit the trust website at <https://thearcofnovatrust.org/> and the ABLE National Resource Center at <http://www.ablenrc.org/>

Whether the home is purchased outright or with a mortgage, SSI payments will be reduced by slightly more than one-third if the **trust pays for household expenses** such as taxes, heat, electricity, water, sewer, and trash collection.

See <https://secure.ssa.gov/poms.nsf/lnx/0500835300> and <https://secure.ssa.gov/poms.nsf/lnx/0500835901>

### **The Representative Payee**

A Representative Payee is appointed by SSA to receive Social Security and/or SSI benefits for someone who cannot manage his or her money. Rep Payees should be comfortable handling financial records and be trusted to keep in mind the best interests of the disabled beneficiary.

A payee must keep records of expenses and be able to account each year for all spending of SSI funds. SSA sends out a **Representative Payee Report** annually; fill out the report promptly and mail it back, or you may submit the report online.

To be designated a Representative Payee, contact the local SSA office (see above). You must then submit an application, form SSA-11, and documents to prove your identity. You will need to provide your social security number, or if you represent an organization, the organization's employer identification number. The SSA requires you to complete the payee application in a face-to-face interview (with certain exceptions).

Note that having power of attorney, being an authorized representative, or having a joint bank account with the beneficiary **do not give** you the legal authority to negotiate and manage the beneficiary's Social Security and/or SSI payments. See [www.socialsecurity.gov/payee](http://www.socialsecurity.gov/payee)

**Reporting Income.** SSI beneficiaries must report any earnings to Social Security. This includes work income, one-time payments, child support, and trust payments. SSI is a needs-based month-to-month benefit. Any delay in reporting to SSA could mean an overpayment of benefits. Keep a record that you sent The documentation to Social Security. Certified mail is best, or if you fax the information, keep the fax confirmation page

### **APPLYING FOR BENEFITS: Medicaid Waiver Programs**

This information is adapted from the The Arc of Northern Virginia's website. For more information, [www.thearcofnova.org/programs/waivers](http://www.thearcofnova.org/programs/waivers)

Family income and family assets are not a consideration under the Medicaid Waiver program if your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria. Visit the YouTube page for a recorded webinar on the new Waiver system effective September 2016.

<https://www.youtube.com/watch?v=6RGssERYtLI>

You can read the latest information on the new Waivers from the state <http://www.mylifemycommunityvirginia.org/> or call their hotline at (844) 603-9248.

### Services Covered Under the Waivers

The Developmental Disability (DD) Waivers: There are 3 DD Waivers, they are the Community Living Waiver, the Family and Individual Supports Waiver, and the Building Independence Waiver. These waivers cover supports in a variety of residential settings, including hourly staff at the home of a child's family and 24-hour staffed group home settings. These three waivers also cover a variety of employment and meaningful daytime supports for people no longer in school. Some additional services include respite care, in-home supports, companion care, assistive technology, environmental modifications, therapeutic consultation, non-emergency medical transportation, private-duty nursing, skilled nursing, and the Personal Emergency Response System (PERS).

- **The Community Living Waiver** is a comprehensive waiver that includes 24/7 residential services for those who require that level of support. It also includes services and supports for adults and children, including those with intense medical and/or behavioral needs.
- **The Family and Individual Supports Waiver** is designed to support individuals living with their families, friends or in their own homes. It supports individuals with medical needs and is available to both adults and children.
- **The Building Independence Waiver** supports adults 18 and older who are able to live in the community with minimal supports. This waiver does not include 24/7 residential services. Individuals will own, lease, or control their own

living arrangements, and supports may need to be complemented by non-waiver funded rent subsidies.

Children receiving waiver services are assessed every two years, and adults are assessed every three years. The assessment is called the Supports Integrity Scale (SIS) and measures the level of their support needs. People can move between these three DD Waivers if their needs change over time. Moving to a waiver that serves people with higher needs may sometimes involve a waiting period, as the programs are administered on a first come/first serve basis.

### Eligibility Criteria

There are criteria everyone must meet to be eligible for a Medicaid Waiver:

**Functioning ability:** This is determined by the VIDES survey. The VIDES has one test for children aged 0-3, one for children ages 3-18, and one for adults. The surveys assess the person's need for assistance with a variety of daily life activities and independence skills.

**Diagnosis:** Persons applying for a Waiver must meet the diagnostic eligibility requirements for the DD Waivers. This means that a person must have a developmental disability as defined in 37-2-100 of the Code of Virginia.

**Developmental Disability (DD)** means a severe, chronic disability of an individual that

1. Is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness
2. Is manifested before the individual reaches 22 years of age
3. Is likely to continue indefinitely
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency

5. Reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized support, or other forms of assistance that are lifelong or of extended duration and individually planned and coordinated

An individual from birth to age nine (until the individual's tenth birthday), who has a substantial developmental delay or specific congenital- or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses 1 through 5 (listed immediately above) if the individual without services and supports, has a high probability of meeting those criteria later in life.

**Financial:** If the functioning and diagnostic criteria are met, then the child's income and assets are considered. Special Needs Trusts and ABLE Accounts are not considered when testing financial eligibility. People over 18 have an asset cap of \$2,000. Everyone receiving a Waiver has a monthly income cap of 300% of the current Social Security Supplemental Security Income amount (SSI is \$783 in 2020, so max monthly income is \$2,349).

**The Commonwealth Coordinated Care (CCC) Plus Waiver** covers personal care, respite care, medication monitoring, private-duty nursing, assistive technology, environmental modifications, and the Personal Emergency Response (PERS) system. Personal care support hours may be approved up to a maximum of 56 hours per week and cannot exceed 480 hours per state fiscal year. To be eligible for this waiver, the person must have a disability and medical nursing needs, as assessed by the Virginia Uniform Instrument (UAI)  
[https://www.dss.virginia.gov/files/division/dfs/as/as\\_intro\\_page/forms/032-02-0168-01-eng.pdf](https://www.dss.virginia.gov/files/division/dfs/as/as_intro_page/forms/032-02-0168-01-eng.pdf)

#### Waiting List Eligibility

You can be on the waiting list for a Developmental Disabilities Waiver and apply for either the CCC Plus or Technology Waiver, assuming you are eligible for the CCC Plus Waiver as well. Many people do this because the CCC PLUS Waiver has no waiting list and can provide some interim supports.

How Long is the Wait?

The Disability Waivers have a waiting list based upon urgency of need. People in Priority One of urgency need services within the year, people in Priority Two need services 1-5 years, and people in Priority Three need services yet later. Wait time is unpredictable and many people on the Priority One list wait many years for a waiver. As your life circumstances change (for example, you or your sponsor become ill, become unemployed), notify your support coordinator, as some of these situations may increase your urgency of need for support services.

To Apply for the Developmental Disabilities Waivers Contact your local Community Services Board. For Harrisonburg and Rockingham:

Harrisonburg Community Services Board  
1241 N. Main Street  
Harrisonburg, VA 22802  
(540) 434-1941  
[www.hrccb.org](http://www.hrccb.org)

To Apply for the CCC Plus Waiver contact your county's Department of Social Services

Harrisonburg-Rockingham DSS  
110 N. Mason Street  
Harrisonburg, VA 22802  
(540) 574-5100

If not in the Harrisonburg-Rockingham area, visit <http://www.dss.virginia.gov/localagency/index.cgi>

#### IFSP Funding

If you are on the waiting list for a waiver, you are eligible to apply for The Individual and Family Support Program (IFSP). This program is designed to assist individuals on the waiting list for the Developmental Disability Medicaid Waivers to access short-term services that will help maintain them in their own homes in their community.

Information, applications, and instructions can be found at:

<http://dbhds.virginia.gov/developmental-services/ifsp>

#### **FINDING A HOME: Residential Program Options**

This section explores alternatives that tie housing and supports into one residential program. For a list of

local housing programs and of residential services providers that provide the money and staff for options here, see the section Local Housing Programs and Providers.

### **1. Residential Options Funded by Medicaid Waiver**

One way to access a residential program is by utilizing the Community Living Waiver. The Waiver funds several support options that are tied to a specific residence (see below). However, you may use other service options under the Family and Individual Supports Waiver, the Building Independence Waiver, or the CCC PLUS Waiver to get care provided in a variety of home settings. We'll explore this topic as we consider each type of housing.

**Congregate Residential Supports.** Often called **group homes**, this support model is comprised of a home (including single family homes, condos, and townhomes) where people with developmental or intellectual disabilities live together in a home operated by a provider in the community. These are often four- to six-person homes, though they can be smaller or larger. In these homes, staff typically rotate in and out on shifts and may be present in the home 24 hours a day. Some providers have staff live in the home with the residents with disabilities.

**Sponsored Residential Supports.** In this option, a person with a disability lives with a paid caregiver in the home of the caregiver. The caregiver could be a single person or a member of a family. The individual supported in this home lives there full time and is treated as a member of the family.

**Shared Living.** In this model, the individual lives with someone other than parents/grandparents who is reimbursed for room and board in exchange for companionship.

**Supported Living.** In this model, the residence is owned by a support provider that offers up to 24/7 help with support needs.

**Independent Living.** In the Independent Living model, supports are brought into the home that focus on skill building and preparing for greater independence.

See the chart below that outlines the different options under each Waiver. Note that under the newly redesigned Waivers (as of September 1, 2016), options are available based upon the need of the person with a disability as well as by which waiver they have. The Community Living Waiver is designed to support individuals with the highest level and most complex needs, the Family and Individual Supports Waiver is designed to support people with mild to high need, and the Building Independence Waiver is for individuals over 18 with limited support needs.

#### **Rent and Qualifications**

It is important to understand that the **waiver pays for the supports an individual receives in these settings but not the cost of the rent or utilities.** This means that the person living in these homes would still have a monthly rent bill.

The cost of rent varies in these models. Some providers take a set amount (such as 75-80%) of an individual's monthly income to cover rent, food, utilities, and activities in the home. In these situations, that income would include an individual's Social Security benefits and possibly any earned income. Some providers charge a flat rate (\$600, for example) for rooms used in the home. The individual can pay for that through Social Security benefits or earned income.

If the individual lives in an apartment, it is likely that they will be responsible for whatever the rent rate is for that apartment. The provider may have worked out a discounted rate with the apartment complex or the complex may have a sliding scale for rent. Utilities may or may not be included. People with developmental disabilities often use housing subsidies such as vouchers to make this option affordable.

#### **Getting Started**

In this situation, you would apply for the waiver for which you qualify. Once you receive the waiver, you would find a provider who offers the services that meet your needs.

The VA Department of Social Services Office of Background Investigations also provides background checks on adult facilities:

[http://www.dss.virginia.gov/family/background\\_investigations.cgi](http://www.dss.virginia.gov/family/background_investigations.cgi)

### **Example of Sponsored Residential Support— One Person’s Story**

I have walked into chaos. There are three teen age girls listening to loud music down the hall, two eight- year old boys are arguing over the rules of a video game, Jasmine the dog is barking at the boys, and a large cat sits on the back of the couch, serenely taking it all in. In the midst of all this activity and noise is our physically- and intellectually-disabled son, bouncing up and down, happy in his home.

Knowing the noise will give me a headache within ten minutes, I cannot help but smile when I think back to our house and how our son would often sit in his room, staring at the walls, watching movies, bored with living with his comparatively sedate parents. He was not unhappy then, but he is happier now. He has stimulation, activity, friends, and frequent interactions with his new family. He now lives rather than simply existing.

