

SECURING A FUTURE FOR YOUR CHILD WITH A DISABILITY

**A Guide to Adult Programs
for Adults with Disabilities
in the City of Harrisonburg,
Rockingham County, and
Vicinity**



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

May 2021

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

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

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

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

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**The Arc of Harrisonburg & Rockingham
620 Simms Avenue
Harrisonburg, VA 22802**

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For additional Resources including:

- Attorneys Specializing in Special Needs Trusts
- Selected List of Support Coordinators for Persons with Disabilities
- Reporting Tips for Beneficiaries of Social Security Disability Programs
- Comparison of Special Needs Trust v. ABLE Act
- And more,

Visit The Arc of Northern Virginia's Transition Tool Kit at

<https://thearcfnova.org/programs/transition/securing-future-child-disability/transition-toolbox/>

LIFESPAN INTRODUCTION

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

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

- 80% of families surveyed don't have enough money for needed care and almost half report having more care-giving responsibilities than they can handle
- 85% report that their adult family member with DD was not employed either full- or part-time
- 62% of families have no long-term care plan
- 75% can't find after school care, community services, or summer activities for their loved one
- 59% report they don't have enough information to make good choices about housing options
- 65% report that they don't have enough help in planning for the future.¹

About LIFESPAN

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

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

1. Receiving a diagnosis and having a child enter an early intervention program;
2. Starting school and entering the special education system;

3. Transitioning out of the school system and into Adult services;
4. Entering the world of work;
5. Finding a home; and
6. Aging with a disability.

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

The information found in this guide is applicable to all people with developmental disabilities and their families, although much of the contact information for resources are particular to the Harrisonburg and Rockingham area. To explore resources specific to your local community, contact the Community Services Board (CSB) in your region. You can find your local CSB by visiting DBHDS (Department of Behavioral Health and Developmental Services at <http://www.dbhds.virginia.gov/community-services-boards-cbssr>). The CSB is the point of entry into the publicly funded system of services for people with mental health, developmental disabilities. Also visit The Arc of Virginia at www.thearcofva.org to find the local Arc Chapter in community. To find the local Department for Aging and Rehabilitative Services in your area, visit <https://www.vadars.org/default.htm#gsc.tab=0>

Help for You, the Parent

We have written six guides to address important issues that parents should consider at each of these important life stages. The guides are designed to help you recognize opportunities, weigh options, and work through decisions. Checklists, timelines, worksheets, and links to other resources are included wherever possible. Each document has also been reviewed by a task force of parents and professionals with relevant experience and expertise. Please visit the Lifespan section of our web page at www.hrarc.org to download each guide.

Although each guide addresses issues related to a specific phase of life, each repeats information parents and caregivers need to know whether their loved one is two, 22, or 62 years old: how to protect your loved one's financial future, how to apply for benefits, and where to go for more help.

Your Rights and Responsibilities

This is not a legal document and does not spell out your or your child's rights and responsibilities under the law. Every effort has been made to verify the information in the document, but please be aware that items such as program regulations, deadlines,

and contact information can change.

Referrals to organizations and individuals are for informational purposes and do not constitute an endorsement of their services.

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

SECURING A FUTURE FOR YOUR CHILD WITH A DISABILITY

As the parent of a child with a disability, until now you and the school system have shared the responsibility of how your child will spend the majority of his or her time during the day. Most likely your child lives with you, goes to school, and perhaps engages in activities sponsored by the school system or in which other peers participate.

However, once your student exits the school system, he or she must meet the eligibility criteria and funding availability to receive services from adult service agencies. The difference between entitlement of public education and adult services based on eligibility can be confusing. The young adult, the parents and family must take the lead in defining and navigating the future. This means researching and advocating for services in areas such as employment, meaningful day supports, recreation, and housing. It also means making arrangements for your child's long-term financial security.

The Center on Transition Innovations at VCU offers Tips on Transition Planning for Parents at www.centerontransition.org.

5. **Be open-minded and think outside the box.** Just because it's never been done, doesn't mean that it can't be done. It can never hurt to discuss an idea concerning transition.

- 1. Love your child unconditionally, believe in him or her, provide encouragement, dream big!** You are your child's biggest advocate. Support and love them as only parents can in this exciting time.
- 2. Insist on student voice.** The student's voice should be present whenever he or she is the subject of conversation.
- 3. Increase student involvement with the transition process.** A great way to build self-determination for a young adult with a disability is through the IEP process.
- 4. Research resources and do your homework.** It is easy to become overwhelmed with emotions during the transition process. Researching best options and practices provides a powerful tool to advocate for your child.

6. Collaborate with adult services. Community adult services provide valuable support and programming once your child exits school services. Learning about the various services and building relationships with providers early will ease the transition to adult services.

7. Increase family involvement in the transition planning process. Your child is the center of the IEP and you know your child best. The more the family is involved, the more your child's voice will be heard.

What's in this Guide

Making decisions for a grown up child with a disability is complicated. To help you with this task, this document addresses the following issues:

Who's in charge of key life decisions. Parents want to give their child the greatest degree of independence possible that still guarantees that person's safety and well-being. The law provides a range of options for safeguarding an adult with a disability, from powers of attorney to guardianship and conservatorship.

Whether your adult child is eligible for government support. Beginning at 18, an adult with a disability may qualify for monthly income from the Social Security Administration and for Medicaid. Some persons with a disability may also benefit from both short- and long-term funding from public funds and Medicaid Waiver funds for services.

What kind of jobs and support services are available. Planning for jobs starts early before a child gets out of school, with vocational assessments and (ideally) some volunteer job experience. If your child is found eligible for adult services, localities may offer vocational testing, as well as help in finding, training for and getting support on the job.

Which recreational activities are best. Recreational activities are important for keeping people healthy as well as giving them a social outlet. Both local governments and non-profit groups offer recreational and sports programs for young adults with a disability.

Where they'll live. This is likely the biggest unknown parents face—where their child will live. Safety, cost, availability, and convenience are all factors in deciding where an adult child with a disability can and wants to live. For more information on housing resources, see The Arc of Harrisonburg and Rockingham's Guide: Finding a Home for People with Disabilities at <http://www.hrarc.org>

Even if your child won't graduate from the school system until age 22, several steps must be taken by the time he or she reaches age 18. Look at tasks marked ASAP in the "Checklist for Parents" for decisions to be made right now.

How will they advocate for themselves. No one has a greater stake in the outcome of lifespan planning than the student. The student should be an active, participating member of the transition team, as well as the focus of all activities. Developing self-knowledge is the first step in self-advocacy skills. Learning about one's self involves the identification of learning styles, strengths and weakness, interests, and preferences.

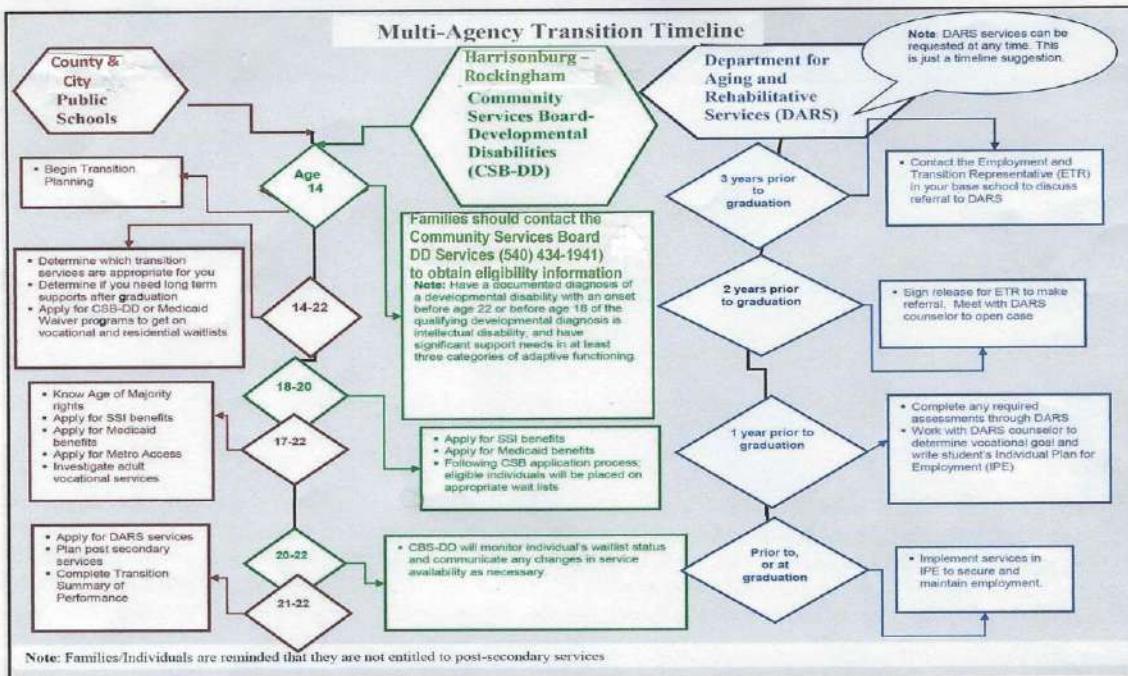
Securing a Future: A Checklist for Parents

Step to Take by Age	Estate/ Legal	Post-HS Education	Job/Day Support	Leisure	Transport	Housing
ASAP						
Create file for key documents	x					
Have a will drawn up for parents	x					
Create a Special Needs Trust	x					
Determine if child with disability qualifies for Supplementary Security Income	x					
Explore person's eligibility for Medicaid waivers. Get on wait list(s).	MAY	BE	LONG	WAIT	LIST	
Ages 12-14						
Keep record of child's aptitudes, vocational & leisure interests			x	x		
Discuss child's needs with local therapeutic recreation department				x		
Age 14-16						
Include transition goals in IEP, as well as transportation and vocational ones; explore eligibility for Department of Aging and Rehabilitative Services (DARS) vocational training		x	x	x	x	
Explore eligibility for adult services with school or CSB; fill out application and release of information forms			x			x
Age 16-18						
If college-bound, research colleges and visit campuses; meet w/ disability support services.		x				
Gather information on employment and day support programs; open case with DARS	Eligibility	is not a	guarantee	x of	DARS	services
Determine eligibility for adult services through appropriate local agency			x			x
Age 17 (or 12-18 mo. before leaving school)						
For the college-bound, take required tests; arrange interviews, visits. Meet with office of disability services and determine eligibility for on-campus services.		x				
Visit employment/support providers			x			

Securing a Future: A Checklist for Parents

Step to Take by Age	Estate/ Legal	Post-HS Education	Job/Day Support	Leisure	Transport	Housing
Fall of senior year						
Apply to post-secondary schools		x				
No earlier than 17 yrs., 6 months						
Explore power of attorney, guardianship or other options. Contact attorney if needed.	x					
1 month before 18th birthday						
If necessary, have attorney prepare final documents for new legal relationship	x					
Month of 18th birthday						
Apply for Supplementary Security Income (SSI)	x					
Age 18-22						
Update will. Inform family about wills, trusts, guardianship, etc.	x					
Explore adult recreational and social programs				x		
Prepare resume, do situational assessments, go on job interviews			x			
Once accepted for SSI, apply for Medicaid.	x					
If working, learn about managing job income and Social Security benefits	x					
If not already done, determine eligibility for Medicaid Waivers	x					
If not yet done, obtain ID card					x	
If eligible for housing supports, visit local providers. If eligible for public housing/vouchers, get on wait lists						x
Age 20-22						
Before graduating, decide on and choose day support or vocational services and the non-profit organization that might provide the service.			x			
Determine potential use of public transportation or specialized transportation services. Explore travel training.					x	

Transitioning from School to Work: A Trip through the Process



Although this timeline is for Harrisonburg-Rockingham, some area CSBs support similar timelines, and their processes for working with the public schools and with the Virginia Department for Aging and Rehabilitative Services are similar. Residents of Rockingham County should call the Harrisonburg Community Services Board at 540-434-1941 for assistance with transition.

