

breaking ground

ISSUE 115



What Happens After I Apply?



Council on
Developmental Disabilities

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breaking ground



COVER: Harrison Pryor poses with his long-time helper, Hannah Culwell. Harrison is enrolled in Employment and Community First CHOICES, which pays for support staff to help him with things like building skills for independence and employment. In this issue, mom Tecia talks about what it was like to apply for the program and shares things she has learned along the way.



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Dear Readers,

Before you dive into the content of this issue of *Breaking Ground*, I want to share news about the staffing structure at our Council. Over the summer, we did a deep dive into our team's strengths and areas of need.

We came out with a new organizational structure and three restructured roles:

- Jolene Sharp has moved from Chief Public Information Officer to Chief Strategy Officer. This broadens Jolene's role beyond communications into helping set the overall strategy for our state plan goal areas, which she has already been doing for several years. All three goal areas (leadership development, public policy, and communications) now report to Jolene.
- Emma (Shouse) Garton has moved from Public Information Specialist to Director of Public Policy. Emma, whose degree is in social work, started at the Council more than 10 years ago as a public policy intern. She has supported public policy behind the scenes ever since. Since early 2023, Emma has been leading our public policy work while maintaining her communications role.
- We will be hiring a new communications support person this fall, which will backfill the role Emma vacates. Stay tuned to our newsletters and social media for more information.

I am so proud of our team for maintaining our work while we've been short staffed. On a small team, that takes 110% from all of us. You can read more about all of our staff on our website (<https://www.tn.gov/cdd/who-we-are/council-staff.html>). We are excited for what this new chapter will bring!

Now, dive into the program updates we have for you in the following pages. We chose these highlights from the topics that have bubbled up the most for us in the past quarter. Let us know what you think: Tnddc@tn.gov.

Happy reading,

Lauren Pearcy
Executive Director

Check This Out! Clinical Consultation Network

The Clinical Consultation Network (CCN) is a weekly learning opportunity led by our partners at the Tennessee Department of Intellectual and Developmental Disabilities (DIDD). Dr. Bruce Davis, DIDD Deputy Commissioner of Clinical Services, hosts the CCN and members of the DIDD Clinical Services Division staff serve as co-hosts.

The CCN meets virtually every Tuesday at 12:30 p.m. CST to discuss topics related to health, behavioral health, and disability. Sometimes meetings focus on sharing an individual "case study" of how different professionals came together to help a person with a disability. Sometimes state or national experts present on research or best practices in the disability field. Meetings are open to the public, recorded, and posted on DIDD's YouTube channel so you can watch past sessions any time. If you are a Tennessean with a disability, family member of people with disabilities, or serve people with disabilities in your job, the CCN is a great way to learn about disability resources and topics!

Learn more, explore the CCN video library, and tune in next Tuesday!

- <https://www.tn.gov/didd/divisions/clinical-services/clinical-consultation-net.html>
- <https://www.tn.gov/didd/divisions/clinical-services/clinical-consultation-net/clinical-consultation-network-faq.html>

CCN SITE



CCN FAQ





What Happens After I Apply?

Stories of what comes next when you apply for Tennessee's disability service programs

Harrison poses with Hannah and her younger brother, Noah Culwell. Hanna recently graduated from college and began her career as a teacher. Noah is under age 18 so not eligible to serve as paid staff through ECF CHOICES. Tecia says she has paid out of pocket for Noah to help out some as she searches for new support staff for Harrison.

You've learned about a disability service program that could help you or a loved one. You're considering or have already applied. But...what next?

People with disabilities and their families tell us this can be a confusing time. They ask questions like:

- What is the enrollment process?
- What will I need to do next?
- How will services really work?
- How will this program help me?
- Who do I talk to if I have a problem or question?

We're setting out to answer some of those questions. In the coming months, we'll be sharing stories of real people who have applied for different disability service programs in Tennessee. They'll share what the process was like, lessons they learned, and how services are working for them.

Have you recently applied for a disability program? We'd love to hear about your experience! Email us at TNDDC@tn.gov.

Tecia and Harrison: An Employment and Community First CHOICES Story

Tecia Puckett Pryor is the former chair of the TN Council on Developmental Disabilities. Her son, Harrison, has autism and is currently in the transition program at DeKalb County High School in Smithville. (Transition

programs help students with disabilities ages 18 – 22 learn skills for employment and independence after graduating from high school.) Tecia recently applied for and enrolled Harrison in Employment and Community First (ECF) CHOICES. ECF CHOICES is Tennessee's program for daily in-home and community supports for people with intellectual and developmental disabilities. (You can learn more here: <https://www.tn.gov/tenncare/long-term-services-supports/employment-and-community-first-choices.html>.) She talked to us about that experience. The interview has been edited for clarity.

