



A WORD OF APPRECIATION FOR THE ARC OF NORTHERN VIRGINIA

The Arc of Northern Virginia's **Transition POINTS 2015**, a futures planning curriculum for Virginians 14 to 22 who have intellectual disabilities and developmental disabilities, was foundational to the formation of the Arc of Southern Virginia's **TRANSITION STEPS**, Section One: *"A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities."*

We are enormously grateful to Diane Monning, Manager, **Transition POINTS 2015**, the Arc of Northern Virginia, who graciously granted permission to the Arc of Southern Virginia to borrow freely from their comprehensive material in *"A Guide to Securing the Future for Your Child with a Disability"* to benefit Southside Virginia's intellectually disabled and developmentally disabled youth in transition. There is no need to reinvent the wheel.

OUR *"A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities"* includes a mix of material borrowed from **Transition POINTS 2015**, some of which has been adapted to better suit largely rural (in contrast to burgeoning Northern Virginia) Southside Virginia's Brunswick, Charlotte, Halifax and Mecklenburg Counties. About eighty-five percent of **TRANSITION STEPS**, Section One, was penned by the Arc of Southern Virginia but it was the Arc of Northern Virginia's **Transition POINTS 2015** which was the inspiration not just for this Section but for much of the **TRANSITION STEPS** project. Therefore, we cannot say exactly where **Transition POINTS 2015** and the Arc of Southern Virginia's contributions begin, end or stand alone.

All of the Arc of Northern Virginia's **Transition POINTS 2015** life planning publications, and a schedule of their training opportunities, are available at: www.TheArcofNOVA.org.

The Arc of Southern Virginia

Please send any comments to:

Diane Monnig
Transition POINTS
The Arc of Northern Virginia
2755 Hartland Road, Suite 200
Falls Church, VA 22043
703-208-1119
monnig@thearcofnova.org

And/or to:

TRANSITION STEPS
The Arc of Southern Virginia, Inc.
P.O. Box 252
Halifax, VA 24520
434-222-8931
thearcofsova@hotmail.com

TRANSITION STEPS: SECTION ONE

“THE BIG PICTURE”

CONTENTS

TRANSITION POINTS “CARE GIVERS IN CRISIS” FACT SHEET, THE ARC OF NORTHERN VIRGINIA

A WORD OF THANKS FOR THE ARC OF NORTHERN VIRGINIA

A STEP BY STEP GUIDE TO A BETTER FUTURE FOR YOUTH AND YOUNG ADULTS WITH DISABILITIES, THE ARC OF SOUTHERN VIRGINIA

The Arc of the United States 2010 FINDS Survey: "Out of the Shadows...into the Light"

Special Education & Transition Planning

What is Transition? Why is Transition Important? How Do We Do Transition?: Virginia Dept. of Education

Eligibility versus Entitlement: Understanding the Differences

“Testing, Testing, One, Two, Three”

Transfer of Rights of Students upon Reaching the Age of Majority

The Summary of Performance

Record Keeping

Benefit Planning

Financial Realities 101 for “Special Needs” Families:

“Our Family Will Never Accept Welfare!” or “Where Will the Money Come From?”

Health Insurance & Medicaid

Medicaid: A Definition

Medicaid’s Health Insurance Premium Payment Program

Early and Periodic Screening, Diagnosis and Treatment

May Medicaid Recipients Work without Losing their Medicaid?

Home and Community Based Medicaid Waivers

Definition

Financial Eligibility Medicaid for Waivers

Five Waivers & Three Waiver-like Options for Individuals with ID, DD & other Disabilities

ID, DS and DD Waivers

Intellectual Disability/ID Waiver

Individual and Family Developmental Disabilities Support Waiver/DD Waiver

What ID and DD Waivers Provide

Day Support Waiver

Waiver Availability

IMPORTANT NOTICE: A Word about Medicaid “Waiver Redesign”

Eligibility Screenings for ID and DD Waivers through FY 2016

The Level of Functioning Survey/LOF: the Gateway to ID, DS and DD Waivers

Elderly or Disabled with Consumer Direction Waiver/EDCD Waiver

Personal Care/Assistant Services Provided by ID, DD and EDCD Waivers & Other Programs

Help while Waiting for an ID or DD Waiver Slot

\$3000 Annual Individual and Family Support Grants & Other Options

What is Available for those Ineligible for an ID and DD Waiver?

Social Security Programs: SSI, SSDI & Medicare

Who is eligible to receive Social Security benefits?

Supplemental Security Income /SSI

SSI and Child Support

Social Security Disability Insurance/SSDI

Medicare

What About those Having both Medicare and Medicaid?

Disability Determination for Adults versus Children

Applying for SSI and SSDI

Important Information for Securing the Date of a SSA Application

Housing and SSI Benefits

Wedding Bells and SSI, SSDI and Medicaid

A Little Known and Under Appreciated SSA Gem!: The “Child in Care Benefit!”
SSA Representative Payee
SSA Authorized Representative Appointment
SSA Online Accounts
SSI, SSDI and/or Medicaid and Employment Earnings
What about those Who Receive a Combination of SSI, SSDI and/or Medicaid?
Free or Reduced Cost School Meals & Supplemental Nutrition Assistance
Requirement to Report all Income and Assets to SSI and/or Medicaid
Exceptions to the \$2000 in Assets Limit

Estate Planning

Letter of Intent
Wills & Special Needs Trusts
 Acting as Trustee
 Retirement, Investment and Bank Accounts

Guardianship & Supported Decision Making

Guardianship, Conservatorship and Alternatives
 Certificate/Letter of Qualification
 Guardianship without Conservatorship
Limited Guardianship
Conservatorship
Limited Conservatorship
Representative Payee
Advanced Medical Directive
Durable Power of Attorney
Limited Power of Attorney
Emergency Order for Adult Protective Services Short-Term Guardianship
Authorized Representative
Transfer of Rights to Students at the Age of Majority
Microboards

Employment and the Department of Aging & Rehabilitative Services /DARS

Exploring Housing Options

Selective Service Registration

Odds 'n Ends

Registering to Vote & Voting

Handicapped Parking

ID Cards for Non-Drivers and Persons with Autism

Recreational Opportunities and Travel Services for Persons with ID/DD

Microboards

Tips for Military "Special Needs" Families

SECURING THE FUTURE FOR VIRGINIA YOUTH WITH A DISABILITY: A CHECKLIST FOR PARENTS & GUARDIANS

THE ARC OF VIRGINIA ACRONYMS LIST 2015

TRANSITION STEPS

A STEP BY STEP GUIDE TO A BETTER FUTURE FOR YOUTH AND YOUNG ADULTS WITH DISABILITIES

What happens to our special education students when the yellow school bus no longer stops at their doors? Special Education entitlement ends at twenty-two. What then? What does the future hold for them? What financial, program, transportation, employment, housing and health care support will they need as adults to live a full life in the community? Who will look after them when their parents are no longer able or die? Without planning they will be at risk for living a long life "on the couch" with nowhere to go and nothing to do. They need a plan!

Intellectual and developmental disabilities (ID/DD) are permanent disabilities. Caring for family members with ID/DD is a lifelong responsibility. While caregivers want to make the best choices for these family members, research shows that many do not have the resources to do so. The Arc of the United States 2010 FINDS Survey (Family and Individual Needs for Disability Supports), "Out of the Shadows...into the Light" found:

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

-85% report that their adult family member with 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.

Families need timely information in order to make, most effectively, a wide range of decisions as their children grow up. Parents and schools share responsibility for how children spend their time during the day. It has been recognized that best results are achieved when planning for adulthood begins in the early teen years. Transition Steps will provide much helpful planning information and materials. So, let's begin!

Special Education & Transition Planning

A Synthesis of the Virginia Department of Education Transition Planning Tools

What is Transition? Why is Transition Important? How Do We Do Transition? Virginia Department of Education

Transition is the process students and their families use to think about life after high school, to identify their desired outcomes, and to plan their community and school experiences to assure that the students acquire the knowledge and skills to achieve their goals.

Steven Covey says to "begin with the end in mind." That idea is the heart of transition planning. If the "end" we have in mind is "educated employees," then the transition planning is the "beginning." It sets the education course for middle and secondary students with disabilities that leads to access to adult services, postsecondary education and the world of work. The idea of transition is simple, but actually carrying out the process can be daunting as we try to weave together the appropriate combination of educational and social services. The legislators who developed the Individuals with Disabilities Education Act (IDEA PL 101-476) included transition components in the legislation with the goal of preparing students with disabilities to access the supports and services they need to become as independent as possible.

The transition planning process should enable the student to move successfully from school to postsecondary education and training, employment, independent living, and community participation based on the student's preferences, interests, and abilities.

Transition Students having an Individualized Education Plan/IEP are entitled by Federal and Virginia law to stay enrolled in school through age 21 or 22 or until they earn a standard diploma. Virginia special education students who have not turned 22 by October 1 may complete the school year. That is, students with an IEP could “graduate” with their class at 18 with an Applied Studies Diploma (formerly the “Special” or “IEP” Diploma) and continue their education and training for another three to four years in an individualized community based transition program focused on developing life skills, prevocational training, and creating linkages with agencies which will provide the services and supports they will need when adults. During these years, students, along with their parents, caregivers, teachers and service providers, will begin to become more engaged in planning for their long term futures through the IEP process.

VDOE's Transition Services website provides support, information and resources designed to improve outcomes for students with disabilities in transition from middle/secondary education to postsecondary education and employment.

**See the extensive collection of materials in TRANSITION STEPS, Section 2: Education and Transition Services and http://www.doe.virginia.gov/special_ed/transition*

ELIGIBILITY VS. ENTITLEMENT: UNDERSTANDING THE DIFFERENCES

When it comes to the discussion of services for persons with disabilities, understanding the differences between “entitlement” and “eligibility” is essential.

An **entitlement** is something to which a person is entitled based upon an established relationship. Beneficiaries of wills are entitled to their inheritance. Uniformed Services Veterans are entitled to VA Home Loans. Workers who have paid into Social Security Retirement, Disability & Survivor/RDSI Insurance and Medicare through payroll deductions, matched by their employers, are entitled to these benefits, as are their widowed spouse, children and adult children disabled before 22.* Under the Federal 2004 Individuals with Disabilities in Education Act/IDEA, special education students are entitled to a Free and Appropriate Public Education/FAPE.

**Persons who are self-employed pay the full employee and employer contribution to Social Security Retirement, Disability and Survivor Insurance and Medicare.*

Access to programs of the Department of Social Services (welfare*), the Department of Behavioral Health and Developmental Services and the Department of Aging and Rehabilitative Services, is eligibility based. Eligibility may be based upon income, diagnosis, age, etc.

**Welfare eligibility programs which may be utilized by persons with disabilities include, but are not limited to; Supplemental Nutrition Assistance Program/SNAP (formerly known as Food Stamps), Medicaid, housing, fuel and child care assistance, Free and Reduced School Meals, Social Security Administration Supplemental Security Income/SSI, etc. Social Security Administration Supplemental Security Income/SSI will be discussed throughout “A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities” and TRANSITION STEPS, Section 7: Uncle Sam’s Social Security Book Shelf.*

Virginia special education students’ entitlement to services ends when they receive a standard diploma (versus an Applied Studies/IEP Diploma) or “age out” of school at 21 or 22. Though recent graduates may easily demonstrate eligibility for adult services or funding, they may not have access to them due to underfunding, limited enrollment, waiting lists, inadequate staffing, a shortage of licensed providers in the community, transportation difficulties, etc.

For these and any number of other reasons, establishing eligibility for a program *does not mean that the program will be available* to an applicant, whereas an entitlement cannot be denied. Therefore, it is critically important to identify well ahead of graduation the services that these students will need when adults. IEP teams, transition students, and their parents or caregivers, must begin this process at 14 for service and funding linkages to be in place before graduation.

In the public arena “entitlement” is used in reference to eligibility programs as well. This is especially the case in political discussions. However, TRANSITION STEPS’ conceptual distinction between entitlement and eligibility is used in other states and is offered here for the purpose of effective transition planning.

“TESTING, TESTING, ONE, TWO, THREE”

Students having an IEP are entitled to psychosocial and educational testing provided by their school every three years at the time of their IEP Triennial Review. One of the items on a transition student’s “to do” list during the last few years of school is to determine with the IEP team which “transition assessments” the school or some other entity needs to provide. They will vary based upon individual students’ needs and interests. These may include Vocational, Psychological, Social History, Speech & Language, Occupational, Interview, Questionnaire, Situational, Adaptive Behavior, Independent Living, Developmental, Medical and other Assessments.

First rate diagnostic evaluations of the quality offered by Virginia Universities and Medical Schools, or available from private provider Ph.D. psychologists, MDs, and other health care professionals, can open doors to services for persons having disabilities. The Department of Aging and Rehabilitation Services/DARS and Woodrow Wilson Rehabilitation Center/WWRC, Fishersville, VA provide a number of these services. DARS can arrange for testing specialists to conduct local testing for an individual student in the community or at school. Social Security, Medicaid, Community Services Boards and other service providers may request or require applicants to submit their educational, vocational and medical records for disability determinations or for individual program planning.

Services of this caliber may be hard to come by, especially in rural communities. Where can one begin to look for these sorts of services, what will it cost and who will pay for it? Private health insurance often covers some or all of the cost of developmental and diagnostic evaluations. Those with Medicaid will be covered in full for these services if received from a Medicaid participating provider. A few Virginia Universities, Medical Schools, and other programs providing such services are listed in TRANSITION STEPS, Section 8: Misc. Information and Resources.

THE SUMMARY OF PERFORMANCE/SOP

The IDEA requires that students exiting school receive a Summary of Performance/SOP, a resume-like document summarizing graduates’ academic, life skills and prevocational functioning. Additionally it projects the level of services the graduate will require in adulthood, such as for living arrangements, employment possibilities, etc. SOPs are versatile documents which can be handed to a personal care assistant, a camp counselor, a health care provider, a Community Services Board, a prospective employer, etc., for a snapshot of graduates’ strengths, challenges, experience and interests.

