SECURING A FUTURE FOR YOUR CHILD WITH A DISABILITY

A Guide to Transitioning from High School to Adult Services For Adults with Disabilities in Alexandria, Arlington, Fairfax & Falls Church





Providing Opportunities, Information, Networking and Transition Support

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

October 2019

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

The printed version of this guide is prepared periodically. As information changes, updated information and resources may be found in the Resource Library on our website www.thearcofnova.org

This guide, as well as, translations of the series of Transition POINTS guides in Spanish, Vietnamese, Chinese, Arabic, and Korean are available to download at https://thearcofnova.org/programs/transition/. Translations are made possible by a grant from the Virginia Board for People with Disabilities. Additional support was provided by the Rotary Club of Alexandria. The Amharic translation of this guide is made possible by a grant from the Alexandria Fund for Human Services.

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For additional Resources on all of these topics, check out The Arc of Northern Virginia's

- Resource Library for fact sheets and sample templates https://thearcofnova.org/programs-services/library/
- Provider Directory for contact information for attorneys, therapists, recreation, and more https://thearcofnova.org/directory/
- Special Needs Trust Website https://thearcofnovatrust.org/ for information on SNT and ABLE
- YouTube Channel with archived webinars on a variety of life planning tools topics https://www.youtube.com/user/VideosatTheArcofNoVA

INTRODUCTION

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

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

- 80% of families surveyed don't have enough money for needed care and almost half report having more caregiving responsibilities than they can handle
- 85% report that their adult family member with ID/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 Transition POINTS

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

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

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

The information found in this guide is applicable to all people with intellectual and developmental disabilities and their families, although much of the contact information for resources are particular to the Northern Virginia area. To explore resources specific to your local community, contact the Community Services Board (CSB) in your region. You can find your local CSB by visiting DBHDS (Department of Behavioral Health and Developmental Services) at

http://www.dbhds.virginia.gov/community-services-boards-csbsor. The CSB is the point of entry into the publically funded system of services for people with mental health, intellectual and developmental disabilities. Also, visit The Arc of Virginia at www.thearcofva.org to find the local Arc chapter in your community. To find the local Department of Aging and Rehabilitative Services in your area, visit https://www.vadars.org/offices.aspx.

Help for You, the Parent

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

<u>www.thearcofnova.org</u>, as well as, our Resource Library <u>https://thearcofnova.org/programs-services/library/</u> to find additional helpful documents and templates.

The Arc of Northern Virginia maintains a library of informative life planning and future planning videos and webinars on YouTube at https://www.youtube.com/user/VideosatTheArcof

NoVA.

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

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. Please send any comments to Diane Monnig, The Arc of Northern Virginia, Transition POINTS, 2755 Hartland Road, Suite 200, Falls Church, VA 22043 dmonnig@thearcofnova.org.

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 longterm financial security.

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

- 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.
- 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.
- 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 day support services are available. Planning for jobs starts early before a child leaves the school system, 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, 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.

How he or she will get around. Transportation training for persons with disabilities is available in all three localities. In addition, local transportation companies (including bus, subway, and taxis) in Alexandria, Arlington, and Fairfax offer programs to increase convenience and reduce the cost of transportation.

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 Northern Virginia's Guide: Finding A Home for People with Disabilities at https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/

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 transition 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

ASAP Create file for key documents	Step to Take by Age	Estate/	Post-HS	Job/Day	Leisure	Transport	Housing
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Securing a Future: A Checklist for Parents

Step to Take by Age	Estate/	Post-HS	Job/Day	Leisure	Transport	Housing
5 H C :	Legal	Education	Support			
Fall of senior year						
Apply to post-secondary schools		X				
No earlier than 17 yrs., 6 months						
Explore decision making options,	X					
including Supported Decision Making, Educational and						
Healthcare Power of Attorney, or						
quardianship.						
1 month before 18th birthday						
If pursuing guardianship, contact an	х					
attorney to prepare final						
documents for new legal						
relationship						
At age 18						
Apply for Supplementary Security	х					
Income (SSI)						
Age 18-22						
Update will. Inform family about	х					
wills, trusts, guardianship, etc.						
Explore adult recreational & social				х		
services					1	
Prepare resume, do situational			×			
assessments, go on job interviews				+		
Once accepted for SSI, apply for Medicaid.	х					
				+	1	
If working, learn about managing	Х					
job income and Social Security benefits						
If not already done, determine	х					
eligibility for Medicaid Waivers and						
contact CSB for an intake						
If not yet done, obtain Metro					х	
reduced-rate transit farecards/ID						
card; apply for Metro Access						
Explore housing resources as you						х
plan for the future						
Age 20-22						
Before graduating, decide on &			х			
choose the service provider that						
best suits your child's needs for						
either employment or day services Determine potential use of public					<u> </u>	
transportation or specialized					X	
transportation of specialized transportation services. Explore						
travel training.						

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
General Financial Planning ASAP	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, you want to safeguard their eligibility for public benefits and services and not jeopardize the relationship between the siblings and family members.	Contact an elder law 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 may also find it useful to see a financial planner.
Special Needs Trust ASAP	Create a special needs trust to allow a person with a disability to have an unlimited amount of assets held in trust without affecting his/her eligibility for federal benefits programs. Create an SNT to allow a person, parent, guardian or court, or grandparent to transfer the individual with a disability's own assets to apply for Federal benefits or to maintain these benefits.	For general information on special needs trusts, visit the Special Needs Trust Alliance at https://www.specialneedsalliance.org/ The Arc of Northern Virginia provides a special needs trust program that provides the family and the individual with a disability an affordable way to save and invest resources to enhance the quality of the person's life. Find out more at www.thearcofnovatrust.org If not using The Arc of Northern Virgini'as trust program, contact an attorney that specializes in elder care law and special needs trusts about writing a special needs trusts. Not all attorneys can prepare these documents. See The Arc of Northern Virginia's online Provider Directory at
Letter of Intent ASAP	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.	https://thearcofnova.org/directory/

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 Supplementary Security Income (SSI)	What Needs to Be Done	Who Can Help
ASAP for benefits for child with a disability	Determine if your <i>child</i> (under age 18) might qualify for SSI. The child must meet the 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 1-800-772-1213 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 http://www.vaaccses.org/wipa/ . In Northern VA, contact Marilyn Morrison, Community Work Incentives Coordinator at vaACCSES at 571-339-1305 mmorrison@vaaccses.org .
At age 18 Benefits for disabled adult	Determine eligibility for SSI as an <i>adult</i> 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.) <i>Parents' income and resources are not counted</i>	Start your application by visiting the website at http://www.socialsecurity.gov/pgm/ssi.htm You also need to call 1-800-772-1213 and ask for an appointment with a Social Security representative to complete the application either by phone or in person.
	Apply for SSI, if your adult child meets the disability and income requirements.	NOTE: Try complete the forms and prepare supporting documentation before meeting with the Social Security representative.
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: It is recommended that you charge your child with a disability who's receiving Social Security benefits for rent in the family home, Rent charged must be at least 30% of the current maximum benefit to get that maximum benefit. See Social Security regulations for details.

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
Explore Decision Making Options And Legal Authority At age 17	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.	For information on supported decision making, http://www.supporteddecisionmaking.org/. For information on varying types of legal authority options and a power of attorney template, visit the Disability Law Center of Virginia at www.dlcv.org. An Education Power or Attorney template can
Not before 17 years and 6 months	If you are seriously considering guardianship, contact an attorney experienced in elder care and disability law.	be found at https://www.fcps.edu/sites/default/files/media/forms/se340.pdf
1 month before 18 th birthday	If pursuing guardianship, have attorney prepare final documents.	To help you determine if you want to pursue guardianship, utilize our "Thinking About Guardianhip Checklist" in our Resource Library https://thearcofnova.org/program
Medicaid Health Insurance ASAP	If your child has qualified for SSI, he or she is automatically eligible for Medicaid. You still need to complete an application.	s-services/library/ For information from the Virginia Guardianship Association, visit www.vgavirginia.org. See attorneys listed online in The Arc of Northern Virginia's Provider Directory https://thearcofnova.org/directory/
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 19.	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. Alexandria: Dept. of Human Services, (703)746-5700 Arlington: DHS/DD Services, (703)228-1300

Fairfax: Department of Family

Services, (703)324-7500

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.

taken care or in the event of a parents death of alsability.			
When to Take Action	What Needs to Be Done	Who Can Help	
Medicaid Waiver Programs ASAP to get on waiting list	Persons with ID/DD may also qualify for services under the Medicaid Waiver Programs. The State of Virginia funds waiver slots, but funding is currently inadequate to meet needs statewide.	See The Arc of Northern Virginia's website https://thearcofnova.org/program s/waivers/all-about-waivers/ For general information, http://mylifemycommunityvirgini a.org/ To Apply for DD Waivers Contact your County's Community Services Board Alexandria City CSB (703)746-3400 Arlington DHS/DD Services: (703)228-1700 Fairfax/Falls Church CSB/DD Services: (703)-324-4400 For the CCC Plus Waiver Contact your County's Department of Social Services Alexandria City: (703)746-5700 Arlington County: (703)228-1350	
Employment/Meaningful Day Support Services ASAP	Begin process of determining your child's eligibility for employment or day support services from your locality.	Fairfax County: (703)324-7948	
	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.

