# AGING WITH A DISABILITY

## A Guide for Older Parents
## And Future Caregivers
## of Adults with Disabilities

The Arc
Northern Virginia

Transition POINTS
Providing Opportunities, Information, Networking
and Transition Support

Produced for the Transition POINTS Program
of The Arc of Northern Virginia

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

All of the guides, including translations in Spanish, Arabic, Vietnamese, Korean, and Chinese can be found at http://www.thearcofnova.org/programs/transition/transition-points. This Aging guide was funded in part by grants from the Falls Church Endowment Fund and the City of Falls Church Community Services Fund. Translations of the Transition POINTS series of guides are made possible by a grant from the Virginia Board for People with Disabilities. Additional support was provided by the Rotary Club of Alexandria.

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# INTRODUCTION

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

While caregivers want to make the best choices for their loved one, research shows that many do not have the resources to do so. A national survey by The Arc found that families have many concerns about the future.

- 54% of families do not have a plan for the future
- 80% reported that they are worried no one else will be able to provide the support they are giving
- 71% reported that they don't know where their loved one will live in the future
- 91% reported that they are concerned the quality of support will go down, if they are not there to advocate
- 63% are worried that their loved one will have to be moved to a congregate facility [1]

**About Transition POINTS**

Families need realistic, actionable information with which they can make a wide range of decisions as their child grows. Providing this information is the mission of a program of The Arc of Northern Virginia, Transition POINTS (Providing Opportunities, Information, Networking and Transition Support).

Transition POINTS focuses on six key decision points in the lifetime of an individual with an intellectual disability:

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

For each transition point, we provide materials in both print and digital formats, online resources, workshops, and webinars.

The information found in this guide is applicable to all people with intellectual and developmental disabilities and their families, although much of the contact information for resources are particular to the Northern Virginia area. To explore resources specific to your local community, contact the Community Services Board (CSB) in your region. You can find your local CSB by visiting DBHDS (Department of Behavioral Health and Developmental Services) at http://www.dbhds.virginia.gov/community-services-boards-csbs. The CSB is the point of entry into the publically funded system of services for people with mental health, intellectual and developmental disabilities. To find your local DARS Office (Department of Aging and Rehabilitative Services) visit, https://vadars.org/offices.aspx. DARS is a federal-state program offering vocational rehabilitation services for individuals with disabilities to prepare for, enter, and maintain employment. To find your local Area Agency on Aging visit http://www.vaaaa.org/. Also, visit The Arc of Virginia at www.thearcofva.org to find the local Arc chapter in community.

**Help for You, the Parent**

We have written six guides to address important issues that parents should consider at each of these important life stages. The guides are designed to help you recognize opportunities, weigh options, and work through decisions; checklists, timelines, worksheets, and links to other resources are included wherever possible. Each document has also been reviewed by a task force of parents and professionals with relevant experience and expertise. Please visit the Transition POINTS page on our website at www.thearcofnova.org to explore tool kits corresponding with each guide that include additional resources. The Arc of Northern Virginia maintains a library of informative life planning and future planning videos and webinars on YouTube at https://www.youtube.com/user/VideosatTheArcofNoVA

A Resource Library with helpful documents, fact sheets, and templates can be found on our website at https://thearcofnova.org/programs-services/library/.

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.

**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.

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1 Anderson, L., Hewitt, A., Pettingell, S., Taylor, M., & Reagan, J. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

# 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.

*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 ID/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 with 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.

*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 haven't already done so, create a will | | x | | | | |
| If haven't already done so, establish a Special Needs Trust | | x | | | | |
| Determine if your adult child with disability qualifies for benefits from Social Security Administration | | | x | | | |
| Explore eligibility for Medicaid Waivers Get on wait list(s). | | MAY | x<br>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** | | | | | | |
| 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 DD Waiver, explore housing options | | | | | | x |
| If adult child DOES NOT have a Waiver, explore creative housing options. See our "Finding a Home" guide | | | | | | 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 spouse & children what role you & they would be willing to play in your sibling's future | x | | | | | |
| Discuss "vision" with parents & other family members; start making decisions regarding future roles | x | x | x | | | |
| Ask parents where key documents are kept & how to get access to them | x | | | | | |
| **While your parents are still alive** | | | | | | |
| Complete "Creating a Circle of Support" form | x | | | | | |
| If needed/desired, make preliminary monthly budget | | | x | | | x |
| Begin spending time w/ 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 Rep Payee status with SSA | | x | | | | |
| **When second parent passes away** | | | | | | |
| Review Letter of Intent & budget | x | | x | | | |
| Inform backup guardian, Rep Payee & 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 & 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 Rep Payee report | | x | | | | |

# *PART ONE*

# *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 ID/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, such as, 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

**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 other 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 www.aarp.org/foundation/preparetocare

- **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.

  Utilize self-advocacy resources, such as **It's My Choice**, a workbook that supports self-advocates to think about and plan for the future. Go to https://mn.gov/mnddc/extra/publications/Its-My-Choice.pdf for more information.

- **Your values around money**. Parents of children

> with ID/DD worry 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 ID/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.

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
- ✓ caseworker in local human services agency
- ✓ staff at local advocacy organizations, such as The Arc of Northern 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. Many people don't feel comfortable taking on the whole plan, but most people are happy to lend advice and some time and effort. Don't be afraid to ask!

**Circle of Support**

### 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).

Utilize the Circle of Support Chart found 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 the long the meeting will last!).

For more information on setting up and running a Circle of Support, see
http://www.iidc.indiana.edu/?pageId=411

## A Changing of the Guard

Parents often serve a variety of legal roles: trustee, guardian, Rep 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

- Consider incorporating someone into the circle of support that can act as a health advocate. A health advocate is a family member, friend, trusted coworker, or a hired professional who can ask questions, write down information, and speak of your adult child with a disability. For more resources on health care advocates, see below.

- Call Social Security Administration and change the Representative Payee

## Resources for Health Care Advocates

Health care advocates can help ensure that all needed health care services are available to accompany the individual to health visit when necessary.

**Tips for Being an Effective Health Care Advocate**
https://www.aarp.org/caregiving/health/info-2018/health-care-advocate.html

**Role of the Patient Advocate**
https://www.npsf.org/page/patientadvocate?

## CREATING A CIRCLE OF SUPPORT

| What roles do parents play now that will have to be replaced? | What skills, interests or expertise are needed to carry out this role? | Who do we know who has these skills or expertise? |
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**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, such as 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

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**What Siblings Want Parents to Know**
Parents and their adult children need to have frank discussions about both side's 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[1]:

- **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 that 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 judgements (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 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 www.siblingsupport.org

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**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. One of the advantages of a microboard is the ability to share knowledge about your family member but 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 a 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 the section on housing in this guide or our Transition POINTS guide, "Finding a Home for People with Disabilities" that can be downloaded from www.thearcofnova.org.

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

For more information, see Virginia Microboard Association at www.virginiamicroboards.org

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**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 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 attorney to determine type of corp (LLC, S Corp, C Corp, etc.) to meet your needs
- Apply to Virginia State Corporation Commission; initial application fee is $75 and annual renewal fee is $25. http://www.scc.virginia.gov/contact.aspx

## STEP 3: ASSESS FINANCIAL RESOURCES

While money doesn't make the world go 'round, 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 Northern 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 ID/DD.