Graduates may want to consider expanding their SOP into personalized portfolios which might include a graduation essay, work samples, a resume of noted accomplishments, interests, skills, volunteer work, hopes for the future, etc.

TRANSFER OF RIGHTS TO THE STUDENT UPON REACHING THE AGE OF MAJORITY

Transfer of Rights of Students upon Reaching the Age of Majority addresses the capacity of students to manage their own educational decision making when they become legal adults at 18. This is discussed in detail in TRANSITION STEPS, Section 2: Special Education & Transition. Legal documents must be signed to allow or disallow a parent or guardian’s access to students’ school records, to sign IEPs, etc.

RECORD KEEPING

The “paper trail” for a “special needs” child, from cradle to grave, is enormous and only grows with time. Keeping the records of a child with a disability in perfect order is an absolute necessity. When this is well done, parents’ or guardians’ futures planning “to do” list advocacy efforts on behalf of their disabled child will be much easier to tackle. A family should come up with a system that makes the most sense to them; it will evolve and change with trial and error over time. It is a good idea to keep multiple copies of important documents on hand because they will be needed for securing benefits and services for children and adults having disabilities. Documents to keep on hand for ready access for the person having a disability, include, but are not limited to, the following:

-Basic identification: birth certificate, naturalization papers, Social Security card, driver license/DMV ID Card, passport, Military Dependent ID, voter registration, Medicaid card, health insurance card, etc. Occasionally agencies may ask to see original documents from time to time.

-Banking records: the individual's own and "for the benefit of" accounts, savings, checking, investment, Representative Payee, trusts, special needs trusts, irrevocable burial fund, Uniform Gifts to Minors, the individual's debit or credit card account numbers, safe deposit box keys, account signature cards, etc.

-Proof of the individual's income and assets: tax returns, pay stubs, life insurance policies, pre-paid funeral or burial insurance policies, auto titles, burial plot titles.

-Any and all Social Security Administration documents: Appointment of a Representative or Rep Payee, denial notices, applications for Appeal, correspondence, etc. Everything from SSA!

-Legal documents: wills, special needs trusts, child support orders, guardianship or conservatorship orders with the related Certificate/Letter of Qualification*, Power of Attorney, names and contact information for attorneys, names and contact information for secondary guardians and trustees.

**The and/or Conservator CERTIFICATE/LETTER OF QUALIFICATION is explained in the Guardianship & Supported Decision Making section of "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities."*

-Medical records: diagnostic evaluations, letters and statements from health care providers re. the individual's disability, past and current treatments and therapies, provider contact information, dates of treatment, facilities where treated and prescription records.

-School IEPs, 504 Plans*, Transfer of Rights to the Student, Report Cards, testing and evaluations, etc.

**Explained later in "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities."*

-Letter of Intent (instructions re. the care of disabled individuals should their caregivers becomes unavailable or die. This is explained more fully in the "Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities" Section on Estate Planning and TRANSITION STEPS, Section 5: Legal and Financial Planning.)

Originals document should be kept in a safe place, preferably a secure fire proof file box.

The frequency with which a plethora of documents will be required to tend to various disabilities specific business is unrelenting. Slightly different versions of this list, tailored to specific needs, will pop up throughout a "A Step by Step Guide" and TRANSITION STEPS.

Paper Trail Tips for Parents and Guardians

Caregivers must hang on to every scrap of paper related to an individual's services. It is not uncommon for important documents to go missing in busy agency offices. When dropping off documents to agencies it is recommended to take along a copy to be stamped, dated and initialed by a receptionist proving the document was submitted. Agency staff may resist doing this, it may be necessary to insist. Important documents should be mailed with Delivery Confirmation, Registered or Certified with a Return Receipt Requested. Postage receipts should be saved. All correspondence from and to persons or agencies in reference to the individual, including enclosures, should be saved. Jotting down notes re. every phone call, appointment, etc., re. the individual's services is a must. The date, time and name staff spoken with at agencies or on the phone, what was discussed and by whom, should be should be recorded. A notebook or large spaced desk calendar should be used exclusively for record keeping purposes. Keeping up with all of this is a daunting task but *it will* pay off because inevitably paperwork will go missing from an agency and being able to prove that it was received will be a huge relief.

After important agency phone contacts or meetings it may be useful to summarize in a letter salient points of the conversation and to ask if the agency representative is in agreement. Audio recordings of interviews or phone calls

may be especially valuable should a misunderstanding arise or important paperwork go missing. Be aware that some agencies demand prior notice of intent to record meetings, conversations, etc.

BENEFIT PLANNING

“OUR FAMILY WILL NEVER ACCEPT WELFARE!” OR “WHERE WILL THE MONEY COME FROM?”

FINANCIAL REALTIES 101 FOR “SPECIAL NEEDS” FAMILIES

It was not that long ago that parents or guardians of a minor child with significant disabilities and/or having a rare complex medical condition had no choice but to surrender custody of their child to the state for the child to receive institutional care because the family could not afford the exorbitant cost of home care. Fortunately, those days are now past. Today, public programs (“welfare”) lend these families a much needed helping hand. Most, but not all, of the wide variety of programs for persons with significant disabilities presented in TRANSITION STEPS are tax funded Federal, State and sometimes local, public programs. Because “welfare” remains a loaded word, TRANSITION STEPS wants to assure parents and guardians that no matter where their family falls on the economic spectrum there is much that they can do to contribute toward securing the future of their child with a disability. This will be discussed more fully in TRANSITION STEPS, SECTION 5: LEGAL AND FINANCIAL PLANNING.

Families would need to be anywhere from quite well-to-do to fabulously wealthy to provide the resources needed for lifetime care of their disabled child. Employed parents or guardians of these children frequently take days off to attend IEP meetings, take their child to numerous appointments or stay at home with their children when they are sick or in the midst of a mental health crisis. These families may cash in their retirement plans, quit their jobs to care full-time for their disabled child, go into debt or even sell their house to provide for their child’s needs in the present. In short they “eat their seed corn.” It is unlikely they will ever recover the lost time needed to secure their family’s long term financial security. None of this is news to those having a special needs child of any age.

Metropolitan Life’s “Met Desk,” a free personalized futures planning service for special needs families, has developed a “Special Needs Calculator” which can give parents and caregivers an idea of the cost of providing lifetime care for their child. A copy is included in TRANSITION STEPS, SECTION 5: LEGAL AND FINANCIAL PLANNING.

While it is commonly accepted that parents are not required to support their children past the age of 18, in Virginia there are statutory exceptions for the support of adult disabled children, as follows:*

Code of Virginia § 20-61. Desertion or nonsupport of wife, husband or children in necessitous circumstances. . . . any parent who deserts or willfully neglects or refuses or fails to provide for the support and maintenance of his or her child under the age of eighteen years of age, or child of whatever age who is crippled or otherwise incapacitated from earning a living, the spouse, child or children being then and there in necessitous circumstances, shall be guilty of a misdemeanor and upon conviction shall be punished by a fine of not exceeding \$500, or confinement in jail not exceeding twelve months, or both, or on work release employment as provided in § 53.1-131 for a period of not less than ninety days nor more than twelve months; or in lieu of the fine or confinement being imposed upon conviction by the court or by verdict of a jury he or she may be required by the court to suffer a forfeiture of an amount not exceeding the sum of \$1,000 and the fine or forfeiture may be directed by the court to be paid in whole or in part to the spouse, or to the guardian, curator, custodian or trustee of the minor child or children, or to some discreet person or responsible organization designated by the court to receive it.

****IMPORTANT NOTE RE. Child Support for Disabled Adults! Custodial parents or Caregivers who are considering petitioning the Court for a Child Support Order Modification to extend child support indefinitely into adulthood must do so before the child's 18th birthday. By Virginia statute, the Court may not retroactively order child support for an adult disabled child. Therefore the petition should be filed before age 17½ or earlier, as needed, to allow sufficient time for the legal process to proceed.***

These Code of Virginia excerpts include only the most pertinent material for this discussion. Caregivers who may want to consider this further should read the entire section from which they were derived.

HEALTH INSURANCE & MEDICAID

Under the Affordable Care Act, adult children may be carried on their parents' health care plan till 26. Generally, adult disabled children may be carried on their parents', and often, their deceased parents' health plan, indefinitely if the premiums are paid. Private insurance companies will provide policy holders with instructions to apply for extended coverage of adult disabled children.

Medicaid *is not* a health *insurance* plan. Funded by Federal-State match, it is a public welfare health care coverage program which pays for medical care and disabilities specific needs for low-income persons who are Elderly, Blind or Disabled/"ABD" and certain categories of children. Generally only Foster Children and the children of low income families are eligible for Medicaid. Eligibility for Virginia Medicaid for adults is limited to those who are "ABD" or pregnant having income no greater than \$784 per month, which is 80% of the Federal Poverty Level, and total assets (savings account, investments, cash on hand, etc.) no greater than \$2000. Should Virginia decide to participate in Medicaid Expansion under the Affordable Care Act eligibility for Medicaid will expand to non-disabled adults who have incomes up to \$1238 monthly which is 133% of 2016 Federal Poverty Level.

**2016 Federal Poverty Level for a single adult is \$11,770 per annum or \$980 per month.*

The Disability Determination Service/DDS of the Virginia Department of Aging and Rehabilitation Services/DARS processes Disability Determinations for both Medicaid and Social Security programs. Processing usually takes at least ninety days. However, during the wait for Medicaid (but not Social Security) Disability Determination the applicant will receive periodic notices about the progress of the process which may include requests for any missing medical records, etc. ABD adults who are found eligible for Medicaid may not necessarily be eligible for Supplemental Security Income/SSI. Should they latter apply for SSI or Social Security Disability they will not need a new Disability Determination, which should speed up the Social Security application process considerably.

Individuals having private health care coverage may also be covered by Medicaid or FAMIS Plus (a Virginia health insurance plan for the children of low income families.) Some Medicaid recipients are also covered by private health insurance and/or Medicare. (Medicare is discussed further in the Social Security section of "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities.") Medicare is the primary payer, private insurance is secondary and Medicaid pays last.

NOTE: Be sure to see the Requirement to Report all Income and Assets to SSI and/or Medicaid in the SSI Section of "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities."

VIRGINIA HEALTH INSURANCE PREMIUM PAYMENT PROGRAM/HIPP & HIPP FOR KIDS

Disabled adults or children enrolled in Medicaid may be eligible for the Health Insurance Premium Payment (HIPP or HIPP for Kids) assistance to help pay all or part of health insurance premiums derived from parents' active (vs. retired) employee based plan *if* it will result in cost savings for Virginia Medicaid. Private health insurance may cover services that are not covered by Medicaid. The HIPP Program can be contacted at 800-432-5924

TRANSITION STEPS, Section 3: Medicaid Health Care and Medicaid Home and Community Based Medicaid Waivers, includes HIPP and HIPP for Kids Fact Sheets. Because it is not uncommon for local Department of Social Services/DSS Benefits Workers to be unfamiliar with these lesser known programs, applicants should take the Fact Sheets with them to their local Department of Social Services initial application appointment.

EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT/EPSTD

from Medicaid.gov

A Federally mandated program, the Early and Periodic Screening, Diagnostic and Treatment, or EPSDT, benefit provides comprehensive and preventive health care services for children under age 21 enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents with disabilities and special health care needs receive appropriate preventive, dental, mental health, developmental and specialty services.

States are required to provide comprehensive services and furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions, based on certain federal guidelines. EPSDT is made up of the following screening, diagnostic, and treatment services.

Early	Assessing and identifying problems early
Periodic	Checking children's health at periodic, age-appropriate intervals
Screening	Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
Diagnostic	Performing diagnostic tests to follow up when a risk is identified, and
Treatment	Controlling, correcting or reducing health problems found.

EPSTD is particularly valuable for Transition Students!

At 18 when transition students become legal adults they become eligible for disability benefits and Medicaid based upon *their own* income. The parent/family income is no longer considered for eligibility for these programs. During the three years between turning eighteen up to the day before their 21st birthday, these young adults remain eligible for the EPSDT program which can provide them with specialized services which may not have been covered or fully covered by their parents' insurance or which the family simply could not afford. This is the time to catch up on needed services. EPSDT covers adaptive equipment such as wheelchairs and communication devices, valuable diagnostic testing and evaluations of the quality provided by Virginia Universities and Medical Schools, hearing screenings, hearing aids, routine dental care, extensive dental restorative services, which will not be covered by Medicaid when these young adults turn 21.

EPSTD is discussed more fully in TRANSITION STEPS, Sections 3: Medicaid Health Care and Medicaid Home and Community Based Medicaid Waivers.

MAY MEDICAID RECIPIENTS WORK WITHOUT LOSING THEIR MEDICAID?

Yes. They need to contact their local Department of Social Services/DSS Benefits Worker and request to be enrolled in Medicaid Works (a Virginia program) which enables employees to keep their Medicaid while earning up to \$34,000 or more per year. The application for Medicaid Works must be submitted BEFORE the first day of employment (even if only the day before). They must also notify their local Social Security Office that they have enrolled in this program. There is detailed information about Medicaid Works in TRANSITION STEPS, Section 3: Medicaid Health Care and Medicaid Home and Community Based Medicaid Waivers.

CAUTION: It is not uncommon for DSS staff to be completely unfamiliar with lesser known programs such as Medicaid Works.

HOME AND COMMUNITY BASED MEDICAID WAIVERS

DEFINITION

Medicaid "Waivers" are special programs designed by the states for specific purposes, thus the usual rules for Medicaid are "waived."* There are two kinds of Medicaid. One is for low income children or Aged, Blind or Disabled/

“ABD” adults to cover their health care. Medicaid *Waivers*, however, provide *non*-medical services to disabled individuals which enable them to live as independently as possible in the community. (Eligibility for Home and Community Based Waivers is limited to specific disabilities.) Types of Waiver programs vary from state to state but many are very similar. Waivers enable persons with intellectual and developmental disabilities to live a full life in the community versus living a more isolated life separated from the community in a state institution.

