

AGING WITH A DISABILITY

**A Guide for Older Parents
and Future Caregivers
of Adults with Disabilities**



Harrisonburg and Rockingham

**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.

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

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 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 our work on these guides. Please 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 of the U.S. found many families struggling to help their loved one with an intellectual disability:

80% of families surveyed don't have enough money for needed care and almost half report having more care giving responsibilities than they can handle

85% report that their adult family member with DD was not employed either full- or part time

62% of families don't have a long-term care plan

75% can't find after-school care, community services or summer activities for their loved one

59% report they don't have enough information to make good choices about housing options

65% report that they don't have enough help in planning for the future

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, VA Lifespan Project.¹

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

1. Receiving a diagnosis and having a child enter an early intervention program
2. Starting school and entering the special education system
3. Transitioning out of the school system and into adult services
4. Entering the world of work
5. Finding a place to live outside the caregiver's home
6. Aging with a disability

Help for You, the Parent

As a first step in Lifespan, we have written six guides to address 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, you'll note that each also repeats some information parents and caregivers need to know whether their loved one is two, 22 or 62 years old: which steps to take to protect your loved one's financial future, how to apply for benefits, and where to go for more help.

¹ Anderson, L.L., Larson, S.A., and Wuorio, A. (2011). 2010 FINDS National Survey Technical Report Family Caregiver Survey. Minneapolis: University of Minnesota, Research and Training Center on Community Living

All of the guides can be found on the website of The Arc of Harrisonburg and Rockingham, Virginia at <http://www.hrarc.org>

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, 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, Executive Director, The Arc of Harrisonburg and Rockingham, Virginia, Lifespan, 620 Simms Avenue, Harrisonburg, VA 22802, execdir@hrarc.org

AGING WITH A DISABILITY: A Guide for Older Parents and Future Caregivers of Adults with Disabilities

As the parent of an adult child with a disability, you have been responsible for making most of the financial, medical, and legal decisions for your family member for many decades. Now that you are getting older, you may want to get ahead of the game and do some future planning. Or perhaps you are facing more short-term challenges: your son or daughter no longer wants to live with you, he or she is old enough to “retire,” or you are no longer able to provide the level of care that is best for your adult child.

However, at some point you will no longer be there to take care of your family member with a disability. Your best gift to your family is to **avoid a crisis** on your death. With some planning on your part, you can ensure that future caregivers will be able to provide the quality of life you have envisioned for your loved one.

This **future planning is for every family**, even if you think you don’t have any money to leave to your loved one or you believe you cannot afford an attorney to do estate planning. Many aspects of future planning (as you’ll see in this guide) are not related to money.

Instead, communicating your vision for the future—and having your son or daughter participate in that conversation—is of primary importance.

Part One: Creating Your Future Plan

This guide is divided into two parts. Part One focuses on parents and the planning they need to do as both they and their adult child with a disability get older. It provides a blueprint for creating a “backup plan” with the key information needed to ensure continuity of care for the family member with DD. This is a project that takes some time, but it is well worth it for the peace of mind it can bring.

If you haven’t already talked to your family about what you’d like to see happen in your own life as you get older, writing the future plan is a good opportunity to talk about hopes and concerns for

both yourself and your son or daughter with a disability. If you’ve already engaged in some future planning, some of the decisions and information-gathering have probably already been done. Either way, look at this process as an opportunity to speak openly about what you’d like the future to look like for the whole family.

Part Two: Carrying Out the Future Plan

Part Two focuses on future caregivers, helping them carry out the plan created by the family. It deals with immediate issues that arise after the death of a parent, such as dealing with grief and getting up to speed on legal and financial arrangements.

What’s In This Guide

To help parents and caregivers with these tasks, this document addresses the following issues:

How to create a future plan for your family.

Future planning focuses on ensuring that resources—human, financial and physical—exist for your loved one with a disability after you are gone. This guide discusses a seven-step process for determining what resources are needed and available and how to get your plan on paper:

1. Establishing your vision and values
2. Building future support networks
3. Assessing financial resources
4. Applying for benefits
5. Following up with estate planning
6. Exploring housing options
7. Getting your plan on paper

Who’s in charge of key life decisions. While you may have been providing all or most of the care for your loved one with a disability for many years, the time comes when others will need to assume that role. It’s important to define who will play what role—caregiver, guardian or trustee, for example—and to ensure that future caregivers understand their role and responsibilities.

Why you need estate planning. As a parent, you need to think ahead to protect any financial resources, including potential inheritances and public benefits, that could support your son or daughter. This means creating or updating your will, establishing or reviewing a special needs trust, and communicating how family members may leave money to a relative with a disability.

Where government benefits play a role. Your adult child with a disability may qualify for benefits from the Social Security Administration, either on their own or as a beneficiary under your Social Security retirement. Some persons with a disability may also benefit from various waiver programs under Medicaid. Now is the time to apply for these programs if you haven't already.

What "retirement" might look like for an older adult with a disability. Your adult child with a disability will eventually "retire" and need to replace work with social and recreational opportunities. Some localities offer adult daycare and programming for older adults with disabilities. Members of your adult child's "circle of support" may also provide some of these recreational and social outlets.

Where your adult child will live. If your adult child has been living at home all his or her life, moving will be especially traumatic after you are gone. However, if at all possible, it is better to make this transition earlier rather than later. Safety, cost, availability, and eligibility for a Medicaid Waiver are all factors in deciding where an adult child with a disability can and wants to live.

Be sure to see our continually updated Resources Guide on our website. The information is listed by categories and includes national, state, and local resources that you will find very helpful.

Read through the "Checklist for Parents" and watch for items marked "ASAP" for steps to take right away.

Aging with a Disability: A Checklist for Older Parents

ASAP	Letter of Intent	Legal	Benefits	Leisure/ Recreation	Transport	Housing
Discuss “vision” with family; make preliminary list of people in circle of support	x					
Begin “downsizing” paperwork; set up file(s) for key documents; share list of key contacts with adult children	x	x				
Make list of financial resources and draw up estimated budget of monthly expenses	x					
Write Letter of Intent	x					
If not already done so, have a will drawn up for parents		x				
If not already done so, get a Special Needs Trust drawn up		x				
Determine if your adult child with disability qualifies for benefits from Social Security Administration			x			
Explore person’s eligibility for Medicaid waivers: ID, IFDDS, Day Support, CCC PLUS. Get on wait list(s).		May	be	long	wait	list
Discuss need for guardianship or other decision-making authority		x				
When first parent begins taking Social Security (at age 62 at earliest)						
Ask SSA about Disabled Adult Child benefits			x			
When second parent begins taking Social Security						

ASAP	Letter of Intent	Legal	Benefits	Leisure/ Recreation	Transport	Housing
Check with SSA to see if your adult child might qualify for a higher benefit.			x			
2-5 years before housing will be needed						
If have ID Waiver, visit group homes, find out about wait lists						x
If adult child DOES NOT have a Waiver, draw up a plan for housing						x
Explore private housing options						x
Every year (if applicable)						
File Representative Payee Report		x				
File Guardianship Report		x				

Aging with a Disability: A Checklist for Future Caregivers

ASAP	Circle of Support	Legal	Financial	Leisure/ Recreation	Transport	Housing
Discuss with your own spouse and children what role you and they would be willing to play in the individual's future	x					
Discuss "vision" with parents and other family members; start making decisions regarding future roles	x	x	x			
Ask parents where key documents are kept and how to get access to them	x					
While your parents are still alive						
Fill in "Creating a Circle of Support" form	x					
If needed/desired, make preliminary monthly budget			x			x
Begin spending time with sibling/introduce yourself to key people in sibling's life	x					
Hold a meeting of Circle of Support; assign roles wherever possible	x					
If taking on legal role, meet with attorney, file Representative Payee status with SSA		x				
When second parent passes away						
Review Letter of Intent and budget	x		x			
Inform backup guardian, Representative Payee, and trustees, if necessary	x		x			
Find out about Social Security survivor benefits			x			
Explore eligibility for Food Stamps, Meals on Wheels, etc.			x			

Coordinate with guardian and trustee about housing, recreation, and transportation if necessary				x	x	x
Consider hiring a geriatric care manager if needed for medical care management, errands, companionship			x	x		
Every year (if applicable)						
File guardianship report		x				
File Representative Payee report		x				

PART ONE

***PREPARING YOUR FUTURE PLAN:
For Older Parents
Of Adult Children with Disabilities***

PART 1—PREPARING YOUR FUTURE PLAN: FOR OLDER PARENTS OF ADULT CHILDREN WITH DISABILITIES

STEP 1: ESTABLISH YOUR VISION AND VALUES

The first step in your future planning is to open discussions with family members about what would be necessary to maintain your adult child's quality of life once you are no longer willing or able to be the principal caregiver(s). These discussions should definitely involve your son or daughter with DD (if they are able to participate), as well as his or her siblings and others in your Circle of Support.

Timing

If you have already had similar talks about your own retirement or end-of-life wishes, this conversation may be a bit easier. If not, this is the time to speak openly and realistically about both your dreams for the future and the practical aspects of daily life with your loved one.

There's no hard and fast rule about when you should open these discussions, but sooner is better than later. Set yourself some kind of deadline—your 55th birthday, your child's 30th birthday, the day after setting up a special needs trust, the month you retire, the date you start taking Social Security—whatever will spur you to proceed. Look at the Checklist for Caregivers to see what steps should be taken immediately; it's especially important to have a will, set up a special needs trust, and review beneficiary designations so that your child will not be disinherited by default.