### Potential Income Sources

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

- Earnings from your son or daughter'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 *estimate whether the pattern of spending will change;* that is, whether more (or less!) money will need to be spent on certain things like 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 or Internet, upkeep)
- Support services/personal care (if not covered by public benefits)
- Clothing (everyday wear, special occasion, outerwear)
- Food, including that for any special dietary needs
- Out-of-pocket medical & dental costs
- Out of pocket costs for prescriptions
- Out-of-pocket vision costs
- Personal toiletries, vitamins 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, 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 ID/DD. See the section "Exploring Housing Options" for a discussion of housing options in Northern Virginia. Also visit The Arc of Northern Virginia at www.thearcofnova.org for our Transition POINTS guide, "Finding a Home for a Person with a Disability" and a toolkit with many helpful documents and links to webinars.

If you haven't already, contact the Social Security Administration to apply for benefits. (See next section.) If your adult child is currently receiving benefits, then ensure that all paperwork is in order. Place all records in chronological order. Make a list of all contacts, addresses, phone numbers to share with a person in the circle of support and who maybe become the representative payee in the future.

## STEP 4: APPLY FOR BENEFITS: Social Security

If you have not already done so, begin the application process for Social Security benefits for your adult child. The first step is to *determine eligibility* for any benefit program; the Social Security Administration (SSA) will decide which program is appropriate. For video and webinar presentations on SSI/SSDI visit The Arc of Northern Virginia's YouTube channel (Videos at The Arc of NoVA) at https://www.youtube.com/user/VideosatTheArcofNoVA

### 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 (physical and/or mental or blind) impairment. Your disability must have lasted or be expected to last for a continuous period of not less than 12 months or result in death. For 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

The steps for applying are:

**Start with a disability report**. Go to the website at http://www.socialsecurity.gov/pgm/ssi.htm and click on Disability Report for Adults. (You may also call 1-800-772-1213 or go to a Social Security Field Office.) Complete as much information here as you can prior to your appointment at the local office. The application asks for names, addresses and telephone numbers of doctors and therapists who have treated your child and information on any hospitalizations. More descriptive medical records, such as a letter explaining a diagnosis or evaluations by therapists or schools—can be brought to the intake meeting (make copies!).

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

*You cannot complete the application process for benefits online; you may complete the online application, but then must call Social Security for an appointment.*

**Call Social Security**. To make an appointment, call **1-800-772-1213** (TTY **1-800-325-0778**) Monday through Friday or contact your local Social Security office. It is best to call the 800 number rather than the local office as field offices are under staffed and the hold times can be very long. You will be greeted by an automated answering attendant, who will prompt you to state why you are calling; say "Apply for SSI."

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

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

**Set up a screening interview.** During the previous phone interview, the representative will set up a screening, which continues the application process, at your local Social Security of office. If outside of the Northern Virginia area, visit http://www.ssa.gov/locator to find your local office.

Contact for all offices: 1-800-772-1213

**Alexandria Office**
PLAZA 500, Suite 190
6295 Edsall Road
Alexandria, VA 22312

**Fairfax Local Office**
11212 Waples Mill Rd
Fairfax, VA 22030-7401

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

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

**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 may begin the whole application process all over again (after 60 days) or you may consider appealing the decision within 60 days.

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

**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.*

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### The Representative Payee

A representative payee is appointed by SSA to receive Social Security and/or SSI benefits for someone who requires support managing his or her money. Rep Payees should be comfortable handling financial records and be trusted to keep in mind the best interests of the disabled beneficiary.

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

To be designated a Rep Payee, contact the local SSA office (see above). You must then submit an application, form SSA-11 and documents to prove your identity. SSA requires you to complete the payee application in a face-to-face interview.

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

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 benefits in addition to their existing SSI or SSDI (see below).

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## Housing and SSI Benefits

**SSI is intended to cover living expenses such as rent, food, and utilities**. For example, it is recommended that you **charge your adult child rent** if he or she lives in the family home. **Rent charged must be at least 30% of the current federal benefit amount** ($750 a month for 2018) to get the maximum SSI benefit. It is recommended that you research comparables for your area of rooms to rent and include that with the rental agreement. Be aware that SSI benefits may be reduced under the following circumstances:

In general, about one-third of your SSI benefit is assumed to be paying for housing expenses (rent or mortgage, utilities, property insurance/renter's insurance, 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). If you have a trust, you can transfer your rent or mortgage money to an ABLE Account, pay the rent from an ABLE Account and SSI will not be reduced. For more information on utilizing ABLE Accounts, visit our trust website at www.thearcofnovatrust.org and the ABLE National Resource Center at www.ablenrc.org and Virginia ABLE at https://www.able-now.com/

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

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

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**Reporting Income**

SSI beneficiaries ***mus***t 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.

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**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.

DAC benefits are approximately 50% of the parent entitlement. If the parent entitlement percentage does not equal the current SSI + $20.00, then SSI will be offset. The adult with the disability would be considered to be dual eligible and fall under both SSI and SSDI working rules.

Once your adult child moves from SSI to SSDI, he or she will be eligible for Medicare, 24 months form the date of eligibility determination.

**When the Second Parent Retires**

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

**NOTE:** On the death of a parent(s), your family member would qualify for Social Security survivor benefits. See Part II of this guide, "Applying for Benefits: Social Security Survivor and Retirement Benefits."

**STEP 4: APPLY FOR BENEFITS: Medicaid Waivers**

This information is adapted from The Arc of Northern Virginia's website. For more information, www.thearcofnova.org/programs/waivers

Family income and family assets are not a consideration under the Medicaid Waiver program. If your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria. To watch our recorded webinar that walks you through Waivers from start to finish, visit The Arc of Northern Virginia's YouTube Channel at https://www.youtube.com/user/VideosatTheArcofNoVA

You can read the latest information on the new Waivers from the state 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 3 DD Waivers; they are the (1) Community Living, (2) Family and Individual Supports, and (3) Building Independence Waivers. 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 waiver does not include 24/7 residential services. Individuals will own, lease, or control their own living arrangements and supports may need to be complemented by non-waiver funded rent subsidies.

Individuals receiving waiver services are assessed every two years (as a child) and every three years (as an adult) with an assessment called the Supports Intensity Scale (SIS) to measure the intensity of their support needs. People can move between these three DD Waivers if their needs change over time. Moving to a waiver that serves people with higher needs may sometimes involve a waiting period, as it is a "first come, first serve" system.

### Eligibility Criteria

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

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

(2) Diagnosis: Persons applying for a Waiver must meet the diagnostic eligibility requirements for the DD Waivers. This means that a person must have a developmental disability as defined in 37.2-100 of the Code of Virginia.

   a. "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; (ii) is manifested before the individual reaches 22 years of age; (iii) is likely to continue indefinitely; (iv) 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 independence living, ore economic self-sufficiency; and(v) reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized support, or other forms of assistance later are lifelong or 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 9i) through (v) if the individual without services and supports, has a high probability of meeting those criteria later in life.

(3) Financial: If the functioning and diagnostic criteria are met, then the child's income and assets are considered. Special Needs Trusts and ABLE Accounts are not considered when testing financial eligibility. People over 18 have an asset cap of $2,000. Everyone receiving a Waiver has a monthly income cap of 300% of the current Social Security Supplemental Security Income amount (SSI is $750 in 2018, so max monthly income is $2,250).