**The term “Waiver” has nothing to do with “waiving” ones entitlement to live in a state institution in order to live in the community. It is a special program for which the rules for standard Medicaid have been “waived.”*

FINANCIAL ELIGIBILITY MEDICAID FOR WAIVERS

Financial eligibility criteria for a Waiver is much more generous than is the case for basic Medicaid. Waiver applicants will qualify financially if their monthly income is less than three times SSI.

Example: SSI for 2016 is \$733 x 3 = \$2199 per month or \$26,388!

FIVE MEDICAID WAIVERS & THREE WAIVER-LIKE OPTIONS FOR INDIVIDUALS WITH ID, DD AND OTHER DISABILITIES

Five Virginia Medicaid Waivers, one Virginia agency Waiver-like program, and two Federal Waiver-like programs, are presented in TRANSITION STEPS, as follows:

- Intellectual Disability or “ID” Waiver
- Day Support Waiver or “DS” Waiver (for persons with ID)
- Individual and Family Developmental Disabilities Support Waiver or “DD Waiver”
- Elderly and Disabled Waiver with Consumer Direction or “EDCD Waiver”
- Technology Waiver* of “Tech Waiver”
- Community Rehabilitation Case Management Services or “CRCMS”**
- Early and Periodic Screening, Diagnosis, and Treatment or “EPSDT”***
- Extended Care Health Option or “ECHO” (for children of Active Duty Military families)****

**The Technology Waiver, not introduced here, is touched on in TRANSITION STEPS, Section 3: Medicaid Health Care and Home and Community Based Medicaid Waivers. The “Tech” Waiver is for disabled persons who may be ventilator dependent, require a digital device to communicate, etc.*

***While very similar to a Medicaid Waiver, this program is NOT a Medicaid Waiver. It is a program of the Virginia Department of Aging and Rehabilitative Services. Persons on the ID and DD Waiver Waiting Lists are not eligible for this program. CRCMS is not means tested. For more information see TRANSITION STEPS, Section 6: Community Living.*

****For Infants, toddlers, children and youth under age 21 who are enrolled in Medicaid. See “A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities” ED CD Waiver Section and TRANSITION STEPS, Section 3: Medicaid Health Care and Medicaid Home and Community Based Waivers.*

*****This is a Waiver-like program, the Extended Care Health Option or “ECHO” of the US Military Exceptional Family Member Program is offered through the Active Duty Tri Care (military health care coverage program.) See the “Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities” Section on “Tips for Military Families.”*

THE ID, DS AND DD WAIVERS

Intellectual Disability/ID Waiver

The ID Waiver is for persons whose IQ is below seventy (70) who were diagnosed with an intellectual disability* (formerly known as mental retardation/MR) during the developmental period before 18.

**The Federal definition of intellectual disability/mental retardation is an IQ up to the range of 70 to 75, depending upon a particular individual's circumstances, but Virginia holds fast, for the most part, to a cut off of below 70.*

Individual and Family Developmental Disabilities Support Waiver/DD Waiver

The DD Waiver is for persons with an IQ greater than 69 whose level of care needs are equivalent to those having an intellectual disability. Developmental Disabilities include, but are not limited to; Autism, Traumatic Brain Injury, Cerebral Palsy, Epilepsy, Spina Bifida, etc., diagnosed before age 22.*

**The Federal definition is diagnosed during the developmental period before age 18.*

ID and DD Waivers Provide:

Personal or attendant care	Personal Emergency Response System/PERS
Respite care	Therapeutic consultations
In-home residential support	Case Management/Service Coordination
Adult companion care	Skilled Nursing
Assistive technology	Therapeutic Consolation
Environmental modifications	Family Training

The ID Waiver also provides congregate residential care (group homes), the DD Waiver does not.

The Day Support Waiver

The Day Support Waiver covers only day support, pre-vocational and supportive employment. Day Support Waivers are for those on the ID Waiver Waiting list; limited help until an ID Wavier becomes available.

WAIVER AVAILABILITY

To receive an ID, Day Support, or DD Waiver there must be what is known as a "Waiver Slot" available. A Slot is a state budget funded package of Waiver services. Due to underfunding, available funded Slots are quite limited. Those found diagnostically and functionally eligible for ID and DD Home and Community Based Medicaid Waivers will be placed on Waiver Waiting Lists. (Legal and Financial eligibility is determined after a Waiver becomes available.) Wait times for the most part stretch on for many years so it is important to be added to the Waiting List as soon as possible. At the close of 2015 the Waiting List for the ID and DD Waivers numbered more than 10,000.

Many of those on the Waiting Lists may find themselves in a crisis situation when their caregiver becomes ill or has died, are at risk of or have suddenly become homeless or become a danger to themselves and/or the community, but even in these circumstances there is no guarantee that a Waiver Slot will become available. The Waiting List will only be reduced when Virginia General Assembly Budgets include funding for more Waiver Slots. The Virginia Association of Community Services Boards, the Arc of Virginia, and other advocacy groups and families work very hard though the year and during the General Assembly Session informing our legislators and the general public about the critical need for more Waivers to be funded for Virginia's ID/DD citizens and their families.

IMPORTANT NOTICE!: A WORD ABOUT VIRGINIA "WAIVER REDESIGN"

Virginia is in the process of closing its residential Intermediate Care Facilities for Intellectual Disability (formerly Mental Retardation)/ICF-MRs) or "Training Centers" for persons with ID or DD in favor of community based living and care. (The rest of the United States has closed all or nearly all of its ICF-IDs. Virginia is the last state among them.) In fact, Virginia is under Federal Court Order to do so and is being monitored for compliance by the US Department of Justice Office of Civil Rights. A major component of the 2011 DOJ vs. the Commonwealth Settlement Agreement is ID, DD and Day Support Waiver Redesign.

Waiver service packages will be tailored to individual needs and preferences, termed "Person Centered Planning." Local CSBs will be the point of entry for persons diagnosed with both ID and DD. However, a diagnosis of ID or DD must have been made before age 22. Eligibility will be based on level of functioning without regard to IQ scores. There will no longer be ID and DD Waivers, the new Waivers are designed for different levels of need.

The Redesigned Waivers are targeted to become operative July 2016.* (Delays to the start of such an enormous undertaking may be inevitable.) At that time, those who have received a copy of TRANSITION STEPS will receive replacement pages for the Waiver information which follows here and Waiver descriptions in Transition Steps, Section 3: Medicaid Health Care and Medicaid Home and Community Based Waivers. See Section 3 for an introduction to the Redesigned Waivers under the heading, “MY LIFE, MY COMMUNITY.”

ELIGIBILITY SCREENINGS FOR ID AND DD WAIVERS THROUGH FY 2016

Diagnostic Eligibility/Disability Determination

The Disability Determination Service of the Virginia Department of Rehabilitative Services conducts disability determinations for Virginia Medicaid and on the Federal level for the Social Security Administration.

Functional Eligibility

Functional eligibility is determined by local Community Service Boards for the ID Waiver and by regional State Health Department Child Development Centers for the DD Waiver.*

**For DD Waiver application instructions see TRANSITION STEPS, Section 3: Medicaid Health Care and Home and Community Based Medicaid Waivers.*

Legal and Financial Eligibility

Local Departments of Social Services determine applicants’ legal eligibility (immigration status, criminal justice system status, etc.)

Financial eligibility for Department of Medical Assistance Services Long Term Care is determined *only after* an applicant on the Waiting List is granted an available Waiver Slot.

THE LEVEL OF FUNCTIONING SURVEY/LOF: THE GATEWAY TO ID, DS AND DD WAIVERS

The same screening tool, the Level of Functioning Survey, is administered to both ID and DD Waiver applicants and is re-administered annually once the applicant is enrolled in a Waiver. Families and caregivers are encouraged to familiarize themselves with the screening survey well in advance of the screening appointment. (A copy of the LOF is included in TRANSITION STEPS, Section 3: Medicaid Health Care and Medicaid Home and Community Based Medicaid Waivers. This will enable applicants and their advocates; parents, caregivers, Legal Guardians, etc., to offer well thought-out accurate responses to the LOF questions, supported by the applicant’s diagnostic, educational and clinical records.

The CSB Case Manager or the Child Development Center Representative administering the LOF should be provided well ahead of the appointment with copies of the applicant’s pertinent medical, psychological and educational records for review. Parents or other caregivers accompanying an adult applicant (over 18) to the screening appointment need to contact the agency ahead of time to discuss questions concerning the applicant’s capacity to self-report responses to the LOF questions and how HIPPA issues will be handled. In the case of adult applicants, if the parent or caregiver accompanying them to the Waiver eligibility screening are not their Legal Guardian, Power of Attorney or Health Care Agent, it may be necessary for the applicants to grant written permission for them to act in their behalf before the screening is underway. The Federally approved State Plan for both of these Waivers clearly explains that discussion of the Survey questions is to be a collaborative process involving the CSB ID Case Manager or the Health Department Child Development Center DD Waiver Eligibility agency Screener, the applicant, family members, service providers, teachers, etc. That is, persons who know the applicant well who may be present for the screening or available by phone.

The LOF is, in many respects, a “relic of another time.” It was designed to screen for eligibility for residential placement in an Intermediate Care Facility for the “Mentally Retarded”/ICF-R. (There may or may not be a similar screening tool used for determining level of functioning eligibility for the new waivers.)

Parents and guardians want to present their children in light of their strengths. However, when it comes to the LOF Survey which is the gateway to ID and DD Waivers, it is better to answer questions in terms of the applicant's worst days. What would happen, what would be needed, if the caregiver were not there, if there were no supports and programs in place to enable the applicant's safety, security, health and welfare? It is one thing to observe persons with a disability flourishing without stopping to think that they flourish only because of all of the supports in place for them, necessities often very hard won by conscientious caregivers' unrelenting advocacy on behalf of these family members. Take it all away and you would see a different picture entirely. Seasoned special needs parents and caregivers know that they must evaluate and report the needs and level of functioning of their disabled family members with ID or DD based upon what their lives would be like without existing supports in place that are maintained only by ever ongoing advocacy. To answer in this way fairly represents the needs of an applicant for disabilities services and it is absolutely honest and ethical.

There are persons with ID and DD who will not be found eligible for a Waiver based upon the LOF survey. That is, they are indeed ID or DD with significant needs but do not meet the ICF-I/DD level of need required for a Waiver. If this happens, go over the process and review the answers to the LOF questions carefully to see if there was room for error and apply again later with a fresh approach and perhaps a different screener. If the applicant is not found eligible, the agency must provide written information to the applicant about the Right to Appeal the decision as well as written notice of functional ineligibility for a Waiver. If these documents are not provided to the applicant in a timely manner the agency should be contacted for an explanation.

ELDERLY OR DISABLED WITH CONSUMER-DIRECTION WAIVER/EDCD

The EDCD Waiver is for children and adults who have significant disabilities with co-occurring medical and/or nursing needs and for frail elderly persons (age 65 and older) who may be in need of a nursing home or other Long Term Care placement but are choosing to remain at home in the community if at all possible. At present, there is no waiting list for this Waiver.

Individuals on the ID Waiver or DD Waiver Waiting lists may be enrolled in the EDCD Waiver until they receive a Waiver Slot. While eligibility for the ID and DD Waivers is established by the Level of Functioning Survey, eligibility for the EDCD Waiver is based on medical and/or nursing needs, Many, perhaps most, children and adults who have ID or DD have co-occurring medical/nursing needs.

If found eligible for the EDCD Waiver, applicants will be enrolled in Medicaid Long Term Care after which their level of care need will be determined. Personal care services will be authorized anywhere from a few hours a day to eight hours per day. In addition to personal care services hours they will receive 480 hours per year of respite care.

The EDCD Waiver is often experienced as a godsend for children and adults with disabilities and their families. A Medicaid card can open the door to services and supports which the individual needs but the family simply cannot afford to provide; such as high out of pocket costs for prescription drugs and for paid skilled caregivers when the family or caregiver needs to be away or needs some respite. A few hours of before and after school EDCD Waiver Personal Care Services Attendant care may enable a parent or guardian to stay employed or to experience a little welcome respite from nearly 24/7 on-call care giving for a disabled family member.

Application is made through local Departments of Social Services' Medicaid Long Term Care section. Applicants should ask to speak with a Medicaid Long Term Care Benefits Worker and explain their interest in being screened for the EDCD Medicaid Waiver. A home visit will be scheduled with the screening team, usually a Registered Nurse and a Social Worker, to administer the screening survey, the Uniformed Assessment Instrument or "UIA." While the UIA is designed for adults there are instructions for adapting it for infants, toddlers and children up to fifteen.

If the applicant is found eligible, the next step is to be screened by DSS Long Term Care staff for financial eligibility for Long Term Care Medicaid Waivers.

Financial eligibility criteria are the same for the ID, DD, DS, EDCD and Technology Waivers.

Waiver eligibility for children is based on the child's income and assets. Family income is not considered.

An EDCD Waiver can provide children with access to critically needed services through Early and Periodic Screening, Diagnosis and Treatment or “EPSDT.”

Individuals with EDCD Waivers do not have Case Managers, rather they have “Service Facilitators” who manage Medicaid paper work, make periodic home visits to keep track of changing care needs and provide training for selecting home care services agencies or hiring one’s own caregivers, often friends and sometimes family members. New enrollees will be offered a choice of Service Facilitators, who may be an with an in-home care agency, a professional Service Facilitation agency or an independent provider.