ESTATE AND BENEFITS PLANNING GOAL: Ensure your adult child will receive federal and state benefits for which he or she may be eligible and will be taken care of in the event of a parent's death or disability.

When to take action	What Needs to be Done	Who Can Help
<i>General Financial Planning--As Soon As Possible</i>	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 an heir with unique needs your planning for each of your children must not jeopardize the benefits or services of your heir with a disability and/or the relationship between the siblings and family members.	Contact your family attorney for a will and general estate planning. A separate document called a special needs trust should be created for the child with a disability (see below). Some families also find it useful to see a financial planner.
<i>Special Needs Trust-- As Soon As Possible</i>	Create a stand-alone trust document to allow a disabled person to have an unlimited amount of assets held in trust without affecting his/her eligibility for federal benefits programs.	For general information on special needs trusts, see Appendix. The Arc of Harrisonburg and Rockingham , Virginia provides a special needs trust referral program that provides the family and the individual with resources to enhance the quality of the person's life. Find out more at: www.hrarc.org
<i>Letter of Intent--As Soon As Possible</i>	This document provides detailed information on your child's life, as well as your wishes for his or her future. Not legally binding, but invaluable to those who may have to take over child's care.	If not using The Arc of Northern Virginia's trust referral program, contact an attorney about writing a special needs trust. Not all attorneys are able to do these documents. See www.hrarc.org

ESTATE AND BENEFITS PLANNING GOAL: Ensure your adult child will receive federal and state benefits for which he or she may be eligible and will be taken care of in the event of a parent's death or disability.

When to take action	What Needs to be Done	Who Can Help
Supplemental Security Income (SSI) --As soon as possible for benefits for child with a disability	Determine if your child (under age 18) might qualify for SSI. The child must meet Social Security Administration's strict definition of disability and must have few or no financial assets. Parents' assets and income are taken into consideration.	You can complete a large part of the application by visiting the website at http://www.socialsecurity.gov/pgm/ssi.htm . You also need to call toll-free at 800-772-1213 and ask for an appointment with a Social Security representative to complete the application either by phone or in person. For help with general rules for applying and managing benefits visit https://www.ssa.gov/benefits/
At age 18 Benefits for adult with disability	Determine eligibility for SSI as an adult with a disability. The adult with the disability must meet functional disability and income/asset requirements (less than \$2,000 of assets in their own name). Parents' income and resources are not counted. Apply for SSI if your adult child meets the disability and income requirements.	Start your application by visiting the website at https://www.ssa.gov/site/signin/en/ . You also need to call toll-free at 800-772-1213 and ask for an appointment with a Social Security representative to complete the application either by phone or in person.
Once receiving Social Security benefits	Beneficiary MUST report any earnings to Social Security, including work income, one-time payments, child support, or payments from a trust	NOTE: Try to complete forms and prepare supporting documentation before meeting with the Social Security representative.
Explore Power of Attorney/Guardianship/Conservatorship At age 17	See Appendix Research information on Supported Decision Making and the pros and cons of different types of legal relationships that guide decision making for an adult with a disability. Options range from a representative payee to guardianship and conservatorship.	NOTE: It is recommended that you charge your child with a disability who's receiving Social Security benefits for rent in the family home, food, medical expenses and clothing. Rent charged must be at least 30% of the current maximum benefit to get that maximum benefit. See Social Security regulations for details.

ESTATE AND BENEFITS PLANNING GOAL: Ensure your adult child will receive federal and state benefits for which he or she may be eligible and will be taken care of in the event of a parent's death or disability.

When to take action	What Needs to be Done	Who Can Help
Not before 17 years and 6 months	If you are seriously considering guardianship, contact an attorney experienced in elder care and disability law.	
1 month before 18th birthday	Have attorney prepare final documents	
Medicaid Health Insurance—As Soon As Possible	If your child has qualified for SSI, he or she is automatically eligible for Medicaid. You still need to fill out an application.	Visit www.dmas.virginia.gov for general information. However, you must apply through your local Dept. of Human Services; if already receiving SSI, ask for the Medicaid short form.
Private Health Insurance	A person with a lifelong disability can stay on their parents' insurance indefinitely. For new insurance plans, a disability cannot be considered a preexisting condition for children under 39.	
Medicaid Waiver Programs—As Soon As Possible to get on waiting list	Persons with DD may also qualify for services under the Medicaid Waiver Programs.	See https://thearcfnova.org/Programs/waivers/all-about-waivers/
At age 17	The State of Virginia funds waiver slots, but funding is currently inadequate to meet needs statewide	For general information see http://www.dhhs.virginia.gov/individuals-and-families/developmental-disabilities-life-my-community To apply for DD Waivers contact your County's Community Services Board

ESTATE AND BENEFITS PLANNING GOAL: Ensure your adult child will receive federal and state benefits for which he or she may be eligible and will be taken care of in the event of a parent's death or disability.

When to take action	What Needs to be Done	Who Can Help
<i>Employment/Day Support Services—As Soon As Possible</i>	<p>Begin process of determining your child's eligibility for employment or day support services from your locality.</p> <p>Your child MUST have a diagnosis of a developmental disability and meet level-of-functioning requirements to be funded by the local Community Development Board. You will need to fill out an application form and provide a psychological evaluation of your child and sign a release allowing DHS access to any needed medical/psychological records.</p>	For the CCC Plus Waiver contact your County's Department of Social Services

POST-SECONDARY, EMPLOYMENT AND DAY SUPPORT SERVICES

GOAL: To arrange for appropriate post-secondary, employment, volunteer and/or day support activities for your child after he or she has left high school.

When to Take Action

Vocational Assessment

Ages 12-14

What Needs to Be Done

Begin and maintain a record of your child's interests and strengths, career exploration activities, and skills

Determine with teachers ways that school activities could prepare your child for employment possibilities

Who Can Help

Vocational assessments and employment services may be coordinated prior to graduation, depending on eligibility and available funds, through your local school system, the Community Services Board, and/or the Virginia Dept. for Aging and Rehabilitative Services (DARS).

Ages 14-16

IEPs should include post-secondary and independent living goals at age 14.

Age 16-22

If not already done, determine your child's eligibility for adult services through appropriate local agency; including support from The Dept. of Aging & Rehabilitative Services (DARS) and the CSB. Your school transition representative and CSB support coordinator can help you navigate this process.

DARS may provide short-term support to adults with disabilities to prepare for and engage in competitive, integrated employment. Students must meet DARS eligibility criteria. See www.vadrs.org

The transition representative at your child's high school is the best first stop resource for information on post-secondary and employment options.

POST-SECONDARY, EMPLOYMENT AND DAY SUPPORT SERVICES

GOAL: To arrange for appropriate post-secondary, employment, volunteer and/or day support activities for your child after he or she has left high school.

When to Take Action	What Needs to Be Done	Who Can Help
Ages 12-17	Research information about organizations that provide employment and day support services through written and online materials and resource fairs	Vendor Resource Fairs
Ages 17 or 18 months before	Meet with transition representative who can help you arrange meetings with provider organizations or you can schedule a meeting on your own	
	Before graduating, decide on the service organization that best suits your child's support needs and determine eligibility	
Post-secondary Academic Options	If your child is interested in post-secondary education, many programs exist to help students with disabilities take courses and/or get a degree	
2 years before leaving high school	Research college programs and make visits with the student and meet with the office of disability services on campus.	
Junior year of high school	Take required tests, arrange interviews and more visits	
Fall of senior year	Apply to post-secondary schools or programs	

RECREATION

GOAL: To enable your child to participate in recreational and leisure activities

When to Take Action

By age 12

Beginning at 12 and repeated as needed throughout lifetime of child

18+

When ready to take a class

What Needs to be Done

Begin and maintain a record of your child's interests and strengths.

Fill out any required accommodation forms; this varies by locality. These would be updated each year and continue on into adulthood.

Contact your local therapeutic rec office or talk to a teacher/case manager to determine activities that would match your young adult's interests.

If new to a TR/adapted program, ask to complete an intake with a Certified Therapeutic Recreation Specialist (CTRS)

Call the Therapeutic Recreation Office and register; request an accommodation if needed.

Your locality may also be able to make accommodations in general recreation (non-TR) classes or camps. Be sure to request accommodations in advance.

Many private organizations have their own intake and assessment processes. Be sure to ask if a free evaluation or intake is available. When requesting accommodations for programs, ask which accommodations they are willing and/or able to make.

Who Can Help

Check The Arc of Harrisonburg and Rockingham's Resources Guide for local resources

See also FCPS Parent Resource Center Adapted Sports and Recreation

Both public and private organizations run sports, social, and therapeutic programs for individuals with disabilities.

TRANSPORTATION

GOAL: To enable as much independence as possible in getting to/from activities by teaching transportation skills and taking advantage of lower-cost transportation options

When to Take Action	What Needs to be Done	Who Can Help
Beginning at age 12	Consider child's readiness to learn travel skills and what skills need to be taught	https://www.dmv.virginia.gov/drivers
Once child/adult is traveling away from home	Obtain a non-driver identification card from the Virginia Dept of Motor Vehicles. These cards have no age restriction and are available for anyone who does not hold a learner's permit or driver's license.	Contact the Transition Coordinator for your child's school and/or Special education support coordinator at school in advance of the IEP meeting
Age 12 - graduation	Include travel skills goals as part of IEP and as part of the Transition Plan	Find out more about accessible transportation options in Virginia

HOUSING OPTIONS

GOAL: To have your child live in the community when the time is right for him or her to leave the family home.

When to Take Action

In child's teenage years

What Needs to Be Done

Planning for housing is very challenging for a variety of emotional and financial reasons. Begin the planning process in early adulthood, even if you want your child to live with you for the foreseeable future. It is much better for housing decisions to be made thoughtfully and methodically over a period of years than in a crisis situation.