**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

## Waiting List Eligibility

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

**How Long is the Wait?**

The Developmental Disability Waivers have a waiting list based upon urgency of need. People in Priority One of urgency need services within the year, people in Priority Two needs 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, 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.

To Apply for the Developmental Disabilities Waivers
Contact your local Community Services Board.
Alexandria City CSB: (703) 746-3400
Arlington DHS/IDD Services: (703) 228-1700
Fairfax/Falls Church CSB/IDS: (703) 324-4400

If not in Northern Virginia, visit http://www.dbhds.virginia.gov/community-services-boards-csbs to find your local CSB

### IFSP Funding

For those on the Waiver Waitlist

If you are on the waiting list for a waiver, you are eligible to apply for The Individual and Family Support Program (IFSP). This program is designed to assist individuals on the waiting list for the Developmental Disability Medicaid Waivers to access short term services that will help maintain them in their own homes in their community. Information, applications, and instructions can be found at http://dbhds.virginia.gov/developmental-services/ifsp

To Apply for the CCC Plus Waiver contact your
county's Department of Social Services
Alexandria City:  (703)746-5700
Arlington:  (703)228-1350
Fairfax/Falls Church:  (703)324-7948

If not in Northern Virginia, visit
http://www.dss.virginia.gov/localagency/index.cgi
to find your local DSS

## Intersection of Social Security Disability Income and Financial Qualifications for Medicaid and Medicaid Waiver

*This section attempts to explain a very complex subject in simple terms. There are additional complexities in each situation that may have an impact on someone's ability to receive and maintain Social Security income and/or Medicaid. Look at the resources at the end of this section for ideas on where to go to best plan for your personal situation.*

### Understanding Supplemental Security Income (SSI):

SSI is a monthly cash benefit for people with <u>limited income</u> AND who are either 65 years old or older, or blind, or <u>disabled</u>, with <u>little or no work history</u>. The recipient's disability must be preventing them from earning "Substantial Gainful Activity," or what is $1220 in 2019 per month. Additionally, they must have no more than $2,000 in total assets; parents' income and assets do not count for adult applicants. However, the recipient may own one house and one car.

The monthly benefit payments are determined by the current standard benefit rate ($771 a month in 2019), minus any countable income. SSI is intended to pay for room and board. A qualified applicant can receive this benefit even if he/she is still in school and living at home, as long as he/she is over 18 years of age and being charged a fair market rent. The rent must be at least 30% of the monthly benefit, or the monthly SSI payment will be reduced by one third. If eligible for SSI, you will also be eligible for Medicaid when you apply.

### Understanding Social Security Disability Income (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. SSDI amounts are higher than SSI amounts, but the total can vary widely since it is based on income paid into the FICA system. Once someone has received SSDI for 24 months, they automatically receive Medicare.

### The move from SSI to SSDI

Once a parent passes away, retires, and/or acquires a disability that prevents them from working which results in them filing to receive their own Social Security benefits, the adult child with a developmental disability is affected as well. The adult child then becomes a "childhood disability beneficiary (CDB)," and moves from the SSI program to SSDI. This move will result in an increased monthly payment. The benefit is approximately 55% of what the parent receives monthly from Social Security, or approximately 75-85% of what a deceased parent would receive if they were alive. If both parents are retired and/or deceased, the payment will be based upon the higher income earner. Note that the move to SSDI and ultimate enrollment in Medicare is not optional and cannot be deferred.

The move to SSDI can also occur if the adult with a disability has worked enough on their own to qualify under their own work history.

### The Intersection with Medicaid

To receive Virginia Medicaid without a Waiver, an adult with a disability must be earning 80% of the Federal Poverty Level or less per month and be determined by Social Security to have a disability. That equates to $810/month for a family of one in 2018. (Note this amount will increase once Virginia completes Medicaid expansion.) SSDI often puts people over that limit, however<u>, if the person was ever eligible for SSI and Medicaid in the past, the move to SSDI will not result in their removal from Medicaid, even if they exceed the monthly income maximum because of SSDI payments.</u> This protection is the result of a federal law commonly called the Pickle Amendment. The SSDI income will be completely disregarded in calculating their Medicaid eligibility, so long as your indicate past SSI and Medicaid eligibility on your application by checking the relevant box.

People protected under the Pickle Amendment are still subject to the working rules of Social Security. This means that Medicaid could still be lost if they are earning over $1,000 per month from working, but you may be able to maintain some benefits, including Medicaid, by enrolling in work incentives programs with Social Security and/or Medicaid Works. Contact your local Work Incentives Coordinator to learn more. http://www.vaaccses.org/contact_us/

There is a rule about "individual threshold" that states that if someone with a Medicaid is working and earning more than 300% of SSI per month, but not earning enough to cover the cost of Medicaid services they are using, they may be able to keep their Medicaid. You can read more about that exception at Social Security https://www.ssa.gov/disabilityresearch/wi/1619b.htm)

### The Intersection with Medicaid Waiver

If you receive Virginia Medicaid and have one of the Waivers (e.g., Community Living Waiver, Family and Individual Supports Waiver, Building Independence Waiver, CCC Plus Waiver), you can earn up to 300% of the current SSI amount and maintain Medicaid eligibility. In 2019, that means you could earn up to $2313/month and still be eligible. However, once your monthly income is greater than $1237 (in 2018 dollars), you'll have to pay essentially all counted income over that amount toward a monthly co-pay for Medicaid Waiver benefits, called a patient pay. If your SSDI income, combined with any other income, will exceed 300% of SSI per month, you may lose your Waiver, even if you're able to keep Medicaid. Waiver Medicaid is called "Long Term Care Medicaid" and it operates with slightly different rules than standard Medicaid.

Note that if income is from working, the rules vary slightly. People working 0-8 hours weekly have no disregard for their earned income, people working 8.01-19.99 hours weekly have a 200% disregard (i.e., can earn up to 200% of SSI monthly), and people working 20 hours or more per week may earn up to the full 300% of SSI amount and maintain eligibility.

### Preparing for the Future

Create an account at My SSA (https://www.ssa.gov/) to monitor how much you have paid into the Social Security system. At any time, you can run a benefits check to see how much Social Security income you and/or your child will receive based upon your payments into the FICA system. You can see how this amount may vary based upon the age at which you retire and begin to collect Social Security benefits.

If you think it is likely that SSDI alone or in combination with other income will be over 300% of SSI in the future, thereby jeopardizing Medicaid Waiver eligibility, plan early. Ensure that any income or payments from life insurance, pensions, annuities, child support, military survivor's benefits, etc. that can go directly into a protected savings account like a Special Needs Trust (https://thearcofnovatrust.org/) or ABLE Account are set up to do that. Note that you cannot have Social Security payments go directly into one of these accounts.

You can also work with your estate planning attorney and/or financial planner to look at the cost of privately funding the services usually accessed through Waiver. Set up a plan with service providers and write in your Letter of Intent how this will work. Share this information with your support team so everyone is prepared.

### Resources and Contacts

Local work incentives coordinators: http://www.vaaccses.org/contact_us/

The Virginia Medicaid Manual, including information on Medicaid eligibility: http://www.dss.virginia.gov/benefit/medical_assistance/manual.cgi

Social Security explanation of the Pickle Amendment: Pickle- https://www.ssa.gov/OP_Home/ssact/title16b/1634.htm

## STEP 4: APPLY FOR BENEFITS: Food and Energy Assistance, Tax Relief

### Supplemental Nutrition Assistance Program

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.fns.usda.gov/snap/eligibility

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://commonhelp.virginia.gov/access/ or visit your local Department of Social Service

Individuals who receive SSI are in most circumstances automatically eligible; *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.