Personal Care Attendants may accompany their the EDCD Waiver client on excursions into the community, such as, but not limited to; medical appointments, social activities, outings, shopping, even school extracurricular activities if no school staff is assigned to the student. They may assist with light housekeeping, preparing meals, etc., but ONLY for the enrollee, not for other members of the household. Other duties which may be assigned to the Personal Care Attendant and additional available EDCD Waiver services which may be appropriate for the enrollee’s needs should be discussed with the Service Facilitator when developing the Waiver enrollee’s initial and annual Plan of Care.

Before the EDCD Waiver Screening appointment, applicants and/or their parents or caregivers are advised to assemble pertinent medical and services records, to familiarize themselves with the Uniform Assessment Instrument and to make notes about specific level of care needs. Some medical/nursing needs which may qualify an applicant for an EDCD Waiver may not readily seem apparent to applicants or their caregivers. For example, Speech Therapy, Occupational Therapy and Physical Therapy are medical/nursing needs if they are included in an IEP and/or are ordered by a physician or other qualified health care provider.

Important Note for potential EDCD Waiver Applicants

DSS offices are not always proficient in their handling of EDCD Waiver inquires and applications. A misunderstanding of this program is pervasive throughout Virginia; DSS offices from region to region often differ in their familiarity with and understanding of EDCD Waiver regulations. The Department of Medical Assistance Services has taken several steps to help ameliorate this situation which can be found in TRANSITION STEPS, Section 3: Medicaid Health Care and Medicaid Home and Community Based Medicaid Waivers. Applicants and/or their caregivers are advised to familiarize themselves with this material before applying to the local DSS office for an EDCD Waiver Screening. Applicants who may run into problems applying for the EDCD Waiver are encouraged to contact their local Chapter of the Arc of Virginia or the Virginia Partnership for People with Disabilities*

**Various advocacy organizations, including Partnership for People with Disabilities, will be introduced throughout TRANSITION STEPS.*

More detailed information about the EDCD Waiver can be found in TRANSITION Steps, Section 3: Medicaid Health Care and Home and Community Based Medicaid Waivers.

ABOUT PERSONAL CARE/ASSISTANT SERVICES PROVIDED BY ID, DD AND EDCD WAIVERS & OTHER PROGRAMS

Those with ID, DD and EDCD Waivers may choose to receive their Personal Assistance/Personal Care* Services services* from a home care agency or the Consumer Directed/CD services option which enables Waiver enrollees to hire their own caregivers, often friends and in some circumstances family members.

The Department of Rehabilitative Services/DARS also provides Personal Care Services. For more information see TRANSITION STEPS, Section 6: Community Living.

**Personal Assistance” is the term used by the ID and DD Waivers and DARS. The EDCD Waiver uses “Personal Care.” The definitions may be slightly different from program to program.*

HELP WHILE WAITING FOR AN ID OR DD WAIVER SLOT
\$1000 ANNUAL INDIVIDUAL AND FAMILY SUPPORT GRANTS & OTHER HELP

To help those on the Waiver Waiting Lists and their families, a relatively new program, the Individual and Family Support Program/IFSP, provides grants of up to \$1000 annually for needed services and supports. Information on the IFSP program and other help for those on Waiver Waiting Lists can be found in [TRANSITION STEPS](#), Section 3: Medicaid Health Care and Home and Community Based Medicaid Waivers.

OTHER HELP: Those on the Waiver Waiting Lists for a very long time have much in common with Waiver Ineligibles. For additional options for persons on the Waiver Waiting Lists see the following discussion, "What is Available for those Ineligible for ID and DD Waivers?"

WHAT IS AVAILABLE FOR THOSE INELIGIBLE FOR ID AND DD WAIVERS?
More than You Might Think!

Not everyone applying for an ID or DD Waiver is eligible. Applicants must be diagnostically, functionally, financially and legally eligible.

Persons having a developmental disability, who are not intellectually disabled, may require a great deal of support to live in the community. Individuals with Autism Spectrum Disorders or Traumatic Brain injuries, who do not have an ID diagnosis, or whose DD diagnosis was after twenty-two, may have impaired adaptive skills (self-care, community living, etc.) requiring the same supports as those who have significant intellectual disabilities.

These transitioning (as well as younger students and Graduates) and their families need not lose heart. Waiver ineligible may be eligible for a number of other programs. The following list includes, but is not limited to, programs which have been introduced, or which will be introduced, in "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities" and throughout [TRANSITION STEPS](#).

1.) Medicaid

Aged, Blind & Disabled/ABD Medicaid/FAMIS, HIPP & HIPP for Kids, EDCD Waiver, Medicaid Works

2.) Social Security

SSI, SSDI, Medicare, SSI Student Earned Income Exclusion, other Employment Incentive Programs

3.) Department of Social Services

Housing Vouchers, SNAP (formerly "Food Stamps"), Free or Reduced School Meals, Fuel Assistance

4.) Community Service Boards

ID and Mental Health Community Based Programs, Child and Family Services, ID & Mental Health Case Management/Service Coordination (if Medicaid eligible)

5.) High School Special Education for Transition*

I'm Determined Conferences (free to students, stipend for parents), 504 Plans**, IEP Transition components funded through the Family Advocacy Planning Team process*** (not funded by the local School System.)

**For more information on I'm Determined see [TRANSITION STEPS](#), Section 2: Special Education and Transition Planning.*

***A "504" Plan refers to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, which specifies that no one with a disability can be excluded from participating in federally funded programs or activities, including elementary, secondary or postsecondary schooling. "Disability" in this context refers to a "physical or mental impairment which substantially limits one or more major life activities." This can include physical impairments; illnesses or injuries; communicable diseases; chronic conditions like asthma, allergies and diabetes; and learning problems. A 504 plan spells out the modifications and accommodations that will be*

needed for these students to have an opportunity perform at the same level as their peers, and might include such things as wheelchair ramps, blood sugar monitoring, an extra set of textbooks, a peanut-free lunch environment, home instruction, or a tape recorder or keyboard for taking notes.

504 Plans are discussed more fully in TRANSITION STEPS, Section 2: Special Education & Transition Services.

*** See TRANSITION STEPS, Section 2: Special Education and Transition Planning for an introduction to the Children's Services Act/CSA for Youth at Risk (formerly the Comprehensive Service Act) and the local Family Advocacy Planning Team funding process for IEP Transition Plan components.

6.) Recreation

Special Needs Camps, Special Olympics, YMCA, local park and recreation programs

7.) Department of Aging and Rehabilitation Services/DARS

Rehabilitation Case Management Services/CRCMS* (a Wavier-like program), Special Education Transition Services, Respite Care Grants, Woodrow Wilson Rehabilitation Center programs, Supported Employment Personal Assistance Services (equivalent to Waiver Personal Assistance Services)

**Per a Department of Aging and Rehabilitation Services provision, persons on the ID or DD Waiver Waiting List are not eligible for the CRCMS program. Even though they may be on a Waiver Waiting list for many years, the fact that they are on the Waiting List demonstrates to DARS their eligibility to be served by another program. For more information see TRANSITION STEPS, Section 6: Community Living.*

8.) Health Insurance for OT, ST & PT

With a physician or Primary Care Provider order, Private Health Insurance/Medicare/Medicaid may cover **habilitative*** services such as Occupational Therapy/OT, Speech Therapy/ST or Physical Therapy/PT for developing communication skills, life skills and independent living skills. For example, an OT may train a client on the use of an iPad or how to safely use public transportation. A Speech Language Pathologist/SLP may work with a client on reciprocity in conversation, how to ask for help when lost, how to use the phone, etc. Physical Therapists may work with clients on Sensory Integration. Etc.

OTs, SLPs and PTs may be key members of a student's IEP Transition Services support team or a Medicaid Waiver or similar program Plan of Care Team when adults. Graduates may continue to benefit with these life skills and functional skills building services into adulthood with funding from health insurance, Medicaid or Medicaid Waivers. (OT, ST and PT may be considered qualified Medical/Nursing needs for EDCD Waiver eligibility.)

** Habilitative services help a person learn, keep, or improve skills and functional abilities that they may not be developing normally or have never developed such as for a child who is not talking at the expected age. Adults can also benefit from habilitative services, particularly those with intellectual disabilities or disorders such as cerebral palsy who may benefit from services at different points in their life to address functional abilities.*

9.) The REACH Program*

REACH is a 24/7 mobile crisis intervention program providing crisis support to persons with Intellectual and Developmental Disabilities who are experiencing crisis due to behavioral or psychiatric needs. REACH provides in-home and community based crisis assistance services to individuals and their families to improve their quality of life and decrease facility and hospitalization placements.

This program available to ALL Virginians with an ID/DD diagnosis; those who have an ID/DD Waiver, those on the ID/DD Waiver Waiting List and those who are ineligible for ID/DD Waivers. For more information on REACH see TRANSITION STEPS, Section 6: Community Living.

REACH is a program of the Department of Behavioral Health and Developmental Services created in response to the 2012 US Department of Justice Settlement Agreement with the Commonwealth.

***Regional, Education, Assessment, Crisis Services, Habilitation**

10.) Other Ideas?

If our readers have other ideas for Waiting List and Wavier ineligible folks please let us know. Send them to: thearcofsova@gmail.com. Your contributions may be included in the 2017 edition of TRANSITION STEPS.

Social Security Programs: SSI, SSDI & Medicare

WHO IS AND ISN'T* ELIGIBLE TO RECEIVE SOCIAL SECURITY BENEFITS?

*You May be Surprised

There is one general requirement that applies to all Social Security programs except for SSI (Supplemental Security Income): The worker on whose earnings record the benefit is to be paid must have worked in "covered employment" for a sufficient number of years. This means that the worker must have earned enough "work credits" by the time he or she claims retirement benefits, becomes disabled, or dies (usually a total of at least ten years of work). Workers without a ten year-equivalent work history as well as persons who have never been employed will not be entitled to Social Security Retirement, Disability and Survivors Insurance coverage or Medicare. Often persons living in poverty fall into these categories.

Some Federal, State or local government agencies are enrolled in pension programs based on earnings *not* covered by Social Security. Some religious workers may "opt out" of, or are not eligible to participate in, Social Security. What does this mean? An example: In some cases an adult disabled child of a disabled or deceased Federal or municipal employee might receive a small fixed benefit which may be offset by Social Security or other public or private benefits. Until 1984, Federal employees were covered under the Civil Service Retirement System (CSRS), not by Social Security. Those who did not transfer to the new Federal Employees Retirement System before 1987 are not covered by Social Security. Federal employees not covered by Social Security contribute to Medicare through payroll deductions, an amount matched by their employer. Religious workers who "opt out" of Social Security will not be eligible for Medicare.

Social Security is a major source of income for children and adult disabled children whose insured parents (or sometimes grandparents) retire, become disabled or die. Children and adult disabled children of parents who are ineligible for Social Security benefits will miss out on this income. In 2015 3% of the total population age 60–89 was ineligible for Social Security Social Security Retirement, Disability and Survivors Insurance benefits and Medicare coverage, largely due to insufficient earnings to accrue 40 quarters of qualifying work credits. These ineligible persons may have no source of income or insurance to provide for a spouse, widowed spouse, children or adult disabled children. (However, some of these individuals 65 or older may be eligible for Supplemental Security Income, discussed in the following Section.)

**<https://www.ssa.gov/retirementpolicy/fact-sheets/never-beneficiaries.html>*

SUPPLEMENTAL SECURITY INCOME /SSI

Supplemental Security Income, or "SSI", is a general assistance money payment program created in the 1970s to replace "*Assistance to Aged, Needy Blind and Permanently and Totally Disabled*" categories of Federal/state welfare assistance. It is paid out of general Federal funds to low income children and adults who are aged, blind or disabled or "ABD". SSI financial eligibility for children is based on family income. SSI financial eligibility for adults 18 and over is based on their OWN income. SSI is intended to cover living expenses such as clothing, housing and food.

SSI applicants' assets (bank accounts, investments, cash on hand, etc.) may not exceed \$2000. Monthly benefits are determined by the current benefit rate (\$733 monthly for 2016), minus any excess assets and "countable" income.

If eligible for SSI, in most states, applicants will also be eligible for Medicaid. However, in Virginia, SSI recipients must apply separately for Medicaid at the local Department of Social Services.

SSI AND CHILD SUPPORT

There is a 1/3 reduction of countable child support for SSI applicants. As long as transition students between 18 and 22 receive child support while enrolled in school, they will maintain the SSA status of a "Child" and remain eligible for the 1/3 reduction. It is likely that local office SSA customer service representatives will be unaware of this provision. Therefore it is important to read all of the related material on the 1/3 reduction in Child Support regulation on SSA.gov and to take a downloaded printed copy to the appointment. If the child is a transition student between 18 and 22, it is important to be sure that the SSA Customer Service Representative understands this.

If a Court Order has directed Child Support to be paid to a Special Needs Trust, it will be completely excluded from SSI financial eligibility calculations. (Special Needs Trusts will be discussed further in [TRANSITION STEPS](#), Section 5: Legal and Financial Planning.) Parents or guardians will need to petition the Family Court for an Order assigning Child Support to Self-Funded Special Needs Trust. Again, it is important in this case as well to read all of the related material on the SSI Special Needs Trust regulation on SSA.gov and to take a downloaded printed copy of it along with the Court Order and a copy of all Trust documents to the local SSA office.

SOCIAL SECURITY DISABILITY INSURANCE/SSDI

While SSI is a means tested, needs based, welfare program, Social Security Disability Insurance is an insurance program with benefits based upon employee/employer contributions to Social Security Retirement, Survivor and Disability Insurance/RSDI through payroll deductions. Disability Insurance is for disabled workers who have not reached their full retirement age. Survivor insurance is just that, a benefit paid to an eligible surviving spouse or a child or an adult disabled child whose parent has died.

To be eligible for an adult disabled child benefit, an applicant's disability must have been diagnosed before the age of 22.

Technically a disabled child's or adult child's benefit is a Child Disability Benefit/CBD if it is derived from a disabled, retired or deceased worker's record, but it amounts to the same thing as SSDI and is generally also called "SSDI."

