

# breaking ground

NUMBER 103

AUGUST 2020



## Looking Back, Looking Forward:

### Celebrating 30 Years of the ADA



Council on  
Developmental Disabilities

Dear readers,

Summer has arrived, and we are half-way through one of the strangest years in my memory. Our disability community continues to weather serious challenges as we navigate the new reality COVID-19 has made for us.

Here at the Council, we are focused both on our work to create long-term change and on adapting to the needs of our community during this crisis. On both fronts, we are guided by the goals of our state plan and our unique role as created by the Developmental Disabilities Act.

You'll read about both types of work in this issue of *Breaking Ground*. Council funding is driving big projects for long-term change while also offering relief to families who needed help staying connected and engaged during social distancing. Our impact can be seen in major statewide systems, and also in the lives of individual people whose stress has been eased by the help we could provide.

This issue also celebrates a huge milestone: the 30th anniversary of the Americans with Disabilities Act. As I think about all that has changed in that time, I am in awe. Our community worked together and showed that real change is possible. It gives me hope for what is possible in the next 30 years.

Our friends at the Tennessee Disability Coalition created a campaign that says it very well: we really are "In This Together."



Sincerely,  
Wanda Willis  
Executive Director

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**On the Cover:** Protesters were successful in pushing the federal government to enact Section 504 regulations that paved the way for the Americans with Disabilities Act. Photo by Anthony Tusler

Learn more about the Tennessee Council on Developmental Disabilities.  
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# ABLE Act Turns Five Years Old

By Shelli King, Communications Director, TN Department of Treasury

Tennessee is nearly five years ABLE!

This year marks five years since the passage of Tennessee's Achieving a Better Life Experience (ABLE) Act. ABLE TN was one of the nation's first ABLE plans. It is a program to help people with disabilities save money for qualified expenses. ABLE TN is run by the Tennessee Department of Treasury. It has helped more than 2,100 people with disabilities save nearly \$19 million for the future.

That \$19 million and all future savings may be used, tax-free, for qualified disability expenses. ABLE TN accounts offer tax savings and the power of compounding interest to help Tennesseans with disabilities pay for things that make their lives better.

## Who can open an ABLE account?

All Tennessee residents with a qualifying disability that happened before their 26th birthday can open an ABLE TN account, if one of these things is true:

- I am eligible for Supplemental Security Income (SSI).
- I am eligible for Social Security Disability Insurance (SSDI).
- I have a disability diagnosis from a doctor.

A tool on ABLEtn.gov, called ABLE Assist, can help you know whether you are eligible to open an ABLE account.

## Why should I get an ABLE account?

As many know, people with disabilities who get federal benefits like Medicaid or Supplemental Security

Income (SSI) have limits on how much money and assets (like houses, cars, etc.) they can own and still keep getting those benefits. An ABLE account allows you to save above those resource limits without causing you to lose your federal benefits.

As long as your ABLE TN account balance is less than \$100,000, there is no impact on many federal benefits. If you save more than \$100,000 in your account, that extra amount will be treated as a "resource" under rules for federal benefits.

## How do I use an ABLE account?

ABLE TN makes it easy to put money in your account. You can access your account online, and others can give money to your account. An ABLE TN account can be opened with as little as \$25. It is easy to set up a monthly amount to be added automatically to your ABLE account from another bank account.

Anyone can contribute to your account, as long as they don't give more than \$15,000 over one year. (This amount is set by the federal rules about ABLE accounts.) Friends and family can use easy gift options with Ugift®, which gives you one simple code to share with anyone you want. It never expires and can help loved ones celebrate special milestones by adding gift amounts to your ABLE TN account.

The funds saved in an ABLE TN account can be used to pay for many different qualified expenses, including education, housing, assistive technology, health expenses, and more.

## What if I work?

A new law in 2017 made changes so people can put even more into their ABLE accounts. Called the "ABLE to Work Act," the law allows you to save more than the \$15,000 per year limit if you:

- Have income from a job.
- Don't participate in a retirement plan through work.

If those things are true, you can deposit more funds into your ABLE TN account each year. The extra amount can be up to the federal poverty guidelines for one person – which is \$12,490 for this year. That means that if you have an ABLE account and work, you can save up to \$27,490 in your account this year.

## How is my ABLE money invested?

ABLE TN offers great investment options at a low cost. With 15 investment options to choose from, you can find a plan to best meet your needs. You can choose based on your savings goals, how much risk you want to take with your money, and how soon you need to spend your money. You can also change your investment plan twice per calendar year.

If you have questions or want to learn more, visit our website at ABLEtn.gov. And be sure to tell your friends with disabilities about this great way to save for the future! ■



# Ensuring Clear Communication

## *TEIS Transition Continues*

By Lauren LeGate, Public Information Officer, TN Department of Intellectual and Developmental Disabilities

When the Department of Intellectual and Developmental Disabilities (DIDD) knew that the Tennessee Early Intervention System (TEIS) was coming on board in July\*, one thing was clear: we had to communicate clearly with the TEIS community statewide. All relationships are made better with effective communication. DIDD leaders know that communicating early and often is vital to the success of the TEIS program.