His transition to his new home started when my wife and I reluctantly acknowledged that someday we are going to die, and so our son would require long term care. We considered group homes, but believed that model was not a good fit as he does not speak and has very limited communication skills, and cannot express his concerns or needs. We thought the sponsored residential model (sometimes called Adult Foster Care), where a disabled individual moves into a caregiver’s home, offered the best alternative. However, we had a concern with the typical sponsored residential housing model in that if, for whatever reason, the caregiver stopped providing care, our son would lose both his caregiver and housing at the same time. Such an event could result in a complete reworking of everything in his life, especially if he had to move from his community.

We had heard of parents buying homes for their disabled children and so we began looking into purchasing a house as a twist on the standard sponsored residential model. By owning the home, and having a caregiver family (or person or persons) move into the home with our son, we ensured he would always remain in a known environment that encompasses his outside the home activities such his day program, recreation, and

favorite local trips, as well as the important people in his life, such as doctors and friends. If the wonderful caregiver we have now does decide to stop caregiving, our son has only one trauma, albeit a major one, to adapt to instead of the multiple shocks that could come with adapting to a new caregiver in a different house in a possibly different town.

Ten days after moving into the house with his caregiver family, our son was given a choice of returning for dinner to Mom and Dad’s, or going to his new family home. Without hesitation he chose his new home.

### **Questions to Ask Housing Service and Support Providers**

- What are some challenges this approach to housing and supports has presented and how did you work through them? What expectations did the individual and family have starting out?
- What do you do when staff members leave? What is your backup staffing plan?
- What is your relationship with the landlord?
- Imagine you could go back in time to when this journey started, but you’d still know everything you know today. What would you tell yourself?
- (For provider agencies) Would you do this again? What do you think is the future of DD housing?
- (For provider agencies) What if someone’s support needs change temporarily or permanently? How do you bring in more help?
- Who handles property management and home repairs?

### **Questions to Ask Residential Service Providers**

#### **1. Residential Setting:**

- Does the individual have a choice of housemates?

- Does an individual have a choice of where they live?
- Are there any requirements for individuals to be involved in day programs?
- What does a typical day look like in a residential setting (both weekday and weekend)?
- Are there prerequisite skills and/or other requirements?
- Do individuals choose and prepare or help prepare meals and snacks?

To what extent will a person's religious beliefs be taken into consideration?

## **2. Cost:**

- What costs are involved for this service and who pays?
- What resources are available to cover costs?
- What do costs are included in this service (food, cable, private phone)?

## **3. Transportation:**

- What type of transportation is provided and for what services do you provide it?
- Who pays for transportation?
  -
- Who arranges transportation?

## **4. Social Interaction/Peer Support:**

- With whom do individuals interact in the community?
- How do you help foster individuals' relationships within the program and the community at large?
- What level of family support is expected?
- Do individuals take part in planning activities?
- Do individuals usually participate in activities in a group or independently?

## **5. Planning and Goal Setting:**

- What is the referral process?
- How frequently does the program evaluate the progress of the individual?
- Who participates in these sessions?
- What is the length of time my child might wait to obtain residential support?
- What feedback do you give to the families?
- What oversight of individual finances do you provide?
- What activities does the program offer for individuals to learn new skills?
- Are there any opportunities outside the program in the community that individuals can pursue? If so, is there any tuition assistance available?
- What would you suggest that parents do now at home to prepare individuals for this setting?
- How do you handle disagreements between roommates?
- How do you support an individual who has difficult behaviors?

## **6. Staff Support:**

- How is your program staffed?
- What background and training does the staff have?
- Is there ongoing training for staff?
- How often does my child interact with the residential counselors?
- Is the supervision ongoing?

**7. Grievance and/or Complaint Procedures:**

- What happens if an individual or family member has a complaint about particular staff?
- With whom should the person speak?
- What should the person do if the complaint is not resolved at this level?
- How does program staff assist individuals with management of public benefits, such as SSI? (Staff should be aware of Social Security Work Incentives)
- What oversight of an individual does the staff provide (i.e., money management)?
- What happens when an individual becomes ill?
- How are medications monitored and administered?
- How are annual regular medical and dental care scheduled?

<b>Residential Program Pros</b>	<b>Residential Program Cons</b>
Housing and supports come together in a bundle.	If an individual living in a congregate setting doesn't like their provider, they may need to leave their home; alternatively, if an individual doesn't like their home, they may need to seek out a new provider. Shared living, independent living, and in-home support options may offer more choices in this situation.
A person with a disability can utilize a waiver to access residential program supports.	The resident needs a Developmental Disabilities Waiver for services in a group home setting to be affordable. The individual must qualify and have risen to the top a long waiting list to have this waiver. The individual must have a waiver that covers the desired service.
Costs tend to be manageable since you're often working directly with a provider who is dedicated to supporting people with disabilities. Costs may vary if using in-home, independent living, or shared living services.	Even though the total cost may be low, the congregate living option still uses almost all of an individual's income to pay for housing, utilities, and food. This varies if utilizing in-home, shared, or independent living, as the individual may be using a housing voucher.
The person receiving supports can tour various providers and pick the setting that best meets their needs, including a place with 24-hour supports.	You may not be able to choose your housemates or staff in a congregate setting. This varies if utilizing in-home shared, or independent living, as the individual may be using a housing voucher.

## 2. Public Housing

Public housing refers to housing units that are federally funded and made available to people with low incomes. Often that means that the units are owned by a housing authority and funded by a federal agency called the Department of Housing and Urban Development (HUD). In public housing, the local Public Housing Authority (PHA) is often responsible for property management and filling the units.

**Rent and Qualifications** To qualify for public housing, an individual must meet the public housing authority's low-income requirements. Tenants pay a portion of their monthly income.

**Use with Waivers and Care Attendants** A person with a disability could use the staff funded under the DD Waivers or CCC PLUS Waiver to receive supports in a public housing unit. In that situation, the person would be the tenant of the apartment. They could have staff come to the home to provide supports periodically or throughout the day and night. The amount of staff support available would be based upon their individualized plan under the waiver.

Another option would be to have a caregiver live in the home full time. When you get on the waiting lists for these programs, you may want to consider requesting a two-bedroom unit so that a caregiver can share the home with you. This may be a reasonable accommodation to make the housing accessible based on your disability. In this case, the attendant would also need to be on the lease. The second bedroom is provided without any cost to the person with a developmental disability or the staff. For more information on live-in caregivers, see The Arc of Northern Virginia's Live-in Caregiver Guide in their Housing Toolkit <https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/housing-toolkit/>

### Getting Started

Unfortunately, the waiting lists for public housing units can sometimes be long. However, at this writing, there are openings on the Harrisonburg and

Rockingham list. If you're interested in public housing, keep in touch with your local housing office.

### Contact:

Harrisonburg Redevelopment and Housing Authority  
PO Box 1071  
Harrisonburg, VA 22803  
(540) 434-7386

### Physical address:

286 Kelley St  
Harrisonburg, VA 22802.

For Section 8 and Family Self-Sufficiency Programs see:

[http://www.harrisonburgrha.com/annual\\_plan.html](http://www.harrisonburgrha.com/annual_plan.html)

- For more information on waiting lists, see **Local Housing Options** later in the guide
- For more information on Finding a Roommate, see later in this guide
- You can be on the waiting lists for Public Housing and a Housing Choice Voucher at the same time. You can also use one of those programs while on the waiting list for the other. However, you may only actively use one program at a time.

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### Your Toolkit for Public Housing

- Medicaid Waiver or other funding stream to pay for support staff
  - Know when waiting lists open
  - Confirm you want to remain on the waiting list when asked—keep your address up to date
  - Consider a roommate
-

Public Housing Pros	Public Housing Cons
<p>You can use a waiver or other funding to bring the supports to your public housing unit. You can change staff and still stay in the unit.</p>	<p>Waiting lists for waivers and public housing are both very long, so you would need to ensure that both services were available at the same time. If you receive a waiver before public housing, you would need to use your waiver in another setting until this housing option was available. If you receive public housing first, you would need to make other arrangements for supports until you receive a waiver.</p>
<p>Rent is very affordable. Once you qualify for a unit, you can stay there as long as you continue to qualify.</p>	<p>You must accept the unit that is made available to you (assuming it provides the correct number of rooms and accessibility features you need) or give up your option to use public housing.</p>
<p>The homes are owned by the PHA, so the buildings will not close and your rent cannot be increased to market rate as could happen with a private owner.</p>	<p>You cannot easily move between homes and cannot live in a home that the PHA does not operate under this specific program. If you leave the locality, you lose your housing support option.</p>
<p>You may be able to live alone affordably.</p>	<p>Your roommate, if you choose to have one, would have to be your caregiver or another person with a disability who also qualifies for public housing. If it was another person with a disability, you would be considered a “disabled family household” and your combined income must still not exceed the maximum per regulations. You need to identify the roommate as a member of household <b>at the time you apply for the wait list</b> (you cannot increase household size once application is made).</p>

### 3. Housing Choice Vouchers

Housing Choice Vouchers (HCVs) used to be called **Section 8 Vouchers**. A voucher allows low-income individuals and low-income families to rent from private landlords at a reduced cost. This means you could rent a home, room, or apartment of your choice within certain size and rent limits.

The voucher is effectively a payment that is made directly to the landlord each month. The renter would pay 30% of their monthly income towards rent, plus the cost difference if the home selected was above HUD's fair market rent. For example, if fair market rent were \$900/month, the unit costs \$1000/month, and the individual's income is \$700/month, the renter would pay \$210 (30% of income) plus \$100 (since the unit is \$100 more per month than market rate for rent) for a total rent of \$310/month.

It is also important to know that you can convert your HCV into mortgage payments to help cover a portion of a mortgage on the purchase of a first home if you aren't able to pay without assistance.

One of the greatest benefits to the Housing Choice Voucher program is that once you have received a voucher, you can take that voucher with you anywhere in the country, including Guam and Puerto Rico. Unfortunately, in many areas waiting lists are long for this program.

#### Rent and Qualifications

Applicants would qualify by meeting their local jurisdiction's low-income guidelines and preferences. A preference may be being a person with a disability. For assistance with a mortgage, the qualified annual income of the adult home-owner with a disability **must not be less** than the monthly Supplemental Security Income (SSI) multiplied by twelve, but still must be lower than the county's low-income guidelines.

In this system, the person with the voucher must find a landlord who is willing to accept the voucher. Then, the person with a voucher must submit to a credit check, provide rental references, consent to a background check, provide proof of income, and meet other criteria set by the individual landlords.

You may be required to put down a security deposit. If the landlord and potential tenant believe they are willing to work together, the tenant should contact their county's housing agency. The county housing agency must approve the contract before it is signed and before anyone moves into the home. The housing office will inspect the home before it can be occupied, and every year thereafter, to ensure that the home continues to comply with housing quality standards.

If you use a Housing Choice Voucher (HCV), each month you would pay 30% of your monthly adjusted income (adjusted for appropriate deductions, such as some medical expenses), 10% of your total monthly income, or \$50, whichever is higher, towards rent. The rest of the rent payment is funded through the voucher. That money goes directly to the landlord each month.

You are limited to selecting a rental unit that is not more expensive than your area's fair-market rent or rent comparable (see glossary for definitions), whichever is lower. A person with a disability may request a unit that is 10-20% higher than fair-market rent if accessibility accommodations are needed.