Breaking Ground: What did you know about the program before you applied?

Tecia: I knew that ECF provides support for people to be out in the community, preparing for employment, preparing for next steps and more independence. I would have researched and learned about options even if I hadn't been on the Council, but it certainly helped to learn about services while I was on the Council.

What made you decide to apply? What benefits did you hope to get from the program?

For years, we have paid for someone to help us in-home with Harrison, to do educational and social activities. This program would help us by paying for a support person that could build on what we have already been doing but also add helping Harrison with household tasks, independence, and job skills. It gets expensive to

have weekly in-home help, and he is going to require long-term care to some degree. The wages this program pays for direct support staff are very competitive for the part-time job market in Smithville. I felt like with ECF CHOICES, we could attract even more qualified folks to work with him. It's a challenge trying to find the right person.

Tell us about the documentation you needed for the application process. Any tips for gathering and organizing it?

I don't remember needing documentation. I logged onto the website and applied one day after a Council meeting last spring, a year ago. Within a few months, we did a phone interview to set up his care plan. I think they did ask me about medications and information I keep at my fingertips and had saved on my phone, but I didn't need to provide a lot of documentation. It might be helpful to start a "draft" application that you don't actually submit so you can see what the steps are. It was fairly simple to apply. The hard part was getting it launched. That took several months.

What do you wish you'd known beforehand?

I didn't know that there would be a wait to find a provider for the employment part after enrolling. I wasn't anticipating that. It took months to get us set up with Easter Seals [the provider agency managing Harrison's "employment exploration" services that helped him learn about jobs he might want to do in the future].

I have realized that over the years, Harrison's therapists have often helped me! I have always appreciated having somebody to help me think through goals and what we should work on right now. I have realized that I don't really have that anymore, as he's gotten older. Our support coordinator does help, but I miss having a team of people who are helping me work with Harrison and think about what's needed next. I think I can do more with the Charting the LifeCourse tools¹ to help me plan and set goals for where we need to go. I'm realizing I need to do more of that. It's hard to find the time!

What was the biggest help to you during the process?

I have a new support coordinator, and she's really great. Last year, I felt like we were stuck and not moving forward with a previous support coordinator. The person I have now is located near where we live. She came out in person and met with our whole family - my husband, John, Harrison and me - to update his care plan. She is very attentive and helps us work through any questions or problems.

¹ The Charting the LifeCourse tools are free, downloadable worksheets that self-advocates, families and professionals can use to do person-centered planning, setting goals for the future, and brainstorming about needed supports: <https://www.lifecoursetools.com/>.

² Learn more about "enabling technology" and how it can support people with disabilities here: <https://www.tn.gov/didd/for-consumers/enabling-technology.html>.

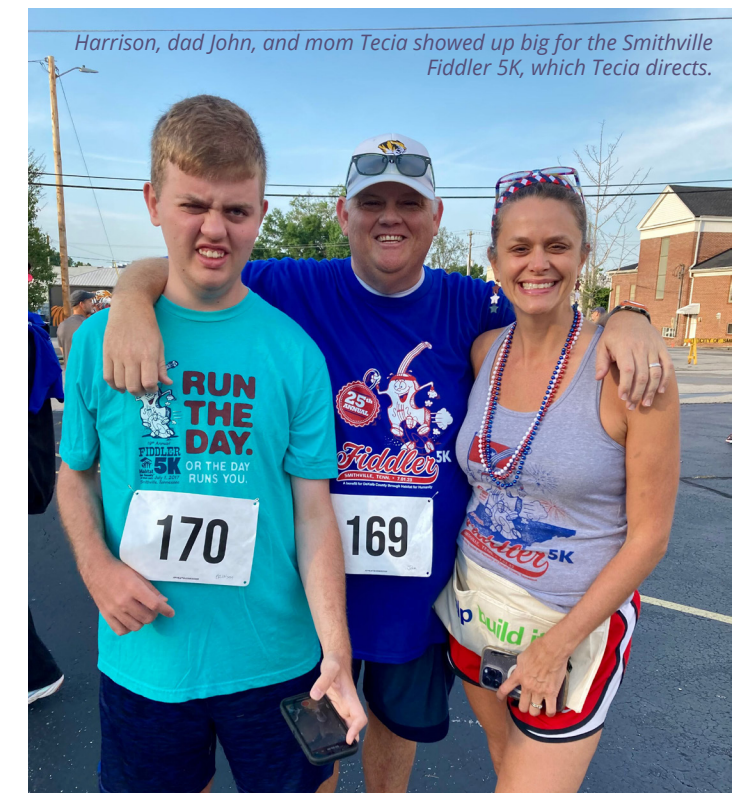
We're actually toying with starting to use some enabling technology² to be able to leave him at home more and work on his independence skills. I just got the proposal yesterday. The support coordinator is helping us think through that.