To start, we wanted to hear from the agencies and partners we rely on to deliver services. It's important to us that we work together with our partners and listen carefully to their feedback.

DIDD sent an anonymous external communications survey to the resource agencies, early interventionists, therapists, and other outside community members who deliver services. Using 16 questions and the always useful comment box, we wanted to understand one thing: **How can we best communicate with the group of people who are the backbone of our program?**

We asked questions about how often people use their email, what they thought about the TEIS website and newsletter, and what they wanted to hear more about. Our most important questions centered on what types of communication



work best for them. At DIDD, we want to know the easiest ways to reach our partners if there is an immediate message we need to communicate. We also want to know: when things aren't urgent, what would you look forward to learning more about when it comes to early intervention in Tennessee?

### **What did we learn?**

In our almost 150 responses, we learned a lot about what people like and where improvements can be made. One thing is clear: email remains the most effective way to engage with people. It is easy to check, easy to use, and many of us are checking it hourly.

People who responded also felt that the TEIS newsletter is a great resource for staying connected to the program. Participants felt

### **TEIS: There's an app for that!**

Tennessee Early Intervention System is excited to announce that families, caregivers, and medical professionals can now refer a child to TEIS on the MyTN app. The MyTN app is meant to be a one-stop-shop for Tennesseans to find useful information about government services. Services range from renewing your driver's license to finding your favorite farmer's market. We are hopeful that this new resource will help even more families and children find their way to TEIS and all of the helpful services that are available. To check out the new app and all it has to offer, download it for free in your device's app store.

\*TEIS provides services for children from birth to age three who have disabilities or developmental delays. TEIS moved July 1 to DIDD from its previous home with the Department of Education.

*Continued on page 17*

# Real Lives, Real Help

## *Stories of the Council's COVID-19 Special Grants*

by Jolene Sharp, Chief Public Information Officer, Council on Developmental Disabilities

COVID-19 brought change for all of us. As it began to take hold in Tennessee, the Council quickly realized we would have to adapt to meet changing needs. One way we did this was by redirecting scholarship funds, which are typically used to help with the costs of attending or hosting in-person disability events.

The first thing we did was listen. We talked with our Council members from across the state. We heard the concerns of members of the disability community across the country.

It was clear the disability community was suffering in unique ways. Schedule disruptions are harder on people who have disabilities, especially children. Access to in-person services and other help, like respite for caregivers, is more urgent. Anxiety about exposure to the virus is greater.

The Council responded. In early April, we announced new, one-time scholarship fund grants to help people with disabilities and their families stay connected and engaged during social distancing. Priority would be given to applicants in rural areas. The response was immediate. Applications flooded in. Within a few days, all funds had been awarded.

Following are the stories of a few people who received these special, one-time grants. We think you will be as moved as we were by the

impact the funds have had on the lives of these families from across our state.

### **Keeping Up with Early Education: Tynleigh Sykes**

*Mom Elizabeth Sykes, of Mason, Tenn.:*

We decided to apply for the Council grant because we knew that Tynleigh was going to suffer more than our other two children with the social distancing requirements. Tynleigh's weekly therapy sessions were shut down as they

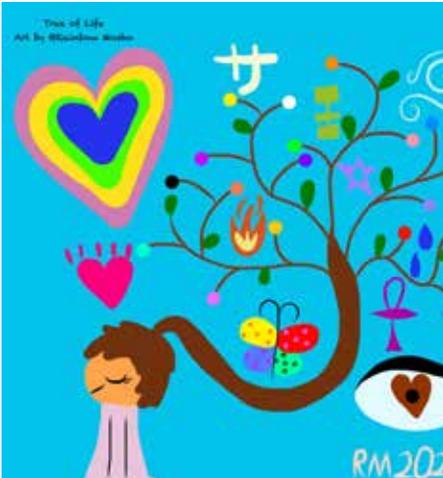
restricted face-to-face visits. We knew the grant would allow us to have another way to carry out her therapy services.

Due to Tynleigh's age, she wasn't in school yet. There really weren't any other programs that could help her out monetarily or with the technology that she was going to require in order to receive teleconference therapy services and doctor appointments.

To say that we were elated and overjoyed once we found out that



*Tynleigh Sykes uses her new iPad for developmental therapy and telehealth services.*



Left: *Tree of Life* - a self-portrait by Rainbow Moshos Center; *Angel in Heaven* - Rainbow Moshos

Tynleigh had received the grant would be an understatement. We knew this was something she truly needed.

Due to the funding and the grant, we were able to purchase an iPad for Tynleigh. This has allowed her to continue her weekly developmental therapy sessions through telehealth. It has truly helped her stay on track in a pivotal developmental period of her life. Where we thought we would see regression, we now have seen continued progress. We cannot express our gratitude enough.