**Use with Waivers and Care Attendants**

As with public housing, a person with a disability could use the staff that are funded under the DD or CCC PLUS Waivers to receive supports in a home they rent with a Housing Choice Voucher. In that situation, the person would be the tenant of the apartment. They could have staff come to the home to provide supports periodically or through- out the day and night. The amount of staff support available would be based upon the individualized plan under the waiver.

Another option would be to have a caregiver live in the home full time. When you get on the waiting lists for these programs, you may want to consider requesting a two-bedroom unit so that a caregiver could share the home with you. This may be a reasonable accommodation to make the housing accessible based on your disability. See the Live-in Care Guide for more information at

<https://thearchofnova.org/progrms/transition/finding-home-adults-disabilities/housing-toolkit/>

**Getting Started**

You would apply for a HCV at your county’s housing office (see contacts in the **Local Housing Options** section).

You can be on the waiting list for public housing and a Housing Choice Voucher at the same time. You can also use one of those programs while on the waiting list for the other. However, you may only actively use one program at a time.

For more information, visit the Arc of Harrisonburg and Rockingham, **Virginia Resource Guide** at <http://www.hrarc.org>.

Housing Choice Voucher Pros	Housing Choice Voucher Cons
You can rent from the landlord of your choice.	You must find the home yourself and get the landlord to agree to accept the voucher; the rent must not be greater than fair-market rent for the area. You must meet the other criteria set by the private landlord (e.g. background check, security deposit).
Once you have a voucher, you can use it anywhere in the country after living in your locality for one full year.	Waiting lists for the voucher are very long and are currently closed, unless you utilize SRAP (State Rental Assistance Program). See the below for more information.
You can use a waiver or other funding to bring the supports to your HCV home. You can change staff and still stay in the unit.	Waiting lists for waivers and HCVs are both very long, so you would need to ensure that both services were available at the same time.
You may be able to live alone affordably.	Your roommate, if you choose to have one, would have to be your caregiver or another person with a disability who also qualifies for public housing. If it was another person with a disability, you would be considered a <b>disabled family household</b> and your combined income must still not exceed the maximum per regulations. You need to identify the roommate as a member of household <b>at the time you apply for the wait list</b> (you cannot increase household size once the application is made).

#### **4. State Rental Assistance Program**

The Department of Behavioral Health and Developmental Services (DBHDS) has created a State Rental Assistance Program (SRAP) to serve individuals with developmental disabilities who want to live in their own housing. The program is designed to provide rental assistance to single-person families that meet the program eligibility criteria so they have the means to lease private market rental housing that meets their needs. Individuals will have the opportunity to choose where they live, with whom they live, and who supports them. Services and supports will be provided through sources separate from their housing, including Medicaid Waiver-funded home and community-based services, natural supports, privately-paid supports, and other community resources.

SRAP helps pay part of the rent so you can afford to lease your own home. You pay 30% of the rent, the same as with a housing voucher. You must rent housing in the cities/counties where it is available, but you can reside anywhere when you apply.

Individuals who would like to access integrated, independent housing using the SRAP must be referred by their support coordinator. You can use the DBHDS referral form at

[http://www.dbhds.virginia.gov/library/developmental%20services/housing/referral%20docs/docs\\_dbhdsvoucherreferral%20form\\_10\\_15\\_16\\_w\\_acknowpageandservdesc.pdf](http://www.dbhds.virginia.gov/library/developmental%20services/housing/referral%20docs/docs_dbhdsvoucherreferral%20form_10_15_16_w_acknowpageandservdesc.pdf)

DBHDS selects referrals to apply in priority order: 1) persons in training centers, ICFs, nursing facilities, or group homes 2) persons who are homeless, at risk of homelessness, at risk of abuse/neglect, 3) paying more than half of their income toward rent, and 4) persons who live with their families.

If you are interested in pursuing SRAP, have your support coordinator make a referral to Jeannie Cummins Eisenhower, Senior Integrated Community Options Specialist Development Services Region 2 DBHDS (804)836-4308  
jcummins@dbhds.virginia.gov.

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#### **Your Toolkit for State Rental Assistance Program (SRAP)**

- You must have a Medicaid Waiver or be on the waiver waiting list
  - You must have a support coordinator to refer you. It can be your active support coordinator or the coordinator who put you on the waiting list
  - You will need someone to help you locate an apartment
  - You may need a caregiver to work in the home. Utilize a waiver or privately hire staff. Consider a live-in caregiver
-

State Rental Assistance Program (SRAP) Pros	State Rental Assistance Program (SRAP) Cons
You can use a Medicaid Waiver or other funding to bring supports into your home. You can change staff and still stay in your own home.	You must reside where the program is available.
You can keep this assistance your whole life and can move to different homes.	This requires a lot of upfront work and planning.
You can have a free room for a live-in caregiver.	Live-in caregivers require work and planning. See the <b>Live-in Caregiver Guide</b> on our website
Flexible in terms of various housing options.	
Funding is available to help with one-time costs i.e. security deposit, housing locator, furniture. This is called “flexible funds.”	

### Reasonable Accommodations

If you are concerned that you may not qualify for the program the way it typically operates or that it may not meet your needs, you can formally request a reasonable accommodation. This usually involves filling out a form explaining how and why your disability mandates an exception to the usual rules. Some examples are:

- You may need to request a unit that is physically accessible due to any mobility needs or adaptive equipment you have
- You may need to request that the maximum rent amount allowed by the voucher is increased 10-20% because it is required to meet your needs
- You can request a second bedroom if your disability needs require a live in staff member. This live in staff member can then provide some limited supports to you exchange for free rent, or you can pay them with Medicaid Waiver of private funds.
- You may need to request a larger unit to accommodate adaptive equipment.
- You may need to ask for considerations despite having a criminal background **if** the criminal

behavior was the result of your disability. For example, if you had been convicted of petty theft because you took something, and your disability prevented you from understanding it needed to be paid for in advance, you might receive an accommodation.

- You may need to request a ground floor unit for ease of access.

### FINDING A HOME: Options With Private Funding

#### 1. Microboards

A circle of support is a group of family and friends who care about a person with a disability and volunteer their time to help support that person. This group can also have members like lawyers, landlords, and accountants who are willing to volunteer their time in support, planning, and management for a person with a disability.

When a circle of supports incorporates itself as a corporate entity, it can engage in business transactions on behalf of the individual with a disability. This is called a microboard. This formal designation as a microboard allows the board to qualify for low-interest home loans through the Virginia Housing Development (VHDA) <http://www.vhda.com> or

contact Bruce DeSimone at (804) 343-5656 or by email [bruce.desimone@vhda.com](mailto:bruce.desimone@vhda.com).

### **Advantages**

Microboards are relatively new in Virginia, but have seen greater use in states such as Tennessee. While microboards do not directly provide funding, they offer a number of advantages and options for people with disabilities and their families.

A microboard allows someone with a disability to have more people than just parents or a sibling working on their supports. While an individual will always have a formal support team that includes a case manager, provider(s), and other people who work to support them, members of that team will change over time if someone leaves their job. The microboard members are friends and family who have known the individual for a long time and will continue to serve on the microboard for the life of the individual, unless they decide to leave for personal reasons.

A microboard also means that there are more than just one or two family members who know someone's history and are involved in their care.

### **Role of Microboards**

Families can use the microboard to:

- Collect and maintain information about someone's needs and wishes so that information remains available if parents or other relatives pass away or become incapacitated
- Lend additional oversight of care. You may even want to consider naming a microboard as the individual's guardian if a guardian is needed
- Manage staff hired to support someone with a disability or manage other waiver services so that burden doesn't fall on a single family member
- Provide solutions and manage supports. When an individual is facing a crisis or a problem, microboards act as a team to help solve problems and assist in managing concerns. A microboard can coordinate informal and sometimes formal resources

Microboards are meant to be sustainable. The microboard will develop bylaws, a meeting schedule, a succession plan, and a scope of authority. All of that can be changed over time, of course, to adapt to changing needs. You can set up a microboard at any time and the microboard can grow in size or scope as needed.

### **Rent and Qualifications**

If a family has a home they would like the person with a disability to live in and receive supports, the microboard can manage that property. In this case, the rent may be reduced if there is little- to no mortgage left on the property. Rent must cover the costs for real estate taxes, HOA or condo fees, property insurance, property management, and upkeep.

In this situation, you wouldn't need a formal incorporated microboard, but could have a less formal board with bylaws that provided support, assistance, and oversight.

You may consider placing a home in a Special Needs Trust. The home will not be considered a resource because the asset is held in an irrevocable trust. The Arc of Northern Virginia's Special Needs Trust program does accept homes. For more information, contact Tia Marsili, Director of Special Needs Trusts at (703) 208-1119.

Total rent costs would vary based upon the needs of the home. If the total rent is more than the individual can pay with SSI, SSDI, or earned income, then consider having roommates and charging them rent. You can use a Special Needs Trust to pay rent, but this will reduce the individual's SSI payment by up to one third.

If renting an existing home is not an option, microboards can qualify for special low-interest loans through the Virginia Housing Development Authority to help a person with a disability live in a home owned and managed by a microboard.

In the Northern Virginia area, the maximum allowable mortgage is \$450,000 for this special program. A loan can be approved for up to 100% of the appraised value of the property. There is a 0.5% application fee.

### **Use with Waivers and Care Attendants**

As mentioned, a microboard can be a team that

manages waiver supports (hiring and training staff). They can provide property management and upkeep, and utilize a private vendor to provide waiver services. Alternatively, the microboard could simply be a source of support to an individual, and waiver attendants can be managed outside the microboard.

### **Getting Started**

You'll want to start by learning more about microboards. No two are identical as they are all tailored to meet the needs of the individual they support.

**To learn more**, visit [Virginiamicroboards.org](http://Virginiamicroboards.org) and contact the Virginia Microboard Association at [VirginiaMicroboards@gmail.com](mailto:VirginiaMicroboards@gmail.com) or (757) 460- 1569. The association was established to help people learn more about microboards and to help them get started. They are available to share resources, ideas, and experiences.

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### **Your Toolkit for Microboards**

- Apply to be a non-stock corporation
  - Create a Board of Directors. Consider including family, neighbors, teachers, and someone with medical or legal expertise
  - Develop bylaws. Visit <http://www.microboard.org> to learn more
  - Create a lease for caregivers who may live in the home. Visit our online toolkit for a sample lease
  - Consider having a caregiver live in the home. Utilize a waiver or privately pay for this support
  - Consider a roommate
  - Consider contacting a lawyer for advice on how to word leases, bylaws, and other legal documents
  - Develop a plan for what will happen with the microboard once the person passes away. If you received a loan from VHDA because you were a microboard, the house must go to another microboard or similarly-minded nonprofit organization
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<b>Microboard Pros</b>	<b>Microboard Cons</b>
You have total control over the housing environment, roommates, and the staff you hire	The burden of the work falls on the Microboard to buy and maintain a home, to screen and admit roommates/staff, and to maintain the property
You can utilize this option with or without an existing home. The Microboard could also rent an apartment and manage or sublease that, simply manage support staff, or add in new services over time	There is no assistance with cost other than the possibility of getting a low interest home loan. Once the Microboard's mission is fulfilled (e.g. the person with a disability dies or no longer needs the home), the Microboard must dispose of the asset. It cannot retain the home or any equity
The Microboard not only works with housing, but can assist with all aspects of life. Information and work is shared between dedicated members	The Microboard members must be found and maintained. They are not paid. If someone leaves, another member must be found or other members must take on the departing member's responsibilities
There is no waiting list to start utilizing this support option	The Virginia Microboard Association is there to help, but you may have to figure out many things on your own

## 2. Shared Apartments

A shared apartment is simply a rented apartment (home, condo, or townhome) shared with one or more other people. The advantages are cost sharing and companionship. You can look to any apartment complex and inquire about rents, other fees (such as utilities), accessibility, access to public transportation, and whatever amenities you would like. There are thousands of apartments in the region from which to choose.