What advice do you have for other families who are considering applying for ECF or other disability support services?

Just do it! Jump in, apply, and push. Figure out what specific services you want to apply for and follow up. Not everyone will reach out to you.

What was the next step after you were approved to enroll?

Because we opted for consumer direction, which means we hire our own support staff, instead of going through a provider agency, we were assigned a representative through the vendor who was paying for the services - a supports broker. And then we went about getting our direct support staff person qualified. We were lucky that we had a support professional already on board, but she had to provide documentation of her CPR certification, had to do some online training. And then we had to get her approved to be paid. That took a little bit of time. She has now graduated from college and gotten a job as a teacher, so we are looking for someone new. Even if we had someone today, it would take about a month to get them through the process.



Harrison, dad John, and mom Tecia showed up big for the Smithville Fiddler 5K, which Tecia directs.



Harrison Pryor

It took until just this past May to get Harrison's "exploration" employment services going. There was a second wait list after we were enrolled to find a provider agency that could offer those services. I kept calling every few weeks to check on progress. Then they wanted to drive him to job locations an hour away. I said, "No, he's going to work here in Smithville. This is his community." It didn't make sense for him to drive an hour away for just a few hours of job exploration per week. After some discussions, I think we are all on the same page that he needs to explore jobs in his local community.

The new job coach is getting to know Harrison now. It takes some time to learn his way of communicating, what he likes and what he needs. She's also going to observe at school to learn more about him.

Who is your main contact about services now? How do they help coordinate services?

I feel like my support coordinator has got my back. She's trying to work problems out. She's very good. She can direct me if she's not the person to answer my questions.

What makes the services worthwhile? What has been the net benefit for your family?

It has shifted my focus to another level of trying to launch Harrison more into independence and into job skills. That's the main thing. Because we have all these different services we can tap into, it's helping us shift our mindset from just meeting his needs as our son to launching him into young adulthood and this next phase of life.



Tennessee Tech Connect

Tennessee Tech Connect is a new collaborative program between TN Disability Pathfinder (www.tnpathfinder.org) and the TN Department of Intellectual and Developmental Disabilities (DIDD). It was developed to provide information to the disability community about assistive and enabling technology.

This new platform connects Tennesseans with disabilities to technology tools that can help you live a better life. Search for devices, apps and other products that can help with:

- job training
- transportation
- independent living and daily tasks like cleaning, cooking, home safety, and taking medicine
- communication
- and much more!

Explore Tennessee Tech Connect today by using the search options for type of need, stage of life, disability, payment options or other categories.



Role of a support coordinator

If you or your loved one gets disability services³ funded by Medicaid, you will have a person helping you manage those services. Depending on what program you are in, these workers can be called:

- Case managers
- Support coordinators
- Independent support coordinators ("ISCs")

In the simplest terms, a support coordinator (or folks with any of the titles above) work to help you and your support system or family learn about and connect to the resources you need to live a good life in your community.

What does that look like?

It is the job of your support coordinator to ...

- Help you understand what services are available through the program you are in
- Help find providers for those services
- Help you understand your rights and responsibilities
- Help you understand how to hire and pay your own workers to provide support you need if you are participating in "consumer direction" or self-directed services
- Write a plan with you (often called a "person-centered support plan") that explains:
 - Your goals and what is important to you, and for you, to live a good, happy, healthy life
 - What supports, services, and people (paid professionals and possibly also friends/family) you need to support those goals
 - Your strengths, skills, and talents
 - How your disability impacts your life
 - Things about your background and life (like your medical history, doctors, cultural or religious preferences, job goals, how you communicate, different kinds of therapies you've tried, what technology you use, community involvement, etc.)
- Meet with you and your family/support team in person at least once a year to talk about your plan, how you are doing, if you need any more support or different services, how your services are working, and what may need to change to help you live a better life.
- Meet or communicate with you ANY TIME (in person, by phone, or virtually – your choice) to update your plan or talk about problems you're having, new goals or activities you want to try, or new services you need. You can contact your coordinator at any time. You don't have to wait for your annual person-centered planning meeting! You can also ask them for a copy of your plan at any time.

