



Informing & Inspiring the Special Needs Community

No. 1  
2019/2020

# EMPOWER

## VIRGINIA

**SPECIAL  
NEEDS TRUSTS**

**Medicaid  
WAIVER REDESIGN**

**(CLOSE TO HOME:  
THE HOUSING CRISIS**

**SOCIAL SECURITY**

**HOW TO GET  
THE JOB**

**Mental Health**

**Teen Transition**

**SBP**

**COLLEGE TALK!**



**The Arc**  
Northern Virginia

Special Needs Trust  
Serving Virginia, MD & DC

A Publication of the Special Needs Trust  
Program at The Arc of Northern Virginia

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# Thank You!

On my first day at The Arc of Northern Virginia I received an information and referral call from an elderly woman. “I’m 85 years old and my disabled son, who lives with me, is 53. If I die, I don’t know what will happen to him.” “Ma’am,” I said, “It’s not if you die, but when you die.”

As the mother of two daughters with Down syndrome, that single conversation had a lasting impact. What should we consider when planning for retirement and our (adult) children with disabilities? What should be in place so we can sleep at night? Who can help?

It’s been over fourteen years since that phone call. I have since been educated on matters from Special Needs Trusts to Social Security benefits, housing options, employment and job development, Virginia’s Medicaid Waivers, exiting the school system, legal authority, supported decision making and more.

I now have the knowledge and drive to effectively advocate for my girls.

Today, I share that knowledge with clients of The Arc of Northern Virginia. As Director of Trusts, I have met hundreds of families and their children, assisting in planning for their child’s future. From documents to policies addressing disability, we can help discern the most complex issues.

This magazine will now become part of the information and planning process. I hope it educates, informs and, of course, empowers.



Tia Marsili  
Publisher  
*Empower Virginia*

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# SPECIAL NEEDS TRUST

— Empower Your Future —

The irony of parenting: doing our jobs well means we end up without one.

When we envision our children as adults, we fleetingly allow ourselves to imagine what life will hold for them after we are gone. Not quite as pleasurable as taking our first sip of morning coffee—but a must-do for those who believe in facing reality and shouldering responsibility.

We've been reminded a time or two to begin with the end in mind, and parenting children with special needs is no different. We get it—planning for their future—financial and otherwise—feels daunting. It upends our experience of status quo. It never feels like the right time to start. But it is more than a good idea. It is both necessary and difficult.

So the first step in working ourselves out of a job is tackling the financial issue. Who and what will fund life's necessities when parents are no longer able to?

A special needs trust (SNT) to manage funds for daily

living is a growing option.

Stability is created—and felt—when there is financial insulation; a safety net in place. An SNT serves this purpose—a metaphorical piggy bank, invisible to providers of government assistance.

The Arc of Northern Virginia SNT—which does not have a limit on financial value—is designed to hold assets exceeding \$2,000. SNTs enable the accumulation of assets without interfering with eligibility for public benefits.

Recipients of Medicaid and Supplemental Security Income (SSI) - including child and adults with special needs are limited to \$ 2,000 in assets and resources to remain eligible. If..., public benefits are jeopardized. ....Establishing an SNT allows parents, the Beneficiary (individual with disabilities), and others to fund accumulate money in a protected asset to fund daily living assistance without interfering with public benefits.

**"INJUSTICE ANYWHERE IS A THREAT  
TO JUSTICE EVERYWHERE."**  
*Martin Luther King, Jr.*

For those who question the fairness of protected assets, here is the justification:

Recipient A, we'll call him Tom, received an unexpected inheritance of \$25,000. Uncle Bob left the inheritance directly to him. Recipient A has Medicaid and SSI. Since this gifted asset exceeds the \$2,000 asset and resource limit Tom could lose his benefits. Tom has heard about SNTs and calls The Arc of Northern Virginia. He meets with the Trust staff (This Arc Trust program serves all of Virginia.) to establish a **Self-funded** (first party) SNT (SF SNT) in the same month in which he received the inheritance. By doing so, his Medicaid and SSI remain in place and the \$25,000 is set aside for things that Medicaid and SSI do not cover. (This SF SNT has a Medicaid payback.)

Recipient B, we'll call her Enisha, has a Medicaid Waiver, SSDI, and Medicare. Her parents want to ensure that they she has money for things that her Waiver and other benefits do not cover. They know they need to do some planning. They meet with The Arc of Northern Virginia Director of Trust to talk about next steps. Futures planning is discussed and they choose to establish a **Family-funded** (third party) SNT (FF SNT) with The Arc. Once established, they meet with their attorney to update their Wills and other estate planning documents, as well as change the Beneficiary designations on their life insurance policies, annuity, etc to reflect the change. They tell their parents and siblings to use the correct language to direct inheritance, gifts, etc to the Trust. By doing so, her means-tested benefits remain in place and future funding is set aside for things

that the Medicaid Waiver do not cover. This FF SNT allows the parents to determine who will inherit when the Beneficiary passes.

We are conditioned to plan in moments of crisis, taking action when time is of the essence and choices are limited. When all appears well, and we're moving along with the wind at our back, we hope—we expect—that the status quo will remain.


Many with disabilities rely on government benefits to pay for housing, food, transportation and healthcare. An SNT can help maximize financial security without threatening eligibility of benefits. Without an SNT, life for individuals with special needs can be placed at risk—even by family and friends.

It is the things we don't think about that set into motion a series of events unable to be righted. There are the obvious elements, like death, that we know must be planned for. What about the situations—the unknowns—that barely register but in hindsight seem obvious.

## PRIVATE— THE RISKS:

When parents designate family members as successor trustees, they are handing over significant responsibility to people who may not want it. Certainly there are many SNTs administered by trustworthy people. Sometimes successor

(Continued on page 8)



You can wonder what his future holds,  
or you can plan for it.

Financial and estate planning can be overwhelming, particularly with a loved one with a disability. It is important to work with a team who specializes in this area and takes the time to understand your unique situation. The Arc of Northern Virginia Special Needs Trust enables families to plan for the future, and people with disabilities to derive the greatest possible benefit. Don't wonder any longer. Call for an appointment today. Establish a trust with us, and secure his future and your peace of mind.

703-208-1119 ext. 101 ♦ [www.TheArcofNovaTrust.org](http://www.TheArcofNovaTrust.org)



**The Arc**  
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# Special Needs Trust...

(from page 7)

trustees, due to their lack of knowledge or motivation, do not disburse from the SNT. For fear of jeopardizing benefits or subjective opinions, they choose not to provide assistance. Lastly, there are those that take advantage of the situation.

Even with the most trustworthy, things can go wrong, without intention or with. A successor trustee is only held responsible for misconduct, not for mistakes.

Any element—from lack of knowledge to disorganization to apathy to abuse—can detour original intent. An SNT with The Arc of Northern Virginia, on the other hand, is professionally managed by a non-profit organization that considers and accounts for potential scenarios while ensuring details are addressed with legal documentation.

Funds in SNTs are managed by a financial institution which offers a range of eight options – conservative, balanced, aggressive and others in between – With The Arc of Northern Virginia, an SNT enjoys greater oversight and increased short and long term involvement by the beneficiary and primary representatives.

## THE UNKNOWNNS:

### Inheritance

If an inheritance is left to an individual with disabilities instead of to a FF SNT, the individual can become ineligible for public benefits. When the inheritance and/or a transfer from a revocable family trust for example is left directly to the individual's FF SNT, no matter the amount, benefits are protected. Planning is key.

### Divorce and

#### Spousal Support

If an adult who receives SSI and Medicaid divorces, payment received from their former spouse can be irrevocably assigned in the court order to the SNT. With benefits protected, the beneficiary may be less reliant on spousal support.

### Child Support

When child support for an individual with disabilities is being discussed, it is advisable to include in the court order that starting at the age of 18 child support will be irrevocably assigned to an SF SNT. The onset of the individual's disabilities must have occurred during the developmental period and is likely to continue. Child support does not count against the individual with disabilities as unearned income prior to the age of 18. At 18, it does. By assigning it irrevocably to an SF SNT it is not counted when applying for adult disability with the Social Security Administration. Thus, the SSI will not be reduced because of the adult child support. In addition, if the parent responsible for paying (adult) child support does not comply with the order, the child support enforcement rules apply. (Please consult with an attorney.)

Another option is for the paying parent to make a voluntary contribution to a FF SNT without calling it child support. In this scenario, one must be sure that the parent will pay. Child enforcement rules do not apply.

### Letter of Intent

It is advisable to create a letter of intent. This is a guidance document usually written by the parents describing the past, present, and intentional future for the person with disabilities. It should address all areas in a person's life, taking a holistic approach. Also describing what works and does not work for the individual is very important. Because this is a guidance document and not a legal document, you may change it as life changes.

### Control

An SNT To ensure that distributions from the SNT are proper and legal, the SNT, Social Security Administration procedures, Medicaid rules, etc must be adhered to.

. Disinheriting an individual with disabilities is not advisable. Even when clear direction is given to the typically developing sibling things can go awry. That sibling (delete child) ... within their control. Life happens – an automobile

accident, an addiction, another family member pressuring them – and the sibling is not at fault but in the end, the individual with disabilities loses.

Another scenario is naming the sibling(s) as successor Trustee. They may wish to be involved in their sibling's life but do not have the wherewithal to administer an SNT. Their plates are full with their own lives. They want to help but are not willing or able to handle the burden of administering an SNT on top of their personal duties and obligations. A FF SNT with The Arc of Northern Virginia gives them this opportunity and reduced level of responsibility.

### Health

Progress in medicine has brought longer lives—including to those with disabilities. Living longer lives means extended financial support—an important consideration in futures planning.

A greater percentage of individuals with special needs suffer from chronic disorders at an earlier age than the general population. An SNT can promise increased financial stability for an extended time.

### Independence

Perhaps the greatest benefit of an SNT is increased independence. A sense of financial empowerment trickles down to other aspects of life and encourages options that might not have been possible.

## TYPES OF SPECIAL NEEDS TRUSTS:

Figuring out which kind of trust is the best for you is not exactly light work. Shades of differences exist, and it can be hard to know which option is correct. It pays to research first—it's a legal commitment.

### Self-funded (First party) and Family-funded (Third party) SNTs:

The first step in setting up an SNT is deciding which type of trust is correct. There are two main types of SNTs: First-Party Trusts (self-funded



or self-settled) and Third-Party Trusts (family-funded).

Among First Party Trusts, there are two subtypes: First-Party Special Needs Trusts and First Party Special Needs Pooled Trusts managed by authorized nonprofits such as The Arc of Northern Virginia. (see infographic on page 48 for a detailed description of differences).

Self-funded trusts are funded with the individual's assets—which may originate from an unexpected inheritance, the proceeds of a structured settlement, a lump-sum payback, military survivor benefits, adult child support, or earnings he/she sets aside for future needs.

Who may establish a Self-funded SNT? The individual with disabilities, the parent(s), grandparent(s), Guardian(s), court or Power of Attorney with authority may establish the SF SNT. This SNT is for the primary benefit of the Beneficiary. It is only established when it is needed. Examples of this are to protect means-tested government benefits, to legally and ethically move assets and resources in order to apply for means-tested public benefits, and when the Beneficiary cannot manage their own money. (They may not have means-tested benefits such as SSI or Medicaid but know that having money in their hands is not a good idea.)

For Self-funded SNTs **only**, upon the death of the Beneficiary there is a Medicaid payback (Medicaid has first dibs if there is a Medicaid lien). When the SF SNT is with The Arc of Northern Virginia, one may also choose Medicaid then name others to inherit, or choose to leave it to The Arc of Northern Virginia's trust program as a contribution.

The Family-funded SNTs on the other hand are funded with family assets and may also accept contributions from anyone but the person with disabilities. This may occur through the Last Will & Testament, a transfer from a revocable family trust, life insurance policy, annuity, retirement, contributions, etc. A key difference between FF and SF SNTs is that with FF SNTs, the person(s) establishing the trust determine who will

inherit when the Beneficiary dies.

Family-funded SNTs are established by (grand-) parents during their estate planning process. We advise parents to establish them sooner rather than later. Our Trust Talk Tuesdays and one-free consultations give family members and others the opportunity to learn more about trusts, benefits and futures planning.

Family-funded trusts allow parents to plan for the financial future of their child/ren with disabilities and prevent dependence on siblings and other family members.

Both types of trusts serve to help individuals with disabilities manage their finances, promote their dignity and independence, and remain eligible for needs-based government benefits.

## SURVIVOR BENEFIT PLAN:

The Survivor Benefit Plan (SBP) benefit has been offered to military members since 1972, but it wasn't until 2015 that it included special needs trusts (SNTs).

The bill finally gave military members the right to name self-funded (first-party) or pooled disability trusts as beneficiaries. Military families can now irrevocably assign SBPs to spouse then the SF SNT for the benefit of the child (-ren) with special needs without compromising their child's benefits like SSI and Medicaid.

Under the 2015 law, the SF SNT can receive any SBP annuity payments that would otherwise be payable to or on behalf of the disabled dependent child.

For military members with a child, this shift changed everything. These children can remain eligible into adulthood, while unmarried, for as long as the disability exists, but only if the disability occurred before age 18, or before age 22 if a full-time student. Without an SF SNT where the (adult) child with disabilities is named as Benefi-

ciary, the SBP would put government benefits in jeopardy—any unearned income over \$20 + \$65 offsets SSI income dollar-for-dollar.

Once SSI income reaches zero, SSI is lost and, and Medicaid may be jeopardized. This could mean the elimination of funds needed for living assistance, job coaching, respite care and other services provided through the Medicaid Waiver.

For more detailed information on the Survivor Benefit Plan, see page 30.

## SETTING UP A TRUST:

Setting up an SNT should be considered a component of estate planning.

Establishing an SNT, both Self- and Family-funded may be done directly with The Arc of Northern Virginia, an elder law, or estate planning attorney. The Arc trust department provides roundtables, consultations, and guidance during the SNT process. The Arc of Northern Virginia's Trust Department has established over 1600 SNTs since 1999. In partnership with Key Private Bank we are managing over 1,000 SNTs in Virginia, Maryland, DC, and other states. We work directly with parents, grandparents and people with disabilities to complete the Trust documents. Our documents were written by attorneys and vetted by various agencies as required. The Arc collaborates with elder law, personal injury and estate planning attorneys as well as agencies, businesses and the community at large. We help you navigate the nuances and complexities of trusts as well as government benefits. The Arc is the largest national community-based organization advocating for and with people disabilities and serving them and their families. We're one of over 730 chapters nationwide and we're here for you.

With The Arc of Northern Virginia and Key Private Bank, investments over \$250,000 may be customized. There are also 8 investment portfolios for clients.

(Continued on page 47)

**I**t is an arduous task to convince certain people—especially employers—to have an open mind. If they are not accepting and inclusive by nature, convincing them to hire people with disabilities may be a hard sell. But persuading them that when people with intellectual or developmental disabilities (I/DD) power their business, it can be stronger, better and more profitable perks ears. It resonates.

But it is hard to explain—and difficult to understand—why someone who has trouble navigating the subway sans help can be a rockstar employee. That people with I/DD will do more than show up and punch the clock. They will contribute. They will shoulder responsibility. They will be loyal. They will learn and grow and rise.

But opportunities feel few and far between. Legislation has made things both easier and harder. It cracked open the HR office door and people with disabilities got a proverbial seat at the table. But it was easier to argue that people with disabilities should be treated like humans than it is to prove why they aren't hired to positions for which they qualify. Progress has left something ephemeral and insidious. Employers can no longer check the "No" box and provide the real reason why—they simply reframe their objection into something more palatable.

But it's time to level the playing field.

And technology plays a paramount role. For some parents, caregivers and people with special needs, technology has revolutionized. It has broken down barriers and swept away obstacles. It has inched us closer to a world where disability means different, not less—to everybody. It has transformed outlooks and daily lives, eased burdens and reduced stress. Innovation has catalyzed learning, independence and empowerment; it has opened new doors parents and caregivers never thought possible. Technology has engendered hope.

Children and adults with special needs—once an untapped market for tech designers—have caught the

attention of innovators. The industry's best have listened, researched, engineered, piloted, designed and launched.