In this model, the person with a disability can share the apartment with people they already know or he or she could conduct a roommate search.

Also, consider looking to clubs or hobby groups in which the person with a disability is a member (such as the Special Olympics), post an ad at your house of worship, talk to friends and family and ask them to spread the word, or look at websites like craigslist.org. If the decision is made to live with a stranger, make sure you meet the person beforehand. Consider having them submit to a background check. Since there is no special program in place here, anyone applying to live in the apartment would be subject to the same credit checks, security deposit fees, and other stipulations the landlord has.

### Rent and Qualifications

Splitting the costs of renting may make it more affordable. Consider total income and expenses to decide what is affordable. Keep in mind that if you supplement your SSI with a Special Needs Trust, donations, or other funds to pay for food and rent, your SSI benefits may be reduced accordingly.

### Use with Waivers and Care Attendants

In this model, one, some, or none of the household members can have a waiver and/or care staff. Each person should have staff there to provide the supports they need. With the waiver, you cannot pool support hours to have staff on site 24 hours/day. Each staff person must provide care for one individual with a disability according to that person's plan of care. If a staff person works with multiple people at the same time, they are not able to bill Medicaid for providing two services simultaneously.

### Getting Started

To begin utilizing a shared apartment, the person with a disability should assess their income and assets, willingness to share space with a roommate, and their

ability to find a roommate. If this option appears to be a good fit, it is time to consider privately-owned apartments in your area.

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### Toolkit for a Shared Apartment

- Medicaid Waiver or other funding stream to pay for support staff. Coordinate with roommates' caregivers as well
  - Someone to help you locate an affordable apartment that meets your needs
  - You may need money for a security deposit. If you are not able to sign your own lease, you will need a legal representative
  - You may need a guarantor or cosigner if you have limited credit history
  - Find a roommate. See the **Roommates** section of this guide
-

Shared Apartment Pros	Shard Apartment Cons
You have total control over the number and selection of roommates	You must find your own roommates. Generally, local laws allow only up to four unrelated people to live together. You must all agree on shared costs, chores, and visitor policies
You can share costs for rent, utilities, and other fees	There is no financial relief, so all costs would have to be paid for through existing income. If one person leaves, you may have to pay their portion of the rent until a new person moves in
You have the option to move out or change support providers at any time unless prohibited by the lease agreement.	You need to ensure than any supports put in place are appropriate for the person they are supposed to serve and aren't misused by other housemates. Waiver hours cannot be pooled or shared
There is no waiting list to begin using a shared apartment	Startup time would include finding a roommate, finding an apartment, and agreeing upon cost sharing

### 3. Renting a Room

A room rental occurs when you rent a bedroom from a homeowner or sub-lease a room from another renter. In this arrangement, the person renting the room typically has a private bedroom as well as access to common areas, like the kitchen and living room. The advantages are cost sharing and companionship. Another advantage is that the homeowner or primary lease holder is responsible for the day-to-day needs of the home. Each situation will vary slightly, but you should ask up front about fees for utilities, accessibility features, access to public transportation, and whatever other amenities you would like.

In this model, the person with a disability can rent a room from someone they do not know, or could ask someone they already know about their willingness to rent a room. You can look for people renting rooms at <http://www.roommates.com>, [www.craigslist.org](http://www.craigslist.org), and classified ads in your local newspaper as well. Consider asking someone you know with an extra bedroom if they'd be willing to rent that space to you. If the decision is made to live with a stranger, make sure you meet the person beforehand. Consider having them submit to a background check.

Since there is no special program in place here, anyone replying to an ad for a roommate could be subject to the same credit checks, security deposit fees, and other stipulations the landlord has. Be sure

to have a lease agreement with basic protections for you as the tenant; it might also be a good idea to check that the homeowner is up to date on the mortgage payments (to avoid being caught in a foreclosure).

#### Rent and Qualifications

Harrisonburg and Rockingham can be an expensive place to rent a home, but renting just a room instead of an entire home or apartment can make it more affordable. People rent rooms in all locations of varying sizes with varying amenities, so costs vary widely, too. Consider total income and expenses to decide what is affordable. Keep in mind that if you supplement your SSI with a Special Needs Trust, donations, or other funds to pay for food and rent, your SSI benefits may be reduced.

#### Use with Waivers and Care Attendants

In this model, the person renting the room could have a waiver and/or care staff, but they would need to disclose such needs and plans when they contact potential homeowners or lease holders to ensure everyone is comfortable with such requirements.

#### Getting Started

To begin renting a room, the person with a disability should assess their income and assets, willingness to share space with a roommate (possibly a stranger),

and their willingness to find and interview people renting space.

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### **Your Toolkit for Renting a Room**

- Medicaid Waiver or other funding stream to pay for support staff. Coordinate with roommate’s caregivers as well
  - Someone to help you locate an affordable apartment that meets your needs
  - You may need money for a security deposit. If you are not able to sign your own lease, you will need a legal representative
  - You may need a guarantor or cosigner if you have a limited credit history
  - Find a roommate. See the **Roommates** section of this guide
- 

<b>Renting a Room Pros</b>	<b>Renting a Room Cons</b>
You can select the area in which you want to live and can interview as many potential roommates as you like	You must find your own roommates who may or may not have a familiarity with people with disabilities. You must all agree on shared costs, chores, and visitor policies
You can share costs for rent, utilities, and other fees. Generally, the person who is the primary lease holder or homeowner would be responsible for a much larger share than you	There is no financial relief, so all costs would have to be paid for through existing income. If the homeowner or primary lease holder leaves, you would need to find another place to live or cover their rent
You have the option to move out or change support providers at any time (as permitted by the lease agreement)	You need to ensure than any supports put in place in the home are agreed upon by everyone in the home
There is no waiting list to consider renting a room	Startup time would include finding a roommate, sorting out in-home supports, and agreeing upon cost sharing

#### 4. Life Estates

A life estate exists when a property is owned by someone only for their lifetime. In a Life Estate, a homeowner grants a **life tenancy** to a person with a disability who is then entitled to live in that home for the remainder of his or her life. Upon the death of the life tenant, ownership of the home would either revert to another family member, a non-profit, or a combination of both. The advantage of a life estate is that a parent can ensure that an adult child with a disability will be able to live in the same home for his or her entire life.

This may be a good option if the family has already paid off their mortgage or only has a small amount of the mortgage remaining. The family could deed or will the home to the adult child. If the home was deeded to the person with a disability while the parents were still alive, the family could decide that the parents would continue to reside there or decide to move out and have the person with a disability stay in the home.

#### Rent and Qualifications

The life tenant is responsible for all of the expenses of the home, or the **remainderman** (who will own the home once the life tenant dies) may be responsible. The home would still need to be maintained even if there was no mortgage, though if the person with a disability was the sole homeowner and they were below local income thresholds, they might be able to have property taxes waived or reduced. To cover the costs of home maintenance and insurance, it might be possible to allow other renters into the home. In such a situation, provisions would need to be made for who would find, screen, and manage any renters.

Alternatively, if you choose to work with a non-profit service provider, you may want to arrange the situation so the non-profit is responsible for providing care attendants and other services in the home 24 hours a day as well as for finding roommates who would also receive supports in the home. Upon the death of the adult child, the non-profit would become the home's owner and would use that home to continue to provide housing for other people with disabilities.

Keep in mind that many service providers would be hesitant to manage supports for a life tenant if they were not deeded the home after the life tenant passed

away. You would also need to have an agreement on care arrangements if the life tenant is no longer able to stay in the home because their needs or wishes change. This is because the provider is also responsible for the other people living in the home and they would not want the people they serve to have to lose their home because the primary tenant died and the home ownership reverted to a sibling or other family member.

#### Use with Waivers and Care Attendants

It would be possible to utilize a waiver service provider to staff the home, manage the home, and/or oversee roommates and other supports. You would need to work with the service provider to ensure the support needs of the other potential housemates could be met and that they had waiver funding to do so.

#### Getting Started

Assess your family's situation. If it seems likely that you can afford to leave your home to an adult child with a disability, contact a non-profit housing organization or waiver service provider to see if they would be willing to work with you.

#### Example of a Life Estate

##### One Person's Story of Utilizing this Option

One possible long-term housing solution for individuals with disabilities is to transfer your house to a donee non-profit organization for eventual use as a group home. This can be done through an irrevocable life estate agreement, so the parents can live in the house until their deaths, at which time the control of the property will permanently pass to the non-profit organization. This permits the individual with a disability to live in their same home for their lifetime. This requires the mortgage on the house to be paid off, and the mortgage company can issue a release of lien on the property.

The first step is to interview and pick which non-profit organization you want to work with. We searched for one that had both extensive experience operating group homes and had a day support program which we viewed as appropriate for our son. An initial search revealed seven possible non-profit organizations operating in Central Virginia. The process can take from between three and six

months to complete.

You may want to check with the Harrisonburg Community Services Board, <http://www.hrccb.org> (540) 434-1941 or see The Arc of Harrisonburg and Rockingham's Resource Guide at <http://www.hrarc.org>.

While the organization search is being conducted, an appraisal of your real property must be done. It can be done by any appraiser.

Once these two steps are complete, the irrevocable life estate agreement and the deed of gift with retained life estate can be done. It can be started before you select a donee organization and the appraisal is completed, but it cannot be finished until the steps are complete. This can cost between \$1500 to \$2000, depending on the complexity of the documents.

After the irrevocable life estate agreement and the deed of gift with retained life estate are signed by the parents and the irrevocable life estate agreement is signed by the donee non-profit organization, the deed must be recorded at the county courthouse. Be sure to use an overnight mailing service when sending the documents around for signatures, so that they can be tracked.

This donation can lead to a substantial charitable tax deduction for the family, depending on the appraised value of the home and the age of the parents. The donation is not the appraised value, but it is reduced based on annuity, life estate, and remainder factors. Ultimately, our charitable tax deduction was a little over half of the appraised value of our home, which we used to offset rollovers of funds from traditional IRAs to Roth IRAs. You can use the deduction to offset up to half of your adjusted gross income for up to five years. You will need to get a copy of the 501c3 IRS determination letter from the donee organizations to verify their public non-profit status in order for the donation to be deductible on an IRS Form 8283. That form must be ultimately signed by the parents, non-profit organization, and the appraiser.

This is a big and irrevocable decision, but it can provide a substantial level of comfort and continuity for your loved one with a disability.