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
Vocational Assessment Ages 12-14	Begin and maintain a record of your child's interests and strengths, career exploration activities, and skills	Vocational assessments and employment services may be coordinated prior to graduation, depending on eligibility and available
	Determine with teachers ways that school activities could prepare your child for employment possibilities	funds, through your local school system, the Community Services Board, and/or the Virginia Dept. for Aging & 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 Department of Aging & Rehabilitative Services (DARS) and the CSB. Your school transition representative and CSB support coordinator can help you navigate this process.	DARS provides Pre-Employment Training Services while in school and 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 Appendix for more information on DARS. 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, vocational, 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
Arlington Schools Transition
Coordinators

Joy Haley, Yorktown HS (703)228-2545 joy.haley@apsva.us

Christina Eagle, Arlington Career Center (703)228-5738 Christinaeagle@apsva.us

Thomas Sweet, Washington-Liberty (703)228-6265 thomas.sweet@apsva.us

Jennifer DeCamp, Wakefield HS 703-228-6728 Jennifer.decamp@apsva.us

Joyce Kelly, Stratford Program 703-228-6450 joyce.kelly@apsva.us

Brian Stapleton, Contract Services 703-228-6360
Brian.stapleton@apsva.us

Fairfax County Public Schools Career & Transition Services

Janelle Ellis, Coordinator (571)423-4150. Fairfax has Employment and Transition Representatives at each of its 29 high schools and centers. For more information on these services visit

https://www.fcps.edu/academics/academic-overview/special-education-instruction/career-and-transition-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	What Needs to be Done	Who Can Help
Age 12-17	Research information about organizations that provide employment and day support services through written and online	Vendor Resource Fairs. Arlington and Fairfax County Public Schools hold annual fairs in the fall.
	materials and resource fairs	Super Transition Saturday hosted by FCPS focuses on elementary and middle school students and is held in the winter.
Age 17 or 18 months before leaving school	Meet with transition representative who can help you arrange meetings with provider organizations or you can schedule a meeting on your own	Flash Forward. Postsecondary Education & Employment Options. Held annually and hosted by Fairfax County Public Schools.
	Before graduating, decide on the service organization that best suits your child's support needs and determine eligibility	Future Quest (George Mason Univ.) College/career event for middle and high school students held every other year; the next one is October 2019
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.	Also visit the Heath Center, an online clearinghouse on post-secondary education for individuals with disabilities, at www.heath.gwu.edu
Junior year of high school	Take required tests; arrange interviews and more visits	For other options, see www.thinkcollege.net
Fall of senior year	Apply to post-secondary schools or programs	See Appendix for post -secondary resources

RECREATION

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

When to Take Action
By age 12
Beginning at 12 and re

repeated as needed throughout lifetime of child

18+

When ready to take a class

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

What Needs to Be Done

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 Alexandria

Alexandria Recreation, Parks & Cultural Activities, Therapeutic https://www.alexandriava.gov/recreat ion/info/default.aspx?id=45758 703-746-5422

Arlington

Department of Parks and Recreation Therapeutic Recreation Office https://parks.arlingtonva.us/therapeut ic-recreation/ 703-228-4740

Fairfax

Fairfax Therapeutic Recreation Services https://www.fairfaxcounty.gov/neighb orhood-communityservices/therapeutic-recreation 703-324-5532

POAC (Parents of Autistic Children) maintains a list of recreation resources. See https://poacnova.org/wpcontent/uploads/2018/02/Adaptedsports-and-rec-list-2018.pdf

FCPS Parent Resource Center maintains a list of camps https://www.fcps.edu/node/31344

Both public and private organizations run sports, social, and therapeutic programs for individuals with disabilities. See our Provider Directory for more information https://thearcofnova.org/businessdirectory/

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 /#id/get_id.asp
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.	Travel training is provided free of charge by the ENDependence Center of Northern Virginia. www.ecnv.org 703-525-3268 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	To download an application for the Metro's Reduced Fare ID card, see: https://www.wmata.com/service/accessibility/reduced-fare.cfm
	To ensure reduced transit fares, obtain a Metro Disability ID card from Washington Metropolitan Transportation Authority. The card enables eligible persons with a disability to obtain reduced rates on Washington-area bus, subway and rail.	Find out more about accessible transportation options in Virginia, see: https://www.commuterpage.com/ways-to-get-around/paratransit-transit-accessibility/ Investigate MetroAccess paratransit options. https://www.wmata.com/service/accessibility/metro-access/ See Appendix for a list of places to obtain applications for the Metro Disability ID card and to purchase SmarTrip cards.

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	What Needs to Be Done	Who Can Help
In child's teenage years	Planning for housing is very challenging for a variety of emotional and financial reasons. Begin the planning process in early adulthood,	For more information on residential resources, see The Arc of Northern Virginia's Guide, "Finding a Home for Adults with
	even if you want your child to live with you for the foreseeable future. It is much better for housing decisions to	Disabilities" at https://thearcofnova.org/programs/transition/finding-home-adults-
At age 18	be made thoughtfully and methodically over a period of years	<u>disabilities/</u>
	than in a crisis situation.	Visit Northern Virginia Housing and Supportive Services at
	Learn the distinctions among options. Visit types of housing arrangements and look at virtual house tours on	http://www.novahss.org/
	YouTube https://www.youtube.com/user/video	
	<u>satTheArcofNoVa</u>	

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: school or work schedules; weekend activities, including religious education or attendance; bedtime routines; food and clothing preferences and sensitivities; preferred toys,

games, and exercise routines; and typical outings, for example.

Medical history: This section can be brief (diagnosis, current treatment and medication regimes) but then should state where to find more detailed information (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, etc., to give future caregivers an idea of how the individual's special needs trust and benefit monies might have to be spent.

Contact information: family members, friends, doctors/therapists, preferred pharmacy, school or employer information, lawyers, trustees and backup guardians, insurance agents, banker and financial planners, etc.

For more on the rationale for a Letter of Intent, see https://www.autism-society.org/living-with-autism/future-planning/letter-of-intent/

The Arc offers an online Future Planning tool that allows you to create, update and maintain a future plan at https://futureplanning.thearc.org/landing.

Documents to Keep on File

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

Basic identification documents: Birth certificate (often need the original), Social Security card, driver or non-driver's license, passport, Medicaid card, health insurance card.

Bank information, including any accounts opened for the benefit of your child, 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 person with a disability, 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 obtain 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 provides 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 obtain 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 on the DMAS website at http://www.dmas.virginia.gov/files/links/966/AmlEligible.pdf or call the HIPP Program at 800-432-5924 https://www.coverva.org/hipp/

Information Resources

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

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

APPENDIX 3: APPLYING FOR BENEFITS: Social Security Disability Programs

You may begin the application process for Social Security benefits once 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 video and webinar presentations on SSI/SSDI visit The Arc of Northern Virginia's YouTube channel (Videos at The Arc of NoVA) at

 $\frac{\text{https://www.youtube.com/user/VideosatTheArcofNoV}}{\underline{A}}$

SSI vs. SSDI

For both Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), a person must meet SSA's definition of disability. Disability is defined as the inability to engage in Substantial Gainful Activity (SGA) by reason of any medical (physical and/or mental or blind) impairment. Your disability must have lasted or be expected to last for a continuous period of not less than 12 months or result in death. For 2019, the wage limit for the SGA is \$1,220 gross income/month.

SSI. SSI is a cash assistance program for those with limited income AND are either 65 years old or older or blind or disabled. Adult SSI beneficiaries must have limited income and resources (\$2,000 in assets); parents' income does not count for adult applicants. You do not have to have any work history. Monthly benefit payments are determined by the current benefit rate (\$771 a month in 2019), minus any "countable income." If eligible for SSI, you will also be eligible for Medicaid.