**City of Alexandria**

Division on Aging and Adult Services
https://seniorservicesalex.org/programs/meals-on-wheels/
703-746-5999
mealsonwheels@seniorservicealex.org

**Arlington County**

Arlington Meals on Wheels
703-522-0811
info@mealsonwheelsarlington.com
www. mealsonwheelsarlington.com

Fairfax
https://www.fairfaxcounty.gov/familyservices/older-adults/fairfax-area-meals-on-wheels
Fairfax Area Meals on Wheels
703-324-5409

**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're 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 Alexandria and the counties of Arlington and Fairfax offer real estate tax relief to citizens who are either 65 or older, or permanently and totally disabled, and who meet the income and asset eligibility requirements.

For the City of Alexandria's eligibility requirements and application, go to https://www.alexandriava.gov/finance/info/default.aspx?id=2886
Contact Tax Services at (703)746- 3901 Option 6

In Arlington, visit https://topics.arlingtonva.us/realestate/taxes-payments/real-estate-tax-relief/
In Fairfax, refer to https://www.fairfaxcounty.gov/taxes/real-estate/exemptions
for eligibility and income requirements. For an application, call 703-222-8234

## STEP 5: FOLLOW THROUGH WITH ESTATE PLANNING

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

**Creating a Will**
A will is critical to ensuring that your wishes are carried out regarding how and to whom your assets are divided after your death. If you have a child with a disability, this is doubly important. Find an attorney who specializes in special needs planning; he or she will be able to address the unique needs of each of your children and not jeopardize the benefits or services of your child with a disability and /or the relationship between the siblings and family members. * A list of attorneys can be found in our Provider Directory on our website at https://thearcofnova.org/directory/. While many wills create family trusts, to avoid jeopardizing the benefits or services of your child with a disability you need to create a separate *special needs trust* (see below).

**Reviewing Beneficiaries**
In addition to naming a special needs trust as the beneficiary for monies inherited through a will, you should also **review the beneficiary designations for resources considered outside your will**, including:

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

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

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

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

**Special Needs Trusts (SNT)**
Special needs trusts (sometimes called supplemental benefits trusts) allow families to provide for the future financial stability of their loved one with a disability. Since some federal benefits programs impose severe limits on beneficiary's assets and resources, your son or daughter could be disqualified from benefits if he or she received, for example an unexpected 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 Northern Virginia, for their child with disabilities. The person establishing the trust, usually called the settlor, chooses to make some of his or her own assets available for the benefit of the beneficiary (person with disabilities).
These trusts may be funded during the parents' lifetime. You can contribute to them while you are still alive or you can fund them upon the death of the

parent(s), friend, etc. with an inheritance, life insurance policy or transfer from another trust.

***First-party trusts*** (self-funded or self-settled) are established by the beneficiary, parent, grandparent, guardian, or court ordered and are funded with resources that belong to the person with disabilities. Common sources of funding for first-party trusts are structured settlements, lump-sum paybacks from Social Security, irrevocably assigned child support for an adult child with disabilities and Survivor Benefits, and inheritances that mistakenly were given directly to the individual with the disability.

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 special needs attorney with expertise in disabilities and this particular kind of trust.

### Setting Up a Trust

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

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

### Uses of Trust Funds

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

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

### Acting as Trustee

A trustee is the person who oversees trust assets and administers the trust provisions, including investing, account reporting and tax reporting, check writing, and disbursements. The Arc of Northern Virginia's trustee is Key Private Bank while The Arc manages the trusts and provides day to day client relations. Professional legal and investment advice are crucial for trustees administering a special needs trust themselves.

For trusts set up with The Arc of Northern Virginia, the family and beneficiary do not have this burden of trust administration. Trust staff perform all administrative tasks and client relations and Key Bank handles all fiduciary and investment duties.

For more information about being a trustee, download a free handbook at:
http://www.specialneedsalliance.org/free-trustee-handbook

To learn more about The Arc of Northern Virginia's Special Needs Trust visit
https://thearcofnovatrust.org
or contact Tia Marsili, Director of Special Needs Trusts for a free consultation at tmarsili@thearcofnova.org or via the website at http://thearcofnovatrust.org/make-an-appointment/

## ABLE Accounts

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

The Achieving a Better Life Experience (ABLE) Act enacted by Congress in late 2014 allows states to establish tax-advantaged savings accounts for certain individuals with disabilities for their disability related expenses. In addition, these funds would generally not be considered for supplemental security income (SSI) program (up to $100,000), Medicaid, and certain other federal means-tested benefits.

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

To learn more about ABLE Accounts, visit www.ablenlc.org. To learn more about ABLE Accounts in Virginia, visit ABLENow at https://www.able-now.com. For a better understanding of the differences between Special Needs Trusts and ABLE Accounts, visit The Arc of Northern Virginia Trusts website at https://thearcofnovatrust.org/pooled-trusts/abel-accounts/

## Advocate Program

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

## Considering Legal Authority

Families often struggle to determine the need for and value of guardianship and other forms of legal authority, especially as they relate to "protecting the person." The answer to what is appropriate depends upon the person. *It is critical to remember that guardianship and similar measures are simply legal authority on a piece of paper. They cannot prevent someone from doing something. They may be helpful in "cleaning up" some financial problems.*

The Disability Law Center of Virginia www.dlcv.org offers information on their website regarding weighing varying legal authority options and also provides templates that can be downloaded to create your own documents for power of attorney and medical directives.

### Dignity of Risk and Supported Decision Making

In recent years, a movement has grown to talk about the "dignity of risk" we all have to make decisions. The concept is simply that all people need help making some decisions and we all learn by making bad decisions. For example, many people without developmental disabilities rely on tax accountants or doctors to explain life decisions in simple terms they can understand. This idea is called "supported decision making" and there is a growing international movement towards this policy. A team of people who care about the person with a disability form a Circle of Support and are asked by the person to work together to help them understand and make decisions. It does not involve taking away legal rights but does build a support team and a way to grow decision making ability and independence over time. It has no cost and is probably what you are already doing. Supported decision making does not give the team any legal authority to speak on behalf of the individual or to override their decisions. You can learn more about Supported Decision Making and view webinars on the topic at http://supporteddecisionmaking.org/

"Dignity of Risk" also means understanding that it is okay to make some bad decisions. We are all allowed and it is often how we learn best. Many people learn from spending too much that it is hard to pay bills and learn from weight gain and health issues that they ate too much. This is a right all people have and exercise every day. People with disabilities should have the same opportunities to make decisions and learn through natural consequences and a support team about how to proceed the next time.

### Legal Authority Options: Weighing Alternatives

The appointment of a guardian or a conservator should be considered as a last resort. See the chart on page 56 for a list and description of legal authority options. Petitioners for guardianship must provide evidence, and a judge must determine, that an individual is "incapacitated" in terms of making certain decisions.

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

### Medical Directive

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

**This information adapted from www.dlcv.org (The Disability Law Center of Virginia.*

### Guardianship and Conservatorship

Guardians and conservators are appointed by a local court to protect an incapacitated person-- 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. An individual is not put under guardianship solely because they have bad judgment, but because their ability to understand and make good choices is impaired.