As mentioned above, after twenty-four months of enrollment in SSDI the beneficiary will receive a Medicare Card. Until recently, young adults between 18 and 22 who may be switching from SSI to SSDI would have lost their SSI derived Medicaid benefit leaving them without health care coverage for two years. However, thanks to Federal legislation called the "Pickle Amendment" they can keep their Medicaid during the twenty-four month wait for their Medicare. This is an important benefit for transition aged students whose parent may have become disabled, has retired or has died.

MEDICARE

Social Security Disability claimants become eligible for Medicare twenty-four months after enrollment. ([TRANSITION STEPS](#), Section 7: Uncle Sam's Social Security Book Shelf, includes more Medicare information.) Social Security Retirement, Disability and Survivor Insurance/RSDI and Medicare are insurance programs toward which employees/employers make contributions through automatic payroll deductions." (Medicaid is a *welfare* program.) It is not uncommon for Medicare recipients to also be enrolled in private insurance and/or Medicaid. Medicare pays first, then private insurance, then Medicaid. Nor is it uncommon for disabled children and adults under 65 to be enrolled in Medicare. For those having Medicaid and Medicare, Medicaid pays the Medicare Part B premium.

WHAT ABOUT THOSE HAVING BOTH MEDICARE AND MEDICAID?

Some Virginians covered by both Medicaid and Medicare are enrolled in a recent “Dual Eligible” Federal/State Demonstration Project, Commonwealth Coordinated Care, which coordinates services between the two programs for better health outcomes and fiscal savings. Participants carry only one, instead of two, health care coverage cards. Those who are dually eligible, having ID, Day Support and DD Waivers or additional health insurance (such as Blue Cross or Tri Care) are excluded from the project during its demonstration period, while those with the EDCD Waiver are included. Participants in areas where the project is operative are automatically enrolled but enrollees may “opt out” if they wish. Brunswick and Mecklenburg Counties *are* included in the geographic area of the Project. Charlotte and Halifax Counties *are not* included in the Project.

SSA DISABILITY DETERMINATION ADULTS VERSUS CHILDREN

Disability determination for a child benefit is DIFFERENT from the disability determination for an adult. Children nearing 18 must have an adult Disability Determination completed to establish eligibility for adult benefits. SSI ends for children on their 18th birthday. (Virginia Medicaid eligibility ends on the child's nineteenth birthday.)

APPLYING FOR SSI AND SSDI

Disabled young adults should apply for SSI and/or SSDI a month or two before their 18th birthday.

For both Supplemental Security Income/SSI and Social Security Disability Insurance/SSDI, applicants must meet SSA's **ADULT** definition of disability defined as the inability to engage in Substantial Gainful Activity (employment)/SGA by reason of any medical (physical and/or mental or blind) impairment. The disability must have lasted or be expected to last for a continuous period of not less than 12 months or result in death. The 2016 employment earnings limit for 2016 SGA is \$1,090 gross monthly.

Parents, caregivers and service providers must be vigilant about keeping track of earned income limits for those receiving SSI and/or SSDI and Medicaid, lest they lose their benefits. This will be discussed further along in this section of A STEP BY STEP GUIDE in “SSI, SSDI and/or Medicaid and Employment Earnings” and throughout TRANSITION STEPS. (This is also the case with Medicaid Waivers and the military adult disabled children Incapacitated Family Member program which will be touched on in TRANSITION STEPS.)

To familiarize themselves with the process, applicants will find it helpful to download the Disability Report for Adults at: <http://www.socialsecurity.gov/pgm/ssi.ht> . Those not having access to a computer may want to request an application by mail at 1-800-772-1213 or from the local Social Security Office.

During the initial call to the SSA 1-800 number a representative will schedule a screening at the applicant's local Social Security office. Any and all information to prove the applicant's age, citizenship, disability, current assets, income or other financial resources, should be taken to the screening appointment, including but not limited to:

- Original birth certificate (and other proof of citizenship as needed) and Social Security card
- Documentation to verify applicant's address

--Copies of important legal documents, such as; special needs trusts, guardianship, conservator and child support Court Orders, birth and death certificates, immigration and naturalization papers, etc.

--Individual Education Plan (IEP) (teachers may send educational records electronically; see the instructional brochure, [TRANSITION STEPS](#), Section 7: Uncle Sam's Social Security Library)

--Medical records and contact information

--Income verification documents for earnings, child support, etc.

--Verification documents for any assets held in the applicant's name including, but not limited to: savings account, Uniform Gifts to Minors, Savings Bonds, investment accounts, life insurance policies, vehicle titles, etc. ***These cannot total more than \$2,000 for SSI benefits*** (unless held in a self-funded special needs trust.) (The value of a car in the applicant's name may or may not be included in the \$2000, depending upon its value and the applicant's transportation needs.)

--Medical Records and contact information not yet provided to SSA.

The representative will enter the requested information the SSA data base which will ***secure the date**** of the application. The document completed during the phone call will be mailed to applicants to be completed, signed and returned within the allotted timeline.

****See the very important information in the next section re. Securing the Date of an SSA application.***

For SSI, SSA considers parent income and assets for children under 18. Applicants over 18 years of age are considered independent units.

Adult disabled children living with their parents/guardians should be prepared to present a signed rental lease, room and board agreement or house sharing agreement to minimize any reductions of the full SSI benefit, though reductions from the full benefit may be taken for other reasons as well.*

**This is a complex subject. Creating such an agreement will require investigation of SSA regulations. Not all local SSA offices or special needs attorneys are of one mind in their understanding of the regulations applicable to this process. This is discussed more fully in "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities."*

Wait for Disability Determination

The agency will send the Disability Report Form and medical history to the Virginia 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. DSS may also request, on behalf of SSA, a medical or psychological exam (SSA pays for the exam by a physician or psychologist chosen by SSA). A decision is made in approximately sixty days. If denied, you have 60 days to appeal.

SSA Office Hours & Locations

Monday, Tuesday, Thursday, Friday 9:00 - 3:00, Wednesday 9:00 - 12:00

See the County by County Resource Chart for the location of the SSA office by County in [TRANSITION STEPS](#), Section 8: Misc. Contacts & Resources."

IMPORTANT INFORMATION FOR SECURING THE DATE OF A SSA APPLICATION

An application for any SSA program is an application* for any and all programs, even programs for which applicants may not have applied but for which they may be eligible. ***Securing the date*** of an application means that when the benefit is approved the payment start date ***will be retroactive to that date.***

**For this reason, it is the SSA Customer Service Representative who should be telling applicants about the 1/3 Child Support Exclusion, Special Needs Trust exclusion, Child in Care Benefit, (which is explained further in this section of the Guide), possible eligibility on a step-parent record, etc. Because this rarely happens, it is better to arrive at SSA appointments with printed copies of pertinent SSA policies in hand. (Search for these by topic on SSA.gov. They are not hard to find.)*

An application may be approved for SSI when in fact, after further investigation, it is determined that the applicant is eligible for an Adult Child Benefit/SSDI on a step-parent's work record. In this case the applicant would receive a lump sum back payment for the difference between SSI and the higher SSDI payment based on the Secured Date from the initial application for SSI. If twenty-four months have passed during the time between the receipt of SSI and the correction to SSDI, the applicant may receive a Medicaid Card in the mail about the same time as the lump sum back payment.*

**Because Medicaid recipients cannot have assets over \$2000, lump sum back SSI and SSDI payments could be problematic but can be managed with careful planning. This is explained in TRANSITION STEPS, Section 5: Legal and Financial Planning, "Special Needs Trusts."*

Therefore, before mailing anything back to the SSA, applicants must be sure to make copies. It is recommended that these documents be mailed with Return Receipt Requested to create proof of the secured *date* should paperwork go missing. It is not unusual for SSA to lose paperwork been mailed or delivered to the local office. **If applicants cannot prove that SSA received an application or required related document, the secured date will be lost!**

If an Application is denied the applicant may submit, twice as needed, a Request for Reconsideration form. There may be a flaw or missing information in the initial application which if corrected could lead to reversal of the denial. In this case the Secured Date remains the date of the initial application. In lieu of a Request for Reconsideration an applicant may be offered the option of submitting a new application for a "fresh start." This is not recommended because the Secured Date of the original application will be lost. It may take many months for these matters to be resolved in which case all of the months of accumulated back payments will be lost when the application is approved. (It is unlikely that local SSA office customer service representatives will volunteer this information.)

HOUSING AND SSI BENEFITS

SSI Recipients who live with their families and pay rent may experience a reduction in their benefit.

It is generally understood by that one-third (1/3) of SSA is to go toward housing (rent, mortgage, utilities, property insurance, etc.) and the other two-thirds (2/3) are to go toward food.

If special needs trust* funds the purchase of a home with a mortgage, and the trust makes monthly mortgage payments, SSI payments will be reduced by about one-third each month (the portion of SSI associated with housing). Whether the home is owned or mortgaged, SSI payments will be reduced by slightly more than one-third if the trust pays for all household expenses, such as, rent or mortgage, taxes, heat, electricity, water, sewer and trash collection.

To avoid this reduction in SSI, adult disabled children living in the family home should pay rent or enter into a house sharing agreement. Rent must be at least 30% of SSI (30% of 2016 \$733 SSI = \$220.) To avoid a reduction of 1/3 or more. Rent must be fair market value. Be advised that rent which parents or caregivers receive is reportable taxable income. Fair market value for rented rooms or for room & board may be found in local newspapers, on Craig's List, etc. House sharing is agreements are on actual shared expenses.

**Special Needs trusts are discussed in full in TRANSITION STEPS, Section 6: Community Living.
<https://secure.ssa.gov/poms.nsf/lnx/0500835300> and <https://secure.ssa.gov/poms.nsf/lnx/0500835901>*

A LITTLE KNOWN AND UNDER APPRECIATED SSA GEM! THE "CHILD IN CARE BENEFIT!"

Spouses up to 62, caring for a child under 16 or a child of any age whose disability was documented before 22, may be eligible for an early SSA benefit for a "Child in Care" on the earnings record of a spouse who is receiving a disability or retirement benefit. The applicant's spouse does not necessarily need to be the child's biological parent. (In some cases, a child or disabled adult child may be eligible to receive a child or disabled adult child benefit on a step-parent's or grandparent's work record.)

A family is limited to a total of 180% of the wage earners benefit. The spouse and children may share up to 80%.

Example: Worker's Benefit \$1000 + Child Benefit \$400* + Spouse Benefit \$400* = \$1800

**40% of Workers Benefit x 2 = \$800 or 80% of Worker's Benefit for a total of \$1800 or 180% of Worker's Benefit.*

Child in Care spousal benefits end when the spouses turns 62, at which time he or she must choose to continue to receive the spousal benefit until full retirement age or to draw a benefit on his or her own earnings record. Child in Care early spousal benefits will not reduce spouses' ultimate benefit between the ages of 62 and 70.

Local Social Security Office Service Representative are often unfamiliar with lesser known benefits such as this one. A parent/spouse applying for this benefit should read all of the material on the Child in Care Benefit at SSA.gov, print a copy and take it and any related needed records, to the SSA office.

SSA REPRESENTATIVE PAYEE

A Representative Payee or "Rep Payee" is appointed by SSA to receive Social Security and/or SSI benefits for Claimants unable to manager their money. Parents and guardians need to be aware that being a SSA Authorized Representative* or having a joint bank account with the Claimant *does not* give a person legal authority to manage a Claimant's SSDI and/or SSI payments. Prospective Rep Payees** must apply in person at their local SSA office, with documents in hand to prove their identity, such as a government issued photo ID. The Representative Payee Application, Form SSA-11, will be submitted during a face to face interview with a Customer Service Representative. SSA will send Rep Payees a simple annual "Representative Payee Report" for documenting how the Claimant's benefit was spent during the past year. It should be promptly completed and returned by mail or on line. See www.socialsecurity.gov/payee.

** SSA Authorized Representative status is explained further in the next section of "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities."*

*** Though less common, institutions, such as nursing homes, may also serve as Rep Payee.*

To set up a dedicated Rep Payee account for Claimants, new Rep Payees must present their SSA appointment document to the financial institution. SSA has very specific requirements for wording the title of and administering Rep Payee Accounts with which banks and credit unions are well acquainted. *SSA will only pay benefits by direct deposit to the account.*

While a Rep Payee Account is required to manage benefits for a child under eighteen, if adults can manage their own money with some support, a Rep Payee is not needed.

Pros and Cons

Before locking themselves into the role of a Rep Payee, parents, guardians and other caregivers need to consider the advantages and disadvantages of being a Rep Payee for their Claimant. *Per SSA policy, Claimants may NEVER have access to their own funds in a Rep Payee dedicated account.* If Claimants' Rep Payees become incapacitated or die, SSA deposits will not resume until a successor Rep Payee has been appointed, a new dedicated account has been opened and direct deposits are reinstated, which could take quite some time, leaving the beneficiary without needed funds for living expenses.

See the SSA Publication "Rep Payee" in [TRANSITION STEPS](#), SECTION 7: UNCLE SAM'S SOCIAL SECURITY LIBRARY.

SSA AUTHORIZED REPRESENTATIVE APPOINTMENT

SSA FORM-1696-U4 (07-2014), Claimant's Appointment of Representative explains:

You can choose to have a Representative help you when you do business with Social Security. We will work with your representative, just as we would with you. It is important that you select a qualified person because, once appointed, your representative may act for you in most Social Security Matters.

Representatives may conduct any business with SSA on behalf of the Claimant in reference to SSA Titles; II (RSDI) Retirement, Survivors and Disability Insurance, XVI (SSI) Supplemental Security Income, XVIII (Medicare).

See SSA FORM-1696-U4 (07-2014), Claimant's Appointment of Representative, [TRANSITION STEPS](#), Section 7: Uncle Sam's Social Security Library.