What if I'm having issues with my support coordinator or getting the help I need?

If you're having trouble reaching your support coordinator, hearing back from them in a timely manner, or working with them, you can:

- (For anyone getting services through Katie Beckett, ECF CHOICES, CHOICES or DIDD's 1915c waivers) Contact Disability Rights TN's Beneficiary Supports System
 - Phone Number: 888-723-8193 / 615-298-1080
 - Email: benefitshelp@disabilityrightstn.org
 - DRT BSS Website: <https://www.ltsshelptn.org/>
- (For those who get services through the DIDD 1915c waivers): Reach out to your local DIDD regional office.
 - West: (901) 745-7200
 - Middle: (800) 654-4839
 - East: (888) 531-9876
- (For those who get services through the ECF CHOICES or CHOICES programs): Call the number for your health plan and ask to speak to the director of the program about issues with your support coordinator.
 - Amerigroup: 866-840-4991
 - BlueCare: 888-747-8955
 - United Health Care: 800-690-1606
- For Katie Beckett Part A: BlueCare: 888-747-8955
- For Katie Beckett Part B: your local DIDD regional office (see above)

Still have questions about the role of support coordinators? Let us know at tnadc@tn.gov and we'll do our best to find an answer!

³ "Disability services" funded by Medicaid are often called "long-term services and supports" (LTSS) and "home- and community-based services" (HCBS). In TN, programs that provide these sorts of services for Tennesseans with intellectual, developmental, and physical disabilities include the Katie Beckett program, the Employment and Community First CHOICES program, the CHOICES program, and the "1915c waivers" under the TN Department of Intellectual and Developmental Disabilities which closed in 2016. Read more about all these programs here: <https://www.tn.gov/tenncare/long-term-services-supports.html>.



What's Happening in Tennessee's Independent Living Network?

Catch up with our Statewide Independent Living Council (SILC) and 6 Centers for Independent Living (CILs)

Just like the Developmental Disabilities Act created councils on developmental disabilities like ours in every state and U.S. territory, another federal law for people with disabilities – the Rehabilitation Act of 1973 – created “centers for independent living” and a statewide council for those organizations. The purpose of these centers, often called “CILs,” is to help people with all types of disabilities:

- Find information and community-based services they need
- Connect to peer support from other adults with disabilities
- Advocate at the individual and systems level for better supports
- Get training for living more independently in their community
- Transition towards more independent living, including helping youth transition to adulthood and helping those in institutions (like nursing homes) transition to community living

CILs are designed and led by people with disabilities. Every state also has a statewide independent living council that helps to coordinate the CILs in that state and develop a statewide plan to promote the “independent living” philosophy. This philosophy is rooted in opportunities for people with disabilities to have control over their own lives and services and play important roles in their communities. CILs across the country have played an important role in the disability rights movement.

Funding for CILs under the Rehabilitation Act in Tennessee comes through the TN Department of Human Services' Division of Rehabilitation Services, which also operates the Vocational Rehabilitation (VR) program and many other disability services.

Learn more about the role that CILs play in supporting people with disabilities from this fact sheet from the Administration for Community Living, the federal agency that oversees both councils like ours and programs for independent living like CILs: https://acl.gov/sites/default/files/programs/2023-07/CIL_FactSheet_2023.508.pdf

Learn more about the history of CILs, including the key role they have played in the history of disability rights, from the National Council on Independent Living. (ncil.org)

So – what's new with Tennessee's independent living council and CILs? We asked them to update you on what they're working on and how you can get involved in their work. Keep reading for more from this powerful network in our state.

SCAN TO VISIT NCIL



SCAN TO VIEW CIL FACTSHEET



Statewide Independent Living Council (SILC) www.silctn.org

If you could make sure all members of TN's disability community knew one thing about the SILC, what would it be?

Tennessee's Statewide Independent Living Council works toward ensuring that all people with disabilities have access to community-based services for independent living.

What are some of the skills or strengths that SILC looks for when recruiting board members? If someone wants to get involved with the SILC, what should they do?

The Governor appoints 12 members to serve on the SILC, whose mission is to improve the lives of people with disabilities. By law, a majority of the SILC's volunteer council members must be people with disabilities, and their membership reflects a cross-section of the independent living movement in Tennessee. Members of the Council serve staggered three-year terms. We look for members who:

- Believe strongly in equal access and equal opportunity
- Are committed to the full inclusion of people with disabilities in all aspects of society
- Show honesty, integrity, and respect for others

SILC-TN wants Tennesseans to contribute their knowledge, experience, and contacts to our work. We benefit from the lived experiences of Tennesseans with varying types of disabilities, as well as those who are family members/caregivers of people with disabilities. Other backgrounds that are needed are in areas such as finance, planning, public relations, writing, social media, etc.