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

Applying for Benefits

The steps for applying are:

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

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

You cannot complete the application 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) Monday through Friday or contact your local Social Security office. It is best to call the 800 number rather than the local office as field offices are under staffed and the hold times can be very long. You will be greeted by an automated answering attendant, who will prompt you to state why you are calling; say "Apply for SSI."

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

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

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

Alexandria Office

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

Fairfax Local Office

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

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

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

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

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

The Representative Payee

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

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

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

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

Housing and SSI Benefits

SSI is intended to cover living expenses such as rent, food, and utilities. For example, it is recommended that you charge your adult child rent if he or she lives in the family home. Rent charged must be at least 30% of the current federal benefit amount (\$771 a month for 2019) to get the maximum SSI benefit. It is recommended that you research comparables for your area of rooms to rent and include that with the rental agreement. Be aware that SSI benefits may be reduced under the following circumstances:

In general, about one-third of your SSI benefit is assumed to be paying for housing expenses (rent or mortgage, utilities, property insurance/renter's insurance, etc.) and the other two-thirds for other eligible expenses like food and clothing. Given Northern Virginia's high cost of living, it can be assumed that more than one third of your SSI benefit will be used to pay for housing expenses. A sample rental template can be found in our Resource Library https://thearcofnova.org/programs-services/library/

If monies from a special needs trust are used to purchase a home with a mortgage, and the **trust makes monthly mortgage payments**, then the beneficiary's SSI payments will be reduced by about one-third each month (the portion of SSI associated with housing). If you have a trust, you can transfer your rent or mortgage money to an ABLE Account, pay the rent from an ABLE Account and SSI will not be reduced. For more information on utilizing ABLE Accounts, visit our trust website at www.thearcofnovatrust.org, the ABLE National Resource Center at www.ablenow.com/.

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

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

Reporting Income

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

For additional information on Reporting Tips for Beneficiaries of Social Security Disability Programs visit our Resource Library at

https://thearcofnova.org/programs-services/library/

APPENDIX 4: APPLYING FOR BENEFITS: Medicaid Waiver Programs

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

Family income and family assets are not a consideration under the Medicaid Waiver program. If your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria. To watch our recorded webinar that walks you through Waivers from start to finish, visit

https://www.youtube.com/watch?v=3sG85EQjuKE

You can read the latest information on the new Waivers from the state at

http://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).

<u>The Community Living Waiver</u> 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.

<u>The Family and Individual Supports Waiver</u> is designed to support individuals living with their families, friends, or in their own homes. It supports

individuals with some medical or behavioral needs and is available to both adults and children.

The Building Independence Waiver supports adults 18 and older who are able to live in the community with minimal supports. This waiver does not include 24/7 residential services. Individuals will own, lease, or control their own living arrangements and supports may need to be complemented by non-waiver funded rent subsidies.

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

Eligibility Criteria

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

- (1) Functioning ability: This is determined by the VIDES survey. The VIDES has one test for children aged o-3, one for children ages 3-18, and one for adults. The surveys assess the person's need for assistance with a variety of daily living and independence skill activities. The VIDES surveys can be found in our Resource Library https://thearcofnova.org/programs-services/library/
- (2) <u>Diagnosis:</u> Persons applying for a Waiver must meet the diagnostic eligibility requirements for the DD Waivers. This means that a person must have a developmental disability as defined in 37.2-100 of the Code of Virginia.
 - a. "Developmental disability" means a severe, chronic disability of an individual that (1) is attributable to a mental or physical impairment, or a combination of mental and physical

impairments, other than a sole diagnosis of mental illness; (ii) is manifested before the individual reaches 22 years of age; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independence living, ore economic selfsufficiency; and(v) reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized support, or other forms of assistance later are lifelong or extended duration and are individually planned and coordinated. An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses 9i) through (v) if the individual without services and supports, has a high probability of meeting those criteria later in life.

(3) Financial: If the functioning and diagnostic criteria are met, then the child's income and assets are considered. Special Needs Trusts and ABLE Accounts are not considered when testing financial eligibility. People over 18 have an asset cap of \$2,000. Everyone receiving a Waiver has a monthly income cap of 300% of the current Social Security Supplemental Security Income amount (SSI is \$771 in 2019, so max monthly income is \$2,313).

The Commonwealth Coordinated Care (CCC) Plus

<u>Waiver</u> covers personal care, respite care, medication monitoring, private duty nursing, assistive technology, environmental modifications, and the Personal

Emergency Response (PERS) system. Personal care support hours may be approved up to a maximum of 56 hours per week and cannot exceed 480 hours per state fiscal year.

To be eligible for this waiver, the person must have a disability and medical nursing needs, as assessed by the Virginia Uniform Instrument (UAI) https://www.dss.virginia.gov/files/division/dfs/as/as_int-ro_page/forms/032-02-0168-01-eng.pdf

Waiting List Eligibility

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

How Long is the Wait?

The Developmental Disability Waivers have a waiting list based upon urgency of need. People in Priority One of urgency need services within the year, people in Priority Two needs services in 1-5 years, and people in Priority Three need services several years out. Wait time is unpredictable and many people on the priority one list wait many years for a waiver. As your life circumstances change, for example, you or your spouse become ill, become unemployed, etc., notify your support coordinator, as these situations will increase your urgency of need for support services.

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

Alexandria City CSB: (703) 746-3400 Arlington DHS/IDD Services: (703) 228-1700 Fairfax/Falls Church CSB/IDS: (703) 324-4400

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

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

Alexandria City: (703)746-5700 Arlington: (703)228-1350

Fairfax/Falls Church: (703)324-7948

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

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 opens one time per year and is designed to assist individuals on the waiting list for the Developmental Disability Medicaid Waivers to access short term services that will help maintain them in their own homes in their community. Information, applications, and instructions can be found at http://dbhds.virginia.gov/developmental-services/ifsp

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 decision making options and 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 attorneys can be found in our Provider Directory on our website at https://thearcofnova.org/directory/. While many wills create family trusts, to avoid jeopardizing the benefits or services of your child with a disability you need to create a separate special needs trust (see below).

Reviewing Beneficiaries

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

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

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

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

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

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

Special Needs Trusts (SNT)

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

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

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

Two Kinds of Trusts

Most special needs trusts are *third-party trusts* (family-funded trusts) established by parents or with an

authorized non-profit, such as The Arc of Northern Virginia, for their child with disabilities. The person establishing the trust, usually called the settlor, chooses to make some of his or her own assets available for the benefit of the beneficiary (person with disabilities).

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

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

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

Setting Up a Trust

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

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

Uses of Trust Funds

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

Here are some examples:

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

Acting as Trustee

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

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

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

https://www.specialneedsalliance.org/

To learn more about The Arc of Northern Virginia's Special Needs Trust visit https://thearcofnovatrust.org/ or contact Tia Marsili, Director of Special Needs Trusts for a free consultation at tmarsili@thearcofnova.org or via the website at https://thearcofnovatrust.org/make-an-appointment/. We also offer Trust Talk Tuesdays twice a month for small group discussions on special needs trusts https://thearcofnovatrust.org/events/.

ABLE Accounts

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

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

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

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

APPENDIX 6: DECISION MAKING SUPPORTS AND LEGAL AUTHORITY OPTIONS

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

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

Dignity of Risk and Supported Decision Making

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

"Dignity of Risk" also means understanding that it is okay to make some bad decisions. We are all allowed and it is often how we learn best. Many people learn from spending too much that it is hard to pay bills and learn from weight gain and health issues that they ate

too much. This is a right all people have and exercise every day. People with disabilities should have the same opportunities to make decisions and learn through natural consequences and a support team about how to proceed the next time.

Legal Authority Options: Weighing Alternatives

The appointment of a guardian or a conservator should be considered as a last resort. See the chart on page 32 for a list and description of legal authority options. Petitioners for guardianship must provide evidence, and a judge must determine, that an individual is "incapacitated" in terms of making certain decisions.

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

Educational Power of Attorney

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

www.doe.virginia.gov/special_ed/regulations/state/tra nsfer rights students disabilities.pdf. A template for Educational Power of Attorney can be found at http://www.doe.virginia.gov/special_ed/regulations/sta te/transfer rights_students_disabilities.pdf. FCPS provides a fillable PDF Education POA https://www.fcps.edu/sites/default/files/media/forms/s e340.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/; You and your child can talk to your doctor about making an Advance Directive; you can hire an attorney to complete an Advance Directive. Once your child's Advance Directive is written, it needs to be signed in the presences of two witnesses. Virginia does not require it to be notarized, but it is a good idea to do so if possible. Once you have the necessary signatures, you should give copies to the Agent, doctors, and other trusted family members. You can also registere the Advance Directive online at www.virginiaregistry.org.