The Vision

In all likelihood, you, your spouse, your adult child with a disability, and his or her siblings already have certain hopes about what the future might look like. Everyone may also have very realistic fears and concerns. Now is the time to air both the positive and the negative and agree on a fundamental direction for the future.

To begin, have a family meeting and ask yourselves as a group some of the questions listed under "Gentle Talk about Tough Issues." At a minimum,

you should come out of these discussions with an idea about:

- **Your vision of your adult child's future.** The discussion should include the goals you have for your adult child's life. Also, if money were no object, what would your child do once you are no longer here (for work and leisure as well as spiritual or religious activities), where they would live, and who would be taking care of them
- **Your adult child's vision of his or her future.** Be sure the conversation includes your son or daughter's own ideas and wishes for their future. Maybe he or she has a favorite family member who should be a strong presence in their life after the death of the primary caregiver(s) or definite notions of the kind of activities they like to do
- **Your values around money.** Parents of children with DD worry a lot about having enough money to support their child after they are gone. However, some money "problems" are actually conflicts over values. **Reiterate your absolutely non-negotiable priorities** for your child's future, such as ensuring his or her health and safety; no future financial decision should go against these fundamental priorities

Next, discuss who might be the person or persons making the financial decisions for the individual with a disability (see more under "Circles of Support"). This person's values and attitudes about money are incredibly important: are they comfortable making financial decisions, would they seek help from professionals if needed, how would they engage the individual with DD in decisions? Responsibility for financial decisions is often split among a trustee(s), a Representative Payee, and a guardian or conservator, so approach several people about their comfort level in handling money and/or investments and working with others on financial affairs.

Only after discussing the "human" aspect of finances should you calculate how much money there may be and where and when it can be spent.

Gentle Talk about Tough Issues

It is not easy to talk about a future without you in it, especially when it will affect a vulnerable individual such as person with a disability. To help you get started, here are some questions to ask yourself before you approach anyone else about the Future Plan:

What are your biggest concerns and priorities as you put together the Future Plan for your son or daughter?

What is the best thing you think might happen as a result of this conversation?

What is the most difficult thing for you to contemplate when you are no longer the main caregiver?

How do you think your son or daughter with a disability might react to conversations about their future without you?

How do you think your other children and family members might react to the conversation?

What kind of support (financial, emotional, legal) do you think others would be able to provide their relative with a disability?

Adapted from AARP's brochure "Prepare to Care" at <http://www.aarp.org/foundation>. Once on the page, search for "Prepare to Care."

Once your family has discussed and written down the basic vision and values for your adult child's future, planning focuses on providing the human, financial, and physical resources needed to make that vision as close to reality as possible. The following sections therefore discuss finding good people to share caregiving responsibilities, projecting income and expenses (including federal and state benefits), and exploring housing options for your adult child with a disability.

STEP 2: BUILD FUTURE SUPPORT NETWORKS

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 when you are no longer able to. This community is often termed 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.

Some members of your loved one's circle of support may be long-term participants, while others may be asked to join for a limited period of time in order to carry out specific tasks or goals.

The Parts of the Circle

Circles of support need to last for a lifetime and should be as diverse as necessary given 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 (maybe from work, church, choir, an art class, etc.)

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

Caseworkers in local human services agencies

Staff at local advocacy organizations, such as The Arc of Harrisonburg and Rockingham, Virginia

Residential provider staff

Everyone has someone who could participate in the Circle of Support, even where there are no siblings or other close relatives.

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 often take on a lot of caregiving after the parents pass away because they know their brother or sister well and are familiar with his or her behaviors, routines, etc. There may also be other 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” at a job or residential facility

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)

If possible, having others assume these roles while the parents are still living can save considerable emotional turmoil, as well as time and energy.

Starting with the Family Circle

Family forms the core of any community of support. Nevertheless, it’s very possible that parents and siblings have not communicated about their desires and concerns for their family member’s future.

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)
- Use the chart on the next page to help you sort out who might play what roles

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 will last).

For more information on setting up and running a Circle of Support, see <https://www.iidc.indiana.edu/irca/articles/creating-a-circle-of-support.html>

A Changing of the Guard

Parents often serve a variety of legal roles—trustee, guardian, Representative Payee—in the life of their adult child with a disability. If possible, having others in the family or Circle of Support assume these roles before a parent passes away can save considerable emotional turmoil, as well as time and energy.

- Alter wills and trust documents to appoint successor trustees and/or co-trustees
 - Change guardianship orders to include a co-guardian (if one is not already mentioned) and/or a backup guardian
 - Call the Social Security Administration and change the Representative Payee
-

Calling All Siblings

As a sibling of a family member with a disability, you will be in your brother or sister's life longer than anyone else. And because you grew up together, you also know him or her better than anyone else.

This special position in the family gives you a unique and valued perspective on your sibling. However, it's OK to be unsure about your role; the key is to understand what you are feeling now and communicate it so that expectations can be set early on.

Again, it's important to **avoid a crisis** once your parents are gone and to start figuring out now what everyone's expectations are. Here are some ideas to help prepare for whatever role you may decide on:

- **Be realistic about the role you are willing to play.** Look at the previous list for some ideas of ways you can support your brother or sister. This role may change as responsibilities in your own life change, or as you accumulate knowledge about an area of care. If you are considering becoming a trustee or a guardian, be sure you understand your legal obligations, including any requisite reporting to government agencies, tax preparation, or financial documentation
- **Spend time with your sibling now.** If you haven't had the opportunity to spend much time with your sibling recently, it's a good idea to begin reacquainting yourself with him or her while your parents are still alive. Go out for an activity, have a meal together, accompany him or her to work or to a religious service, or just talk
- **Get to know the key people in your sibling's daily life:** friends, roommate(s), home healthcare aides, employer, residential staff, Special Olympics coach, etc. Knowing who and how these people contribute to your sibling's daily routine will make any transition much easier
- If you plan to assume a legal role (such as trustee or guardian), you may also want to **introduce yourself to relevant professionals,**

such as your parents' attorney, financial advisor, bank manager, etc

- **Know where your parents' important documents are kept** and how to access them. Have your parents share an **emergency contact list** with phone numbers of your sibling's workplace and/or residence, doctor and mental health professional, transportation service, local caseworker, and other family members. Information on the whereabouts of The Letter of Intent (see Step 7: Get Your Plan on Paper) and contact information for others in the Circle of Support can be added as they are developed

For support and more resources, see The Sibling Support Project at <https://www.siblingsupport.org/>

What Siblings Want Parents to Know

Parents and their adult children need to have frank discussions about both sides' expectations about who will take care of a family member with a disability. Here are some recommendations offered by adult siblings through the Sibling Support Project at <https://www.siblingsupport.org>

Please have a plan. Research shows siblings appreciate their parents leaving them specific information on the who, what, and how of taking care of their sibling. Having a will, a list of instructions (such as a Letter of Intent), and some financial resources in place saves time and emotional energy for the grieving family—and ensures continuity in routine for the sibling with a disability

Involve siblings from the beginning in future planning. Involving adult children early on in the planning stage ensures “buy in” and avoids surprises and hard feelings later. Both sons and daughters need to be included in these discussions

Acknowledge the fact that siblings have a right to their own lives. Parents need to encourage their typically-developing children to pursue their own goals so that their future involvement with their sibling will be a choice instead of an obligation. Parents should not make judgments (as difficult as that is) about when and how much responsibility a sibling may assume in the future

Recognize *all* of the feelings siblings may have about their brother or sister. Adult siblings’ emotions about a brother’s or sister’s special needs may be positive or negative, or just ambivalent. Parents and others need to acknowledge this gamut of feelings and also expect that those feelings may change over time

Adapted from “What Siblings Would Like Parents and Service Providers to Know” from The Sibling Support Project. Downloaded April 28, 2015 from <https://www.siblingsupport.org>, and <https://www.siblingsupport.org/documents-for-site/WhatSiblingsWouldLikeParentsandServiceProvidertoKnow.pdf>

Using a Microboard as a Circle of Support

Some families are considering a more formalized version of a Circle of Support called a microboard.

In Virginia a microboard must incorporate itself by registering with the Virginia State Corporation Commission, including developing bylaws, a meeting schedule, a succession plan, and a scope of authority.

As with Circles of Support, a microboard should be composed of family, friends, and professionals who are willing to volunteer their time and expertise to identify and fulfill the needs and wishes of your family member. Advantages of a microboard include the ability to share knowledge about your family member, and also to formally share the responsibility for solving issues that arise in his or her life. For example, microboards may:

Advocate as a legal entity for vocational, day support, residential, financial, medical, or social services

- Manage waiver supports (e.g. hire and train staff)
- Provide property management and upkeep
- Act as guardian or co-guardian (this is rare but has been done in Virginia)
- Provide referrals to and/or coordinate resources
- Act as a sounding board and source of creative problem solving
- Engage in business transactions on behalf of your family member, including the purchase and sale of real estate. Microboards may qualify for low- interest mortgage loans through the Virginia Housing Development Authority (see **STEP 6: EXPLORE HOUSING OPTIONS** section in this guide)

A microboard would dissolve upon the death of the individual it serves.

