

breaking ground

NUMBER 92

MAY 2018



“

Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.

”



Council on
Developmental Disabilities



Table of Contents

- 3 55 Years of the Developmental Disabilities Act
- 6 Career Connections
- 8 Camp EmPower, MePower: An adult learning experience

10 Enabling Technology: Modernizing supports for people with disabilities

12 Partners 2017-18 Class Graduates

14 What Independent Living Is (and is not)

15 Partners 2018 Annual Reunion Conference

16 Martin McGrath: An independent living story

19 Remembering Council Member and Partners Graduate Douglass Hall

19 New Council Member Craig W. Lemak



Tennessee Council on Developmental Disabilities, Authorization No. 344067, May 2018, 27,000 copies. This public document was promulgated at a cost of \$0.83 per copy.

Learn more about the Tennessee Council on Developmental Disabilities.
615.532.6615 | www.tn.gov/cdd | www.facebook.com/TNCouncilonDD | Tnddc@tn.gov
Subscriptions to Breaking Ground are free and available through the Council office.
Contact us by phone or email with subscription updates or requests, and please include name and mailing or email address.

55 Years of the Developmental Disabilities Act

by Lauren Pearcy, Council Director of Public Policy and
Emma Shouse Garton, Council Director of Communications

A brief history of the DD Act

State Councils on Developmental Disabilities, including Tennessee's, are established by a federal law known as the Developmental Disabilities Assistance and Bill of Rights Act¹ (commonly referred to as "the DD Act"). This law originated from historic legislation signed in 1963 by President John F. Kennedy. The DD Act was unprecedented at the time, because it drew attention to the lives of citizens who had previously been institutionalized, marginalized and even subjected to sterilization and experimentation.² Kennedy's administration ushered in a new era of focus on citizens with developmental disabilities and specifically called for reducing the number of citizens living in institutional settings.³



24 October 1963 Bill Signing, H. R. 7544, Maternal and Child Health and Mental Retardation Planning Amendments of 1963. President Kennedy hands signing pen to Eunice Kennedy Shriver.

These actions coincided with a broader civil rights movement in America. Alongside the executive actions of the time, community members and grassroots advocacy groups accelerated the progress of the DD Act and other disability laws throughout the 1960s and '70s.⁴

“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”

Thanks to the unrelenting work by the disability advocacy community, the DD Act has continued to evolve to reflect the most current research and best practices over time. Remarkably, the same founding principles have remained the same: self-determination, independence, productivity, integration and inclusion in all facets of community life for individuals with developmental disabilities. The DD Act's principles, unparalleled when enacted, are still tested today. State Councils on Developmental Disabilities still look to the DD Act as a guidepost for our work. In everything we do, we look at those principles and ask if our projects and initiatives uphold those values. As the Tennessee Council's Executive Director, Wanda Willis, often says, "The DD Act is as relevant today as it's ever been."

The DD Act's Strategy for Implementing Change: The Creation of the DD Network Programs

In 1961, President Kennedy convened the first-ever President's Panel focused on citizens with developmental disabilities. The panel's findings included the need for more professional expertise about the causes of developmental disabilities, more societal awareness about how to support citizens with developmental disabilities,

Continued on page 4

1. <https://www.acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000>

2. <http://www.nclid-youth.info/index.php?id=61>

3. <https://www.jfklibrary.org/JFK/JFK-in-History/JFK-and-People-with-Intellectual-Disabilities.aspx>

4. https://en.wikipedia.org/wiki/Timeline_of_disability_rights_in_the_United_States#cite_note-nads.org-35

55 Years ... *Continued from page 3*

and enforcement of laws that protect the rights of citizens with developmental disabilities.⁵

To address those findings, the DD Act created a network of programs that could not only implement change, but help address the cultural barriers facing citizens with disabilities. These three programs together are known as the “DD Network”. Like the Act itself, these programs are still necessary today for addressing persistent gaps in our systems and communities to adequately support people with developmental disabilities and their families that existed 55 years ago.

Overview of the DD Network Programs:

- **State Councils on Developmental Disabilities** are charged with assessing the overall disability system in their state (or territory) and working to make improvements on behalf of citizens with developmental disabilities. Councils have considerable flexibility to identify their own projects and collaborate with local stakeholders based on their citizens’ unique needs.

Councils are expected to leverage collaboration to make big, lasting impact with relatively small staff and budgets. Most importantly, Councils are expected to empower individuals with disabilities and their families to exert influence over the disability system; that is, the policies and practices that affect their lives. Accordingly, Council members are individuals with disabilities and family members of people with disabilities, which comprise 60% of membership. The remaining members are representatives of State agencies who oversee disability policy and services. Membership necessitates direct interaction between policymakers and the citizens they impact. Representatives of the other DD Network programs also serve on the Council. In Tennessee, the Council on Developmental Disabilities is an independent office in the executive branch of State government.



Council on
Developmental Disabilities

- **Protection and Advocacy (P&A)** systems exist to protect the legal and human rights of individuals with developmental disabilities through a mix of legal action and proactive advocacy. They work to inform people of their rights, investigate suspected abuse and neglect and provide free legal representation to people with disabilities. They have broad legal authority to access records, facilities, and individuals when conducting investigations, placing them in a unique position to detect and address abuse. Protection and Advocacy systems also serve individuals with behavioral or mental health diagnoses. In Tennessee, the P & A is Disability Rights Tennessee, a nonprofit legal services organization.



- **University Centers for Excellence in Developmental Disabilities (UCEDDs)** were created to address the significant need for professional expertise in developmental disabilities. Today, UCEDDs offer cross-discipline training, technical assistance, and continuing education to professionals and community members. They conduct cutting-edge research, public policy analysis and broad information dissemination efforts. Many UCEDDs offer direct services to different populations of individuals with disabilities and lead model demonstration projects. In Tennessee, we are fortunate to have two UCEDDs: the Boling Center at the University of Tennessee in Memphis and the Kennedy Center at Vanderbilt University in Nashville.



How does the DD Network “work”?