*This information is adapted from <u>www.dlcv.org</u> (The Disability Law Center of Virginia.

Guardianship and Conservatorship

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

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

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

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

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

Considering Guardianship

the judge's order and in the Virginia code.

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 **flexible system in Virginia**.
- Guardianships can be tailored to the needs of your child, allowing parents to remain in a strong advocacy position.
- As part of that flexibility, guardianship need not take away all of the individual's rights. It is very common, for example, to preserve the right to vote, the right to hold a driver's license, and other rights.
- Even under guardianship, your adult child can still participate in decision-making about his or her life to the extent of their capabilities. The guardianship order will typically say that the individual with a disability will be consulted and his/her wishes taken into account.

- Your child remains eligible for government benefits. There is no loss of government benefits because someone has a guardian. The guardian's income and assets are not counted when computing benefits for an adult individual with a disability.
- Guardianship does not make you financially responsible for the person under guardianship. For example, parents who are guardians do not have to provide food and shelter for their child but would be responsible for making the decisions about where their child would live and the kind of care he or she would receive.
- As a guardian, you are not responsible for the financial, civil or criminal liabilities of your child. If an individual under guardianship hurts someone or something, the guardian is not liable. If they were, few people would be willing to serve as a guardian. Guardians do have a duty to try to arrange a safe environment for the individual.

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

To help determine if guardianship is the appropriate choice for your young adult, complete the screener. "Thinking About Guardianship Checklist" in our Resource Library under Legal Authority at http://www.virginiaadvancedirectives.org/.

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

When the petition is filed, the court appoints a guardian ad litem (GAL). The GAL is an attorney in private practice appointed from an approved list. The GAL's

primary job is to ensure that the rights of the individual with the disability are protected. The GAL will therefore meet the individual, serve him or her with the court paper-work, and explain their rights. The GAL will also make a report to the Court giving an opinion as to whether the appointment of a guardian is necessary and who should be appointed.

After the GAL has filed a report, a hearing is held at the Court. Usually the persons being appointed as guardians must attend the hearing, and after the hearing will go to the Clerk of the Court's office to complete all necessary paper-work. The individual for whom the guardian is being appointed may choose to attend the hearing or not. The typical time frame for obtaining guardianship is approximately 3 months, but may take up to 6 months. As a guardian, you are required to submit a report every year to the local Department of Social Services; the court will provide a form.

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

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

Determining a Decision-Making Role

Туре	Decision-making Responsibilities	Notes
Supported	Individual with disability makes decisions, with	www.supporteddecisonmaking.com
Decision Making	support from family or others with relevant	www.sopporteddecisonmaking.com
Decision Making	expertise	
Emorgonov	Short-term guardianship (15 days) to handle an	Local Department of Social Services must
Emergency order for adult	emergency or correct conditions causing an	apply to Circuit Court for temporary
	1	
protective	emergency	guardianship order
services	AM 211 and the 21 and 22 and 23 and 24 and 25 and 2	A I
Durable power	Written authority giving a parent or another person	Agent cannot override decisions
of attorney	(agent) power to make decisions on behalf of the	Power ends if principal revokes it or dies
	individual with a disability (the principal). Agent	
	may act even if principal becomes incapacitated.	
Power of	Written authority giving a parent or another person	Sample forms can be found at FCPS
Attorney for	power of attorney for educational decisions made	https://www.fcps.edu/sites/default/files/medi
Educational	under the IDEA	a/forms/se340.pdf and VDOE
Decisions		http://www.doe.virginia.gov/special_ed/regul
		ations/state/transfer_rights_students_disabil
		<u>ities.pdf</u>
Advance	Person with disability provides instructions about	Agent's powers are defined in the document.
Directive	his or her wishes for health care treatment and	Agent cannot override decisions.
	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.	
Health Care	Similar to durable general power of attorney, but	Enables someone to make any or all
Power of	directed exclusively at healthcare.	healthcare decisions if the individual
Attorney	Choosing the right agent is very important; make	becomes incapacitated.
	sure he or she knows the individual's wishes, values,	Doctor and family will be able to know and
	and preference and will be a strong advocate	respect the individual's wishes
Representative	Receives another person's government benefits on	Individual must be unable to manage
payee	behalf of that person; responsible for using benefit	finances. Rep Payee must report annually to
	to pay beneficiary's living expenses	the Social Security Administration
Limited	Decisions on specific financial matters, such as	Individual must be incapacitated.
conservatorship	paying bills or filling out tax returns, as specified by	Conservator must file report on income and
·	the judge. Conservator must post surety bond.	expenses
Full	All financial decisions, including paying bills,	Conservator must file annual report on all
conservatorship	investing money, and selling property. Conservator	financial transactions
'	must post a surety bond.	
Standby	Person designated in quardianship order to	Does not assume any duties until death of
guardian	become guardian when current guardian dies	primary quardian
300.01011	god ald. Then content god didn dies	F, g-aa-a
Limited	Decisions on specific issues (e.g., only health care),	Individual must be incapacitated.
guardianship	as determined by a judge. This leaves the person	Guardian must file an annual report with
300.0.0.0.0	free to make all other decisions.	Dept of Social Services
Full	Guardian makes all financial, legal, personal care,	Individual must be incapacitated.
guardianship	and social decisions	Guardian must file an annual report with
Godialansinh	and social accisions	Dept of Social Services
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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. Ask the transition coordinator in your student's high 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 jobreadiness 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.

City of Alexandria

Transition Coordinators

Based out of T.C. Williams High School, 3330 King Street, Alexandria

Ameeta Shah, Employment Specialist, Project SEARCH (703) 504-3687 ameeta.shah@acps.k12.va.us Jim Cooney, Employment Support Specialist 703-824-6800 ext.6892 James.cooney@acps.k12.va.us

Angela Brown, Employment Support Specialist (703) 824-6800, ext. 6254 angela.brown@acps.k12.va.us

Project Search

www.projectsearch.us/Home.aspx

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 Alexandria City Public Schools, visit http://www.acps.k12.va.us/curriculum/specialeducation/transition/

Arlington County Transition Coordinators

Joy Haley, Yorktown HS (703)228-2545 joy.haley@apsva.us

Christina Eagle, Arlington Career Center (703)228-5738 Christinaeagle@apsva.us

Thomas Sweet, Washington-Liberty (703)228-6265 <u>thomas.sweet@apsva.us</u>

Jennifer DeCamp, Wakefield HS 703-228-6728 Jennifer.decamp@apsva.us

Joyce Kelly, Stratford Program 703-228-6450 joyce.kelly@apsva.us

Brian Stapleton, Contract Services 703-228-6360 Brian.stapleton@apsva.us

Program for Employment Preparedness (PEP)

is a transition program, located at the Arlington Career Center. PEP opportunities are based on current business trends and needs so that students may gain relevant skills for obtaining employment in today's market, including the requisite social skills necessary to secure and maintain long-term, meaningful employment. The program is designed for students to receive internship/apprenticeship experiences and may lead to trade certifications, licenses, college credit, networking connections, and/or employment directly upon graduation.

PEP aims to increase students' work readiness skills to enhance the possibility of their obtaining and maintaining work as an adult.

Depending on student's needs, job experiences may range from a fully supported on-campus program to a fully independent work experience at a local business. Certain students will participate in Career Technical Education (CTE) courses as an adjunct to their job site experiences. PEP teachers and administrators coordinate with DARS and Arlington County IDDS case managers to support transition into adulthood.

Arlington students aged 18-21 with IEPs may be eligible for PEP. Contact your high school transition coordinator for more information or email Christina Eagle Christinaeagle@apsva.us

For more information on transition services available in Arlington Public Schools, visit http://www.apsva.us/transition-services/

Fairfax County Transition Coordinators

Career & Transition Services, 571-423-4150
Janelle Ellis, Coordinator
Fairfax has Employment and Transition
Representatives (ETRs) at each of its 29 high schools and centers. For more information on these services, visit https://www.fcps.edu/academics/academic-overview/special-education-instruction/career-and-transition-services

For students who have been placed in private schools that contract with FCPS, contact Multi Agency Services https://www.fcps.edu/node/32709. Adam Cahuantzi,

Program Manager <u>agcahuantzi@fcps.edu</u> 571-423-4030.

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 & Transition (WAT) class, Education for Employment (EFE) class, Education for Employment in the Office (EFEO), Job Coaching, and Academy Support.