### Using Art to Process Hard Times: *Rainbow Moshos*

*Mom Yadira Calderon, of Lebanon, Tenn.:*

As a parent, knowing there is an opportunity to receive support from an organization that exists to enhance the quality of life of individuals with disabilities, I immediately jumped at the opportunity. It was so timely, as I had just gotten confirmation that my job would no longer need me. We had just found out that school was stopping. We needed to help the family because

my mom was in a terminal stage. It was too many realities at once and knowing financial support was available to build on peace at home was a Godsend.

The school system does not offer supports that address realities of life that go beyond academics. Other programs do not have the funds to acquire goods that build on maintaining a routine at home and that emphasize creativity.

[When I found out we had been approved,] I took a deep breath. I gave thanks to the Creator. A few tears humidified my eyes. I began to plan with my daughter to confirm my instinct. Yes, we would be able to get more markers, paints, canvas, brushes, pay for an online class and two sessions of adaptive exercise classes. None of this would have been possible without the Council grant.

My daughter does not need to ask if we can get additional elements/tools so she can keep creating beautiful art, full of color and emotion. This was especially important during this time when we also cared for her grandma, who passed away. Art was incredibly important



*Rainbow Moshos at work with art supplies purchased through the Council grant*

to facilitate the expression of emotions and concerns. Less than one hour after finding out her grandma was gone, she drew this special piece... *Angel in Heaven*... That says it all...

Also, she created a powerful painting: a self-portrait – called *The Tree of Life*. She drew herself and her hair becomes the tree that holds all her dreams, desires, frustrations, and sources of love. She used a larger canvas, metallic acrylic paint, and markers that were acquired recently, thanks to the grant.

As a parent, I have no greater satisfaction than knowing that my child has an outlet to promote growth and help her become an incredible young lady, whom the world may see as disabled, but her abilities will prove otherwise.

### Continuing School Progress with a Familiar Device: **Beckett Nelson**

*Mom Amanda Nelson, of Pulaski, Tenn.:*

We decided to apply for the Council grant after becoming concerned about our son falling behind in school due to coronavirus closures. Our son, Beckett, has cerebral palsy and is in third grade. He attends a special education class in Pulaski, Tenn. Because we live in a rural area, our school system is not requiring online coursework, but it is encouraged. We did not have any way for Beckett to attend Zoom meetings with his class or access online curriculum without an iPad or tablet. Beckett had previously been using an iPad in his classroom and was making good progress with it. However, our school system



*Beckett Nelson's new iPad allows him to continue his school progress.*

could not provide iPads/tablets to all students while closed.

When we found out we were approved for the grant, we were thrilled! It has been wonderful for Beckett to have a device that he is already familiar with to do his work on. It has also helped us as parents so that we can now access his online curriculum and see exactly what skills he should be working on. This funding has made a huge impact on Beckett in keeping him from regressing during this time. It has provided some normalcy with familiar schoolwork and a sense of togetherness with being able to "meet" virtually with his teachers and friends. We are so grateful!

### Growing through Home Therapy and a Communication App: **Corban Neale**

*Mom Lauren Neale, of Columbia, Tenn.:*

We are so thankful for the opportunity to receive this grant. I decided to apply because many of the toys and tools that are needed for children with autism can be very expensive. Adding that with therapy expenses, costs can be quite high. Because of COVID-19, our in-home therapist wasn't able to come any more, and attending occupational therapy in a clinic was not an option. Therefore, I became a therapist to our son. We started working every day in our sensory/therapy room. The grant helped me furnish his space with toys he can use for his sensory needs and tools to teach him basic skills like writing and naming everyday items.

Corban is not currently enrolled in school, so the grant helped us purchase an iPad for him, which we are using strictly for a communication app. Our hopes are that he can



*Corban Neale, 4, uses a yoga ball to expel energy while completing a task at his table. The grant provided the ball and other equipment to help Corban continue his therapies at home.*

communicate with us via photos, since he is non-verbal right now.

Corban's learning style is hand-over-hand and repetition. We will use all of these tools provided by the grant for weeks, months, and possibly years to come as we practice these skills over and over. I am thrilled that he has the opportunity to communicate with us via the iPad. It will take him a while to be trained to this device, but already he has chosen a few photos to tell us he wanted his sippy cup. The opportunities with that are endless! ■

# Disability Rights Tennessee's Client Assistance Program

By Disability Rights TN staff Tricia Griggs and Becky Allen

Are you a person with a disability getting help with employment from Vocational Rehabilitation (VR)? Are you working with an Independent Living (IL) Center? Have you ever asked your VR counselor for something to help achieve your goals and they said "No"? Do you ever feel confused about what services or help they could give you? Do you have problems with your counselor not calling you back?

If you have answered "YES" to any of these questions and have a problem like this now, you can call Disability Rights Tennessee (DRT) for help. You can talk to an advocate to see how we might be able to assist you. The Client Assistance Program (CAP) at DRT can help you resolve these kinds of problems and many others. Every state has a Client Assistance Program created by the Rehabilitation Act. (That's the federal law that created Vocational Rehabilitation and Independent Living programs.)