All DD Network programs are expected to be “carried out in a manner consistent with the principles of the DD

5. <https://mn.gov/mnddc/parallels2/pdf/60s/63/63-ROT-PPMR.pdf>, page 41

Act”,⁶ which unites the programs as natural partners. In Tennessee, the programs partner extensively, serving on each other’s boards, meeting regularly and working jointly on projects. In fact, the Tennessee DD Network’s⁷ level of collaboration is praised as a national model.

A few recent examples of the DD Network’s collaboration in Tennessee:

- During the national healthcare debate in 2017 when Congress proposed historic changes to the Medicaid program, the DD Network developed an education strategy to ensure elected officials understood the impact of such changes on citizens with disabilities.



Next Steps students take #WithoutMedicaid photo



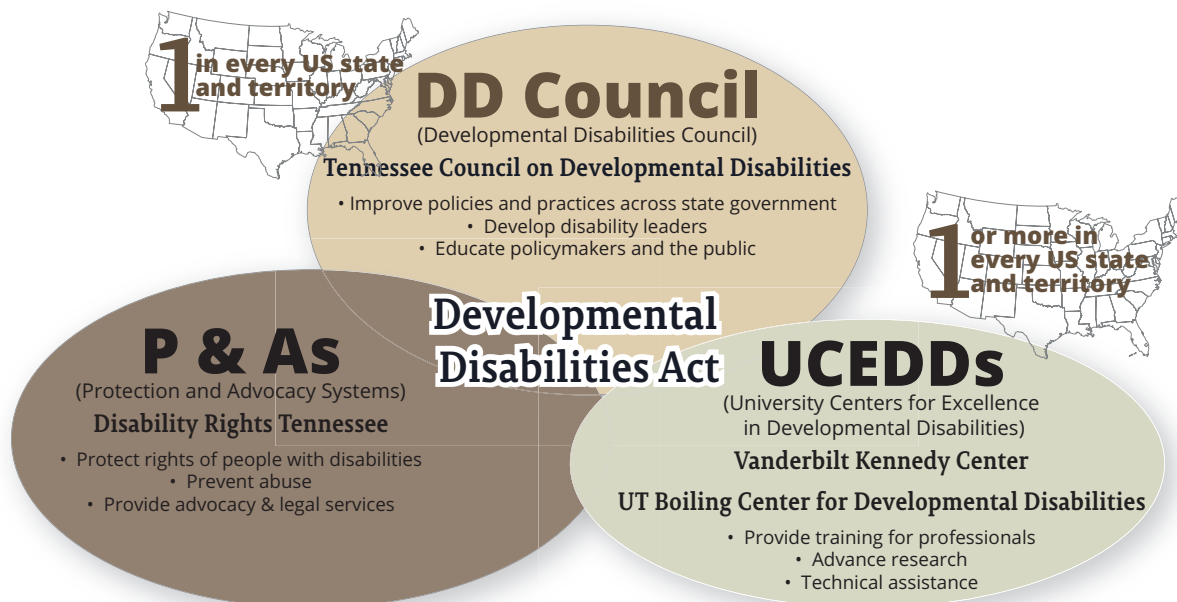
SDM Workgroup after testimony

- Starting in 2016, the Vanderbilt Kennedy Center established a small working group to discuss an emerging best practice in the disability field called “Supported Decision Making”. Since its inception, other DD Network Partners have taken leadership roles as well. Disability Rights Tennessee hosts the workgroup meetings and held the state’s first “grassroots” forum for stakeholders across Tennessee. The Council on Developmental Disabilities has led the agenda development and meeting notes during each workgroup meeting, plus the sponsorship of national expert Jonathan Martinis to inform the workgroup’s efforts.

Nationally, the three programs work closely to influence policy at the federal level. Unlike many other disability organizations, the three DD Network programs exist in the federal government as part of the U.S. Dept. of Health and

Human Services. This position allows them to maintain close relationships with the other federal programs that impact citizens with disabilities like Medicaid, Vocational Rehabilitation and Special Education. As part of the same bigger system as those programs, the DD Network can be particularly

Continued on page 6



6. https://www.acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf, page 5
7. <https://www.tn.gov/cdd/about-the-council/developmental-disabilities-network.html>

Career Connections

by Jennifer Eppley

Photo: by Jennifer Eppley

It all began in 2015 when Kendrise Colebrooke met Robbie Broom at the Knox Area Employment Consortium (KAEC). Kendrise is the Community Employment Coordinator for Breakthrough Corporation (a disability service provider in Knoxville, primarily serving clients with autism), and Robbie is a Career Specialist with the Tennessee Department of Labor & Workforce Development, stationed at the American Job Center in Knoxville.

American Job Centers are designed as a “one stop” place for assistance finding a job and they exist in communities across every state. In 2014, the federal law creating American Job Centers, which is called the Workforce Innovation and Opportunities Act, was updated to put an even greater emphasis on serving people with disabilities.

Robbie joined KAEC to better serve individuals with disabilities by connecting them to employment services and opportunities. The KAEC mission is to “improve the quality of life and general welfare for people with

55 Years ... *Continued from page 5*

effective at getting information about disability services and relaying feedback from the citizens who utilize those services at the federal level.

Here is an example of how the DD Network is particularly effective at getting information to citizens:

- After the federal Home and Community-Based Settings Rule (HCBS Settings Rule) was announced, the national DD Network associations launched a website with information for citizens with disabilities and advocates: <https://hcbsadvocacy.org/>. The HCBS Settings Rule is an example of a complex and technical rule that was hard for the average citizen to digest, but directly affected many citizens with disabilities, and getting information out to communities was essential. The DD Network was perfectly positioned to assist; in fact, the network’s oversight agency, the Administration on Community Living, was tasked with reviewing states’ plans for compliance with the new rule. Because of this, the DD Network had more insight than virtually any other entity in the country about the rule.

And, here are two examples of how the DD Network gives feedback directly to national policymakers:

- First, the DD Network programs in every state have to report regularly to the federal government about

the issues affecting citizens with developmental disabilities. The State Councils do this every five years with its “Comprehensive Review and Assessment”, which surveys both private citizens and state agencies that provide disability services.