For students choosing to continue their education up to age 22, Career and Transition Services offers a number of programs focused on employability and life skills including the Davis and Pulley Career Centers and the Secondary Transition to Employment Programs (STEP) based at Chantilly, South Lakes, Marshall, and Mount Vernon High Schools and Transition to Independence (TIP). TIP provides students enrolled at Davis or Pulley Centers to build employability skills on the Annandale and Alexandria campuses of Northern Virginia Community College.

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—Fairfax County Public Schools and Arlington Public Schools hold annual Resource Fairs in the Fall for students seeking adult services resources.

Flash Forward – Post-secondary Education & Employment Options. Held annually in the spring and hosted by FCPS. The event includes a vendor fair and workshops.

Super Transition Saturday held annually in the winter and hosted by FCPS. This event provides information to elementary and middle school students as they prepare for transition.

Future Quest (George Mason Univ.) College and career event for middle and high school students held every other year; the next one is October 2019.

Parent Resource Centers: Alexandria City PRC

https://www.acps.k12.va.us/Page/397 Special Education Family Resource Center TC Williams HS, 3801 West Braddock Rd, Alexandria, VA (703)824-0129

Arlington Public Schools PRC

https://www.apsva.us/special-education/parentresource-center/ 2110 Washington Boulevard, Suite 158, Arlington, VA 22204 (703) 228-7239

Fairfax County Public Schools PRC

https://www.fcps.edu/resources/familyengagement/parent-resource-center Dunn Loring Center for Parent Services 2334 Gallows Road, Rm 105, Dunn Loring, VA 22027 (703)204-3941 prc@fcps.edu

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 students with disabilities with a 5-10 day 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: http://wwrc.virginia.gov/PERT.htm

Appendix 8: EXPLORING INTERNSHIP PROGRAMS AND TRANSITION SUPPORTS

Internship Programs John Hudson Internship Program

This is a summer internship program in Fairfax County Government for college students and recent graduates with disabilities

(703) 324-5421 or

https://www.fairfaxcounty.gov/familyservices/disabilities/john-hudson-internship

Educating Youth through Employment (EYE)

This program is a summer initiative coordinated by SkillSource in collaboration with Fairfax County's Department of Family Services. The program recruits, screens and matches youth ages 18-24 with professional opportunities in the private sector and other area businesses.

http://www.myskillsource.org/page/id/42/eyeprogram

Organizations that Provide Transition Supports

Adult and Community Education (ACE)

ACE is a program of Fairfax County Public Schools for people of all ages with an emphasis on career and work readiness. It offers a wide range of training opportunities in apprenticeship, certificate programs, business, information technology, health and medical, and trade and industrial programs. For more information, visit

https://aceclasses.fcps.edu/PolicyDetails.aspx?StaticPage=About%20U

STEMSkills

www.stemskills.org

Focuses on youth with disabilities that are interested in working in innovative and tech-driven industries. Provides services around life coaching, job discovery, job exploration, apprenticeships, and customized employment. STEMSkills also offers a community camp for youth with Autism, ADHD, and LD to explore work culture norms and build executive functioning

skills. Contact Eric Duer at EDuer@stemskills.org. (202)744-2452

Social Graces, LLC

www.socialgracellc.com

Provides support to young adults with disabilities and their families. Services include advocacy, along with individualized support, programs, and plans targeted to improve social skills, executive function, and skills required to succeed in school, jobs, and real life. Also provides summer camps. Contact Ginny Conroy info@socialgrace.llc (703)593-9224

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.

<u>www.nextleveltransition.com</u> Contact: Scott Wilbur, Transition Director (571)332-2992 scottwilbur@nextleveltranstion.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

Inclusion Consultants

Provides individuals with the tools to build and enjoy rewarding and inclusive lives through the following services: counseling, coaching, consulting, and connecting. Their services seek to implement inclusive practices at every stage of life and across communities.

www.inclusionconsultants.com
Contact Nancy Mercer (703)304-8537
nancy@inclusionconsultants.com

Post Secondary 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, http://www.jfgh.org/services/services/ Contact Marcie Bennett, MOST Program Administrator, 240-283-6031 MBennett@JFGH.org

Appendix 9: Exploring Post-Secondary Resources & Education Supports

Preparing for College Life

Adaptive College Experience (ACE)

www.neuroscience-inc.com/adaptive-college-experience/

The ACE program consists of twice monthly group sessions designed to support transitioning students or students already in college with ASD, ADHD, or anxiety in the areas of adaptive skills for a college setting including organizational, self-regulation, and social skills. Contact Dr. Sajjad Khan 703-787-9090

The Faison Center

https://www.faisoncenter.org/college-101program Offers Ready. Set. Go! a Summer College 101 Program designed to provide rising High School Seniors an opportunity to experience college. The program provides a two week overnight college experience on the University of Richmond campus. (804)612-1947

Strive Program at NVCC Annandale

The STRIVE Program provides opportunities for young adults with learning disabilities to transition from school to post-secondary training, employment and successful community living

Contact Richard Stone striveo5@icloud.com
571-212-4482

Non Degree College Experiences

Mason LIFE Program

is a post-secondary program for young adults with intellectual and 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

VCU's ACE-IT in College Program

ACE-IT in College is an inclusive college experience for students with intellectual disabilities. Students audit classes and participate in a variety of campus activities, work experiences, and activities with the assistance of a job coach. The ultimate goal is competitive employment in the students' interest areas. www.aceitincollege.org

College Programs

Mason Autism Support Initiative (MASI)

Is a comprehensive, fee based program that provides additional intensive support service to students on the Autism Spectrum beyond typical higher education accommodations. Students have access to peer mentoring, a learning strategist, skill building classes, and monthly social events.

https://ds.gmu.edu/mason-autism-support-initiative/ (703)993-2474

Northern Virginia Community College

Director of Disability Services https://www.nvcc.edu/disability-services

College Steps

is a fee for service program at the Annandale, Alexandria, and Loudon NOVA Campuses that provides specialized resources and supports for students with disabilities. The program partners with NOVA to support students with disabilities, ages 17-26, with their college pursuits through peer coaching and on-campus support services. Hourly fee for service model. www.collegesteps.org 1-888-732-1022 or contactus@collegesteps.org

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 703-323-3000

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. 8304 Old Courthouse Road, Suite B, Vienna, VA 703-462-0654 www.basseducationalservices.com

Post Secondary Online Resources

<u>www.heath.gwu.edu</u> an online clearinghouse on postsecondary education for individuals with disabilities

<u>www.thinkcollege.net</u> an online database to research college programs for students with intellectual disabilities.

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

HIGH SCHOOL vs. 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.	Otherwise qualified 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 10: PREPARING FOR EMPLOYMENT & WORKING WITH DARS

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 Alexandria, Arlington, Fairfax & Falls Church online at

http://www.thearcofnova.org/programs/transition/transition-points.

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; internships, 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

Volunteer Alexandria

Phone: (703) 836-2176

Web: http://www.volunteeralexandria.org/

Volunteer Arlington

Phone: (703) 228-1760

Web: https://volunteer.leadercenter.org/

Volunteer Fairfax/Falls Church

Phone: (703) 246-3460

Web: http://www.volunteerfairfax.org

Assess Work Interests and Skills

Use the Positive Personal Profile to get an overall picture of 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, etc.
- Your commute. Factoring in how long the 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.

POSITIVE PERSONAL PROFILE

Dreams and Goals	Talents
Chille and Knowledge	Lagraina Chidae
Skills and Knowledge	Learning Styles
Interests	Positive personality traits
Temperament	Values
Life and Work Experiences	Support System
Specific Challenges	Creative Solutions and Accommodations
Environmental Preferences	Dislikes
Creative Possibilities and Ideas	

Source: Dr. George Tilson, Transcen, Inc. 1 . "Developing a Positive Personal Profile" **Note**: A fillable PDF of this tool along with helpful tips can be found at https://www.pdffiller.com/jsfiller-desk15/?projectId=335224385&expId=5498&expBranch=1#f87f164cf996551do27c7e87eb50

Meet with the Transition Coordinator

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

Apply for Pre-ETS (Employment Transition Services with DARS

Beginning in 2019, DARS (Department of Aging and Rehabilitative Services) has begun offering Pre-ETS Services to students beginning at age 14 as part of the overall transition plan. This new service has expanded the population of students DARS can work with and the breadth of services provided. Your school Employment and Transition Representative can help you to apply for services or you can contact DARS directly. It is simple one page application to apply.