The Client Assistance Program provides education, advocacy, and representation to people with disabilities being served by VR and IL programs, if needed. CAP's role is to help people with disabilities using VR and IL programs:

- understand their rights and responsibilities under these programs,
- solve problems and misunderstandings between counselors and customers,
- assist customers with appeal efforts, and
- advocate for appropriate transition services.

Our CAP staff will explain VR policies and federal law. We can give you options to solve the problem you are having with VR. Sometimes, CAP advocates will explain to



you why VR cannot give you the service you want. At other times, the advocate can help you get the services you need to help you find and succeed in the job you want. VR can provide certain services and not others. Your CAP advocate will help you understand the VR program and help you and your counselor get back on the same page. We all disagree sometimes. However, we need to work together so you get the services you need to achieve your job goal.

VR is required to provide their customers with information about CAP, including how to contact us. These are the times when you are working with VR that they must give you this information:

- when you apply for VR services,
- when you are assigned to a priority category,
- when your Individualized Plan for Employment (IPE) is developed, and
- when any of your VR services are suspended, reduced, or ended.

Be sure to read any papers VR gives you at these times and look for our CAP information.

CAP can also help if you have concerns or questions about services from a Center for Independent Living. We can help you understand the core services which all IL programs must provide. CAP can help you in working with IL staff to develop your independent living plan. We can also help if you have been denied services or your case has been closed and you disagree with that decision.

CAP staff mainly help individuals with issues about services from Vocational Rehabilitation or Centers for Independent Living. CAP also assists in other ways:

- Explain employment rights under the Americans with Disabilities Act
- Meet with the VR administration to try to solve common problems for VR customers
- Review VR policies and discuss concerns with VR
- Provide training about CAP services to VR staff and customers

The goal of CAP is to help customers who have problems with IL or VR programs, which also helps make services better for future customers. Contact us if you need help with a current problem at 1-800-342-1660 or [gethelp@disabilityrightstn.org](mailto:gethelp@disabilityrightstn.org) ■



Council on  
Developmental Disabilities

# Looking Back Looking Forward

By Stephanie Brewer Cook,  
ADA Coordinator,  
City of Knoxville

Photography by  
Anthony Tusler

*Celebrating 30 Years of the Americans with Disabilities Act*





**T**hirty years after the Americans with Disabilities Act (ADA) became federal law, how far have we come? It seems so long ago that advocates before us had to chain their wheelchairs together. They did this to force the government to recognize that a lack of accessible public transportation was keeping people with disabilities from leaving their homes (or the institution in which they lived). This meant they were unable to participate in society equally to people without disabilities.

It was even longer ago (1977) that advocates held a lock-in of the federal Health, Education and Welfare (HEW) Building in San Francisco. They wanted to draw attention to a federal law (the Rehabilitation Act of 1973 or "Rehab Act") that banned discrimination against people with disabilities in federally-funded programs. The law

was not being enforced because its regulations had not yet been signed. Some of these advocates "camped in" for almost a month, at the peril of their own health and well-being. Was it a drastic move? Some may say "yes," but it was necessary. Without that selfless, bold act, we would not have seen action on the regulations for including people with disabilities in federal programs.

After the Rehab Act's regulations were finally signed in 1977, advocates turned their focus to the inclusion of people with disabilities in broader ways, beyond just federal programs. In the 1980s, people with disabilities crawled out of their wheelchairs and dragged their

Left: *The Section 504 Sit-In at the federal Health, Education and Welfare (HEW) Building in San Francisco became the longest non-violent take-over of a federal building in U.S. history. Right: Protesters gather inside the HEW Building in 1977. Top: Protesters at UN Plaza outside the HEW Building, April 5, 1977.*





Above: The ADA recognized in law the right of people with disabilities to access their communities. The work continues to fully realize access and belonging for all Americans.

bodies up the U.S. Capitol steps. They demanded that the government pass legislation that would guarantee people with disabilities the opportunity to:

- participate in government,
- visit commercial businesses,
- seek and obtain employment, and
- use public transportation.

On July 26, 1990, the ADA was signed into federal law, giving people with disabilities civil rights protection from discrimination and a promise of a level playing field in all aspects of life.

In 2002, 12 years after we were “guaranteed equality” by the ADA, Americans with disabilities were promised the ability to vote at the location of their choice. The Help America Vote Act (HAVA) gave details on how voting precincts and processes are to be accessible to people with disabilities. HAVA strengthened the collective voice of people with disabilities by making it easier for us to vote.

Three decades after the ADA became a reality, we can agree that we’ve seen some very positive changes. The built environment is more accessible. Cities and

counties are creating pedestrian pathways, changing policies or procedures, and increasing access to their programs. However, we can also agree that we have a good ways to go if we are to experience true, equal access: in employment, education, home and community-based services, appropriate accommodations, access to healthcare, and more.