- Additionally, the DD Network programs each have their own associations⁸ which engage in policy advocacy in Washington, DC. The directors of those programs regularly author position papers, statements about policy changes and letters directly to policymakers – including Congress – on behalf of citizens with developmental disabilities across the country.

Without the DD Network in federal government, no entity would be dedicated to the perspective of the citizen using disability services. Thanks to the DD Act, people with developmental disabilities have a space inside the federal government for their voices to be prioritized and heard.

The intro to the DD Act makes it very clear:

“Congress finds that disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”

8. The National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD)



Robbie Broom (left) of the American Job Center and Sheliia Williams (right) of Breakthrough Corporation discuss job fairs and job club.

disabilities as it relates to employment issues". Robbie let Kendrise know that the American Job Center was the main meeting place in their community for personal job development activities, especially mock interviews and résumé writing. What began as a brief first connection at a local employment consortium meeting blossomed into a relationship with the American Job Center which has increased services and opportunities for Breakthrough participants, and which continues to expand.

The current picture

Those initial contacts have developed into a real presence for Breakthrough Corporation at the American Job Center. Breakthrough's Sheliia Williams connects with many of her participants for job search meetings at the American Job Center. She sees three to four participants each day, on Mondays, Wednesdays and Fridays. In addition to providing individualized employment coaching and counseling to participants, she connects them with single-company and multi-employer job fairs held each month at the American Job Center and helps them get assistance in the Center's Resource Room.

Sheliia also encourages participants to explore the www.Jobs4TN.gov website on the days that they are not working

or volunteering. That helps participants to practice checking emails and exploring job opportunities on a regular basis. Through www.Jobs4TN.gov, participants are able to expand their potential employment opportunities and further develop their career exploration skills.

In addition to individual assistance, help in a group format is also available. Breakthrough Job Club has expanded from one to two times per month, and is typically held every other Friday afternoon. The sessions are conducted in a smaller assessment room with limited distractions for a more suitable sensory environment. Parents and staff often attend the Job Clubs with the participants.

Growth for the future

As an added layer of support, Sheliia is planning to attend one of Robbie's Jobs4TN intensive workshops for social service providers. This two-hour training provides tips and tools for social service providers to assist them in better guiding their participants in career exploration. Instructive guidelines include registering, searching for jobs, using the virtual recruiter, researching labor market information and exploring education and training information and opportunities.

Kendrise believes that the change in environment and exposure to opportunities at the American Job Center is a positive for Breakthrough participants. By coming to the American Job Center, Breakthrough participants are able to see other people looking for employment, too, and thus join others in the overall goal of career exploration, development and attainment.

For more information or resources, please contact:

- Knoxville Area Employment Consortium:
<https://www.kaectn.org/>
- Breakthrough Corporation, Knoxville:
<http://breakthroughknoxville.com>
- American Job Center, Knoxville:
<http://www.tncknox.org>
- American Job Center employment resources and services: www.jobs4TN.gov

Jennifer Eppley is the Director of One Stop Operations at the American Job Center in Knoxville. The following individuals also contributed to this article: Robbie Broom (American Job Center), Kendrise Colebrooke (Breakthrough Corporation), Sheliia Williams (Breakthrough Corporation), and Jay Coffman (American Job Center).

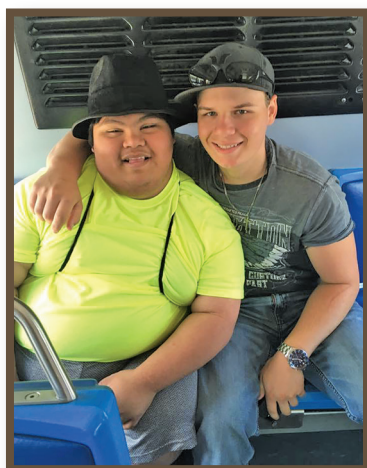
Camp EmPower, MePower:

An adult learning experience

by **Debbie Riffle**

The Down Syndrome Association of West TN (DSAWT) may be a small nonprofit but we pride ourselves in developing programs with a BIG impact for individuals we serve in West Tennessee. Each year our board meets to discuss new program opportunities that can fill a need in our community. Over the years, we have discussed the growing need of serving our adult population with Down syndrome. After much discussion, planning and researching natural community supports, the DSAWT was excited to introduce Camp EmPower, MePower in 2017. EmPower, MePower is a one-week adult learning experience for individuals with Down syndrome ages 18 and up. The purpose of this program is to empower individuals by teaching independence and self-determination through fun, meaningful experiences such as utilizing public transportation, exploring the community and providing opportunities to develop natural friendships with peers.

One of the biggest challenges for individuals with disabilities in accessing their community is the lack of transportation. Our campers rely solely on transportation by a friend or family member, which is very limiting. Our number one priority for camp was to introduce them to the Jackson



Transit Authority, our local public transportation system. We wanted our campers out in the community every day, riding the bus to and from their destinations.

This goal was high for our first year of camp and the planning and logistics were no easy task. The teachers and I soon realized that we had a lot to learn about public transportation ourselves, before we could teach



the campers. We had to learn bus routes, rules and expectations, and how to be prepared for unexpected changes. After much preparation, the teachers decided to do a trial run before camp started. While proudly standing on the side of the road waiting for the bus to arrive, they were speechless when it drove right past because they were standing on the WRONG side of the road! They broke out into laughter as they realized there was obviously a bit more work to be done.

With additional homework we were finally ready for the first day of camp. Each day we rode the bus to and from our outings. The campers loved learning how to use bus passes and riding the bus, as well as meeting other passengers. They did a great job learning bus rules, which included entering and exiting safely and quickly. Our bus trips were definitely the highlight of every day for not only our campers and volunteers, but also for our friendly JTA bus drivers and other passengers.

Another goal for camp was to provide fun, meaningful opportunities through community outings and recreational and learning activities with guests from our community.