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### Your Toolkit for a Life Estate

- Contact a lawyer to draw up paperwork on the Life Estate
  - You may need to contact providers and arrange how to manage the home and provide care
  - You will need a lease for caregivers or roommates who may live in the home. A sample lease can be found in our online toolkit
  - Consider using a Medicaid Waiver or privately hire staff if you need a caregiver to provide supports
  - Consider a roommate. See the **Roommates** section of this guide
-

Life Estates Pros	Life Estates Cons
There is no waiting list to get started	You must already have a home that you could leave for the person with a disability
When you set up your agreement with the managing non-profit, you have a lot of control over the situation (selection of initial roommates, house policies, etcetera).	You cannot control lifetime roommates
You can ensure your adult child has an enduring residence	You cannot leave the home to your other children once the person with a disability dies if the home is left to the non-profit in exchange for their lifetime management
This should be very affordable for the person with a disability because there is no mortgage, roommates could share property maintenance costs, and the county may reduce or waive real estate taxes	Roommates would likely still be necessary to cover property management and other costs

**5. Shared Home Purchase**

A group of families could get together and purchase a home. For example, three families could each put up a portion of the cost of a three bedroom home. One person with a disability from each family could live in the home.

**Rent and Qualifications**

For this model to work, the families would likely have to buy the home outright. If there were a mortgage, it would be very difficult to get the loans and deeds to work together and it would be incredibly hard to manage if someone wanted to move out. Thus, if the home was paid off, the rent costs would come from each individual living there to cover property maintenance, insurance, and any real estate taxes. Individuals could fund this through their Social Security income and other earned income.

One of the easiest ways to figure out the cost for each share of the home would be by the square footage of the bedrooms. To do this, divide the cost of the home by the total square footage of the bedrooms to get a cost per square foot. Multiply the per-square-foot cost

by the square footage of each bedroom to get the total cost.

For example, if you purchased a home with four bedrooms for \$400,000, you would measure each bedroom. If the master bedroom was 15’x20’, the two medium sized rooms were 12’x15’, and the smallest room was 10x10,’ the calculations would be as follows:

Bedroom size	Square footage	Cost per sq. ft.(\$400,000/ total BR sq footage)	Cost per share
15x20 feet	300 sq. feet	\$526.32 per square foot	\$157,896
12x15 feet	180 sq feet	\$526.32 per square foot	\$94, 737
12x15 feet	180 sq feet	\$526.32 per square foot	\$94, 737
10x10 feet	100 sq feet	\$526.32 per square foot	\$52,632
TOTAL:	760 sq feet	TOTAL:	Approx. \$400,000

### **Use with Waivers and Care Attendants**

Several people might have waivers and need support. Support staff might need to be coordinated.

### **Getting Started**

To begin, families who believe their loved ones with disabilities would want to live together would need to find and purchase a home. The families should work with their lawyers to draw up rules for selling shares of the home and shared costs.

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### **Your Toolkit for a Shared Home Purchase**

- A Medicaid Waiver or another funding stream to pay for support staff. Coordination of care with roommates' caregivers might also be needed
  - You will need someone to help you locate an affordable home that meets your needs. A realtor can assist with this
  - You will need enough money to buy the home outright, as well as a funding stream for property maintenance
  - You will need a lawyer to draw up paperwork on the terms of the shared home's usage, as well as provisions for any people wishing to move out
  - Find a roommate. See the **Roommate** section of this guide
-

Shared Home Pros	Shared Home Cons
There are no waiting lists to begin	Families need to find each other and ensure their loved ones are willing to live together
You have total control over the location and tenants of the home	If someone decides to leave the home, you must locate another co-owner who is compatible and can afford the home. No one can be evicted since everyone co-owns the home. Someone's share must be purchased for them to leave. You may need to limit equity growth to make sure it would be affordable for another partner to purchase a share when someone wants to leave
Most costs are controlled since there is no Mortgage	Families would need a lot of up-front capital to purchase the home
This can be used whether or not someone has a waiver and regardless of their level of need for support services	It would be necessary to coordinate support staff. You would also need to coordinate long-term maintenance plans and capital replacements

## **FINDING A ROOMMATE**

It can be difficult to afford rent or a mortgage in Virginia without having a roommate. Unfortunately, there are few resources for people with disabilities to find a roommate. If you think you or your loved one needs a roommate, consider these options:

Ask a friend, even if they haven't mentioned they may be looking for a new living situation. Ask your friends if they know of anyone who may be looking for a roommate. Ask people in the clubs you're in, like Special Olympics or People First.

- Find a roommate who will rent a new place with you
- Find a roommate who will rent available space in your home
- Find a roommate who is interested in providing you some assistance in exchange for reduced rent

Post an ad online at [craigslist.org](http://craigslist.org). Make sure to be very clear about who you would find to be an acceptable roommate.

### **Guidelines for Getting a Roommate**

Keep in mind that even though you may know someone or be friends with him or her, you may not be a good match as roommates. To find out if someone may be a good roommate for you, try the following:

- Spend time together. Have several meals or activities together to see if you really get along
- Meet the person's friends. Determine if they plan have friends or boyfriends/girlfriends over. Is that okay with you?
- Find someone who has the same interests or hobbies as you
- Come up with clear rules for what you need. Do you need lots of privacy or more social time? Do you need someone who is very tidy or are you okay with a little mess? Does the potential roommate get up early like you or do they sleep late?

- Do they like a cold house or warmer temperatures? Are you okay with pets, smoking, or drinking in the house?
- Consider asking for a background check, references from past roommates, or proof that they can afford the rent and utilities

You may obtain a criminal background check from the Virginia State Police at

[http://www.vsp.state.va.us/CJIS\\_Criminal\\_Record\\_Check.shtm](http://www.vsp.state.va.us/CJIS_Criminal_Record_Check.shtm)

### Questions to Ask Potential Housemates

Shared living has many advantages: it costs less than living alone, offers a built-in social network, and may give you access to shared resources that you would not have on your own. However, these advantages may not look great if you live with someone who is too noisy, is a slob, or invades your privacy. That is why it is important to interview potential housemates: you can ask questions and discover whose personal habits, preferences, schedule, and approach to shared living are the best match for you.

Below is a list of questions that you can use. Pick the questions that are most important to you.

When you set up your interview, make sure it is in a public place with plenty of people around, like a coffee shop or recreation center. Ask for references who you can call or email to find out more about the individual's habits and background.

Finally, do some research on the Internet to make sure the person is not listed in the Virginia sex offender registry (<http://sex-offender.vsp.virginia.gov/sor/zipSearch.html>).

Also try Googling the person and looking on Facebook to see what information comes up.

1. How often do you clean the place you live now? Which chores do you like? Which chores do you really hate?
2. What do you like to do on weekends?
3. Do you like to have friends over or go out with friends?
4. How often, if ever, do you smoke at home? Drink at home? Do drugs at home? If the person does illegal drugs, this is a RED FLAG.
5. Have you lived with a roommate before? What did you like/dislike about that experience? Are you still friends with your former roommates? If the person only has negative stories to share about prior housemates and takes no responsibility for the problematic situations, this is a RED FLAG.
6. What time do you wake up and go to bed?
7. What do you do during weekdays?
8. Do you expect a lot of out of town guests?
9. What is your romantic situation? If the person has a significant other, ask how often that person spends the night. Frequent overnights are a RED FLAG.
10. Do you have any pets? Plans to get any pets?
11. Why are you leaving your current place?
12. How much is your rent now? (If it's much less than what they would pay after moving in, they might not be able to afford the new rent.)
13. How do you think we should handle buying shared supplies like toilet paper, garbage bags, etc.?
14. What do you think is the best way to handle paying the rent and utilities?
15. How do you think we should handle the chores, like cleaning the common areas and washing the dishes?
16. Do you like the apartment temperature more on the chilly or warm side?
17. Do you have any food allergies?
18. How you feel about sharing stuff, such as a cable/Internet subscription, kitchen equipment or a vacuum cleaner?
19. What do you want in a roommate?
20. How often do you cook?
21. How long do you plan to stay?
22. What are challenges you've faced in past living situations?
23. Do you have references? Ask for phone numbers and email addresses.
24. Anything else I should know?

## A WORD ABOUT PROPERTY MANAGERS

If you're considering leaving a home to a person with a disability in a Life Estate, buying shares of a home, or using a microboard to purchase a home, someone will need to maintain the property. If the person with a disability, a family member, a member of the microboard, or someone you already know is willing to do this, that is great. However, property management can be a lot of work, so if you do not have someone who is willing to do this job for free, you may need to hire a property management organization.

Professional property managers can

- Advertise for renters
- Negotiate leases with new roommates (including live-in caregivers)
- Pay real estate taxes and lawn maintenance, trash removal and other routine fees
- Make minor and major repairs to the home or find a contractor who is able to do the work
- Collect monthly rent

To hire a property manager, fees may be determined by the size and age of the property. To find a property manager in your area and to inquire about costs, visit <http://www.allpropertymanagement.com> and enter the location and value of your home. Contact the property management groups listed to get quotes and to find out if they can offer the services you need.

## LOCAL HOUSING PROGRAMS AND PROVIDERS

The Harrisonburg Redevelopment and Housing Authority is a good place to start . They are located at:

286 Kelley St  
Harrisonburg, VA 22802  
(540) 434-7836  
[www.harrisonburgha.com](http://www.harrisonburgha.com)

Harrisonburg and vicinity continue to pursue opportunities to preserve and create affordable

housing. The City and County continues to maintain its level of tax support and increase its commitment for affordable housing and homelessness prevention and other high-priority safety net programs that are critical in the current economic environment. They provide developers with incentives to continue building affordable housing, and details are provided on the county's website.

See:

[http://www.harrisonburgha.com/public\\_housing.html](http://www.harrisonburgha.com/public_housing.html)

### **Housing Choice Voucher—(Section 8) federal rental assistance**

The Section 8 Housing Choice Voucher Program is a federal rental assistance program funded by the Department of Housing and Urban Development (HUD) and administered by Rockingham County's Housing Choice Voucher Program Office for county residents.

For Help Paying Bills:

[http://www.needhelppayingbills.com/html/rockingham\\_and\\_harrisonburg\\_co.html](http://www.needhelppayingbills.com/html/rockingham_and_harrisonburg_co.html)

**The waiting list is currently closed.** When it opens in the future, notification is made through community social service agencies, newspapers, the county website, and other public communication media. The applicant's income must fall below income limits established by HUD.

The waiting period may take as long as five years to reach the top. There are some priority preferences, so when there are vacancies, people with those preference points may be called in for an application.

## RENTAL ACCESSIBILITY MODIFICATION PROGRAM

**Purpose:** To assist low- and moderate income tenants with physical disabilities in completing accessibility modifications to their residences.

**Eligibility Criteria:** Physically disabled renters meeting the federal Section 8 low income limits.

**Description:** This program provides grants up to \$50,000 for primary residence modifications that are necessary to accommodate the particular

circumstances of the disabled member of the household.

This program also provides mini-grants to assist households needing limited modifications of up to \$1,500. The RAMP program is funded through the Federal Community Development Block Grant (CDBG) program, while the mini-grants program receives funding through the city's Housing Trust fund. Landlords are encouraged to deem any modifications to be permanent improvements to the rehabilitated rental property. City residents may also be eligible for a VHDA Accessibility Rental Modification Grant.

## **OTHER FINANCIAL ASSISTANCE**

Individuals with disabilities who have very low incomes may be eligible for additional programs to help with living expenses. The programs below do not cover the cost of rent or a mortgage, but they do help cover the cost of other needs related to living independently. They may help you make ends meet in your overall budget.

