The Arc®
Northern Virginia

Aging with a Disability

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

The Arc
Northern Virginia

This guide is one of six developed for the developmental disability community 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; school and special education; transitioning out of the school system; securing employment or day services; finding a place to live outside the caregiver's home; and aging with a disability.

All of the guides can be found at
https://thearcofnova.org/program/transition-points.

As information changes, updated content and resources may be found in the Resource Library on our website at https://thearcofnova.org/resource-library.

This is not a legal document and does not spell out your or your loved one'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.

www.thearcofnova.org

INTRODUCTION

Supporting a loved one with an intellectual or developmental disability (IDD) is a journey that evolves across a lifetime. As children grow into teens and adults, and then aging, families often find themselves navigating new decisions, new systems, and new possibilities. Along the way, there may be moments of uncertainty, but also moments of tremendous pride, resilience, growth, and joy.

Every person with IDD has unique strengths, goals, preferences, and talents. With the right supports, meaningful relationships, and opportunities, individuals with disabilities can lead fulfilling lives as active members of their communities. This means learning, working, building connections, contributing their gifts, and making choices about their own future. Families and caregivers play a vital role in helping make those opportunities possible.

This guide was created to support you through that process, with a particular focus on the later years of life when parent caregivers may no longer be able to provide a lot of care and oversight.

No two individuals or families will follow the exact same path. Some decisions may feel urgent, while others unfold gradually over time. This guide is designed to be flexible and practical, allowing you to use the information in ways that best fit your family's needs, priorities, and values.

You do not need to have every answer today. What matters most is continuing to take thoughtful steps forward, seeking support when needed, and recognizing that planning for the future is an ongoing process—not a single moment in time. With the right information, community connections, and person-centered planning, individuals with IDD can continue to grow, thrive, and lead meaningful lives throughout adulthood and aging.

ABOUT TRANSITION POINTS

Families need realistic, actionable information to make important decisions as their loved one grows and their needs change over time. Providing this information is the mission of The Arc of Northern Virginia's Transition POINTS program (Providing Opportunities, Information, Networking, and Transition Support).

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

1. Receiving a diagnosis and entering early intervention services
2. Starting school and entering the special education system
3. Transitioning out of the school system into adulthood and adult services
4. Entering the world of work and meaningful community engagement
5. Exploring housing and supportive living options
6. Aging with a disability and planning for long-term quality of life

Providing Opportunities, Information, Networking and Transition Support

For each transition point, Transition POINTS provides guides in print and digital formats, online resources, workshops, webinars, and practical tools to help families navigate complex systems and make informed decisions with confidence.

Many of these resources can be found on The Arc of Northern Virginia website. The Arc of Northern Virginia also maintains a library of informative life-planning and future-planning webinars and videos on the The Arc of Northern Virginia YouTube Channel.

The information in this guide is intended to support individuals with intellectual and developmental disabilities and their families broadly, although some resources referenced are specific to Northern Virginia and the Commonwealth of Virginia. To identify services in your local community, contact your regional Community Services Board (CSB). Information about Virginia CSBs can be found through Virginia DBHDS (Department of Behavioral Health and Developmental Services). In addition, The Arc of Virginia can help families locate local Arc chapters and additional community-based resources throughout the state.

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When you first open Aging With a Disability, it's natural to feel overwhelmed by the amount of information it contains. This guide is meant to be a resource you can return to again and again—not something you need to read or act on all at once. Every family's journey is different, and not every section will apply to your child or your situation right now. Think of it as a toolbox: use the pieces that are most relevant today, and know that you can come back later as your child grows and your family's needs change. Take it step by step, focus on what feels most important, and allow this guide to support you rather than add pressure.

GENERAL NOTES

A CHECKLIST FOR FAMILIES

A CHECKLIST FOR FAMILIES

STEPS TO TAKE ASAP	CHECK IF DONE	NOTES
ASAP		
Discuss "vision" with loved ones; make preliminary list of people in circle of support **pg. 20**		
Discuss who will play what roles in the future **pg. 25**		
Start regular schedule of circle of support meetings or communication **pg. 27**		
Create plan to ensure all future supporters are regularly in contact with the person with a disability and begin to use this plan **pg. 27**		
Begin "downsizing" paperwork; set up file(s) for key documents and share with relevant parties; share list of key contacts with adult children **pg. 69**		
Make list of financial resources and draw up estimated budget of monthly expenses. **pg. 31**		
Write Letter of Intent **pg. 70**		
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STEPS TO TAKE ASAP	CHECK IF DONE	NOTES
WHEN FIRST PARENT IS RETIRING OR OTHERWISE CLAIMING THEIR OWN SOCIAL SECURITY BENEFITS:		
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WHEN BOTH PARENTS HAVE PASSED AWAY:		
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Consider hiring a geriatric care manager if needed for medical care management, errands, companionship. You can find providers at https://thearcofnova.org/resources/business-directory		
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STEPS TO TAKE ASAP	CHECK IF DONE	NOTES
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GENERAL NOTES

GENERAL NOTES

MAKING A PLAN FOR SUCCESSFUL FUTURES

MAKING A PLAN FOR SUCCESSFUL FUTURES

As the family of an adult child with a disability, you may have been responsible for making the most of the financial, medical, and legal decisions for your family member for many decades. As you look toward the future and a time when you or other family members may not be able to do this, it is time to engage in more in-depth future planning. It can feel weighty and impossible to think about handing this off. 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. Through planning ahead as much as possible, you can ensure that future caregivers will be able to provide the quality of life you have envisioned for your loved one AND give yourself a lot of much needed peace of mind.

This future planning is for every family, even if you think you don't have any money to leave to your loved one or you believe you cannot afford an attorney to do estate planning. Many aspects of future planning (as you'll see in this guide) are not related to money. Instead, communicating your vision for the future and working to ensure your loved one with a disability is at the center in that conversation is of primary importance.

PART ONE: CREATING YOUR FUTURE PLAN

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

If you haven't already talked to your family about what you'd like to see happen in your own life as you get older, writing the future plan is a good opportunity to talk about hopes and concerns for both yourself and your son or daughter with a disability. If you've already engaged in some future planning, some of the decisions and information-gathering have probably already been done. Either way, look at this process as an opportunity to speak openly about what you'd like the future to look like for the whole family.

PART TWO: CARRYING OUT THE FUTURE PLAN

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

WHAT'S IN THIS GUIDE

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

How to create a future plan for your loved one. 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 since they can have waiting lists or may take a longtime to fully establish.

WHAT RETIREMENT MIGHT LOOK LIKE FOR AN OLDER ADULT WITH A DISABILITY.

Your loved one with a disability will eventually retire from their working or other meaningful daytime activities, and then need to replace that time with social and recreational opportunities. Some localities offer adult day services for older adults with disabilities. Members of your loved one's "circle of support" may also provide some of these recreational and social outlets.

WHERE YOUR LOVED ONE WILL LIVE.

If your loved one 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 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.

GENERAL NOTES

PART ONE

A GUIDE FOR PARENTS PREPARING YOUR FUTURE PLAN

PART ONE: A GUIDE FOR PARENTS PREPARING YOUR FUTURE PLAN

STEP 1: ESTABLISH YOUR VISION AND VALUES

The first step in your future planning is to open discussions with family members and other trusted friends and professionals about what would be necessary to maintain your loved one's quality of life once you are no longer willing or able to be the principal caregiver(s). These discussions should definitely involve your son or daughter with DD to the greatest possible extent.

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. This is always harder and scarier before you start, but feels much easier once you get going. Remember you're also alleviating a lot of anxiety for your child with a disability, their siblings, and their support network by getting this started.

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, or whatever will spur you to proceed. Look at the Checklist at the beginning of this guide 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 or disqualified from public benefits 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 adult's vision of his or her future.** All conversations should focus on your son's 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. This should be the driving force in any plan that is developed.
- **Your vision of your adult'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? Though money is a barrier for many things, starting by thinking big often helps us realize that many things can be done with fewer financial resources than we may fear.
- **Your values around money.** Parents of children with DD often worry a lot about having enough money to support their child after they are gone. However, some money "problems" are actually conflicts over values. Reiterate your absolutely non-negotiable priorities for your child's future, such as ensuring his or her health and safety or preserving an annual vacation that is the highlight of their year; no future financial decision should go against these fundamental priorities.

NOTES

How does your loved one describe their dream life/future?

What are three things that are key to your loved one's joy and success?

What are things your loved one detests, finds overwhelming, or always wants someone else to handle?

When you think about people you trust with caregiving, paperwork, money, medical oversight, and personal issues, who comes to mind?

What do you want to make sure is funded no matter what for your loved one's entire life?

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:

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What are your priorities as you put together the Future Plan for your son or daughter?	**What kind of support (financial, emotional, legal) do you think others would be able to provide their relative with a disability? What kinds of support can you leave behind?**
What are the concerns you want to be sure are hammered out before you can no longer oversee them?	**What are some ways to explain this to your loved one with a disability that would help them understand and contribute their ideas?**
What is the one thing you most want someone to help you get done now?	**What scares you the most about this journey? What is one thing that could help with that fear?**

Next, discuss who might be the person or persons making the financial decisions for the individual with a disability (see more under "Circles of Support"). This person's values and attitudes about money are incredibly important. Are they comfortable making financial decisions, would they seek help from professionals if needed, how would they engage the individual with DD in decisions?