Our outings included a painting session at Painting with a Twist, a visit to Casey Jones Village and Train Museum, lunch with friends at the Old Country Store, a guided tour of the hospital, and a morning at the Fire Station for fun and hands-on activities. We also invited guests to camp each afternoon for activities such as yoga, zumba, music with instruments and learning basic banking skills. With our bus rides and outings each morning, preparing and serving lunch and snacks and our guest activities in the afternoon, we made the most of every busy day.

Last but not least, our amazing volunteers were some of our greatest assets at camp. We wanted a natural environment that included typical peers and opportunities to make new friends. Our volunteers were in the same age group as our campers. We had close to the same number of volunteers as campers so there were plenty of friends to go around! The volunteers and campers “hung out” together, helped each other, laughed, danced, took selfies, and got to know each other - just like any new friend. By the end of the week, everyone was already dreaming of camp next year and planning to see each other again soon. Several campers and volunteers have even stayed in touch throughout the year. That’s just what friends do! Our volunteers made camp a memorable experience for everyone.

The DSAWT set out with big dreams and goals to make a difference in the lives of adults with Down syndrome by providing opportunities to increase their independence and self-determination skills while building new friendships along the way. We may be a small organization that started with only one week of camp but the outcomes were momentous in the lives of our campers, their

families, the volunteers and individuals that we met throughout the community.

In 2018, the DSAWT is very proud to be extending Camp EmPower, MePower to two weeks. In remembering the quote by Margaret Mead, “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

A special thank you to the Jackson Center for Independent Living (JCIL), Beth James, and her staff for the gracious offer to use their facility and their encouragement and support.

Debbie Riffle is the mother of an adult son with Down syndrome, a Partners grad, a DSAWT board member and a former long-standing Council member from Jackson.

For more information about DSAWT, please email dsawt@att.net or call 731.499.1065.



Enabling Technology:

Modernizing supports for people with disabilities

by **Cara Kumari, DIDD Director of Communications**

The Department of Intellectual and Developmental Disabilities (DIDD) prides itself on blazing new trails when it comes to providing supports for people with disabilities, whether it's being the first state to receive Person-Centered Excellence Accreditation from the national Council on Quality and Leadership, becoming a national leader in Employment First, or closing its large, congregate developmental centers in favor of individualized supports in the community. These have been monumental changes in the way the state provides supports for people with disabilities, and they are leading to better outcomes and a higher quality of life. Now, it's time to take the next step in that journey.

Many of us have already embraced technology, wholeheartedly, in our everyday lives. Many people with disabilities check Facebook on their phones like the rest of us, and enjoy using tablets for news, information, games, videos and taking pictures. However, even though technology is all around us, we have relied on the traditional methods of providing supports to people with disabilities: 24/7 in-person supports. And while that level of support is absolutely essential for some people receiving DIDD services, there are countless others that can be and want to be more independent. That's where enabling technology comes in.

The term "enabling technology" encompasses many different methods of providing support to people with disabilities in a way that fosters independence. It can be a mobile application that provides step-by-step alerts to a person who wants to use public transportation, to make sure they get to where they want to go. It can be a tablet loaded with individualized prompts to ensure they remember all of their scheduled tasks or appointments while working in the community. It can be a sensor on a bed, stove or door to allow a person to live independently,

but alert a "tele-caregiver" if something deviates from the normal routine. All of these scenarios are already playing out in other service-delivery systems in some other states, with very promising results.

This "Technology First" movement is beginning in Tennessee. DIDD has carefully researched the options, the outcomes, the successes and the lessons learned from other states for the past year. Four DIDD providers were selected to begin testing enabling technology in April. Those providers are in the process of talking to the people they support and their families to see if the various enabling technology options may help them achieve their life goals.

As we are having these conversations, we want to emphasize what this move towards technology is, and what it is not. A word we haven't been using when talking tech is the word "monitor". Oftentimes people hear "cameras" and think that a person's every move will be watched or that this is a way to spy on staff. That is not the case. Cameras are one option in the myriad of technology options available to people and their families, and the purpose is to provide assistance only when it is needed, nothing more, nothing less. And it's also important to stress that this is a choice - no one is being forced to

use enabling technology if they don't want to. While we believe there are hundreds of people in DIDD services who can benefit from this, we also understand there are still hundreds of others who do not want remote supports or aren't ready to be supported without in-person support staff.



Cara Kumari



Enabling Technology - A Parent's Perspective

by Bonnie Micheli, Partners Graduate and Parent Advocate for Nicole Micheli

Many states have already brought technology into the day-to-day lives of those with intellectual disabilities as a tool to allow maximum independence yet still have the assistance needed by the supported individuals. Now the Department of Intellectual and Developmental Disabilities is bringing technology to providers to create more independence in a safe environment for the people they serve.

Imagine a home with a monitor to remind you to shut off the stove after you're finished using it. Or a medication dispenser that prompts you when it's time to take your medications, dispenses the correct pills, and alerts you if you miss a dose. Or sensors that monitor when you get out of bed at night and go to the bathroom – and notice if you are in there longer than normal. Maybe a two-way camera with audio to discuss the weather and clothing choices with a remote-staff member before leaving for work in the morning. These are real examples of how technology can play a role in caring for our supported family members, so they can live a more independent life.

It sounds a lot like how I live each day. I have apps on my phone that can remind me when it's time to do an activity; my computer allows me to Skype with anyone around the world with a click of a button; and I daily ask



Bonnie, Nicole and Brian Michelli

Amazon's Alexa to buy my Prime purchases and Google Home what the weather is, so I know what to wear before I leave the house.

This is 2018. We embrace new technology every day to make our lives easier and our days fuller. The introduction of technology as a tool that providers and those supported can choose to add into their daily plan is long overdue. I dream of the day that my daughter's provider will be able to set up her home, so she can use her communication device to control her surroundings independently.

Each person who chooses to test enabling technology will be selecting the type of technology they believe will help them live the lives they envision for themselves. The beauty of this type of support is that it isn't "one size fits all", nor is it limited to one type of technology. A person-centered assessment will be the first step in determining what options may lead to a person's desired outcomes. A detailed and comprehensive technology support plan will be developed and included in a person's individualized support plan.