For more information, see Virginia Microboard Association at <http://www.virginiamicroboards.org>

Seven Steps to a Microboard

Identify potential members

Meet informally with potential candidates and discuss your vision, goals, etc. From this group, identify 5-9 members

Choose a name for microboard (be sure the name is not already registered by checking the State Corporation Commission website)

Create bylaws, which would include frequency of meetings (the board must meet at least once a year)

Create Articles of Incorporation

Consult an attorney to determine type of corporation (LLC, S Corp, C Corp, etc.) to meet your needs

Apply to Virginia State Corporation Commission; initial application fee is \$100 and annual renewal fee is \$50.
<http://www.scc.virginia.gov/contact.aspx>

STEP 3: ASSESS FINANCIAL RESOURCES

It is very important to discuss with family members *now* the financial resources that will be available to support your adult child once you are no longer the caregiver.

Housing is probably the most costly item that needs to be worked into a future budget, particularly in the Central Virginia area, and it behooves parents to start thinking early about residential options.

This section provides basic information for creating a budget using estimates of future income sources and future expenditures and details on how to apply

for benefits that could become an important source of ongoing income for your adult child with DD.

Potential Income Sources

Financial resources that may be available to support your loved one in the future include:

- Earnings from the individual's job
- Social Security payments (SSI, SSDI, and DAC)
- Dependent/survivor veterans' benefits
- Life insurance payouts
- Inheritance from you or your spouse
- Inheritances from other family members
- Sale of a family-owned business
- Sale of real estate
- Sale of other assets, such as cars or furniture

Medicaid or Medicare benefits are not an income source, but they would reduce the amount of money spent on medical-related expenses.

Whatever the size of the inheritance you may leave your loved one, **remember that your son or daughter cannot have more than \$2,000 in assets if they are to remain eligible for many federal and state benefits.**

You must create a special needs trust and have the trust named as the beneficiary (not your child personally) for any monies you would like him or her to inherit. If other family members or friends would like to leave money to your son or daughter, they must also name the special needs trust as the beneficiary in their will.

Potential Expenses

A good approach to predicting future expenses is to use current spending to project both expense categories and costs. A key element here is to **anticipate whether the pattern of spending will change**; that is, whether more (or less) money will

need to be spent on certain things (such as housing, transportation, or vacations) than before.

Your budget may need to include estimates for the following expenses:

- Housing (rent, mortgage, home or renters' insurance, taxes, utilities, cable and/or Internet, upkeep)
- Support services/personal care (such as not covered by public benefits)
- Clothing (everyday wear, special occasion, outerwear)
- Food, including for any special dietary needs
- Out-of-pocket medical and dental costs
- Out of pocket costs for prescriptions
- Out-of-pocket vision costs
- Personal toiletries, vitamins and/or supplements
- Employment-related expenses, such as work uniform or safety equipment
- Transportation (to work, to social activities, to medical appointments, etc.)
- Maintenance of vehicles
- Hobbies and recreational activities
- Trips or vacations
- Entertainment such as movies or ballgames
- Computers, CDs or DVDs, apps, video games
- Household items such as bed linens, furniture, decor, etc.

Again, housing is the most challenging part of future planning for an individual with DD. See the section **“STEP 6: EXPLORING HOUSING OPTIONS”** for a discussion of housing programs in Central Virginia.

If you haven't already, contact the Social Security Administration about applying for benefits. (See **STEP: 4 APPLY FOR BENEFITS/Social Security**.)

STEP 4: APPLY FOR BENEFITS

Social Security

Benefits from the Social Security Administration can be an important income source for your loved one with a disability. Your son or daughter may already be receiving Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). Once you begin taking your own Social Security retirement benefits (the earliest would be at age 62), your dependent child may receive Disabled Adult Child (DAC) benefits in addition to their existing SSI or SSDI (see below).

You may begin the application process for Social Security benefits in the month your child turns 18. The first step is to determine eligibility for any benefit program; the Social Security Administration (SSA) will decide which program is appropriate.

SSI VS 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 impairment (physical and/or mental, or blindness). The disability must have lasted or be expected to last for a continuous period of not less than 12 months or result in death. In 2018, the wage limit for the SGA is \$1,180 gross income/month.

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

You do not have to have any work history. Monthly benefit payments are determined by the current benefit rate (\$750 a month in 2018), 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 FICA . Monthly benefit payments are based on the worker’s lifetime average earnings covered by Social Security.

Applying for Benefits

You may apply online at <https://www.ssa.gov/benefits/ssi/>. Click the “Apply Online for SSI and Disability Benefits” button about midway down the webpage. It is suggested that the application form may take one- to two hours to complete. You will have to establish an online login if you do not already have one, and you will be required to login to complete the process. You can save your progress on the form and return to it later if you cannot complete it all at one time.

At the time of this writing, Social Security Administration (SSA) offices are closed due to the COVID-19 crisis.

The automated SSA phone system at **1-800-772-1213** (TTY **1-800-325-0778**) is available 24 hours a day.

To apply for benefits by phone, you will be required to speak with a representative. Representatives are available from 8:00 am to 5:30 pm, Monday through Friday, at **1-800-772-1213** (TTY **1-800-325-0778**).

Documents and information you may need to complete your application include

- 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
- Income slips if your child has income
- Information on any assets your child owns, such as 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**

- Checkbook or other papers that show a bank account number to have benefits deposited directly to a Representative Payee account
- A signed rent agreement between parent and child (to receive the full benefit). See “Housing and SSI Benefits” in this section

The physical address of the SSA office in Harrisonburg, Virginia, is

351 N. Mason Street
Harrisonburg, VA 22802
1-800-772-1213
1-866-964-1718

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.

Set up a Representative Payee account. 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.

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. Representative Payees should be comfortable handling financial records and be trusted to keep in mind the best interests of the 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; it must be filled out promptly and mailed back, or the report may be submitted 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.

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 <http://www.socialsecurity.gov/payee>

When the First Parent Retires

Parents who have been working and paying into Social Security may start taking their own retirement benefits beginning at age 65 to 67 depending on when they were born. If your adult child with a disability is already receiving SSI, then when the first parent starts receiving Social Security benefits, your adult child qualifies for Disabled Adult Child (DAC) benefits and is moved from SSI to SSDI.

You need to make an appointment with your local Social Security office to do the paperwork. Working may complicate eligibility for DAC benefits.

When the Second Parent Retires

If the second parent's benefit entitlement is higher than the first, then your child would receive one-half of the higher benefit.

Housing and SSI Benefits

SSI is intended to cover living expenses like rent, food, and utilities. 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, etc.) 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).

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 in 2020) to get the maximum SSI benefit.

Be aware that SSI benefits may be reduced under the following circumstances:

If the special needs trust is used to purchase a home and pay the mortgage.

If the trust pays for household expenses.

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

<http://policy.ssa.gov/poms.nsf/lnx/0500835300>
and

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

Reporting Income

SSI beneficiaries must report any earnings to Social Security. This includes work income, one-time payments, child support, trust payments, etc. SSI is a needs-based month-to-month benefit. Any delay in reporting to SSA could mean an overpayment of benefits.

NOTE: On the death of a parent(s), your family member would qualify for Social Security survivor benefits. See PART TWO of this guide, “**APPLYING FOR BENEFITS: Social Security Survivor and Retirement Benefits.**”

Medicaid Waivers Programs

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

To watch a webinar produced by The Arc of Northern Virginia that explains the waiver system in depth, see <https://youtu.be/BQjUfRuIdY8>

You can read the latest information on the state’s new Waivers at <http://www.mylifemycommunityvirginia.org/> or call their hotline at **1-844-603-9248**

Services Covered Under the Waivers

The Developmental Disability (DD) Waivers

There are three DD Waivers; they are the (1) Community Living Waiver, (2) Family and Individual Supports Waiver, and (3) 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 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 some medical or behavioral 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 is a supports waiver that 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.

People receiving waiver services are assessed every two to three years with an assessment called the Supports Intensity Scale (SIS) to measure the degree 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.

Eligibility Criteria

There are three criteria a child under 18 must meet in order to be eligible for a Medicaid DD Waiver;

- (1) Functioning ability, (2) Diagnosis, and (3) Financial

1. **Functioning ability** is determined by VIDES survey. 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 living and independence skill activities.

2. **Diagnosis.** Persons applying for a Waiver must meet the diagnostic eligibility requirements for DD Waivers. This means that a person must have a development disability as defined in 37.2-100 of Code of Virginia.
3. **Financial:** If functioning and diagnostic criteria are met, then the child's income and assets are assessed. 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).

“Developmental Disability” 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, and 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 later that are lifelong or of extended duration and are individually planned and coordinated.

An individual from birth to age nine inclusive, 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) above if the individual without services and supports has a high probability of meeting those criteria later in life.

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 and <https://sp.wvrc.net/VDProviders/Shared%20Documents/UAI%20User%20Manual.pdf>

Wait List Eligibility

You can be on the waiting list for a Developmental Disabilities Waiver and apply for the CCC PLUS Waiver, assuming you meet the eligibility for the CCC PLUS Waiver as well. Many people do this because the CCC PLUS Waiver have no waiting list and can provide some interim supports.

How Long is the Wait?

The Developmental Disability Waivers have a waiting list based upon urgency of need. People in Priority One need services within the year, people in Priority Two need services in 1-5 years, and people in Priority Three need services several years out. 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, if you or your spouse become ill, become unemployed, etc., notify your support coordinator, as these situations will increase your urgency of need for support services.

The **Community Living Waiver** is the one waiver that pays for 24/7 staffing which is awarded based

upon the needs of the person who will be receiving support.