At age 18

Learn the distinctions among options. Visit types of housing arrangements and look at virtual house tours on YouTube

For further information, see The Arc of Harrisonburg and Rockingham's "Finding a Home for people with Disabilities" Guide. See www.hrarc.org

APPENDIX 1: KEEPING GOOD RECORDS

Gathering information for and keeping key documents on hand will make it easier to carry out the advocacy and caregiving tasks you will face throughout the lifetime of your child with a disability. For example, when applying for SSI, you must demonstrate that your child has a qualifying disability. If you are a Representative Payee, you must file annual reports on how benefits were spent. You may have to prove guardianship to doctors, pharmacies, health insurance companies, banks, and social service agencies.

The first step is to establish a filing 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.**

Letter of Intent

One of the most important documents to have in your child's file is a Letter of Intent in which you describe your child's current life and express your values, wishes and vision for his or her future. Although not legally binding, a Letter of Intent is invaluable to those who will take over the care of your child. What goes into the document will vary with the individual but would probably include:

Your vision of your child's future: what goals you have for your child's life, where they would live and with whom, and what activities to maintain.

Your child's vision of his or her future. Whenever possible, include your child's ideas and desires in the document, such as ensuring that a favorite family remains a strong presence in their life, keeping a pet, or working in a specific industry or worksite.

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

Specifics on the individual's daily life: For example school or work schedules, weekend activities (including religious education or attendance), bedtime routines, food and clothing preferences and sensitivities, preferred toys,

games, exercise routines, and typical outings, and the like.

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

Living expenses. Consider including annual costs of items such as food and rent, medical visits and equipment, health insurance, recreational activities and vacations, etcetera, to give future caregivers an idea of how the individual's special needs trust and benefit monies might have to be spent.

Contact information: family members, friends, doctors/therapists, preferred pharmacy, school or employer information, lawyers, trustees and backup guardians, insurance agents, banker and financial planners, and anyone else of relevance to your child's life.

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 (the original is often necessary), Social Security card, driver or non-driver's ID, passport, Medicaid card, health insurance card.

Bank information, including any accounts opened for the benefit of your child, Representative Payee accounts, numbers of any debit or credit cards your child is allowed to use, and associated PIN numbers.

Legal documents such as wills, special needs trusts, guardianship orders, power of attorney or 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 disabled person, tax returns, pay stubs or other evidence of income, and payments for medical services and equipment.

APPENDIX 2: ENSURING HEALTH INSURANCE

Having adequate health insurance is an important element in securing your child's financial as well as physical health. Adult children with a lifelong disability may stay on their parents' health insurance indefinitely (non-disabled children are not covered after age 26). Steps you can take now include:

- Applying for Supplemental Security Income payments for your child with a disability. If your child qualifies for this program, it is much easier to get him or her Medicaid coverage.
- Exploring options and costs of health insurance for your child once you are no longer working.

Private Employer Health Plans

The Affordable Care Act of 2010 extended healthcare coverage for families and individuals and provided important protections for individuals with disabilities.

Dependents with a lifelong disability can remain under your employer-sponsored policy beyond age 26. Also, job-based and new individual plans won't be allowed to deny or exclude coverage to any child under age 19 based on a pre-existing condition, including a disability. These same plans won't be able to exclude anyone from coverage or charge a higher premium for a pre-existing condition including a disability.

Medicaid

Medicaid is a federal health insurance program available to low-income persons, the elderly and people with a disability. One way to get Medicaid is to qualify for Supplemental Security Income (SSI). If you meet the requirements for SSI, you will meet those for Medicaid.

You can have private health insurance and still be covered by Medicaid or FAMIS Plus (excluding Plan First). *If you have other insurance, the other insurance plan pays for medical services first.* Having other health insurance does not change the Medicaid co-payment amount, if one is required, that you will pay to providers as a Medicaid enrollee.

Health Insurance Premium Payment Program

If your child has Medicaid, the Health Insurance Premium Payment (HIPP) can help pay all or part of your health insurance premiums.

Your health insurance plan may cover services that are not covered by Medicaid. HIPP allows you to have health insurance you might not otherwise be able to afford. HIPP evaluates the services covered under your health insurance plan and compares the average Medicaid cost for your Medicaid eligible family member to the cost of your health insurance premium.

Information is available at

<https://www.coverva.org/hipp/> or call the HIPP Program at 800-432-5924.

Information Resources

For more information on changes to private healthcare under the Affordable Care Act, see

www.healthcare.gov.

For help with understanding Medicaid and private insurance issues, contact Virginia Insurance Counseling and Assistance Program, 703-324-5851.

More information can also be found at the website

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

APPENDIX 3: APPLYING FOR BENEFITS: Social Security Disability Programs

You may begin the application process for Social Security benefits in the month your child turns 18. The first step is to *determine eligibility* for any benefit program; the Social Security Administration (SSA) will decide which program is appropriate. For a video presentation on SSI/SSDI visit The Arc of Northern Virginia's YouTube channel at

<https://www.youtube.com/watch?v=lFjtZzX68pQ&feature=youtu.be>

SSI vs. SSDI

For both Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), *a person must meet the SSA's definition of disability*. Disability is defined as the inability to engage in Substantial Gainful Activity (SGA) by reason of any medical impairment (physical and/or mental and/or blindness). 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 2021, the wage limit for the SGA is \$2,190 for those with blindness and \$1,310 gross income/month for those not blind.

SSI. SSI is a cash assistance program for those with limited income AND are either 65 years old or older or blind or disabled. Adult SSI beneficiaries must have limited income and resources (\$2,000 in assets); parents' income does not count for adult applicants. You do not have to have any work history. Monthly benefit payments are determined by the current benefit rate (\$794 a month in 2021), minus any "countable income." If eligible for SSI, you will also be eligible for Medicaid.

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

Applying for Benefits

The steps for applying are:

Start with a disability report. Go to the website at

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

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

You cannot complete the application for benefits online; you must call Social Security for an appointment.

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

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

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

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

U.S. Social Security Administration
351 N. Mason Street
Harrisonburg, VA 22802
1-866-964-1718 (local)
1-800-772-1213

SSA Office Hours:
Monday, Tuesday, Thursday, Friday 9:00 - 4:00
Wednesday 9:00 - 12:00, closed Saturday &
Sunday & Federal Holidays

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

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

Wait for eligibility determination. The agency will send your Disability Report Form and medical history to the Disability Determination Service (DDS). DDS may or may not request more information, such as

work history, when the disability began, and what treatment has been given. DDS may also request, on behalf of SSA, a medical or psychological exam (SSA pays for the exam by a physician chosen by SSA).

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

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

The Representative Payee

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

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

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

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

Housing and SSI Benefits

SSI is intended to cover living expenses like rent, food, and utilities. For example, it is recommended that you **charge your adult child rent** if he or she lives in the family home. **Rent charged must be at least 30% of the current federal benefit amount** (\$794 a month for 2021) to get the maximum SSI benefit. It is recommended that you research comparable costs for rooms to rent in your area and include that with the rental agreement. Be aware that SSI benefits may be reduced under the following circumstances:

In general, about one-third of your SSI benefit is assumed to be paying for housing expenses (rent or mortgage, utilities, property insurance/renter's insurance, and additional associated expenses) and the other two-thirds for other eligible expenses like food and clothing. If monies from a special needs trust are used to purchase a home with a mortgage, and the **trust makes monthly mortgage payments**, then the beneficiary's SSI payments will be reduced by about one-third each month (the portion of SSI associated with housing). If you have a trust, you can transfer your rent or mortgage money to an ABLE Account and SSI will not be reduced. For more information on utilizing ABLE Accounts, visit our trust website at www.theearcofnovatrust.org and the ABLE National Resource Center at www.ablenrc.org.

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

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

For additional information on Reporting Tips for Beneficiaries of Social Security Disability Programs visit our Transition Toolkit online at <https://theearcofnova.org/programs/transition/securing-future-child-disability/transition-toolbox/>

Reporting Income

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

APPENDIX 4: APPLYING FOR BENEFITS: Medicaid Waiver Programs

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

Family income and family assets are not a consideration under the Medicaid Waiver program if your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria.

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

Services Covered Under the Waivers

The Developmental Disability (DD) Waivers: There are 3 DD Waivers; they are the (1) Community Living, (2) Family and Individual Supports, and (3) Building Independence Waivers. These waivers cover supports in a variety of residential settings, including hourly staff at the home of a child's family and 24-hour staffed group home settings. These three waivers also cover a variety of employment and meaningful daytime supports for people no longer in school. Some additional services include respite care in-home supports, companion care, assistive technology, environmental modifications therapeutic consultation, non-emergency medical transportation private duty nursing, skilled nursing, and Personal Emergency Response System (PERS).

The Community Living Waiver is a comprehensive waiver that includes 24/7 residential services for those who require that level of support. It also includes services and supports for adults and children, including those with intense medical and/or behavioral needs.

The Family and Individual Supports Waiver is designed to support individuals living with their families, friends, or in their own homes. It supports individuals with some medical or behavioral needs and is available to both adults and children.

The Building Independence Waiver supports adults 18 and older who are able to live in the community with

minimal supports. This waiver does not include 24/7 residential services. Individuals will own, lease, or control their own living arrangements and supports may need to be complemented by non-waiver funded rent subsidies.

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

Eligibility Criteria

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

- (1) **Functioning ability:** This is determined by the VIDES survey. The VIDES has one test for children aged 0-3, one for children ages 3-18, and one for adults. The surveys assess the person's need for assistance with a variety of daily live and independence skill activities.
- (2) **Diagnosis:** Persons applying for a Waiver must meet the diagnostic eligibility requirements for DD Waivers. This means that a person must have a 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, are 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 that are lifelong or of extended duration and are individually planned and coordinated. An individual from birth to age nine 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 \$794 in 2021, so max monthly income is \$2,382).

The Commonwealth Coordinated Care (CCC) Plus Waiver covers personal care, respite care, medication monitoring, private duty nursing, assistive technology, environmental modifications, and Personal Emergency Response (PERS) system. Personal care support hours may be approved up to a maximum of 56 hours per week and cannot exceed 480 hours per state fiscal year. To be eligible for this waiver the person must have a disability and medical nursing needs, as assessed by the Virginia Uniform Instrument (UAI).

https://www.dss.virginia.gov/files/division/dfs/as/as_intr_o_page/forms/032-02-0168-01-eng.pdf

Waiting List Eligibility

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

How Long is the Wait?

The Developmental Disability Waivers have a waiting list based upon urgency of need. People in Priority One of urgency need services within the year, people in Priority Two 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, you or your spouse become ill or unemployed, notify your support coordinator. Such situations may increase the urgency of your need for support services.

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

Harrisonburg and Rockingham Community Services Board
1241 N. Main Street
Harrisonburg, VA 22802
(540) 434-1941

IFSP Funding

For those on the Waiver Waitlist

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

<https://dbhds.virginia.gov/index.php>

APPENDIX 5: CREATING AN ESTATE PLAN

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

If your child is approaching his or her 18th birthday (age of majority), you might also consider some form of legal support if he or she needs and will continue to need help with medical, financial, and legal decision-making. (See the next appendix on understanding legal authority.)