Responsibility for financial decisions is often split among a trustee(s), a Representative Payee, and a guardian or conservator, so approach several people about their comfort level in handling money and/or investments and working with others on financial affairs. Thing about how they may work together, and who has strengths in each area.

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.

GENERAL NOTES

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," but you can call it whatever you like.

A Circle of Support begins with members of the immediate family and then radiates out to include people who give 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 part of things for a limited time. While no one has a group of 15 people ready to step in and do all of the work of a parent, we all have some people in our lives. Don't let the perfect be the enemy of the good. If we accept that we likely won't be around to take care of our loved one forever, the best thing we can do is build a network of people who can do that work, even if it is imperfect.

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. That is normal and natural, just like other friendships and partnerships evolve over time. The important thing is to maintain a balance of the types of people in the circle beyond family, with a focus on people who seemed to have a special bond or relationship with your loved one. These may include:

- 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 managing everything, but most people are happy to lend advice, time, and effort. Don't be afraid to ask, and frame it as something flattering, because it is. Say things like "(Child's name) always seemed to have a special connection with you. Would you be willing to play a role in helping us look out for them in the future?" or "We have so much respect for the way you (manage money, organize documents, understand medical care, etc.). Do you think you'd share some of that expertise with my loved one's network when needed? We'd love to have you on board as an expert in that area."

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. Some people may prefer these sorts of formal roles that utilize their expertise. Other people will be more casual advisors, provide social support, or other less detail-oriented work.
- **Current and anticipated time commitments around family and career.** Discuss how much time and effort would actually be involved in the role you imagine someone playing, and whether they could realistically perform that commitment on a consistent basis. This can change overtime as people pass through seasons of life.
- **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. It also gives new circle members time to learn alongside parents and caregivers and try things out.

STARTING WITH THE FAMILY CIRCLE

For most people, family forms the core of a community of support. This can be biological family or people you consider family. 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).
- Start to match the list of people with the list of duties to see where you're strong and where there are opportunities for others to jump in and help.

Utilize the Circle of Support information link on the following 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 Zoom, FaceTime, or email, texts, etc.

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!). As people join the circle, make the related changes in documents to help them step into their new roles. For example:

- 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
- Sign HIPAA releases so circle members can start to communicate with doctors or join someone's MyChart account

For more information on setting up and running a Circle of Support, see https://www.slarc.org/wp-content/uploads/2025/02/Circle-of-Support-Workbook-2021.pdf

GENERAL NOTES

CREATING A CIRCLE OF SUPPORT, A WORKSHEET

WHAT ROLES DO PARENTS AND OTHERS 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?

CALLING ALL SIBLINGS

As a sibling of a family member with a disability, you will be in your brother's 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

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 Project1:

- **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. Write down as much as you can, keep it organized, and update it at least once a year. Even small details are comforting and helpful.

- **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. They may have new ideas on how to connect, who to include, and even help find and recruit experts and circle members.
- **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 sibling's disability 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

NOTES

After a family discussion, what were the biggest areas of concern that were shared?	**What did people most want?**
What were areas of easy agreement?	**What needs more research?**
When do we want to meet next?	**How does the group best communicate and stay in touch?**

STEP 3: ASSESS FINANCIAL RESOURCES

While money doesn't make the world go 'round, it is very important to discuss with the circle of support now the financial resources that will be available to support your loved one 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 service options.

This section provides basic information for creating a budget using estimates of future income sources and future expenditures and details on how to apply for benefits that could become an important source of ongoing income for your adult child with DD.

POTENTIAL INCOME SOURCES

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

POTENTIAL INCOME SOURCES	NOTES
Earnings from your child's job	
Social Security payments (SSI, SSDI and DAC)	
Dependent/survivor veterans' benefits	
Life insurance payouts, including amount and when they would be awarded	
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	
SNAP benefits	
Energy assistance	
Other	

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

Whatever the size of the inheritance you may leave your loved one, **remember that adults with disabilities 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. ABLE accounts can be alternatives to Special Needs Trusts, but they have strict annual contribution limits that can make it difficult for them to receive an entire inheritance. Meet with The Arc of Northern Virginia for free at a Trust Talk Tuesday or similar session to talk through what would be most advantageous in your situation.

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.

GENERAL NOTES

POTENTIAL EXPENSES	NOTES
Housing (rent, mortgage, home or renters' insurance, taxes, utilities, cable/streaming, Internet, upkeep). Is there a rental subsidy or potential for one?	
Support services/personal care (if not covered by public benefits), or if extra 1:1 time is privately hired in addition to 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.	
Memberships	
Other	

For many families, housing is the most challenging part of future planning for an individual with DD. See the section "Exploring Housing Options" for a discussion of housing options in Northern Virginia.

NOTES

Are there any benefits we still need to apply for?	**Who usually provides transportation and how is that set up or changed?**
Who do we need to inform about the Trust and directing income/inheritance to it?	**List of doctors/providers seen regularly**
How is rent/mortgage paid, along with all utilities, account numbers, contacts, log ins?	**Where clothing is usually purchased**
Who are trusted paid caregivers?	**Usual contacts for trip planning**
Where are membership cards and similar information kept?	**Favorite events/activities throughout the year**

STEP 4A: APPLY FOR BENEFITS: SOCIAL SECURITY DISABILITY PROGRAMS

You may begin the application process for Social Security benefits the month after your child turns 18 (or at any age if the entire household meets the low-income qualifications). The first step is to determine eligibility for any benefit program; the Social Security Administration (SSA) will decide which program is appropriate. For webinar presentations on SSI/SSDI visit The Arc of Northern Virginia's YouTube channel at https://www.youtube.com/@VideosatTheArcofNoVA.

SSI VS. SSDI

For both Supplemental Security Income (SSI) and Social Security Disability Insurance (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 2026, the wage limit for the SGA is $1,690 gross income/month.

SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a cash assistance program for those with limited income AND who 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 ($994 a month in 2026), minus any "countable income." If eligible for SSI, you will also be eligible for Medicaid. ** Note: It can take close to one year to begin receiving payment, but back payments will go back to the date of the approved application.

SOCIAL SECURITY DISABILITY INSURANCE (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:

1. **Start with a disability report.** Go to the website at https://www.ssa.gov/ssi and click on How to Apply (You may also call 1-800-772-1213) to get started. 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 of anything you give Social Security, along with notes on when and how it was provided). 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 fully complete the application for benefits online; you must request an appointment online or by calling Social Security.
2. **Call Social Security.** To make an appointment, call 1-800-772-1213 (TTY 1-800-325-0778) Monday through Friday between 8am to 7pm, or contact your local Social Security office or schedule online at https://www.ssa.gov/manage-benefits/make-an-appointment. 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 timeframe.
    - 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.
3. **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 office. If outside of the Northern Virginia area, visit https://www.ssa.gov/locator to find your local office.

ALEXANDRIA OFFICE

5510 Cherokee Ave., Suite 200
Alexandria, VA 22312
800-472-2402

FAIRFAX OFFICE

10800 Park Ridge Drive, Suite 100
Reston, VA 20190
800-829-3158

MANASSAS OFFICE

9500 Center St.
Manassas, VA 20110
800-325-0778

4. **Go to the screening interview.** Bring to the intake interview 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, ABLE Account, guardianship and/or conservator order and letter of qualification
    - Individual Education Program (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 or an ABLE Account.
    - A signed rent agreement between parent and child (to receive the full benefit). SSI is intended to cover expenses like rent and utilities. It is recommended that you charge your adult child rent if he or she lives in the family home. Note that as of 2024, SSI recipients may receive family assistance with covering most food costs without penalty. A recipient must be spending at least current Presumed Maximum Value (PMV) on rent and utilities to avoid a penalty or reduction in benefits. For much more detailed information on calculating rent in the family home, keeping receipts, and a sample lease agreement, visit our resource library at https://thearcofnova.org/resource-library/#social-security.
5. **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 and in 2026, decisions are taking 9-10 months on average. If you are denied, you have 60 days to appeal.
6. **Set up a Representative Payee account.** While applying, you will need to set up a Representative Payee account at a bank; be sure to title the account correctly (SSA has suggested wording). Automatic deposit of benefits is required. Alternatively, you can also set up an ABLE Account for deposits from SSA. For more information on ABLE Accounts, visit https://www.ablenow.com and visit our YouTube Channel for a webinar on this topic at https://www.youtube.com/@VideosatTheArcofNoVA.

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. For more information on being a Representative Payee, visit our Resource Library at https://thearcofnova.org/resource-library/#social-security and https://www.ssa.gov/payee.

THE REPRESENTATIVE PAYEE

A Representative Payee (Rep 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. 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. A payee must keep records of how the payments are spent or saved, and be able to make all records available for review if requested by SSA.