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

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

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

The court may appoint only a guardian, only a conservator, or both. For most young adults with a disability, only a guardian is necessary. Typically, the young adult has less than $2,000 in assets; the only income is from SSI or earnings that typically can be managed by a Representative Payee or by the individual with some assistance. The extent of the guardian's or conservator's authority will be set forth in the judge's order and in the Virginia code.

**Considering Guardianship**

In a guardianship, the law strikes a balance between preserving the rights and personal autonomy of an adult and the duty of the Commonwealth of Virginia to protect individuals who lack sufficient capacity to make decisions regarding themselves or their property.

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

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

not liable. If they were, few people would be willing to serve as a guardian. Guardians do have a duty to try to arrange a safe environment for the individual.

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

To help determine if guardianship is the appropriate choice for your young adult, complete the screener at http://www.thearcofnova.org/wp-content/uploads/2011/05/Thinking-about-Guardianship-checklist-2.pdf

**Obtaining Guardianship**

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

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

After the GAL has filed a report, a hearing is held at the Court. Usually the persons being appointed as guardians must attend the hearing, and after the hearing will go to the Clerk of the Court's office to complete all necessary paper-work. The individual for whom the guardian is being appointed may choose to attend the hearing or not. The typical time frame for obtaining guardianship is approximately 3 months, but may take up to 6 months.

[1]Thank you to Kelly Thompson, Esq., and Loretta Morris Williams, Esq. for work on this section and insights on issues parents face in deciding on guardianship

As a guardian, you are required to submit a report every year to the local Department of Social Services; the court will provide a form.

If you are interested in pursuing guardianship or other legal authority options, visit The Arc of Northern Virginia's Provider Directory for a list of elder care attorneys at https://thearcofnova.org/directory/

**Guardian of Last Resort**

When there is no one who is willing or able to serve as guardian, a public guardian of last resort can be an option. The Department of Aging and Rehabilitation Services oversees 13 public guardianship programs across Virginia. The Arc of Northern Virginia is one of those programs and services Arlington, Fairfax, and Prince William counties, as well as City of Alexandria. There are four criteria for the public guardianship programs:

1. The individual must be at least 18-years old
2. The individual must be deemed incapacitated
3. The individual must be indigent
4. There must no one else who is willing or appropriate to serve

For more information, please contact Noelle C. St. Amant-Aden at 703-208-1119 ext. 122 or Noelle@TheArcOfNoVA.org.

## 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 | www.supporteddecisonmaking.com |
| Emergency order for adult protective services | Short-term guardianship (15 days) to handle an emergency or correct conditions causing an emergency | Local Department of Social Services must apply to Circuit Court for temporary guardianship order |
| Durable power of attorney | Written authority giving a parent or another person (agent) power to make decisions on behalf of the individual with a disability (the principal). Agent may act even if principal becomes incapacitated. | Agent cannot override decisions<br>Power ends if principal revokes it or dies |
| Advance 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. May be combined with Medical Power of Attorney. Must be witnessed in Virginia. | Agent's powers are defined in the document.<br>Agent cannot override decisions. |
| Health Care Power of Attorney | Similar to durable general power of attorney, but directed exclusively at healthcare.<br><br>Choosing the right agent is very important; make sure he or she knows the individual's wishes, values, and preference and will be a strong advocate | Enables someone to make any or all healthcare decisions if the individual becomes incapacitated.<br>Doctor and family will be able to know and respect the individual's wishes |
| Representative payee | Receives another person's government benefits on behalf of that person; responsible for using benefit to pay beneficiary's living expenses | Individual must be unable to manage finances.<br>Rep Payee must report annually to the Social Security Administration |
| Limited conservatorship | Decisions on specific financial matters, such as paying bills or filling out tax returns, as specified by the judge. Conservator must post surety bond. | Individual must be incapacitated.<br>Conservator must file report on income and expenses |
| Full conservatorship | All financial decisions, including paying bills, investing money, and selling property. Conservator must post a surety bond. | Conservator must file annual report on all financial transactions |
| Standby guardian | Person designated in guardianship order to become guardian when current guardian dies | Does not assume any duties until death of primary guardian |
| Limited guardianship | Decisions on specific issues (e.g., only health care), as determined by a judge. This leaves the person free to make all other decisions. | Individual must be incapacitated.<br>Guardian must file an annual report with Dept of Social Services |
| Full guardianship | Guardian makes all financial, legal, personal care, and social decisions | Individual must be incapacitated.<br>Guardian must file an annual report with Dept of Social Services |

## 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 at the moment. This section outlines in very general terms the housing options available for persons with and without a Medicaid Waiver. For more detailed descriptions of the housing options listed here, see *Finding a Home for Adults with Disabilities* on the Arc of Northern Virginia's website at https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/
Also visit Northern Virginia Housing and Supportive Services at www.novahss.org.

**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 (house, apartment, rented room), the bricks and mortar, where one lives **or** the rental assistance to pay to stay in the physical home. (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.

However, for some residential programs such as group homes, the physical housing and the residential services are tied together; the *housing is considered a residential service (not bricks and mortar). Because the cost of these programs is so high, only persons with Medicaid waivers typically can afford them.* Even with a waiver, the individual still has to pay a residential fee.

Thus, the three basic options are:

1. **For those with a Developmental Disabilities Waiver including the including the Community Living Waiver, Family and Individual Supports Waiver, and the Building Independence Waiver**, the cost of support services is paid for by the Waiver once your support team identifies and secures an appropriate service. However, the cost of rent is separate and must be paid for by the individual with a disability. This is typically done with Social Security income, earned income, and possibly an additional housing subsidy.

2. **For those without a Developmental Disabilities Waiver**, it will be necessary to find resources to pay for the physical housing **and** support services (if needed by the individual).

3. **For those eligible for Waivers**, it is important to note that as of the printing of this guide, Virginia has limited funding from the "State Rental Assistance Program" set aside to allow people with developmental disabilities to live in affordable housing options. This program works like a housing voucher or rent subsidy. These are available to people not only with Developmental Disability Waivers, but also those on the waiting list for these Waivers. A number of people on the waiting list have used these funds to move and worked with either a live in attendant, natural supports (e.g., family coming by to help), and/or privately hired help to secure this limited housing opportunity while waiting for a Waiver. You can contact Jeannie Cummins (j.cummins@dbhds.virginia.gov) to learn more about this program.

Because access to affordable housing is a challenge, there are lots of plans in the works to grow housing options. The redesigned Developmental Disabilities Waivers offer a range of new options that provide or are tied to a range of residential services. Families are considering ways to privately fund housing, or to leverage a home they already own. To see more about the options available and how to make them work for you, visit our online toolkit that includes recorded webinars, slides, and other information on housing. https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/home-toolbox/housing-toolkit/

**1. Residential Options Funded by Medicaid Waiver.** If your loved one has a Medicaid Waiver, he or she will have some options for how may be able to live and get supports in a range of settings that combine or work with a variety of residences. These options are outlined below. Note that under the newly redesigned Waivers (as of September 1, 2016), options are available based upon the need of the person with a disability as well as the Waiver they have. The Community Living Waiver is designed to support individuals with the highest level and most complex needs, the Family and Individual Supports Waiver is designed to support people with anywhere from mild to high need, the Building Independence Waiver is for individuals over 18, with limited support needs. For more details on the Waivers, see page 24 of this guide.

| **Disability Waiver Services** | **Community Living Waiver** | **Family & Individual Supports Waiver** | **Building Independence Waiver** |
|---|---|---|---|
| **Group Homes**- 24/7 staffed home where 3-7 people with disabilities live. Homes usually have staff that rotate around the clock on shifts. | X | | |
| **Shared Living**- Individual lives with someone without a disability who is reimbursed for room and board in exchange for companionship | X | X | X |
| **Independent Living**- Supports brought into the home focused on skill building and preparing for greater independence | | | X |
| **Sponsored Residential-** Option where person with disability lives with a paid caregiver in the home of the caregiver | X | | |
| **Supported Living**- Residence owned by a support provider that offers up to 24/7 help with support needs | X | X | |

Visit https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/home-toolbox/housing-toolkit/ for a huge online toolkit filled with information about non-congregate residential options. The site also showcases stories of people living in integrated housing options with a range of support needs.