And The Arc has pioneered the movement. The Arc of Northern Virginia's award-winning app, TravelMate, enables people with I/DD to travel to and from work independently. TravelMate, compatible with most smart phones and tablets, serves as a virtual coach to help individuals with I/DD navigate the community. Helpers (such as therapists and caregivers) interface with the back end of the app, importing visual and auditory reminders, checklists and social stories that best match the learning style of the user. Photos or videos loaded on the app—showcasing the bus stop shelter or landmarks on the walking route, for instance—serve as visual reminders to the user their journey is (or is not) on track. It is a customizable application, allowing it to serve individuals with a range of needs, abilities and learning styles.

Whether the user is traveling by subway, bus, plane, train, Uber or cab the application metaphorically holds a hand, accompanying the user on his/her journey and providing step-by-step guidance. If the unexpected happens—anxiety or confusion sets in, buses get delayed or the user exits at the wrong stop—tapping the emergency but-

ton on the screen contacts the caregiver. The app is linked to a GPS, enabling the helper to track the user's progress from afar.

But to be helpful, TravelMate must be understood by caregivers, helpers and users. An instructional curriculum—created through a collaboration between The Arc and SpecialNeedsWare, Inc.—was created to instruct teachers, job coaches, therapists, assistive technology specialists and family members how to train individuals with I/DD to use the TravelMate app.

The curriculum-funded through the Federal Transit Authority via Washington Council of Governments is being implemented in Fairfax County, Arlington County and the cities of Falls Church and Alexandria.

But it didn't stop there.

# FROM CAN'T TO CAN. **how transformative** TECHNOLOGY CHANGES THE GAME.

Technology's value lies in its ability to be useful, to be accessed by the very people who need it. Connecting users with just the right technology, through the Tech Toolbox search platform, makes that possible. The Comcast Foundation provided the initial funding for the project, which has now grown to include tech coaching centers—places where people can come to maintain and update their devices, discover new technology and have their technology needs evaluated.

The Arc announced a \$1.4M dollar grant from Google.org in December, 2015 to expand the features of Tech Toolbox. Google.org's Director, Jacquelline Fuller, noted:

*"At Google, we know that good things happen when you help people find the right information. We're thrilled to support The Arc's efforts to make it as easy as possible for people with disabilities and their families to find the right technology to meet their needs. In the long run, we see the Tech Toolbox becoming a go-to resource for information about the ways that technology can change the lives of people with intellectual and developmental disabilities by sharing information about solutions that really work."*

Abe Rafi, Director of Digital Strategy and Online Services for The Arc of the United States, notes,

*"The online dimensions of life are becoming more important than we even realize. Going back to the '50s and '60s, the challenge was getting through brick and mortar walls. Today, the walls are digital."*

Tech Toolbox works to transcend those digital walls, relying on a crowdsourcing paradigm that benefits users. Technologies are reviewed and rated, ideas are shared. Obstacles are identified and circumvented.

With the ability to filter by age, product, goal, feature, age and price this platform searches and selects technol-

ogy to suit user needs. For instance, if fine motor control is limited and the user prefers to control the mouse by mouth, Tech Toolbox may suggest Glassouse (\$399), which enables the user to move the mouse through head movements, and click and double click with a bite switch.

Tech Toolbox introduces users to game-changing technologies, but Rafi knows his work is far from done. He notes:

*"To address gaps in technology, people with disabilities need to be included in user research. Talk to the users, include them iteratively in the design process. When people with disabilities are included early in the process, the gaps are addressed. When they are not, the game becomes 'how can I get developers to include features that will work for me?'"*

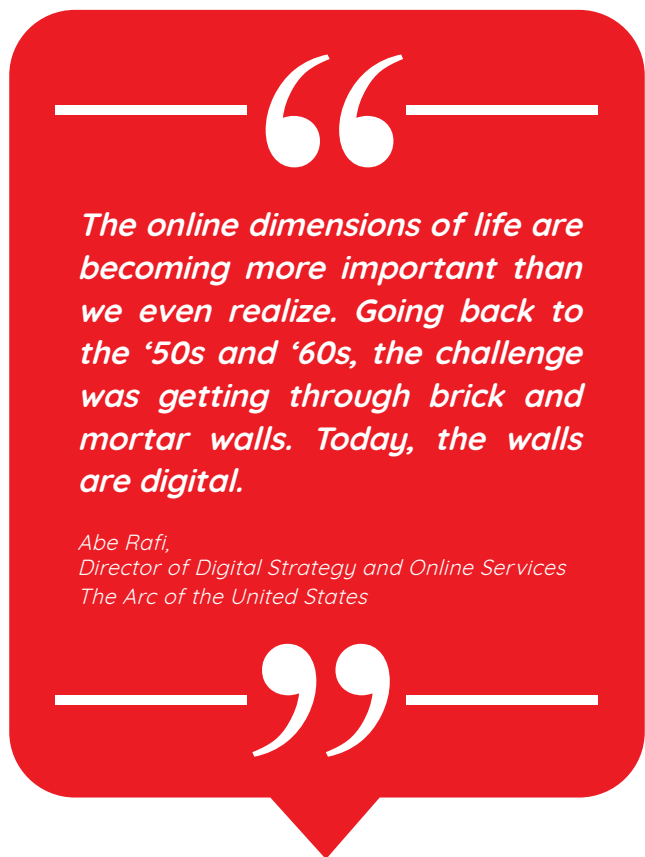
Designing technology to suit people with a range of learning styles, abilities, and disabilities makes sense—and including potential users in the beginning stages is integral.

Doug Meeker, founder and CEO of the Life Sherpa application has done just that. As a parent of a son with autism, he knows where gaps in technology solutions exist.

From years of involvement in the DD community, Meeker knows the breadth of DD—involving a multitude of users in his pilot programs will inch him closer to a more universal product with staying power.

Advances in technology, research and best practices have moved the needle; for most, life holds more opportunity and promise than times past. But transformation has yet to occur—there is work to be done.

Technological developments have catalyzed change and provided opportunities. But a universal mentality of acceptance, inclusion and equality is a work in progress. Without it, even the most innovative technologies will fall short. ■



# Disability Rights

## A Brief History



■ **1918**  
*Smith-Sears Veterans Vocational Rehabilitation Act* is passed, establishing a federal vocational rehabilitation act for soldiers with disabilities.

■ **1946**  
 The National Mental Health Foundation is founded by World War II objectors who served at state mental institutions, rather than in the war, and exposed abusive conditions.

■ **1947**  
*National Employ the Physically Handicapped Week* is held in Washington, D.C. Publicity campaigns emphasize the value of people with disabilities in the workplace.



■ **1965**  
 Medicaid is established. The *Social Security Amendments of 1965* provide for the first time, providing subsidies for health care for low-income Americans covered by Social Security.

■ **1971**  
 In New York, the *State of Respite Services for School Children* is established.

1910

1930

1940

1950

1960

1970

■ **1924**  
 Virginia passes a law allowing forced sterilization of individuals found to be "feeble-minded, insane, depressed, mentally handicapped, epileptic and other."

■ **1935**  
 Social Security Act grants matching funds to states for dependent mothers and children, people with disabilities and public health services.



■ **1963**  
 President Kennedy calls for persons confined to institutions be moved and integrated into the community.



■ **1973**  
 The *Rehabilitation Act of 1973* is passed. Sections 501, 503 and 504 prohibit discrimination in federal programs and services and other programs receiving federal funds.

■ **1927**  
 The U.S. Supreme Court, in *Buck v. Bell*, rules that the forced sterilization of people with disabilities is not a violation of their constitutional rights.



■ **1956**  
 Social Security Amendments of 1956 creates the *Social Security Disability Insurance (SSDI)* program for disabled workers age 50-64.

■ **Early 1970s**  
 The *Physically Disabled Students Program (PDSP)* is founded by Ed Roberts, John Hessler, Hale Zukas and others at UC Berkeley.

lished through the  
 emendments of 1965,  
 ized health care to disabled  
 ed  
 y.



2  
 v York ARC v. Rockefeller, parents  
 dents at the Willowbrook State  
 l file suit to end inhumane  
 ions at the institution.

1974  
 Housing and Community  
 Development Block Grant (CDBG)  
 funds removal of physical  
 barriers in public facilities.

■ 1990  
 The Americans with  
 Disabilities Act is  
 signed by George W.  
 Bush. The Act  
 provides comprehen-  
 sive civil rights  
 protection for people  
 with disabilities.



■ 1990  
 Individuals with  
 Disabilities Education Act  
 requires schools to  
 prepare students for  
 transition to adulthood by  
 including needed services  
 into the student's Individ-  
 ualized Education Plan  
 (IEP) no later than age 16.

■ 2006  
 Combating Autism Act increases funding to  
 NIH and the CDC for education, screening  
 and other programs for children with autism.

■ 2010  
 Affordable Care Act  
 contains provisions  
 that greatly benefit  
 people with  
 disabilities, including prohibiting  
 preexisting condition exclusions.



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1975  
 Individuals with Disabilities  
 Act (IDEA) was enacted by  
 Congress in 1975 to ensure  
 that children with disabilities  
 have the opportunity to  
 receive a free appropriate  
 public education, just like  
 other children.



■ 1988  
 The Fair Housing Act  
 prohibits housing discrimi-  
 nation against people with  
 disabilities and families  
 with children.

■ 1985  
 The Mental Illness Bill of Rights  
 Act requires states to provide  
 protection and advocacy  
 services for individuals with  
 psychological disabilities.

1999  
 In *Olmstead v. L.C.  
 and E.W.*, the Supreme  
 Court rules individuals  
 with disabilities must be  
 offered services in the  
 most integrated setting.



■ 2011  
 Facilities licensed by the  
 Massachusetts Department  
 of Developmental Services,  
 including the *Judge Roten-  
 berg Center*, are banned  
 from subjecting new admis-  
 sions to severe behavioral  
 interventions.

2014  
 The Workforce Innovation  
 and Opportunity Act of 2014  
 reauthorizes and updates existing  
 federal workforce development  
 programs. WIOA focuses on  
 youth transition and on  
 integrated, competitive  
 employment.



# WORKING FOR YOU

## How The Arc Helps Those with Disabilities

The Arc, a national nonprofit organization, believes people with intellectual and developmental disabilities should have the opportunity to participate in their communities—and provides support and services to make it possible.

“The Arc promotes and protects human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.”

Working with children and adults representing more than 100 different disabilities, The Arc provides residential, vocational and educational services as well as individual and public policy advocacy.

What started as the voice of a small group of like-minded parents and community members in 1950

has evolved into the largest nonprofit organization for parents and children with disabilities. As agents of change—assembling in church basements and mid-century livingrooms—The Arc’s founders believed disabilities should not preclude children and adults from educational opportunities, work programs and daycare.

They were parents and citizens who were willing to question mores, dispute status quo and accept the challenges of speaking up and speaking out.

They were parents and community members who were willing to take a risk to become catalysts for change.

Now more than 650 chapters strong, The Arc has grown and evolved in its 68 year history. Hurdles and victories have shifted paradigms and altered courses. New

challenges have emerged as the by-product of progress, and The Arc continues to rely on its network of chapters to catalyze change at all levels.

The Arc has been instrumental in creating opportunities for people with disabilities—advocating for the creation of Supplemental Security Income in the 1970s and catalyzing a paradigm shift from institutions to community living.

The Arc funded research to discover treatment for phenylketonuria (PKU), to expose the link between lead poisoning and brain damage and to define Fetal Alcohol Syndrome.

More recently, The Arc won expanded provisions in the Individuals with Disabilities Education Act and the Higher Education Act, helping students move from public schooling to higher education, employment and adult life.

The Arc established the National Housing Trust Fund to provide over 50,000 new public housing vouchers for people with disabilities.

The Arc’s staff and board of directors is committed to The Arc’s core values and the belief that children and adults with Intellectual/Developmental Disability (I/DD) should have access to information, advocacy and skills to participate as active community members.

## THE ARC'S CORE VALUES INCLUDE:

### People First

The Arc believes that all people with intellectual and developmental disabilities are defined by their own strengths, abilities and inherent value, not by their disability.

(Continued on page 51)

# Q&A *with* Tia Marsili

## Q. Please discuss your role as Director of Trusts for The Arc of Northern Virginia:

**A:** The most interesting part of my role as Director of Trusts is meeting new people whom I can help to develop a futures plan for their child or client. Much of my time is spent educating the community through presentations, providing 1:1 consultations, and developing relationships. Outreach is a large part of the position. Whether it is the individual with disabilities, parents, siblings, agencies, attorneys, financial planners, or other professionals, people need to know about their options in order to make informed decisions. This process can seem daunting but my job is to simplify every step of the process. Each of my clients is dealing with different circumstances and is treated with that understanding in mind.

## Q. What are the greatest benefits of a Special Needs Trust?

**A:** When created properly, a SNT protects means-tested government benefits such as Supplemental Security Income, Medicaid, Medicaid Waivers, housing, etc. These benefits provide for the basics and will not be jeopardized when funds are in a SNT and disbursed correctly.

For those with disabilities who do not receive means-tested benefits, but instead receive Social Security Disability Insurance (SSDI) and Medicare, for example, or have no benefits at all but cannot manage their money and may be at risk for financial abuse, a SNT with The Arc of Northern Virginia provides three levels of checks and balances before money is disbursed.

When a SNT is established with The Arc of Northern Virginia it unburdens the family from having to learn all the rules required to properly administer a SNT while keeping familial relations healthy and intact. I've heard many sad stories my clients experienced before coming to The Arc. Parents often choose their neurotypical children as successor trustees of the SNT. It may sound like a good idea, but it rarely is. Adult children have their

own lives to manage, their own children, jobs, homes, and more. Being able to allow them to continue as siblings, not take on the role of parent and trust administration, is a huge benefit.

We work daily assisting with disbursements and understanding the myriad of government systems. Our trustee, Key Private Bank, performs the fiduciary duties. They are responsible for asset management and allocation, tax and account reporting, check writing and disbursements. Our trust can also hold real property, customize investments over \$250,000, and offers the ability to make in-kind transfers of most stock. Together we ensure the proper use of the trust, preserving benefits and extending the trust's funds for as long as possible while providing a voice for clients.

## Q. When is a third-party (family-funded) (FF) SNT more appropriate?

**A:** FF SNT is appropriate when family and/or friends wish to provide for a person with disabilities. Anyone but the person with disabilities may establish and fund it. When the beneficiary passes away, the person establishing the trust determined who would inherit the remainder.

A first-party or self-funded (SF) SNT is appropriate when a person with disabilities receives unexpected funds, such as an inheritance that was not directed to the FF SNT, a lump-sum payback from the Social Security Administration, adult child support, alimony, military survivor benefits (SBP), a settlement or jury judgment from an accident, income. The person with disabilities may establish the SF SNT, their parent(s), grandparent(s), guardian, or court. This trust has a requirement to pay back the Medicaid, their heirs, or leave the remainder to The Arc of Northern Virginia.

The biggest difference is whose money it is. Establish a FF SNT when family and/or friends are contributing money. This is part of your futures planning.

(Continued on page 41)

# MENTAL HEALTH: Broken Processes, Failed Citizens and a Senator Determined

**T**he story of Virginia Senator Creigh Deeds (Bath-D) painfully illustrates the shortfalls of Virginia's mental health system and has resonated with parents who struggle to access care for their children—both under and over 18.

In November 2013, Deeds' 24-year old son, Austin "Gus" Deeds, was held under an emergency custody order—the state had probable cause to believe he was a danger to himself or others. Creigh Deeds' had pursued the order after growing concern about his son's deteriorating mental status.

An emergency custody order's six hour time limit would enable the sheriff's office to pick Gus up from his home and hold him for six hours while a psychiatric bed was obtained. Michael Gentry—the mental health evaluator working on behalf of the Rockbridge Community Services Board (CSB)—failed to secure a psychiatric bed for Gus within the emergency custody orders six hour time limit.

A review of the records indicate there were beds available in Virginia on November 12, 2013, but Gentry had failed to contact those facilities.

As a representative of the CSB—which provides access to state-funded services for mental health, intellectual disabilities and substance abuse—Gentry would release Gus Deeds, despite his parents' pleadings. Thirteen hours later, Gus would proceed to stab his father twelve times before fatally shooting himself at the family's Bath County home.