TIPS FOR REPRESENTATIVE PAYEES

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

When you call SSA (**1-800-772-1213**), keep a record: date, name of the person you spoke to, what you asked, what they told you.

- Make copies of all documents you give to SSA.
- Promptly open and read ALL mail sent by SSA. When SSA gives a deadline response date, compliance within that date is required. Seek help immediately if needed. Keep ALL paperwork, letters, and mailing envelopes in your file.
- Report by mail, online, or using the SSA app. Keep wage records in your file.
- If a person receives SSI and/or Medicaid, remember to keep all resources/assets below $2000 in any month to maintain eligibility.
- Everyone should have their own my Social Security account – needed to report earnings, apply for benefits and track application status.
- When a major life change occurs (address, marriage, employment, loss of job) report to SSA immediately, both to the **1-800-772-1213** and to the local SSA field office.
- If you need help managing Social Security and benefits, work with a benefits counselor to help you manage this. Benefits counselors are available at the Endependence Center https://endependence.org/services/benefits-counseling and the Endependence Center of Northern Virginia (ECNV) https://www.ecnv.org.

For additional information on Reporting Tips for Beneficiaries of Social Security Disability Programs, visit the Resource Library on our website at https://thearcofnova.org/resource-library/#social-security

If you need additional guidance navigating the application process or other Social Security related questions, reach out to us through The Arc of Northern Virginia's I&R Portal at https://thearcofnova.org/answers for resources on fee based services that can provide one on one support such as Inclusion Consultants https://inclusionconsultants.com.

NOTES	CHECK IF DONE	NOTES
Checked to ensure you have all of the needed documents?		
Lease prepared? Comparable rents ready?		
Rep Payee account set up? Bank name and account info?		
Date applied for SSI?		
Notified all listed doctors they may get called?		
Date of scheduled calls?		
Documents submitted to Social Security and when? Where are copies of submitted info kept?		
Rep Payee confirmed?		

HOUSING AND SSI

In general, at least 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). ** Note: this is not the case if you use an ABLE Account. ABLE accounts can pay rent without penalty.

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

NOTES	CHECK IF DONE	NOTES
Date work began		
Date work reported to SSI		
Calendar reminder for regularly submitting paystubs?		
Working with a benefits counselor?		

STEP 4B: APPLY FOR BENEFITS: MEDICAID WAIVERS

This section provides a basic overview of Medicaid Waivers. For more comprehensive information, watch recorded webinars on our YouTube Channel at https://www.youtube.com/@VideosatTheArcofNoVA and visit our Resource Library at https://thearcofnova.org/resource-library/#waivers. You can also call Virginia's Waiver assistance hotline at 1-844-603-9248 or visit the Department of Behavioral Health and Developmental Services' website at http://www.mylifemycommunityvirginia.org.

WHAT IS A WAIVER?

A Waiver is a long-term support system for someone who will have long-term care needs. Once you're awarded a Waiver, you will have access to a menu of services offered by your Waiver. Frequently used services include attendants who work one-on-one with the person with a disability, respite care so parents can have a break from care provision, group home supports where a person with a disability lives in a home shared by other people with disabilities, long term employment or meaningful day services, assistive technology, environmental modifications, nursing, and more. These services are offered at no or very low cost.

Waivers are funded by Medicaid and are often called Medicaid Waivers. The person with a disability must qualify for long-term care Medicaid to use a Waiver. As of 2026, this means that the person with a disability cannot have more than $2,000 in assets in their name (no cap if under 18 years old), unless those assets are in a Special Needs Trust or ABLE Account, and they cannot earn more than (in 2026) $2,982 per month. The income limit generally increases each year due to Cost-of-Living Adjustments. The person with a disability will get Medicaid once they get an active Waiver (not when they are placed on a waiting list).

WHO NEEDS A WAIVER?

People who need assistance with taking care of themselves, managing their environment, working toward greater independence, or maintaining a job because of a disability should consider Waivers. It is the only public funding for long term developmental disability supports.

WHY SHOULD I APPLY?

Anyone with a developmental disability should apply. You will need a psychological evaluation with an IQ score to apply. Submit the evaluations that you have already on hand and if a new evaluation is requested and you need a practitioner, reach out to The Arc of Northern Virginia's Information and Referral Portal at https://thearcofnova.org/answers.

Even though some Waivers have waiting lists, if you qualify for a Waiver, you will eventually receive services. As you grow and change, you can use more or fewer Waiver services to meet your needs. The Waiver should grow with you over time and provides the supports you need to be as independent as possible in your community. You can apply for both Waivers if you think you may be eligible for both. Then, you'll move from one to another with more services as they're made available.

Also, as a result of a Department of Justice settlement agreement with Virginia, if you're on the waiting list for a DD Waiver, you can apply for up to $500-$1,000 each year to purchase supports you need to be independent and safe. This is called the **Individual and Family Supports Program (IFSP)**. Information, applications, and instructions can be found at https://mylifemycommunityvirginia.org/resources. You can go to https://dbhds.virginia.gov/developmental-services/ifsp to receive routine emails from DBHDS to stay updated on when the program opens each year.

HOW DO I GET A WAIVER?

Virginia currently has two main types of Waivers. One type, the Developmental Disabilities (DD) Waivers, are most commonly used by people with developmental disabilities. They're called the Community Living Waiver, the Family and Individual Supports Waiver, and the Building Independence Waiver. People with disabilities and medical support needs often use the Commonwealth Coordinated Care (CCC) Plus Waiver. The DD Waivers are far more robust and offer many more services than the CCC Plus Waiver. Follow the general guidelines below to figure out which Waiver(s) may be right for you, how to apply, and what to expect.

SERVICES COVERED UNDER THE WAIVERS

The Developmental Disability (DD) Waivers: There are 3 DD Waivers: (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. The Community Living Waiver is the only waiver that provides 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.

ELIGIBILITY CRITERIA

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

1. **Functioning ability:** This is determined by the Virginia Intellectual Developmental Eligibility Survey (VIDES). 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. Families are encouraged to review the VIDES assessment available on our website prior to the intake. You can review copies of the VIDES assessment in our Resource Library at https://thearcofnova.org/resource-library/#waivers
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 (i) 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, or 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 (i) 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 $994 in 2026), so max monthly income is $2,982. The income limit for SSI generally increases each year due to Cost-of-Living Adjustments.

If you qualify, you will be put on a Waiting List. You will be given one of the of the three disability Waivers based upon the type of services you need.

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 need services in 1-5 years, and people in Priority Three need services several years out. Wait time is unpredictable and many people on the priority one list wait many years for a waiver. As your life circumstances change, for example, behavioral or medical needs change, 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.

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.

Visit our Resource Library https://thearcofnova.org/resource-library/#waivers for a handout on "Navigating the DD Waiver Waiting List"

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 see if you may be eligible for the CCC Plus Waiver, you can utilize a self-assessment online eligibility tool offered by Mom's in Motion at https://momsinmotion.net/commonwealth-coordinated-care-plus-eligibility-self-help-tool. To be eligible for this waiver, the person must have a disability and medical nursing needs, as assessed by the Virginia Uniform Instrument (UAI). You can view the UAI in our Resource Library at https://thearcofnova.org/resource-library/#waivers.

To Apply for the Developmental Disabilities Waivers, Contact your local Community Services Board

ALEXANDRIA CITY CSB
703-746-5999

ARLINGTON DHS/IDD SERVICES
703-228-1700

FAIRFAX/FALLS CHURCH CSB/IDS
703-324-4400

LOUDOUN CSB
703-777-0597

PRINCE WILLIAM CSB
703-792-7800

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

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

ALEXANDRIA CITY
571-213-7963 / **703-746-5999** (if over 18)

ARLINGTON
703-228-1297 / 7**03-228-1700** (if over 18)

FAIRFAX/FALLS CHURCH
703-324-7948

LOUDOUN
703-737-8949

PRINCE WILLIAM
703-792-7500

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

NOTES	CHECK IF DONE	NOTES
Date applied for DD Waiver		
Date sent in Waiver paperwork		
Date VIDES completed		
Date applied for CCC Plus Waiver		
Waiver status (waiting list priority or have Waiver)		
Name of Waiver Support Coordinator		
Last time talked to CSB		
On IFSP email list if on the waiting list?		
Years applied for IFSP and what requested?		

STEP 4C: 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 see if you may be eligible, fill out the eligibility tool at https://www.vplc.org/snap-calculator.

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

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 several weekly meals, both hot and cold, 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
https://mealsonwheelsarlington.com

FAIRFAX

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

LOUDOUN

Loudoun County Nutrition Services
https://www.loudoun.gov/1119/Nutrition-Services
aaa@loudoun.gov
703-771-5012

PRINCE WILLIAM

Prince William Area Agency on Aging
https://www.pwcva.gov/department/area-agency-aging/nutrition-services
703-792-6374

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 following Northern Virginia localities 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.