Visit http://www.youtube.com/user/VideosatTheArcofNoVA to see "virtual tours" of housing option.

**Residential (Public) Program Options**
Options that provide housing and allow you to use either a Waiver, private funds, or natural supports to bring in services include:

**2. 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). To qualify for public housing, an individual must meet the public housing authority's low income requirements. In this situation, the individual must live in the specific housing developments built and owned by the local PHA in order to qualify for the subsidized housing. You could apply to have an additional bedroom in the unit for a live-in aide, if needed.

Unfortunately, the waiting lists for public housing units are very long. At the present time, no one is even able to get onto the waiting lists for Alexandria or Fairfax (the only Northern Virginia localities that operate Public Housing).

### 3. Housing Choice Vouchers

Housing Choice Vouchers (HCVs) used to be called "Section 8 Vouchers." A voucher allows low-income individuals and low-income families to rent from private landlords at a reduced cost. The tenant pays 30% of their income towards rent, and the voucher subsidizes the rest of the cost, up to an approved Fair Market Rent amount. Once you have received a voucher, you can take that voucher with you anywhere in the country after one year, assuming the new location is willing to accept and operate the voucher for you. You could apply to have an additional bedroom in the unit for a live-in aide, if needed. Waiting lists are long for this general population program, and at the present time the waiting lists are closed in Arlington, Alexandria, and Fairfax.

The Arc of Northern Virginia created two guidebooks to help people with disabilities and their weigh the option of a live-in caregiver, learn how to proceed, and troubleshoot along the way. The parallel version for live-in caregivers will help them understand the requirements of the job, how to perform this work well, and what to do if they have problems. You can download the guides from our website at https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/housing-toolkit/

### 4. State Rental Assistance Program (SRAP)

Virginia has limited funding from the "State Rental Assistance Program" set aside to allow people with developmental disabilities to live in affordable housing options. This program works like a housing voucher or rent subsidy. These are available to people not only with Developmental Disability Waivers, but also those on the waiting list for these Waivers. A number of people on the waiting list have used these funds to move and worked with either a live in attendant, natural supports (e.g., family coming by to help), and/or privately hired help to secure this limited housing opportunity while waiting for a Waiver. You can contact Jeannie Cummins j.cummins@dbhds.virginia.gov to learn more about this program.

As with public housing, a person with a disability could use staff funded with their Developmental Disability Waiver or their 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 and others are on long waiting lists for these services; 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.

### 1. Microboards

A circle of support is a group of family and friends who care about a person with a disability and volunteer their time to help support that person. 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), www.vhda.com You can contact Bruce DeSimone at 804-343-5656 bruce.desimone@vhda.com to learn more.

In addition, microboards can:

- manage waiver supports (e.g. hire and train staff);
- provide property management and upkeep;
- hire a private vendor to provide waiver services;
- help problem solve during a crisis;
- provide referrals to and/or coordinate resources;
- act as a sounding board

Microboards are meant to be sustainable. The microboard will develop bylaws, a meeting schedule, a succession plan, and a scope of authority. To learn more, contact the Virginia Microboard Association at 757-460-1569, http://virginiamicroboards.org/, orVirginiaMicroboards@gmail.com.

### 2. Shared Apartments

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

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.

### 3. **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 be up front about this need and plan when they contact potential homeowners or lease holders to ensure everyone is comfortable with this situation.

### 4. **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 they were not deeded the home after the life tenant passed away.* You would also need to have an agreement on care arrangements if the life tenant is no longer able to stay in the home because their needs or wishes change.

### 5. **Shared Home Purchase**

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

For an in-depth review of housing, download our Transition POINTS Guide: Finding a Home for Adults with Disabilities at https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/

### 6. **Tax Credit Units**

Developers identify a certain number of units at a property and provide a preference in leasing these units to people with developmental disabilities. Note that some tax credit properties with units that have a leasing preference have project-based rent subsidies, while others accept rent subsidies like Housing Choice Vouchers or State Rental Assistance. To find out more, contact the DBHDS Housing Specialist, Jeannie Cummins at j.cummins@dbhds.virginia.gov and visit http://www.dbhds.virginia.gov/developmental-services/housing/housing-team

## 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, 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.

You've also discovered that having a loved one with a disability increases your household paperwork quotient! Through the years you've accumulated all kinds of paper on him or her: 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 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?

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*.

### 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:

1. 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.

2. Reconfirm commitments from people who have agreed to take on responsibilities as executor of your estate, trustees, standby guardians, conservators, health care advocate, Representative Payees, etc.
3. Update existing documents such as wills and trusts, changing the names of executors, trustees, etc., if needed per the preceding step.
4. Review beneficiary designations in insurance policies, 401Ks, etc. (see Step 5: Follow Through with Estate Planning).
5. Write your Letter of Intent or update it.
6. 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.
7. Get rid of paper! Consider scanning some documents that you don't use but might want to refer to (if you are comfortable reading on your computer or online).
8. Pull everything together in one place or one file.
9. 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 & 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 case manager, transportation provider (such as MetroAccess), lawyers, trustees and backup guardians, insurance agents, banker and financial planners, etc.

For more on the rationale for a Letter of Intent, see http://www.child-autism-parent-cafe.com/letter-of-intent.html

You may purchase a fill-in-the-blank Letter of Intent at www.specialneedsplanning.net for $10.00

### 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:** 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, Rep 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 conservatorship 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.

### 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.

### No Need to be Original

One of the benefits of working on your future plan is less paperwork and better organized files. While eliminating duplicate 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)
Wage statements or pay stubs

# *PART II*

# *CARRYING OUT THE PLAN*
## *For Future Caregivers*
## *Of Adults with Disabilities*

## PART II: CARRYING OUT THE PLAN: For Future Caregivers of Adults with Disabilities

Part II 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 ID/DD even when the affected individuals are able to express their sadness and anguish. Persons with ID/DD may actually be under extraordinary stress in times of mourning.[1] 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 ID/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 ID/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."[2]

**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 and not to "protect" them 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

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[1] 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] Ibid

## ENSURE 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

For more detailed explanations of decision-making roles, government benefits, and estate planning, review the appropriate sections in the first part of this guide. 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 SunTrust 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:
http://www.specialneedsalliance.org/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. Complete the report promptly and mail it back, or you may submit the report online.