The **CCC PLUS Waiver** covers personal care, respite care, Medication monitoring, and the Personal Emergency Response (PERS) system. Support hours are generally capped at 56 hours/week, though exceptions can be made.

Required Diagnostic Documentation

A psychological evaluation confirming a diagnosis of intellectual disability is required. This is based upon the definition by the American Association on Intellectual and Developmental Disabilities (AAIDD), which states “Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.”

Where to Apply

Early intervention teams usually do the intakes for waivers. If they cannot, see

Harrisonburg Community Services Board

1241 N. Main Street

Harrisonburg, VA 22802

(540) 434-1941

<http://www.hrcsb.org>

The screening form should be completed and sent to your local health department:

Virginia Department of Health

110 N. Mason Street

Harrisonburg, VA 22802

(540) 574-5101

Where to Apply for the CCC Plus Waiver

To apply for the CCC Plus waiver, the screening form should be completed and sent to your local health department:

Virginia Department of Health

110 N. Mason Street

Harrisonburg, VA 22802

(540) 574-5101

Food and Energy Assistance, Tax Relief

Supplemental Nutrition Assistance Program (SNAP)

The Supplemental Nutrition Assistance Program 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

https://www.dss.virginia.gov/files/division/bp/fs/intro_page/income_limits/Income_Chart.pdf

If approved, SNAP benefits would be loaded onto an electronic benefit transfer card every month (an EBT). 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://www.dss.virginia.gov/benefit/snap.cgi> or visit your local Department of Social Services.

Individuals who receive SSI are in most circumstances automatically eligible this program *if they live alone*— they are "categorically" eligible. Categorical eligibility also applies to multiple-person households in which all members receive SSI, TANF, or General Assistance income. However, if an SSI recipient lives with others *who are not public assistance recipients*, eligibility is assessed on the basis of total household income and composition, and the resources of the household may make the entire group, including SSI recipients, ineligible.

To inquire about the SNAP program in Virginia, call the hotline at 1-800-552-3431 or 804-726-7000

Meals on Wheels

Meals on Wheels delivers two meals a day, a hot lunch and a cold meal (such as a sandwich and/or salad), directly to an individual's home. The program is aimed at maintaining the health and nutritional status of older residents or other individuals who **cannot shop for or prepare their own meals or have no one available to prepare meals**. Volunteers deliver the meals.

Family members, caregivers, friends and medical professionals can make referrals. Eligibility and cost of the programs are determined by each locality.

**Valley Program For Aging Services
(Harrisonburg and Rockingham County)**
975 S. High Street
Harrisonburg, VA 22801
<https://www.vpas.info/meals-wheels>

Energy Assistance

For heating/fuel assistance in the winter, the local Department of Social Services accepts applications every year from the second Tuesday in October through the second Friday in November. 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 are approved. To see the income guidelines, visit <http://www.dss.virginia.gov/benefit/ea/index.cgi>

In the summer, 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 15th each year if you qualify.

Tax Relief

The City of Harrisonburg and the county of Rockingham offer real estate tax relief to citizens who are either 65 or older, or are permanently and totally disabled, and who meet the income and asset eligibility requirements.

Family Self-Sufficiency Program

The Family Self-Sufficiency Program is offered by the Harrisonburg Redevelopment and Housing Authority and details are on their web site at <https://harrisonburgrha.com/family-self-sufficiency/>

STEP 5: FOLLOW THROUGH WITH ESTATE PLANNING

Key aspects of estate planning are creating/revising your will, reviewing your beneficiary designations, creating a special needs trust for your adult child with DD, and possibly naming a guardian or conservator.

Creating or Revising Your 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. While many wills create family trusts, to avoid jeopardizing the benefits or services of your heir 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 designations for resources considered outside your will. These include:

- 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 (special cautions may apply as outlined below)
- 401K and 403(b) accounts (special cautions may apply as outlined below)
- SEP Plans (special cautions may apply as outlined below)
- Thrift Savings Plans (special cautions may apply as outlined below)
- 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 (as specified above). Typically,

when someone inherits a retirement account, they have to start receiving periodic payments from the account; however, this would most likely disqualify your family member for federal benefits such as SSI and Medicaid since assets are limited to \$2,000.

The document creating the Special Needs Trust (whether it is a will or a stand-alone trust) therefore needs to state that the trust is “an accumulation trust” for purpose of receiving distributions from retirement accounts.

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 Note for Military Families

With the passage of the National Defense Authorization Act of 2015, military members may now name special needs trusts as beneficiaries of their Survivor Benefit Plans (SBP).

Through SBPs members of the military may elect to defer a portion of their retirement pay so a surviving spouse or dependent child will receive up to 55 percent of their retirement payments. However, up until now, military members were only able to name individuals—not trusts—as the beneficiaries of these SBPs. With the new law, military families have the same opportunities as other families to provide for their heir with a disability without jeopardizing that person’s federal or state benefits.

Drawing up a Special Needs Trust (SNT)

Special needs trusts (sometimes called supplemental needs 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; these 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 Harrisonburg and Rockingham, 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. These trusts may be funded during the parents’ lifetime (you can put money in them), but that money would no longer be available to you as the parent once it is in the trust. This is why most third-party trusts are funded from inheritances.

First-party trusts (self-funded or self-settled) 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.

Setting Up a Trust

Special needs trusts (SNTs) can, and should be, set up as early as possible as part of the parents’ overall estate planning. Third-party special needs trusts can be funded while the parents are still alive (with the caveat that any money put in the trust cannot be withdrawn except to pay for services for the beneficiary).

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 this particular kind of trust. Special needs trusts may be set up using an attorney in private practice (see the list in the resources section) or through the auspices of a trust managed by a nonprofit organization, such as The Arc of Northern Virginia (<http://thearcofnovatrust.org>).

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 Trust program does not require a minimum deposit.

Uses of Trust Funds

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

- Supplemental education and tutoring
- Out-of-pocket medical and dental costs
- Transportation (including purchase of a vehicle)
- Maintenance of vehicles
- Materials for a hobby or recreational activity
- Trips or vacations
- Entertainment such as movies or ballgames
- Computers, videos, furniture, or electronics\
- Athletic training or competition
- Special dietary needs
- Personal care attendant or escort

- Housing costs (although 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 reporting, tax reporting, check writing, and disbursements. **Professional legal and investment advice are crucial for trustees administering a special needs trust themselves.** However, for a special needs trust set up with The Arc of Northern Virginia, the family does not have this burden: trust staff performs 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:

<https://www.specialneedsalliance.org/special-needs-101/free-trustee-handbook/>

To learn more about The Arc of Northern Virginia's Special Needs Trust visit <https://thearcofnovatrust.org>

A Trustee Advocate

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 Trust Advocate is here to help on these and many other issues. Call The Arc of Northern Virginia at (703) 208-1119 for more information on resources available through this service. There is an hourly fee for the services offered, which can be paid with monies from the special needs trust.

Guardians and conservators are appointed by a local court to protect an incapacitated person—that is, someone who cannot receive or evaluate information effectively to meet his or her own health, care, and safety needs, or to manage property or financial affairs.

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.

Timing

In the past, some parents never sought guardianship of their adult children with disabilities. They knew the doctor and the banker and could pretty much make decisions without any formal legal authority. At some point, however, especially if the parents are very elderly or disabled, siblings or other relatives might consider seeking guardianship to avoid a crisis later on.

When seeking guardianship for someone in their 40s or 50s with lifelong disability, there are usually fewer "unknowns" than for a younger adult. You know whether they have been voting or driving. You know whether or not they are easily swayed by others.

How Guardianship and Conservatorship Work

In essence, **guardianship** makes someone (or two individuals as co-guardians) responsible for **making medical, social, and personal decisions** (such as where to live) 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 attorney experienced in elder law or special needs planning can assist you in crafting a guardianship that fits the individual and allows the guardian 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 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 State of Virginia to protect individuals who lack sufficient capacity to make decisions regarding themselves or their property.

Families should consider less restrictive alternatives before petitioning for guardianship if they believe the individual may not fit the criterion of incapacitated (see below). Siblings and parents should keep in mind that:

The individual will not be labeled incompetent. Virginia has eliminated that term from the law. Now a person is found to be "incapacitated" to the extent that they cannot make certain decisions

Overall, it is important to realize that guardianship is a very flexible system in Virginia

- Guardianships can be **tailored to the needs of the adult with the disability**, allowing siblings or others appointed as guardians 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, or other rights. Again, if seeking guardianship later in life, it may be obvious from long experience to know what kind of decisions the individual with the disability is or is not able to make
- Even under guardianship, your loved **one 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
- **The adult with the disability 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 the guardian financially responsible for the person under guardianship.** For example, siblings who are guardians do not have to provide food and shelter for their brother or sister but would be responsible for making the **decisions** about where their sibling 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 the person under guardianship.** If an individual under guardianship hurts someone or something, the guardian is not liable. If they were, few people would be willing to serve as a guardian. However, the guardian is **required to take reasonable steps to protect the incapacitated adult** and others

Once parents are no longer willing or able to be guardians, siblings, other family members, an attorney, a friend, or (in extreme circumstances) a public guardian may also serve in this capacity.

Obtaining Guardianship

To obtain guardianship, parents need to file a petition with the Circuit Court of the county in which the individual lives. Typically parents are appointed as co-guardians, which allows either to act independently. If only one parent can serve, **a sibling or another trusted person can be named as a co-guardian**; this would make an easier transition when the parent-guardian passes away.