CITY OF ALEXANDRIA:
https://www.alexandriava.gov/finance/info/default.aspx?id=2886

ARLINGTON:
https://www.arlingtonva.us/Government/Topics/Real-Estate/Tax-Payments/Exemptions

FAIRFAX:
https://www.fairfaxcounty.gov/taxes/real-estate/exemptions

LOUDOUN:
https://www.loudoun.gov/1609/Tax-Relief-for-Older-Adults-Residents-wi

PRINCE WILLIAM COUNTY:
https://www.pwcva.gov/department/tax-administration/elderly-and-disabled

NOTES

We may be eligible for

Programs applied for/when

Programs to circle back to in the future

STEP 5: FOLLOW THROUGH WITH ESTATE PLANNING

WILLS, TRUSTS, AND ABLE ACCOUNTS

All parents should have a will, and those who have children with a disability also need to create a family-funded 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/resources/business-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.

REVIEWING BENEFICIARIES

In addition to naming a (third-party/family-funded) 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. You will need to use specific language to designate these monies to the SNT. Please check with the trustee to determine proper wording.

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 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 allow families to provide for the future financial stability of their loved one with a disability. Since some federal benefits programs impose 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 as these programs limit your loved one to just $2,000 in assets to remain eligible.

In the event that one receives an unexpected inheritance, or other forms of unexpected income, these would be directed to what we refer to as a self-funded trust (aka a first party special needs trust). While this is a feasible option for someone who is over-resourced or needed assistance managing their finances, this is often a last resort type of trust given the requirement of a Medicaid payback; in contrast, a family-funded trust is not subject to a Medicaid payback and therefore it's beneficial to elect this route if an option to plan for the future is available.

TWO KINDS OF TRUSTS

Family-Funded Trusts (third-party trusts) are 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 grantor, 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 or after the parents' lifetime for anyone electing to provide monies to the person with a disability without directly paying funds to their pocket and therefore jeopardizing means-tested benefits. 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.

In a family-funded trust, the Grantors decide who will inherit any funds remaining after the Beneficiary passes away. Frequently grantors leave the funds to other family members, including siblings, as well as, to charitable organizations.

Self-funded trusts (first-party trusts) are established by the beneficiary, parent, grandparent, guardian, or court order 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. The first-party SNT involves a mandatory Medicaid-payback clause which means any funds remaining in the trust after the Beneficiary's death must first reimburse Medicaid for any Medicaid-funded care the individual received during his or her lifetime. In The Arc of Northern Virginia's Special Needs Trust program, there is one exception to the Medicaid payback requirement: Instead of electing to satisfy the Medicaid payback, grantors can elect to leave the remaining funds to The Foundation of The Arc of Northern Virginia's Personal Support Self-Funded Trust.

While many legal matters can be undertaken with a lawyer with a general background, SNTs 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 allows for a trust to be established while remaining unfunded, or funding can be elected with a minimum of $500 seed money.

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. Funds from the trust 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 not covered by insurance
- 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 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 more information about being a trustee, download a free handbook at:
http://www.specialneedsalliance.org/free-trustee-handbook

THE ARC OF NORTHERN VIRGINIA'S SPECIAL NEEDS TRUST

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

Our program offers a handful of ways on how to pull funds from a trust, pending review and approval of submissions. These methods include:

One Time Disbursement: good for one-time expenses where we're reviewing and issuing payment to a vendor (ex: one-time payment for reimbursement to a person who paid for an item on the beneficiary's behalf). Supporting documentation includes disbursement form, receipt/invoice, and statement showing charge (if someone is requesting reimbursement).

Recurring Disbursement: good for recurring bills (ex: a monthly car insurance payment). Supporting documentation includes completion of a recurring disbursement form for us to retain on file, and submission of the bill each month it's received to enable us to initiate payment.

ABLE ACCOUNTS

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

The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to establish tax-advantaged savings accounts for certain individuals with disabilities for their disability related expenses. Contributions of up to $20,000 (in 2026) a year can be made to an ABLE Account and up to a total of $100,000 without endangering eligibility for certain means tested benefits such as Supplemental Security Income (SSI) and Medicaid. An eligible individual is someone who developed the onset of their disability before age 46 and; is entitled to Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits based on blindness or disability; and self-certifies that they have a qualifying disability diagnosis from a physician.

An eligible individual over the age of 18 may open and manage an ABLE account independently or an Authorized Representative may open and manage an ABLE account on behalf of the eligible individual. Authorized Representatives include an eligible family member (spouse, parent, grandparent, or sibling), legal guardian, someone with Power of Attorney, or a care representative. An eligible individual may only have one ABLE account. Any person may contribute to an ABLE account for an eligible beneficiary.

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 be used for Qualified Disability Related Expenses. Qualified Disability Expenses are expenses that maintain the health, independence, and quality of life of the individual with a disability. 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.

The ABLE program in Virginia, ABLEnow is administered by Commonwealth Savers (formerly known as Virginia 529). To learn more about ABLEnow go to www.ablenow.com. The National ABLE Resource Center https://www.ablenrc.org offers lots of good information and allows you to compare programs in different states. No matter where you reside, you can open an ABLE account in any state that accepts outside residents into their program.

For a better understanding of the differences between Special Needs Trusts and ABLE Accounts visit the Resource Library on our website at https://thearcofnova.org/resource-library/#s-n-t.

NOTES	CHECK IF DONE	NOTES
Will created? Location? Update plans?		
Beneficiaries updated on all stocks, bank accounts, etc.?		
Special Needs Trust webinar attendance plan		
Special Needs Trust establishment date		
ABLE account information		

LEGAL AUTHORITY AND SUPPORTED DECISION MAKING

We at The Arc of Northern Virginia are often asked about the need and value of guardianship and other forms of legal authority, especially as they relate to "protecting the person" as they reach age 18 years old. 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 manage behavior, prevent someone from doing something, or undo many decisions they have been made.

DIGNITY OF RISK AND SUPPORTED DECISION MAKING

In recent decades, a movement has grown 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. And, many of us have learned the most from our biggest mistakes. People with disabilities should have the same opportunities to make decisions and learn through natural consequences and a support team about how to proceed next time. We all express preferences in some ways. Using those preferences, along with support from a person-centered team, to make educated decisions is called "supported decision-making". A team of people (one person or more) who care about the person with a disability are asked by the person to work together to help them understand and make decisions. It does not involve taking away legal rights; instead, it builds a foundation for growing decision-making ability and independence over time, centered around working with the person on expressing their preferences. It has no cost and is probably what you are already doing. You can learn more about Supported Decision Making and view webinars on this topic on our website at https://thearcofnova.org/SDM. SDM can be used on its own and in conjunction with all forms of legal authority.

THE SPECTRUM OF LEGAL SUPPORTS

Special Educational Power of Attorney

This document allows an appointed decision maker to participate in/consent to IEPs and other school documents. It is only valid in public primary and secondary schools, not universities/colleges. You can find a template at https://www.dlcv.org/wp-content/uploads/2020/03/Educational-Power-of-Attorney.pdf. Fairfax County Public Schools also has a fillable PDF that can be found at https://www.fcps.edu/sites/default/files/media/forms/se340.pdf. This document can be shared with the IEP Team.

Medical Power of Attorney

An agreement that grants an individual the authority to act on someone else's behalf for health-related matters. This allows the individuals to make decisions about things like medical treatment, prescriptions, and nursing home arrangements.

Durable Power of Attorney

A durable power of attorney will remain in effect for the person designated as an individual with the authority to act on someone's behalf even if the individual later becomes mentally incapacitated. Powers of Attorney can be drafted by attorneys or you can use an online template. They can be notarized, which can be done by your local bank or any other notary. The cost is minimal or free. You can buy and customize low cost POAs at sites like www.legalzoom.com. Powers of Attorney can be created and signed on the day your child turns 18.

Medical Directive

An Advance Directive helps you and your child prepare for a time when he or she may not be able to make informed decisions or communicate his or her wishes. An "agent" (parent, relative, or other trusted adult) can make healthcare decisions when necessary, while still protecting the individual's 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 https://virginiaadvancedirectives.org; You and your child can talk to your doctor about making an Advance Directive; you can hire an attorney to complete an Advance Directive. Once your child's Advance Directive is written, it needs to be signed in the presence of two witnesses. Virginia does not require 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 Connect Virginia https://www.vdh.virginia.gov/commissioner/administration/advance-health-care-directive-registry.

Guardianship and Conservatorship are legal, court-ordered relationships in which one individual is appointed by the court to become the substitute decision maker for another. This is the most restrictive form of limiting civil rights. Guardians handle contract and medical decisions. Conservators manage financial affairs. You can have both or either restriction in place, and the same person can serve in both roles. If you do explore guardianship or other legal authority, remember that no matter what you legally sign and agree to do, the person with a disability ultimately consents by participating or not.