Services are designed to be an early start at job exploration for students with disability and to enrich transition planning and the continuum of services necessary to prepare students to enter successful careers and adult life. These services are not subject to student/family financial participation and are available to students with disabilities in secondary, post-secondary or other recognized program; who re 14-21 years old (22 if still in high school); and receiving special education or related services. All services are free and provided by DARS counselors and staff and employment service organizations.

The 5 Pre-ETS Job Exploration Counseling

Supports students in learning about career pathways, in-demand industries and occupations, the labor market and their career interests. Examples include interest inventories and exploration.

Work Based Learning Experiences

Support students in exploring the world of work and various occupations and career pathways and provides opportunities to practice and improve work skills. Examples include informational interviews, workplace tours, job shadowing, volunteering, internships, etc.

Counseling on Post Secondary Education and Training Opportunities

Supports students in developing an awareness of post secondary educational and occupational training opportunities and emphasizes a career pathways approach. Examples include educating about admission requirements, supporting attendance at college/vocational program fairs and tours, identifying financial aid options, and promoting use of executive functioning skills.

Workplace Readiness Training

Supports preparation for adult life and the development of commonly expected skills that employers seek from most employees. Examples include training in soft skills, social/interpersonal skills, training in job seeking skills, and training in independent living skills.

Instruction in Self-Advocacy

Supports development of effective communication and decision making skills and emphasizes self-determination. Examples include setting goals, training in problem solving skills, teaching students how to disclose their disability, effectively expressing wants and needs, taking responsibility to plan their lives, and accepting feedback, etc.

How Parents May Help

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

WORKING WITH DEPARTMENT OF AGING AND REHABILITATION SERVICES (DARS)

DARS is a federal-state program that provides <u>short-term tailored services</u> to help individuals with disabilities prepare for the workplace, find a job, and get needed support once on the job. DARS focuses on integrated, community based competitive employment.

DARS recommends that students explore Vocational Rehabilitation (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, Onthe-Job Training, Postsecondary Training and Education, PERT, Supported Employment, and Vocational Evaluation and Assessment. For more information on DARS services and to download their quide, visit

https://www.vadars.org/drs/transitionservices.htm

The Role of Your Counselor

Your Vocational Rehabilitation (VR) counselor is an expert in disability and career counseling. There is a counselor assigned to schools in Alexandria, Arlington, Fairfax and Falls Church. 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 DARS at 800-552-5019.

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 must have a documented physical, mental, emotional, sensory or learning disability that causes a substantial barrier to getting or keeping a job.

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, if students receive Social Security Disability (SSDI) or Supplemental Security Income (SSI) due to 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. Even if you have a disability, you and your counselor must decide if you meet all the eligibility criteria.

To apply, complete an intake with a DARS Rehabilitation Counselor. You will need a social security card, a photo ID, all applicable documentation that includes a diagnosis, health insurance information, and parental consent if the student is under 18. 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)

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:

- Reflect the individual's career interests and informed choice
- 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, WWRC 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

Post-Secondary Education Rehabilitation and Transition Program (PERT)

The PERT program is a school to work initiative at the WWRC that provides high school students with disabilities with a 5-10 day 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 Evaluations
- Therapeutic Evaluations
- Vocational Training Programs

To apply for PERT, contact the transition coordinator in your high school. You would need to have an open case with DARS to be considered. For more information, go to:

http://wwrc.virginia.gov/PERT.htm

Pre-Employment and Education Readiness Program (PREP)

This nine week introductory program is 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. Goals include an introductory exposure to soft skills that support a student's ability to seek and secure employment, increase awareness of interpersonal interactions and expand and enhance personal management skills. 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

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).

Regional DARS Office Locations Alexandria DRS Offices

Serves Arlington and Alexandria 5904 Old Richmond Highway Suite 410 Alexandria, VA 22303 <u>Karen.Brown@dars.virginia.gov</u> (703) 960-3411

Fairfax/Falls Church DRS Office

11150 Fairfax Blvd. Suite 300 Fairfax, VA 22030 Leanne.rerko@dars.virginia.gov (703) 359-1124

Manassas DRS Office

9300 West Courthouse Road, Suite 302, Manassas, VA <u>Tiffany.Jenkins@dars.virginia.gov</u> (703)335-5550

If outside of the Northern Virginia area, visit https://vadars.org/offices.aspx to find your local office.

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. A list of these providers begins on page 50.

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 (ESO) that has contracted with DARS. More information on ESO's is found in the next section. 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 & resumes; assist you with initial training as needed; 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: works with the employer to find out about available jobs; works closely with hiring manager to determine

the scope of work; analyzes the work environment to identify the essential tasks and cultural aspects of the department; Assist the human resources department with scheduling and planning the interview; Identify accommodations and/or adaptations you may need; communicate with the employer to evaluate your progress; provide disability awareness training for coworkers 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.

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 individual. The job coach begins to fade as the individual is able to perform without assistance and things are going well on the job.

Once the individual is stable on the job with less 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.

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 they can be built upon.

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 discuss options for reopening your case or reapplying for services as appropriate to your specific needs. You may also contact the ESO that provided and worked with DARS to provide your services.

APPENDIX 11: WORKING WITH THE COMMUNITY SERVICES BOARD (CSB) AND EMPLOYMENT SERVICE ORGANIZATIONS (ESO)

Once DARS funding ends, money for continuing, long-term support through an Employment Service Organization may be funded by a Developmental Disabilities Medicaid Waiver, the local Community Services Board (CSB), or privately paid by the family.

In Virginia, Community Services Boards are the "local public entities" that determine eligibility and provide for long-term "case management" services, also known as "support coordination." CSBs coordinate community-based supports for individuals diagnosed with developmental disabilities (including intellectual disability).

CSB support coordinators help individuals and families identify and link to needed services and resources. They coordinate and monitor services, provide technical assistance, and advocate for the individual. Individualized services and supports may include medical, educational, employment/vocational, housing, financial, transportation, recreational, legal, and problem-solving skills development services.

CSB support coordinators provide eligibility determination for the Home and Community-Based Medicaid Waivers for Individuals with Developmental Disability. For more information on how to apply for services from the CSB and the Medicaid Waiver in your locality, see page 23.

The CSB coordinates with employment service organizations to provide employment or meaningful day supports. The CSB's Employment and Day Services provide multiple levels of supported employment and day support services for people with developmental disabilities, serious mental illness, and/or substance use disorders.

You may want to interview a number of service providers (list begins on page 50) 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 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 question!
- 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 of 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 have never thought of. This is okay! If you feel the need to do second interviews to complete a more specific comparison of services, take the extratime 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

- (i.e. job coach, natural supports set up, co-worker, trainer, etc.)?
- 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 SourcesAt present, employment and day support services for

individuals with disabilities fall into the varying models described below. The table on page 51 shows types of service models used and sources of funding for different employment service organizations. However, 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.

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.

** Several employment service organizations in the Northern Virginia area have AbilityOne contracts with the Federal Government. For more information, visit www.abilityone.gov. The AbilityOne Program creates employment and training opportunities for people who are blind or who have other severe disabilities, empowering them to lead more productive and independent lives. Its primary means of doing so is by requiring Government agencies to purchase selected products and services from nonprofit organizations employing such individuals.

Job Search & 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/

Fairfax County One Stop Skill Source Centers

Job seekers and employers in Northern Virginia have access to a comprehensive system of employment and training services and resources delivered and coordinated through one-stop employment resource centers, locally known as SkillSource
Centers. Services are offered at no cost and include: resume writing and interview preparation workshops, career coaching, basic employment assessments, access to computers, phones, copiers, and the

and ongoing customer support.

www.fairfaxcounty.gov/dfs/ss/employtraining.htm

internet for employment search, job lead assistance,

Fairfax: (703) 324-7280 Annandale: (703) 533-5400 Alexandria: (703) 704-6286 Reston: (703) 787-4974

For more information on any of these, see:

http://www.myskillsource.org

SkillSource is also a Ticket to Work Program helping people with disabilities who receive social security benefits find employment. Services may include comprehensive assessments, development of individual employment plans as well as career counseling, career planning, and access to job-related training opportunities.

(703) 752-1606 or MyTicket@myskillsource.org

Hire Autism

www.hireautism.org

Created by the Organization for Autism Research (OAR). 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 require more support to develop vocational skills.

If the person does not want to work, Day Support Services can be pursued through the waiver or the CSB without going through DARS first. DARS will not fund day support services since it not related to employment. See the chart on the following pages for Employment and Day Service Organizations.