Be sure to nominate a standby guardian when you first petition the court. If no standby guardian is named, and the guardian(s) cannot or is/are no longer willing to serve, **no one will be able to act as guardian until another hearing is held.**

You must provide a medical or psychological evaluation that supports the need for guardianship.

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. The GAL does not represent the parents or assist with writing the guardianship petition or order.

After the GAL has filed a report, then a hearing is held at the Court. Typically 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 paperwork. 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 you a form for the report.

Weighing Alternatives

The appointment of a guardian or a conservator should be considered only as a last resort. Again, petitioners for guardianship must provide evidence, and a judge must determine that an individual is "incapacitated" in terms of making certain decisions.

If the person is not considered incapacitated but still needs help, the individual and his or her family may choose among several other options. These alternatives range from having a caregiver (who has no legal authority to make medical or financial decisions) to giving a trusted person a durable power-of-attorney (may make all 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.

It's important to remember that the individual must be capable of understanding what they are doing when they execute a Power of Attorney or Medical Directive. A Power of Attorney or Medical Directive **does not allow you as the agent to override the**

decision of the individual with the disability. If the individual enters into a contract he or she did not understand, the agent under a Power of Attorney cannot void that contract. If the individual is in the emergency room yelling that they do not want a shot or test, the agent under the Medical Directive cannot override that decision.

Guardian of Last Resort

If no family or other appropriate person is willing to serve as a guardian, but your family member still requires support in making decisions, the State of Virginia may assign a Guardian of Last Resort (GOLR) to serve that role. The Arc of Northern Virginia is a state-designated GOLR and currently serves 30 individuals in the region. For more information, contact The Arc of Northern Virginia at (703) 208-1119..

The table that follows summarizes the decision-making responsibilities of different options.

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	<ul style="list-style-type: none"> • http://www.supporteddecisionmaking.org
Full guardianship	All financial, legal, personal care, and social decisions	<ul style="list-style-type: none"> • Individual must be incapacitated • Guardian must file an annual report
Limited guardianship	Decisions on specific issues (e.g., just health care), as determined by the judge	<ul style="list-style-type: none"> • Individual must be incapacitated • Guardian must file an annual report
Standby guardian	Person designated in guardianship order to become guardian when current guardian dies	<ul style="list-style-type: none"> • Does not assume any duties until death of primary guardian
Full conservatorship	All financial decisions, including paying bills, investing money, and selling property. Conservator must post a surety bond.	<ul style="list-style-type: none"> • Individual must be incapacitated • Conservator must file annual report on all financial transactions
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.	<ul style="list-style-type: none"> • Individual must be incapacitated • Conservator must file report on income and expenses
Representative payee	Receives another person's government benefits on behalf of that person; responsible for using benefit to pay beneficiary's living expenses	<ul style="list-style-type: none"> • Representative Payee must report annually to relevant agency (e.g., Social Security Administration)
Advance medical directive	Person with disability provides instructions about his or her wishes for health care treatment and designates an agent to make health care decisions when he or she cannot	<ul style="list-style-type: none"> • Agent's powers are defined in the document • Agent cannot override decisions
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.	<ul style="list-style-type: none"> • Agent cannot override decisions • Power ends if principal revokes it or dies.
Emergency order for adult protective services	Short-term guardianship (15 days) to handle an emergency or correct conditions causing an emergency	<ul style="list-style-type: none"> • Local department of social services must apply to Circuit Court for temporary guardianship order
Caregiver	Individual providing care, paid or unpaid, to someone who cannot care for him or herself. No power to make medical, legal or financial decisions	

Type	Decision-making Responsibilities	Notes
Advance Directive for Health Care (Living Will)	Written instructions spelling out medical treatment wishes (usually about sustaining life support) if you are unable to speak for yourself. Must be witnessed in Virginia. May be combined with Medical Power of Attorney	<ul style="list-style-type: none"> • Helps ensure your wishes are known and carried out • Does not appoint an agent and applies only to end-of-life decision-making • Be sure to give to your doctor for inclusion in your medical record
Medical Power of Attorney	<p>Similar to durable general power of attorney but directed exclusively at health care.</p> <p>Choosing the right agent is very important; make sure he or she knows your wishes, values, preferences, and will be a strong advocate for you.</p>	<ul style="list-style-type: none"> • Enables you to appoint someone to make any or all health care decisions if you become incapacitated. You control what actions to be taken in what circumstances • Doctor and family will be able to know and respect your wishes

STEP 6: EXPLORE HOUSING OPTIONS

Finding safe, convenient, and affordable housing for an adult with a disability is one of the most difficult challenges facing families. This section outlines in very general terms the housing options available for persons with and without a Medicaid Waiver.

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 adult child's options.

Housing is the physical place, the bricks and mortar, where one lives or 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).

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, rented rooms, etc., 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 help 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 (not simply the “bricks and mortar” location, but the service is included as well). The cost of these programs is high, and for the most part residential providers are only accepting persons with the Medicaid DD waiver.** Even with a waiver, the individual still has to pay a residential fee.

Thus, the two basic options are:

For those with a DD Waiver, the cost of support services is paid for (in certain approved settings) but cost of rent is separate and must be paid for by the individual with DD.

For those without a DD Waiver, it will be necessary to find resources to pay for the physical

housing **and** support services (if needed by the individual).

Because access to public housing and group home-type options is very limited, parents and housing advocates are working to develop alternatives.

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.

Budgeting for Staff Support

Remember that unless personal care support is being funded through a Medicaid Waiver, you may also need to consider the costs of support staff. 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.

Factor the cost of support staff into your monthly budget. Currently the Medicaid Waiver pays \$11.47/hour for Consumer-Directed staff. Many families report having a great deal of trouble finding someone who is willing to work for that salary who is well qualified to support their loved one.

It is important to note that if you're using a waiver to hire staff, you may not legally supplement their rate of pay. 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.

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 waiting lists, if you haven't already

Explore housing options in your community

Make a housing budget

Timing a Move

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 before there's a crisis.

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 have envisioned for your son or daughter. Issues to consider in looking for housing, and the timing for your search, include

Best estimate of when your loved one would be interested in/need a new housing situation (one year, three years, five years, etc.)

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

Identifying 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/healthcare, 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 of the home

Reviewing 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 (i.e., down payment, mortgage, rent); and (2) the cost of support services (i.e., payment for people who provide supervision, caregiving, and similar services) for the individual.

For those with a DD Waiver: The cost of support services is paid for (in certain approved settings), but cost of rent is separate and must be paid for by the individual with DD.

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

As discussed in the Financial Resources section, consider assets such as current savings and investments, real estate, income from benefits such as SSI, potential inheritances, etc. as ways to pay for

housing. Again, although funds from a special needs trust may be used to support housing, doing so will reduce SSI benefits.

Once you have assessed your family member's needs and desires regarding housing, the next step is to explore the options that are open to you.

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
TOTAL:	TOTAL:

Residential (Public Funding) Program Options

This section explores alternatives that tie housing and supports into one residential program. There are a number of **Residential Options Funded by Medicaid Waiver**, there is **Public Housing**, and there are **Housing Choice Vouchers**.

Residential Options Funded by Medicaid Waiver If your loved one has a Medicaid Waiver, he or she may be able to live and get supports in one of the following types of housing.

Congregate Residential Supports. Often called “group homes,” this support model is comprised of a home (including single family homes, condos, town homes, etc.) where people with intellectual

disabilities live together in a home operated by a provider in the community.

Sponsored Residential Supports. In the Sponsored Residential model, a person with a disability lives with their caregiver. The caregiver could be a single person or a member of a family.

Apartments. Some DD Waiver service providers have special leases worked out with apartment complexes so that the individuals they serve have access to apartment rentals. In this model, an individual may lease the apartment in their name or sublet from the provider, but they are only eligible to live in that apartment as long as they’re receiving services with a certain provider.

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.

Public Housing

Public housing is federally-funded housing made available to people with low incomes. Units are often owned by a local housing authority (PHA) and funded by the federal Department of Housing and Urban Development (HUD). The PHA is often responsible for property management and filling the units.

To qualify for public housing, an individual must meet the public housing authority's low-income requirements. A person with a disability could use the DD or CCC Plus Waiver to receive supports in a public housing unit.

Unfortunately, the waiting lists for public housing units can be very long. If you're interested in public housing, keep in touch with your local housing office to know when the waiting lists open.

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.

One of the greatest benefits of the Housing Choice Voucher program is that once you have received a voucher, you can take that voucher with you anywhere in the country. Unfortunately, waiting lists are often long for this program.

As with public housing, a person with a disability could use staff funded under the DD Waiver or CCC Plus Waiver 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

Options with Private Funding

Many individuals with disabilities do not qualify for a Medicaid Waiver; their families must not only find appropriate housing but find ways to pay for it. However, housing created by families often has the

advantage of more closely matching the individual's needs and preferences, as well as having "built-in" monitoring and quality assurance mechanisms.

Microboards

When a circle of support incorporates itself as a corporate entity, it can engage in business transactions on behalf of the individual with a disability and become a microboard.