Generally, the person seeking guardianship hires an attorney who meets with the individual who may be in need of decision-making support. The attorney will ask for evaluations showing a diminished ability to make decisions and relevant diagnoses. Then, the attorney will work with the courts to have a Guardian ad Litem (GAL) appointed. The GAL is an independent attorney who should meet with the individual and proposed guardian to ensure the proposed guardian is appropriate and that the individual understands what is going on to the best of their ability. If all goes well, the parties appear briefly before a judge in civil court for a legal appointment to take place. It is very important to work with an attorney experienced in this field. The process usually takes 2-3 months and costs about $3000-$4000 in the Northern Virginia area. You can request payment plans or reduced fees, but there is no guarantee of either. You can begin the guardianship process as early as 17.5 years of age, and can be done at any time over the age of 18.

Parents can be appointed as co-guardians, which allows either to act independently. You may ask the court to appoint "standby" guardians, who would serve when the appointed guardians are no longer able to serve. Standby guardians can act as guardians for up to 30 days, but must got to Court to become the permanent legal guardian. Once the individual with a disability has a guardian appointed, someone must always be a guardian, unless the rights of the individual are restored by the Court, following a request or petition to do so. Guardians are required to submit a report every year to the local Department of Social Services; the court will provide a form. Guardians must all take a one-time training from the state to explain the roles and responsibilities of a guardian, and certify that they have done this training on their annual reports. To take the training visit https://dars.virginia.gov/virginia-guardian-training-live.

Limited Guardian of the Person

The courts can limit or specify the authority and responsibilities of the guardian to specific areas of the individual's life; such as medical and health care decisions. The Courts can retain specific rights for an individual through a written order, like the rights involving voting, marriage, and driving.

Temporary Guardianship

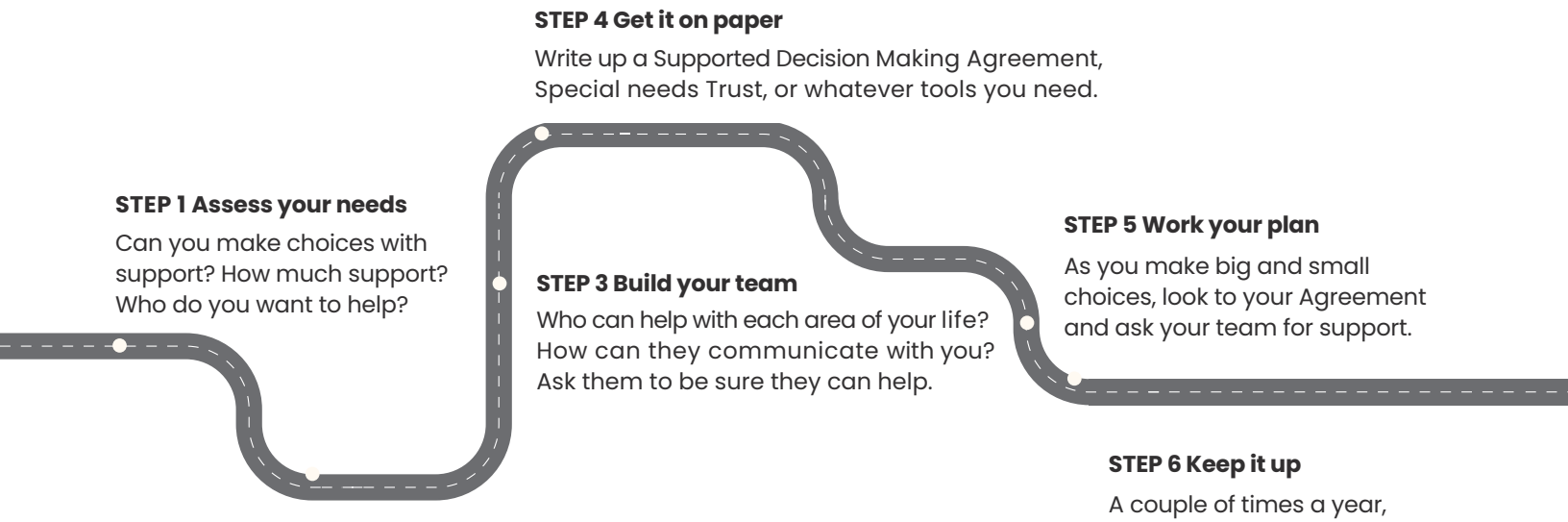
For specific reasons, a person can be appointed as temporary guardian on a time limited basis. For example: to assist in moving an individual to a residential placement; to make medical decisions, etc.

SUPPORTED DECISION MAKING CAN BE USED WITH ALL FORMS OF LEGAL AUTHORITY AND VARIOUS SUPPORT OPTIONS

SDM doesn't involve any cost or court relationship. It is a matter of working as a team to present information to the person with a disability in a way they understand it and using guiding principles important to the person to help them. You can use tools like Powers of Attorney, Special Needs Trust, or any other options that will be helpful in ensuring the person with a disability gets the right support. You can see a sample SDM agreement, along with tips on filling it out and educating selected supporters, at https://dbhds.virginia.gov/supported-decision-making-supported-decision-making-agreements

GENERAL NOTES

ROADMAP TO SUPPORTED DECISION MAKING



STEP 1 Assess your needs

Can you make choices with support? How much support? Who do you want to help?

STEP 2 Explore options

Read about decision making options, watch videos, talk to others. What kind of ideas work for you?

STEP 3 Build your team

Who can help with each area of your life? How can they communicate with you? Ask them to be sure they can help.

STEP 4 Get it on paper

Write up a Supported Decision Making Agreement, Special needs Trust, or whatever tools you need.

STEP 5 Work your plan

As you make big and small choices, look to your Agreement and ask your team for support.

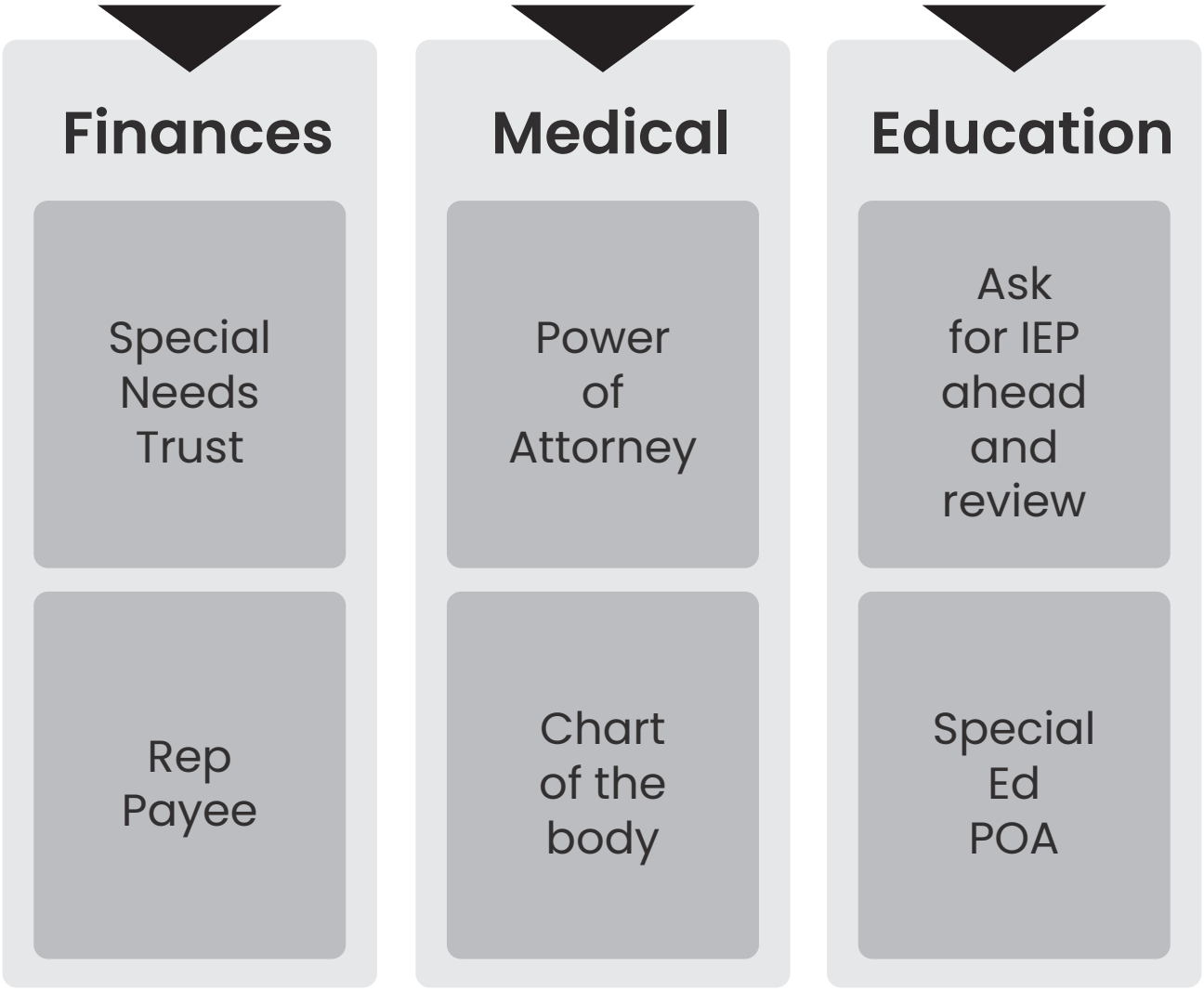
STEP 6 Keep it up

A couple of times a year, review your agreement. See what is working. Change your plan as your needs change.