SSA ONLINE ACCOUNTS

Social Security Claimants may want to set up an online account, "*my Social Security account*", to keep track of earnings and benefits records and to enable ready printing of needed documents. Lost benefits letters, 1099s, Medicaid cards, etc., can be easily replaced with an on-line account.

CAUTION: my Social Security account Create an Account instructions state:

You cannot create an account on behalf of another person or using another person's information or identity, even if you have that person's written permission.

For example, you cannot create an account for another person:

- With whom you have a business relationship
- For whom you are a representative payee, or
- For whom you are an appointed representative.

Unauthorized use of this service may subject you to criminal or civil penalties, or both.

SSI, SSDI AND/OR MEDICAID AND EMPLOYMENT EARNINGS

The most desirable outcome for individuals having disabilities is to participate in employment within the limits of their abilities. However, great care must be taken not to jeopardize their essential Medicaid and SSI benefits. Many of these individuals known to the disabilities community have marginal situations and for these individuals in particular it is essential that short term work incentives not lead to long term disqualifications for benefits which would affect them perhaps even for the remainder of their lives. The disabilities that we are addressing are long term situations and sometimes what may seem temporarily expedient may fade when caregivers age or are no longer in the picture and the individuals are left to their own devices to champion meeting their own needs. Persons with disabilities not having an advocate to assist them with complex compliance requirements for these programs may fall into an unexpected trap and lose their benefits. [TRANSITION STEPS](#) includes information about work incentive programs for SSI and SSDI recipients. Benefits Specialists are available to explain employment incentive programs. This is addressed in more detail [TRANSITION STEPS](#), SECTION 4: The World of Work.

WHAT ABOUT THOSE WHO RECEIVE A COMBINATION OF SSI, SSDI AND/OR MEDICAID?

SSDI beneficiaries whose benefits are less than SSI, \$733 monthly for 2016, may be eligible for supplementation up to the \$733 from SSI. Families may want to consider whether or not in their child's situation receiving a few dollars of SSI is worth the assumption of stringent SSI restrictions. This should be explored concerning situations where SSI represents only a small amount. Similarly, persons with SSDI having a Medicaid Waiver need to be cautious about making financial decisions which could jeopardize their financial eligibility for their Medicaid Waiver.

These complex subjects cannot not be addressed fully in limited space. If you have questions about these issues consult a Benefits Specialist or contact your local Chapter of the Arc, or the Arc of Virginia.

FREE OR REDUCED COST SCHOOL MEALS & SUPPLEMENTAL NUTRITION ASSISTANCE*

(*SNAP, formerly known as Food Stamps)

Adult Transition students over 18 receiving Medicaid and/or SSI may be eligible for SNAP, they should apply at their local Department of Social Services/DSS. Students receiving SNAP, SSI and/or Medicaid are *automatically* eligible for Free or Reduced Cost School Meals because their parent/family income is NOT considered for eligibility and as legal adults they are considered to be an independent economic unit. Parents and guardians, be careful. If applying for Free or Reduced School Meals enter ONLY your adult disabled child's income. Put a footnote at the bottom of the application explaining that your child is legally an independent economic unit for whom family income is excluded from financial eligibility calculations for this program. If the school does not understand this, contact the local Department of Social Services for assistance or the local Chapter of the Arc. If parents or guardians do not have a Power of Attorney or Guardianship Order for the student then the student must sign the program application.

REQUIREMENT TO REPORT ALL INCOME AND ASSETS TO SSI AND/OR MEDICAID

Recipients of SSI and/or Medicaid must report to the Social Security Administration and/or their local Department of Social Services any and all income including, one-time payments, child support, even as little as \$15 cash or a gift card in a birthday card, etc. SSI is a needs-based month-to-month benefit. Any delay in reporting an increase in income from month-to-month or an increase in assets to more than \$2000 could mean an overpayment of benefits which the recipient will have to pay back to SSI or will owe as a "Patient Pay" amount toward their Medicaid or Medicaid Waiver care and services.

Failing to report any changes to income or assets on a timely basis could result in loss of benefits. Failing to report any changes to income or assets at all is a crime, "Welfare Fraud", which could be prosecuted.

EXCEPTIONS TO THE \$2000 IN ASSETS LIMIT

In some cases resources greater than \$2000 may be conserved; including but not limited to, the Virginia Medicaid Works Program, the SSA SSI Program for Achieving Self-Support/PASS, Virginia Medicaid and SSA SSI allow a limited amount of additional resources to be set aside in a burial fund, etc. These programs are addressed in detail in various Sections of TRANSITIONS STEPS.

WEDDING BELLS AND SSI, SSDI AND MEDICAID

Young adults fall in love and want to get married. However, before setting the date they are advised, along with their families, caregivers and services providers, to thoroughly investigate the financial ramifications of getting married, most significantly the probable loss of SSDI, SSI, Medicaid and other benefits.

Those contemplating marriage, needing help with calculating the potential loss of benefits, should contact their local Social Security field office for assistance. If that is not an entirely helpful process, they may need to consider contacting a disabilities advocacy organization.

How Marriage Affects SSDI Benefits

Adult disabled children whose benefit is derived from their parent's work record will lose their SSDI. However, if their new spouse is also disabled and receiving SSDI they *may* be both be able to keep their benefit.

How Marriage Affects SSI Benefits

When an SSI recipient marries a non SSI recipient, a portion of the new spouse's income and assets is counted as belonging to the spouse receiving SSI. In SSA terms this is known as "deeming." When earnings from the couple's employment, SSDI benefits and other income is added together, it is likely that the disabled spouse's SSI will be lost due to an excess of income and assets.

However, if the new spouse also receives SSI, it is likely that they will both keep their SSI with a 25% reduction and will be limited to \$3000 in assets.

For more information see: <https://www.ssa.gov/policy/docs/issuepapers/ip2003-01.html>

ESTATE PLANNING

LETTER OF INTENT

One of the most important documents to have in the files of a disabled individual is Letter of Intent in which parents or caregivers leave detailed information about their children; including but not limited to, such things as:

-**A vision of the individual's future:** goals, where will he or she live and with whom, what activities to maintain.

-**The Individual's vision of his or her future.** Whenever possible, the individual's ideas and desires should be included in the document, such as ensuring that a favorite family remains a strong presence in his or her life, keeping a pet, working in a specific job, etc.

-**A description of the individual's personal qualities.** Future caregivers would benefit from knowing the unique aspects of the individual: overall personality and mood, talents and strengths, degree of independence, medical or behavioral challenges, sense of humor, etc.

-**Specifics on the individual's daily life:** school or work schedules; weekend activities, religious observance, bedtime routines, food and clothing preferences and sensitivities, preferred toys and games, exercise routines, typical outings, etc.

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

-**Living expenses.** Consider including annual costs of items such as food, 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 income 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.

Though a Letter of Intent is not legally binding, it will be invaluable to those who will take over the care of a disabled child or an adult disabled child.

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

WILLS & SPECIAL NEEDS TRUSTS

A will is critical to ensuring that family members' wishes are carried out regarding how and to whom their assets will be distributed after their death. However, to avoid jeopardizing the benefits or services of an heir with a disability the creation of a ***Family Funded Special Needs Trust is a MUST.***

Inheritance, proceeds from a lawsuit, substantial gifts, insurance settlements, etc., may be entirely disqualifying or partially offset SSI and Medicaid financial eligibility. Federal law allows families to establish special needs trusts which may designate beneficiary of these resources. Family funded, or third party special needs trusts, hold the resources of family and friends for the benefit of the disabled beneficiary. Self-funded trusts hold the resources of the disabled individual. However, disbursements for the benefit of the beneficiary of a special needs trust are made at the discretion of the Trustee(s).

Parents or guardians of disabled children, or adult disabled children, eligible for, or already receiving, SSI and/or Medicaid should be aware of the absolute necessity of establishing a special needs trust to be certain their child retains eligibility. These programs limit assets to \$2,000 at any time.

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

Uses of Trust Funds

Special Needs Trust funds are prohibited from being distributed directly to the beneficiary. They are usually disbursed to third party providers of goods and services for the use of the beneficiary. Trust funds may be used for "supplemental needs", such as:

Supplemental education and tutoring	Out-of-pocket medical and dental costs
Transportation (including purchase of a vehicle)	clothing
Materials for hobby or recreational activity	Trips or vacations
Entertainment such as movies or ballgames	Special Dietary needs
Computers, electronics, videos, cell phones	Furniture
Athletic training or competitions	Personal care attendant or escort
Housing for SSDI beneficiaries (will reduce SSI)	Memberships/Dues (YWCA, etc.)

Acting as Trustee

A trustee is the person overseeing trust assets and administering trust provisions; including investing, tax filing, and disbursements. Professional legal and investment advice are crucial for trustees administering a special needs trust. However, for pooled trusts set up by a non-profit organization, trust staff perform all administrative and the trusts' financial institution handles all fiduciary and investment duties.

*See *TRANSITION STEPS, Section 5: Legal and Financial Planning for additional non-profit Virginia Pooled Trust options*

A free Trustee Handbook is available at: <http://www.specialneedsalliance.org/free-trusteehandbook>

Retirement, Investment and Bank Accounts

To avoid affecting SSI and Medicaid eligibility, the beneficiary of an IRA, ROTH IRA, 401K, other types of retirement accounts and insurance policies, there should be a special needs trust established for the benefit of the disabled individual. The type of special needs trust will depend upon the source of the retirement funds. However, some Federal and/or state government retirement funds may ONLY be paid to person, excluding the possibility of designating a special needs trust as beneficiary.

Achieving a Better Life Experience/ABLE Accounts

Achieving a Better Life Experience Act (ABLE) Act became in December 2014. ABLE accounts create a new option for some people with I/DD and their families to save for the future, while protecting eligibility for public benefits. This new type of account will become available after the U.S. Treasury Department issues regulations and states take action to make the accounts available to their residents with I/DD and their families. – The Arc of the United States

For more detailed information about ABLE Accounts see [TRANSITION STEPS](#), SECTION 5: LEGAL & FINANCIAL PLANNING.

Help with Legal and Financial Planning

This is a complex subject which cannot be adequately addressed in [TRANSITION STEPS](#). Families may do well to call upon a Special Needs Planner affiliated with the Academy of Special Need Planners.

See: <http://www.specialneedsplanners.com/>, <https://www.facebook.com/Academy-of-Special-Needs-Planners>

GUARDIANSHIP & SUPPORTED DECISION MAKING

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 and/or to manage property or financial affairs. Only a Circuit Court judge can decide that a person is incapacitated and appoint a guardian and/or a conservator to act for the person. A petition for the appointment of a guardian or conservator should be taken very seriously; it is not a routine matter.

The court may appoint only a guardian, only a conservator, or both. The extent of the guardian's or conservator's authority will be set forth in the judge's order and in the Virginia Code. If it is determined that there is a need for both Guardianship and Conservatorship, it may be advisable to petition for both at the same time to avoid paying for two separate processes, one at later time than the other.

GUARDIANSHIP, CONSERVATORSHIP AND ALTERNATIVES

Guardianship

Guardianship makes someone (such as a parent) responsible for making medical, social, and legal decisions on behalf of persons who cannot make those decisions completely by themselves. In Virginia, a guardianship can be structured to fit the individual, with some rights taken away and others retained. Guardianship need not take away all or even most of the individual's rights. It is very common, for example, to preserve the right to vote, the right to hold a driver's license, and other rights. Even under guardianship, disabled adults can still participate in decision-making to the extent of their capabilities. The order will typically say that the individual will be consulted and his/her wishes taken into account. An experienced attorney can assist the petitioner in crafting a guardianship tailored to the individual which supports the petitioner as a strong advocate for the individual with a disability. The person under Guardianship will not be labeled "incompetent."

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 a person with a disability. Guardianship does not make the Guardian financially responsible for the person under guardianship. For example, parents who are guardians do not have to provide food and shelter for their adult child (unless the child's parent is under court order to pay child support for an adult disabled 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.

Family members, an attorney, a friend, or a public guardian may serve as Guardians and/or Conservators.

To obtain guardianship, parents or the legal guardian of a child under 18 need to file a petition with the Circuit Court of the jurisdiction in which the individual lives.

In guardianship proceedings for adults, notices of the hearings will be mailed to other relatives who will have an opportunity to object to the proceedings. The Court will take into consideration medical and psychological evaluations of the individual's need for guardianship and/or the physician may be asked to complete a simple standard medical review survey of the individual. When the petition is filed, the court will appoint a guardian ad litem (GAL), an attorney in private practice appointed from an approved list or attorneys to represent individuals with a disability to ensure that their rights are protected. The GAL will meet the individual to explain his or her rights and serve him or her with the Court paperwork. The GAL will also make a report to the Court giving an opinion as to whether the appointment of a guardian is necessary. In the case of Medicaid recipients, the GAL will be paid by Medicaid. The petitioner(s) however will pay privately for the petitioning attorney and related Court fees. After the GAL's report has been filed, a hearing will be held. Those to be appointed as guardians must attend the hearing. The person for whom the guardian is being appointed may attend the hearing but is not required to be present. Petitioners may ask the Court to appoint "standby" guardians to serve when the person serving as guardian is no longer able or available. Typically parents are appointed as co-guardians which allow either to act independently. After the hearing all necessary follow up paper-work must be completed in the Clerk of the Court's office.

The Petitioner(s), the disabled individual's GAL, as well as those in opposition, will present evidence at the hearing. Based upon the evidence the judge will determine whether or not the individual is "incapacitated" in terms of making certain decisions. If the petition is denied, the petitioner will have no legal authority to make decisions on behalf of the individual and will need to explore with him or her less restrictive alternatives such a Power of Attorney, Advanced Medical Directive, Representative Payee, etc.