This formal designation as a microboard allows the board to qualify for low-interest home loans through the Virginia Housing Development Authority (VHDA). Contact

<https://www.vhda.com/Pages/Home.aspx>

Microboards may also carry out the following housing-related tasks:

- Find a real estate attorney and other professionals to help purchase, finance or sell real estate
- Help create and review leases
- Provide property management and upkeep
- Pay bills for utilities, insurance, taxes and maintenance
- Obtain renters insurance for all parties living in the property
- Manage/comply with relevant licensure regulations, inspections, etc.
- Accept a Section 8/Housing Choice voucher (acting as landlord)

Shared Apartments

A shared apartment is simply a rented apartment (home, condo, or town home) shared with one or more other people. The advantages are cost sharing and companionship.

In a shared apartment, one, some, or none of the household members can have a waiver and/or care staff. However, 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.

Renting a Room

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.

Again, the person renting the room could have a waiver and/or care staff, but they would need to disclose this need and plan when they contact potential homeowners or lease holders to ensure everyone is comfortable with this situation.

Life Estates

In a life estate, a homeowner grants a "life tenancy" to a person with a disability (your child, for example) 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 revert to another family member, a non-profit, or a combination of both.

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 were deeded to the person with a disability while the parents were still alive, the parents could continue to reside there or decide to move out while the person with a disability continues to stay in the home.

Keep in mind that **many service providers would be hesitant to manage supports for a life tenant if the 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.

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 would then live in the home.

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, particularly if/when one of the residents wanted to move out. The families should work with their lawyers to draw up rules for selling shares of the home and shared costs.

Finding a Roommate

It can be difficult to afford rent or a mortgage in Central Virginia without having a roommate. Unfortunately, there are few resources for people with disabilities to find a roommate. You or your circle of support may find a roommate through friends, people in social or recreational clubs like Special Olympics, or online sites such as craigslist.org

Keep in mind that good friends do not necessarily make good roommates. To find out if someone may be a good roommate, try the following

- Spend time together
- Meet the person's friends
- Find someone who has the same interests or hobbies as you
- Come up with clear rules for what you need and can tolerate in a roommate (privacy, tidiness, noise, pets, etc.) Consider asking for a background check, references from past roommates, or proof that they can afford the rent and utilities

STEP 7: GET YOUR PLAN ON PAPER

After decades of being a parent of a child with a disability, you have discussed many times with family and friends your vision for your child's future. You've talked about what your child loves to do (and doesn't love to do), who they get along with, and what their medical issues are. However, talking about these vital issues is not enough: it is extremely important that your hopes, concerns, and plans get

written down and shared with the appropriate people.

Over an individual's life, many important documents accumulate: medical records, prescription lists, wage statements, tax returns, behavior plans, correspondence from the Social Security Administration, copies of wills and trusts, and lists of PINs and passwords, just to name a few.

Keeping these documents updated and organized becomes more important as you age and begin handing over caregiving responsibilities: leaving a literal "paper trail" helps future caregivers make decisions more in line with your vision and your child's own desires for his or her life.

The culmination of everything you've done to this point will be a large written (or online) document, your Future Plan.

The Future Plan is a collection of documents, put in one place, that forms the basis for future decision-making about your adult child. Of course, nothing can replace you as the parent, and no amount of paperwork can adequately draw a picture of your family's life. But the having a future plan does make it much easier for the next generation of caregivers to step into your adult child's life with the least amount of disruption.

Putting your plan in place can be part of a larger process of retirement and estate planning and should be started no later than your own retirement; the plan can be updated as your needs and circumstances change.

Getting Started on Your Future Plan

Ideally, your plan would include everything anyone would need to know to begin taking care of your adult child with a disability—and appear magically in your filing cabinet. Realistically, this is a task that might take some soul-searching, discussions with family members, meetings with attorneys, review of

financial resources, and a few weeks (or even months) to pull together.

The key is to break down the task into smaller, manageable steps; **delegate some tasks to your spouse or children or others in your Circle of Support.**

The Big Picture Questions

The Letter of Intent should answer for future caregivers some of the big questions about your vision for your child's future and who will be responsible for carrying out that vision.

- What are the most important wishes and/or personal thoughts you have for the future caregiver and for your child?
- If money were not a concern, what would your dream be for your child?
- When you are gone, what do you wish your child's future to look like?
- What does your child's life look like without you in it?
- What do you want most for your child's future? Where do you envision your child to live?
- How do you see the guardian(s), trustee(s) and trust advisor(s) interacting with each other and your child?
- What roles do you see siblings and other relatives having with your special needs child?
- What traditions should be followed?

Immediate First Steps

The most urgent need is to pull together two kinds of information: (1) specific instructions for the one or two people who will be stepping in immediately to care for your adult child should you become disabled or die (particularly important if your adult child is still living in your home); and (2) adequate

information for them to bring in other needed resources and professionals.

Steps in the Process

Once these two tasks are done, you can turn your attention to completing the Future Plan:

Decide where and how your Future Plan will be stored—on paper, in a computer (backed up on an external hard drive), online, or a combination of the above.

Reconfirm commitments from people who have agreed to take on responsibilities as executor of your estate, trustees, standby guardians, conservators, Representative Payees, etc.

Update existing documents such as wills and trusts, changing the names of executors, trustees, etc., if needed per the preceding step

Review beneficiary designations in insurance policies, 401Ks, etc. (see Step 5: Follow Through with Estate Planning)

Write your Letter of Intent or update it

Review the lists of documents in this section and collect any you are missing. Or, make a phone call and confirm that someone else has the document, such as making sure the doctor has a current prescription list in your child's medical chart

Reduce filing—assess what information is reliably stored elsewhere by other parties (such as online). In many cases, you don't need copies of everything if someone else has the original document. Keep only the latest version of a document. Consider scanning some documents that you don't use, but might want for future reference (if you are comfortable reading on your computer or online)

Pull everything together in one place or one file

Tell future caregivers and your attorney where your plan document is (in a file at home, for example) and how to access it (e.g., where you've hidden the key to the file cabinet)

The Letter of Intent

One of the most important documents to have in the future plan is a Letter of Intent. In it, you have an opportunity to describe your adult child's current life and to express your values, wishes, and vision for his or her future—a summation of your “Values and Vision” discussions with family. Although not legally binding, a Letter of Intent is invaluable to those who will take over the care of your adult child.

If you've already drafted a Letter of Intent, take some time to review and update it; be sure to date the document (software programs can time-stamp documents).

What goes into the document will vary with the individual but should include:

Values and vision statement (see Step 1: Establish Your Vision and Values), both yours as parent(s) and your grown child's.

Description of personal qualities. Future caregivers would benefit from knowing the unique aspects of your child: overall personality and mood, talents and strengths, degree of independence, medical or behavioral challenges, and sense of humor.

Specifics on the individual's daily life. This section could include work or day program schedules; weekend activities, including religious education or attendance; bedtime routines; food and clothing preferences and sensitivities; preferred games and exercise routines; and typical outings, for example.

This is also a good place to mention how independent your son or daughter is and how much (and on what occasions) he or she may want/need assistance.

Medical history. This section can be brief—diagnosis, current treatment and medication regimes. However, if your child has a disability requiring daily or frequent interventions, this section should outline appropriate behavior or medical management techniques and refer to the contact list for doctors and therapists.

Living expenses. It may be helpful to include annual costs of items such as food and rent, medical visits and equipment, health insurance, recreational activities and vacations, etc., to give future caregivers an idea of how the individual's trust and benefit monies might have to be spent.

Contact information. Include the address, phone and email of siblings and other relatives, friends, doctors and therapists, preferred pharmacy, work supervisor, residential staff, local caseworker, transportation provider, lawyers, trustees and backup guardians, insurance agents, banker and financial planners, etc.

What To Do Next

Once the Letter of Intent is written and documents organized:

Let people know the plan exists. At a minimum, tell your family and your attorney where the file is and how to get in it (where the key is, what the password is, who has the combination to the safe, etc.). You could also inform a close friend, neighbor, or religious leader.

Update the Future Plan on a regular basis. Select one day out of each year (such as the New Year's Day or your birthday) to review it. For example, put in any new contact information, include any new vital medical information (such as a change in a medication), review daily/weekly schedule if your adult child's activities or interests have changed, and update financial information

Engaging Your Adult Child in the Future Plan

Whenever possible, engage your son or daughter in creating the Letter of Intent.

Start by talking within the family about the “big picture” items to outline the contents of the document

Decide what items in the Letter of Intent might be of most interest to your child

If talking about life without you seems upsetting, make the discussion more general

Be sure to explain that all answers the child gives can be changed and that it’s ok to ask questions about the future.

Documents to Keep on File

In addition to a Letter of Intent, create and/or collect and keep on file:

- **Basic identification documents**, such as Birth certificate (often need the original), Social Security card, driver or non-driver’s license, passport, Medicaid card, health insurance card.
 - **Bank information**, including any accounts opened for the benefit of your child, Representative Payee accounts, numbers of any debit or credit cards your child is allowed to use and associated PIN numbers.
 - **Legal documents** such as wills, special needs trusts, guardianship orders, power of attorney or conservator- ship papers. Names of backup guardians and trustees can be kept here as well as named in the Letter of Intent.
 - **Medical history**, including diagnosis, evaluations, past and current treatments and therapies (including providers’ contact information, dates of treatment, and facility where treated), and prescription records.
 - **Financial records**, including any evidence relating to assets or resources your adult child may own, tax returns, pay stubs or other evidence of income, and payments for medical services and equipment.
-
- ### No Need to be Original
- One of the benefits of working on your future plan is less paperwork and better organized files. While eliminating duplicates and keeping digital versions of many documents is valuable, it’s best to keep the original paper version of the following documents. Store these in a waterproof, fireproof safe if possible:
- Birth certificate
 - Marriage license
 - Passport
 - Death certificates (to prove eligibility for Social Security survivor benefits, for example)
 - Guardianship court orders
 - Social Security cards
 - Medicaid cards
 - Driver’s/non-driver’s license
 - Wills, trusts, powers of attorney (unless the original is stored with your attorney)
 - Car titles, mortgages/deeds
 - Last 7 years of tax returns (if not stored with your accountant)
 - Latest month’s wage statement or pay stub
-

PART TWO

***CARRYING OUT THE PLAN:
For Future Caregivers
Of Adults With Disabilities***

PART 2: CARRYING OUT THE PLAN FOR FUTURE CAREGIVERS OF ADULTS WITH DISABILITIES

Part 2 of **Aging with a Disability** is designed for those who will be caring for, or supervising the care of, an adult with a disability when the parent(s) are no longer able to play that role.