We will be evaluating throughout the process whether the person is satisfied with the technology supports they chose, if the outcomes identified by the person are being met by the use of remote supports, and if necessary, what needs to be modified or added to achieve those goals.

DIDD has regional tech staff designated to interface with both providers and families to answer questions and address any concerns that might arise. A Technology Advisory Council, which includes representation from the Council on Developmental Disabilities, has been meeting to ensure all stakeholder voices and views are considered as we gear up to start the test project.

This is an exciting time for people supported by DIDD. We are now at the point where we can modernize the way we provide high-quality, person-centered supports. We believe enabling technology is a key component to allowing people to achieve their employment and community living goals, and are excited to start this program and find ways to blaze new trails in offering progressive supports with technology.



Carla Gipson and sister, Tara Tate



Jonathan McGee with his mom, Kathy

Partners 2017-18 Class Graduates

by Ned Andrew Solomon, Council Editor-in-Chief of Breaking Ground

On April 14, 28 individuals graduated from the 2017-18 Partners in Policymaking™ Leadership Institute. It was the most geographically diverse class ever, with nine participants from West, Tennessee, nine from Middle and ten from East, some traveling from typically underrepresented cities and towns like Ooltewah, Lakeland, Paris, Maryville, Tullahoma, Munford, Charlotte and Hixson.

While other states have struggled to keep their Partners programs funded or alive with interest, the Tennessee program has continued to grow, thanks to the ongoing support of the Tennessee Council on Developmental Disabilities, and the positive word of mouth of those who have completed the intensive seven-weekend training,

with informative and thought-provoking sessions taught by local and national experts in the disability field.

This class is on fire. Before the end of the program, these Partners were establishing relationships with their policymakers and contacting them about legislation they were passionate about; brain-storming about and initiating programs that enhanced social and recreational opportunities, expanded employment and transportation options; and promoted more inclusive and welcoming environments for people with disabilities. Without exception, they moved beyond the personal issues that brought them to Partners, and explored ways to make systems and society more accessible to people of all disabilities and challenging life experiences.

For those interested in applying to Partners, applications are available all year long. Please contact me at 615.532.6556 or ned.solomon@tn.gov, or apply on-line at <https://www.tn.gov/cdd/training-and-news/leadership-training-and-development/partners-in-policymaking.html>.



Deborah Todd and family



Zavion Williams & Family



Chrystal Murphy with her husband, Mike



Zennia Nesmith with her husband, Allen



Cheron Evans and mom, Mary



I am so proud to welcome the following Tennesseans into the Partners graduate network:

Angelica Allsup, Cordova

Carla Bourdeau, Murfreesboro

Emily Bowlan, Arlington

Sheila Carson, Hendersonville

Kristie Clemmons, Jackson

Roddey Coe, Ooltewah

Jennifer Coleman, Paris

Clarisse Durnell, Nashville

Erika Engler, Nashville

Cheron Evans, Collierville

Terri Fought, Lakeland

Tatum Bryan Fowler, Knoxville

Carla Gipson, Memphis

Gloria Huber, Cleveland

Larry Huber, Cleveland

Sadiatou Jallow, Knoxville

Jean-Marie Lawrence, Chattanooga

Jonathan McGee, Maryville

Chrystal Murphy, Chattanooga

Zennia Nesmith, Chattanooga

Tracy Qua, Tullahoma

Bill Radtke, Munford

Christy Ray, Madison

Robin Rogers, Old Hickory

Sara Scott, Hixson

Brenda Stroud, Charlotte

Deborah Todd, Knoxville

Zavion Williams, Memphis



Carla Bourdeau and friends



Angelica Allsup & Ned Andrew Solomon



Kristie Clemmons and family



Erika Engler and mom, Brenda



What Independent Living Is (and is not)

by Paul A. Choquette, MA, Programs Director, Empower TN

When people ask me about my new job at Empower TN, the Center for Independent Living in Middle Tennessee, they almost always say, "is it a nice place to live?" And I say, "well, it's an office with a lot of desks and phones and computers and not very cozy". All kidding aside, Independent Living can mean a lot of things, depending on the context in which it is being used. It can be a thing... it can be a place... it can be an attitude... it can be a service that you get from a provider agency, but at its core it all boils down to one thing: not letting a disability or difference in how we live our life prevent us from making our own life choices.

When I came to Empower TN a few months ago I completed a professional and personal journey that began way back when I was four years old in Rhode Island. I was in a car accident that left me paralyzed from the waist down and reliant on using a wheelchair to get around for the rest of my life. That journey took me through elementary, middle and high school and on to college where I got my Bachelor's degree.

I started working in the field of disability services back in 1993 at a Center for Independent Living in Rhode Island, where I discovered that I could use my own personal experience as a person with a disability to help others who were experiencing what I had experienced in my own life. After a while I decided that I wanted to help even more people on an even larger scale so I got my Master's degree and worked at a rehabilitation hospital and then for Medicaid in Rhode Island where I could help design whole programs to provide services to those people who needed help and support to achieve their goals. That eventually led me here to Tennessee where I worked for TennCare, helping to transform how things are done so that people with disabilities have the same opportunities as everyone else to achieve whatever life goals they may have.

I came to realize that while Medicaid and the services it provides are important to promote and maintain independence, there is more to the picture, so I came back to my personal and professional roots by accepting a position as programs director at Empower TN, one of six federally funded and designated Centers for Independent Living (or CILs) in Tennessee.

Here's where a little history might be helpful. During the process of closing big institutions for persons with disabilities in the 1960s, some people with significant disabilities were released from nursing homes and other institutional settings, enabling many, for the very first time, to live free and independent lives. This created the birth of a community, a culture and a movement.



Paul A. Choquette

This movement came about at the same time other major civil rights movements were taking place. Leaders of the disability community realized that their basic human rights and freedoms might have to be advocated and even fought for too. Although attitudes and services have improved greatly, much remains to be advocated for.