### **Energy Assistance**

Your local Department of Social Services accepts applications every year from the second Tuesday in October through the second Friday in November for heating/fuel assistance. This program can help cover the heating bill, late charges, and installation and/or connection charges for heating equipment. Funds are made available in December if you're approved. To see the income guidelines, visit:

[http://www.dss.virginia.gov/files/division/bp/ea/intro\\_page/forms/032-03-0661-08-eng.pdf](http://www.dss.virginia.gov/files/division/bp/ea/intro_page/forms/032-03-0661-08-eng.pdf)

Energy assistance helps with the cost of cooling a home. Cooling assistance funds are available to purchase or repair cooling equipment or to pay for the operation of cooling equipment. You must meet the same income guidelines as heating assistance and the household must have a member who has a disability, is a child under 6, or is over 60 years of age. Apply between June and August 15<sup>th</sup> each year if you qualify.

Additional resources:

Centers for Independent Living in Virginia  
<http://www.vacil.org/news.htm>

Medicaid Waiver Services Guide

<https://www.cildrc.org/wp-content/uploads2014/01/Waiver-Guide-302013.pdf>

### **SNAP Benefits**

The Supplemental Nutrition Assistance Program (SNAP) assists with the cost of buying food in low-income households. Qualifications are determined by income. To view the most up to date income limits, visit <http://www.benefits.gov/benefits/benefit-details/1593>. If approved, SNAP benefits would be loaded onto an EBT card every month. An EBT card looks like a debit card and can be used in grocery stores or other places that have the EBT logo. To apply, go online to <https://commonhelp.virginia.gov/access/> or visit your local Department of Social Services.

## **HOUSING – GENERAL**

Harrisonburg Redevelopment and Housing Authority  
P.O. Box 1071

Harrisonburg, VA 22803

<http://www.harrisonburgha.com>

(540) 434-7386

Helps with housing and Section 8 Vouchers

Virginia Home

1101 Hampton St

Richmond, VA 23220

Lifelong residential care for adults with permanent physical disabilities

Assisted Technology Loan Fund Authority

1602 Rolling Hills Dr

Richmond, VA 23229

<http://www.atlfa.org>

(804) 662-9000

Low-interest loans for a variety of special equipment for eligible persons

Virginia Housing Development Authority

601 S Belvidere St

Richmond, VA 23220

<http://www.vhda.com/Renters/Pages/accessibleRentalHousing.aspx>

Information about applying for microboard loans and info about grants to make accessibility modifications to rental units

Virginia Individual Development Accounts Program

(VIDA)

For individuals saving for a down payment on a home, business, business equipment, and inventory, or post-secondary education tuition payments. Eligible participants receive training, support, and \$2 in match funds for every \$2 the participant saves, up to a \$4,000 match

Shenandoah Valley Community Residences, Inc  
301 N. Cameron Street.  
Winchester, VA 22601  
(540) 536-0336  
Residences for adults with intellectual and/or developmental disabilities

Access VA, <http://www.accessva.org>  
This is a website that provides links to different accessible housing resources, including government agencies  
And services

Federal Home Loan Bank of Atlanta  
<http://www.fhlbatl.com/ahp/Set-aside/first-time-ahp/Set-aside/first-time-homebuyer.html>

Virginia Housing Search  
<http://www.virginiahousingsearch.com>  
Online databases with over 87,000 listings for rental Homes, about 20% of the homes on this site are Accessible

Virginia Livable Homes Tax Credit  
Virginia Dept. of Housing and Community Development  
600 E Main St, Suite 300  
Richmond, VA 23219  
<http://www.dhc.virginia.gov/index.php/housing-programs-and-assistance/tax-credit-programs/livable-homes-tax-credit-html>

Also see:  
Centers for Independent Living in Virginia:  
<http://www.vacil.org/news.htm>

Medicaid Waiver Services Guide:  
<https://www.cildrc.org/wp-content/uploads2014/01/Waiver-Guide-3.2013.pdf>

## **HOUSING –LOCAL**

C.J. Design

Judy Otto  
9904 Turleytown Rd  
Singers Glen, VA 22850  
(540) 833-5205

Collins & Collins, Inc.  
Andrew Collins  
6724 Brocks Gap Rd  
Broadway, VA 22815  
(540) 383-3884

DePaul Community Resources  
Debbie McIvor  
4859 Waterlick Rd  
Suites A through D  
Forest, VA 24551  
(434) 528-0184

Fair Haven Residential Services  
John Humphreys  
8386 S Eastside Hwy  
Elkton, VA 22827  
(540) 289-3174

Good Life Corp.  
Clif McDonald  
PO Box 925  
New Market, VA 22842  
(540) 740-4677

Pleasant View, Inc  
Heather Corbin  
14883 Spar Mine Rd  
Broadway, VA 22815  
(540) 896-8255

Family Sharing (Sponsored residential services)  
Jennifer Moore  
PO Box 665  
Fishersville, VA 22939  
(540) 480-0182  
(Sponsored residential)

Wall Residences  
Jack Wall  
PO Box 235  
Floyd, VA 24091  
(540) 745-4216

## SECURING A FUTURE: Estate Planning

All parents should have a will, and those who have children with a disability also need to create a Special Needs Trust to protect any public benefits that child may receive.

If your child is approaching his or her 18th birthday (age of majority), you might also consider some form of legal support if he or she needs and will continue to need help with medical, financial, and legal decision-making. (See the next section **Supported Decision making and Options for Legal Authority**.)

### Creating a Will

A will is critical to ensuring that your wishes are carried out regarding how and to whom your assets are divided after your death. If you have a child with a disability, this is doubly important. Find an attorney who specializes in special needs planning; he or she will be able to address the unique needs of each of your children and not jeopardize the benefits or services of your child with a disability. A list of some of our attorneys in the Harrisonburg-Rockingham area can be found later in this guide and in our Resources Guide. While many wills create family trusts, to avoid jeopardizing the benefits or services of your child with a disability you need to create a separate Special Needs Trust (see below).

### Reviewing Beneficiaries

In addition to naming a Special Needs Trust as the beneficiary for monies inherited through a will, you should also review the beneficiary designation for resources considered outside your will, including:

- Employer provided life insurance (if both parents work and have insurance through their jobs, be sure to check beneficiaries for both)
- Private life insurance policies (again check beneficiaries for all policies)
- Individual retirement accounts (including Roth IRAs\*, 401K and 403(b) accounts\*; SEP Plans\*, and Thrift Savings Plans\*)
- Individual checking and savings accounts
- Brokerage accounts
- Savings Bonds

Special cautions apply when designating a Special Needs Trust as a beneficiary of one or more of your retirement accounts (those marked with an \*). The document creating the Special Needs Trust (whether it is a will or a stand-alone trust) needs to state that the trust is an **accumulation trust** for the purpose of receiving distributions from retirement accounts.

(This comes into play once your child with a disability turns 18 and may be eligible for SSI as an adult. After age 18, an adult receiving SSI can only have \$2,000 in assets. Typically, when someone inherits a retirement account, they have to start receiving periodic payments from the account which would most likely disqualify them for federal benefits such as SSI and Medicaid.)

If siblings, other family members, or friends wish to leave your loved one some money, be sure to inform them that they must designate the special needs trust as the beneficiary. Give them the exact name of the trust and the date it was created.

### Special Needs Trusts (SNT)

Special Needs Trusts (sometimes called supplemental benefits trusts) allow families to provide for the future financial stability of their loved one with a disability. Since some federal benefits programs impose severe limits on beneficiary's assets and resources, your son or daughter could be disqualified from benefits if he or she received (for example) an inheritance or proceeds from a lawsuit. However, the law allows families to set up a special needs trust (SNT) that can act as a repository for an inheritance, stocks, property, insurance settlements or other assets **without** a loss of public benefits.

If your family member with a disability receives Supplemental Security Income (SSI) and Medicaid (or you are contemplating having them apply for these benefits), creating a Special Needs Trust is a necessity; such programs limit your loved one to just \$2,000 in assets to remain eligible.

Although no income or asset limits currently exist for the Social Security Disability Income (SSDI) program, individuals receiving SSDI benefits may also set up a first-party Special Needs Trust (see below) for money management purposes.

## Two Kinds of Trusts

Most special needs trusts are **third-party trusts** (family-funded trusts) established by parents or with an authorized non-profit, such as The Arc of Northern Virginia, for their children with a disability. The person establishing the trust, usually called the settlor, chooses to make some of his or her own assets available for the benefit of the beneficiary (person with disabilities).

These trusts may be funded during the parents' lifetime. You can contribute to them while you are still alive or you can fund them upon the death of the parent(s) or other individuals providing an inheritance, proceeds from a life insurance policy, or transfer from another trust.

**First-party trusts** (self-funded or self-settled trusts) are established by the beneficiary and always funded with **their own** resources. Common sources of funding for first-party trusts are structured settlements, paybacks from Social Security, and inheritances that mistakenly were given directly to the individual with the disability instead of to that individual's trust.

While many legal matters can be undertaken with a lawyer with a general background, SNTs are complicated enough to require the services of an elder law or estate attorney with expertise in disabilities and with this particular kind of trust.

## Setting Up a Trust

Special Needs Trusts can, and should be, set up as early as possible as part of the parents' overall estate planning.

For either option, you will have to pay fees to set up the trust and, possibly, to manage the funds. The Arc of Northern Virginia's Special Needs Trust program does not require a minimum deposit.

## Uses of Trust Funds

Funds from the trust are usually not distributed directly to the beneficiary, as that may jeopardize government benefits. Instead, they are usually disbursed to third parties who provide goods and services for the use and enjoyment of the beneficiary. Trust funds can be used for a variety of life-enhancing expenditures without compromising your loved one's eligibility for government benefits:

- Education and tutoring
- Out-of-pocket medical and dental costs
- Transportation (including purchase of a vehicle)
- Maintenance of vehicles, car insurance
- Materials for a hobby or recreational activity
- Trips or vacations, hotels, airline tickets
- Entertainment such as movies or sporting events
- Computers, videos, furniture, or electronics
- Athletic training or competitions
- Special dietary needs
- Clothing
- Housing costs (this may reduce SSI benefits)

## Acting as Trustee

A trustee is the person who oversees trust assets and administers the trust provisions, including investing, account and tax reporting, check writing, and disbursements. Professional legal and investment advice are crucial for trustees administering a Special Needs Trust themselves.

Trusts set up with The Arc of Northern Virginia do not have so many burdens on the family; trust staff perform all administrative tasks and client relations, and SunTrust Bank handles all fiduciary and investment duties.

For more information about being a trustee, download a free handbook at:

<http://www.specialneedsalliance.org/free-trustee-handbook>

## ABLE Accounts

ABLE Accounts are an additional tool that may be used for some people with disabilities and their families to save for the future while protecting eligibility benefits.

The Achieving a Better Life Experience (ABLE) Act enacted by Congress in late 2014 allows states to establish tax-advantaged savings accounts for certain individuals with disabilities for their disability related expenses. In addition, these funds would generally not be considered for supplemental security income (SSI) program, Medicaid, and certain other federal means-tested benefits.

ABLE Accounts do not replace the need for a Family Funded Special Needs Trust, but may be used in conjunction. Funds in an ABLE Account may only be used for Qualified Disability Related Expenditures. Key aspects of ABLE Accounts are similar to First Party or Self-Funded Trusts in that they require a Medicaid payback upon the death of the beneficiary.