Dealing with a Grieving Loved One

The loss of a parent is a major emotional event for anyone, but especially for someone who may have lived with or been dependent on that person for decades. Every person grieves differently, and one cannot predict how your loved one with a disability will react to the death of a parent. In all likelihood the individual with the disability is grieving, although he or she may not be able to express this strong emotion.

Studies indicate that caregivers sometimes underestimate the impact of grief on individuals with DD even when the affected individuals are able to express their sadness and anguish. Persons with DD may actually be under extraordinary stress in times of mourning.² Things you can do to help your family member at this time of stress include:

Be alert to changes in behavior. Keep an eye out for changes in behavior—in eating, sleeping, desire to engage in normal activities, or aggressiveness—that could signal a grief reaction. Changes that last more than two months may signal a more complicated grief reaction.

Understand “secondary loss.” When a loved one dies, the loss is not only of that person **but of a way of life** for the individual with DD. At the very least, schedules are disrupted and routines lost (at least temporarily).

Even more disruptive would be major changes in where the individual with DD lives and with whom.

To an individual who cannot live alone or support himself financially, these losses may seem as “immutable and final as death itself.”³

Provide opportunities for your loved one to talk or otherwise demonstrate his or her feelings. It is important to allow the grieving individual to express him- or herself. Do not try to “protect” the individual by not speaking of the deceased or of negative feelings.

Ask if he or she would like to attend the funeral or visit the gravesite. Look at photo albums or participate in an activity that would allow your loved one to talk about how they are feeling. If this is too difficult, consider going to a mental health professional who specializes in grief counseling.

Allow yourself to grieve. If you are a sibling or close family relative, you are also dealing with your own feelings. Take a break from caregiving and allow yourself to experience your own grief. Getting over loss takes time.

Continuing with Caregiving

This section supports caregivers in carrying out their desire to:

- Maintain the dignity and safety of the adult with the disability
- Ensure his or her financial well-being
- Retain and replenish the circle of support

Communicate with, and replace when necessary, those with legal roles to play such as trustees, guardians and Representative Payees

For more detailed explanations of decision-making roles, government benefits, and estate planning, review the appropriate sections in the first part of this guide.

1. ² Brickell, Claire, BS and Munir, Kerim MD, MPH DSc “Grief and Its Complications in Individuals with Intellectual Disability.” *Harvard Review of Psychiatry*, 2008; 16(1)

2. ³ Ibid

For more information, see our Resources Guide on our website <http://www.hrarc.org>, which is continually updated. The information is listed by categories and includes national, state, and local valuable resources.

Information about respite care for children with special needs can be found at <http://www.iihhs.jmu.edu/precioustime/>

ENSURING A CONTINUITY OF ROLES

In addition to caregiving, parents often serve a variety of legal roles in the life of their adult child with a disability, such as trustee, guardian, or Representative Payee (or a combination of these). Now these roles need to be reassigned, and maybe reassessed, within your loved one's Circle of Support. Many families decide to divide up the responsibilities.

If you haven't done so already, you must at this point

Alter wills and trust documents to appoint successor trustees and/or co-trustees

Change guardianship orders to include a co-guardian (if one is not already mentioned) and/or a backup guardian

Call Social Security Administration and change the Representative Payee

Remember that trustees, conservators, guardians, and Representative Payees have legal and fiduciary responsibilities under the law; whoever serves in these roles should be comfortable with handling money and doing some paperwork.

Families should also expect that the individuals (or even institutions) acting as a trustee or guardian will likely change over the course of your loved one's lifetime. This section discusses the general responsibilities of and the process for ensuring a continuity in these key roles.

Trustees

A trustee oversees trust assets and administers the trust provisions, including investing, account reporting and tax reporting, check writing, and disbursements.

Professional legal and investment advice are crucial for trustees administering a special needs trust themselves.

For special needs trusts set up with The Arc of Northern Virginia, the family does not have this burden; trust staff performs all administrative tasks and client relations, and Sun Trust Bank handles all fiduciary and investment duties.

Special needs trusts can pay for a wide variety of goods and services that would enhance the life of the individual with a disability. These range from tuition and medical expenses to the purchase of a car, vacation or computer, and the cost of a personal care attendant or escort. Funds from a special needs trust may be used to pay for housing, but this will reduce SSI benefits. See Part I section on "Applying for Benefits" for more information.

Trustees and successor trustees are named in wills or stand-alone trust documents. Trustees named under wills are qualified by the local Circuit Court; if there is a need for a successor trustee, that person will also need to be certified by the court. For documents other than wills, the terms of the document outline how the successor trustees will be appointed.

For more information about being a trustee, download a free handbook at <https://www.specialneedsalliance.org/special-needs-101/free-trustee-handbook>

Guardians

Guardians and conservators are appointed by a local court (i.e., a judge makes the decision) to protect an incapacitated person—that is, someone who cannot receive or evaluate information effectively to meet his or her health, care, and safety needs, or to manage property or financial affairs.

In essence, **guardianship** makes someone 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.

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.

Guardians and conservators need not be living with the individual with a disability. However, guardians need to be available to make decisions, sometimes quickly, if there is a medical or financial emergency.

Co-guardians or back-up guardians are often named in the initial petition for guardianship; if so, then that person assumes the guardianship role and there is no need to go back to court. However, if no successor guardian was named in the original document, then an attorney must be hired and another hearing held to appoint someone.

Representative Payee

A representative payee is an individual or organization appointed by the Social Security Administration to receive Social Security-related benefits for someone who cannot manage his or her money.

A payee must keep records of expenses and be able to account for all spending of SSI funds. SSA sends out a "Representative Payee Report" once a year. This report must be filled out promptly and mailed back, or the report may be submitted online.

SSI benefits may be used to support current and future needs such as housing (rent, maintenance, home insurance, utilities), food and clothing.

You must apply to SSA to be appointed a Representative Payee; contact your local SSA office (see below).

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.

To change the individual names as Representative Payee for SSI beneficiaries, contact the Social Security Administration as soon as possible at 1-800-772-1213 (TTY 1-800-325-0778) between 8:00 am and 5:30 pm on business days, contact your local SSA office, or go online at <http://www.socialsecurity.gov/payee>

Harrisonburg Social Security Office
351 N. Mason Street
Harrisonburg, VA 22802
(800) 772-1213
Local: 1-866-964-1718

Assuming New Roles and Responsibilities

Type	Decision-making Responsibilities	Reporting Tasks	How to Change
Trustee(s) of special needs trust	<p>Oversight of investment decisions</p> <p>Approve eligible spending of trust monies</p>	File trust income tax return every year	Successor trustees are named in the will or trust document.
Full guardianship	All financial, legal, personal care, and social decisions	Guardian must file an annual report to local court	<p>Co-guardian first in line to assume responsibilities, then backup guardian if one is named in the guardianship order.</p> <p>If no co-guardian or backup, then must go to court to appoint one.</p>
Limited guardianship	<p>Decisions on specific issues (e.g., just health care),</p> <p>as determined by the judge</p>	Guardian must file an annual report to local court	<p>Co-guardian first in line to assume responsibilities, then backup guardian if one is named in the guardianship order.</p> <p>If no co-guardian or backup, then must go to court to appoint one.</p>
Full conservatorship	All financial decisions, including paying bills, investing money, and selling property.	<p>Must post surety bond.</p> <p>Conservator must file annual report on all financial transactions to local court</p>	<p>Co-conservator first in line to assume responsibilities, then backup conservator if one is named in court order.</p> <p>If no backups, then have to go to court to appoint a new conservator</p>

Limited conservatorship	Decisions on specific financial matters, such as paying bills or filling out tax returns, as specified by the judge.	Must post surety bond. Conservator must file report on income and expenses	
Representative payee	If not already done, set up Representative Payee account at a bank; automatic deposit of benefits is required. Paying for SSI beneficiary's eligible expenses (about 1/3 for housing and 2/3 for food and clothing).	Representative Payee must file annual report to Social Security Administration	Call SSA 1-800-772-1213 or go to http://www.socialsecurity.gov/ If need to change bank where account is held, be sure to title account correctly.

APPLY FOR BENEFITS: Social Security Survivor and Retirement Benefits

If your family member is currently receiving SSI or SSDI, they would automatically qualify for survivor benefits on the death of the parent (assuming the parent worked enough to qualify him/herself for Social Security). When he or she reaches retirement age (see below), SSI and SSDI convert to regular retirement benefits.

If your family member has not yet applied for Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) benefits, see “Applying for Benefits” in the first section of this guide for information on eligibility and the application process.