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

C change the individual names as Representative Payee for SSI beneficiaries, contact the Social Security Administration as soon as possible at 1-800-772-1213 or contact your local SSA office, or go online at www.socialsecurity.gov/payee

**Alexandria Office**
PLAZA 500, Suite 190
6295 Edsall Road
Alexandria, VA 22312
1-800-772-1213

**Fairfax Local Office**
11212 Waples Mill Rd
Fairfax, VA 22030-7401
1-800-772-1213

### Assuming New Roles and Responsibilities

| Type | Decision-making Responsibilities | Reporting Tasks | How to Change |
|---|---|---|---|
| Trustee(s) of special needs trust | Oversight of investment decisions<br>Approve eligible spending of trust monies | 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 | Co-guardian first in line to assume responsibilities, then backup guardian if one is named in the guardianship order.<br>If no co-guardian or backup, then must go to court to appoint one. |
| Limited guardianship | Decisions on specific issues (e.g., just health care), as determined by the judge | Guardian must file an annual report to local court | Co-guardian first in line to assume responsibilities, then backup guardian if one is named in the guardianship order.<br>If no co-guardian or backup, then must go to court to appoint one. |
| Full conservatorship | All financial decisions, including paying bills, investing money, and selling property. | Must post surety bond.<br>Conservator must file annual report on all financial transactions to local court | Co-conservator first in line to assume responsibilities, then backup conservator if one is named in court order.<br>If no backups, then have to go to court to appoint a new conservator |
| 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.<br>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.<br>Paying for SSI beneficiary's eligible expenses (about 1/3 for housing and 2/3 for food and clothing). | Rep Payee must file annual report to Social Security Administration | Call SSA 1-800-772-1213 or go to www.socialsecurity.gov/payee<br>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.

**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 the individual with a disability has a Medicaid Waiver, review the section in the first part of this guide on **Intersection of Social Security Disability Income and Financial Qualifications for Medicaid and Medicaid Waiver**

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

## Explore Alternatives to Employment

Perhaps your loved one with a disability would like to retire and is interested in exploring other meaningful activities.

**Self Directed Services in Fairfax County**

Self-Directed (SD) Services is an alternative to the traditional model of support for people with intellectual disabilities. The individual/family is ultimately responsible to determine service needs (with input from the individual's Community Services Board support coordinator and Interdisciplinary Team), identify a service schedule, and recruit, hire, train, supervise, compensate, and evaluate direct service providers. SD Services:

- Increase and expand individualized service options and plans
- Bring greater control and supervision of services to the individual/family
- Allow greater flexibility in scheduling and receiving services, and
- Can be provided in the community closer to the individual's home

SD Services are available to individuals with intellectual disabilities who meet CSB service eligibility requirements and currently receive or will be authorized to receive day support or employment services funding. For more information, contact Joel Friedman at (703)324-4433 or joel.friedman@fairfaxcounty.gov.

**SPARC (Specially Adapted Resource Clubs)**

Is a clubhouse model day program that supports adults with disabilities over the age of 22 with life skills development, entrepreneurial projects and enrichment activities such as music and art therapies. Clubs are located in Arlington Reston, McLean and Fairfax. Fees are $400 per month for 3+days a week, $340 per month for 2 days per week, and $260 per month for 1 day a week. For more information, visit www.sparcsolutions.org or call (703)338-6185.

**Adults with Disabilities Day Program (ADDP)**

Is facilitated by McLean Bible Church and focuses on spiritual formation, literacy, personal care and independence, recreation and leisure, social skills, travel training and community navigation, and self-advocacy. There is a monthly fee based on the number of days enrolled per
week. For more information, https://www.mcleanbible.org/connect/adults-disabilities-day-program-addp

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.

**Senior Community Inclusion Program**

This is a partnership with Fairfax County Neighborhood and Community Services and ServiceSource, Inc. Senior Services provides supportive services that focus on social inclusion to enable seniors with disabilities to actively participate in the day-to-day activities at Fairfax County Senior Centers.

The senior supportive services are divided into two main functions: Therapeutic Recreation and Case Management. For more information, visithttps://www.servicesource.org/service/senior-services/ or contact VASEniorServices@servicesours.org or 703-970-3636

**Adult Day Health Care**

For adults who need supervision during the day. Activities are designed to provide socialization, mental stimulation and enhance physical health.

Fairfax County Adult Day Health Care www.fairfaxcountylgov/hd/adhc or hdadhc@fairfaxcounty.gov . Door to door transportation is provided in Fairfax County by Fastran.

Arlington Adult Day Health Care https://aging-disability.arlingtonva.us/programs/adult-day/ or adultdayprogram@arlingtonva.us or call 73-228-5340. Door to door transportation is provided by Arlington STAR.

**Local Therapeutic Recreation Agencies**

All three localities have Therapeutic Recreation Offices providing recreation and leisure opportunities for adults with disabilities.

Some 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.

**City of Alexandria**
The Therapeutic Recreation Office can be reached at 703-746-5422 or visit https://www.alexandriava.gov/recreation/info/default.aspx?id=45758

**Arlington County**
The Therapeutic Recreation Office can be reached at 703-228-4740, or
TRInfo@arlingtonva.us. You can visit https://parks.arlingtonva.us/therapeutic-recreation/

**Fairfax County**
The Therapeutic Recreation Office can be reached at 703-324-5532, or www.fairfaxcounty.gov/ncs/trs

**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 on local programs for older adults with and without disabilities.

**City of Alexandria**
2525 Mount Vernon Avenue, Unit 5
Alexandria, VA 22301-1159
https://www.alexandriava.gov/Aging
703-746-5999

**Arlington County**
2100 Washington Boulevard, 4th Floor
Arlington, VA 22204
http://www.arlingtonva.us/aging
(703) 228-1700

**Fairfax County/City of Falls Church**
Division of Adult and Aging Services
703-324-5277, TTY 711
www.fairfaxcounty.gov/OlderAdults

*Aging, Disability and Caregiver Resource Line*
703-324-7948, TTY 711
*Find service information at:*
www.fairfaxcounty.gov/olderadults
www.fairfaxcounty.gov/dfs/disabilities

**Private Service Providers**

***ArtStream.*** Drama and movement classes for adults with disabilities http://www.art-stream.org or call 301-565-4567 . Classes are offered throughout the Northern VA area.gu

## EXPLORE Transportation Options

Older individuals with disabilities may benefit from travel training and from reduced fares for Washington-area buses, taxis, and Metro.

**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.

All of the information a customer needs to prepare for a DMV visit is available on the DMV web site https://www.dmv.virginia.gov/drivers/#id/get_id.asp or by calling the agency's toll-free telephone number at 1-866-DMV-LINE

**Travel Training**
A key element of independence is being able to get around on public transportation for one's work and social life. The ENDependence Center of Northern Virginia offers ***free*** travel training on Washington-area bus and subway routes for people with disabilities. www.ecnv.org 2300 Clarendon Blvd., Arlington, VA. Call (703) 525-3268.

**Metro Disability ID Card**
All jurisdictions in the Washington area offer reduced transportation fares, but you will first need to obtain a free Metro Disability ID card. You will need to fill out an application and have a health care professional certify the individual's disability. Call 202-962-2700 or download an application from http://www.wmata.com/accessibility/doc/Reduced_Fare_Application.pdf
The Metro Disability ID card is good on Metro buses in the District as well as ART in Arlington. CUE, Fairfax Connector, RideOn, TheBus, VRE and MARC also accept it.