So what is a CIL and what does a CIL do? Well first of all, it is NOT a place to live (that's an assisted living center). A CIL is an organization run and staffed by people with disabilities. In fact, in order to maintain its federal funding and designation, a CIL is required to have more than half of its board of directors and half of its program staff be made up of people with disabilities. Why is that important, you may ask? Well, who knows what a person with a disability is dealing with better than another person with a disability? Learning from other peers with disabilities is a powerful and lasting way of acquiring new information and promoting independence.

The primary role of CILs is to provide five core independent living services, which are; Independent Living Skills Training, Advocacy, Peer Support, Information and Referral, and Transition Assistance, which involves working with individuals who are entering or re-entering the community from an institutional setting, as well as high school students transitioning to adulthood. At Empower TN we also provide additional services to help people with disabilities manage their Social Security disability benefits while returning to work through the Work Incentives Planning and Assistance (WIPA) program, and assist them in preparing for and finding a job through our Employment Network program.

One of the most important things that anyone needs to know about Empower TN and CILs in general is that we don't do things FOR you, we do things WITH you. That means we partner up with you to find out what your goals are and what we can do to help you reach them. We help you figure out what needs to be done to reach your goals and will work with you through the entire process doing as much (or as little) as you need. But don't expect us to do it all - that's what makes us different. You see, as people with disabilities ourselves, we understand how valuable and rewarding doing things for ourselves can be. There is no better feeling in the world than to set a goal for yourself, work hard at it and then accomplish it. That's what independent living is all about.

So if you want to increase your independence in any way - like learning how to use technology to access a computer or iPad if you are blind; knowing how to plan meals, shop and cook your own food; finding affordable accessible housing; or just connecting with a peer who has the same things happening in their life as you do so you can bounce ideas off of each other, CILs like Empower TN are the place to go.

For more information about Empower TN check out our website www.empowertn.org. If you live outside of the metro Nashville area and you want to find the CIL closest to you, visit the Statewide Independent Living Council's website at www.silctn.org/centers.

Partners 2018 Annual Reunion Conference

by **Ned Andrew Solomon, Director of Partners, Council on Developmental Disabilities**

It was a beautiful March weekend, as more than 130 folks gathered at the Franklin Cool Springs Marriott for the 2018 Partners Annual Reunion Conference. With the 2017-18 Partners class (see Partners graduation article in this issue) serving as "hosts" for this event, attendees listened to a keynote by Derrick Dufresne about believing in yourself and not taking "no" for an answer; breakout sessions by Derrick (making a difference) and Partners grads, Jen Vogus (photography as a communication tool) and Brandi Brown (successful employment at UPS); a legislative overview and update by the Council's Director of Public Policy, Lauren Percy and Executive Director Wanda Willis; a panel discussion on the Employment and Community First CHOICES (ECF) program; and an inspiring closing keynote about disability pride by Erica Powell.

We were also lucky to have Karen Mevis, Partners grad and Information & Referral Coordinator at Tennessee Disability Pathfinder, who conducted one-on-one scheduled meetings with individuals who sought help finding needed services and resources.

There was ample time for networking with new friends and old, and even dancing to a DJ, which brought people of all ages and abilities out on the floor.



The 2019 Annual Reunion Conference will take place March 15 & 16 at the Franklin Cool Spring Marriott.

If you are a graduate, please save that date! If you are not a Partner yet, then get with the program! But don't just take my word for it – read what the Reunion attendees had to say:

"There are times as a disabled person I am home making phone calls and writing letters and it feel like I am the only one doing anything. Then I come to Partners and it feels like a family reunion. I'm reminded I'm not alone."

"I always look forward to the Reunion as a means to reconnect with fellow self-advocates and recharge my advocacy batteries."

"I had become very frustrated with my own community and lack of progress on disability access, services, rights. This Reunion has been very motivational and I feel a renewed sense of purpose and energy. I am more motivated now to go back home and get back to work."

Martin McGrath: *An independent living story*

by Deana Claiborne, Executive Director, United Cerebral Palsy of Middle Tennessee

At the March 22, 2018 meeting of the Board of Directors of United Cerebral Palsy of Middle Tennessee (UCP), long time UCP volunteer Martin McGrath was presented with a genuine surprise. On that day, in front of Martin's extended family members who had gathered at the UCP office for a celebratory luncheon, the Board of Directors established "The Martin McGrath Fund," a perpetual endowment, named in Martin's honor.

The fund was created through a \$200,000 contribution from William Millard Choate of Atlanta, Georgia through the Choate Family Fund at the Community Foundation for Atlanta.

Martin has known Millard Choate since childhood. "He is connected to my family by marriage, and even though Millard is not my blood relative, that's how we think of each other," said Martin.

According to Choate, "Martin McGrath has been a pivotal influence in my life. He is a man of compassion and intelligence, and I admire his positive outlook on life. I appreciate his commitment to do all he has done for UCP. This gift is in the form of a challenge for the community to raise another \$100,000 so the annual distributions from the endowment can make a positive difference for United Cerebral Palsy and the people that Martin cares about so deeply."

When Martin was born in 1950, children with severe cerebral palsy were routinely institutionalized. At 68 years old, Martin doesn't hesitate when he explains why he was never placed in an institution, "I was blessed with a good family. We are caring and loving."

Martin's recognition of his family's love did not shield him from the stark realities of life for people with disabilities growing up in the 1950's and 60's. His mother died when he was only 14 years old. "After that, there was never a time when I didn't worry about where I was going to live," he said. "It has always been on my mind."

After his mother died, Martin shared time between his dad's and his maternal grandparents' home. By the time Martin was 23, his dad had also passed away. "My

grandparents and my uncles told me not to worry; that I would be cared for," recalled Martin. "But that couldn't stop me from worrying."

Martin grew up in Nashville. He attended Calvert School, where he was placed in special education classes. After graduation in June 1971, Martin was presented with a unique opportunity: he and four other young adults with disabilities were invited to participate in a five-day experiment sponsored by George Peabody College for Teachers (now a part of Vanderbilt University). "Looking back," he said, "this five-day excursion led me to the discovery of the most wonderful phrase in our English language, 'being independent.'"