When the First Parent Dies

When the first parent dies, the beneficiary receives approximately 80% of the parent's benefit.

When the Second Parent Dies

Survivor benefit will be the higher of the two parents' benefits.

From SSDI to Retirement Social Security

If your family member is receiving SSDI benefits, these benefits will convert to regular retirement benefits when he or she reaches retirement age. The SSA will simply change the disability benefit to a retirement benefit once he or she has reached full retirement age (see below).

Once a person is moved to regular retirement SSA from SSDI, there are no more working rules. A person may earn as much as he or she wishes without penalty. **However, if a person is receiving Medicaid, there will always be resource and earnings thresholds.**

If your family member also receives a reduced widow(er)'s benefit, be sure to contact Social Security when you reach full retirement age so that they can make any necessary adjustment in benefits.

“Full retirement age” depends on the year a person was born.

1938 – 65 years and 2 months

1939 – 65 years and 4 months

1940 – 65 years and 6 months

1941 – 65 years and 8 months

1942 – 65 years and 10 months

1943 through 1954 – 66 years

1955 – 66 years and 2 months

1956 – 66 years and 4 months

1957 – 66 years and 6 months

1958 – 66 years and 8 months

1959 – 66 years and 10 months

1960 and later – 67 years

MAINTAIN QUALITY OF LIFE

Aging brings an increased risk of social isolation for those both with and without intellectual disabilities. Future planning needs to incorporate activities that provide both recreational and social outlets. Transportation needs to be part of that planning also.

Local Therapeutic Recreation Agencies

The Harrisonburg-Rockingham Parks and Recreation provides limited recreation and leisure opportunities for adults with disabilities.

Some Central Virginia localities can also accommodate individuals with disabilities in their non-adaptive courses and classes.

If you are new to the area, you may request that an assessment be completed to help the staff understand the needs of your family member.

Area Agencies on Aging

Created in 1973 by the Older Americans Act, these agencies do not run their own recreation programs but are good resources for local programs for older adults with and without disabilities. See

Valley Program for Aging Services

975 S High Street

Harrisonburg, VA 22801

<https://www.vpas.info/services> and

<https://www.vpas.info/search/node/harrisonburg>

(540) 217-0474

EXPLORE TRANSPORTATION OPTIONS

For local transportation in the Harrisonburg-Rockingham area, contact:

Harrisonburg Department of Public Transportation (HDPT)

475 E Washington St

Harrisonburg, VA 22802

(540) 432-0492

Valley Program for Aging Services

975 South High Street

Harrisonburg, VA 22801

<https://www.vpas.info/services> and

<https://www.vpas.info/search/node/harrisonburg>

(540) 217-0474

Non-Driver Identification Card

Since many reduced fare programs—whether for students, persons with a disability or senior citizens—require proof of age and/ or photo identification, a worthwhile first step is to obtain a non-driver identification card from the Virginia Department of Motor Vehicles (DMV). (This ID can also be used as photo identification when traveling by air.)

You must be a resident of Virginia to obtain an ID card. These cards have no age restriction and are

available for an adult or child who does not hold a learner's permit or driver's license.

An adult ID card expires at the end of the month in which you were born when you reach an age divisible by five; e.g. 20, 25, 30, etc. A child ID card expires on the child's 16th birthday.

A list of all of the information a customer needs to prepare for a DMV visit is available on the DMV web site at <https://www.dmv.virginia.gov/#/> or by calling (804) 497-7100 (TTY 1-800-272-9268)

Handicapped Placard/Plates

In Virginia you need to get a MED-10 form for a handicapped parking placard or license plate. You can pick one up at the Department of Motor Vehicles (DMV), or you can get one from their website at

https://www.dmv.virginia.gov/drivers/#disabilityplates_assist.asp

GETTING MORE HELP

Legal Resources

Elder Care and Special Needs Trust Attorneys

Clark & Bradshaw, PC
92 N. Liberty Street
Harrisonburg, VA 22802
<http://www.clark-bradshaw.com>
(540) 433-2601
Special Needs Trusts, etc.

Sellers Law Firm PLLC
66 Court Square
Harrisonburg, VA 22801
<https://sellers.law/>
(540) 437-9400
Special Needs Trusts, etc.

Michael Layman Law Group PC
268 Newman Avenue
Harrisonburg, VA 22801
<http://laymanlawgroup.com/>
(540) 433-2121
Estate Planning, etc.

Blue Ridge Legal Services
204 N. High Street, P.O. Box 551
Harrisonburg, VA 22803
<http://www.brsls.org>
(540) 433-1830
Non-profit legal aid society

Disability Law Center of Virginia
1512 Willow Lane, Suite 100
Richmond, VA 23230
(800) 552-3962
(804) 225-2042
<https://www.dlcv.org/>

Guardianship and Conservatorship

Supreme Court of Virginia Certified Guardians ad Litem

This is the public listing of approved Guardians ad Litem in the Commonwealth used by the Virginia Circuit Courts (District 26, which includes Harrisonburg and Rockingham county)

For children
<https://eapps.courts.state.va.us/GalRegistry/public/publicHome.html#/reports/gallistmap/26/C>

For incapacitated adults
<https://eapps.courts.state.va.us/GalRegistry/public/publicHome.html#/reports/gallistmap/26/A>

Virginia Public Guardianship Program

Virginia state government site
<https://www.vda.virginia.gov/publicguardianship.htm>

Valley Program for Aging Services
(serving Harrisonburg, Rockingham, Highland, Augusta, Bath, and Rockbridge counties)
<https://www.vpas.info/>

Senior Virginians Handbook – Legal Information and Resources
<https://www.vsb.org/site/publications/senior-virginians-handbook>
and
https://www.vsb.org/docs/Senior_Handbook.pdf
Guide to Consent & Substitute Decision Making
<http://www.virginiaadvancedirectives.org/>

A retail publication is

Planning for the Future—Providing a Meaningful life for a Child with a Disability After Your Death by L. Mark Russell, Arnold E. Grant, Suzanne M. Joseph, and Richard W. Fee.

Safety and Crisis

The Department of Health and Social Services assesses and provides services to adults and children and families in an effort to protect children, preserve families whenever possible, 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
<https://www.rockinghamcountyva.gov/206/Social-Services>

Child Protective Services (CPS) information:
<http://www.dss.virginia.gov/family/cps/>

Valley Children's Advocacy Center
1105 Greenville Avenue
Staunton, VA 24401
(540) 213-0592
Out-of-state hotline (804) 786-8536
In-state hotline (800) 552-7096
<http://www.valleychildrenscenter.org>

If the person with DD has been injured or suffered mental trauma, it is recommended to take them 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 individual or the caretaker.

Teach your person with DD about inappropriate touching, sexual or physical abuse, etc. Department of Health and Social Services have manuals on this subject and can be obtained in person or via their web site
<https://www.vadars.org/aps/AdultProtServ.htm>

Harrisonburg-Rockingham Community Services Board (HR CSB)
1241 N Main St
Harrisonburg, VA 22802
Office (540) 434-1941
Emergency Services (540) 434-1766

Health; sexual violence, advocacy, and prevention, etc.

Harrisonburg-Rockingham Community Services Board (HR CSB) 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 aged 18 years 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 and families, case managers, and other natural supports in the person's life.

Access. HR CSB 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 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.

Compass Counseling Services of Virginia
298 S. Liberty Street
Harrisonburg, VA 22801
(540) 437-1605
<https://compassva.com/location/harrisonburg/>

Resources on Aging

Publications and Online Resources

Planning resources for aging in general: AARP, “Prepare to Care”
<https://www.aarp.org/caregiving/prepare-to-care-planning-guide/?intcmp=AE-CAR-CRC-LL>

Person-Centered Planning
<http://rtc.umn.edu/docs/pcpmanual1.pdf>

Federal government website to verify what benefits your older family member may qualify for
<https://www.benefitscheckup.org/>

“Aging and Down Syndrome: A Health and Well-Being Handbook” by the National Down Syndrome Society at <http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>

National Council on Aging
Benefits navigator, resources, and advocacy information
<http://www.ncoa.org>

M&L Special Needs Planning,
<http://www.specialneedsplanning.net>, or
(855) 344-9771 or
(202) 248-7113

Microboards

Virginia Microboard Association at
<http://www.virginiamicroboards.org>

Vela Canada Microboard Association
<http://www.velacanada.org>

Circles Network <http://www.circlesnetwork.org.uk>

Community Works -David & Faye Wetherow
<http://www.communityworks.info>

GETTING SUPPORT

Selected List of Case Managers for Individual and Family Developmental Disabilities (DD) Waiver

Ability Home Care LLC
1205 S Main St
Woodstock, VA 22664
Service area: Winchester city, Shenandoah county, Clarke County, Page County, Fauquier County, Frederick County, Warren County

Harrisonburg-Rockingham
Community Services Board
1241 N. Main Street
Harrisonburg, VA 22802
<http://www.hrcsb.org>
(540) 434-1941

Moms In Motion
PO Box 609
Front Royal, VA 22630
(800) 417-0908
Service area: Winchester, Front Royal, Warrenton, Fauquier, Northern Virginia area, Alexandria, Arlington, Fairfax, Prince William, Springfield, Manassas, Spotsylvania, Fredericksburg, Woodbridge, Virginia Beach, Norfolk, Chesapeake, Portsmouth, Hampton, Williamsburg, Newport News, Charlottesville, Waynesboro, Harrisonburg

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