For those interested in applying to serve on the SILC, visit www.silctn.org/become-a-member.html, complete the PDF application, and submit your resume.

The SILC recently led a statewide survey as part of developing the next state plan for independent living. How will the results shape the SILC's focus areas for the next few years?

Our biggest priority right now is developing the new State Plan for Independent Living (SPIL) for 2025 through 2027. We hosted community conversations to make sure people with disabilities across the state were engaged in the process. The goal of the SPIL is to ensure that Tennesseans' voices are heard and that accessible

services are helping people enjoy fuller, healthier lives, with greater independence. The SILC-TN will make sure that the goals outlined in the SPIL are met by continuous monitoring and reviewing.



TN's independent living network recently sent representatives to the nation's capital for the annual conference of the National Council on Independent Living (NCIL). The NCIL conference is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. The conference features a variety of influential speakers and educational workshops. It ends with its annual iconic march to the Capitol on the anniversary of the signing of the Americans with Disabilities Act (July 26).



T.A.R.P. Center for Independent Living – Paris, TN
www.tarp1.org

The T.A.R.P. Center for Independent Living is nestled in the rural landscapes of Henry County in northwest Tennessee. (TARP stands for the core functions of CILs: Training of Independent Living Skills and Transition; Advocacy for Individuals and Systems; Referral and Information; and Peer Counseling.) This non-profit organization stands as a beacon of support for people with disabilities, fostering independence and self-sufficiency.

T.A.R.P. is a valuable resource in our rural area, which includes Benton, Dickson, Henry, Houston, Humphreys, Montgomery, Stewart, and Weakley Counties. The scope of this service area spans about 3,900 square miles, housing a total population of 366,745. Notably, within this population, approximately 24%, or 88,019 people, are living with disabilities.

The T.A.R.P. Center's offerings encompass an array of programs designed to enhance various aspects of independent living. That includes the tools all CILs are designed to use: training, advocacy, referral, peer support, and transition.

"Training" is like a school that teaches important life skills. Think about things like cooking, handling money, and taking care of yourself. T.A.R.P. wants everyone to feel confident and capable in these areas.

The next tool is "Advocacy." This means standing up for what you believe in. T.A.R.P. helps people speak up for themselves. They also talk to important people to make sure that rules and laws are fair for everyone.

Have you ever been lost and needed directions? That's what "Referral" is like. T.A.R.P. knows about many helpful resources in the community. They can help you find doctors, job opportunities, and other useful things.

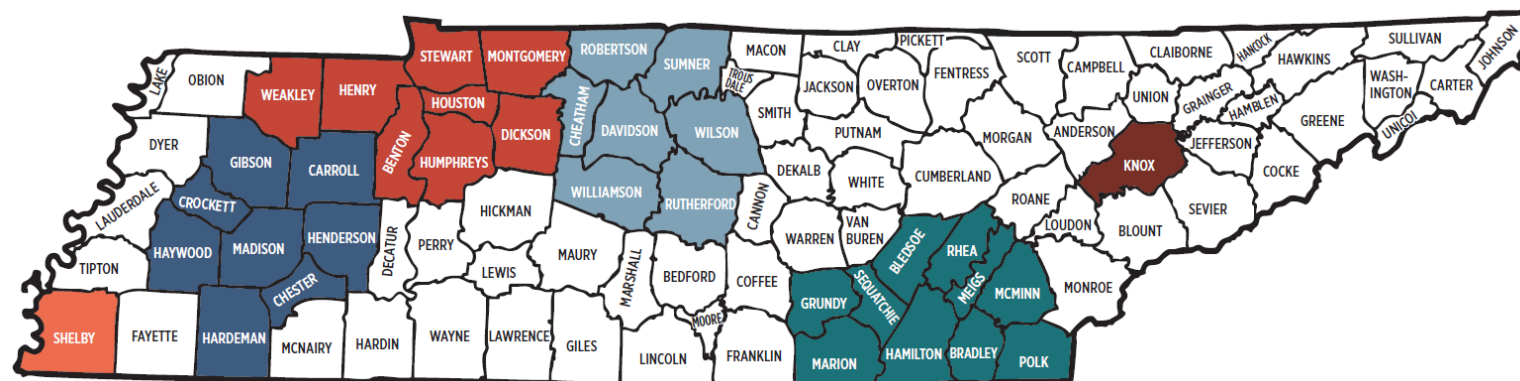
"Peer support" is like having a friend who truly gets what you're going through. T.A.R.P. connects people who have faced similar challenges. They talk and help each other out.