Creating a Will

A will is critical to ensuring that your wishes are carried out regarding how and to whom your assets are divided after your death. If you have a child with a disability, this is doubly important. Find an attorney who specializes in special needs planning; he or she will be able to address the unique needs of each of your children and not jeopardize the benefits or services of your child with a disability and/or the relationship between the siblings and family members. A list of local attorneys can be found in The Arc of Harrisonburg and Rockingham's Resources Guide. While many wills create family trusts, to avoid jeopardizing the benefits or services of your child with a disability you need to create a separate special needs trust (see below).

Reviewing beneficiaries

In addition to naming a special needs trust as the beneficiary for monies inherited through a will, you should also review the beneficiary 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; and savings bonds.

Special cautions apply when designating a special needs trust as a beneficiary of one or more of your retirement accounts (those marked with an*). The document creating the special needs trust (whether it

is a will or a stand alone trust) needs to state that the trust is "an accumulation trust" for the purpose of receiving distributions from retirement accounts.

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

Special Needs Trusts (SNT)

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

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

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

Two Kinds of Trusts

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

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

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

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

Setting Up a Trust

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

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

See The Arc of Harrisonburg and Rockingham's Resources Guide for local attorneys experienced in setting up Special Needs Trusts.

Uses of Trust Funds

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

- Education and tutoring

- Out-of-pocket medical and dental costs
- Transportation (including purchase of a vehicle)
- Maintenance of vehicles, car insurance
- Materials for a hobby or recreational activity
- Trips, 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 (this may reduce SSI benefits)

Acting as Trustee

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

However, for trusts set up with The Arc of Northern Virginia, the family does not have this burden: trust staff perform all administrative tasks and client relations and SunTrust Bank handles all fiduciary and investment duties.

Advocate Program

Having problems applying for benefits, developing a budget, finding a social outlet, or figuring out housing options for your loved one with a disability? If you've created a Special Needs Trust through The Arc of Harrisonburg-Rockingham Virginia referral, our Beneficiary Advocate is here to help on these and many other issues. Call (540) 437-9214 for more information on resources available through this service. There is an hourly fee, which can be paid with monies from the Special Needs Trust.

ABLE Accounts

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

The Achieving a Better Life Experience (ABLE) Act enacted by Congress in late 2014 allows states to establish tax-advantaged savings accounts for certain individuals with disabilities for their disability related expenses. In addition, these funds would

generally not be considered for supplemental security income (SSI) program, Medicaid, and certain other federal means-tested benefits.

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

APPENDIX 6: UNDERSTANDING LEGAL AUTHORITY

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

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

Dignity of Risk and Supported Decision Making

In recent years, a movement has grown to talk about the dignity of risk we all have to make decisions. The concept is simply that all people need help making some decisions, and that people learn by making bad decisions. For example, many people without developmental disabilities rely on tax accountants or doctors to explain life decisions in simple terms they can understand. This idea is called supported decision making and there is a growing international movement towards this policy. A team of people who care about the person with a disability for a Circle of Support and are asked by the person to work together to help them understand and make decisions. It does not involve taking away legal rights but does build a support team and a way to grow decision making ability and independence over time. Supported decision making does not give the team any legal authority to speak on behalf of the individual or to override their decisions. You can learn more about Supported Decision Making and view webinars on the topic at <http://supporteddecisionmaking.org/>

Dignity of Risk also means taking responsibility for decisions. People with disabilities should have the same opportunities to make decisions and learn through natural consequences as do people without disabilities. All individuals frequently consult a support team for advice about decisions, but the decision

remains the responsibility of the individual.

Legal Authority Options: Weighing Alternatives

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

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

Educational Power of Attorney

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

Medical Directive

An Advance Directive helps you and your child prepare for a future time he or she may not be able to make informed decisions or communicate his or her wishes. An Agent (parent, relative, or other trusted adult) can make healthcare decisions when necessary while still allowing the individuals the right to make decisions he or she is able to make. There are several ways to make an Advance Directive: Sample forms can be found at <http://www.virginiaadvancedirectives.org/picking-an-ad-form.html>. You and your child can talk to your doctor about making an Advance Directive, or 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 www.virginiaregistry.org.

*This information is adapted from www.dicv.org (The Disability Law Center of Virginia).

Guardianship and Conservatorship

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

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

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

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

The court may appoint only a guardian, only a conservator, or both. For most young adults with a disability, only a guardian is necessary. Typically, the young adult has less than \$2,000 in assets; the only income is from SSI or earnings that typically

can be managed by a Representative Payee or by the individual with some assistance. The extent of the guardian's or conservator's authority will be set forth in the judge's order and in the Virginia Code.

Considering Guardianship

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

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

- Overall, it is important to realize that guardianship is a **very flexible system in Virginia**.
- Guardianships can be **tailored to the needs of your child**, allowing parents to remain in a strong advocacy position.
- As part of that flexibility, **guardianship need not take away all or even many of the individual's rights**. It is very common, for example, to preserve the right to vote, the right to hold a driver's license, and other rights.
- Even under guardianship, your adult child **can still participate in decision-making** about his or her life to the extent of their capabilities. The guardianship order will typically say that the individual with a disability will be consulted and his/her wishes taken into account.
- **Guardianship does not make you financially responsible for the person under guardianship**. For example, parents who are guardians do not have to provide food and shelter for their child but would be responsible for making the *decisions* about where their child would live and the kind of care he or she would receive.
- As a guardian, **you are not responsible for the financial, civil, or criminal liabilities of your child**. If an individual under guardianship hurts

someone or something, the guardian is not liable. If they were, few people would be willing to serve as a guardian.

- Your child remains eligible for government benefits. There is no loss of government benefits because someone has a guardian. The guardian's income and assets are not counted when computing benefits for one adult individual with a disability.

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

Obtaining Guardianship

To obtain guardianship, parents need to file a petition with the Circuit Court of the jurisdiction in which the individual lives. Typically, parents are appointed as co-guardians, which allows either parent to act independently.

You must provide a medical or psychological evaluation of your loved one that supports the need for guardianship. You may ask the court to appoint standby guardians who would serve when you no longer can.

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

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

year to the local Department of Social Services—the court will provide a form.

If you are interested in pursuing guardianship or other legal authority options, visit The Arc of Harrisonburg and Rockingham's Resource Guide at www.hrarc.org

Weighing Alternatives

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

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

For example, an individual needing some assistance may be able to sign a Power of Attorney or Advance Medical Directive, appointing you or another family member as their agent for decision-making.

It's important to remember that the individual must be capable of understanding what they are doing when they execute a Power of Attorney or Medical Directive. A Power of Attorney or Medical Directive *does not allow you as the agent to override the decision of the individual with the disability*. So if the individual enters into a contract he or she did not understand, the agent under a Power of Attorney cannot void that contract. If the individual is in the emergency room yelling that they do not want a shot or test, the agent under the Medical Directive cannot override that decision.

¹Thanks to Kelly Thompson, Esq., for her work on this section and her insights on issues parents face in deciding on guardianship

Determining a Decision-Making Role

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

APPENDIX 7: WORKING WITH SCHOOL-BASED TRANSITION SERVICES

All three localities offer transition and employment services to students aging out of the school system and into the adult world. In fact, one should ask their school counselor at age 14 about getting into the DARS system. Ask the transition coordinator in your student's school about how the transition process works and for recommendations to both school-based and public vocational programs.

Localities vary in the services they offer to transitioning students. Ask if your school system offers any of the following:

Functional life skills programs to provide various skill development activities to increase career/technical integration, social competence, community integration, personal growth, health and fitness, domestic living, and functional academic skills.

Job coaching services for students who display job-readiness skills for independent employment, but who will need specialized, short-term support and training.

School-based career assessments to provide simple career interests and aptitude reviews to assist students in selecting fields of exploration or training.

Individualized career assessments, which may include individualized set of interest inventories, standardized tests and exploration activities designed to build a comprehensive picture of a student's interests, aptitudes, employability behaviors, and career decision-making skills.

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Harrisonburg City Public Schools
1 Court Square
Harrisonburg, VA 22802
(540) 434-9916
www.harrisonburg.k12.va.us

Rockingham County Public Schools
57 Mt. Clinton Pike
Harrisonburg, VA 22802
(540) 564-3230
www.rockingham.k12.va.us

Virginia DARS Office
351 N. Mason Street
Harrisonburg, VA 22802
(540) 434-5981
John.Jackson@dars.virginia.gov

Project Search

<https://www.projectsearch.us/>

Locally, Project SEARCH operates a program at Inova Alexandria Hospital. This high school transition program is a one-year, school-to-work program that takes place entirely at the workplace. Total workplace immersion facilitates classroom instruction, career exploration, and relevant job skills training.

For more information on transition services available in The Harrisonburg-Rockingham area, contact your local High school guidance counselor or Special Education Teacher.

ETRs facilitate students' transition to post-secondary life by providing transition and employment services while the student is still in school. Employment services include job-seeking skills, job development and job placement, job maintenance, and work-based learning. Transition services include information sharing about postsecondary options and resources, referrals to school-based services, support to students in their final year of school, and referrals to adult service agencies upon graduation.

Career and Transition Services also provides a number of services and instructional programs to enhance career and college readiness. These include Career Assessment, Work Awareness and Transition (WAT)

class, Education for Employment (EFE) class, and Academy Support.

Exploring Resources

High school transition coordinators can also give you more information on the following adult service events held throughout the year.

Provider Resource Fairs—Check with local colleges, Trade, and High Schools.

Future Quest (at local Universities.) College and career event for middle and high school students.

Wilson Workforce and Rehabilitation Center (WWRC)

In addition to the local school systems, The Commonwealth of Virginia also offers programs through the Wilson Workforce and Rehabilitation Center (WWRC) to help transitioning students:

Post-Secondary Education Rehabilitation and Transition Program (PERT)

The PERT program provides public high school comprehensive assessment of vocational, and independent living, social and recreational skills. Eligible students must be age 16 and older, with a full scale IQ of 60 or evidence of good adaptive skills; the student must be returning to school the fall after the PERT session (in other words, you cannot be in your last year of school).

PERT offers the following:

- Life Skills Evaluation
- Vocational Evaluation
- Therapeutic Evaluation
- Vocational Training Programs

To apply for PERT, contact the transition coordinator in your high school. You would need to have an open case with Department for Aging and Rehabilitative Services (DARS) to be considered. For more information about PERT, go to

<https://www.wwrc.net/pert.htm>

Appendix 8: EXPLORING INTERNSHIP PROGRAMS, TRANSITION PROGRAMS, AND POST-SECONDARY RESOURCES

Northern Virginia Community College

Director of Disability Services

Dr. Joan Ehrlich; www.nvcc.edu/disability-services

Transition Programs

MOST Program

Meaningful Opportunities for Successful Transitions (MOST) is a one year individualized program of activities and training designed to facilitate successful transition into the adult community. The program focuses on facilitating outcomes for participants in three domains:

- Self-sufficiency — including self-help, independent living and safety skills.
- Community — including social skills, transportation and recreation.
- Vocation — including employment, education, vocational training and day habilitation.

MOST accepts CSB and Waiver funding. For more information,

<https://www.jfgh.org/services/services/>

Post-Secondary Resources

George Mason University LIFE

Program is a post-secondary program for young adults with Developmental Disabilities who desire a university experience in a supportive academic environment.