The young adults were provided with a house, but that was it; no way to get up the steps; no one to cook or clean. The group started by figuring out how to acquire lumber and they built a wheelchair ramp. Once they were safely inside, they collaborated on cooking, cleaning and all the other things necessary to run a home.

They fell down (literally) and got back up and started all over again. The group planned their own daily activities; shopping for groceries and even a trout fishing venture. Most importantly, they talked, and talked – sometimes staying up until 2:00 in the morning. "For the first time in my life, I really felt in command of things," said Martin.

These five days led Martin to take on one of the biggest challenges of his life. He became determined to enroll at George Peabody College. This was no small feat, as his high school diploma was a special education degree. He had to convince the Dean of Admission and the Chairman of the Special Education Department that he was capable of performing college-level work. He had to find funding for tuition, and he needed personal assistants to make it possible for him to live in a dormitory and attend classes.

What Martin learned was that he was ready for college, but college was not ready for him. In 1972, there was no Americans with Disabilities Act mandating public accommodations. There were architectural barriers all over campus. He couldn't even access the library



Martin at home

for essential classwork because there were no ramps. His special education coursework had left gaps in his academic preparation, so Martin had to work hard to catch up. Despite this, Martin thrived in his classes, and he discovered to his great delight that he could compete academically with his non-disabled peers.

The higher education barrier he ultimately could not overcome was the need for quality personal assistance. Vocational Rehabilitation Services (VR) had agreed to pay students to assist Martin with activities of daily living. Unfortunately, the students were not always reliable in meeting Martin's needs, sometimes because they had their own activities far from Martin in other areas of the campus; often because they stayed out late and simply failed to show up.

"For the first time in my life, I began to realize that the values of friendship do not always hold things together!" Martin said. "Throughout my life, I had things done for me either out of love or friendship and I did not have to worry about a price tag. My parents had tried to get this same point across to me when I was young, emphasizing that although I might have difficulty in doing things for myself, there would not always be someone around to help."

Due to barriers outside his control, Martin had to leave Peabody before he attained his degree. Despite this, he credits his college experience as one of the most satisfying times in his life. "During my two years at Peabody, I developed and discovered a lot of self-help skills I did not know I had," he said. "In fact, I am more proud of this than I am of my other accomplishments."

Martin returned to live with his grandparents. He didn't let his higher education experience go to waste. In 1978, Martin published a book, "Give Us the Knife, Carving a Lifestyle". By then, Martin had connected with Jackie Page, another adult in the Nashville area who was advocating for independent living options for people with disabilities. They reached out to other people with disabilities, locally and across the nation who were coming to similar conclusions about the need for a disability civil rights movement. In 1990, the combined efforts of Martin, Jackie, and countless other advocates across the country led to the passage of the Americans with Disabilities Act, the nation's first comprehensive civil rights law for people with disabilities.

Martin credits former Nashville Mayor Richard Fulton as being one of the greatest influences in his life. Mayor



Martin McGrath with Mr. and Mrs. William Millard Choate and members of the Board of Directors of United Cerebral Palsy of Middle Tennessee. Left to right (front to back): Shirley Shea, Erik Milam, Mr. and Mrs. Choate, Martin McGrath (seated) Billy Carter, Sherry West, Errol Elshtain, (2nd row) Peter Harmon, Joe Haase, Ken Roth, Wick Ruehling, Jim Catalano, Mike Francisco, Claudia Weber, Andrew Eckstein and Randy Brown.

Fulton was one of the founders of United Cerebral Palsy of Middle Tennessee. Martin served on the Board of UCP, and in 2005, Martin became the President of the Board of Directors, the first President of the UCP board to have a significant lifetime disability.

During his time on the Board of Directors, Martin worked with families at UCP to develop the Durable Medical Equipment Exchange Program, through which thousands of people with all types of disabilities receive essential equipment for independence, mobility and safety. He also worked with UCP to develop the agency's Wheelchair Ramp program, which has, to date, constructed over 2,600 wheelchair ramps onto the homes of people with disabilities throughout Tennessee. In 2006, Martin received Nashville's highest award for volunteerism, the Mary Catherine Strobel Award, for his leadership and public policy advocacy with UCP.

After Martin's grandparents passed away, he lived with his uncles. Subsequently, each of his uncles passed away, one by one. With nowhere else to go, Martin was faced with the very real possibility of having to move into a nursing home. With unflinching persistence, a lot of faith and prayers and characteristic inventiveness, Martin and his extended family members worked out an independent living arrangement through the Tennessee Choices Program. Martin now lives in a private home in northwest Nashville with a roommate.

For more information about UCP and the Martin McGrath Fund, go to <http://www.ucpmidtn.org>



T E N N E S S E E D I S A B I L I T Y

MEGACONFERENCE

Empowerment • Inclusion • Self-determination • Choice

The 2018 Tennessee Disability MegaConference

The Council on Developmental Disabilities is proud to have been a primary sponsor of this annual statewide cross-disability conference since 2003.

May 24 & 25 at the Nashville Airport Marriott
600 Marriott Drive in Nashville

Conference highlights include:

- Nationally-renowned speakers:
Joe MacBeth (National Alliance for Direct Support Professionals)
and Jonathan Martinis (Quality Trust for Individuals with Disabilities & Supported Decision Making Expert)
- Informative and educational sessions
- Interactive workshops and discussions
- Thursday evening entertainment
- Exhibits of disability products and services and self-advocate entrepreneur goods
- Continuing education credits

To register or to find out more information, visit:
www.tndisabilitymegaconference.org or call 615.248.5878

The Council is very proud and pleased to announce that we will be collaborating once again with the Vanderbilt Kennedy Center on Breaking Ground II at the Vanderbilt Kennedy Center. This is an exhibit of original work and reproductions of art and writings by and about Tennesseans with disabilities that are featured in our annual arts issue of Breaking Ground magazine. The works will be displayed through September 2018 at 110 Magnolia Circle, Nashville, TN 37203. Map and directions are available at <https://vkc.mc.vanderbilt.edu/vkc/contact/>. For further information, please contact Laurie Fleming at 615.936.8852 or laurie.fleming@vumc.org.