If someone is leaving a nursing home to go back to their own home, T.A.R.P. steps in to make sure it all goes smoothly. This is called "Transition." They also help young people who finish high school figure out what's next. This is called "Youth Transition."

T.A.R.P. administers the Family Support program, funded through the TN Department of Intellectual and Developmental Disabilities, for Benton, Carroll, Gibson, Henry, and Weakley counties. The program provides financial help to people with disabilities and their families for all sorts of disability-related needs.

Another notable service provided by the T.A.R.P. Center is the Durable Medical Equipment Exchange. This initiative addresses a critical gap in healthcare access by offering a loan program for essential medical equipment. With insurance limitations and financial barriers often hindering access to such equipment, we step in to fill this void, relying on public donations, local grants, and state funding whenever available.

The T.A.R.P. Center isn't just an organization; it's a lifeline for countless individuals seeking to lead more independent lives. Through our comprehensive programs and community-driven approach, it serves as a testament to the power of unity and support. Visit <https://www.tarp1.org/> to learn more about our work and get involved.



Jackson Center for Independent Living (JCIL) – Jackson, TN
<https://www.j-cil.com/>

JCIL was established in 1996 for people with disabilities in our area to have access to resources, services, and advocacy. Our programs are designed to provide access, training, encouragement, solutions, and open a wide range of possibilities and freedom of choice. We believe "Independent Living" is a way of life and a way of thinking about life. It is being in control and advocating for yourself.

Early in the pandemic, JCIL recognized the need to keep our community linked and informed. To achieve this, we began a comprehensive program that included distributing 600 iPads, tablets, Chromebooks, and computers with the goal of ensuring digital connection. In addition to providing hardware, we also held training on using Zoom and provided technical support. To encourage "community," we have held monthly events and classes on subjects including:

- voting rights,
- cooking,
- crafts,
- travel,
- book clubs,
- holiday parties,
- budgeting,
- game days,
- and more.



Many of our classes have been in collaboration with T.A.R.P., allowing each center to offer more to our consumers.

JCIL is excited for expanding our American Sign Language (ASL) classes in the community. Through a partnership with the Jackson-Madison County Library, we are offering hybrid ASL classes that are both in person and on Facebook Live. The classes continue to grow and average 30-40 participants a week.

We are proud of our Home Sweet Home program that uses funding from United Way and other sources to provide home modifications that allow Tennesseans with disabilities to stay in their own homes. Last year, we provided more than 200 pieces of durable medical equipment and built 70 ramps. Each item makes a difference in someone's life and choices.

JCIL is always looking for more community participation in our programs. A person can volunteer to work in the office, teach a class, be a board member, pick up/drop off equipment to consumers, or help build a ramp. Visit www.j-cil.com/contact-us.html to reach out!



Disability Connection Midsouth – Memphis, TN
www.disabilitymidsouth.org

Disability Connection Midsouth is the new name for the long-time Memphis Center for Independent Living. For 38 years, people with disabilities have led this non-profit organization.

This agency not only has a new name and logo but also a new home at the First Congregational Church in Cooper-Young at 1000 S Cooper Street. Our entrance is off the back of the church with the blue door and maroon awning.

"The staff is excited about the new name and the move," said Sandi Klink, the Executive Director of Disability Connection Midsouth. "I am excited about rebranding ourselves, the new opportunities for growth, advocacy, peer support, and shared vision for the community."

Since 1985, Disability Connection has been the center of a network of action, information, and resources to assist people with disabilities to conquer barriers, overcome isolation, and end dependency. Today's mission continues the work for full integration of people with disabilities in all aspects of community life.

Disability Connection encourages people with disabilities to work with staff and peers with disabilities to build a new, accessible, welcoming community. While Disability Connection will remain a Center for Independent Living, we have added Midsouth to our name to reflect regional outreach.

Disability Connection has a long history of advocacy for citizens with disabilities and is mostly known for support for accessible transportation, fair housing, and promoting the Americans with Disabilities Act. Disability Connection will work to connect people with disabilities to options other than living in facilities and nursing homes. Disability Connection offers a transition program to assist people to live in their own home rather than an expensive institution.

People with disabilities are a powerful and significant part of our community, yet as a group, our social roles have been marginalized by bigotry, discrimination, poverty, isolation, dependency, and pity. Americans with disabilities have not had access to transportation, housing, and employment that other citizens have enjoyed. Visit our new website at www.disabilitymidsouth.org to get involved and learn about our current work.