<https://masonlife.gmu.edu/>

Program Director: Heidi J. Graff,
Ph.D. (703) 993-3905

College Living Experience

Provides post-secondary supports to young adults with varying disabilities.

www.experiencecle.com

Montgomery College, 401 North Washington Street, Suite 420 Rockville, MD

CLE also offers a 3-week summer program for diverse learners entering their senior year or who have recently graduated.

<http://experiencecle.com/summer-program-2/>

College Internship Program (CIP)

www.cipworldwide.org

A comprehensive post-secondary support program
For young adults on the autism spectrum and for
those with learning differences.

Bass Educational Services, LLC

Provides educational consultation for families and
Students with learning differences.

www.basseducationalservices.com

Post Secondary Online Resources

www.heath.gwu.edu is an online clearinghouse on
post- secondary education for individuals with
disabilities

www.thinkcollege.net is an online database to
research college programs for students with
intellectual disabilities.

www.bestcolleges.com/resources/disabled-students/
provides an overview of college resources for people
with disabilities.

HIGH SCHOOL versus COLLEGE
Individuals with Disabilities Education Improvement Act
And the Americans with Disabilities Act

High School (IDEIA)	College (ADA)
An IEP drives all accommodations and services, involves the teachers and counselors, and always requires a parent's signature for students under age 18.	There is no educational plan, and instructors are not contacted except by the student. Parents often may not receive a student's grades without written permission from the student.
A student qualifies for public education because he/she is the appropriate age and has a disability.	<i>Otherwise qualified</i> means that a student must meet all entrance and academic requirements, whether or not they receive accommodations.
Under IDEA, children with disabilities are entitled to a "free and appropriate public education."	Students have civil rights for which they must advocate to ensure equal access to higher education. No one is entitled to anything.
Public schools are responsible for appropriate assessment of a student's disabilities.	Colleges are not required to assess students, but can expect students to provide proof of disabilities with accepted guidelines.
Student placement is determined by the student's IEP team. Placement must be in the least restrictive environment that is appropriate for the student.	Students are integrated in the college community, and the environment may be adjusted through accommodations. Colleges do not deliberate to select an environment in advance.
A student's disability and needs are documented in his/her IEP. This information is available for staff involved with the student.	Need to Know: Students must give express permission for college professors to be notified of their disabilities. Students must initiate all actions toward receiving accommodations with each individual professor, for each course, for each semester. Students have the civil right to refuse accommodations they do not want or need.
Assessment, physical or occupational therapy, speech and language services, personal care, and/or any other therapy is provided by the school, as outlined in the student's educational plan.	College students are responsible for any and all personal services, such as personal or medical care, just as if they were living independently and not attending college.
A student may receive untimed tests if the need is documented in his/her educational plan.	Untimed tests are not considered reasonable. Time extensions may be reasonable (typically time and one-half, but no more than double time).

APPENDIX 9: PREPARING FOR WORK

Figuring out what to do for a job or career is a challenge for every young adult. While your child may already know what jobs he or she would be good at (or what they really *don't* want to do), most young adults are not very familiar with what it takes to prepare for and get a job.

And it takes time to figure it all out. Parents and students should take these five steps and get started in middle and high school thinking about work and work-related skills. For more information on employment for individuals with disabilities, see *Entering the World of Work: A Guide to Employment Programs for Adults with Disabilities* in online at <http://www.hrarc.org>

Step 1: Get Work-Type Experience

Be creative in thinking about what your child already does and how that might teach job skills or be expanded into a career interest. Most people begin learning about the world of work through activities such as: chores at home; volunteering; activities pursued in Boy or Girl Scouts; and through courses that teach job-related skills like computer repair or animal care.

For volunteer experiences, explore the following:

Volunteer Match

www.volunteermatch.org

Step 2. Assess Work Interests and Skills

Use the Positive Personal Profile to get an overall picture what your son or daughter would like to do for a job or career and what talents, traits and skills they bring to the workplace. As much as possible, have your transitioning student participate in this conversation; this is the place for him or her to be honest about likes and dislikes and about any support they feel might be needed.

The profile will also help you figure out what things *other* than skills and talents would make you happy and successful on a job, such as:

- The type of job you'd prefer, such as service jobs that entail a lot of customer/client contact vs. production or materials handling

jobs that may involve less contact with the public or co-workers.

- The on-the-job environment, which includes the size of the physical space you'd work in, noise level, and indoors vs. outdoors.
- Your boss and co-workers (preferences for working as part of a team vs. more independently)
- Your work schedule: full time, part time, weekdays vs. weekends, day vs. night shifts
- Commute. Factoring in how to get to a job, how long that commute takes, and how much it costs is important in considering a job's suitability.

The profile should be a work-in-progress; consider reviewing it every year as you get more academic, volunteer or paid work experience.

Step 3. Meet with the Transition Coordinator

The transition coordinator at your high school is the best first stop for information on post-secondary options, including vocational, employment, day support programs, college, and DARS. Localities vary in the services they offer to transitioning students.

How Parents May Help

- Help your child draft a resume. Share with transition staff at school and DARS counselor.
 - Discuss with the transition team any accommodations and supports that you and your student have agreed might be needed.
 - Advocate when needed, but let your child speak for him or herself as much as possible.
 - Attend IEP meetings, share the Positive Profile, and contribute your ideas for IPEs and other plans or goals related to your student's employment.
-

POSITIVE PERSONAL PROFILE

Name: _____

Dreams and Goals	Talents
Skills and Knowledge	Learning Styles
Interests	Positive personality traits
Temperament	Values
Work Experiences	Support System
Specific Challenges	Solutions and Accommodations

Work Experience ideas and possibilities to explore:

Source: Richard G. Luecking. *The Way to Work: How to Facilitate Work Experiences for Youth in Transition.* (Baltimore: Paul H. Brooks Publishing Co., 2009), pg. 55

4. Pursue Eligibility for DARS

NOTE: DARS is updating their mission scope at this time. Suggest contacting one's school counselor for the latest information.

DARS provides short term support services to help individuals with disabilities prepare for the workplace, find a job, and get needed support once on the job. DARS focuses on community-based competitive employment (offering at least minimum wage).

Ask your school counselor **at age 14** regarding DARS. DARS recommends that students explore Vocational Rehabilitation (VR) services three years before they plan to graduate high school. This early involvement helps students get to know their VR Counselor and helps the counselor work with the student to outline activities that lead to achievement of the employment goal.

DARS Services include: Assistive Technology, Career Exploration, Career Guidance and Counseling, Job Development, Job Placement, Job Shadowing, On-the-Job Training, Postsecondary Training and Education, PERT, Supported Employment, and Vocational Evaluation and Assessment. For more information on DARS services and to download their guide, visit

<https://www.vadars.org/default.htm#gsc.tab=0>

The Role of Your Counselor

Your Vocational Rehabilitation (VR) counselor is an expert in disability and career counseling. There is a counselor assigned to every high school in Harrisonburg and Rockingham. He or she will determine your eligibility for DARS services, help identify any barriers to competitive employment, and work on your Individualized Plan for Employment (IPE) with you.

You (or your parent) may have to sign a release so that your counselor may speak with, or get documents from, your doctors, therapists, former employers (if any), and school staff.

Becoming a DARS Client

To participate, you will go through the following steps: referral, intake, eligibility determination, needs

assessment, and plan development and implementation.

Referral

Students with disabilities (those who have IEPs or a 504 Plan) are encouraged to apply for DARS vocational services. Ask your transition specialist to refer you or you may call DRS at 800-552-5019 (voice) or 800-464-9950 (TTY)

VR (Vocational Rehabilitation) Intake

If you are still in school, your transition coordinator can set up an initial meeting for you with a DARS counselor, or you may call the local office yourself. The purpose of this first meeting is to talk about your job plans, disability, education, and any work history, as well as how DRS may be able to assist you.

At this meeting, your counselor may ask for additional information or testing (at no cost to you), such as a psychological evaluation or a rehabilitation technology assessment. You will be asked to sign a release so DARS can request your records.

Eligibility

You may be eligible for DARS if you have a goal of competitive employment in an integrated job setting and meet the criteria for eligibility. Eligible individuals have a physical, mental, emotional, sensory or learning disability that interferes with their ability to work.

Financial eligibility is based on family income. DARS uses a sliding scale which is subject to the number of dependents claimed on the latest income tax return. However, when students receive Social Security Disability (SSDI) or Supplemental Security Income (SSI) for their disability, they are presumed eligible for DARS services, if they intend to become employed.

Information from you, your records, and any new reports will be used to learn about your disability, how it affects your work capabilities and limits, and whether DARS services can help you become employed.

Eligibility review is completed within 60 days of the initial meeting. You can help by getting your records for your counselor or authorizing your counselor to request them and keeping appointments.

Evaluating Needs

If you meet the eligibility criteria, you and your counselor will discuss your vocational goal and work together to choose the type of job that's right for you.

If you need more information, your counselor may suggest a vocational evaluation (at no cost to you). A vocational evaluation can include counseling, testing, work samples, and on-the-job evaluations. The results help you both learn about the types of jobs you can do and are most interested in doing.

Next, you and your counselor will jointly decide **what services** you need to get ready for and find that type of job. Services provided without cost include:

- Career Exploration
- Career Guidance and Counseling
- Disability Awareness Counseling
- Follow-up Services after job placement
- Job seeking and placement (no required job coach)
- Vocational Assessment
- On-the-Job Training program
- Unpaid Work Experiences

Services that may have a cost share include:

- College
- Training programs
- Durable medical equipment or other goods
- Assistive technology
- Therapies or other medical services
- Supported employment (working with a job coach)
- Job seeking
- Job placement follow-along services

Individualized Plan for Employment (IPE) After DARS eligibility is established, you and your family work with the VR counselor and/or a potential service provider to write an Individualized Plan for Employment (IPE). The IPE:

- Focuses on the goal of employment
- Outlines steps needed for employment goal
- Plans for necessary services and funding

In thinking about necessary services, you, your parents, and the VR counselor take into consideration anything that may affect your ability

to prepare, qualify, or apply for a job or stay on a job. These issues include: mobility, self-direction, self-care, interpersonal skills, communication skills, work skills, organizational skills, self-advocacy skills, stamina, money management, and medication management.

By signing the IPE, you are promising to take the steps in your plan to become employed. You also show that you made the IPE planning decisions jointly with your counselor, parents or guardians. Ask questions to be sure you understand your role, rights, and responsibilities under the IPE. IPEs are reviewed at least once a year.

You must tell your counselor about any changes that affect your vocational rehabilitation (address or telephone number, financial situation or family size, medical insurance, your disability or general health, or government benefits).