NOTE OF CAUTION for New Guardians and Conservators

A Judge's signed Order alone does not establish Guardianship/Conservatorship status. **A newly appointed Guardian and/or Conservator must be sworn in by the Court Clerk** and all related paper work should be in order before departing the Court House with the one page CERTIFICATE/LETTER OF QUALIFICATION in hand. This document will read:

CERTIFICATE/LETTER OF QUALIFICATION

(Name of Court) Circuit Court

I, the duly qualified clerk of the Court, Certify that on (date) (name of new Guardian or Conservator) duly qualified in this court, under applicable provisions of the law, as (either Guardian/Conservator) of (name of individual under Guardianship/Conservatorship.)

The Power of the fiduciary named above continues in full force and effect.
\$ (amount) bond* has been posted.

Given under my hand and seal of this Court on (date.)
(Signature), Clerk

***About bond.** Posting bond is required for both Guardianship and Conservatorship. However, in the case of Guardianship the new Guardian is considered to automatically be covered for \$1000 bond without actually paying it. Petitioners for Guardianships and/or Conservatorship should discuss with their attorney, well ahead of the hearing, the posting of bond when sworn in by the Clerk.

A CERTIFICATE/LETTER OF QUALIFICATION should suffice as proof of Guardianship and/or Conservatorship. Guardianship/Conservatorship Court Orders are usually mailed to the petitioner within a few weeks of a hearing.

What can happen if the petitioner skips the visit to the Clerk's Office? Medicaid and other official entities will not accept a Guardianship/Conservatorship Order as valid if the appointee has not been sworn in.

The attorney representing a petitioner *should* emphasize the necessity of going straight to the Clerk's Office following the hearing!

Limited Guardianship

Limited guardianship is limited to specific decisions, such as just health care, as determined by a judge.

Conservatorship

A conservator's decision-making responsibility is focused on managing a person's financial and property affairs, including paying bills, investing money, and selling property. A conservator must post a surety bond and file annual reports for the court through the local Department of Social Services.

Disabled young adults ordinarily have less than \$2,000 in assets. The only additions to their income, with the exception perhaps of modest earnings from supported employment, is from SSI or SSDI which can be managed by a Representative Payee or by the individual himself.

CAUTION: re. Guardianship without Conservatorship

Circumstances may arise in which persons under guardianship, as well as their Guardians, may be prevented from making financial transactions with the disabled adults' money in the case of a particular institution or entity. The reasoning is as follows: the Guardian (even though an actual parent) is not also the Conservator and, therefore, cannot "do anything" with the adult child's resources. Neither can the adult disabled child "do anything" with his or her own resources because the Guardianship Order has found him or her to be "incapacitated." This should be discussed with the attorney handling a Guardianship proceeding so that parents or caregivers will not be caught off-guard should such a situation come up.

A Power of Attorney dated prior to a Guardianship hearing, and some other legal documents, remain legally valid *after* a Guardianship is in effect. A pre Guardianship POA may suffice for managing limited, simple, financial matters on behalf of the person having a disability whether the Guardian or another person is the POA agent.

The principal must be able to understand the nature and consequences of the power of attorney at the time he or she signs it in order for the power of attorney to be legally valid. This decision is made at the time you sign it, so it is still valid even if the principal later becomes incapacitated (if the power of attorney is "durable"). - *Power of Attorney*, Virginia Poverty Law Center, www.valegalaid.org

Limited Conservatorship

Limited Conservatorship is limited to specific financial matters, such as paying bills or selling property, filling tax returns, etc. as specified by the judge.

Representative Payee

Representative Payees are discussed in "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities." For additional information see [TRANSITION STEPS](#), Section 7: Uncle Sam's Social Security Library, the SAA brochure *When a Representative Payee Manages Your Benefits*."

Advanced Medical Directive*

An individual provides instructions about his or her wishes for health care treatment and designates an agent to make health care decisions when unable. Agent's powers are defined in the document; agents cannot override decisions.

Durable Power of Attorney *

Durable power of attorney is written authority giving their agent power to make decisions on behalf of the individual (the principal). Agent may act even if principal becomes incapacitated.

Limited Power of Attorney*

Is limited to a specific purpose such as selling or managing property.

**An Advanced Medical Directive or a Durable or Limited Power of Attorney does not allow the agent to override the decision of the disabled individual. If the individual refuses medical treatment the agent under the cannot override the decision. If the individual enters into a contract he or she did not understand, the agent under a Power of Attorney cannot void the contract.*

Emergency Order for Adult Protective Services Short-Term Guardianship

Emergency order for adult protective services Short-term guardianship (15 days) to handle emergency or correct conditions causing an emergency. Local Department of Social Services must apply to the Circuit Court for a temporary guardianship order. A short-term guardian/caregiver provides care, paid or unpaid, to an individual who cannot care for himself or herself. The short-term guardian has no power to make medical, legal or financial decisions with the Emergency Order.

Authorized Representative

Authorized Representatives are *agency specific* substitute decision makers for a person with a disability. Agencies may have different criteria for who can serve as an Authorized Representative. Programs Licensed by the Department of Behavioral Health and Developmental Services (including Community Services Boards), the Department of Medicaid Assistance Services/Medicaid and the Social Security Administration, allow clients to appoint Authorized Representatives to act in their behalf in all matters relating to the respective agencies' services. Except in the case of the Social Security Administration, persons under full Guardianship do not need an Authorized Representative.

Transfer of Rights to Students upon reaching the Age of Majority

Virginia Schools observe the TRANSFER OF RIGHTS TO STUDENTS UPON REACHING THE AGE OF MAJORITY. At 18 students must provide legal written permission for a parent or another person to have access to their educational records and/or to act in their behalf to make educational decisions, sign IEPs, etc.

This was touched on in *A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities Section on Special Education and Transition Planning* and is fully discussed in TRANSITION STEPS, Section 2: Special Education and Transition Planning.

Microboard*

A Microboard is a formalized (legal) and self-sustaining circle of support providing oversight and guidance for an individual with a disability over the course of his or her life. A microboard is a legal Virginia company (usually a non-stock, not-for-profit corporation) that can be named as Representative Payee, Authorized Representative, or Guardian for a person with a disability, thus eliminating the need for changing legal documents when individual agents become unavailable. The Board of Directors of the microboard may change over time but the microboard itself has perpetual existence so that the person with a disability receives continuous support and advocacy for his or her entire lifetime.

** For more information see "A Step by Step Guide to a Better Future for Youth and Young Adults with Disabilities" Microboard Section in "Odds 'd Ends" and <http://virginiamicroboards.org/authorized-representatives/>*

See Also: TRANSITION STEPS, Section 5: Legal and Financial Planning, "Determining a Decision-Making Role"

EMPLOYMENT AND THE DEPARTMENT OF AGING & REHABILITATIVE SERVICES/DARS

The Virginia Department of Aging and Rehabilitative Services (DARS) serves those having disabilities to prepare for employment, to find a job and receive needed support once on the job. DARS focuses on community based competitive employment (paying at least Federal minimum wage @ 7.25 per hour for 2016.) It does not fund services in nonintegrated employment settings such as sheltered workshops.

DARS has prioritized waiting lists (Categories I, II, III and IV) based on applicants' level of need. While transition students may not need intensive DARS services while in school, by the time they graduate their category of need may be well funded. Therefore, transition students should consider becoming a DARS Client while still in school. Research shows that getting help early usually results in better employment outcomes. Applicants will need to

progress through referral, intake, eligibility determination, needs assessment, the development of an Individualized Plan for Employment/IPE and its implementation. DARS contracts with employment services agencies to provide many of their services.

Local offices of DARS may provide Vocational Rehabilitation/VR counselors to local high schools. Students should feel free to contact their local DARS office for an appointment with a VR Counselor who will determine their eligibility for services, help identify any barriers to competitive employment and assist them with the development of an Individualized Plan for Employment/IPE. They can also arrange Vocational Assessments and Benefits Counseling.

More information about DARS services for transition students may be found in TRANSITION STEPS, Section 4: The World of Work. See: <http://www.vadars.org/downloads/publications/TransitionServicesGuideFinal08272013.pdf>

EXPLORING HOUSING OPTIONS

An Overview in a Nutshell

Finding safe, convenient and affordable housing for an adult with a disability is one of the most difficult challenges facing families. Therefore, much of this discussion is and will remain largely moot until finding appropriate housing for these individuals becomes less challenging.

Many individuals having disabilities need both housing and residential support services to be able to live in the community. It is important to understand the differences between them to understand the options for an adult with a disability.

Housing is the physical place (house, apartment, room) where one lives. The individual needs adequate income and, often, a supplemental funding source such as rental assistance, to pay for housing. Public housing is federally funded housing made available to people with low incomes. Units are often owned by a local Public Housing Authority and funded by the Federal Department of Housing and Urban Development (HUD). Additional options include Housing Choice Vouchers (HCVs) formerly known as "Section 8 Vouchers. Home ownership may also be an option in some cases.

Residential Services refer to the in-home support and supervision provided by caregivers hired by individuals or through an agency.

With congregate residential housing (group homes), the house and residential services are tied together.

In a sponsored residential placement, the resident lives in a private family home as a member of the family. These homes have the same licensing requirements as group homes, and, as with group homes, the house and residential services are tied together.

Congregate residential services providers usually collect a supplemental fee, ordinarily 90% of SSI or SSDI, from residents whose placement is funded with a Medicaid Waiver.

Persons not having a Medicaid Waiver are rarely able to privately pay for these residential options. Without a Waiver it will be necessary to obtain funding to pay for physical housing and support services (as needed). Because access to public housing and group home-type options is very limited, parents and housing advocates are working to develop alternatives

The DD Waiver provides then support services needed to live as independently as possible in the community in one's own house (owned or rented) or apartment but does not fund congregate residential or sponsored residential options.

Selective Service Registration

It may come as a surprise to parents and caregivers that men with disabilities who are between the ages of 18 and 26 must register with the Selective Service (unless they are residing in an institutional placement), explained on sss.gov as follows:

Men with disabilities that would disqualify them from military service still must register with Selective Service. Selective Service does not presently have authority to classify men, so even men with obvious handicaps must register now, and if needed, classifications would be determined later.

How to Register:

On Line Registration is preferred at: <https://www.sss.gov/Registration> Selective Service Registration Forms are available in any Post Office. Reminder Mail-Back Card. A young man may also register by filling out a reminder mail-back card received in the mail. Selective Service sends this card to many men around the time they turn 18 years old. A man can fill out the card at home and mail it directly to Selective Service.

Registration Acknowledgment Card and Selective Services Registration Number

It may take as long as 90 days to process registrations.

More Information can be found in TRANSITION STEPS, Section 6: Community Living.

ODDS 'N ENDS

REGISTERING TO VOTE & VOTING

Young adults turning 18, depending upon their cognitive level of functioning, should be encouraged to register to vote and to participate in elections as they are able. Some may only feel comfortable participating in Presidential Elections. Friends, family members or caregivers *may not* accompany a disabled person into the voting booth. An election clerk will assist these voters with accessing the voting booth and completing their ballot.

Poll workers may question the voting rights of persons having cognitive disabilities or attempt to deter them from voting. If disabled voters believe that their rights have been violated they should immediately contact the Virginia Department of Elections. For more information see:

<http://elections.virginia.gov/casting-a-ballot/index.html>

Voters with Special Needs, Virginia Department of Elections > Registration > Voters with Special Needs

www.ada.gov/ada_voting/ada_voting_ta.htm

The Americans with Disabilities Act and Other Federal Laws Protecting the Rights of Voters with Disabilities.

**Persons petitioning the Court to become a disabled person's Legal Guardian may request, as appropriate, that the Guardianship Order retain the disabled person's right to vote.*

HANDICAPPED PARKING

Handicapped Parking Placards and License Plates are not limited to persons with physical disabilities or certain medical conditions. Persons with ID/DD, Autism Spectrum Disorders, etc., are also eligible. The application, Form Med10, must be signed by the applicant's physician or other primary care provider. It is available on line at www.dmv.state.va.us and at local DMV service centers. Placards can move with individuals to any vehicle in which they are a driver or a passenger. Applicants may receive both a Placard and a Plate, which are available on the spot at DMV service centers or are available by mail to those who apply online.

ID CARDS FOR NON-DRIVERS AND PERSONS WITH AUTISM

Virginia Non-driver DMV ID cards are available to both children and adults. A 2015 Virginia Assembly provision offers the option of including “Autism Spectrum Disorder” on the ID Card which would be very helpful to rescue services and law enforcement responding to persons with an ASD. Applicants for ID Cards should log on to www.dmv.state.va.us to ensure having required identification documentation in hand for the application process.

RECREATIONAL OPPORTUNITIES AND TRAVEL SERVICES FOR PERSONS WITH ID/DD

Camps, National Park Service and Virginia Park State Passes, Special Olympics (which is limited to persons who have ID or related cognitive disabilities) and other services and programs are available to enable persons with disabilities to access recreational opportunities. This is addressed in more detail in the Community Living section of Transition.

MICROBOARDS

A circle of support, a Microboard is a circle 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 Or contact Bruce DeSimone at 804-343-5656 bruce.desimone@vhda.com.

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 solve problems during a crisis, provide referrals to and/or coordinate resources and 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 or VirginiaMicroboards@gmail.com

Tips FOR MILITARY “SPECIAL NEEDS” FAMILIES

Though Brunswick, Charlotte, Halifax and Mecklenburg Counties are not close to any large military bases*, there are children and adult disabled children living in the region whose parents are active duty or retired members of the Uniformed Services.** (Disabled children and adults of active duty parents or retired parents who were members of the National Guard or Reserve components of the Uniformed Services may be eligible for family member benefits. In most cases, retired National Guard or Reserve parents must be age 60 to receive various benefits for themselves and their eligible family members, most significantly Tri Care military health care coverage

**The closest military bases to this region are Ft. Lee, Petersburg, an operational base with medical and other family services available, and Ft. Pickett, Blackstone, with only very limited services available to military families.*

***The “Uniformed Services” include the Department of Defense “Armed Forces”; the Army, Air Force, Navy and Marine Corps, was well as the non-“Armed” services; the US Coast Guard under the Homeland Security Administration, the US Public Health Services/USPH and the National Oceanographic and Atmospheric Administration/NOAA.*

Disabled children of active duty military families who are enrolled in Tri Care’s Exceptional Family Member Program may be eligible for a Tri Care Waiver-equivalent program, the Extended Care Health Option/ECHO, which provides “financial assistance to beneficiaries with special needs for an integrated set of services and supplies.” This program is typically offered to children under the age of 18 but in some circumstances eligibility may be extended beyond 18.