The 2018 Arts issue featuring these works is available on the Council's website at tn.gov/cdd.

BREAKING GROUND II

at the Vanderbilt Kennedy Center



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

TN Council on Developmental Disabilities

APRIL-SEPTEMBER 2018

Remembering Council Member and Partners Graduate Douglass Hall

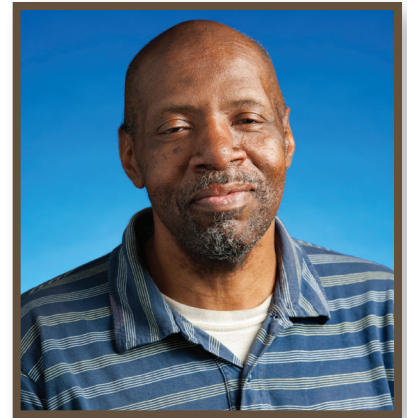
The Council mourns the loss of dedicated Council member and advocate Douglass Hall of Memphis, who passed away in January 2018 at the age of 62. Douglass served as the Memphis Delta Development District representative on the Council since being appointed by Governor Bill Haslam in 2015. He was also a graduate of our 2014-15 Partners in Policymaking™ Leadership Institute and often spoke about what a life-changing experience the Partners program was for him.

Council Partners in Policymaking Director Ned Andrew Solomon shared: "Douglass graduated with the 2014-15 Partners class. He was beloved by his classmates, and, although he was not a man of many words, he could always be counted on to say something incredibly insightful that would perfectly frame a point of discussion. He was always supporting others with disabilities despite his own health and sight limitations. His intelligence, humor and kindness will be missed."

Douglass spent the major part of his scholastic and professional careers in the information technology field after completing extensive IT training at Southwest Tennessee Community

College. He worked as a network and information specialist for Goodwill Homes Head Start, Family Services of the Mid-South and the Childcare Resource and Referral Center. He was an entrepreneur who established two businesses: Byte Size Networking Services and the Memphis Technology LunchBox.

An expert in the use of technology, Douglass had a passion for helping people with disabilities, especially the blind, find those "tools" that would help them succeed. He was also a regular fixture at his local public library where he assisted blind people in accessing the library's resources and services.



Doug Hall with Partners peer and fellow Council member, Karen West

Council Executive Director Wanda Willis shared: "Doug's loss will be felt by all who knew and loved him, and to know him was to love him. He had an uncommon ability to make you feel relaxed and warm, as if you were the most important person in the room. Doug inspired me more than he'll ever know."



New Council Member Craig W. Lemak

Craig Lemak represents the East Tennessee Development District. He is Chief Operations Officer with Knoxville Center of the Deaf, which serves 20 surrounding counties by providing sign language interpreting, information, referrals, advocacy, and job placement services. Craig graduated with a Master of Science in Rehabilitation Counseling with a Deaf and Hard of Hearing focus from the University of Tennessee-Knoxville. Craig has a hearing loss and has been involved in the deafness-related field since 1997. He has served on the Mayor's City of Knoxville's Council on Disabilities Issues (CODI) since 2012.

Tennessee Council on Developmental Disabilities

Davy Crockett Tower, 1st Floor
500 James Robertson Parkway
Nashville, TN 37243

Return service requested

MEMBERSHIP AND STAFF

COUNCIL CHAIRPERSONS

Tecia Puckett Pryor, Chair
Serina Gilbert, Vice Chair

COUNCIL MEMBERS

Amy Allen, Milan
Jody Cheek, Johnson City
Roddey Coe, Ooltewah
Jennifer Coleman, Paris
Ryan Durham, Lawrenceburg
Evan Espey, Antioch
Tatum Fowler, Knoxville
Dawn Fry, Cookeville
Lesley Guilaran, Jackson
Clancey Hopper, Antioch
Lisa Johnson, Greeneville
Jean-Marie Lawrence, Chattanooga
Craig Lemak, Knoxville
William Lovell, Hohenwald
Steven Sheegog, Memphis
Gina Summer, Jackson
Karen West, Gallatin
Martez Williams, Nashville

STATE AGENCY REPRESENTATIVES

Commissioner Debra Payne,
Department of Intellectual and
Developmental Disabilities
Commissioner Candice McQueen,
Department of Education
Assistant Commissioner
Cherrell Campbell-Street,
Department of Human Services,
Vocational Rehabilitation Services
Commissioner Marie Williams,
Department of Mental Health and
Substance Abuse Services
Deputy Commissioner Michael D. Warren, M.D.,
Population Health, Department of Health
Assistant Commissioner Patti Killingsworth,
Bureau of TennCare
Executive Director Linda O'Neal,
Commission on Children and Youth
Executive Director Ralph Perry,
Tennessee Housing Development Agency
Executive Director Jim Shulman,
Commission on Aging and Disability

UNIVERSITY CENTERS FOR EXCELLENCE REPRESENTATIVES

Elise McMillan, J.D., Co-Director,
Vanderbilt Kennedy Center for Excellence
in Developmental Disabilities

Bruce L. Keisling, Ph.D., Associate Director,
Boling Center for
Developmental Disabilities

PROTECTION & ADVOCACY

Lisa Primm, Executive Director,
Disability Rights Tennessee

LOCAL NONGOVERNMENTAL AGENCY

Sarah Kassas, Bilingual Information and
Referral Coordinator, Tennessee Disability
Pathfinder

COUNCIL STAFF

Wanda Willis, Executive Director
Lynette Porter, Deputy Director
JoEllen Fowler, Administrative Assistant
Mildred Sparkman, Administrative Secretary
Alicia Cone, Director of Grant Program
Lauren Percy, Director of Public Policy
Emma Shouse Garton, Director of Communications
Ned Andrew Solomon, Director of Partners in
Policymaking™ Leadership Institute