Empower Tennessee – Nashville, TN
empowertennessee.org

Empower Tennessee – like all Centers for Independent Living – works on a model of people with disabilities helping one another navigate the various challenges and opportunities life throws at us. In that spirit, we offer multiple opportunities for people with disabilities to get involved, including our Peer Support groups, EmpowerCon webinars, Mental Health First Aid trainings, and other programs and events related to independent living.

During the pandemic, we moved quickly to address folks' feelings of isolation and inability to connect in person by providing opportunities for peer support through virtual meetups and text threads. Those approaches remain popular as transportation and other barriers

continue to make in-person meetings difficult. Our current peer support groups include:

- Empowered Gents
- Empowered Ladies
- Living Your Best Empowered Life
- BLAST, a technology support group for people who are blind or have low vision
- Youth Leadership Academy, and
- the Empowered Rainbow Crew, a therapeutic support group facilitated by a Licensed Clinical Social Worker for LGBTQ+ people with disabilities.

In each of these offerings, clients meet with others to share, learn, and engage with their community. New groups form based on the interests and needs of our clients and community members.

We are fully aware of how emergencies can impact the people we serve, as our offices were destroyed by a tornado in 2020. In response, we host regular meetups for people to learn how to be prepared in an emergency. Clients can join one of our scheduled EmpowerCon Emergency Preparedness events or request a one-on-one planning session to develop their individualized emergency plan.

Through another new program, Empower Tennessee offers access to mental health services and resource navigation for our clients and community. We host discounted Mental Health First Aid training classes for Tennesseans with disabilities, the CIL network, and other people who work with people with disabilities in our state.

Empower Tennessee is also sensitive to the impacts of inflation and increased housing prices in our area. As resources become scarcer, we've redoubled our efforts to provide clients with resource navigation support as they apply for services and find ways to make ends meet.

One of our clients and his mom were unhoused for over 18 months, traveling long distances for doctor appointments, and sleeping in their car most days. During one of our EmpowerCon webinars, they learned about Empower Tennessee's Living Your Best Empowered Life Peer Support group, which teaches participants about housing and employment resources. They began attending the group, building their network, and working with an Independent Living Specialist. Within a year, they received Section 8 funding to help pay for housing and found a beautiful, accessible space for the two of them. In the hopes of making the challenges they experienced easier for others, they have advocated with legislators, advisory councils, local citizens, and organizations to spread awareness about the scarcity of affordable and accessible housing. We welcome members of our community to join us for an event, volunteer with us, and serve on our Board of Directors. Your support empowers others. Visit our website at <https://empowertennessee.org> to learn more and get involved.



Tri-State Resource and Advocacy Corporation (TRAC) – Chattanooga, TN
1trac.net

The Tri-State Resource and Advocacy Corporation was founded 36 years ago and is the second oldest Center for Independent Living in Tennessee, serving the largest number of counties.

TRAC has launched many successful programs, such as:

- Feed the Need, which has provided more than 100,000 pounds of food to consumers. Many people told us that this program meant that they could now spend money on medicine.
- Yearn-2-Learn teaches people to become more independent through identifying each person's learning style and customizing the Independent Living skills classes for them.
- Pair-n-Share is a program that provides people options to share housing costs through locating a roommate. This was launched to address the housing crisis that escalated during the COVID-19 pandemic.

During the COVID-19 pandemic, TRAC maintained a position on the front lines with our consumers, as they requested. TRAC understood the term "essential" included us. We knew that consumers would need heightened services. TRAC's current staff worked evenings and weekends during the pandemic. Our consumers needed us at different times and needed services delivered in different ways than they had before. Our ability to adapt is a poignant example of responding to a crisis without compromising service delivery. It is important to note that increased funding during this time was a critical component. Our consumers worked with a dedicated team of collaborators, staff, and volunteers on the front lines to meet the high demand for services, making this one of our most successful years.



disABILITY Resource Center – Knoxville, TN
drctn.org

The disABILITY Resource Center (dRC) is located in Knoxville, on Cross Park Drive.

In addition to the core services provided by all CILs, we're proud to offer our "Disability Etiquette and Awareness" training to all types of community entities upon request. These presentations include our X-Treme Challenge, where participants learn to play "beep kickball." This is a version of kickball using blindfolds and a ball and bases that audibly beep. Participants also complete a wheelchair obstacle course, play "Simon Says" using sign language only, and learn the basics of utilizing a white cane via our white cane walk. Having people without disabilities participate in our X-Treme Challenge helps attendees realize that people with a diverse range of disabilities can do all types of things, just in a different way. dRC also provides Disability Etiquette and Awareness training to our Knoxville Police Academy recruits, educating them regarding all types of disabilities, person-first language, service animal laws and ethics, etc. We emphasize the Independent Living Philosophy in every service and presentation we provide.