EMPLOYMENT & DAY SUPPORT SERVICE ORGANIZATIONS

	THEN I & DAY SUPPORT SERV		_ "
Provider	Websites	Services Provided	Funding Sources
The Arc Greater Prince William/INSIGHT 13505 Hillendale Drive Woodbridge, VA 22193 (703) 670-4800	www.arcgpw.org	Supported Employment Day Support Services	Waiver CSB DARS
Best Buddies Capital Region 131 East Broad Street, Suite 205 Falls Church, VA 22046 (703)533-9420	www.bestbuddies.org./capitalr egion	Individual Supported Employment	DARS CSB Private Pay
Career Support Systems 3801 Westerre Parkway, Suite C Richmond, VA 23233 517-354-8458 ** Although headquartered in Richmond, employment specialists are located throughout Northern VA	www.careersupport.net	Individual Supported Employment Group Supported Employment Independent Living Skills Training	DARS Waiver
Chimes, Inc. 3951 Pender Drive, #120 Fairfax, VA 22030 (703) 267-6558	www.chimes.org	Day Support Services	Waiver CSB DARS Private Pay
The Choice Group 4807 Radford Ave. #106 Richmond, VA 23230 (804)278-9151 ** Although headquartered in Richmond, employment specialists are located throughout Northern VA	www.thechoicegroup.com	Individual Supported Employment	Waiver DARS CSB Private Pay
Community Visions, LLC 3460 Commission Court, Suite 101 Woodbridge, VA 22192 Charming Concepts Workhouse Arts Center 9601 Ox Road	www.comvsllc.net	Pre-Vocational Services Day Support Services	Waiver CSB DARS Private Pay
Lorton, VA 22079 Didlake, Inc. 8641 Breeden Ave. Manassas, VA 20110 (703) 361-4195	www.didlake.org	Supported Employment Day Support Services	Waiver CSB DARS Private pay

EMPLOYMENT & DAY SUPPORT SERVICE ORGANIZATIONS

Provider	Provider Websites Services Funding Sources					
Provider	websites	Provided	Funding Sources			
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 DARS private pay			
(JSSA) Jewish Social Service Agency 3025 Hamaker Ct, Suite 450 Fairfax, VA 22030 (703)204-9100	https://www.jssa.org/ get-help/specialized- employment/	Supported Employment Career Assessment	Private pay			
Job Discovery, Inc. 10345 Democracy Lane Fairfax, VA 22030 (703) 385-0041	www.jobdiscovery.or g	Supported Employment Day Support Services	Waiver CSB DARS private pay			
Melwood 750 South 23rd Street Arlington, VA 22202 (703) 521-4441	www.melwood.org	Supported Employment Day Support Services Career Readiness	Waiver CSB DARS 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 DARS			
Outstanding Possibilities Revealed 3022 Javier Road, Suite 130 Fairfax, VA 22031 (202)888-6533	www.oprservices.org	Supported Employment	DARS Private pay			
ServiceSource, Inc. 10467 White Granite Drive Oakton, VA 22124 (703)461-6000	www.servicesource.or g	Supported Employment Day Support Services Assistive Technology Screening Career Center	Waiver CSB DARS 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 DARS 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 ART Options	Waiver CSB DARS private pay			
Work Opportunities Unlimited 11002 Veirs Mill Road, Wheaton, MD (202)615-4467 ** Although headquartered in MD, employment specialists are located throughout Northern VA	www.workopportuniti es.net	Supported Employment Life Skills Training	Waiver DARS CSB Private Pay			

Alternatives to Traditional Employment & Day Services

Self Directed Services in Fairfax County

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

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

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

SPARC Solutions (Specially Adapted Resource Clubs)

Offers community based meaningful day opportunities. It Is a clubhouse model day program that supports adults with disabilities over the age of 22 with life skills development, entrepreneurial projects and enrichment activities such as music and art therapies. Clubs are located in Reston, McLean, Arlington, and Fairfax. Fees range from \$250-\$750 per month based on number of days attending per week.

SPARC Works

Offers individual employment training.

SPARC C.A.N. (Continuing Education Advocacy Navigating the community)

A one year 5 day/week curriculum that provides skills

tutors for individuals who wish to live independently and find work.

For information on all of these programs, visit www.sparcsolutions.org or contact Donna Goldbranson (703)338-6185 donna@sparcsolutions.org

Adults with Disabilities Day Program (ADDP)

Is facilitated by McLean Bible Church at their Tyson's and Prince William locations for high school graduates and focuses on spiritual formation, literacy, vocational training, personal care and independence, recreation and leisure, social skills, travel training and community navigation, and self-advocacy. There is a monthly fee based on the number of days enrolled per week. The program operates five days a week, Mon-Fri 10am-3pm. For more information,

https://www.mcleanbible.org/connect/adults-disabilities-day-program-addp-mbc-tysons-prince-william?field campus tid=1

Creative Models of Employment

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

Wildflour Bakery Chef-In-Training Program

Started August 2016, in partnership with the Fairfax-Falls Church CSB Employment and Day Services provides cooking skills and food safety training over a 26 month period. For more information, contact Alberto Sangiorgio at Wildflour Catering (703)263-1951. https://wildflourcaterers.com/about-us/becoming-a-chef-2/

Arlington Weaves

ArlingtonWeaves, Etc. provides support to adults with developmental disabilities by teaching them technical and social skills and by helping to improve their

self-sufficiency. The program is operated by ServiceSource, on a contract basis with the Arlington County Department of Human Services. For more information, contact Arlington DD Services at 703-228-1700.

For additional information on Employment, read The Arc of Northern Virginia's Transition POINTS Guide: Entering the World of Work https://thearcofnova.org/programs/transition/entering-world-work/

Interested in Starting Your Own Business?

The website listed offers ideas and additional resources for those who are looking for non-traditional employment

https://www.commercialcapitaltraining.com/business-resources/business-ideas/business-ideas-people-disabilities/

The marketplace has really diversified over the past few years. People with disabilities are embracing new technology and launching businesses to help others, make life more convenient, or strike out on a new path to generate substantial income while doing something enriching and satisfying. From franchises to niche startups, people with disabilities make up a good portion of the growing number of entrepreneurs in the United States. Visit the website to see ab overview of what is required and for some of the best business opportunities available for people with disabilities.

APPENDIX 12: HAVING FUN

Public Therapeutic Recreation Agencies

All three localities have Therapeutic Recreation Offices providing 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.

City of Alexandria

Alexandria Recreation, Parks & Cultural Activities, Therapeutic

 $\frac{https://www.alexandriava.gov/recreation/info/default.a}{spx?id=45758}$

703-746-5422

Arlington County

Department of Parks and Recreation
Therapeutic Recreation Office
https://parks.arlingtonva.us/therapeutic-recreation/703-228-4740

Fairfax County

Fairfax Therapeutic Recreation Services www.fairfaxcounty.gov/ncs/trs 703-324-5532

See also FCPS Parent Resource Center Adapted Sports and Recreation http://www2.fcps.edu/dss/osp/prc/documents/AdaptedSportsRecreationGuide2016.pdf

Private Vendors

Adaptive Learn-to-Skate Kettler Iceplex offers Adaptive Learning I and II on Saturday mornings. Call 571-224-0555, LTS@kettlercapitalsiceplex.com, or visit http://kettlercapitals.pointstreaksites.com.

Adaptive Martial Arts (4-18) Jhoon Rhee Tae Kwon Do has beginner thru advanced classes to improve motor skills, coordination, focus and self-control. Call Anna Rome at 703-532-7433, visit www.adaptivetkd.com, or email adaptivetkd@tkdlifeskills.com for more information.

ArtStream Drama and movement classes for children and adults with disabilities. Classes in Silver Spring,

MD, and Arlington, VA. http://www.art-stream.org or call 301-565-4567

Capernaum. An outreach mission of Young Life, a non-denominational Christian youth organization, Capernaum offers summer camp and twice-monthly social gatherings for teens 14-22 with physical and intellectual disabilities. Arlington & McLean: caleb.younglife@gmail.com

Central Fairfax: wonkamas@gmail.com
Northwest Fairfax: younglifemike@gmail.com

Cool Aspies Club of Northern Virginia a social club 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

Easter Seals of Northern Virginia Recreational day programs offered at Walter Reed Community Center in Arlington (for adults only, 18+), minimum 2 days a week. 703-228-0964

Expressive Therapeutic Movement. Classes for ages 13+ with intellectual disabilities. Yoga, breathing exercises, rhythmic music, and body awareness are used to develop strength, flexibility, calmness, motor planning and self-empowerment. Springfield & Herndon, 703-218-0751 etm.movements@gmail.com

Jewish Social Service Agency (JSSA) Offers workshops and groups for young adults. https://www.jssa.org/service/individuals-with-special-needs/

Jewish Community Center of Northern Virginia (JCCNV) Offers groups and social clubs. http://www.jccnv.org/specialneeds/special-needs/

Lifechanging Fitness (all ages) Group and individual fitness sessions for individuals with disabilities. Program can help with cardio, strength, and even learning sports skills. Visit their website www.lifechangingfitness.org or call Ricardo Cunningham at 703-909-7971.