Knowing that there is work still left to do, how will you encourage change on behalf of people with disabilities? There are many ways that we can continue to advocate for equity and inclusion of people with disabilities. Consider engaging in your community as a person with a disability:

- Volunteer at a favorite charity.
- Visit the local park.
- Sign up for a class with your local parks and recreation department.
- Get nominated for a public advisory body.
- Send an email to an elected official about something that matters to you.

It is my hope that after 30 years, we all have more choices in the ways we advocate for ourselves and other people with disabilities. In my personal and

professional experience, I find many opportunities for people with disabilities to advocate, including:

- Request a meeting with your local government representative.
- Ask about the efforts being made to include more people with disabilities in local programs.
- Go to public meetings and give your thoughts on proposed new developments or policy changes.
- Sign up to speak at public forums.

In other words, be present and get involved!

Today and in the years to come, we must continue to focus on better access to employment, healthcare, civic participation, accessible housing, transportation and pedestrian pathways, public facilities, and online experiences equal to people who do not have disabilities. If we keep educating and advocating, can you imagine where we will be when we celebrate the ADA's 50th anniversary of becoming federal law?

Will we speak up and educate when a public policy or space seems to exclude people with disabilities? Will we work with our lawmakers to change laws that negatively impact people with disabilities? Whatever we do, let's be mindful of the advocates and people with disabilities who will come after us. In 2030, 2040, and 2050, what will they say about the advocates that came before them? The answer to that question lies with each of us.

*Stephanie Brewer Cook is a Partners in Policymaking graduate, former Chair of the TN Council on Developmental Disabilities, UT Knoxville alumnus and the ADA Coordinator for the City of Knoxville.*

*Special thanks to Anthony Tusler, who gave us permission to use his photos of the first day of Section 504 protests in San Francisco, April 5, 1977, and his compelling photos of the modern lives of people with disabilities. ■*

*Below: Musician Gaelynn Lea won NPR's Tiny Desk Contest in 2016 and has since graced the stages of renowned venues like Nashville's Music City Roots, The Kennedy Center, and House of Blues Chicago. As access improves, people with disabilities are slowly achieving greater public representation.*



# Changing Minds and Systems with Council Funds

By Council staff

If you've heard the Council talk about "systems change," you might have wondered what that means. What systems are we changing? How? Why?

The Developmental Disabilities Act created councils and gave us this work of creating positive, long-term change in systems that serve people with disabilities. That might be state government services, or other community systems. The change should give people with disabilities more control and access to live the lives they want for themselves.

Our Tennessee Council state plan says we will create this change by:

- developing leaders,
- improving policies and practice,
- and informing stakeholders (that's people in the disability community).

This year, members of our Council reviewed and approved grants for

new projects that support those state plan goals. Keep reading for more about how each of these projects is creating change for people with lifelong disabilities in our state.

## Developing Leaders:

### *Advocacy through the Arts*

*Disability Arts Access in Rural Tennessee (Partner: Friend's Life Community)*

Friends Life Community, a disability agency, uses the arts (dance, acting, pottery, painting, songwriting, and more) to teach self-advocacy and leadership skills to Tennesseans with intellectual and developmental disabilities. This past year, the Council began funding an expansion of the Advocacy Through the Arts program to allow more adults with disabilities to build confidence and express themselves in new ways.

This new grant will further expand the program, including through videos to share these

## Help Guide Our Work!

**Take the Council Public Input Survey before 9/30/20**

Tell us what's most important to you and what people with disabilities in your community need. Your input and stories will help us write our new five-year state plan that will guide our work from 2022-2026. Our state plan is our road map for how we do the work laid out for us by the Developmental Disabilities Act.

Take the survey at [bit.ly/PublicInput2020](https://bit.ly/PublicInput2020). You can also learn more and find the survey at [www.tn.gov/cdd](http://www.tn.gov/cdd). If you need help filling out the survey, call Council Director of Program Operations Alicia Cone at (615) 253-1105.



*Friends Life Community uses the arts to teach self-advocacy and leadership skills to Tennesseans with intellectual and developmental disabilities.*

remarkable works of art with a wider audience. Funding will also support Friend's Life to create a guide to help other agencies create similar programs. Through this project, art serves as a way for people with intellectual and developmental disabilities to share their gifts and voices with the world.

**Improving Policies and Practice:  
Advancing Best Practices in  
Tennessee for 40+ Years**

The Council has a long history of spurring systems change through training and best practices. That's the unique role of Councils across the country: we can make long-term, system-wide investments and continue them through partnerships. In the 1990s, the Council started Tennessee's "Employment First" efforts. In the early 2000s, we invested in the first person-centered practices training. Tennessee now leads the nation in both those topics, thanks to long-term commitments by the Department of Intellectual and Developmental Disabilities and TennCare.

The Council continues investing in training that will spur systems change. Here are our investments in 2020:

*Mental Health Crisis Training  
(Partner: Department of Intellectual  
and Developmental Disabilities)*

An estimated 40% of people with intellectual disabilities also have a mental health diagnosis. This means the professionals supporting people with intellectual disabilities often end up responding to mental health crises. To help with those needs, the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) is proposing to launch specially-trained crisis teams



*Alison Gauld, Fermina Lopez, Lauren Percy, and Naveh Eldar last year led a person-centered practice training for VR. The Council's new grant will pay for intensive, year-long training for all VR staff.*

across Tennessee. The Council is excited to be partnering with DIDD to provide training by the renowned Center for START Services.