For more information see: <http://tricare.mil/Plans/SpecialPrograms/ECHO>

Military families have been hesitant to name their disabled children as beneficiaries of a retired parents' Survivor Benefit Plan lest this inherited income stream puts the child's essential Medicaid, Waiver, SSA and other public benefits at risk. Because Federal benefits must be paid "to a person", a Special Needs Trust has not been an option for these parents. However, December 2014 the President signed into law the, "Military Child Protection Act" which allows a single exception to the provision that Federal benefits may only be paid to a person. Military parents may now name a Self-Funded Special Needs Trust for the Benefit of their disabled child as beneficiary of their Survivor Benefit Plan.

S.1076 — 113th Congress (2013-2014) Disabled Military Child Protection Act of 2013 on 12/19/2014. Authorizes monthly annuity payments under the Survivor Benefit Plan (SBP) to a supplemental or special needs trust established for the sole benefit of a disabled dependent child who is incapable of self-support because of mental or physical incapacity. (*Became Public Law 113-291*)

Because Military families move frequently from state to state and/or may live overseas, their children who are eligible for Medicaid Waivers are seldom placed on state Waiver waiting lists. In 2015 the Virginia General Assembly enacted a provision that will allow Wavier eligible children of military families to be included on the Virginia Waiver waiting lists *if* Virginia is the family's military "Home of Record." That is, if the family lives in Virginia and/or returns to Virginia for Retirement, their children may have a Waiver slot waiting for them "on hold" in Virginia. This is very good news!

VIRGINIA ACTS OF ASSEMBLY - 2015 SESSION - CHAPTER 671

An Act to require the Department of Medical Assistance Services to amend waiver eligibility criteria to allow dependents of active duty military members to remain on waiting lists for services when stationed outside the Commonwealth. [S 1036] Approved March 27, 2015

Be it enacted by the General Assembly of Virginia:

1. § 1. That the Department of Medical Assistance Services shall amend eligibility criteria for waivers supporting individuals with intellectual and developmental disabilities to allow the dependent of an active duty member of the military who was added to the waiting list for services through such waivers while he was a resident of the commonwealth to maintain his position on the waiting list following a transfer of the active duty military member to an assignment outside of the Commonwealth, so long as the active duty military member maintains the Commonwealth as his legal residence to which he intends to return following completion of military service.

Disabled children over eighteen with an active duty or retired parent may be eligible for indefinite "Incapacitated Family Member" status providing them with a military ID Card, Tri Care health care coverage and other military benefits. The qualifying disability must be diagnosed before 21, or 23 if a full-time college student. While the military makes its own disability determinations, the process is similar to that for Medicaid and Social Security. This is a means tested program; the military sponsor must provide 50% of the Incapacitated Family Member's support and demonstrate continuing financial eligibility every four years. In some circumstances uncompensated caregiving provided by the family is included in the calculations for determining 50% of support.)

"Tips for Military Families" has provided only an elemental introduction to this subject. However, a wealth of resources are only a mouse click away. For help with an online investigation of what is available and how it can be accessed see:

<https://www.dmdc.osd.mil/milconnect/>

**"That's all folks
but there is always more to be learned**

TRANSITION STEPS
Section 2: Special Education & Transition Planning

Contents

Secondary Transition: Why is it Important to Plan Early?

VDOE

Tri-State Transition Slide Guide

*Pennsylvania, Delaware and Virginia Departments of Education
Provided to the Arc of Southern Virginia by VDOE*

Transition Services

Virginia Intercommunity Transition Council

The Difference Between IEPs and 504 Plans

The Virginia Families Special Education Connection

Virginia Department of Education Diplomas

Diploma Options

Virginia Family Special Education Connection

Applied Studies Diploma Bulletin, July 2015

VDOE

Changes to Virginia's Diploma Options

Virginia Parent Educational Advocacy Training Center/PEATC, www.peatc.org

What Parents Need to Know

The Basics

What are Credit Accommodations?

Possible Credit Accommodations

Actions Parents Can Take Today

I'm Determined

VDOE I'm Determined Project

When Negotiations on Special Education Issues Are Difficult: Mediation

VDOE Dispute Resolution and Administrative Services

Training Options after High School

Virginia Intercommunity Transition Council

Education Options after High School

Virginia Intercommunity Transition Council

High School vs. College

*Individuals with Disabilities in Education Act vs. the Americans with Disabilities Act
[Transition Points 2015](#), the Arc of Northern Virginia, p. 25*

Think College!

Program for Adults in Vocational Education/ PAVE

J. Sergeant Reynolds Community College

ACE-IT in College
Virginia Commonwealth University

The Mason LIFE Program
George Mason University

Apex Day Support Ninety Day Transition Assessment
Apex Day Support Services, Charlotte Court House, Charlotte County

Transfer of Rights to Students Upon Reaching the Age of Majority
VDOE

Summary of Performance/SOP

The Summary of Performance: Wrights Law
wrightslaw.com

Summary of Performance Regulations:
VDOE and the Code of Federal Regulations
VDOE

SOP Template Sample
National Transition Documentation Conference 2005

Children's Services Act*/CSA and Special Education
**Prior to FY 2015 the "Comprehensive Services Act"*

Funding Under the Comprehensive Services Act (CSA) for Students with Disabilities
VDOE Division of Special Education and Student Services

About CSA, FAPT, CPMT & Special Education in Virginia
WWW.CSA.state.va.us & *the Arc of Southern Virginia*

FAPT Individual and Family Services Plan Template Sample
Halifax County FAPT

Notes:

See Additional TRANSITION STEPS Topics Related to Special Education and Transition Planning

Section 2: The Word of Work, SSA Student Earned Income Exclusion

*Section 4: All of Section Four
for Teachers, see Teacher's Student Referral to DRS & the SSA Student Earned Income Exclusion*

Section 7: Uncle Sam's SSA Book Shelf, Using Electronic Records Express to Send School Records

Section 8: Misc. Resources

2016 Transition Steps Resource Directory by County

Transition Web Sites:

*National Technical assistance Center on Transition
Center on Transition Innovations*

Age Appropriate Transition Assessment

Mobile Technology Apps for Promoting Independent in Students with Special Needs

Virginia Family Special Education Connection

Writeslaw, Enforcing State Compliance with IDEA

About Transition Councils

TRANSITION STEPS

Section 3: Medicaid health Care & Home and Community Based Medicaid Waivers

Contents

Medicaid Introduction

CMS.gov

Virginia Medicaid

Virginia DMAS

Family Access to Medical Insurance Security / FAMIS

Virginia DMAS

Health Insurance Premium Payment Program / HIPP

Virginia DMAS

HIPP for Adults

HIPP for Kids

Early, Periodic, Screenings Diagnosis and Treatment / ESPDT

Fact Sheet

Virginia DMAS

ESPDТ Specialized Services Prior Authorizations Requirements

Virginia DMAS

Medicaid Non-Emergency Medical Transportation: A Program of LogistiCare of Virginia

www.logistiCare.com

Virginia Home and Community Based Medicaid Waivers

FACT Sheet

The Arc of Virginia

Services Chart by Type of Waiver

The Arc of Virginia

EDCD Waiver Questions Answered

By permission, Edward Zetlin, Esq. Board Member, the Autism Society of Northern Virginia

DD Medicaid Waiver and ID Medicaid Waiver Level of Functioning Survey

DMAS, DBHDS, Other

Medicaid Waiver Redesign: "My Life, My Community"

What You Need to Know Concerning Virginia I/DD Waiver Redesign
DBHDS

Waiver Redesign Frequently Asked Questions
DBHDS

Individual and Family Support (grant) Program for Persons on the DD and ID Waiver Waiting Lists
DBHDS

Notes:

See *TRANSITION STEPS, Section 4: The World of Work, for Virginia Medicaid work incentive programs, Medicaid Works & the Medicaid Waiver Special Earnings Allowance*

See *TRANSITION STEPS, Section 8: Misc., for Information on the EDCD Waiver Application Process*

TRANSITION STEPS
Section 4: The World of Work

Contents

DRS Transition Services Get Connected Flyer
Virginia DARS

DRS Transition Services: A Roadmap to Successful Employment for Virginia's Youth
Virginia DARS

Employment
Virginia Intercommunity Transition Council

Workforce Services for Students with Disabilities
Virginia Intercommunity Transition Council

Postsecondary Education Rehabilitation Transition /PERT
Woodrow Wilson Rehabilitation Center, DARS

Division of Rehabilitative Services Student Referral to DRS
Virginia DARS

DMAS Order of Selection
Virginia DARS

Work Incentive Planning, Employment Options and Supports for the TRANSITION STEPS' Region

Work Incentive and Benefits Planning
Virginia Intercommunity Transition Council

Employment Services of the Arc of Southside
(City of Danville and Pittsylvania & serving TRANSITION STEPS' Region)

Goodwill Industries of South Central Virginia

goodwillscv.org

SSA Work Incentive for SSI Beneficiaries: Continued Medicaid Eligibility (Section 1629 (b))

ssa.gov

Virginia Home & Community Based Medicaid Waiver Work Incentive:

The Special Earnings Allowance

Virginia DMAS Medicaid Manual

vaAccess Work Incentive Planning and Assistance/WIPA TRANSITION STEPS' Region

vaACCESS.org

SSA Student Earned Income Exclusion Fact Sheet

Indiana Institute on Disability Community, Indiana University, www.idc.indiana

TRANSITION STEPS Section 5: Legal & Financial Planning

Contents

Selective Service Registration

sss.gov

Determining a Decision Making Role

<https://thearcofnova.org>

Future Planning 101

[Futureplanning.thearc.org](http://futureplanning.thearc.org)

Met Life Special Needs Calculator

<https://www.metlife.com/individual/planning/special-needs/index.html#overview>

Special Needs Trusts

[Futureplanning.thearc.org](http://futureplanning.thearc.org)

ABLE Accounts

[Futureplanning.thearc.org](http://futureplanning.thearc.org)

Virginia Non-Profit Pooled Special Needs Trusts

The Arc of Northern Virginia Special Needs Trust programs

<http://thearcofnovatrust.org/>

Commonwealth Community Trust
www.commonwealthcommunitytrust.org

Shared Horizons
www.shared-horizons.org

TRANSITION STEPS
Section 6: Life in the Community

Contents

Voters with Special Needs

Virginia Department of Elections, elections.virginia.gov/

Fast Facts: Community Services Boards, Services for Youth with Mental Health Disabilities

Virginia Commonwealth University, www.centerontransition.org

Transition for Youth with Serious Mental Illness

Virginia Commonwealth University, www.centerontransition.org

Reach Region IV

DBHDS

REACH Adult Crisis Services

REACH in Transition Step's Region

Regional Virginia Special Needs Camps for Children and Adults

Camp Easter Seals UPS Virginia and North Carolina

Camp Virginia Jaycees
Camp Rainbow Connection
Camp Baker

DARS-It's Not Just about Employment!
DARS Programs & Supports for Life in the Community for Individuals with Disabilities
vaDARS.org

Personal Assistance Services

State Funded Services for People with Brain Injury in Virginia

DARS Respite Voucher Program

News Release January 2015
Virginia Lifespan respite Voucher Program and Reimbursement Procedures
Virginia Lifespan Respite Voucher Program Application

Community Rehabilitation Case Management Program

Program Description
Application

Transition Steps Brochure Rack Envelope: This 'n That Collection of Program & Service Provider Brochures*

**See the clear storage envelope inside binder back cover.*

Note:

See Section 8: Misc. Resources, for information on Special Olympics and the 2016 Transition Steps Resource Directory by County for Special Olympics Contact Information

TRANSITION STEPS
Section 7: Uncle Sam's Social Security Book Shelf

Contents

All from SSA.gov

2015/2016 Benefits Update

Benefits for Children

Supplemental Nutrition Assistance Program Facts

Employment Networks In SSA's Ticket to Work Program

Your Ticket to Work: What You Need to Know to Keep it Working for You

Reporting Wages When You Receive Supplemental Security Income (SS)

Sample Application for Representative Payee/“Rep Payee”

Sample Application for Authorized Representative

SSA Booklets

Understanding the Benefits

Disability Benefits

How Work Affects Your Benefits

Your Ticket to Work

Working While Disabled--A Guide to a Plans for Achieving Self-Support

What You Need to Know to Get Social Security Benefits

Benefits for Children with Disabilities

Using Electronic Records Express to Send Health Records

Using Electronic Records Express to Send School Records

When a Representative Payee Manages Your Money

TRANSITION STEPS

Section 8: Miscellaneous Resources

Contents

2016 Transition Steps Resource Directory by County: Brunswick, Charlotte, Halifax & Mecklenburg Counties

Mobile Technology Apps for Promoting Independent in Students with Special Needs

Transition Web Sites

National Technical assistance Center on Transition

Center on Transition Innovations
Age Appropriate Transition Assessment

Virginia family Special Education Connection

Writeslaw: Enforcing State Compliance with IDEA

GCF LearnFree.org

Resources for Securing Clinical Diagnostic Evaluations and Consultations for Persons with Disabilities

On Line Resource Sites for Persons with ID & DD

The Arc of Virginia

Partnership for People with Disabilities (advocacy and support)

About Special Olympics

About Applying for an EDCD Waiver

About Transition Councils

Transition Steps Business Card File