Little League Baseball/Challenger League.

Ages 5-22. This volunteer-run program provides an opportunity to play ball. Players are teamed with a

Majors 1 player, who acts as a buddy. Season is spring and fall. 703-351-5111 or visit www.arlingtonlittleleaque.org

Parents of Autistic Children (POAC)

Maintains a current list of adapted sports and recreation opportunities.

https://poac-nova.org/wp-

<u>content/uploads/2018/02/Adapted-sports-and-rec-list-</u>2018.pdf

Special Olympics. Provides opportunities for ages 8+ with intellectual disabilities to train and compete in a variety of Olympic-type sports. Contact Northern VA Special Olympics at 703-359-4301 or see www.novasova.org/contact.html

Springfield Challenger Baseball

Offers three divisions of baseball for children with special needs ages 4-18, for youth up to age 22 still enrolled in schools, and for adults of ages. www.springfieldchllenger.org

TOPSoccer Ages 4-19. This is a volunteer-run skill development program. Season runs fall, winter and spring. In Alexandria, contact Bill Dwyer, wmdwyerprop@aol.com, 703-684-5425 or http://www.alexandria-soccer.com/tops.htm. In Arlington, see www.arlingtonsoccer.com/clubs/topsoccer. or contact Joe Lerner, 703-522-5866 (home); 703-395-7379 (cell).

For TOPSoccer in Burke, Chantilly, McLean and Reston, see the TOPSoccer website http://www.vysa.com/programs/34617/34707.html

Short-Term Respite Care

For occasional, short-term respite care:

Jill's House

www.jillshouse.org

9011 Leesburg Pike, Vienna, VA 22182 703-639-5660

Provides respite for children with disabilities (ages 6 to 17) in the Greater Washington DC area.

Camp Baker

http://www.richmondarc.org/services/developmentalservices/camp-baker-services/ 3600 Saunders Avenue, Richmond, VA 23227 Contact (804) 748-4789 or <u>CampBaker@RichmondARC.org</u> Respite care services and summer camp for ages 6 through adult.

Hartwood Foundation

https://www.hartwoodfoundation.com/programs/ Contact info@hartwoodfoundation.com 703-273-0939 3702 Pender Dr. Suite 410 Fairfax, VA 22303 Provides respite services for children and adults with intellectual disabilities.

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 http://www.peatc.org/peatc.cgim?template=news_a nd events.template

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 13: Getting Around

People with disabilities may benefit from travel training and from reduced fares for Washington-area bus and subway. Taxi companies 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 http://dmv.state.va.us/webdoc/citizen/legal_presqa.asp or by calling the agency's toll-free telephone number at 1-866-DMV-LINE.

Travel Training

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

Metro Disability ID Card

All jurisdictions in the Washington area offer reduced transportation fares, but you will first need to obtain a free Metro Disability ID card. You will need to fill out an application and have a health care professional certify the individual's disability. Call 202-962-2700 or download an application from http://www.wmata.com/accessibility/doc/Reduced Fare Application.pdf

The Metro Disability ID card is good on Metro buses in the District as well as ART in Arlington. CUE, Fairfax Connector, RideOn, TheBus, VRE and MARC also accept it.

Reduced Farecards/Bus Passes and/or SmarTrip Card

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

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

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

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

Using Public Transportation

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

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

Disabled Placard/Plates

In Virginia you need to get a MED-10 form for a disabled parking placard or license plate. You can pick one up at the Department of Motor Vehicles (DMV), or you can get one from their website at http://dmv.state.va.us. A physician must fill out the

form. Bring the completed form to the DMV. You can get a placard or a plate, or both. Placards offer flexibility since you can move it into any car in which you are the driver or a passenger.

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

Paratransit Options

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

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

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

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

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

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

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

STAR (Arlington County)

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

Arlington County residents currently certified eligible for MetroAccess are automatically certified for STAR. Rides are provided on a curb-to-curb basis. Drivers park in front of the address and assist riders into and out of the vehicle.

For more information on STAR: (703) 892-8747 (Voice) STAR@arlingtontransit.com (E-mail)

TaxiAccess (Fairfax County)

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

Fastran (Fairfax)

Fastran offers specialized transportation services for Fairfax County and the Cities of Fairfax and Falls Church residents who participate in human service agency programs. All Fastran riders must be certified by a participating agency before utilizing the service. http://www.fairfaxcounty.gov/ncs/forms/darapprev5.pd f

DOT

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

The eligibility process is similar to that for Metro Access. For more information or to receive an application, please contact the Paratransit Coordinator at (703) 746-4079.

https://www.alexandriava.gov/tes/info/default.aspx?id= 6538

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. For more information on Uber, visit

https://accessibility.uber.com/. Lyft allows fees to be paid via an ABLE account.

Technology to Empower Young Adults for Transition to the Work Place

Empowering Employment, a suite of curriculum apps on the ONEder software platform created by The Arc of Northern Virginia in collaboration with ONEder, a technology partner. The TravelMATE and EmployMATE apps support a person with I/DD regarding traveling on public transit, Uber/Lyft, taxis and planes and provide supports for their employment. In 2014 The Arc of Northern Virginia designed and launched the first curriculum, TravelMATE, which provides the user with step by step interactive instruction on how to navigate public transit between home and work. In 2016 EmployMate was launched, helping individuals navigate their duties and the changing dynamics in the workplace. ONEder's software is unique in its ability to support a spectrum of functional needs. It can easily customize each user's program with visual smart scenes and stories, video modeling, a grid-based sentence builder, GPS technology, training data tracking and lesson sharing

including a content library. It can also be used in any language (text and audio) and also uses pictures and videos from the young adult's real-life situation.

Once TravelMate and EmployMate are set up to meet an individual's specific needs, the individual can view the steps repeatedly on their own or with family and friends. Through viewing the scenarios with real-time videos and photos, family members more easily let go of feelings of concern and anxiety about their young person traveling and working as independently as they are able.

This feature enables and empowers the person with ID/DD to get to and perform their job without needing to involve colleagues to show them what they need to do on a regular basis. By having control over their own ability to do their job, they are not as dependent on peers, but more like equals as employees and colleagues. To learn more about this curriculum suite, contact Kymberly DeLoatche at kdeloatche@thearcofnova.org or Peter Leisen at pleisen@thearcofnova.org.

Appendix 14: 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 leading 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//extra/publications/choice/lts-My-choice.pdf

"Dude, Where's My Transition Plan?"

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

http://www.tnstep.org/uploads/files/Final%20Dude%20 Transition%20Book.pdf

People First for Young Adults

The Arc of Northern Virginia offers People First for Young Adults, a social and self-advocacy group for youth with disabilities ages 14-26. The group meets the second Tuesday of every month. For more information, visit www.thearcofnova.org.

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/learningcenter/independent-community-living/selfdetermination.asp

Parent Center Hub

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

Sound Out

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

APPENDIX 15: 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 Northern Virginia's website at http://www.thearcofnova.org/programs/transition/transition-points. Also visit Northern Virginia Housing and Supportive Services at www.novahss.org.

Housing vs. Residential Services

Many individuals with developmental disabilities will need both housing <u>and</u> 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 <u>some</u> 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:

For those with a Developmental Disabilities
 Waiver including the including the
 Community Living Waiver, Family and
 Individual Supports Waiver, and the Building
 Independence Waiver, the cost of support
 services is paid for by the Waiver once your

support team identifies and secures an appropriate service. However, the cost of rent is separate and must be paid for by the individual with a disability. This is typically done with Social Security income, earned income, and possibly an additional housing subsidy.

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

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

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

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

Visit

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

Visit

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

Residential (Public) Program Options

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

2. Public Housing

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

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

3. Housing Choice Vouchers

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

4. State Rental Assistance Program (SRAP)

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

this program.

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

Options with Private Funding

Many individuals with disabilities do not qualify for a Medicaid Waiver <u>and others are on long waiting lists for these services</u>; 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 Transition POINTS Guide: Finding a Home for Adults with Disabilities at

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

6. Tax Credit Units

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

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Each year the guide is reviewed by professionals Representing various public, non-profit, and private organizations, as well as, parents and then updated with current information.

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