It never should have happened. If a psychiatric bed was secured, it may never have. Gentry's search was less than thorough; records indicate he stopped his search after contacting only 8 of the 10 available hospitals.

Virginia ranks 38 of 50 states for access to insurance and treatment, quality and cost of insurance, access to special education, and workforce availability (Mental Health America).

And mental illness doesn't discriminate. The National Alliance on Mental Illness (NAMI) reports 1 in 5 adults experience mental illness in any given year, and about 1 in 25 lives with a serious mental illness. The rate of depression in youth has worsened—increasing from 8.5% in 2011 to 11.1% in 2017 (Mental Health America). The problem is documented and growing, but what about the solutions?

The Deeds' family tragedy would catalyze change. Deeds authored legislation (SB260) two months after his son's death, which would propose reforming the intake process of psychiatric emergencies; this included doubling the length of emergency custody orders to twelve hours, which allowed more time for CSB representatives to secure safe and appropriate placements.

The legislation also proposed the establishment of a state registry for psychiatric beds, which would streamline the process of identifying available beds for those under emergency custody orders.



Finally, it mandated state acceptance of patients in need of a psychiatric bed if private beds were unavailable. But there was more to be done. The mental health system would need to be studied and scrutinized.

A broken system could not be fixed without a thorough understanding of damaged pieces, parts and processes.

Deeds sponsored a resolution to initiate a four-year comprehensive study of Virginia's mental health system, passed by the General Assembly as SJ 47 in March, 2014. This bill would establish a joint subcommittee to study mental health services in the 21st century. The Honorable R. Creigh Deeds was listed as chair.

As Deeds told *The Roanoke Times*:

"That study resolution was more important to me than any single bill. The crisis intervention piece of it needed to be fixed. The gaps in that system were startlingly clear after the situation I was involved in. But that was the easy stuff really. We have to address the flaws in the existing system."

The ongoing study has continued to shed light on areas of need, and the joint subcommittee identified and initiated legislation to address several areas requiring reform. Virginia's 2017 General Assembly session would provide funding to strengthen Virginia's mental health system. Delegate Farrell (R-Henrico) and Senator Hanger (R-Augusta) introduced bills (HB 1549 and SB 1105 respectively) which passed in the 2017 session of the General Assembly, increasing requirements of CSBs to provide same day mental health screening services and outpatient primary care screening and monitoring (effective July 1, 2019).

\$6.2 million of new funding was allocated for same day mental health screenings. By July 2021, CSBs will also be required to provide crisis services, outpatient mental health and substance abuse services, psychiatric rehabilitation services, peer support and family support services, mental health services for certain members of the armed forces, care coordination and case management services.

The Assembly also voted to expand permanent and supportive housing, and made changes to credential regulations for members of the Board of Corrections.

Mental illness has emerged as the force behind numerous national tragedies—in school classrooms, family homes and government buildings—leading many to demand more funding, awareness and access to treatment. Virginia citizens are no exception. Tragedies spark debate, dominate headlines and spotlight mental illness—but it is not enough. The broken mental health system must continue to garner attention and financial

support from lawmakers until tragedies fueled by mental illness are no longer commonplace.

New national healthcare legislation will impact mental health services for Virginians—the question remains, how and to what extent?

Former President Obama's 2010 Affordable Care Act (ACA) requires all health plans operating in the Health Insurance Marketplace to cover mental health, substance use disorders, rehabilitative and habilitative services. This represents one of the largest expansions of mental health and substance use services in recent history.

Under the proposed replacement legislation, the American Health Care Act (AHCA), pre-existing conditions still could not be excluded from coverage, but AHCA does not include a cap on how much you can be charged because of a pre-existing condition. Translated, the cost of coverage for pre-existing mental health conditions will preclude many from purchasing coverage at all.

According to [Medicaid.gov](http://Medicaid.gov), Medicaid is the United States' largest payer of mental health services, and reimbursement of substance use disorder services has increased over time. The AHCA proposes significant cuts to Medicaid funding, and people with mental health conditions will be among the most affected. H.R. 1628 would establish a \$15 billion fund for maternity care, mental health and substance use disorders. However, the nonpartisan Congressional Budget Office (CBO) cautions the fund will not compensate for the cuts to mental health coverage.

According to the CBO Cost Estimate Report on H.R. 1628 (*as passed by the House of Representatives on May 4, 2017*):

"Services or benefits likely to be excluded from the EHBs [Essential Health Benefits] in some states include maternity care, mental health and substance abuse benefits, rehabilitative and habilitative services, and pediatric dental benefits.

In particular, out-of-pocket spending on maternity care and mental health and substance abuse services could increase by thousands of dollars in a given year for the nongroup enrollees who would use those services."

Time will reveal what legislative changes will occur and how they will affect care and coverage for people with mental health conditions.

Virginians will experience positive changes and expanded services initiated by Senator Deeds—but they will be forced to turn their attention to the Capitol

(Continued on page 18)

# Mental Health...

(from page 17)

building and The White House to discern how national legislative changes in costs, coverage and care will impact their future.

Parents and caregivers of children and adults with mental health conditions are in touch with its unpredictability. A focus on futures planning combats disempowerment and can engender control and stability—for both the person with a mental health condition and caregiver.



Starting a plan can feel daunting—even painful. It forces us to stare at reality, which may be less reminiscent of a Norman Rockwell painting than we once imagined. But starting the planning process can help you feel in control, prepared and on it. Finances, housing and medical/mental health care are among parents' top concerns—exploring resources and potential solutions is a solid first step.

Planning for your child's financial future is a good place to start. Establishing a Special Needs Trust (SNT) is an option to explore for futures planning. More than 60% of SNTs established through The Arc of Northern Virginia are for the benefit of (adult) children with a mental health condition.

Once established and funded, SNTs can provide daily living assistance to the beneficiary. SNTs can be self-funded, by a lawsuit for example, or family-funded, by life insurance and a will. SNTs at The Arc of Northern Virginia do not have a limit on financial value, and allow for the accumulation of assets without impacting public benefit eligibility. For a detailed discussion of SNTs, see page 8.

Supplemental Security Income (SSI) is based on financial need and available to people with certain disabilities—including some mental disorders—that meet eligi-

bility criteria.

On the Social Security Administration's (SSA) website under 'listing of impairments', 11 categories fall under 'mental disorders' including neurocognitive disorders; schizophrenia spectrum and other psychotic disorders; depressive, bipolar and related disorders; intellectual disorder; anxiety and obsessive-compulsive disorders; somatic symptom and related disorders; personality and impulse-control disorders; autism spectrum disorder; neurodevelopmental disorders; eating disorders; and trauma and stressor-related disorders.

Supplemental Security Disability Insurance (SSDI) is another benefit offered by the SSA for which the person may be eligible, as well as Medicare.

Identifying housing options for people who live with chronic and persistent mental health conditions is often a challenge. Adult children often reside with their parents or on the street—identifying an alternative housing option is prudent in the event parents are precluded from independent living. (See the housing article on page 26 for more options.)

Also identify an advocate—a close family member or friend, for example—who understands the complexities of the illness and treatment and is willing to assume additional responsibilities if parents are no longer able to. (See page 41 for more information on The Arc of Northern Virginia's Advocate program.)

People living with chronic mental illness may benefit from exploring a psychiatric advance directive (PAD), also known as a mental health advance directive. PADs can boost the person's sense of empowerment, independence and autonomy. Go to [namivirginia.org/mental-health-resources/advance-directives](http://namivirginia.org/mental-health-resources/advance-directives) for more information.

There are two kinds of PADs—Proxy PADs and Instructive PADs. A Proxy PAD assigns an agent to make treatment decisions should its creator lose legal capacity for decision making. An Instructive PAD includes specific treatment preferences and instructions during an acute mental health crisis. A PAD is signed by its creator during a time period of competency, and must be witnessed by two other adults. PADs do not require a notary, an attorney or a preprinted form.

Mental health conditions are the great equalizer—they affect people of all ages, education levels, races and religions across the world. Developing a futures plan engenders empowerment. ■

# Key Private Bank



*A Solution to the Housing Crisis*

The housing dilemma for people with special needs weighs heavy—if worry filled buckets, this one would overflow. Cost, availability, location, logistics and effect on public benefit eligibility are a few considerations and sources of angst. Parents, siblings, and transitioning adults with special needs feel the crisis deep in their bones. There is no panacea, elixir or cure-all. Meticulous due diligence, copious stacks of paperwork, tense shoulders and a supreme investment of time will likely accompany any decision made. The decision can feel mountainous, emotional and downright scary.

But research, data-gathering and conversations with experts go far—gathering possibilities is the first step. One possibility to consider that may be right for your family is placing your home in trust with Key Private Bank Trust Real Estate Services. Key Private Bank is the trustee for The Arc of Northern Virginia's Special Needs Trust program which serves all of Virginia, Maryland, and Washington, D.C. In collaboration, The Arc of Northern Virginia and Key Private Bank guide you through the process (see page 8 for further details).

Here are some principal benefits: your adult child resides in the home; Key Private Bank manages the property and pays the bills via funds from the trust. Because the home is held in trust rather than in the adult child's name, eligibility for means-tested public benefits is not impacted.

Holding real estate assets in trust is more than an exercise in convenience. There is a plethora of advantages; the most oft-cited is the elimination of the need for probate and out-of-state ancillary administration and continuity of management in the event of death, incapacity or other unseen circumstances. Holding real estate assets in trust can be a strategic way to optimize estate planning. Key Bank employs expert Trust Real Estate Officers to assist clients in navigating complexities of placing real estate assets in trust. Key Bank is committed to the mission of managing client's property to realize its maximum potential.

Key Private Bank Real Estate Services provides professional property management for real property held in trust, as well as access to comprehensive master insurance policies for flood, earthquake and vacancy coverage. Key Private Bank has offered real estate solutions for decades, and is adept at managing a variety of real

estate assets including: commercial, residential, office, agricultural, industrial and mineral.

Key Private Bank is an industry leader in lease negotiation and long-term strategy development to maximize investment performance. Credentials of incumbent real estate officers include Certified Property Manager Institute of Real Estate Management Professional Landman, American Association of Professional Landmen; and Licensed Real Estate Brokers in various states. Six regional offices coast-to-coast allow for a nationwide service area. On average, Key Private Bank real estate officers have more than 28 years of trust banking experience and almost twenty years of property management experience.

Through Key Private Bank's nationwide property management services, you can rely on timely payment of utilities, property taxes, insurance and real-estate related expenses. Key Private Bank will oversee repairs, renovations and capital improvements, collect rent, enforce leases and adherence to property obligations. Client communication, accounting and recordkeeping are managed by the bank as well as the purchase sale and leasing of the real estate property.

Key Private Bank earns customer's confidence by:

- Ensuring adherence to fiduciary standards of care
- Comprehensive due diligence process for vendor selection and payment
- Structured, disciplined decision-making
- Overseeing activities by both internal and external examiners
- Formal annual property review procedure
- Ensuring ongoing internal and external training and education of real estate officers

When it becomes time to explore housing options for your transitioning child, Key Private Bank will value the opportunity to participate in the conversation. We will discuss the impact of placing your home in trust, the management options available, and lead you confidentially through the process. To start the conversation, contact Tia Marsili, Director of Trusts at 703-208-1119 ext. 115 or [tmarsili@thearcofnova.org](mailto:tmarsili@thearcofnova.org). For more information visit [thearcofnovatrust.org/posted-trusts/real-estate-snt/](http://thearcofnovatrust.org/posted-trusts/real-estate-snt/) ■

# The Medicaid

## Why the Redesign?

Virginia was ranked as the 8th wealthiest state in the country, but only 49th in its spending for individuals with I/DD (Intellectual and/or Developmental Disabilities). The number of individuals with I/DD requiring services continues to rise and rates paid to providers of some services have not been updated to reflect minimum industry standards. Long waiting lists and many providers unable and unwilling to deliver services are direct results of this growing need.

—Source: Virginia Department of Behavioral Health & Developmental Services (2014)

**B**efore the redesign, the Medicaid waiver system was a fractured system, ill-equipped and underfunded. Virginia had fallen behind most states in almost every aspect of the Medicaid waiver process, boasting an antiquated system far short of current standards.

The system had to change—a settlement agreement with the Department of Justice would demand it.

In order to comply with the Department of Justice VA Settlement Agreement and new federal requirements from the Centers for Medicare and Medicaid Services (CMS) the system would require a redesign.

A Medicaid waiver, also referred to as Home and Community Based Services (HCBS), combines federal and state funds to provide ongoing support for individuals with disabilities. A waiver is a long-term support system for someone who will have long-term care needs, like someone with a developmental disability.

Virginia's Medicaid waivers may cover for example respite, personal care, assistive technology, employment or residential services, nursing and behavioral supports.

The redesign brought additional funding from the Commonwealth of Virginia, prompting an increase of available slots, for a growing population reliant on need-

ed services. The redesign would provide better coverage and improved access for applicants.

Gone are the days when institutions served as the default place of care for individuals with disabilities. The redesign centered on community-integration and broader independence.

The new Developmental Disabilities (DD) Medicaid Waiver Program takes a more individualized and flexible approach:

The Day Support Waiver is now the **Building Independence Waiver**. It provides supports for adults able to live independently in the community with additional service and housing subsidies, if needed. This waiver serves adults 18 years and older who own, lease or control their own living arrangements.

The Individual and Family Developmental Disabilities Supports (IFDDS) Waiver is now the **Family and Individual Supports Waiver**. It provides supports for individuals living with family, friends or in their own homes, including supports for medical or behavioral needs, as necessary. This waiver is available to children and adults.

The Intellectual Disability Waiver is now the **Community Living Waiver**. It allows for 24/7 services and

# Waiver Redesign

supports for individuals with greater medical and/or behavioral support needs through licensed services. Residential supports and extensive medical, behavioral and non-medical supports are included. This waiver is available to people of any age with the most comprehensive continuum of services available in the DD Waiver Program.

Each waiver is designed to offer services and supports that address a specific range of services, with some offered across all waivers. Waivers are determined by need—with slots for different waivers at different levels. This construct is more cost effective and better able to meet individual needs.

For children and adults with special needs, the family's assets and resources are not a factor, but the individual's are. In order to qualify, the applicant must meet Virginia's definition of developmental disability. Under the Virginia DD Waiver Program there is a wait-list, so do not apply for Medicaid until you've applied for a DD waiver and a slot has been awarded.

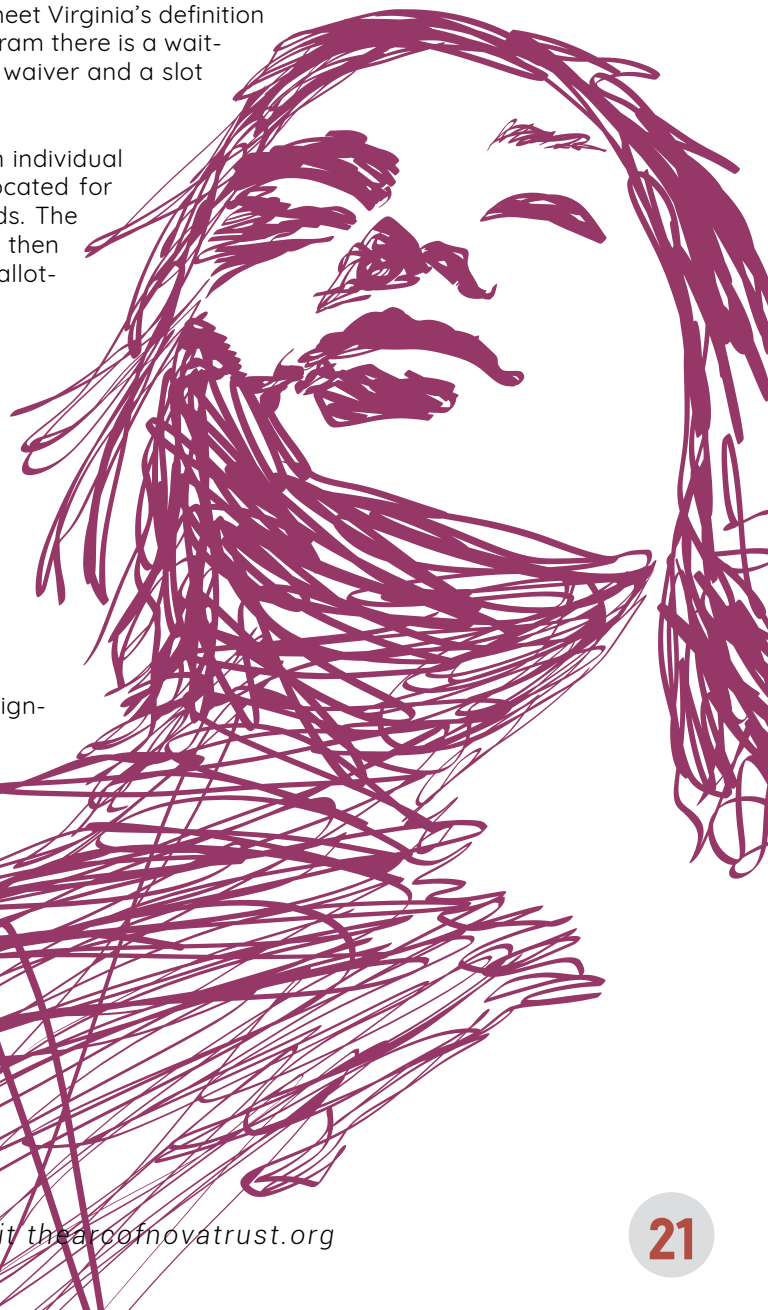
For adults, Medicaid funding will be determined by where an individual lives and how they spend their day. The funding amount allocated for each individual is determined by an assessment of their needs. The number of hours dedicated and types of services offered are then individually customized within this budget. While Virginia has allotted additional waivers, the number falls far short of demand.