To learn more about ABLE Accounts, visit [www.ablenlc.org](http://www.ablenlc.org). For a better understanding of the differences between Special Needs Trusts and ABLE Accounts visit, the Securing a Future for Your Child Toolbox on the website <https://thearcofnova.org/programs/transition/securing-future-child-disability/transition-toolbox/>

#### Advocate Program

Having problems applying for benefits, developing a budget, finding a social outlet, or figuring out housing options for your loved one with a disability? If you've created a Special Needs Trust with The Arc of Northern Virginia, our Beneficiary Advocate is here to help on these and many other issues. Call (703) 208-1119 extension 120 for more information on resources available through this service. There is an hourly fee, which can be paid with monies from the Special Needs Trust.

### SUPPORTED DECISION MAKING AND OPTIONS FOR LEGAL AUTHORITY

Families often struggle to determine the need for and value of guardianship and other forms of legal authority, especially as they relate to protecting the person with a disability. The answer to what is appropriate depends upon the person. **It is critical to remember that guardianship and similar measures are simply legal authority on a piece of paper. They cannot prevent someone from doing**

**something. They may be helpful in addressing some financial problems.**

The Disability Law Center of Virginia (<http://www.dlcva.org>) offers information on their website comparing different legal authority options and also provides templates that can be downloaded to create your own documents for power-of-attorney and medical directives.

**Dignity of Risk and Supported Decision Making** In recent years, a movement has grown to talk about the **dignity of risk** we all have to make decisions. The concept is simply that people should be free to make decisions, even poor ones, and given the opportunity to learn from their mistakes.

**Dignity of Risk** also means understanding that it is okay to make some bad decisions. Everybody should have the right to make mistakes, and it is often how we learn best. Many people learn from spending too much that it is hard to manage money. This is a right all people have and exercise every day. People with disabilities should have the same opportunities to make decisions and learn through natural consequences.

Alternatively, many people without developmental disabilities rely on tax accountants or doctors to explain life decisions in simple terms they can understand and provide advice. This idea is called **supported decision making**, and there is a growing international movement towards this idea. A team of people who care about the person with a disability form a Circle of Support and are asked by the person to work together to help them understand and make decisions. It does not involve taking away legal rights, but does build a support team and a way to foster decision making ability and independence over time. It has no cost and is probably what you are already doing. Supported decision making does not give the team any legal authority to speak on behalf of the individual or to override their decisions. You can learn more about Supported Decision Making and view webinars on the topic at <http://supporteddecisionmaking.org/>

#### Legal Authority Options: Assessing Alternatives

The appointment of a guardian or a conservator should be considered as a last resort. See the chart later in the guide for a list and description of legal

authority options. Petitioners for guardianship must provide evidence, and a judge must determine, that an individual is incapacitated in terms of making certain decisions.

However, if the person is not considered incapacitated but still needs help, the individual and his or her family may choose among several options. These alternatives range from having a caregiver (who has no legal authority to make decisions) to giving a trusted person a durable power-of-attorney that may make educational, medical, legal, and financial decisions. For example, an individual needing some assistance may be able to sign a Power-of-Attorney or Advance Medical Directive, appointing you or another family member as their agent for decision-making.

### **Educational Power of Attorney**

Talk to your IEP team about the transfer of rights and consider an educational power of attorney. This option keeps the student in control of decision making. An educational representative is a parent, family member, or other adult authorized to make educational decisions on behalf of an adult student. More information on the transfer of rights for students with disabilities can be found at: [http://www.doe.virginia.gov/special\\_ed/regulations/state/transfer\\_rights\\_students\\_disabilities.pdf](http://www.doe.virginia.gov/special_ed/regulations/state/transfer_rights_students_disabilities.pdf)

### **Medical Directive**

An Advance Directive helps you and your child prepare for a future time when he or she may not be able to make informed decisions or communicate his or her wishes. An agent (parent, relative, or other trusted adult) can make healthcare decisions when necessary while still allowing the individuals the right to make decisions he or she is able to make. There are several ways to make an Advance Directive. Sample forms can be found at <http://www.virginiaadvancedirectives.org/picking-an-ad-form.html>. You and your child can talk to your doctor about making an Advance Directive. You can hire an attorney to complete an Advance Directive. Once your child's Advance Directive is written, it needs to be signed in the presence of two witnesses. Virginia does not require Advanced Directives to be notarized, but it is a good idea to do so if possible. Once you have the necessary signatures, you should give copies to the agent, doctors, and other trusted

family members. You can also register the Advance Directive online at <http://www.virginiaregistry.org>.

This information is adapted from <http://www.dlcv.org> (The Disability Law Center of Virginia).

### **Guardianship and Conservatorship**

Guardians and conservators are appointed by a local court to protect an incapacitated person. Someone is deemed incapacitated if they are unable to receive or evaluate information effectively to meet health, care, and safety needs, or to manage property or financial affairs. An individual is not put under guardianship solely because they have bad judgment, but because their ability to understand and make good choices is impaired.

A guardian and/or conservator is often appointed for a person with a disability. However, **only a Circuit Court judge can decide that a person is incapacitated** and appoint a guardian and/or a conservator to act for the person. The appointment of a guardian or conservator is not a routine matter, and it is appropriate to take it very seriously, as the legal system does.

In essence, **guardianship** makes someone (like parents) responsible for **making financial, medical, social, and legal decisions** on behalf of a person who cannot make those decisions completely by themselves. In Virginia, a guardianship can be structured to fit the individual, with some rights taken away and others retained. An experienced attorney can assist you in crafting a guardianship that fits the individual and allows you to remain as a strong advocate for the individual with a disability.

A **conservator's** decision-making responsibility is focused on managing a person's financial and property affairs. A conservator's authority, like that of a guardian, may also be limited depending on the situation of the incapacitated person.

The court may appoint only a guardian, only a conservator, or both. For most young adults with a disability, only a guardian is necessary. The extent of the guardian's or conservator's authority will be set forth in the judge's order and in the Virginia Code.

### **Considering Guardianship**

In a guardianship, the law strikes a balance between

preserving the rights and personal autonomy of an adult and the duty of the Commonwealth of Virginia to protect individuals who lack sufficient capacity to make decisions regarding themselves or their property.

Typically, the young adult has less than \$2,000 in assets; the only income is from SSI or earnings that typically can be managed by a representative payee or by the individual with some assistance.

Families should consider less restrictive alternatives before petitioning for guardianship if they believe the individual may not fit the criterion of incapacitated. Parents considering guardianship should keep in mind that:

- Overall, it is important to realize that guardianship is a **very flexible system in Virginia**
- Guardianships can be **tailored to the needs of your child**, allowing parents to remain in a strong advocacy position
- As part of that flexibility, **guardianship need not take away all or even most of the individual's rights**. It is very common, for example, to preserve the right to vote, the right to hold a driver's license, and other rights
- Even under guardianship, your adult child **can still participate in decision-making** about his or her life to the extent of their capabilities. The guardianship order will typically say that the individual with a disability will be consulted and his/her wishes taken into account
- **Your child remains eligible for government benefits**. There is no loss of government benefits because someone has a guardian. The guardian's income and assets are not counted when computing benefits for an adult individual with a disability
- Guardianship **does not make you financially responsible for the person under guardianship**. For example, parents who are guardians do not have to provide food and shelter for their child but would be responsible for making the **decisions** about where their child would live and the kind of

care he or she would receive

- As a guardian, **you are not responsible for the financial, civil, or criminal liabilities of your child**. If an individual under guardianship hurts someone or damages something, the guardian is not held liable. If they were, few people would be willing to serve as a guardian. Guardians do have a duty to try to arrange a safe environment for the individual

Parents are frequently appointed as guardians, but other family members, an attorney, a friend, or a public guardian may also serve in this capacity.

To help determine if guardianship is the appropriate choice for your young adult, fill out the screener at <http://www.markwynn.com/wp-content/uploads/Thinking-About-Guardianship.pdf>

### Obtaining Guardianship

To obtain guardianship, parents need to file a petition with the Circuit Court of the jurisdiction in which the individual lives. Typically, parents are appointed as co-guardians, which allows either to act independently. You must provide a medical or psychological evaluation of your loved one that supports the need for guardianship. You may ask the court to appoint standby guardians who would serve when you no longer can.

When the petition is filed, the court appoints a guardian ad litem (GAL). The GAL is an attorney in private practice appointed from an approved list. The GAL's primary job is to ensure that the rights of the individual with the disability are protected. The GAL will therefore meet the individual, serve him or her with the court paperwork, and explain their rights. The GAL will also make a report to the Court giving an opinion as to whether the appointment of a guardian is necessary and who should be appointed.

After the GAL has filed a report, a hearing is held at the Court. Usually the persons being appointed as guardians must attend the hearing, and after the hearing will go to the Clerk of the Court's office to complete all necessary paper-work. The individual for whom the guardian is being appointed may choose to attend the hearing or not. As a guardian, you are required to submit a report every year to the local

Department of Social Services; the court will provide a form.

## **SAFETY AND CRISIS**

The Department of Health and Social Services assesses and provides services to adults, children, and families in an effort to protect children, preserve families, and prevent further maltreatment. Adult and Child protective services is non-punitive in its approach and is directed toward enabling families to provide adequate care for their family members. Local departments of social services are responsible for receiving reports of abuse and neglect, conducting investigations to determine the validity of the reports, and providing services that enhance safety and prevent further abuse and neglect to families and children. If you suspect your person with DD has been abused or neglected, report it. The contact information is as follows:

Department of Health and Social Services  
110 N Mason Street  
Harrisonburg, VA 22802  
(540) 574-5100  
<http://www.rockinghamcountyva.gov/206/social-services>

For further CPS information:  
<http://www.dss.virginia.gov/family/cps/index.cgi>

Valley Children's Advocacy Center  
1234-E Middlebrook Avenue  
Staunton, VA 24401  
M-F, 8:30-4:30  
(540) 213-0592  
Out of State (804) 786-8536  
CPS Hotline (800) 552-7096  
[www.valleychildrenscenter.org](http://www.valleychildrenscenter.org)

If the person with DD has been injured, or suffered mental trauma, they should be taken to the nearest hospital Emergency Room.

Not only do hospitals treat injuries, Sentara RMH has a Psychiatric Emergency Team (PET) that is available 24/7, and will be of assistance and provide guidance to the caretaker. For Sentara RMH, the POC for Inpatient and Outpatient Behavioral Health is Ms. Tina Bibb (540) 689-5451. The POC for Integrated Case

Management at Sentara RMH is Ms Cindy Harlowe.

Teach your person with DD about inappropriate touching, sexual, and physical abuse. The Department of Health and Social Services have manuals on this subject and can be obtained in person or via their web site <http://www.dss.virginia.gov/family/cps/index.cgi>

Although most of the information in their manuals is geared to children, most is applicable to adults as well.

REACH, Area One  
672 Berkmar Circle  
Charlottesville, VA 22901  
(855) 917-8278 (Adult Crisis Line)  
Health, sexual violence,  
advocacy, and prevention

Reach is the area's regional crisis service that supports adults with intellectual, developmental, and mental health disabilities or who otherwise exhibit challenging behaviors that are negatively affecting their quality of life. Reach emphasizes the prevention of crises before they occur. This is done through early identification of individuals, development of crisis response plans, training, and technical assistance. Individuals age 18 and over with a developmental disability including intellectual disability, and a mental health or behavioral need are eligible for this service. Referrals can be made by individuals, families, case managers, and other natural supports in the person's life.

**Access.** Reach provides mobile support services to individuals in order to maintain stability in their current placement/residential situation. Services can be provided on a planned or emergency basis. The clinical team will provide 24/7 consultation as well as ongoing preventative, cross systems planning for eligible adults. Once the immediate crisis is resolved, the REACH clinician will continue to work with the individual and his/her system of supports and services in order to problem solve, reduce the frequency of emergency interventions, and assist with ongoing stability.