DARS Resources

Wilson Workforce and Rehabilitation Center

(WWRC) located in Fishersville, VAWWRC provides people with disabilities comprehensive and individualized services that lead to employment and improved independence. WWRC provides vocational evaluation and training, medical rehabilitation, life skills evaluation and training, assistive technology, and other services. To learn more about WWRC, visit <http://wwrc.virginia.gov>

Pre-Employment Readiness and Education Program (PREP)

PREP is a nine week introductory program divided into three week modules at the WWRC. Clients participate in classes designed to provide a foundation of soft skills as part of their transition to employment and independence. On- and off-campus activities provide an introduction to issues ranging from money management, grocery shopping and cooking, to personal health care, disability awareness, self-advocacy, and job-seeking skills. For more information, go to

<http://wwrc.net/LSTP.htm>

Additionally, clients have an opportunity to earn the Career Readiness Certificate (CRC) while in the Pre-Employment Readiness and Education Program. Virginia's CRC is an assessment-based credential that gives employers, career seekers, and workforce

professionals information and access to a uniform measure of key workplace skills demonstrated by a client.

To apply, contact your DARS counselor. If the team is in agreement, you complete an application with your counselor; the application then goes to the WWRC admissions committee, which makes the final decision.

DARS Limitations

DARS does not guarantee a job at any time. You must continue to conduct your own job search. It also cannot promise to send you to school or other type of training.

If and when DARS funding is limited, the law requires DARS to prioritize its services (called Order of Selection) to those with the most severe disabilities and functional limitations (defined by DARS as a vocational barrier or impediment due to a disability that affects mobility, self-direction, self-care, interpersonal skills, work skills, communication or work tolerance).

WORKING WITH AN EMPLOYMENT SERVICE ORGANIZATION

DARS contracts with outside vendors called Employment Service Organizations (ESO) to provide many of the short -term employment services to eligible clients. For example, you may meet with a VR Counselor to determine that you are eligible for situational assessments, but then the VR Counselor from DARS will contract with an employment specialist from an ESO to actually take you to participate in a situational assessment. These vendors may be private nonprofit or for-profit organizations.

The Role of the Employment Specialist

Once a DARS client, you will work closely with either a vocational counselor from DARS or an employment specialist from the employment service organization that has contracted with DARS. As a prospective employee, the employment specialist helps you: prepare for, get and stay on a job communicate with your family about your progress; complete necessary applications and resumes; assist you with initial

training as needed; and identify transportation resources as well as travel training.

Employment specialists also work with individual employers to ensure there's a match between the job requirements and your skills, including: working with the employer to find out about available jobs; working closely with hiring manager to determine the scope of work; analyzing the work environment to identify the essential tasks and cultural aspects of the department; assisting the human resources department with scheduling and planning the interview; identifying accommodations and/or adaptations you may need; communication with the employer to evaluate your progress; and providing disability awareness training for co-workers as needed.

The specialist also coordinates with your DARS counselor on job strategies, concerns of the employer and co-workers, and development of natural supports in the workplace.

Job Development Process

There are four phases to the job development process:

Situational Assessments (about 1 month)

Situational assessments (going to a job site and practicing the tasks) allow the job coach to see how an individual might perform in a particular type of job. Information gathered during the assessment helps determine interest, skill level, preferred environment, and other issues before the job search begins. Not everyone wants or needs a situational assessment.

How Parents May Help

- ✓ Reinforce workplace expectations with your son or daughter, such as grooming, appropriate dress, and punctuality
- ✓ Provide feedback to counselors about the work experience from what you are seeing and hearing at home from your child
- ✓ Ask for feedback about how your child is doing on the job from the employment specialist's and the employer's point of view
- ✓ Offer to help solve challenges on issues such as transportation and special accommodations
- ✓ Support your child with increasing their responsibilities, such as having them be accountable for chores around the house. No task/responsibility is too small to start with and can be built upon.

Job Development (2-6 months)

This phase comprises the actual job search and preparation for job interviews: networking, looking for job openings, writing or updating the resume, developing a cover letter, practice filling out employment applications and interviewing.

Placement and Training

When an appropriate job is found, the vendor can go on the interview, and help determine any needed accommodation. Once on the job, your specialist becomes a job coach to help train you for the job and communicate with you, the employer and your family on how strategies to ensure you are successful.

Job coaching with competitive employment has a limited time frame; you go through an initial phase of working together very closely until you feel comfortable being independent. The amount of intervention on the job depends on the need of the consumer. The job coach begins to fade as the client is able to perform without assistance and things are going well on the job.

Once the client is stable on the job with less than 20% intervention from the job coach, the team will discuss next steps. Travel training may be part of the contract with the vendor. Coaching may also include referrals to outside community resources needed for success in the placement.

Closing your Case In general, after you have been working and stable on the job for at least 90 days, you and your counselor will close your DARS case. Before closing your case, your counselor will stay in touch to make sure the job is right for you and that you and your employer are satisfied.

DARS may also close your case if you are no longer eligible, if services will not result in your employment, or you have not met your responsibilities.

If you think you need additional DARS services after your case is closed, you may ask your counselor to re-open your case. You may also contact the ESO that provided worked with DARS to provide your services.

Choosing an Employment Services Organization

Once DARS funding ends, money for continuing, long-term support may be funded by a Medicaid Waiver, the local Community Services Board (CSB), or privately paid by the family. The CSB is the first point of entry into the publicly funded system of services for people with Developmental Disabilities.

You may want to interview a number of providers and then select the one who you think will be most successful for you. Begin by visiting their websites and then schedule a meeting.

Reminders

- The following questions are a general guideline to assist you as you meet with and tour employment service organizations. As you prepare, you will begin to think of questions that are more specifically related to the particular needs of your son or daughter. Don't hesitate to ask any questions
- Prior to the meeting with the ESO, it is suggested that you have a firm understanding of what funding sources you are affiliated with (Community Service Boards, Department for Aging and Rehabilitative Services, Medicaid Waiver, Self-Directed Services). Learn about what support options are available to you.
- As you begin to interview ESOs, the process will raise additional questions that you may never have considered. If you feel the need to do second interviews to complete a more specific comparison of services, take the extra time to re-interview.
- Share your capabilities, skills, needs and goals.
- Consider the following when making your decision: How did the provider answer your questions? Did they treat you with respect? Do you like the staff members? Did they present themselves in a professional manner?

Examples of Questions to Ask Employment Service Organizations (ESOs)

- How does your organization develop job leads for people?
 - What companies have you placed people at and in what types of jobs?
 - What type of feedback on job development and training do you provide for the family?
 - Will the job developer also provide the on the job training or will another individual be hired to do so (job coach, natural supports set up, co-worker, trainer)?
 - Describe some of the factors you consider when matching an employment site and the individual.
 - What is your marketing approach with a new, prospective employer?
 - How many people does your organization service in supported employment?
 - What kind of activities will you do with the individual to better acquaint yourself with them?
 - Do you provide travel training to and from the job site?
 - What costs are involved and who pays? What sources of funding do you accept?
 - What will our communication look like?
 - What other support services or training does your organization provide? Social skills, independent living skills, communications skills training? Volunteer experiences? Community Integration Services?
 - What do you do if I need additional help after I have found a job?
 - Do you offer any services while I am looking for a job? For example, soft skills instruction, meaningful community and/or volunteer experiences? If yes, describe them. How often are services provided in the community?
-

Employment First is a national movement rooted in the premise that all people, including individuals with significant disabilities, are capable of competitive, community-based employment.

Employment First is a framework for systems change efforts. The initiative calls for raising expectations, implementing better practices, and aligning policies and reimbursement structures to promote competitive, integrated employment opportunities for all.

In February 2012, Virginia Senate Joint Resolution No. 127 was passed, establishing a formal Employment First policy in the Commonwealth. Employment in the general workforce is the first and preferred option for Virginians with disabilities receiving assistance from publicly financed systems.

Models of Employment & Funding Sources

At present, employment and day support services for individuals with disabilities fall into the varying models described below.

Under the Employment First legislation, the first option should always be placement of individuals with disabilities in community *competitive* employment, making *minimum wage or higher*, in an integrated setting.

DARS is the first payer for short term services needed to place individuals in Individual Supported Employment. Once an individual is able to obtain and maintain a job for 90 days, DARS funding phases out and if available, Waiver or CSB (Community Services Board) funding phases in. If DARS cannot serve an individual (he/she may not be found eligible by DARS or there is a waiting list, Waiver can provide all the funding from the beginning).

The CSB is the initial point of entry for public funding in your locality for support for individuals with developmental disabilities. Services include support coordination, individual and group supported employment and day support services. Services are contingent on funding availability and eligibility criteria.

Supported employment falls into two models:

Individual Supported Employment is defined as intermittent support, usually provided one-on-one by a job coach to an individual in a supported position who,

during most of the time on the job site, performs independently.

Group Supported Employment is defined as continuous support provided by staff to eight or fewer individuals with disabilities in a contract position with a local company or for a mobile work crew that does jobs in a variety of places around the community.

Job Search and Training Resources Workforce Innovation and Opportunity Act (WIOA)

A Federal job training program sponsored by the Department of Labor. Through a network of One Stop Centers, WIOA offers employers and job seekers universal access to free employment and training services. WIOA assists workers with tools to manage their career and helps employers find skilled workers. The primary goal is to increase employment, job retention, earnings, and occupational skills among all employer and job seeker populations including individuals with disabilities. To find a One Stop Center in your local area, visit

<http://www.elevatevirginia.org/career-seekers/one-stop-centers/>

Hire Autism

www.hireautism.org

Created by the Organization for Autism Research (DAR). This website is for individuals on the autism spectrum offering a job board, direct access to local employment opportunities, a profile builder, and helpful resources for the workplace.

Day Support Services

These services should provide meaningful day activities and do not involve paid employment. Activities are provided in small group or one-to-one settings. The focus is on supporting people with disabilities to access community activities where most people involved do not have disabilities. Activities include general community integration activities such as recreation and leisure, improving social skills, activities of daily living practiced in the community and volunteer experience. This

option typically serves individuals who have a high level of daily living support needs throughout the day and who need more support to develop vocational skills.

If the person does not want to work, Day Services can be pursued through the waiver or the CSB without needing to go through DARS first. DARS will not fund Day Support because it is not related to employment.