With the Council's funding, the Center for START Services will help develop five regional crisis teams to serve people with dual diagnosis who get services through the Tennessee Department of Intellectual and Developmental Disabilities (DIDD). The crisis teams will include specially trained:

- DIDD staff,
- first responders,
- law enforcement,
- and mental health providers.

With help from the experts at the Center for START Services, the new crisis teams will:

- Plan crisis intervention and prevention.
- Develop emergency and planned respite care options.
- Reach out to people with dual diagnosis and their families.
- Collect data about the teams' work.

*Person-Centered Training:  
Transforming Tennessee's Largest  
Disability Employment System (Partner:  
Department of Human Services)*

Despite the obvious turmoil of 2020, it is an exciting time for Tennessee's Division of Rehabilitation Services. The division oversees the state's largest employment program for people with disabilities, the Vocational Rehabilitation program, or VR. Under the umbrella of VR, there are several specialized programs:

- Pre-Employment Transition Services
- Business Services
- Tennessee Rehabilitation Center located in Smyrna (TRC Smyrna)
- Community Tennessee Rehabilitation Centers located in communities across the state
- Deaf, Deaf-Blind, and Hard of Hearing Services
- Blind and Visually Impaired Services

Under the leadership of Commissioner Danielle Barnes and Assistant Commissioner Mandy Johnson, the

program is undergoing a complete transformation. The goal is to design everything the division does for a better experience for the customer – the person with a disability.

The Council is excited to support this effort by investing in a year-long, nationally recognized person-centered training for ALL division staff, from front-line counselors to top leadership. Everyone will participate

*A Tennessee Center for Decision-Making (Partners: The Arc Tennessee and Disability Rights Tennessee)*

Decision-making is a key issue for people with disabilities who may need help making and expressing decisions. For example, a person might face barriers communicating or understanding information needed to make a decision. The Council strongly supports the right

Importantly, the Center’s staff will offer trainings, information and referral, and one-on-one support to people with disabilities and families.

Disability Rights Tennessee will complement the Center’s work with legal services and first-of-its-kind research in:

- Best practices in conservatorship.
- Data on conservatorships issued in Tennessee.
- Legal expertise and training in decision-making supports for Tennesseans with disabilities.
- Legal help for Tennesseans with disabilities who wish to reverse their conservatorships when they are no longer needed.



*Robyn and James Lampley and Jasmyn Cheatham shared their stories on a panel about supported decision-making at a recent special education conference.*

*First-of-its-kind Upgrade to Tennessee Disability Pathfinder (Partner: Vanderbilt Kennedy Center)*

“I am completely overwhelmed trying to find the disability services I need.” We hear this theme often from our community. To address the issue, the Council helped launch and still funds a program that keeps track of all Tennessee’s disability services and helps people navigate them: Tennessee Disability Pathfinder. Pathfinder was launched in 1997 through a partnership between the Council and the Vanderbilt Kennedy Center. It has connected many thousands of Tennesseans of all ages, types of disabilities, and

in intensive training with nationally recognized employment consultants Griffin Hammis Associates (GHA). GHA is known nationally as an expert in “customized employment,” which matches a person’s skills and dreams with an employer’s unique business needs. This model rejects the idea that there is any person not capable of meaningful employment.

The division will also work with GHA to review and update policies as needed to embody the person-centered philosophy. The change will embed a strengths-based approach that honors every person’s skills and dreams. Together, these changes will build a positive customer experience in every engagement with the division’s programs.

of ALL people with disabilities to make their own decisions, with any help that is needed. The Council has focused for several years on learning about and sharing tools that protect that right even while a person gets help with decision-making (known as “supported decision-making”). The Council is now taking everything we’ve learned, together with partner organizations, and investing in the state’s first Center for Decision-Making.

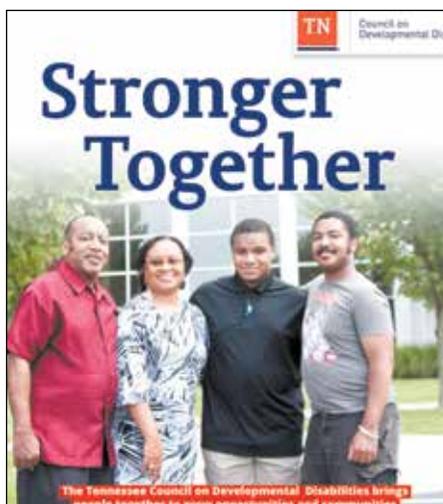
The Arc Tennessee will lead the new Center for Decision-Making, which will offer a website with easy-to-understand information about different options to help people make important life decisions.



spoken languages to the disability services and supports they needed. Tennessee is one of the few states in the nation with anything like it.