SUPPORTED DECISION MAKING RESOURCES	WHERE TO FIND IT
The Arc of Northern Virginia's SDM Toolkit with SDM in action videos, ideas on how to use and get started with SDM, 3 minute and extended recorded presentation on SDM, and SDM handouts and quick guides.	https://thearcofnova.org/sdm
Webinars on SDM implementation and team building	https://youtube.com/user/VideosatTheArcofNoVA
Asking any SDM questions	https://thearcofnova.org/answers
"Setting the Wheels in Motion" article by Suzanne Francisco for a description of how a mom of three kids with DD implemented SDM for all of them, including her worksheets on getting started	https://tinyurl.com/SDM-Wheels
Jenny Hatch Justic Project info on start of SDM in VA and SDM data	http://www.jennyhatchjusticeproject.org
National Resource Center for SDM's stories, videos, agreemtns, and research	http://www.supporteddecisionmaking.org
"When Do I Want Support" SDM tool for a tool you can use to start creating your own SDM plan	https://tinyurl.com/SDM-ACLU
Center for Public Representation's SDM forms, stories, news, and laws	https://supporteddecisions.org
The Arc's national SDM toolkit with a SDM agreement building tool and more SDM in action stories	https://tinyurl.com/ArcSDMtools
DisAbility Law Center for free Power of Attorney builder, help with advanced directives, and information on rights and choices	https://ww.dlcv.org/supported-decisionmaking

HOW MIGHT THIS WORK...

SDM PLAN



For more examples of how SDM can be used in all aspects of life, see 100 Ways to Use Supported Decision Making on our website at https://thearcofnova.org/sdm/.

NOTES	CHECK IF DONE	NOTES
Explored decision making options?		
Options to try first?		
SDM plan creation date and location where kept?		
Power of Attorney creation date and location where kept?		
Guardianship/ Conservatorship explored?		
Attorney contacted?		
Court date?		
Date finalized and qualified?		
Copies kept?		

STEP 6: EXPLORE HOUSING OPTIONS

HOUSING OPTIONS FOR THE FUTURE

As your loved one ages, it's important to start thinking about where and how they will live in the future. Housing is a key part of building an independent and fulfilling life, and exploring options early can help create a stable and supportive living arrangement that meets your loved one's unique needs. Whether your child may live independently, with support, in a group setting, or at home, planning ahead allows you to consider financial resources, support services, and their goals and preferences.

HOUSING AND SERVICES

When you begin to think about long term housing plans, one of the first things to consider is whether or not support services (e.g., personal care assistance, skill development, nursing, etc.) will be needed as well. If so, you'll need to plan for how the services needed will work with the housing option you select. To learn more about publicly funded services through the Medicaid Waiver, visit https://thearcofnova.org/resource-library/#waivers. To see options for hiring drop in care staff, visit https://thearcofnova.org/resource-library/#c-d-s, or https://thearcofnova.org/resource-library/#l-i-c for information on live-in caregivers.

WEIGHING THE OPTIONS

As you explore these choices, think about what you value. Ensure you are looking at options that respect your wishes for independence and flexibility, as well as offer options to bring in any and all services you need. You may try more than one option over time, which is perfectly normal. Options may be more or less appealing at certain points in the lifespan or as services available to you change.

WAITING TIMES

Waiting times for affordable housing options can vary widely. If you've prepared a budget, know where you'd like to live, have materials needed for your home, and have services and/or subsidies available to support you, you could be ready to move in just a few months. If you have restrictions on where exactly you can live, the type of housing you want, you are still waiting for a Medicaid Waiver, or want an option that has a waiting list, the wait can be many years in some cases.

TYPES OF HOUSING

It is never too early to start weighing housing options since some require more time, planning, and resources than others. Here are some brief descriptions of common housing options for adults with developmental disabilities. In all of these models, you could use Medicaid Waiver support options and/or private pay to bring in services.

Housing Resources

1. For more in-depth information on this topic visit https://thearcofnova.org/programs/transition/finding-home-adults-disabilities to download our guide on Finding a Home for Adults with Disabilities.
2. To watch recorded webinars that walk you through housing tours, options, and resources, visit https://www.youtube.com/user/VideosatTheArcofNoVA
3. To sign up for The Arc of Northern Virginia's e-newsletter that shares housing news and learning opportunities https://thearcofnova.org/about-us/newsroom/newsletters

HOUSING TYPE	FUNDING FOR HOUSING	GETTING STARTED
Owned or rented apartment or other home where services and supports can be brought in up to 24/7, or can allow for live-in staff.	Use income or a rental subsidy to fund the rental costs and/or look for a "tax credit unit" that may have lower rents.	Talk to your Waiver Support Coordinator (even if on the waiting list) about preparing for this option. You could move within months if you're prepared.
Shared Living Waiver service where person with a Waiver has live-in staff, plus other staff as needed.	Use income or a rental subsidy to fund the rental costs.	Talk to your Waiver Support Coordinator about preparing for this option. You could move within months if you're prepared and have a Waiver.
Supported Living Waiver service that involves moving into a unit owned by a service provider or leased by person with disability, and provider then brings in staff.	Use income or rental subsidy to fund the rental costs.	Talk to your Waiver Support Coordinator about preparing for this option. You could move within months if you're prepared and have a Waiver.
Group Homes are usually 4-7 unrelated people living in a home staffed and owned by a service provider.	Use income to pay for rent, food, and program fees.	Talk to your Waiver Support Coordinator about preparing for this option. You could move within months if you're prepared and have a Waiver.
Sponsored Residential is a Waiver service where a person with a disability lives with a caregiver who provides needed services, usually in the home of the caregiver.	Use income or rental subsidy to fund the rental costs.	Talk to your Waiver Support Coordinator about preparing for this option. You could move within months if you're prepared and have a Waiver.
Shared a home or rent a room in someone else's home to keep rent costs low.	Use income or rental subsidy to fund the rental costs.	Work with your support team to figure out a budget, identify, and select a good fit.
Buy a home with a low interest microboard or other loan. See more about microboards below*	Use income or rental subsidy to fund the rental costs.	Research low interest loans and figure out what you can where, for how much, and what type of home you'd need.
Public housing is a housing unit owned and maintained by a local government.	Use income to pay for reduced rental costs.	See if your locality has public housing and get on waiting lists when they open.

*ABOUT MICROBOARDS

A microboard is essentially a circle of support, 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. The microboard is an effective tool to make sure that this question of what happens to my loved one when we are no longer here can be answered.

WHAT IS A MICROBOARD?

- Circle of support providing ongoing advocacy to an individual with a disability.
- Registered, legal entity established through articles of incorporation and administered by a board of directors who follow an agreed upon set of bylaws.
- The board of directors are like-minded people who care about the individual and commit to understanding and advocating for them.

WHO IS ON THE BOARD?

Just like a board of directors serving on behalf of a non-profit organization, the microboard similarly works together to support an individual with a disability. It includes: volunteers who care about the person and are willing to work together for their benefit; friends, neighbors, family members, former teachers and therapists, or anyone who may have a connection to the individual with a disability; people who can't or wouldn't be able to help on their own because of time, distance, or knowledge constraints, but could help as part of a larger team.

DETAILS OF THE BOARD

Often a microboard has a certain size, such as up to 9 members, with some serving in leadership positions. Meeting minutes are taken and recorded and all officers and members will need training to develop in-depth knowledge of the individual with a disability, their strengths, needs, preferences, routines, and services.

HOW IS THE BOARD CREATED?

In Virginia, microboards are registered as non-stock corporations through the State Corporation Commission (SCC). There is an initial registration fee and an annual fee to keep the board registered. You'll need to name a Director of your microboard, which is often the founding member, and establish an official address where you can receive mailings and notifications as needed. You will need to establish article of incorporation, as well as, bylaws. Bylaws describe how the microboard is run. Bylaws can also highlight key support areas for the individual such as having a running agenda that helps the board to discuss and address important topics such as housing, funding, and medical supports. Similar to a letter of intent, it can also contain the parents' wishes for their child and help guide the board as to how they make decisions about their advocacy efforts.

To learn more about establishing a Microboard, contact All Needs Planning https://allneedsplanning.com / **804-223-1511**.

NOTES	CHECK IF DONE	NOTES
First thoughts on viable housing models		
Housing tours and locations		
Funding available (e.g., Waiver, voucher, loan, SNT)		
Housing models to explore further		
Budget completed		
CSB told of housing preference		
Housing service provider and contact		
Housing plan		
Move in date		
Housing checklist completed (from TP Housing Guide)		

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.

GENERAL NOTES

GETTING STARTED ON YOUR FUTURE PLAN

GETTING STARTED ON YOUR FUTURE PLAN

Ideally, your plan would include everything anyone would need to know to begin taking care of your adult child with a disability, and appear magically in your filing cabinet. Realistically, this is a task that might take some soul-searching, discussions with family members, meetings with attorneys, review of financial resources, and a few weeks (or even months) to pull together.