**Reduced Farecards/Bus Passes and/or SmarTrip Card**
One option for reduced fares is a reduced fare bus pass or farecard (metro). These are sold at many area Giant and Safeway stores, Metro sales offices and transit stores. You may have to show your Metro Disability ID and photo identification.

Use your Metro Disability ID to purchase a SmarTrip card that is encoded for discount fares. SmarTrip cards can be purchased online at www.MetroOpensDoors.com and click under "Fares." (you must be a registered Metro Disability ID cardholder and you'll have to use a major credit card); at Metro sales offices; and transit stores (see list at end of this appendix). Every public transit service in the region is using SmarTrip *except* for The Bus, OmniRide, OmniLink, MARC and VRE.

It is highly recommended that you register your SmarTrip card. If you lose it, you will get a replacement card for $5 that includes the fare value of the lost card at the time you reported the loss.

Add value to your SmarTrip card in any Metro station at the farecard machines or on Metrobus.

**Using Public Transportation**
A good place to start to learn about available routes is CommuterPage.com with links to Virginia and Maryland bus and rail services. See www.comuterpage.com

In Alexandria, see www.dashbus.com
In Arlington, see www.arlingtontransit.com
In Fairfax, see www.fairfaxcounty.gov/connector/
In Fairfax City, see www.cuebus.org

**Disabled Placard/Plates**
In Virginia you need to get a MED-10 form for a disabled 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 http://dmv.state.va.us . A physician must complete the form. Bring the completed form to the DMV.
You can get a placard or a plate, or both. Placards offer flexibility since you can move it into any car in which

you are the driver or a passenger.
You will need to pay a fee and you will receive your placard or plate on the spot. You can do it by mail, but the process does take longer.

**Paratransit Options**
MetroAccess is the regional shared-ride door to door service established by the Washington Metropolitan Area Transit Authority (WMATA) under provisions of the Americans with Disabilities Act. MetroAccess provides transportation services to persons who, under certain circumstances, are unable to travel to or from a bus stop or rail station.

To be eligible for MetroAccess service, a person must meet one of the following conditions:

(1) Have a disability as defined by the ADA **AND** be unable as a result of disability to utilize fixed-route transportation (Metrobus and Metrorail);

OR (2) Need to use a ramp or wheelchair lift to use a public transit vehicle, but an accessible public transit vehicle is not being used at the time, date, and on the route you would travel. (Please note: All Metrobuses are wheelchair accessible);

OR (3) Be unable to travel to or from a bus stop or rail station due to a disability.

An application must be completed and certified by a health care professional detailing your disability and the need for paratransit services. An in-person interview and functional assessment is also required. This process can take up to three months.

You may register to travel with a personal care assistant at the time of application. The personal care assistant rides free of charge when travelling with you on MetroAccess. (301) 562-5360 (Voice), (301) 588-7535 (TTY) www.wmata.com/metroaccess.

**STAR (Arlington County)**
STAR is Arlington’s prearranged, reserved-trip service for persons with disabilities who are eligible for MetroAccess. STAR fares and ticket books for discounted taxi fares are available through the Commuter Stores and CommuterDirect.com. Eligible seniors and disabled persons may register to order these products by calling Commuter Direct.com® at (703) 228-RIDE (7433), TDD (Virginia Relay Center - hearing impaired only): (800) 828-1120.

Arlington County residents currently certified eligible for MetroAccess are automatically certified for STAR. Rides are provided on a curb-to-curb basis. Drivers park in front of the address and assist riders into and out of the vehicle. For more information on STAR: Contact (703) 892-8747 STAR@arlingtontransit.com
http://www.arlingtontransit.com/pages/star/

***TaxiAccess (Fairfax County)***
TaxiAccess is a program that provides subsidized taxicab service to Fairfax County residents who are registered with MetroAccess. Like STAR in Arlington, TaxiAccess users can purchase coupon books good toward taxicab rides at one-third of the face value. See https://www.fairfaxcounty.gov/neighborhood-community-services/transportation/taxi-voucher-program for information on how to apply, obtain coupons, and Fairfax-area cab companies that accept the coupons.

***Fastran (Fairfax)***
Fastran offers specialized transportation services for Fairfax County and the Cities of Fairfax and Falls Church residents who participate in human service agency programs. All Fastran riders must be certified by a participating agency before utilizing the service.
https://www.fairfaxcounty.gov/neighborhood-community-services/transportation/fastran

***DOT***
DOT is the City of Alexandria's specialized transportation service for residents of Alexandria and visitors who cannot use regular transit buses or rail due to their disability. Trips are provided by taxicabs and wheelchair accessible vans.

The eligibility process is similar to that for Metro Access. For more information or to receive an application, please contact the Paratransit Coordinator at (703) 746-4079.
https://www.alexandriava.gov/tes/info/default.aspx?id=6538

**Uber and Lyft**
Uber and Lyft are ride hailing companies, utilized through apps. Both offer accessible technology for people with hearing and vision impairments.

## GETTING MORE HELP: Resources on Aging

The Arc of Northern Virginia maintains a Provider Directory and Resource Library with links and information on variety of services and resources in the community.  Visit https://thearcofnova.org/programs-services/library/#a-w-d and https://thearcofnova.org/directory/

**Publications & Online Resources**
Planning resources for aging in general:
AARP, "Prepare to Care"
www.aarp.org/foundation/preparetocare

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

Benefits Check-Up
www.BenefitsCheckUp. org
Federal government website to verify what benefits your older family member may qualify for

"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
http://www.ncoa.org
Benefits navigator, resources, and advocacy information

http://inclusion.com/circlesoffriends.html
Publications and other media on Circles of Support

**Grief Resources**
**Supporting People with Disabilities Coping with Grief and Loss**
is an easy-to-read booklet outlining the strategies you can use to help people with a disability deal with grief in their lives.
https://www.scopeaust.org.au/shop/supporting-people-grief-loss/

Visit https://connectability.ca/2015/03/09/grief-and-bereavement-2/ for several resources and a webinar on to view a webinar on Grief and Bereavement for People with Disabilities.

**Geriatric Care Managers**
**Buckley's for Seniors**
www.buckleys4seniors.com
(703) 390-0535
Geriatric care management, transportation for medical or shopping, errands, companionship, bill paying, home maintenance management

**Aging Network Services**
(301) 657-4329
www.agingnetworkservices.com
In-home assessments, advocacy, hiring/monitoring of caregivers, psychotherapy (by licensed social workers)

**Coordinating Senior Care**
http://coordinatingseniorcare.com
(301)765-8926
In-home medical and psycho-social assessments, client advocacy, hire/train/supervise caregivers, monitor care, paperwork assistance

**IKOR of the Greater DC Area**
(703) 879-6992
http://www.ikorglobal.com/locations/greater-dc-area/
Medical and psycho-social assessments, advocacy and guardianship services for seniors and those with special needs, disability advocacy, assistance with admission to group homes & assisted living, care/case management.

**Other Service Providers for Seniors**
**Shepard Centers (Fairfax County)**
Providing transportation and support to seniors
http://www.scwfc.org/

**A Second Me (errand service)**
Professional errand service that saves you and your family time, specializing in special needs, seniors, caretakers and professionals.
asecondme.com/

**Behavior Therapists**
Visit The Arc of Northern Virginia's Provider Directory at www.thearcofnova.org.

**Guardianship and Conservatorship**
**Virginia Guardianship  Association** 804-261-4046.
Website:  www.vgavirginia.org

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