Now, the Council is investing in a thorough evaluation of Pathfinder to celebrate what is working well and help us know what needs to improve. The evaluation will also help us know how to keep measuring how we're doing. The evaluation will be led by Dr. Erik Carter, Cornelius Vanderbilt Professor in the Department of Special Education. Members of the disability community will be invited to give feedback through focus groups and Pathfinder user surveys.

"We are excited that we get to work with Dr. Erik Carter, who happens to be one of our nation's premier disability researchers, to capture the incredible value of Pathfinder in Tennessee – and keep improving," said Wanda Willis, Executive Director of the Council.



**Informing Stakeholders:**  
*Rural outreach through community newspapers*

"Stronger Together"  
(Partner: N&R Publications)

Stories help us take in information and shape how we see the world. The Council worked with N&R Publications in 2019 to share our work with rural communities through the personal stories of people with developmental disabilities. The stories were featured in an eight-page newspaper insert that ran in six community newspapers. Two of the stories were developed into hugely popular short videos shared on the Council's social media feeds.

The new grant will expand this project by running the newspaper insert in many more rural counties across Tennessee. It will also fund two new videos. ■

**View our *Stronger Together* newspaper insert online:**  
<https://bit.ly/STinsert>. Follow us on Facebook to see our videos and other updates.

**Ensuring Clear Communication...** *Continued from page 5*

strongly that they wanted to hear more about changes in policies or procedures and learn more about what their colleagues are doing in other parts of the state.

At the end of the two-week survey, it was evident that what is most important is frequent, clear communication with all our partners. It means people are being heard and it validates the hard work they do every day.

**What will change?**

As the transition to DIDD is complete, we are anxious to put what we learned to good use. We are rolling out a new TEIS website

with the same useful information, but with added features and helpful resources. Our newsletter will have a new look and will now be available twice a month. You will also start to hear more about TEIS through DIDD's social media pages and look for us on Twitter at TEIS\_TN!

One thing is certain: you can't build relationships without communication. At DIDD, our mission is to make sure babies and toddlers in Tennessee are reaching their full potential, and we can't do that without strong relationships with our partners across the entire state. ■



# All About IEPs: *Tips from a Specialist*

By Alison Gauld, Low Incidence and Autism Coordinator for Special Populations, TN Department of Education

The Individuals with Disabilities Education Act (IDEA) protects the right of students with disabilities to a free and appropriate education. IDEA makes certain each student gets the education and support they need to be successful adults. One important part of the IDEA law is the individualized educational program, called an "IEP." An IEP plans the education goals for a student with a disability and describes the help the student will get to reach those goals.

The IEP meeting is a time for everyone to talk about your child's strengths and needs and then create a plan together at least once a year. It is important that you attend the meeting, so make sure you let the school know when you're available. Also, share any concerns you have about your child's education with the teacher or principal before the meeting to make sure there is enough time for discussion. You should get a draft of the IEP before the meeting to review if one is created. It will typically be sent to you two days before the meeting. If you need more time to review it, make sure you let the school know.

Preparing notes and thoughts before the meeting can be very helpful. Here are a few questions to help you prepare:

- What are your child's strengths?
- What do they do best?
- What do they most enjoy doing?
- What do you dream for your child's future?
- What will they do for fun?
- What are you most concerned about?
- Is there anything that you think will limit or get in the way of your child's success?
- What worked best for your child this past year?
- What didn't work as well as you hoped or what needs to be changed?
- How does your child feel about school?
- What are the things you hope your child learns this year?
- Were there any changes at home that the school should be aware of?

For students over 13 years old, as the student, family and IEP team begins to think about what life might look like for the student after high school:

- Will they live on their own once they are an adult?
- What will they do as a career?
- What will they do with friends, family, and their neighbors?
- How will they get the training they need for work?
- What help will they need to be independent?

At the meeting, make sure you share your thoughts and participate in the discussion. You are the expert on your child and want them to be successful. The school wants them to be successful, too.

Remembering that everyone has the same goal can help the discussion stay positive even when there are different opinions. Someone should be taking notes at the meeting, but you may find it helpful to take your own notes, as well. You should receive a final version of the IEP with the notes and changes from the meeting.

The IEP is written for a school year, but if you have a concern or feel that there need to be changes during other parts of the year, you can ask for a meeting at any time.

Parenting is hard work, and some days are harder than others. The IEP team meetings can be an opportunity to work with your child's teachers to plan for the hard days and celebrate the good ones together.