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

GENERAL NOTES

IMMEDIATE FIRST STEPS

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 in the cloud), online, or a combination. Label everything with dates. Ideas on tools to help you are below.
2. Reconfirm commitments from people who have agreed to take on responsibilities as executor of your estate, trustees, standby guardians, conservators, 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! You don't need copies of everything if someone else has the original. Keep only the latest version of a document. 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)

TOOLS FOR WRITING YOUR FUTURE PLAN

Charting the LifeCourse https://www.lifecoursetools.com is a framework designed to help individuals with disabilities and their families plan for a meaningful and fulfilling life and future. It provides tools and strategies to explore possibilities, set goals, and develop a vision for the future. This approach encourages families to think about various life domains—including employment, independent living, relationships, and community engagement to ensure a well-rounded life. By using the LifeCourse framework, parents can identify strengths, resources, and needed supports, empowering their loved one to navigate the path toward greater independence and inclusion in society.

The Arc's Center for Future Planning https://thearc.org/our-initiatives/future-planning offers a tool that enables families to create accounts and begin to build their plans within the Center.

DOCUMENT ORGANIZATION

Use an organization system that works for you, then copy or scan important documents for easy access and keep originals in a safe place. Be sure family members and your attorney know where these documents are. Check out The DaniPlan https://daniplan.com a subscription service created by parents of a child with a disability that provides a centralized hub to organize and consolidate all information needed to care for an individual with special needs. Visit The Arc of Northern Virginia's YouTube Channel to see our webinar on this service at https://www.youtube.com/@VideosatTheArcofNoVA.

NOTES	CHECK IF DONE	NOTES
Plan system you chose (Digital or Binder)		
Location where kept?		

DOCUMENTS

LETTER OF INTENT

An important document to have is a Letter of Intent in which you describe your loved one's current life and express your values, wishes and vision for their future. Although not legally binding, a Letter of Intent is invaluable to those who will support the care needed in the future. For a free Letter of Intent template go to https://www.specialneedstrustsonline.com/letter-of-intent/form.

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

YOUR LOVED ONE'S VISION OF THEIR OWN FUTURE

Their ideas, wishes, dreams, and preferences should guide this document. This could include things like ensuring that a favorite family remains a strong presence in their life, keeping a pet, or working in a specific industry or worksite. Emphasize that this document can change overtime, but that you want them to be the driver of their own life. Do it in small chunks, with examples, or in any way that suits the learning and sharing style of your loved one.

YOUR VISION OF YOUR LOVED ONE'S FUTURE:

Though their own goals and dreams should take priority, this is a place to augment those wishes with the goals you have for your son or daughter's life. Examples may be where they would live and with whom, and what activities to maintain.

DESCRIPTION OF PERSONAL QUALITIES

Future caregivers would benefit from knowing the unique aspects of your adult: 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

Be as specific as possible. Use multiple examples to show work schedules; weekend activities, including religious education or attendance; bedtime routines; food and clothing preferences and sensitivities; preferred activities and exercise routines; and typical outings, for example.

MEDICAL HISTORY

This section can be brief (diagnosis, current treatment and medication regimes) but then should state where to find more detailed information.

LIVING EXPENSES

Consider including 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 special needs trust and benefit monies might have to be spent.

CONTACT INFORMATION

Put as many ways to reach people as you can. Include family members, friends, doctors/therapists, preferred pharmacy, school or employer information, lawyers, trustees and backup guardians, insurance agents, banker and financial planners, etc.

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.

Tip: Create a system to track important deadlines for updating documents. Use a digital calendar, reminder app, or physical planner to set alerts at least a month before each due date. Keep a master list of documents with their renewal timelines in one place, and review it at least twice a year to stay ahead of deadlines.

BANK INFORMATION

Including any accounts opened for the benefit of your child, Representative Payee accounts, ABLE Account numbers, any debit or credit cards your adult child uses and associated PIN numbers.

LEGAL DOCUMENTS

Such as wills, special needs trusts, power of attorney, guardianship 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 of the person with a disability, tax returns, pay stubs or other evidence of income, and payments for medical services and equipment.

These documents often need to be original:

- Birth certificate
- Marriage license
- Passport
- Death certificates (to prove eligibility for Social Security survivor benefits, for example)
- Guardianship court orders
- Social Security cards
- Medicaid cards
- Driver's/non-driver's license
- Wills, trusts, powers of attorney (unless the original is stored with your attorney)
- Car titles, mortgages/deeds
- Last 7 years of tax returns (if not stored with your accountant)
- Latest month's wage statement or pay stub

NOTES	CHECK IF DONE	NOTES
Letter of intent created? Where is it kept?		
Calendar reminder to update annually?		
Discussion with your child about their dreams? What are their dreams/goals?		
Check to ensure birth certificate, account info, medical documents, etc. are updated. Where are they kept?		
Have state ID?		
Will created?		
Special Needs Trust Created?		
Where are tax documents and related papers kept?		

PART TWO

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. It is a quick version of many of the topics reviewed in Part I, and it is still wise to review all of Part I when you feel able to do so.

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

BE ALERT TO CHANGES IN BEHAVIOR.

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

UNDERSTAND "SECONDARY LOSS."

When a loved one dies, the loss is not only of that person but of a way of life for the individual with DD. At the very least, schedules are disrupted and routines lost (at least temporarily). Even more disruptive would be major changes in where the individual with DD lives and with whom. To an individual who cannot live alone or support himself financially, these losses may seem as "immutable and final as death itself." To Keep as many routines as consistent as possible to offer some stability.

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 they enjoy and movies that feature loss, consider watching them together and using this as a springboard to talk about their thoughts and feelings. If this is too difficult, consider going to a mental health professional who specializes in grief counseling. The provider directory at https://thearcofnova.org/resources/business-directory have ideas on professionals in the field.

ALLOW YOURSELF TO GRIEVE.

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

CONTINUING WITH CAREGIVING

This section supports caregivers in carrying out their desire to:

- Maintain the dignity and safety of the adult with the disability
- Ensure his or her financial well-being
- Retain and replenish the circle of support
- Communicate with, and replace when necessary, those with legal roles to play such as trustees, guardians and Representative Payees

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

NOTES	CHECK IF DONE	NOTES
Any behavioral changes note		
Past mental health professionals who were helpful		
Mental health professionals/ resources used		

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. Make sure your own will and end of life planning is updated, as described in the Part I of this guide.
- Change guardianship orders to include a co-guardian (if one is not already mentioned) and/or a backup guardian, if not already done. If there is a backup guardian now acting as full guardian, remember they must go to court within 60 days to make this permanent. They should use an elder law attorney and can find one in our Provider Directory at https://thearcofnova.org/resources/business-directory.
- Call Social Security Administration and change the Representative Payee to whoever will manage that money. Make sure you know the income and asset limits, as well as requirements for reporting changes and annual filings.

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 Key Private 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

POWERS OF ATTORNEY

Powers of Attorney (POA) are tools that allow a supported to work alongside with the person with a disability to help them understand and make choices, and can allow the acting POA to do things on behalf of the person with a disability (e.g., consent to a surgery) if needed. Powers of Attorney can be updated anytime, and should then be notarized. If parents were in a POA role, the outdated Power of Attorney documents should be reviewed, updated, signed by the new supporters and person with a disability, then notarized. Give updated copies to relevant professionals, like banks and doctors. Look at the explanation on page 53 of this guide for more details.

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 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. You may be able to avoid the need for a conservator by using tools like Special Needs Trusts and Representative Payees, which are generally cheaper and more flexible.

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 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, or if a backup guardian was named, then an attorney must be hired and another hearing held to either make the backup appointment permanent, or to appoint someone new altogether. Look at the explanation on page 53 of this guide for more details.

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. Look at the explanation on page 35 of this guide for more details.

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. Fill out 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. You will need either guardianship, or for the person with a disability to join you on calls and meetings.

To change the individual names as Representative Payee for SSI beneficiaries, contact the Social Security Administration as soon as possible at 1-800-772-1213 between 7 a.m. and 7 p.m. on business days, or contact your local SSA office, or go online at www.socialsecurity.gov/payee. See page 36 for Social Security Offices in Northern Virginia.

APPLY FOR BENEFITS

SOCIAL SECURITY SURVIVOR AND RETIREMENT BENEFITS

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

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

WHEN THE FIRST PARENT DIES

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

WHEN THE SECOND PARENT DIES

Survivor benefit will be 80% of the higher of the two parents’ benefits.

FROM SSDI TO RETIREMENT SOCIAL SECURITY

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

Once a person is moved to regular retirement SSA from SSDI, there is more flexibility in spending and saving. However, if a person is receiving Medicaid, there will always be resource and earnings thresholds.