EMPLOYMENT AND DAY SUPPORT SERVICE ORGANIZATIONS

Vendor	Websites	Services Provided	Funding Sources
The Arc of Harrisonburg-and Rockingham 620 Simms Avenue Harrisonburg, VA 22802 (540) 437-9214	www.hrarc.org	Day Support Services	Waiver CSB DARS
Friendship Industries 801 Friendship Drive Harrisonburg, VA 22802 (540) 434-9586	www.friendship-industries.com	Individual Supported Employment Training	DARS CSB
Consumer Vocational Rehabilitation DRS Harrisonburg Office 1909 E. Market St. Harrisonburg, VA 22801 (540) 434-5981	https://vadars.org	Provides some training Helps people get ready for, find, and keep a job	Funds provided for those that are eligible. Funds can be provided on a sliding scale.
Wilson Workforce Rehabilitation Center 243 Woodrow Wilson Ave. Fishersville, VA 22939 (540) 332-7065 1-800-345-9972	https://www.wwrc.net/	Comprehensive and individualized services that lead to employment and independence	DARS
Shen-Paco Industries, Inc. 1030 Wissler Road Quicksburg, VA 22847 (540) 477-2049	https://shen-paco.org/	Vocational, educational, developmental, and rehabilitation services to Shenandoah and Page Counties Supported employment	CSB DRS Waiver
The Choice Group 4807 Radford Ave. #106 Richmond, VA 23230 (804)278-9151 <i>Although headquartered in Richmond, employment specialists are located throughout Northern VA</i>	www.thechoicegroup.com	Individual Supported Employment	Waiver DARS Private Pay

EMPLOYMENT AND DAY SUPPORT ORGANIZATIONS

Vendor	Websites	Services Provided	Funding Sources
Didlake, Inc. 8641 Breeden Ave. Manassas, VA 20110 (703) 361-4195	www.didlake.org	Supported Employment Day Support Services	Waiver CSB DARS Private pay
Every Citizen Has Opportunities (ECHO) 71 Lawson Road, SE Leesburg, VA 20177 (703) 779-2100	www.echoworks.org	Supported Employment Day Support Services	Waiver CSB DRS private pay
Job Discovery, Inc. 10345 Democracy Lane Fairfax, VA 22030 (703) 385-0041	www.jobdiscovery.org	Supported Employment Day Support Services	Waiver CSB private pay
Linden Resources, Inc. 750 South 23rd Street Arlington, VA 22202 (703) 521-4441	www.linden.org	Career Readiness Transition Program Supported Employment Day Support Services	Waiver CSB DRS private pay
MVLE, Inc. 7420 Fullerton Road Suite 110 Springfield, VA 22153 (703) 569-3900	www.mvle.org	Supported Employment Day Support Services	Waiver CSB DRS
ServiceSource, Inc. 10467 White Granite Drive Oakton, VA 22124 (703) 461-6000	www.servicesource.org	Supported Employment Day Support Services Assistive Technology Screening Career Center	Waiver CSB DRS private pay
Saint Coletta of Greater Washington 207 S. Peyton Street Alexandria, VA 22314 571-438-6940	www.stcoletta.org	Supported Employment Day Support Services Life Skills Training	Waiver CSB DRS private pay
St. John's Community Services, Inc. 7611 Little River Turnpike #404, Annandale, VA 22003 (703) 914-2755	www.sjcs.org	Supported Employment Day Support Services	Waiver CSB DRS private pay

Alternatives to Traditional Employment & Day Services

Self Directed Services in Rockingham County

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

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

SD Services are available to individuals with intellectual disabilities who meet CSB service eligibility requirements and currently receive or will be authorized to receive day support or employment services funding.

SPARC (Specially Adapted Resource Clubs)

Is a clubhouse model day program that supports adults with disabilities over the age of 22 with life skills development, entrepreneurial projects and enrichment activities such as music and art therapies.

Employment & Transition Support Service Providers

Next Level Transition Consulting

Provides support for transition services, career exploration, career planning and job coaching, and drop-in independent living support. Accepts private pay and DARS funding.

www.nextleveltransition.com Contact: Scott Wilbur, Transition Director (571)332-2992
scottwilbur@nextleveltransntion.com

Starfish Savers

Services provided include consultation and advocacy, coaching and life skills, and community based transition coaching. Accepts private pay and DARS funding.

www.starfishsavers.com

Contact: Larrie Ellen Randall (703) 631-9551
Larrie.Ellen@starfishsavers.com

Creative Models of Employment Support

Cameron's Coffee & Chocolates

Started in 2013, Every1 Can Work is a non-profit organization that employs people with disabilities at their business enterprise, Cameron's Coffee & Chocolates. Employees learn kitchen and life skills working with coaches.

www.every1canwork.com

9639 Fairfax Blvd., Fairfax, VA (703)278-2627

Breadworks Bakery & Deli

Provides jobs and job training to people with disabilities.
Preston Plaza Shopping Center
923 Preston Avenue
Charlottesville, VA 22903
info@breadworks.org
www.breadworks.org
(434) 296-4663

Shen Paco Industries, Inc.

A non-profit organization providing vocational, Developmental, educational, and rehabilitative services to adults with disabilities in Shenandoah and Page Counties.

1032 Wissler Road
Quicksburg, VA 22847
Shenpacoinustries.vpweb.com

For additional information on Employment, read The Arc of Harrisonburg & Rockingham's Lifespan Guide, "Entering the World of Work" www.hrarc.org.

APPENDIX 10: HAVING FUN:

Public Therapeutic Recreation Agencies

Therapeutic Recreation Offices provide recreation and leisure opportunities for individuals with disabilities. Offerings for young adults include adapted classes, social clubs, and summer camps. If you are new to the area, you may request that an assessment be completed to help the staff understand the needs of your child.

Harrisonburg-Rockingham
Community Services Board
57 N. Main Street
Harrisonburg, VA 22802
(540) 434-1941

Parks & Recreation
305 South Dogwood Drive
Harrisonburg, VA 22801
(540) 433-9168
All Harrisonburg city parks are
handicapped accessible

Dreams Come True Playground
1050 Neff Avenue
Harrisonburg, VA 22801
(540) 433-9168
Created for people with disabilities

See also FCPS Parent Resource Center
Adapted Sports and Recreation
<https://www.fcps.edu/resources>

For young adults with Asperger's Syndrome and HF autism Contact alexaspies@gmail.com or visit on Facebook
<http://www.facebook.com/pages/Cool-Aspies/329777750424551>

Jewish Social Service Agency (JSSA) Offers workshops and groups for young adults.
<https://www.jssa.org/>

Special Olympics provides opportunities for people with intellectual disabilities to train and compete in a variety of Olympic-type sports. For Harrisonburg and Rockingham, contact:

Daniel Leake
Special Olympics
21 Southgate Court
Harrisonburg, VA 22801
(540) 433-7475
dleake@specialolympicsva.org

Serves Harrisonburg, Rockingham, Page, and Shenandoah Counties. Provides training and Coaching in seasonal sports

Sentara RMH Wellness Center
2500 Wellness Drive
Harrisonburg, VA 22801
<http://www.rmhwellnesscenter.com/wellness/WellnessCenterHome.aspx>
(540) 564-5682
Chair exercises, balance improvement, swim classes and more. Membership is required

Camp Baker
<https://www.soar365.org/>
3600 Saunders Avenue, Richmond, VA 23227
Contact (804) 358-1872
or CampBaker@RichmondARC.org
Respite care services and summer camp for ages 6 through adult.

Boys and Girls Club
620 Simms Avenue
Harrisonburg, VA 22802
<http://www.bgchr.org/>
(540) 434-6060

For additional recreational venues, see the Harrisonburg & Rockingham Resources Guide on the website at:
www.hrarc.org

Summer Camps

Local therapeutic recreation agencies offer summer programs for youngsters with disabilities. In addition, look at the following resources:

Parent Educational Advocacy Training Center (PEATC)

List of summer camps/programs in Virginia for individuals with physical and developmental disabilities
<https://PEATC.org/>

College Internship Program, Summer at CIP

Two-week program teaching independent living skills and giving young adults a taste of the college experience
www.cipworldwide.org

College Living Experience

Three-week summer program for diverse learners entering their senior year or who have recently graduated. <https://experiencecle.com/>

Jewish Community Center Camp JCC

<http://www.jccgw.org/camp-youth-teens/camp-jcc/>

Summit Camp

www.summitcamp.com

Sleep-away, travel and weekend camps for teens and young adults with attention and social issues

Young Life Capernaum Camp

Five-day camp at Rockbridge in Goshen, VA for children, teens and young adults up to 23 years old.

APPENDIX 11: Getting Around

People with disabilities may benefit from travel training and from reduced fares. Taxi companies may also provide reduced rates and special services for persons with disabilities.

Non-Driver Identification Card

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

You must be a resident of Virginia to obtain an ID card. These cards have no age restriction and are available for an adult or child who does not hold a learner's permit or driver's license.

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

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

Travel Training

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

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, 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.

GETTING AROUND IN HARRISONBURG-ROCKINGHAM AREA:

Harrisonburg Transit
475 E. Washington Street
Harrisonburg, VA 22802
(540) 432-0492
<https://www.facebook.com/rideHDPT/>

Explore the Potential for Driving

The Woodrow Wilson Workforce Center (WWRC) offers comprehensive driving services.

Driving services are managed and provided through the Occupational Therapy (OT) Department. This state-certified program is comprised of Certified Driving Instructors (CDI's) and Driver Rehabilitation Specialists (CDRS's).

Occupational Therapists assess vision, perception, cognition and motor skills in order to determine an individual's feasibility for obtaining a driver's license. Having a learner's permit or driver's license is not a prerequisite for this service. Following the evaluation, a report is generated with detailed, individualized recommendations. For more information, visit <http://www.wwrc.virginia.gov/DrivingServices.htm>

Uber and Lyft

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

Appendix 12: Self-Advocacy

Increase student involvement with the transition process. A great way to build self-determination for a young adult with a disability is through the IEP process. Begin student IEP involvement early. Assist your child in communicating his or her needs, wants and dreams, but let his or her voice be heard!

- Have the student attend all meetings.
- Assist in understanding your child's abilities, interests, needs, and preferences.
- Let the student express dreams and aspirations.
- Have the student be a part of the decision-making process.
- Practice participating and learning IEP meetings at home.
- Allow your child some freedom under safe circumstances. Yes, students might not succeed, but they need to find out how to handle adversity while you can still provide assistance.
- Allow your child to experiment and try different interventions and strategies. If one intervention, strategy, or approach doesn't work, don't give up, try another!
- Encourage your son or daughter to communicate with community agencies with your support.

Resources for Self-Advocacy

I'm Determined

The I'm Determined project is a state directed project funded by the Virginia Department of Education, focuses on providing direct instruction, models, and opportunities to practice skills associated with I'm Determined behavior. The I'm Determined website offers valuable tools for youth to learn and for parents to help teach these skills. www.imdetermined.org

It's My Choice

By William T. Allen, PhD from the Minnesota Governor's Council on Developmental Disabilities

www.Mn.gov/mnddc/extr/Publications/choice/Its_My_Choice.pdf

"Dude, Where's My Transition Plan?"

A guide to promote student involvement in planning for life after high school.

<http://www.trstep.org/uploads/files/Final%20Dude%20Transition%20Book.pdf>

Autism Speaks

<https://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/self-advocacy>

Pacers (National Parent Center on Transition and Employment)

<http://www.pacer.org/transition/learning-center/independent-community-living/self-determination.asp>

Parent Center Hub

<http://www.parentcenterhub.org/repository/priority-selfadvocacy/>

Sound Out

<https://soundout.org/intro-to-student-voice/>

APPENDIX 13: EXPLORING HOUSING OPTIONS

Finding safe, convenient and affordable housing for an adult with a disability is one of the most difficult challenges facing families at the moment. This section outlines in very general terms the housing options available for persons with and without a Medicaid Waiver. For more detailed descriptions of the housing options listed here, see *Finding a Home for Adults with Disabilities* on the Arc of Harrisonburg & Rockingham Virginia's website at <http://www.hrarc.org>

Housing vs. Residential Services

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

Housing is the physical place (house, apartment, rented room), the bricks and mortar, where one lives **or** the rental assistance to pay to stay in the physical home. (Group homes are not housing in this sense, see below).