*Alison Gauld is Low Incidence and Autism Coordinator for Special Populations for the Tennessee Department of Education. She taught special education for children with low incidence disabilities within the public schools for more than 20 years. At the department, Alison*



Alison Gauld

*has been involved in policy, guidance, and training for IEPs, teaching strategies, behavior, the occupational diploma, the alternate academic diploma, transition, supported decision-making and alternate assessment. Alison's work reflects her strong belief that all students can and will achieve. She has a BA in Special Education and a MA in Educational Leadership from Arizona State University. ■*

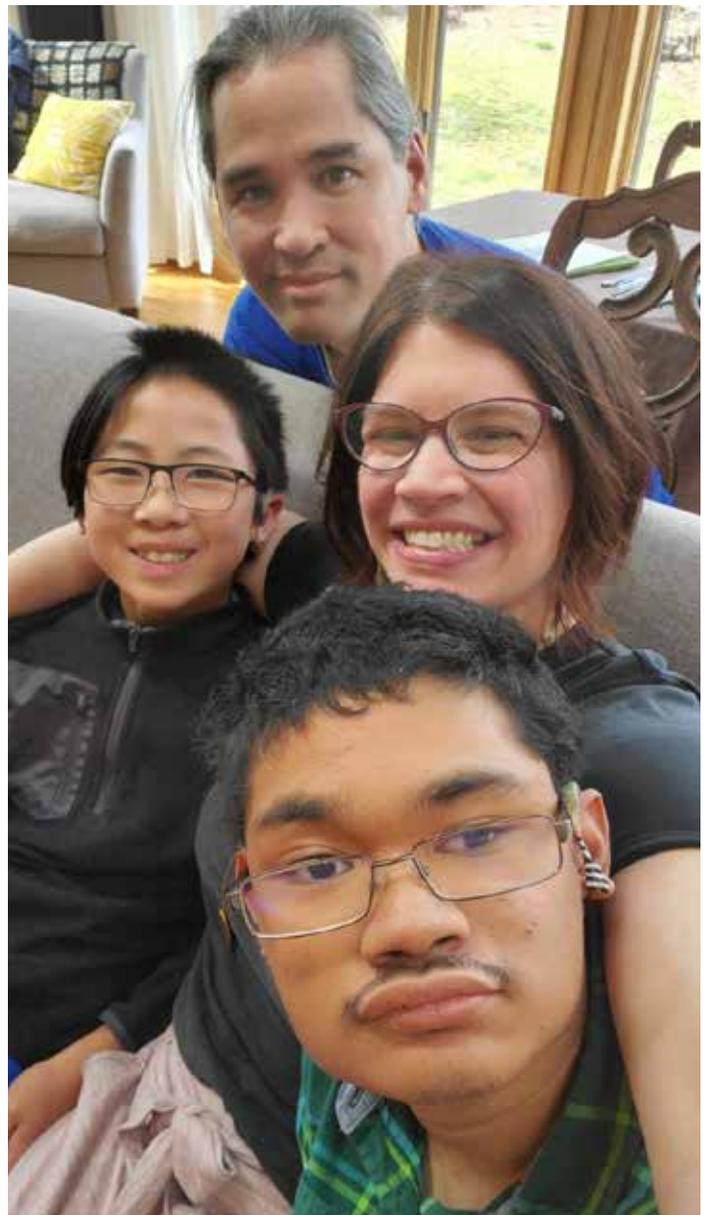
# All About IEPs: *Tips from a Parent and Teacher*

**By Lesley Guilaran, Council Member representing the Southwest TN Development District for the Tennessee Council on Developmental Disabilities**

As a special education teacher and the parent of children who also have IEPs, I have made some observations about what helps to make an IEP meeting successful.

- Make sure that everyone at the table understands from the beginning of the meeting that this meeting is a team effort. Everyone at the table has an equal say and valuable input to give regarding the student.
- A positive attitude can go a long way. Come in with an assumption that the people at the table are there for your child/young adult's benefit and have good intentions. I know that sometimes there are situations that prove difficult. Tensions can be high if you are on opposing sides of an issue. Please, always advocate for your child. However, coming in angry and with your guard up just makes the situation more difficult and more challenging to find solutions.
- Bring your child/young adult with a disability to the meeting! Talk to them about their IEP from a young age. Hopefully, their special education teacher is also doing that, so that they learn from a young age how to advocate for themselves. For some students, I understand that this can be a challenge. However, teaching your child/young adult that they CAN ask for a meeting if they are unhappy about something or see something that needs to be changed is incredibly empowering and valuable to a successful life in the future. Learning to advocate for yourself is an amazing skill! I got to see this happen personally. My oldest son, who has multiple disabilities, asked for a meeting this past year because he wanted something changed. We had the meeting, and he walked through the door signing what he wanted changed! The team was so proud and all agreed that the change needed to be made. That was a powerful moment for him.
- One of my favorite memories from a meeting as a special education teacher was when the parent came into the meeting with a mason jar of flowers she had picked from her yard, and gave them as a "thank you" to me. That simple kindness was such a gift and a mercy to me and I still think about it often.

*Lesley Guilaran lives in Jackson with her husband, Fonsie, and their two young adult sons. Their older son is Deaf-blind and has autism, and their younger son is Deaf. Lesley works as a special education teacher in Jackson-Madison County Schools. Lesley has served on the Council on Developmental Disabilities since her appointment by Governor Haslam in 2016. ■*



*Lesley Guilaran, husband Fonsie, and sons Xiao Yu and Angel*

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