The process to apply for a waiver has also been streamlined. The single point of entry is the local Community Services Board (CSB) no matter which DD Waiver is being sought. The CSB provides eligibility screening for all three waivers.

The CSB assesses each case along with the applicant to establish a priority level of 1, 2 or 3. The initial eligibility screening is the same no matter which waiver is being sought. If found to be eligible the applicant is placed on a single, consolidated waiting list, based on urgency—not chronology. One of three waivers will eventually be awarded to the applicant.

When waiver slots are available, your anonymous Slot Assignment Review Form is submitted to the local CSB's Waiver Slot Assignment Committee. Each applicant is then provided a score and the applicant most in need will be awarded the next waiver slot.

A limited number of emergency waivers are available and assigned by the Virginia Department of Behavioral Health and Developmental Services to those who meet the emergency criteria.



(Continued on page 51)

# Revolutionaries at Work



Those with special needs can sometimes fall off society's radar, swallowed by a system that doesn't always recognize their exceptional skills and endless drive. They have dreams, passions and goals—just like everyone else.

There are organizations that believe equality refers to more than just the law. These revolutionaries have crushed a belief system that has underestimated a population rich with talent.

## A PLACE TO BE: TRAILBLAZERS IN ARTS & MUSIC

It is rare that an organization can't be aptly described, but some kind of magic happens at A Place to Be (APTB) that defies definition. Words fail to capture the spirit of this organization and the determination of its directors, staff and students.

After an APTB show—as a participant or as an audience member—a person is never the same. They have a broader perspective, a grander understanding of the world around them. They are a better version of themselves.

The mission of APTB is to work with people to face, navigate and overcome medical and life challenges using music and expressive arts therapy.

The organization helps people with traditional and non-traditional disabilities and challenges find their voice and inspire others to do the same. All people are seen as equal and recognized for their gifts and abilities.

Programs are fully integrated with people working through a wide variety of challenges:

- Physical/Medical Challenges (ex: cerebral palsy, cancer, visually impaired, TBI)
- Behavioral/Learning Challenges (ex: ADD, dyslexia)
- Intellectual/Developmental (ex: autism, Down syndrome)
- Social/Emotional/Psychological Challenges (ex: social anxiety, depression)
- Life Challenges (ex: life transition, grief, bullied, shy)

By helping people find their personal voice and their unique contributions and strengths, participants develop higher self-confidence and personal efficacy that can expand into further community participation, stronger families and brighter futures.

APTB offers seven core programs that serve people ages 1-100:

### The Same Sky Project:

This theatrical touring production gives voice to teenagers with diverse challenges while educating audiences about acceptance, empathy and differences. The project alters participants' lives—helping them gain confidence through having the chance to be seen, share their stories and make meaning out of challenges and triumphs. The transformative impact it has on audiences inspires and educates young people to have conversations about acceptance of others and of themselves.

Shows in the Same Sky Project have been seen by over 50,000 school and community audience members. The show "Behind The Label" was the keynote opening performance for the National American Music Therapy Conference and for the National Institute of Health's Conference on Rehab Medicine.

Other programs include:

- Private Sessions in Music Therapy or Expressive Arts Therapy:
- Social Therapeutic Groups:
- The Immersion Program:
- Lunch Bunch:
- Summer Camps:
- INOVA Hospital – Medical Music Therapy:

## INCLUSION FILMS: WRITING YOUR OWN STORY

In film, anything is possible. We explore the farthest reaches of our universe while saving the world from certain destruction. We scale mountains and sail seas—invincible, tough, unscathed. Film allows our minds to wander with possibility. It is a visual teacher of acceptance, empathy and the human condition. We are forced to open our eyes and really see the world around us, how it was and how it could be.



As a storyteller, film is art. It's therapy. It's a reflection of inner fear and great hope—the most intimate side of ourselves. Whether telling a great story or simply watching one, movies make us feel a little less alone in this great big world.

Veteran filmmaker Joey Travolta understands the transformative power of film. In 2005, Travolta had the opportunity to mentor an aspiring filmmaker, a fifteen-year old boy with autism. The two would go on to direct and produce *Normal People Scare Me*, a documentary from the perspective of a person with autism.

*Normal People Scare Me* was a 10-minute film that would go on to be a spectacular success and set Travolta on a new path. There were others with similar dreams, those who needed Travolta's guidance and his ability to see beyond society's expectations.

So in 2007, Travolta would establish Inclusion Films, a teaching studio for aspiring filmmakers with developmental disabilities. With five locations throughout California, Travolta and his team travel across the country hosting workshops, shooting films and breaking boundaries.

(Continued on page 47)

# ChairsForStairs.com

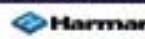
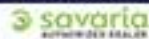
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# SSI v. SSDI

## KNOW THE DIFFERENCE

Chances are you've heard both acronyms before. But to many, their ring is more familiar than their meaning. But the value of each to those who qualify is unquestionable.

Both Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are administered by the Social Security Administration (SSA) and determine medical eligibility for disability using the same criteria. That's where the similarities end.

SSI and SSDI are distinctly different federally-funded programs designed to serve different populations. SSDI recipients qualify by disability and employment history, whereas SSI recipients qualify based on disability alone.

People 65 and older without disabilities who meet the income and financial requirements can also qualify for SSI.

SSI can be a source of income for people who are blind, elderly, or have a disability. SSI is a needs-based federally-funded program that does not require prior contributions from the recipient.

SSI applicants are means-tested—individuals must prove low income and ownership of less than \$2,000 of assets. The asset threshold for couples is \$3,000. Recipients of SSI automatically qualify for Med-

icaid in most states.

The Federal Benefit Rate (FBR) for SSI determines the maximum amount of money a recipient can receive from the federal government, which can vary from year to year. The 2018 rate is \$750 per month for individuals and \$1,125 for couples. When an SSI recipient turns 18, s/he must undergo a redetermination of eligibility.

Recipients who earn income while receiving SSI benefits can exclude the first \$65 per month plus one-half of the remainder (SSA.Gov). Recipients can exclude \$20 of unearned income per month.

The Commonwealth of Virginia supplements federal SSI payments. The amount, referred to as a "state supplement", varies, depending upon marital status of the recipient and whether he/she lives independently, in assisted living or a nursing home.

SSDI is designed for people with a severe, long-term, total disability who have accumulated a minimum amount of work credits and paid Federal Insurance Contributions Act (FICA) Social Security taxes, but who cannot work due to their disability. Work credits are calculated by the SSA based on earnings. The monthly benefit amount is determined by earning history.



Social Security Act Signing, 1935



Once disabled, there is a five month waiting period for SSDI benefits. After two years of SSDI enrollment, recipients are eligible for Medicare. The spouse and children of SSDI recipients are eligible to receive auxiliary benefits.

If your household income exceeds the income threshold, income taxes will be required. A Continuing Disability Review (CDR) will occur for SSDI recipients every 1-3 years to assess whether recipients remain eligible for benefits. The SSA publishes an impairment listing manual, commonly referred to as the blue book.

Applicants may still qualify if their specific disability is not listed, as long as the SSA considers the impairment to be medically equivalent to a listing in the blue book.

#### Impairment Categories for Adults:

- Musculoskeletal Systems
- Special Senses and Speech
- Respiratory Disorders
- Cardiovascular System
- Digestive System
- Genitourinary Disorders
- Hematological Disorders
- Skin Disorders
- Endocrine Disorders
- Congenital Disorders that Affect Multiple Body Systems
- Neurological Disorders
- Mental Disorders
- Cancer (Malignant Neoplastic Diseases)
- Immune System Disorders

#### Impairment Categories for Children:

- Low Birth Weight and Failure to Thrive
- Musculoskeletal System
- Special Senses and Speech
- Respiratory Disorders
- Cardiovascular System
- Digestive System
- Genitourinary Disorders
- Hematological Disorders
- Skin Disorders
- Endocrine Disorders
- Congenital Disorders that Affect Multiple body systems
- Neurological Disorders
- Mental Disorders
- Cancer (Malignant Neoplastic Diseases)
- Immune System Disorders

## HOW TO APPLY FOR SSI:

Under 18, the family's assets and resources are considered the individual's assets and resources. Apply at age 18 years, 1 month or later. Applications can be completed online (for adults with disabilities only, certain restrictions apply), in person at the local SSA office, or on the phone by calling 1.800.772.1213 (or TTY 1.800.325. 0778 if you are deaf or hard of hearing) and making a telephone appointment.

The following documents are required (check the SSA website for a detailed discussion of needed documents and any updates on documentation requirements): Social Security Card or number, proof of age, citizenship or alien status record, proof of income, proof of resources, proof of living arrangements, medical sources (if you are filing as blind or disabled), and work history.

## HOW TO APPLY FOR SSDI:

The SSA recommends you complete the application for adult disability as soon as you become disabled. The application may be completed online, via phone, 1.800.772-1213 (If deaf or hard of hearing, call TTY 1-800-325-0778), or through calling or visiting your local Social Security office.

#### Required documents:

- Social security number
- Proof of age
- Names, addresses and phone numbers of doctors, caseworkers, hospitals, and clinics and visit dates
- Medication list (names and dosages)
- Medical records from doctors, therapists, hospitals, clinics and caseworkers that you possess
- Laboratory and test results
- A summary of where you worked and the kind of work you did
- Most recent W-2 form or if you were self employed a copy of your federal tax return

Be prepared to provide social security numbers and proof of age for each family member who may qualify for benefits. If your spouse is applying for benefits, proof of marriage and dates of prior marriages will be requested. Original documents or copies certified by the issuing office are required. Never leave your originals. [videosatthearcofnova.org](https://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm). ■

The absence of a listing-level impairment does not mean the individual is not disabled. <https://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm>

# Building No.6

## The Housing Crisis, Then and Now

In 1972, with film crew in tow, investigative journalist Geraldo Rivera would enter Ward B, Building Number 6 of Willowbrook State School in Staten Island, New York.

He was not prepared for what he would witness; a place he would describe later as “a dark corner where we throw our children.”

Patients are stripped bare. Sitting in their own filth, they lay across dirty floors and crouch in corners. Others are abandoned to cribs crammed back-to-back, many wailing a guttural cry.

The smell, Rivera later said, would stay with him.

The documentary, *Willowbrook: The Last Great Disgrace*, would spark a public outrage and force legislative action toward real and permanent change.

Rivera was not the first to publicly address the issues at Willowbrook. In 1965, during an unannounced visit, Senator Robert Kennedy witnessed thousands of residents “living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo.”

Kennedy would go on to describe Willowbrook as a “snake pit”. A class action lawsuit filed by parents would result in the Willowbrook Consent Judgment: *New York State ARC, Inc., et al., v. Hugh L. Carey*, 393 F. Supp. 715 (1975). The judgment would demand change at Willow-

brook: the treatment of residents, food and nutrition, dental and medical care, hiring of personnel and education, among other key issues.

The Consent Judgment’s primary directive to the New York Department of Mental Hygiene, responsible for state institutions, was to prepare each resident for community living. Change would come, slowly. The issues with the New York institution system were systemic and required more than a generous bump in the budget to fix. This would require a moral shift in society.

Public outcry from *Willowbrook: The Last Great Disgrace* would lead to impactful legislation, including *The Civil Rights of Institutionalized Persons Act* (CRIPA). The law requires the Department of Justice (DOJ) to protect rights of people living in state institutions and allows the Attorney General to bring lawsuits in federal court to protect those rights.

Enacted in 1980, CRIPA remains relevant today. Under the law, DOJ and advocacy groups have had great success in enacting needed change. With increased oversight, many states have been mandated to reduce the number of residents in institutions and provide a better quality of life for those that remain.

The National Council on Disability writes, “*The isolated nature of institutions and the vulnerability of their residents combine to create environments ripe for abuse.*”



A William Britt painting hangs on the wall of The Arc of Rockland in New York. Britt lived at Willowbrook State School for 34 years.

*Olmstead v. L.C.*, 527 U.S. 581 (1999) has also been pivotal in the fight to protect quality of life for people living with disabilities. The case began with two women from Georgia—Lois Curtis and Elaine Wilson—both with intellectual disabilities and mental health conditions.

With no community-based care available to Curtis and Wilson, the only treatment offered came from a state mental health hospital. Treatment required dozens of hospital stays. Doctors agreed that with appropriate supports, the two women were capable of living in the community. The lawsuit challenged the state of Georgia for those supports.

The Supreme Court agreed, citing that under the *Americans with Disabilities Act* (ADA) Georgia had discriminated against Curtis and Wilson by segregating the two women in the state hospital in order to receive needed treatment.

*Olmstead* established that people with disabilities have the right to receive care in the most integrated setting: if that is what they want, if their doctors agree and if it doesn't fundamentally change how the state provides services to people with disabilities. Although the DOJ would make *Olmstead* a cornerstone of its Civil Rights division, most states have fallen short of compliance.

But efforts have been made. Settlement agreements from *Olmstead* include expanded community-based supports and new integrated permanent supportive housing (PSH) opportunities.

The DOJ would find Virginia in violation of the ADA and *Olmstead v. L.C.* when the Commonwealth failed to provide services to individuals with disabilities in the most integrated setting. The DOJ settlement would require services to be offered to thousands more and improve in quality and oversight. Medicaid Home and Community-based Waivers would provide priority to those previously institutionalized in Virginia. Greater detail on the DOJ settlement agreement can be found at [https://www.justice.gov/sites/default/files/crt/legacy/2012/02/10/va-ada\\_factsheet.pdf](https://www.justice.gov/sites/default/files/crt/legacy/2012/02/10/va-ada_factsheet.pdf).

*Priced Out in 2014*, a report by the Technical Assistance Collaborative (TAC) and Consortium for Citizens with Disabilities (CCD), tackles the current crisis. According to the report, “under current federal standards a household is recognized as ‘cost burdened’ when its housing costs exceed 30% or more of monthly income.” But rents for apartments are typically *more than 100% of the entire monthly income of an SSI recipient*. SSI is the federal program that assists people with significant and long-term disabilities who have “few or no assets and often no other source of income.”

The study charges that those most affected by the

affordable housing crisis are non-elderly adults with serious and long-term disabilities who rely on SSI for income. Their choice is often between homelessness or placement in an institution.

Virginia is struggling with its own efforts to provide affordable housing. Resources are available and preparation may make the difference. *The Housing Toolkit*, offered online by The Arc of Northern Virginia, offers a wide variety of resources that will help guide the search. Budget guidance, a household spending plan, case studies, participating properties and a variety of lists and contact information in *The Housing Toolkit* will support a smoother transition. Also addressed are new housing resources, including State Rental Assistance (SRAP), Low Income Housing Tax Credit (LIHTC) Lease Preference and Flexible Funds.