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

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

1938 – 65 years and 2 months

1939 – 65 years and 4 months

1940 – 65 years and 6 months

1941 – 65 years and 8 months

1942 – 65 years and 10 months

1943 through 1954 – 66 years

1955 – 66 years and 2 months

1956 – 66 years and 4 months

1957 – 66 years and 6 months

1958 – 66 years and 8 months

1959 – 66 years and 10 months

1960 and later – 67 years

NOTES	CHECK IF DONE	NOTES
Trustee updates needed, date done, contacts		
Power of Attorney updates needed, date done, where filed		
Guardianship updates needed, when done, by whom		
Social Security contacted, date, outcome		
Representative Payee updates		

MAINTAIN QUALITY OF LIFE

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

Visit our Resource Library, https://thearcofnova.org/resource-library, to get ideas for social and recreation options. You can also explore your local offices of Therapeutic Recreation and Area Agencies on Aging.

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.

All of the information a customer needs to prepare for a DMV visit is available on the DMV web site at https://www.dmv.virginia.gov/appointments, where you can schedule an appointment in advance.

TRAVEL TRAINING

A key element of independence is being able to get around on public transportation for one's work and social life.

Dulles Area Transportation Association https://datatrans.org offers no cost travel training for older adults and adults with disabilities in Northern Virginia.

ECNV (The ENDependence Center of Northern Virginia) offers free travel training on Washington-area bus and subway routes for people with disabilities. www.ecnv.org

WMATA https://www.wmata.com/service/accessibility/MetroReady-Travel-Training-and-System-Orientation.cfm offers MetroReady Travel Training at no cost to seniors and people with disabilities. MetroReady is short-term, comprehensive, intensive instruction designed to teach customers how to travel safely and independently on the accessible Metrobus and Metrorail public transportation systems.

The Arc of Northern Virginia's Tech for Independent Living (TFIL) Program offers travel training experiences to gain independence and confidence. With hands-on guidance, participants will receive an orientation to the various transit systems throughout the DMV. These trips aim to boost safety awareness, introduce problem-solving skills, and promote independence. To learn more or register for an event, visit our website at https://thearcofnova.org/tfil-events or contact techforindependence@gmail.com.

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 complete 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 fare card (metro). Use your Metro Disability ID to purchase a SmarTrip card that is encoded for discount fares. This provides 50% off Metrorail and Metrobus fares for all reduced fare programs. Customers also receive a discounted fare on regional bus service providers that accept the SmarTrip card such as Alexandria Transit Company (DASH), Arlington Transition (ART), CUE Bus System (Fairfax), Fairfax Connector, and OmniRide/PRTC (Prince William County).

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 fare card machines or on Metrobus.

USING PUBLIC TRANSPORTATION

A good place to start to learn about available routes is www.CommuterPage.com with links to Virginia and Maryland bus and rail services.

Alexandria
www.dashbus.com

Arlington
www.arlingtontransit.com

Fairfax
www.fairfaxcounty.gov/connector

Fairfax City
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 fill out 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 area's ADA paratransit service that provides shared-ride, door-to-door service that operates during the same hours of operation as corresponding Metrorail and bus service. Unlike non-emergency medical transportation, MetroAccess is a shared ride public transportation service for people who are unable to use the accessible fixed-route Metrobus and Metrorail public transit due to disability. MetroAccess can be used for any trip purpose within 3/4 of a mile of areas serviced by Metrobus and Metrorail, during the same hours of operation as regular Metrobus and Metrorail service. "Shared ride" means that multiple passengers may ride together in the same vehicle.

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. To apply, you can download an application at https://www.wmata.com/service/accessibility/metro-access/eligibility.cfm. You will then need to set up an in-person appointment with the Transit Accessibility Center of by calling **202-962-2700**. 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.

Once you have been approved, you can schedule your ride 1-7 days in advance by calling **301-562-5360**, TTY **301-588-7535** or book online. Fare is calculated by doubling the fastest comparable route fare on bus and/or Metrorail up to $4.50 each way.

TOPS (TRANSPORTATION, OPTIONS, PROGRAMS & SERVICES)

https://www.fairfaxcounty.gov/neighborhood-community-services/transportation/tops

TOPS provides subsidized transportation funds on an easy-to-use debit card for eligible older adults, persons with disabilities, and those with limited income who are residents of Fairfax County, the City of Fairfax, or the City of Falls Church. TOPS connects riders with a variety of transportation modes and options including taxicabs, rideshare services (Uber and Lyft), public transportation, and Capital BikeShare rentals, enabling them to travel affordably, safely, and independently.

STAR (ARLINGTON COUNTY)

STAR https://www.arlingtontransit.com/star is the paratransit component of Arlington Transit – ART. ART provides public fixed route bus services in Arlington County. STAR serves Arlington residents who have difficulty using public fixed route transit due to the effects of age or disability. STAR is a shared ride paratransit service intended to provide a comparable level of transportation as provided by ART, Metrobus and Metrorail. STAR riders share trips if they are generally traveling in the same direction at the same time. Trips are scheduled, with a few exceptions, without regard to the purpose of the trip. All rides are arranged in advance through the STAR Call Center, or online through their website. STAR riders must preplan activities and schedule STAR trips in advance as same day service is generally not available.

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.

FASTRAN (FAIRFAX COUNTY)

https://www.fairfaxcounty.gov/transportation/fastran

Fastran offers specialized transportation services for residents of Fairfax County and the Cities of Fairfax and Falls Church participating in human services agency programs. To apply, request an application by calling **703-222-9764**.

MODIVCARE

https://www.modivcare.com

Transportation for Medicaid recipients to a non-emergency Medicaid-covered service.

DOT

https://www.alexandriava.gov/Paratransit

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.

NOTES	CHECK IF DONE	NOTES
ID received date		
ID renewal date on the calendar for auto reminder		
Travel options that seem viable		
Travel programs applied for		

ELDER CARE & SPECIAL NEEDS TRUST ATTORNEYS

We have information on many options at https://thearcofnova.org/resources/business-directory. Remember to look for attorneys who have expertise in elder and disability law. Many will offer a lower cost or free initial consultation. If your family is not able to hire an attorney, Legal Services of Northern Virginia's Elder Law unit provides legal assistance to persons 60 and older on such matters as Medicaid, Medicare, & other healthcare issues, nursing home & assisted living issues & guardianship. They may also prepare wills. https://lsnv.org

NOTES	CHECK IF DONE	NOTES
Attorney needs		
Attorneys contacted and dates		
Plan for attorney to do updates		

GETTING MORE HELP: RESOURCES ON AGING

PUBLICATIONS & ONLINE RESOURCES

PLANNING RESOURCES FOR AGING IN GENERAL:
ARP "A Simple Planning Guide for Families"
https://www.aarp.org/membership/benefits/caregiving/aarp-family-caregiving-guides

BENEFITSCHECKUP.ORG
Free 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
https://ndss.org/resources/aging-and-down-syndrome-health-well-being-guidebook

NATIONAL COUNCIL ON AGING
https://www.ncoa.org
Benefits navigator, resources, and advocacy information

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GLOSSARY OF COMMON ACRONYMS

A

AAA: Area Agency on Aging
ADA: Americans with Disabilities Act
ADLs: Activities of Daily Living
ASD: Autism Spectrum Disorder
AT: Assistive Technology
ABLE Accounts: Achieving a Better Life Experience

B

BI Waiver: Building Independence Waiver

C

CCC+: Commonwealth Coordinated Care
CMS: Centers for Medicare & Medicaid Services
CIL : Center for Independent Living
CDS: Consumer Directed Services
CL Waiver: Community Living Waiver
CSB: Community Services Board

D

DD: Developmental Disability
DAC: Disabled Adult Child
DBHDS: Department of Behavioral Health and Developmental Services
DDS: Disability Determination Service
DMAS: Department of Medical Assistance Services
DARS: Department of Aging and Rehabilitative Services
DSP: Direct Support Professional
DSS: Department of Social Services

F

FIS Waiver: Family and Individual Supports Waiver

G

GAL: Guardian Ad Litem
GSE: Group Supported Employment

H

HCBS: Home and Community-Based Services
HCV: Housing Choice Voucher
HIPP: Health Insurance Premium Payment program
HIPAA: Health Insurance Portability and ccountability Act

I

IDD: Intellectual and Developmental Disabilities
ISP: Individual Service Plan

L

LRE : Least Restrictive Environment
LTSS: Long-Term Services and Supports

P

PCA: Personal Care Attendant
PERS: Personal Emergency Response System
POA: Power of Attorney

S

SSI: Supplemental Security Income
SIS: Support Intensity Scale
SDS: Self-Directed Services
SGA: Substantial Gainful Activity
SSA: Social Security Administration
SRAP: State Rental Assistance Program
SNT: Special Needs TrustSSDI – Social Security Disability Insurance

T

TANF: Temporary Assistance for Needy Families

U

UAI: Uniform Assessment Instrument

V

VIDES: Virginia Individual Developmental Eligibility Survey

OTHER GUIDES IN THIS SERIES:

— Starting Life with Your Child with a Disability

— Getting the Most from Special Education

— Transition from School to Adult Life

— Entering the World of Work

— Finding a Home for Adults with Disabilities

Transition POINTS

Providing Opportunities, Information, Networking and Transition Support