Residential services refers to the support and supervision provided by caregivers hired by individuals or through an agency.

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

Thus, the three basic options are:

1. **For those with a Developmental Disabilities Waiver including the Community Living Waiver, Family and Individual Supports Waiver, and the Building Independence Waiver, the cost of support services is paid for by the Waiver once your support team identifies and secures an appropriate service.** However, the cost of rent is separate and must be paid for by the

individual with a disability. This is typically done with Social Security income, earned income, and possibly an additional housing subsidy.

2. **For those without a Developmental Disabilities Waiver,** it will be necessary to find resources to pay for the physical housing **and** support services (if needed by the individual).
3. **For those eligible for Waivers,** it is important to note that as of the printing of this guide, Virginia has limited funding from the "State Rental Assistance Program" set aside to allow people with developmental disabilities to live in affordable housing options. This program works like a housing voucher or rent subsidy. These are available to people not only with Developmental Disability Waivers, but also those on the waiting list for these Waivers. A number of people on the waiting list have used these funds to move and worked with either a live in attendant, natural supports (e.g., family coming by to help), and/or privately hired help to secure this limited housing opportunity while waiting for a Waiver. It is estimated this program will be open through at least 2017. Have you case manager contact Jeannie Cummins (j.cummins@dbhds.virginia.gov) to learn more about this program or locally, the **Harrisonburg Redevelopment & Housing Authority at (540) 434-7836.**

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

Residential Options Funded by Medicaid Waiver. If your loved one has a Medicaid Waiver, he or she will have some options for how may be able to live and get supports in a range of settings that combine or work with a variety of residences. These options are outlined below. Note that under the newly redesigned Waivers (as of September 1, 2016), options are available based upon the need of the person with a disability as well as the Waiver they have. The Community Living Waiver is designed to support individuals with the highest level and most complex needs, the Family and Individual Supports Waiver is designed to support people with anywhere from mild to high need, the Building Independence Waiver is for individuals over 18, with limited support needs. For more details on the Waivers, see page 23 of this guide.

Also, note the services followed by an asterisk are new as of September 1, 2016 and are still in the process of being brought online and licensed by providers, though they are available per regulations and funded.

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

Visit

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

Visit

<http://www.youtube.com/user/VideosatTheArcofNoVA> to see "virtual tours" of group homes, a sponsored residential, and a supported apartment.

Residential (Public) Program Options

Options that provide housing and allow you to use either a Waiver, private funds, or natural supports to bring in services include:

1. Public Housing

Public housing is federally funded housing made available to people with low incomes. Units are often owned by a local housing authority (PHA) and funded by the Federal Department of Housing and Urban Development (HUD). To qualify for public housing, an individual must meet the public housing authority's low income requirements. In this situation, the individual must live in the specific housing developments built and owned by the local PHA in order to qualify for the subsidized housing. You could apply to have an additional bedroom in the unit for a live-in aide, if needed.

Unfortunately, the waiting lists for public housing units are very long.

2. Housing Choice Vouchers

Housing Choice Vouchers (HCVs) used to be called "Section 8 Vouchers." A voucher allows low-income individuals and low-income families to rent from private landlords at a reduced cost. The tenant pays 30% of their income towards rent, and the voucher subsidizes the rest of the cost, up to an approved Fair Market Rent amount. Once you have received a voucher, you can take that voucher with you anywhere in the country after one year, assuming the new location is willing to accept and operate the voucher for

you. You could apply to have an additional bedroom in the unit for a live-in aide, if needed.

Waiting lists are long for this general population program. However, there may be openings through the **Harrisonburg Redevelopment & Housing Authority** **(540) 434-7836.**

4. State Rental Assistance Program (SRAP)

Virginia has limited funding from the "State Rental Assistance Program" set aside to allow people with developmental disabilities to live in affordable housing options. This program works like a housing voucher or rent subsidy. These are available to people not only with Developmental Disability Waivers, but also those on the waiting list for these Waivers. A number of people on the waiting list have used these funds to move and worked with either a live in attendant, natural supports (e.g., family coming by to help), and/or privately hired help to secure this limited housing opportunity while waiting for a Waiver. It is estimated this program will be open through at least 2017. Have your case manager contact Jeannie Cummins (j.cummins@dbhds.virginia.gov) to learn more about this program.

As with public housing, a person with a disability could use staff funded with their Developmental Disability Waiver or their CCC PLUS Waiver to receive supports in a home they rent with a Housing Choice Voucher. In that situation, the person would be the tenant of the apartment.

Options with Private Funding

Many individuals with disabilities do not qualify for a Medicaid Waiver and others are on long waiting lists for these services; their families must not only find appropriate housing but find ways to pay for it. However, housing created by families often has the advantage of more closely matching the individual's needs and preferences, as well as having "built-in" monitoring and quality assurance mechanisms.

1. Microboards

A circle of support is a group of family and friends who care about a person with a disability and volunteer their time to help support that person. When a circle of support incorporates itself as a corporate entity, it can engage in business transactions on behalf of the

individual with a disability and become a microboard. This formal designation as a microboard allows the board to qualify for low-interest home loans through the Virginia Housing Development Authority (VHDA), www.vhda.com. You can contact Bruce DeSimone at 804-343-5656 bruce.desimone@vhda.com to learn more.

In addition, microboards can:

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

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

2. Shared Apartments

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

In a shared apartment, one, some, or none of the household members can have a waiver and/or care staff. However, with the waiver, you cannot "pool" support hours to have staff on site 24 hours/day. Each staff person must provide care for one individual with a disability according to that person's plan of care.

3. Renting a Room

In this arrangement, the person renting the room typically has a private bedroom as well as access to common areas, like the kitchen and living room. The advantages are cost sharing and companionship. Another advantage is that the homeowner or primary lease-holder is responsible for the day-to-day needs of the home.

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

4. Life Estates

In a life estate, a homeowner grants a "life tenancy" to a person with a disability (your child, for example) who is then entitled to live in that home for the remainder of his or her life. Upon the death of the life tenant, ownership of the home would revert to another family member, a non-profit, or a combination of both.

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

Keep in mind that *many service providers would be hesitant to manage supports for a life tenant if they were not deeded the home after the life tenant passed away.* You would also need to have an agreement on care arrangements if the life tenant is no longer able to stay in the home because their needs or wishes change.

5. Shared Home Purchase

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

For this model to work, the families would likely have to buy the home outright. If there were a mortgage, it would be very difficult to get the loans and deeds to work together, particularly if/when one of the residents wanted to move out. The families should work with their lawyers to draw up rules for selling shares of the home and shared costs.

For an in-depth review of housing, download our Lifespan Guide: Finding a Home for Adults with Disabilities at www.hrarc.org

6. Tax Credit Units

Developers identify a certain number of units at a property and provide a preference in leasing these units to people with developmental disabilities. Note that some tax credit properties with units that have a leasing preference have project-based rent subsidies, while others accept rent subsidies like Housing Choice Vouchers

or State Rental Assistance. To find out more, contact the DBHDS Housing Specialist, Jeannie Cummins at cummins@dbhds.virginia.gov and visit <http://www.dbhds.virginia.gov/developmental-services/housing/housing-team>

HOUSING - General

Harrisonburg Redevelopment & Housing Authority
286 Kelley Street, 22802, PO. Box 1071
Harrisonburg, VA 22803
www.harisonburgrha.com
(540) 434-7386
Helps with housing and Section 8 Housing Vouchers

Virginia Home
1101 Hampton Street
Richmond, VA 23220
Lifelong residential care to adults with permanent physical disabilities

Assisted Technology Loan Fund Authority
1602 Rolling Hills Drive
Richmond, VA 23229
www.atlfa.org
(804) 662-9000
Low interest loans for a variety of Special equipment for eligible persons

Virginia Housing Development Authority
601 S. Belvidere Street
Richmond, VA 23220
<http://www.vhda.com/Renters/Pages/accessibleRentalHousing.aspx>
Info about applying for microboard loans and info about grants to make accessibility modifications to rented units

Virginia Individual Development Accounts Program (VIDA)
For individuals saving for a down payment on a home, business, business equip, and inventory or post-secondary education tuition payments. Eligible participants receive training, support and \$2 in match funds for every \$1 the participant saves, up to \$4,000 match

Shenandoah Valley Community Residences, Inc.
301 N. Cameron St.
Winchester, VA 22601
(540) 536-0336
Residences for adults with I/DD

Access VA, www.accessva.org
This is a website that provides links to different accessible housing resources, incl. gov. agencies, services, etc.

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

Virginia Housing Search
www.virginiahousingsearch.com
Online database with over 87,000 listings for rental homes, about 20% of the homes on this site are accessible

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

HOUSING – Local

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

Collins & Collins, Inc.
Andrew Collins
6714 Brocks Gap Rd.
Broadway, VA 22815
(540) 383-3884

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

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

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

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

Wall Residences
Jack Wall
P.O. Box 235
Floyd, VA 24091
(540) 745-4216

Family Sharing
Jenifer Moore
P.O. Box 665
Fishersville, VA 22939
(540) 480-0182
(Sponsored residential)

RESOURCES

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

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

For further CPS information:
[www.dss.virginia.gov/family/cps/
index.cgi](http://www.dss.virginia.gov/family/cps/index.cgi)

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

If the person with DD has been injured, or suffered mental trauma, recommend taking them to the nearest hospital Emergency Room.

Not only do hospitals treat injuries, Sentara RMH has a Psychiatric Emergency Team (PET)

that is available 24/7, and will be of assistance and provide guidance to the caretaker. For Sentara RMH, the POC for In-patient and Outpatient Behavioral Health is Ms. Tina Bibb (540) 689-5451. The POC for Integrated Case Management at Sentara RMH is Ms. Cindy Harlowe.

Teach your person with DD about inappropriate touching, sexual or physical abuse, etc. Department of Health & Social Services have manuals on this subject and can be obtained in person or via their web site.

<http://www.dss.virginia.gov/family/cps/index.cgi>

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

REACH, Area One
672 Berkmar Circle
Charlottesville, VA 22901
(855) 917-8278 (Adult crisis line)
Health; sexual violence,
advocacy, & prevention, etc.

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

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

Compass Counseling Services of Virginia
298 S. Liberty Street
Harrisonburg, VA 22801
(540) 437-1605

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Stephanie Sampson
Author and Editor
Chair, Transition POINTS Committee
The Arc of Northern Virginia
sampsonstephanie5@gmail.com

Diane Monnig
Contributing Editor
Transition Manager
The Arc of Northern Virginia
dmonnig@thearcfnova.org

The Arc of Harrisonburg and Rockingham:
www.hrarc.org

John Malone, Harrisonburg-Rockingham CSB

Tom Moran, PM,
Overcoming Barriers, JMU

Shenandoah Valley Wellness
Inclusive Coalition

Renee Scholten, Executive
Director
REACH