Virginia Department of Behavioral Health and Developmental Services (DBHDS) created SRAP in specific areas to serve individuals with developmental disabilities in the Settlement Agreement population who want to live in their own housing. There is a referral process and eligibility criteria.

The LIHTC offers affordable housing to low and moderate income households. Rents are set for specific income ranges and may be higher than what a person on SSI/SSDI can afford without rent assistance. Some LIHTC properties offer preference to Virginia's settlement agreement population. While rent assistance is attached to some apartments, other apartments have no rent assistance and individuals who receive SRAP can use it for rent in unassisted apartments. A referral is provided by a DBHDS support coordinator.

Flexible Funding can help cover a wide range of expenses, up to \$5,000 for expenses associated with rent and up to \$5,000 in maintenance. While payment is not made directly to individuals or families, the tenant can either present receipts and get reimbursed or the Community Services Board (CSB) will pay vendors directly. A referral must be provided by the CSB.

Willowbrook was a tragedy that exposed the ugly underbelly of the nation's treatment of people living in institutions. The faces of Willowbrook and *Olmstead* would drive real and permanent change. But thousands of institutionalized residents would eventually be released to a system that was unprepared and underfunded. The 21st century has brought no great insight or budget that might, in any small way, address current needs. Efforts are underway with public and private advocacy groups partnering for creative solutions and new programs have brought additional housing opportunities. But the affordable housing crisis remains unsolved. ■



# Housing: *The Basics*

## SUBSIDIZED HOUSING:

Subsidized housing is owned and operated by private owners who receive subsidies for renting to lower-income people, including individuals with disabilities.

- Subsidized housing is financed with federal funds provided by the United States Department of Housing and Urban Development (HUD) and given to local Public Housing Authorities (PHAs).
- PHAs manage housing for residents with special needs. The PHA also handles the Housing Choice Voucher Program (formerly known as Section 8) and other low income housing subsidies.
- Housing choice vouchers allow the participant to choose any housing that meets program requirements and is not limited to units in subsidized housing projects.
- A housing choice voucher is portable. If an individual receives a voucher, they can literally apply it to another state should they move.
- An individual or family that is issued a housing voucher is responsible for finding a housing unit where the owner agrees to rent under the program. This unit may include their current residence.

## PUBLIC HOUSING:

In public housing, the housing authority owns the building and serves as the landlord.

- HUD administers federal aid to PHAs, which manage housing for low-income residents, including persons with disabilities, at rents they can afford.
- HUD furnishes technical and professional assistance in planning, developing and managing these developments.
- Public housing ranges from single family houses to highrise apartments.
- A PHA determines eligibility based on annual gross income, whether you qualify as elderly, a person with a disability or as a family. It's also based on citizenship and/or immigration status.
- PHAs use income limits developed by HUD. HUD sets the lower income limits at 80% and very low income limits at 50% of the median income for the area in which you live. Income limits vary so you may be eligible at one PHA but not at another.
- The PHA can provide you with the income levels for your area. ■

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Resource Links:

[https://www.hud.gov/program\\_offices/public\\_indian\\_housing/pha/contacts/va](https://www.hud.gov/program_offices/public_indian_housing/pha/contacts/va)  
<https://thearcfnova.org/?s=housing>

# Medicaid Matters

## PEOPLE WITH DISABILITIES BRACE FOR CHANGE

Discussion of Medicaid and affordable healthcare has dominated radio talk shows, garnered front page real estate and beckoned subject matter experts to prime time. Navigating healthcare options—albeit The Affordable Care Act (ACA) or Medicaid—requires grit, tenacity and a knack for understanding complexities and reading fine print.

Pundits and consumers have called it a crisis—skyrocketing premiums and stacks of unpaid medical bills. Viable across-the-aisle solutions have been less than prolific. Medicaid—which provides healthcare to over 1 million Virginians—is a mainstay in budget cut discussions. (Virginia Department of Medical Assistance Services, 2017).

Children and adults with disabilities receive 49% of Virginia's Medicaid funds. Currently, there is no limit, or "cap", on the amount of Medicaid funds spent on people with disabilities.

Medicaid provides more than acute medical care—it funds long-term services such as skilled nursing, medical equipment, day programs and therapies. Virginia's Medicaid program served 227,501 people with disabilities, 79,815 senior citizens, 642,391 children from low-income families, and 363,643 parents, caregivers and pregnant women.

A failed attempt to pass new legislation—the Graham-Cassidy-Heller-Johnson Block Grant—in late September blocked change in 2017. However, if the block grant proves to be a precursor to ACA's replacement, disability advocates will be busy.

The plan, which was not voted on

by the Senate, would have eliminated the Affordable Care Act's (ACA) Medicaid expansion by 2026, instituted a per capita limit for seniors and people with disabilities, and removed protections for pre-existing conditions.

If the federal government funds Medicaid through a block grant, federal funding becomes finite, rather than a bottomless account based on Virginia's spending.

What happens with the delta—will services be cut or will Virginia compensate for the deficit?

Concurrently, the Congressional Budget Office (CBO) anticipates 4.4% annual growth in Medicaid costs over the next ten years.

Questions are more prolific than answers when it comes to the future of healthcare.

New legislation is inevitable; whether it is palatable for people with disabilities remains to be seen. Bipartisan cooperation, robust advocacy efforts, and a comprehensive understanding of the impact of funding cuts will be key to ensure the needs of people with disabilities are considered in the solution. ■

# SURVIVOR BENEFIT PLAN

FOR THOSE WHO SACRIFICE

Sacrifices made by military members and their families are often recognized by legislators. Appreciation is imbued in almost every speech on a campaign trail and after every raising of the American flag. But proving true appreciation for the sacrifice made by all military families requires far more than a good sound bite.

With the Survivor Benefit Plan (SBP), members defer a percentage of retirement pay so that after death a surviving spouse or dependent child can receive up to 55 percent of their retirement payments.

The SBP protects the retiree's beneficiaries against loss of financial security. Unlike life insurance, SBP protects the survivor from outliving the benefit and protects against inflation through Cost of Living Adjustments (COLAs).

At retirement, service members can elect to choose from several SBP options:

- Spouse Coverage
- Former Spouse Coverage
- Child Coverage
- Spouse (Former Spouse) and Children Coverage
- Person with Insurable Interest Coverage
- Coverage for Disabled Dependents

The service member pays about 6.5% of retirement pay for a spouse and only about \$20/month for dependent children. The government pays a significant portion of SBP premiums and all program operating costs. SBP premiums reduce the retiree's taxable income and the cost of coverage, making it affordable for most members. They are taxed as income to the survivor with a tax rate typically less than the member's current tax rate.

If the member declines SBP at retirement, they will, most likely, not be eligible later. Some military retirees count on open enrollment, but these opportunities have been rare. At retirement, basic SBP for spouse and children will take effect automatically if no other choice has been made. Spouses will automatically receive coverage unless written consent by the spouse has otherwise been provided. Children remain beneficiaries until age 18 or age 22 if a full-time, unmarried student, or have a long-term disability.

The SBP has been offered to military members since 1972, but it wasn't until 2015 that it included special needs trusts (SNTs). The bill finally gave military members the right to name self-funded (SF) (first-party) or pooled disability trusts as beneficiaries. Military families can now irrevocably assign SBPs to a self-funded SNT for the benefit of the child with special needs without compromising their child's benefits like Supplemental Security Income (SSI) and Medicaid. Under the 2015 law, the SF SNT can receive any SBP annuity payments that would otherwise be payable to or on behalf of the dependent child with disabilities.

For military members with a child with disabilities, this shift changed everything. Children with a disability can remain eligible into adulthood, while unmarried, for as long as the disability exists, as long as the disability occurred before age 18, or before age 22 if a full-time student.

Without an SNT as beneficiary, the SBP would put government benefits in jeopardy—any unearned income over \$20 offsets SSI income dollar-for-dollar. Once SSI income reaches zero, SSI may be lost and, Medicaid may be jeopardized. This could mean the elimination of funds needed for living assistance, job coaching, respite care and other services provided through Medicaid Waivers.

To elect the SNT option, there must be an established and certified SNT. If the member is alive and if they have previously elected Spouse and Child or Child Only coverage under the SBP, they may make the designation to direct payment on behalf of a beneficiary to a SNT at any time. After the death of a member, if they had elected Spouse and Child or Child Only coverage, any surviving parent, grandparent or court appointed legal guardian may make the designation on behalf of a beneficiary.

The SBP is generally an irrevocable decision, with certain exceptions, so all circumstances and scenarios should be considered. An SBP is now considered a viable option for *all* military members. The Arc of Northern Virginia establishes these trusts, provides the certification letter from their attorney, as well as a letter for the Defense Finance and Accounting Service. ■

It took eight years for the Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014—known as the ABLE Act—to pass the United States Congress and become law.

Whether it meets expectations depends on who you ask and their personal needs. But many in the advocacy community, maybe even most, recognize its benefits as limited.

The concept of the ABLE Act is similar to the 529 education savings plan utilized by families to save for college. It permits individuals with disabilities, and their families, to establish a savings account dedicated to disability-related expenses. Before the ABLE Act, savings—even for disability-related costs—were considered income and threatened federal benefits, including Social Security and Medicaid.

But there's a catch. Quite a few.

Age limitations are specific and leave many advocates and supporters with questions and concerns. An individual is only eligible with an established disability before the age of 26. Advocates have argued against an age limitation, arguing no “philosophical basis” for the age limit. Efforts to rectify this shortcoming, in a new bill called The ABLE Age Adjustment Act, was introduced in Congress in 2017 and is now under consideration by the Senate. It would allow individuals diagnosed with a disability later in life—before the age of 46—to now qualify.

The U.S. Senate passed The ABLE to Work Act, allowing individuals with special needs who are employed and earning an income—to save additional money each year in ABLE accounts, without penalty. The ABLE Financial Planning Act allows money initially saved for a person with a disability in a 529 college savings plan to be

rolled over to an ABLE account.

Many limitations of ABLE accounts remain unchallenged.

Eligibility is limited to those receiving Social Security Disability Insurance (SSDI), Social Security Income (SSI) or those that file a disability certification accepted by the IRS. Contributions up to \$2,000 may be tax deducted in Virginia. All investments earnings remain untaxed as long as

# The ABLE Act:

## *Understanding its Limitations*

the money is used for “qualified disability expenses” (QDE). A QDE must 1) be incurred at a time you were considered an “Eligible Individual”; 2) relate to person’s blindness or disability; and 3) help maintain or improve health, independence, or quality of life.

Expenses used with an ABLE account are limited to:

- Education
- Housing
- Transportation
- Employment training and support
- Assistive technology
- Personal support services
- Health prevention and wellness
- Financial management and administrative services
- Legal fees
- Expenses for oversight and monitoring
- Funeral and burial expenses

If not carefully managed, an ABLE account can put federal benefits at risk. If the account exceeds \$100,000, SSI benefits would be suspended—but not terminated. Medicaid would not be impacted. In addition to the asset cap of \$100,000 for SSI recipients—there is a contribution limit. Annual contributions are limited to \$15,000 from all contributors combined (2019).

Perhaps the most impactful difference between an SNT and an ABLE account is management. Usually an ABLE account is managed by a family member or the beneficiary. A Third Party Special Needs Trust, on the other hand, may be administered and managed by a nonprofit entity. Deciding which savings vehicle is best is dependent on specific circumstances. The ABLE account, while providing new opportunity to the disability community, does have significant and relevant limitations. Multiple tools may be needed when planning for the future.

Those considering an ABLE account find that a special needs trust—self-funded and/or family-funded—may offer more flexibility under a broader range of circumstances. ■

# WORKINPROGRESS

## FROM SHELTERED WORKSHOPS TO FORTUNE 500'S

Mr. Kenneth Henry, the misguided and merciless owner of Henry's Turkey Service, the now defunct and shamed company that once supplied hard labor to the factory lines of West Liberty Foods, may never receive due punishment.

The decades his company spent depleting the strength and will of a group of men with disabilities—hundreds over a span of decades—are over. But the memories of what happened in that little schoolhouse in Atalissa, Iowa will remain forever with those who lived the tragedy.

The failures in this case were not born from malicious minds alone. They were byproducts of a system with broken oversight. A government system built to fail the most vulnerable, including that group of men in Atalissa, and their families.

Kenneth Henry exploited a legal loophole, created by the federal government, and blew a hole right through it.

The federal government—and most of the 50 states, including Virginia—support subminimum wage, the legal right to pay a worker with a disability less than those without one, section 14(c) of the Fair Labor Standards Act.

The injustice of this case isn't only about those with disabilities making less than their coworkers. It's about negligence and abuse. It's about looking the other way.

According to reports, these men endured the worst kind of treatment. Handcuffed, restrained, confined and physically beaten. They were denied medical care. They lived in squalor amongst roaches and mice and rats, resting exhausted and worn bodies on moldy mattresses.

Perhaps *Des Moines Register* described it best: "For almost 40 years, Henry's Turkey Service operated as a labor broker, sending hundreds of mentally disabled men from Texas to labor camps based in seven states."

Their job was to eviscerate—*disembowel*—turkeys. More than 20,000 daily. Day in, day out, with a monthly take home pay of \$65.

In 2009, when law enforcement, agencies and advocates descended upon Atalissa, they found men malnourished and in need of medical attention.

Reports told of hands malformed from decades of gutting turkeys.

Efforts to tighten this legal loophole came when President Barack Obama signed into law the *Workforce Innovation and Opportunity Act of 2014* (WIOA).

WIOA reauthorizes and revises current federal workforce rehabilitation programs. It does not prohibit sheltered workshops—organizations that segregate employees with disabilities and pay subminimum wage—but does reduce their number and limits the right of employers to pay subminimum wage.

Under WIOA, individuals with disabilities, age 24 and younger, will no longer be allowed to work for less than minimum wage—unless first receiving school transition and vocational rehabilitation services. Specific exceptions include a grandfather clause.

WIOA's Federal Advisory Committee, comprised of members from the federal government, national advocacy groups and self-advocates, will make recommendations on integrated, competitive employment and take responsibility for oversight of 14(c) certificates.

Whether WIOA would prevent a tragedy like Atalissa, it's impossible to know. A law still requires a commit-



# “NO ONE DESERVES TO WORK AND LIVE THE WAY THESE VULNERABLE MEN WERE FORCED TO. IT WASN'T AN ACCIDENT.”

ment to enforce it.

It was 2009 before the government stepped in to shut down Henry's Turkey Service—only after a concerned relative and *The Des Moines Register* brought it to the attention of authorities. Occasional phone calls and letters over decades were ignored by the U.S. Department of Labor and the Iowa Department of Human Services.

*“No one deserves to work and live the way these vulnerable men were forced to,”* said then Iowa Governor Chet Culver. *“It wasn't an accident.”*

It's been less than a decade since Henry's Turkey Service was shut down. Progress has been made. Not just legislative, but across private industry as well.

Big business, most notably the tech sector, is beginning to figure it out. They have begun to understand—not what employees with special needs *can't* do—but what they can.

Business would have to change rules mired in tradition, crafted by their own industry, set in stone by a culture that knew nothing else.

But innovative companies are no stranger to change. They exploit their own adaptability in order to further progress.

And they would begin with the interview format.

It is well documented that individuals with autism often struggle with social cues and interaction. So the typical interview process, which requires some level of banter, eye contact and a handshake can be difficult for those with the neurodevelopmental disorder.

So instead of the typical candidate interview, companies have created hiring programs geared towards autism and other disabilities.

Microsoft is the third largest global tech company, defined by a diverse workforce that is waning in more traditional corporations. From positions in administration to coding, Microsoft

seeks out and markets to candidates with special needs.

The Microsoft Autism Hiring Program kicked-off in 2015, with a tightly defined goal: hire people with autism for full-time positions. Instead of a series of stressful job interviews that might fail to showcase their abilities, candidates visit the Microsoft campus over a two-week period. They casually work on projects while talking with managers in a relaxed environment.

Microsoft may be the biggest, but they're not the only company that recognizes the win-win. Companies like SAP, Freddie Mac and Tower Watson have established their own programs.

It's about more than doing a good deed. It's about what's good for business. According to *workology.com*, employing people with autism leads to “longer tenure, less turnover and improved employee engagement.”