Claude Moore Precious Time,  
<http://www.claudemoorefoundation.org>  
Provides respite care

### Determining a Decision-Making Role

Type	Decision Making Responsibilities	Notes
Supported Decision Making	Individual with disability makes decisions, with support from family or others with relevant expertise	<a href="http://www.supporteddecisionmaking.com">http://www.supporteddecisionmaking.com</a>
Emergency order for adult protective services	Short-term guardianship (15 days) to handle an emergency or correct conditions causing an emergency	Local Department of Social Services must apply to Circuit Court for temporary guardianship order
Durable power of attorney	Written authority giving a parent or another person (agent) power to make decisions on behalf of the individual with a disability (the principal). Agent may act even if principal becomes incapacitated	Agent cannot override decisions Power ends if principal revokes it or dies
Advance Directive	Person with disability provides instructions about his health care treatment wishes and designates an agent to make healthcare decisions when he or she cannot. May be combined with Medical Power of Attorney. Must be witnessed in Virginia	Agent's powers are defined in the document. Agent cannot override decisions
Healthcare Power of Attorney	Similar to durable general power of attorney, but directed exclusively at healthcare  Choosing the right agent is very important—make sure he or she knows the individual's wishes, values, preferences, and will be a strong advocate.	Enables someone to make any or all healthcare decisions if the individual becomes incapacitated. Doctor and family will be able to know and respect the individual's wishes
Representative payee	Receives another person's government benefits on behalf of that person, responsible for using benefit to pay beneficiary's living expenses	Individual must be able to manage finances  Representative payee must report annually to the Social Security Administration
Limited conservatorship	Decisions on specific financial matters, such as paying bills or filling out tax returns, as specified by the judge. Conservator must post surety bond.	Individual must be incapacitated. Conservator must file report on income and expenses
Full conservatorship	All financial decisions, including paying bills, Investing money, and selling property. Conservator must post a surety bond	Conservator must file annual report on all financial transactions
Standby guardian	Person designated in guardianship order to become guardian when current guardian dies	Does not assume any duties until death of primary guardian

### Determining a Decision-Making Role

Type	Decision Making Responsibilities	Notes
Limited guardianship	Decisions on specific issues (such as only healthcare), as determined by a judge. This leaves the person free to make all other decisions	Individual must be incapacitated. Guardian must file an annual report with Department of Social Services
Full guardianship	Guardian makes all financial, legal, personal care, and social decisions	Individual must be incapacitated. Guardian must file an annual report with Department of Social Services

### ADDITIONAL RESOURCES

“A Family Guide to Residential Planning for Adults with Disabilities” by Dafna Krouk-Gordon and Barbara D. Jackins.

Visit The Arc of Northern Virginia’s Online Toolkit at <https://thearcofnova.org/housing-toolkit/> for the following support tools:

- Housing Choice Vouchers 2016 VideoSeries
- Support and Housing Needs Self-Assessment
- Housing Needs Profile
- Circle of Support Checklist
- Moving Expenses Budget Sheet
- Creating a Spending Plan
- Sample Roommate Agreements
- Sample Renter Resume and Cover Letter
- Household Budget Guidance
- Where Can I Find Affordable Housing in Northern Virginia
- Non-Profit Housing Providers in Northern Virginia
- Apartment Properties with Section 8 Housing Contracts in Northern Virginia
- The Arc of Northern Virginia’s Care Attendant Guide

## GLOSSARY

**Asset waiver Resources** you have to help you secure housing and supports. Assets can be financial or people in your life who want to help you.

**Circle of Support** The group of people who are involved in the life of the person with a disability and want to help create a plan for sustainable housing and support. This group can include family members, teachers, doctors, family friends, neighbors, lawyers, realtors, financial planners, co-workers, and anyone who would like to help.

**Congregate Residential** Often referred to as group homes, congregate housing is a model where the person with a disability lives with other people with disabilities in a home that has paid staff. Generally, 4-6 people with disabilities live in a congregate home and staff is on site 24 hours/day. This model is commonly used in combination with a Medicaid Waiver.

**Fair Housing Act** A federal law that prohibits discrimination in the sale or rental of housing based upon race, color, national origin, religion, sex, familial status, or disability. This means that when you're looking to rent, sell, or buy a home, you cannot be discriminated against because you have a disability. The law also states that any buildings that opened after March 31, 1991 and also have an elevator and four or more units must ensure that all public areas are accessible, the entry/exit and transit routes in the unit are accessible, bathroom walls are strong enough to allow for grab bars, and kitchens/bathrooms can be used by someone in a wheelchair. In buildings that opened after March 31, 1991 and have four or more units but no elevator, these standards apply to the ground floor units.

**Housing** The physical structure where the person with a disability will live. Options are further discussed in this guide.

**Housing Choice Voucher** Formally known as Section 8 Vouchers, Housing Choice Vouchers allow low-income individuals and low-income families to rent from private landlords at a reduced cost. This means you could rent a home, room, or apartment of

your choice. The voucher is effectively a payment that is made directly to the landlord each month. The renter would pay 30% of their monthly income towards rent, plus the cost difference if the home selected was above market rate.

**Lease** A legal document you sign to rent a home. You may be signing a lease because you're renting a home or you may ask that roommates sign a lease if they're going to rent a room in your home. Leases have legal language and should be tailored to your situation and reviewed by a lawyer if you need help understanding or clarifying the language.

**Life Estate** A life estate exists when a property is owned by someone only for their lifetime. In a Life Estate, a homeowner grants a **life tenancy** to a person with a disability who is then entitled to live in that home for the remainder of their life.

**Microboard** A formalized circle of support that helps a person with a disability secure housing and/or services. The microboard may choose to become a mini-corporation which entitles them to low-interest housing loan options with the Virginia Housing Development Authority.

**Property Manager** The person or group responsible for maintaining some or all components of a housing situation. For example, property managers may be hired to ensure exterior work is complete (lawns are mowed, siding is washed) and to see that interior work is up to date (all lights inside the home work, appliances are functioning).

**Public Housing** Housing units that are federally-funded and made available to people with low incomes. They are normally run by local governments.

**Shared Apartment** A rented apartment (home, condo, or townhome) shared with one or more other people, usually unrelated to each other.

**Shared Home** A home purchased jointly by several families so that their loved ones can live in the home and share costs and/or supports.

**Sponsored Residential** A housing-and-supports model where a person with a disability lives with their caretaker. The caretaker could be a single person or a

member of a family. The individual supported in this home lives there full time and is treated as a member of the family.

**Supported Apartment** A combined housing and supports model where a support provider works with an apartment complex or buys housing stock, then ensures those homes are set aside for people with disabilities. The supports provider then brings services into the home as often as needed. In some cases, several homes may exist near each other so support staff can be share (clustered apartments).

**Supports** The assistance a person with a disability needs to live as safely and independently as possible. Supports may partner with your housing choice (a congregate waiver home, for example) or may be paid for separately (a hired care attendant you bring into your own home)

**Waiver** A menu of services and supports from which the person with a disability can select the services they need. Waivers are governed by states and are publicly funded. They have long waiting lists. You can use a waiver-funded attendant in almost any housing situation.

### State-Wide Resources for Housing Finance

Contact Person or Organization	Why Contact Them?
<p>Access VA www.accessva.org</p>	<p>This is a website that provides links to different accessible housing resources, including government agencies, services, and adaptable or universally-designed appliances for your home</p>
<p><b>Assisted Technology Loan Fund Authority (ATLFA)</b> 1602 Rolling Hills Drive Richmond, VA 23229 (804) 662-9000</p>	<p>Low-interest loans for a variety of special equipment to eligible applicants. The interest rate is typically well below normal market rates, and loans are available with no down payment and longer terms which reduces monthly payments</p>
<p><b>ENdependence Center of Northern Virginia (ECNV)</b> 2300 Clarendon Blvd. Arlington, VA 22201 (703) 525-3268 TTY (703) 525-3553 FAX (703) 525-3585 <a href="http://www.ecnv.org/FAQs/homemod.html">http://www.ecnv.org/FAQs/homemod.html</a></p>	<p>Our local Center for Independent Living has housing FAQs and other resource options to help people with disabilities live an independently as possible</p>
<p><b>Federal Home Loan Bank of Atlanta</b> Down payment and closing cost program for first-time homebuyers <a href="http://www.fhlbatl.com/ahp/Set-aside/first-time-homebuyer.html">http://www.fhlbatl.com/ahp/Set-aside/first-time-homebuyer.html</a></p>	<p>FHL Bank Atlanta's first-time Homebuyer Program (FHP) provides up to \$5,000 in matching funds for the down payments and closing costs of first-time homebuyers</p>
<p><b>Virginia Department for Aging and Rehabilitative Services (DARS)</b> 8004 Franklin Farms Dr Richmond, VA 23229 (804) 662-7000 (V/Relay) (800) 552-5019 (Toll free V/TTY) (804) 662-9232 (Fax) <a href="http://dars@dars.virginia.gov">http://dars@dars.virginia.gov</a> <a href="http://www.vadars.org">www.vadars.org</a></p>	<p>Assists individuals with disabilities with determining whether home modifications are needed to reach their employment goals and identifying resources to help cover the cost of these services</p>

<p><b>Virginia Housing Development Authority</b>          601 South Belvidere Street          Richmond, VA 23220          (877) VHDA-123          TTY (804) 783-6705  <a href="http://www.vhda.com/Renters/Pages/AccessibleRentalHousing.aspx">http://www.vhda.com/Renters/Pages/AccessibleRentalHousing.aspx</a></p> <p>Bruce DeSimone, AICP (contact for Microboards)          Senior Community Living Office          (804) 343-5656  <a href="mailto:Bruce.desimone@vhda.com">Bruce.desimone@vhda.com</a>  <a href="http://www.vhda.com/Renters/Pages/AccessibleRentalHousing.aspx#b">http://www.vhda.com/Renters/Pages/AccessibleRentalHousing.aspx#b</a></p>	<p>Information about applying for microboards loans and information about grants to make accessibility modifications to rented units</p>
<p><b>Virginia Housing Search</b>  <a href="http://www.virginiahousingsearch.com">http://www.virginiahousingsearch.com</a></p>	<p>This is an online database with over 87,000 listings for rental homes. About 20% of the homes on the site are accessible. You can search for homes in your price range and homes that accept housing vouchers</p>
<p><b>Virginia Individual Development Accounts Program (VIDA)</b></p>	<p>For individuals saving for a down payment on a home, business equipment, and inventory or post-secondary education tuition payments. Eligible participants receive training, support, and \$2 in match funds for every \$1 the participant saves, with the award capped at \$4,000</p>
<p><b>Virginia Livable Homes Tax Credit</b>          Virginia Department of Housing and Community Development          Main Street Centre          600 East Main Street, Ste 300          Richmond, VA 23219          (804) 371-7000  <a href="http://www.dhcd.virginia.gov/index.php/housing-programs-and-assistance/tax-credit-program/livable-homes-tax-credit.html">http://www.dhcd.virginia.gov/index.php/housing-programs-and-assistance/tax-credit-program/livable-homes-tax-credit.html</a></p>	<p>Tax credits are available for up to \$5,000 for the purchase/construction of a new accessible residence and up to 50 percent for the cost of retrofitting existing units, not to exceed \$5,000</p>

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