Perhaps no single company, no single person, has brought more tangible progress than Specialisterne (Danish for *the specialists*) and its devout and determined CEO, Thorkil Sonne.

Sonne has begun a minor revolution that has caught fire across the innovative startups of Silicon Valley, HR departments of the Midwest and the corner offices of Wall Street.

A revolution often begins with a single person. The movement began with son, Lars. The Sonnes had always been amazed with what their son was able to do. They would provide Lars a day, month and year, and—rapid fire—Lars could identify the day of the week. He memorized, down to the detail, all of Denmark's major train routes.

His father's creative mind recognized the broader implications—a mind like Lars, with his focus on detail and memory recall, could be very valuable to a wide range of industries.

Sonne refers to this concept as “The Autism Advantage.” And he isn't alone. Dr. Laurent Mottron, from the University of Montreal's Centre for Excellence in Pervasive Development Disorders, is

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— Former Iowa Governor Chet Culver

# The Architect

Senator Tom Harkin, creator of the ADA and WIOA talks to Empower Virginia about innovation, determination, and the struggle for equal rights.



**Q: What inspired your advocacy efforts on behalf of individuals with disabilities?**

**A:** My brother Frank had a disability. His genuine heart and determination in life inspired me to really begin my advocacy efforts on behalf of individuals with disabilities. Upon passage of the ADA, I delivered my speech on the Senate floor in sign language.

My work for expanding the rights of persons with disabilities was not only one of my top priorities in office but drives my life's work. It remains a key area of focus for The Harkin Institute for Public Policy and Citizen Engagement, where we conduct research and host events related to disability employment.

While working on the ADA I heard many stories from individuals who had to crawl on their hands and knees to go up a flight of stairs, who couldn't ride a bus because there wasn't a lift, and who could not even cross the street because there were no curb cuts.

These stories always helped drive my passion to fight for meaningful policies to help them and their families reach equal opportunity, full

participation, self-determination, independent living, and economic self-sufficiency.

**Q: As an architect of the Americans with Disabilities Act (ADA) and Workforce Innovation Opportunity Act (WIOA) your efforts have been instrumental in securing fundamental rights of individuals with disabilities. As private citizens, how can we best advocate and ensure "nothing about us, without us"?**

**A:** It is a continual fight. We, as a society, will not have reached our full potential until everyone, including persons with disabilities, is given equal opportunity. We cannot make assumptions about the obstacles they face, we must include them at every step in our advocacy efforts. Individually, we need to remind our legislators of the importance of policies that increase accessibility. Get involved in your communities and engage with your neighbors and colleagues who have disabilities. Never settle for anything that gives them less than their full equal opportunity.

**Q: Since the passage of the ADA, in which areas have you**

**witnessed the most progress? In which areas the least?**

**A:** We have seen great progress. There is now an entire generation of Americans that has lived their entire lives with the law prohibiting discrimination against people with disabilities.

There are curb cuts in sidewalks, individuals can move more easily in public and enjoy life a little more simply thanks to the increase in accessibility. We see individuals enjoying movies, plays, and concerts in ways we didn't see before.

However, individuals simply cannot reach equal opportunity, full participation, self-determination, independent living, and economic self-sufficiency until disability employment is improved. There are no better problem solvers than those who solve problems just to navigate the everyday. This issue does not only exist in the U.S. but across the globe. That is why The Harkin Institute has created the Harkin International Disability Employment Summit. We bring together thought leaders, business leaders, government officials, and advocates from developing countries and industrialized nations to define and create

strategies to ensure that people with disabilities not only have a supported life, but an employed life, including all the benefits that come with having a job and a career.

**Q: Although progress has been made, post-secondary education opportunities for people with disabilities lack variety. What changes still need to occur to diversify opportunities?**

**A:** Passing of the Americans with Disabilities Act greatly expanded accessibility for thousands of disabled people living in the U.S., including education and training. But as you mentioned, there is still a lack of opportunities for post-secondary education. This falls largely on a partnership between universities and the businesses. More internships and apprenticeships need to be created and publicized. Integrated workforce opportunities expand the variety of opportunities for post-secondary education by providing individuals a chance to build the skills and experience they need so businesses are able to hire them.

**Q: How relevant is innovative thinking and creative solutions to equality for all?**

**A:** There simply are not words to adequately articulate the importance of innovative thinking and creative problem solving when it comes to increasing accessibility and ending discrimination.

This is how groups like Cisco Systems, are creating new pipelines for individuals with disabilities to enter the workforce. Through innovative thinking Cisco has created an efficient apprenticeship program that allows individuals to get real hands-on experience early in their career, creating a supply of well-trained professionals for the demand of businesses and companies looking to hire persons with disabilities. Technological advancements are creating even more opportuni-

ties and accommodations to help individuals with disabilities perform tasks in ways that weren't imaginable just a few years ago.

These are reasons why we need to include as many people as possible in these discussions. You never know where the next great idea is going to come.

**Q: Can you discuss the systemic discrimination against those suffering with mental illness and how vital the ACA is to affordable and proper treatment?**

**A:** An estimated one in five Americans has a mental health condition, yet the stigma surrounding mental health keeps many from speaking out or seeking the help they need. The Affordable Care Act has ensured coverage is available for individuals with severe mental health issues who had struggled to obtain health insurance in the past. The ACA helps Americans take preventative measures to manage behavioral disorders by requiring coverage for therapy, medication and depression screenings. The Affordable Care Act was a major step forward in the fight for greater health care access for those living with mental health conditions and the fight to end the negative perceptions associated with mental illness.

**Q: Can you discuss public-private partnerships with integrative workforce opportunities for persons with special needs?**

**A:** It is vital that institutions and businesses are working together for integrative workforce opportunities. Events such as The Harkin International Disability Employment Summit and the ILO Conference on Global Workforce bring together individuals to discuss best practices, innovative ideas, and how we can accelerate change. These discussions need to be ongoing and need to result in tangible change for everyone involved.


Often it is not that businesses don't want to hire a person with disabilities, but that they don't know where to begin looking. Or businesses are eager to hire individuals with disabilities, knowing they are some of the best problem solvers in our society, but those individuals lack the technical experience employers are searching for. It is vital that we continue to build integrative workforce opportunities for individuals to grow their skillset and gain experience, while our businesses are able to fully realize the potential that sits before them.

**Q: What changes to Medicaid would support increased community integration as opposed to institutionalization?**

**A:** The Disability Integration Act of 2017 that is pending in the House and Senate would get rid of the Medicaid "bias" towards institutionalization by providing community-based services first. The Americans with Disabilities Act mandates integration and this bill would help further enforce that mandate.

**Q: How does the current divisive political climate affect needed legislative change for persons with disabilities?**

**A:** Any time the political climate is so divisive that it takes the focus away from issues such as the needed legislative changes for persons with disabilities, it is absolutely to the detriment of society. The ADA was passed almost unanimously, and has been supported by each administration, regardless of party, since 1990. However, it is not enough to support the bill that passed 27 years ago. We need to bring disability rights, accessibility and employment back to the forefront to better enhance opportunities for individuals living with disabilities. ■



Spring is a time of college acceptance letters, envelopes reflective of effort and determination, even defiance. But students with intellectual disabilities—and their families—typically receive nothing. There is sporadic discussion of what comes next, but it lacks energy and enthusiasm. It can be a time of anxiety and fear.

And often for good reason. Most counties and states—even our country at large—are still struggling with the post-secondary life of a special needs high school graduate.

Long gone are the days when an institution is the next and final stop—a mark we recognize as progress. But society remains in a transitional period and change is far too slow. Progress is not enough. The status quo is not enough.

Post-secondary programs often lack individualization, adopting a one-size-fits-all approach, leaving many students wanting.

While neurotypical college students may study business, science or theatre (the choices are endless), neurodivergent students are often focused on employment with few options...and sometimes at subminimum wage.

And these are often the lucky ones.

With purpose, a steady paycheck and greater stability, this is a relief to many individuals and their families—understandably so. But there's nothing wrong with having different dreams—including dreams of a college diploma.

Fueled by government funding, budgets are typically stretched and not created to accommodate personal

dreams. But the private sector has begun to recognize the possibilities and change is underway.

The path begins with research. Read, inquire. Know your rights—and your options.

## TAKE COLLEGE STEPS

Plans for college may be discussed but it is all too seldom encouraged by many public schools. There are exceptions, of course—some counties haven't waited for government mandates or public pressure. These school systems realize *equality* is about more than the law. It's about the diversity of opportunity. And that comes with good leadership—from the top down. Many colleges understand that investment in students with special needs is more than the future—it's the present. Take College Steps.

College Steps offers individualized social support and academic programs for each student. Just like other innovative organizations, College Steps began small—with just four students and one full-time staff member in 2012. It has since grown to more than 150 students across six states.

To understand the impetus for this growth, one simply has to look at the numbers.

Only one in three individuals with special needs go on to college. Even fewer earn a degree. Colleges have slowly begun to understand the numbers and recognize this untapped market. It's not simply about moral sense. For colleges, it's good business sense.

And partnering with an organization with an established specialty skill set is a big step towards building a successful program.

College Steps offers a choice of three programs. The High School Program is provided to students still in high school and offers an experience of college campus life. The second is a Certification Program emphasizing independent life and social skills. The College Matriculation Program emphasizes supported academic study with the goal of a college degree.

# Climbing the Mountain:

## Life After Public School

College Steps offers a distinct philosophical approach. Students offered individualized academic supports in four core areas—executive functioning, social integration, authentic experience and peer mentor relationship.

Applications are required for both the academic institution and the College Steps Program, and students are encouraged to apply early for consideration. With roughly 80-85 percent of College Steps students receiving some form of financial aid, at least 35-40 percent of these students receive financial support from Community Service Boards.

When asked about the future of College Steps, CEO Aaron Rakow is quick to note “We hope to work ourselves out of a job...a post-secondary education should be a fundamental right.”

As Former Senator Tom Harkin (D-Iowa), chairman of the Senate Health, Education, Labor and Pensions Committee, noted:

“As this committee examines how to improve educational opportunities and outcomes for all Americans, we must remember to include our fellow citizens with disabilities to ensure they have access to postsecondary education and to succeed once enrolled in those programs.

To provide those opportunities, we need to understand the barriers students with disabilities face, and the services and supports that facilitate their success.”

(Note: The provisions of the Individuals with Disabilities Education Act (IDEA) and the Individualized Education Program (IEP) do not apply to postsecondary schools.)

## INTERGRATED TRANSITION SERVICES

In Loudoun County, for example, Community and Schools Together (CAST) is a partnership between the public school system, the community, adult service providers, students and their families.

The CAST program supports the transition for young adults with disabilities between the ages of 18-22. CAST works to provide and support employment and community participation.

Students selected for the CAST program graduate with their peers and do not return to school.

Students spend non-work time in integrated community environments learning life skills and developing relationships with adult service providers to support a smooth transition from school to post-school life.

## VOCATIONAL TRAINING PROGRAMS

In partnership with the Department of Aging and Rehabilitation Services (DARS), Wilson Workforce and Rehabilitation Center’s (WWRC) Vocational Training Program, located on the WWRC campus in Fishersville, Virginia, provides workforce training and education with industry-recognized credentials.

Instruction is competency-based and programs are updated regularly by Advisory Committees to ensure current business and industry standards are met. Vocational Training Programs are accredited by the postsecondary accreditation body of the Accrediting Commission of the Council on Occupational Education (COE). Students can live in on-campus dormitories during their vocational training or commute to campus daily. A rehabilitation counselor provides counseling and case management to help the client access services needed at WWRC and assist in the transition home after training. Internships are available at the conclusion of most training programs.

Workforce Training targets three high growth occupational areas across Virginia:

### Business and Information Technology:

- Business and Information Technology (Computer Support Specialist, Data Entry Clerk and General Office/Administrative Assistant)
- External Training Option (Community-Based Training)

### Manufacturing and Production:

- Manufacturing Technology Training
- Materials Handling (Stock Clerk)
- Production and Assembly Worker

### Services and Trades:

- Auto Mechanics
- Culinary Skills/Food Service (Cafeteria Attendant, Dishwasher, Kitchen Assistant, and Cook’s Assistant)
- Health Occupations (Nurse Aide and Personal Care Aide)

WWRC’s Vocational Training Department also offers courses that can either stand-alone or serve as part of an accredited workforce training program:

- CRC Stand-Alone Program
- Forklift Operator

While enrolled in a Vocational Training Program, students also have the opportunity to earn the Career Readiness Certificate (CRC). ■

# History Lesson:

## When Good Men Do Nothing

History may have a feel of forever, centuries between now and then. But history was a decade ago, last year, yesterday.

The past should be a nagging reminder, painful as it is, to see the world through truthful eyes. We have to glance back if this is to serve as a lesson.

For marginalized populations, history—the messy version—is a necessary reminder of injustice and the role of humanity as judge and jury.

Every land has a beauty, specific to the place and people. That same land, at one time or another, has been the source of darker times. Take Virginia. It played a significant part in the birth of our country. As one of thirteen original colonies, it was the first area settled by the English. Eight presidents have called Virginia home. But Virginia has murky chapters, too. Shameful times, absent from most history books and unknown to the most enlightened.

Virginia was not the first state to embrace the movement called eugenics, but it became one of the most committed.

First coined by Francis Galton in 1883, the mission of eugenics was to “cleanse America’s gene pool.” The movement took hold in the United States in the early 1900’s, led by prominent scientists and industry leaders.

The philosophy of eugenics was supported and advanced by a Commonwealth of Virginia case, *Buck v. Bell*, 274 U.S. 200 (1927).

In 1924, Virginia adopted a statute authorizing the forced sterilization of the intellectually disabled, mentally ill, epileptic, criminal, promiscuous and the poor. Seeking to test if the law would survive legal scrutiny, Dr. Albert Priddy, superintendent of what was then called the Virginia State Colony for Epileptics and Feebleminded, filed a petition to sterilize eighteen-year old patient Carrie Buck.

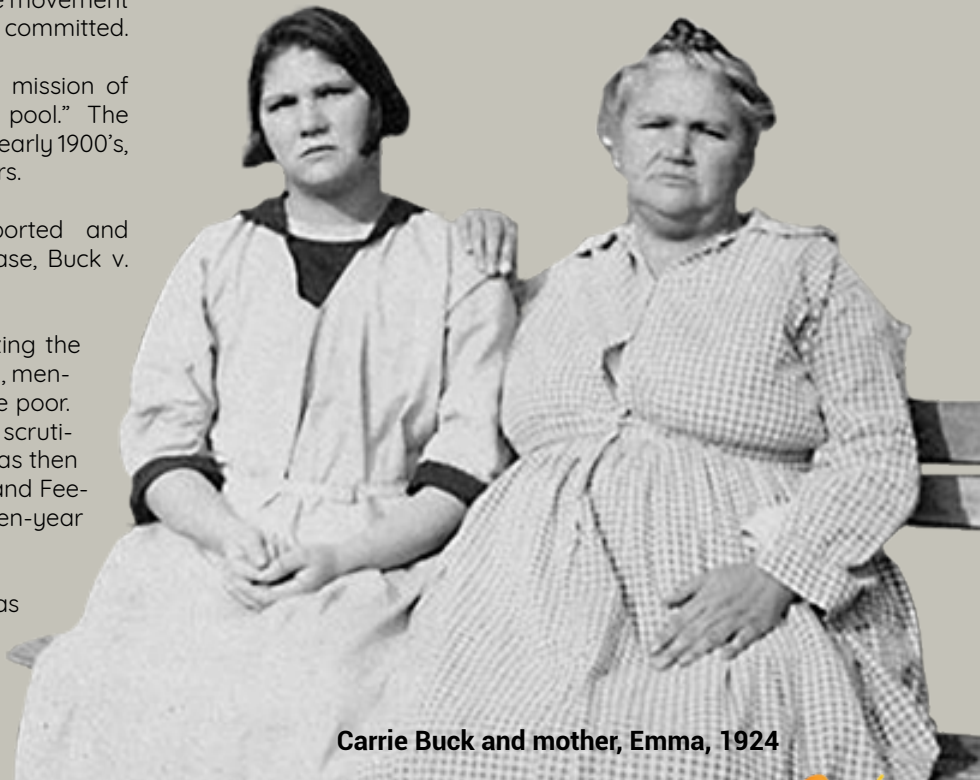
Priddy named Buck a genetic threat. She was “defended” by Aubrey Strode, a supporter of the new law who would focus more on the benefits of sterilization than on the rights of Carrie Buck.

After a series of appeals were heard by lower courts, in 1927, it reached the highest law of the land. In an 8-1 decision, the United States Supreme Court ruled in favor of the state. Carrie Buck would be forcibly sterilized.

A precedent was now in place, caselaw to be referenced for decades to come.

The ruling legitimized Virginia’s sterilization procedures until their repeal in 1974. The law, and the people who enforced it, would claim more than 7,000 victims in Virginia alone. Even after its decline, eugenics would experience eras of resurgence.

In 1933, when Adolf Hitler came to power, he used the Virginia Sterilization Act as a model for medical experiments and race purification methods. At the Nuremberg Trials, after the end of World War II, Nazi doctors cited *Buck v. Bell* as part of their defense.



Carrie Buck and mother, Emma, 1924

The philosophy of eugenics has now been thoroughly and completely discredited in the scientific community. But, *Buck v. Bell* has never been overturned. It remains in the occasional diatribes of lawyers, desperate for precedence.

The Virginia State Colony for Epileptics and Feeble-minded, once home to Carrie Buck, would later earn a new name, the Central Virginia Training Center (CVTC).

Although forced sterilizations had ceased in the 1970's, concerns of the treatment of CVTC residents would continue.

In 2008, the United States Department of Justice (DOJ) would begin an investigation of CVTC, one of Virginia's

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## Between March 2015 and May 2016, the Office of the Chief Medical Examiner reported 6 Deaths attributable to UTI's at CVTC

—From a 2017 dLCV report, *"Death by Infection"*

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five training centers. Recognizing system-wide issues, the probe soon expanded to all five.

Training centers are large facilities that provide housing and services to residents with special needs. Many refer to them as institutions.

In 2011, DOJ released the results of their investigation. DOJ's probe, initially based on the Civil Rights of Institutionalized Persons Act of 1980, was later expanded to include Virginia's violation of the Americans with Disabilities Act of 1990 (ADA). The ADA is a law that requires people with disabilities move from institutions to community settings.

That was 1990. But by 2011, Virginia had made little

progress.

The federal government found the Commonwealth was still denying citizens with disabilities the right to be part of the broader community.

Even more disturbing, the investigative report revealed patients were unnecessarily restrained, sedated and over-medicated.

There were additional findings. The state maintained an unreasonably long waiting list for Medicaid waiver services—federal and state government subsidies to pay for care and services for residents with special needs. The entire system would need a new strategy—a complete overhaul.

DOJ and Virginia would settle on a plan, later approved by the Court. But critics remained skeptical.

The plan would affect more than the residents in the training centers. Virginia has long waiver waiting lists, more than 11,000 requesting services. Any plan to reduce the training center population would need to address the big picture. The number of Medicaid waivers would have to increase, along with required funding.

And that would require the buy-in from the Virginia General Assembly—both the House of Delegates and State Senate.

Virginia had spent so much money on training centers that little was left for waivers—resulting in extensive waiting lists. Under the proposed settlement, Virginia would add 4,170 waiver slots, divided among current training center residents, disabled residents living in other facilities and those already on the Medicaid waiver waiting list.

The settlement also addressed how Virginia should administer services. A joint effort by the Department of Behavioral Health and Developmental Services (DBHDS) and local Community Service Boards (CSBs) would ensure proper transition from institution to community life. An independent reviewer would regularly report to the Court on progress of implementation.

All things have not gone smoothly. Under a 2014 Virginia code adopted as part of Virginia's plan, all revenue from training center property sales should be reinvested toward community-placement efforts.

But that is not what happened.

The sale of land from the first institution brought \$5.4 million. Instead of reinvesting the dollars into the community-placement services, the money replaced a budget shortfall for DBHDS.

(Continued on page 40)

## History...

(from page 39)

State budget instructions from the Virginia General Assembly had changed the original plan. They would later mandate that DBHDS use proceeds to address a budget shortfall.

But advocates were watching and so was the DOJ. Stakeholders demanded future sales be properly applied toward community-placement efforts.

Still further problems stunted progress. According to the independent reviewer, Virginia delayed implementation of the promised redesign of its Medicaid waiver system and fell far short of the number of needed slots.

Even more troubling issues have since surfaced in a report published by the disAbility Law Center of Virginia (dLCV), a nonprofit that oversees Virginia institutions through “announced and unannounced on-site visits, review of critical incident reports, facility death summaries and reports prepared by the Office of the Chief Medical Examiner.”

The dLCV investigation unearthed a number of deaths at CVTC, attributable to complications relating to Urinary Tract Infections (UTI’s). UTI’s are avoidable with proper hydration and sanitation practices. Left untreated, a UTI can be fatal. The deaths occurred in spite of numerous warnings. In 2015, DBHDS had released a written alert regarding UTI’s.

## Work...

(from page 33)

a researcher, clinician and lab director “concentrating on the cognitive neuroscience of autism.” In a research paper, “*The Power of Autism*,” published by Dr. Mottron, he writes:

*“Other studies have shown that most autistic people outperform other individuals in auditory tasks (such as discriminatory sound pitches), detecting visual structures, and mentally manipulating complex three-dimensional shapes. They also do better in Raven’s Matrices, a classic intelligence test in which subjects use analytical skills to complete an ongoing visual pattern. In one of my group’s experiments, autistics completed this test an average of 40% faster than did non-autistics.”*

Mottron practices what he preaches. Eight individuals with autism have worked with his group: four research assistants, three students and a researcher. Dr. Mottron and research assistant, Michele Dawson, have coauthored 13 papers and several book chapters. Dawson has autism.

Mottron believes employers are largely uninformed about contributions individuals with autism can bring to the workplace, including in STEM-related jobs. According to Mottron, the autistic brain can process significant amounts of perceptual information with a better and more accurate memory than a neurotypical brain.

So why is private industry still largely in the dark? He

Also, that same year, Donald Fletcher, the independent reviewer, recommended Virginia take “aggressive action to identify early indicators of potential harm, including UTI’s”.

On September 26, 2016, dLCV notified DBHDS of the alarming conditions at CVTC “leading to prolonged and painful death for some individuals.”

By late 2016, the CVTC held a UTI Workgroup “with the goal of taking action on several fronts to prevent the occurrence of UTI’s for individuals....”

But not everybody supports closing Virginia’s remaining institutions. Many families with loved ones at a state training center are worried. They are unsure if community-placement care will be comparable. But most organizations representing those with disabilities continue to pressure the state to keep their promise—intact, complete and on time.

Eugenics, forced sterilizations and the institutionalization of those with disabilities are a disturbing pattern in Virginia’s history. Progress has been made, but the future remains in question. Talk to those with disabilities, advocates, families and caregivers, and the message is clear. This shouldn’t be a political issue. It’s an issue about basic humanity, dignity and inclusion. It’s about human rights. ■

blames the issue, in large part, on perception:

*“When autistics outperform others in certain tasks, their strengths are frequently viewed as compensatory of other deficits, even when no such deficit has been demonstrated empirically.”*

In a report by the Centers for Disease Control (CDC), about half of autistic children have average or above-average intellectual ability—with varying reports of unemployment between 70-90 percent. Perception really is everything, and it has to change.

The landmark case, *EEOC v. Henry’s Turkey Service*, was a tragic lesson for the hundreds of men forced into involuntary servitude at the hands of Kenneth Henry, unprotected by the blind eye of the state government. The case remains without justice, the men without compensation. While this did not headline the evening news, or draw the ire of protesters on the streets of the nation’s capital, this case has brought progress. WIOA has been one of the most impactful legislative successes in employment rights, garnering bipartisan and bicameral support. Innovative companies have seized on a skilled and growing special needs population, hiring for competitive and integrated employment, proving that a neurodiverse workforce makes for a stronger and more stable company. ■



# Q&A with Tia Marsili

(from page 15)

The SF SNT is used when there was no prior planning and money comes to the person and needs to be moved out of their name.

**Q. Can you share what it was like to establish a special needs trust for your children?**

**A:** The first time I created a trust was with an attorney. I really didn't know what it was but it was part of the package the attorney recommended - Wills, Powers of Attorney, Advanced Medical Directives and the SNTs. She never mentioned the option of using an authorized nonprofit that manages trusts. We never used the trusts, they just sat there unfunded. When I started at The Arc of Northern Virginia I learned about the nonprofit management option. It was obvious to me that this was the best option for my family.

With The Arc of Northern Virginia it was simple. We met to complete the documents; it only took 60 minutes. We provided copies of our government issued photo IDs, proof of disability, and copies of the girls' health insurance cards. Both trusts will remain unfunded, our life insurance policies and estates will fund them after our death. At any time, we may choose to fund them. I told family members about the trusts, too, in case they wanted to include them in their Wills, as we had.

My daughters, Sheridan and Skye, will work directly with The Arc of Northern Virginia to request disbursements from their FF SNTs. As back up, we've named a few cousins and other trusted individuals who may also request disbursements on their behalf. Now I am working on writing their Long-Term Advocacy Plans, guidance documents about each of the girls' past, present, and potential futures, which The Arc of Northern Virginia refers to when disbursing from the trust.

**Q. What are the greatest misconceptions about SNTs?**

**A:** That you only use SNTs through nonprofits when funding is small. Our trustee, Key Private Bank, professionally handles all investments. We have large trusts as well as small.

- That the remainder in the SNT goes to Medicaid or The Arc of Northern Virginia. With FF SNTs the Grantor (person establishing the SNT) decides who will inherit if there are funds remaining in the trust when the individual passes. On a SF SNT, depending on the Grantor's authority, by law, the remainder goes to Medicaid, then the heirs of the person or, in lieu of Medicaid any remainder funds may go to support The Arc of Northern Virginia's trust program and its clients.
- That it is difficult to disburse. It is not. We require a

disbursement request form and supporting documentation. We verify all aspects within 24 hours of receipt before sending the request to Key Bank. A guide at [www.thearcofnovatrust.org](http://www.thearcofnovatrust.org) explains the disbursement process.

- You lose all control. You don't. You gain peace of mind, allowing professionals to do the work for you. There's no "instant gratification", but isn't it better to have us verify all aspects before disbursing so benefits are not jeopardized?
- Trusts are free! They're not. There is an enrollment, management, and trustee fee.

**Q. For those not in a financial position to fund a trust but understand its importance, what are the options?**

**A:** The FF SNT is often funded upon the death of the parent(s). You can establish the trust then save a little at a time. Ask family members to consider your child in their Will.

**Q. What are the most practical benefits of including real estate in a special needs trust plan?**

**A:** Ownership is not in the hands of the person with disabilities or a family member. Thus, creditors cannot claim it, liens may not be put against it, it is not considered part of a divorce, lawsuit, etc. In some jurisdictions, property taxes will be waived primarily when the person with disabilities is living in the home. Property management may be handled by the trustee. Your child has a home as long as they wish to live there, or are able to live there. When the home needs to be sold, there's already a trustee in place to handle this. Other real property may also be held in trust.

**Q. What is the process of establishing a SNT? What's the first step?**

**A:** Step one is to read about our trust at [www.thearcofnovatrust.org](http://www.thearcofnovatrust.org). Then, RSVP to our twice-monthly Trust Talk Tuesdays, a facilitated roundtable, to have trust and benefits questions answered. Next, email me at [tmarsili@thearcofnova.org](mailto:tmarsili@thearcofnova.org) to schedule an appointment to establish the trust.

**Q. What documents are required to create a SNT?**

**A:** We require copies of government issued photo IDs of the grantors and beneficiary or birth certificate, their health insurance cards and proof of disability. If there is legal guardianship and/or conservatorship, powers of attorney, advanced medical directives or other legal authority, we request those copies as well. ■

*Disclaimer: This is not legal advice and the Arc is not a law firm.*

# Free Trade

## VIRGINIA PROVIDES VOCATIONAL TRAINING TO ANSWER INDUSTRY DEMAND

Society recognizes two distinct paths after high school: attend a four year university—a proud and expensive endeavor—or enter the workforce, inadequately trained and underemployed. A lack of options leave many highly-capable graduates working (and earning) as low-skilled labor.

Consider a third option: vocational training.

Vocational training doesn't come with the price tag of college, a debt that long lingers after the tassel is moved. Programs for individuals with disabilities, offered by the Commonwealth of Virginia and many municipalities, are funded in part by the Workforce Initiative Opportunity Act (WIOA). Virginia is now a growing resource for individuals seeking vocational training needed to gain middle-skill employment.

For industries that call Virginia home, job openings related to manufacturing

and information technology (IT) have been difficult to fill.

According to the Virginia Department of Aging and Rehabilitation Services (DARS), "Of the 1.5 million job vacancies expected in the next decade in Virginia, more than half will require more than a high school diploma but less than a bachelor's degree." Market statistics demonstrate that businesses increasingly hire job applicants with an associate's degree or industry-recognized certifications.

DARS has become instrumental to those with disabilities seeking vocational training for stable employment and a livable wage. In 2015, a five-year Career Pathways for Individuals with Disabilities (CPID) grant was awarded to DARS and the Department for the Blind and Vision Impaired. The CPID grant helps participants train for high-demand industries including advanced manufacturing and IT.

CPID is a workforce development strategy and industry driven. The program offers credentials that participants can "stack" to gain employment in high-demand jobs with solid wages. According to DARS, CPID could eventually grow to become a national model.

The process is individualized for each participant—abilities, interests and goals are assessed. DARS provides each

student an assistive technology assessment and vocational evaluation. DARS informs the business community about skills and abilities of program participants.

Through a partnership with the Wilson Workforce Rehabilitation Center (WWRC), DARS offers three accredited training programs in industrial sectors experiencing high growth in Virginia: business/information technology, manufacturing and production, and services and trades.


Under the business/IT program, WWRC offers training programs for Computer Support Specialist, Data Entry Clerk and General Office/Administrative Assistant.

Under the manufacturing and production program, WWRC offers training programs for manufacturing technology, production and assembly worker, stock clerk and forklift operator.

Under services and trades program, WWRC offers training programs in automotive, health occupations and culinary and food service.

Through the CPID grant, DARS has made progress in closing the skill and interest gaps by 2020. Middle-skill jobs account for 49 percent of Virginia's labor market, but only 40 percent of the state's workers are trained to the middle-skill level, according to the National Skills Coalition.

Many localities, working in conjunction with public school systems, have developed their own vocational training programs. These programs work in conjunction with local corporate partners and area organizations to connect skilled workers with area employers offering livable wages and health benefits. ■



Ensuring a child with complex disabilities receives

necessary services and proper support requires a multitude of logistical challenges. Identifying organizations that offer social opportunities, ensure financial security and provide appropriate living arrangements can present a significant challenge. The Arc of Northern Virginia serves individuals with the full scope of developmental disabilities across their lifespan, as well as their loved ones. This is the foundation on which The Arc was built.

The Arc of Northern Virginia works with clients to address Social Security benefits, Medicaid Waivers, employment and most other services that work to improve lives and expand independence and inclusion. Supports are customized for the needs of each client. An individual with complex challenges may, or may not, choose full-time employment. Our role is to find a job that best suits their requirements and abilities. Perhaps it's a job that requires a few hours a week or a job with regular breaks or a job in a quiet environment. A client with limited physical control, for example, may use adaptive technology. It should be a custom fit.

Opportunities to live and work are now firmly established by some of the most important civil rights laws in the country. The Individuals with Disabilities Education Act (IDEA) opened school doors to all students. The Fair Housing Act of 1968 made it illegal to discriminate against people with disabilities in search of housing. The Civil Rights of Institutionalized Persons Act of 1980 and the Olmstead Decision from 1999 served to protect the rights of people still living in institutions and paved the way for everyone, no matter the severity of their disability, to have the right to enjoy life in a community setting.

The landmark 1990 Americans with Disabilities Act

ensured protections and accommodations in work, public spaces and government programs. These laws and decisions were hard fought by people with disabilities and families who demanded equality and equity. Individuals who require 24/7 support can now move into their own apartments. Employment opportunities for these same individuals have also expanded. People who need hands on care for daily living cheer on their favorite sports teams from accessible seats in the front row of the stadium.

We're a stronger nation when everyone is encouraged to be an active part of our community. Research demonstrates the inclusion of those with significant disabilities creates a positive impact on the individual and their families.

After the last Virginia institution closed in 2016, many individuals would move into a home for the first time. Those who had previously struggled behind walls of an institution, segregated from human interaction, began to smile, move and communicate. Progress was swift.

Life exists in shades of grey. Planning the future for a loved one with a significant disability can be daunting. But each piece of planning - finding a home, saving for what matters, and more - will change the trajectory of a life. ■

# FOR THOSE WITH COMPLEX DISABILITIES

# COMING OF AGE

## UNDERSTANDING GUARDIANSHIP

As children with disabilities come of age, parents are faced with choices, decisions and challenges. Understanding children's strengths and needs—and our own doubts and fears—can be an eye-opening process.

The cusp of adulthood can be a pivotal time for both children and parents. Although legal adults, many eighteen-year-olds have not reached maturation in many realms. Disabilities—whether intellectual, developmental, physical or mental—adds a layer of complexity. Teens can be on track in the academic realm, but lag in emotional or social development. Deciding how to handle decision making once your child becomes a legal adult is challenging—understanding the different options is imperative.

Guardianship—the most restrictive model—is a legal relationship not easily reversed. Serious thought, careful research and a thorough legal understanding of how your child's disability affects his or her decision making capacity should precede the establishment of a guardianship.

A guardianship is sanctioned by a circuit court judge that imparts the authority to a guardian to make decisions for another person. In cases of total incapacitation, guardianships are an ideal solution.

But there are some drawbacks to guardianship, accentuated in cases where decision making capacity is not clear.

In a guardianship arrangement, individual rights are stripped from the individual. Once a guardian is appointed, the individual loses the right to vote, get married, sign contracts (including leases) and make medical

decisions. Depriving someone of individual rights is no small decision—and historically, once a guardianship is established, it is difficult to legally reverse. The deprivation of individual rights can feel stigmatizing to those impacted; preventing adults from experiencing the hallmark benefits of adulthood: self-determination and independence.

In cases where capacity exists but is limited, a limited guardianship may be explored. This arrangement keeps some rights of the individual in tact, but transfers some of the decision making power to the guardian. Limited guardianships clearly define which decisions are reserved for the individual to make and which decisions should be made by the guardian. The court order can specify the guardianship arrangement is limited to medical and financial decision making, so the individual's right to marry and vote is retained, for example.

Less restrictive alternatives—such as supported decision making—should be examined and considered before guardianship is pursued. (See page 44 for a complete discussion on supported decision making.)

Deciding whether a guardianship—or an alternative—is suitable for your child requires exploration, research and analysis. It's legal permanency demands treading carefully and consideration of all options. ■

# PEDIATRIC THERAPY STUDIO

We provide Applied Behavior Analytic (ABA) services  
in the following areas:

Pre-academic (learning-to-learn) skills

Communication skills

Group skills

Play skills

Daily living skills

Social skills

Vocational skills

Parent training

Severe behavior services

And more!



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# WITH ME, NOT FOR ME

With empowerment as its underpinning and self-determination its fuel, the growing popularity of Supported Decision Making (SDM) is hardly surprising. It reflects the evolution of mindsets; the diachronic sea change in beliefs about power, capability and fundamental human rights of people with disabilities.

## Empowerment through Supported Decision Making

Supported Decision Making—the concept of making life decisions with assistance from a team of supporters—has gained traction and acclaim in the advocacy community.

It feels modern, progressive and quintessentially fair—respectful of the rights and preferences of people with disabilities and imparting independence and control over life decisions. From where to live to how much to spend, people with disabilities are participating in life decisions based on their own preferences and values.

Supported Decision Making is predicated on a thorough analysis of potential consequences of each decision, soliciting feedback from a close group of trusted supporters that understand the fragile balance between best interest and self-determination. It is reminiscent of the natural decision-making process of many adults without disabilities—solicit feedback from respected point persons, weigh options then decide. SDM arrangements in Virginia can be formal, but are not (yet) considered legal agreements. Advocacy groups—such as The Arc—are working to galvanize the power of SDM by educating professionals to accept and respect decisions made by people with disabilities.

SDM is a lesser restrictive alternative to guardianship (see page 44 for a full discussion) for people with disabilities who have the capacity to participate in and communicate about life decisions. Individual rights—such as the right to make medical decisions, sign contracts, vote and get married—are not impacted by a supported decision-making arrangement. Those rights, along with

others, are forfeited in guardianship arrangements.

In SDM, supporters help people with disabilities make their own decisions, aiding them in identifying the strengths and drawbacks of each alternative. Guidance is available from supporters, but for people with disabilities, the right to make decisions both big and small is retained.

For many, making decisions independently is a by-product of adulthood; living with their ramifications, an opportunity for personal growth and lessons learned. When people with disabilities are empowered to make important life decisions, they are given the chance to understand lessons and insights that accompany success and failure.

Making responsible and sound decisions is a skill learned diachronically; the supported-decision making model supports this learning. When people with disabilities are involved in the decision making process—even leading it—values and preferences become clear and personal responsibility and accountability are practiced and reinforced.

Supported decision making is considered best practice by many disability advocates—it respects and protects the basic human rights of people with disabilities. But for progress to continue, the word must spread. Supported Decision Making catalyzes growth, respects uniqueness of each individual and provides a deserved voice to people with disabilities. ■

## Special Needs Trust...

(from page 9)

### WHAT SNT FUNDS CAN BE USED FOR:

Although SNT funds do not come with carte blanche, there is a substantial range of acceptable expenditures.

If the beneficiary receives public benefits, funds are disbursed to a 3rd party rather than to the beneficiary to protect eligibility.

If the beneficiary does not receive public benefits, funds may be disbursed directly to him/her.

Funds can be used, for example, for communication devices (including computers), furniture, electronics, videos, special dietary needs, athletic training or competitions, vacations and recreational activities, vehicle maintenance and insurance, entertainment, service animals and assistive technology expenses, dental care costs, and foot care and special therapies not covered by Medicaid or SSI.

In certain instances, housing costs can be funded by a trust fund; however, this may impact SSI benefits. (See housing article on page 21).

### TAXES & TRUSTEE FEES:

The Commonwealth of Virginia does allow legal, guardianship and trust-

ee fees to be paid from SNT funds.

### THE PLAYERS:

The Trustee is the metaphorical team captain—overseeing trust assets and administering trust provisions, including investing, account reporting, tax reporting, check writing and disbursements.

The Arc of Northern Virginia serves as manager for trusts set up through its Trust Department—relieving families of trust-related administrative burdens.

Key Bank handles fiduciary and investment duties for SNTs established through The Arc of Northern Virginia.

The beneficiary is the child or adult for whom the trust was established. With the Arc of Northern Virginia, the person who establishes the trust is the grantor. The grantor typically funds the trust—there is often more than one grantor.

### REAL ESTATE IN TRUST:

The Arc of Northern Virginia, with Key Private Bank as partner, now has the capability to hold real property.

To many families and individuals with special needs, the ability to hold house

and property in a SNT allows new possibilities, a future on their terms. If a house or property is left to an SNT, the beneficiary now has choices. Decisions regarding property left in trust are typically made before the death of the property owners, but not always. The decision, sometimes, is left up to those assisting the beneficiary. If those assisting choose to remain in the home, that is now an option—the house can be managed, maintained and paid for by the trustee. If the trustee needs to sell the property, the trustee can hire professionals that can ready it for sale.

Trust real estate holdings require expertise. Key Private Bank Trust Real Estate Officers are skilled in managing professional resources essential to the overall investment performance. From lease negotiation to long-term strategy, Key Private Bank offers property management to its clients as both a solution and convenience. ■

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for more information

## Revolutionaries...

(from page 23)

Inclusion Films offers two programs: summer camps and vocational film workshops.

Short film camps teach teens and young adults the principles of filmmaking. Campers work in small groups to develop a script, act and shoot a film using professional equipment with the guidance of experts. The program encourages communication, confidence and collaboration through acting and digital filmmaking. Each of three age groups produces a short film based on a specific theme.

Vocational film workshops take filmmaking to the next level. Over the course of a semester, students are taught all aspects of film production—from big picture to subtle detail. A thesis film is developed and shot. Smaller video projects are created and fine-tuned. The goal is to teach skills that can be applied in the field and earn students a long term position within the film and media industry. The organization leads by example. Clients including Ford Motor Company, NBA Cares, Sacramento Kings, 211LA, Easter Seals, Phoenix Suns, Uber Content and the National Inclusion Project hire Inclusion Films, and their students, for a wide variety of projects.

It's not surprising that Joey Travolta's brainchild has reached this level of success. Before Inclusion Films, Travolta served as a special education teacher. His belief in the project, in the students and in the mission drives an expanding organization that has now served thousands of students—future innovators of an industry known for pushing boundaries and redefining what is possible. ■

For information on The Arc of Northern Virginia's Special Needs Trust program, please visit [thearcofnovatrust.org](http://thearcofnovatrust.org).

For more information visit [thearcofnovatrust.org](http://thearcofnovatrust.org)

# SNAPSHOT:

## First-Party Special Needs Trust

- Must be established and funded before age 65
- Individual's money funds trust
- No limit on annual contributions
- No limit on amount held in trust
- Earnings from account investments are taxed
- Individual, parent, grandparent, guardian, POA or court can establish trust
- Beneficiary cannot be changed
- Disbursements should not jeopardize SSI/Medicaid
- Disbursements for sole benefit of individual
- No limit on number of trusts
- No disability redetermination
- Trustee determines investment choices
- Trustee manages the account
- Legal fees, management fees, investment fees
- Medicaid expenditures reimbursed to the state after beneficiary's death
- Distribution request made after beneficiary's death to pay expenses including funeral must be approved by Medicaid

## The Arc of Northern Virginia's First-Party (Self-Funded) Special Needs Pooled Trust

- Must be established and funded before age 65
- Individual's money funds trust
- No limit on annual contributions
- No limit on amount held in trust
- Earnings from account investments are taxed
- Beneficiary, parent, grandparent, guardian or court can establish trust
- Beneficiary can't be changed
- Disbursements should not jeopardize SSI/Medicaid
- Disbursements for sole benefit of individual
- No limit on number of trusts
- No disability redetermination
- Pooled Trustee with grantor determines investments
- Trustee/non-profit manages the account
- Non-profit management, trustee and establishment fees
- Medicaid expenditures are reimbursed to the state only if funds are not left to the non-profit for other beneficiaries with disabilities
- Distribution request made after beneficiary's death to pay expenses including funeral must be approved by Medicaid





# SNTs & ABLE

## The Arc of Northern Virginia's Third-Party (Family-Funded) Special Needs Trust

- Can be established at any age
- Anyone's but individual's money funds trust
- No limit on annual contribution
- No limit on amount held in trust
- Earnings from account investments are taxed
- Any third party can establish and fund trust
- Disbursements should not jeopardize SSI/Medicaid
- Flexibility with how funds may be used
- The beneficiary cannot be changed
- No limit on number of trusts
- No disability redetermination required
- Trustee/nonprofit and grantor determine investments
- Trustee/nonprofit manages the SNT
- Non-profit management, trustee and establishment fees
- Medicaid reimbursements not required after beneficiary's death
- Grantor determines who inherits at death of Beneficiary
- Distributions can be made after beneficiary's death to pay expenses including funeral

## ABLE Accounts

- Beneficiary determined disabled before age 26
- Limit on annual contributions—annual contributions may not exceed \$15,000 (2019)
- Limit set by state on amount held in account (VA \$500k); if account exceeds 100k, SSI suspended, Medicaid retained
- Anyone's money funds ABLE
- Earnings from investments not taxed if distributions pay for qualified expenses
- Beneficiary or a person on behalf of the beneficiary can establish trust (parent, guardian, or power of attorney)
- Beneficiary can be changed to sibling or step-sibling if they meet ABLE requirements
- May be used for housing and not be counted by SSA
- Disbursements are limited to qualified disability-related expenses (QDE)
- ABLE Accounts are limited to one account per beneficiary
- There are disability redeterminations
- Investment choices are determined by the state ABLE manager and Beneficiary
- Designated manager is responsible to manage account and maintain records
- Costs are dependent on state
- Medicaid expenditures are reimbursed to state after beneficiary's death
- Distributions can be made after beneficiary's death to pay qualified expenses including funeral
- Beneficiary who is working may contribute an additional \$12,140, as long as they can't have a retirement plan with employer. ■

For more information visit [thearcofnovatrust.org](http://thearcofnovatrust.org)

# SOCIAL DEVELOPMENT THERAPY GROUPS

DSA is launching three new innovative therapy groups focused on promoting social development for children, youths, and adults with developmental, behavioral, and mental health challenges.

## SATURDAY GROUPS NOW FORMING

**Developmental Support Associates** is launching 3 new innovative *therapy groups* focused on promoting *social development for children, youth, and adults* with developmental, behavioral, and mental health challenges. DSA employs a gaming and art milieu to promote social development. Saturday-meeting groups are forming for *children age 6-16, youth age 16-21, and adults age 18 and over*. Falls Church, VA. For more information see the DSA website at [www.developmentalsupport.com](http://www.developmentalsupport.com)

# Magellan COMPLETE CARE

## Subsidized...

(from page 28)

- A housing subsidy is paid to the landlord directly by the PHA on behalf of the tenant. The tenant then pays the difference between the actual rent charged by the landlord and the amount subsidized by the program. Under specific circumstances a tenant may use its voucher to purchase a home.
- Eligibility for a housing voucher is determined by the PHA and is based on the total annual gross income and the number of tenants in the residence. In general, tenant income may not exceed 50% of the median income for the area.
- A PHA must provide 75% of its vouchers to applicants whose incomes do not exceed 30% of the area median income. Median income levels are published by HUD and vary by location. The local PHA can provide income limits for your area and family size.
- If the PHA determines that you are eligible, your name will be placed on a waiting list, unless it is able to assist you immediately. Once your name is reached on the waiting list, the PHA will issue you a housing voucher.

*To apply for a Section 8 voucher, you can apply to any PHA that runs a Section 8 voucher program. You can also apply to one of the regional nonprofit housing agencies where Section 8 vouchers are available. ■*

## Public...

(from page 28)

To apply for public housing, you must submit an application to the PHA in the city or town where you would like to live. You can apply to as many as you want. In some cases you may apply to the individual development and/or to the private management company that operates the development.

*The Virginia PHA contact information is ordered by city. You may also view it ordered by zip. [https://www.hud.gov/program\\_offices/public\\_in-dian\\_housing/pha/contacts/va](https://www.hud.gov/program_offices/public_in-dian_housing/pha/contacts/va). ■*

## Waiver...

(from page 21)

Without pressure from the federal government and advocacy groups, Virginia's Medicaid waivers may have never undergone a redesign.

The process has brought an increase in funding, additional waiver slots and improved services. Those with disabilities now receive more individualized support and are better positioned to succeed and prosper in the community.

But...there is a long way to go for the system to be optimal and it remains underfunded. As of January 16, 2018, 12,360 Virginians were on the DD Waiver waitlist stifled by bureaucratic red tape and anemic federal and state budgets. ■

## Arc...

(from page 14)

### Equity

The Arc believes that people with intellectual and developmental disabilities are entitled to the respect, dignity, equality, safety and security accorded to other members of society and are equal before the law.

### Community

The Arc believes that people with intellectual and developmental disabilities belong in the community and have fundamental moral, civil and constitutional rights to be fully included and actively participate in all aspects of society.

### Self-determination

The Arc believes in self-determination and self-advocacy. People with intellectual and developmental disabilities, with appropriate resources and supports, can make decisions about their own lives and must be heard on issues that affect their well-being.

### Diversity

The Arc believes that society in general and The Arc in particular benefit from the contributions of people with diverse personal characteristics (including but not limited to race, ethnicity, religion, age, geographic location, sexual orientation, gender and type of disability).

The Arc works with its federation of state and local chapters to create a network of human service agencies ensuring they have the strongest civil rights advocates promoting and protecting needs at all levels.

Founded in 1950, The Arc was comprised of a small group of concerned and passionate parents and community members who would be a catalyst for changing the public perception of children with disabilities. The Arc has continued to grow and evolve along with the changing needs and issues people with disabilities and their families face. ■

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