We have strong collaborations throughout our community, including the Mayor's Council on Disability Issues, the Knox County Disability Advisory Council, the Knox Area Employment Consortium, and Knox Area Transit. Through these partnerships, we work to promote physical and programmatic equal access and inclusion. We work to get rid of the attitudinal barriers which people with disabilities confront in numerous areas of our daily lives.

To receive services or volunteer with dRC, you can contact us by calling 865-637-3666 or emailing mshipstad@drctn.org.





Tennessee's Natural Beauty Within Reach

By Tennessee State Parks

From left, Radnor Lake State Park Ranger Dameon Fontenot poses with Kara and Triniti Kelsor.

Tennessee State Parks are known for their breathtaking natural beauty, preserved historic sites, and stunning scenery, attracting millions of visitors each year. However, some people face barriers that may keep them from fully enjoying these special places. To ensure that Tennessee State Parks are accessible to all Tennesseans, the state parks system is striving to identify and eliminate barriers to these public spaces.

"Tennessee State Parks are treasured, cherished places that are kept in the public trust for all Tennesseans," said Tennessee Department of Environment and Conservation Deputy Commissioner Greer Tidwell. "We have been and will continue to improve our parks' accessibility, so our parks are welcoming and inviting for everyone to enjoy the great outdoors."

A key way that Tennessee State Parks is addressing accessibility is by providing all-terrain wheelchairs. These wheelchairs are built to navigate uneven surfaces where those with mobility challenges may have difficulty. All-terrain wheelchairs are available free of charge. Four Tennessee State Parks currently offer all-terrain wheelchairs to use free of charge to visitors:

- Radnor Lake State Park in Davidson County,
- Tims Ford State Park in Franklin County,
- Lamar Alexander Rocky Fork State Park in Unicoi County,
- and Henry Horton State Park in Marshall County.

These chairs were acquired through generous donations from community partners, including:

- the Tennessee State Parks Conservancy,
- the Tennessee Valley Authority,
- the Friends of Radnor Lake,
- The Hays Foundation,
- the Friends of Rocky Fork State Park,
- and the Christopher & Dana Reeve Foundation National Paralysis Resource Center.

Tennessee Gov. Bill Lee, in his 2023 State of the State Address, stated the goal of having the "most accessible park system in the nation." Tennessee State Parks is one of only seven state park systems in the country that provides free entry to visitors. Lee and the Tennessee General Assembly recently appropriated more than \$1.2 million for additional all-terrain wheelchairs to be placed in the state parks system, along with \$1.6 million to make improvements on trail accessibility.

Tennessee State Parks has been in consultation with the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) in its ongoing efforts to make state parks more accessible. DIDD Commissioner Brad Turner, who oversees nearly 2,000 employees and services and supports for approximately 25,000 children and adults with intellectual and developmental disabilities, has already taken advantage of the all-terrain wheelchair offerings with his daughter.



An August 29 event at Radnor Lake State Park celebrated a TVA grant to support accessibility in State Parks. From left are Commissioner Brad Turner, Tennessee Department of Intellectual and Developmental Disabilities; Ann Tidwell, board member, Friends of Radnor Lake and Tennessee State Parks Conservancy; Deputy Commissioner Greer Tidwell, Tennessee Department of Environment and Conservation; Gina Hancock, executive director, Tennessee State Parks Conservancy; Gary Harris, director of government & community relations for the north region, Tennessee Valley Authority.

"My family was able to enjoy the trails at Radnor Lake for the very first time together because of the all-terrain wheelchair," said Turner. "I'm proud of the commitment Tennessee State Parks has made to prioritize inclusion and give all Tennesseans the opportunity to experience the incredible natural beauty within our state's borders."



Former Council member Alison Bynum and daughter Charlotte enjoy the new accessibility of Radnor Lake State Park.

Various parks across the state provide people with disabilities the opportunity for meaningful outdoor experiences in our state parks, including:

- accessible trails,
- colorblind viewers,
- accessible canoe/kayak launches (available at Booker T. Washington State Park in Hamilton County and Meeman-Shelby Forest State Park in Shelby County),
- and more.



"My family was able to enjoy the trails at Radnor Lake for the very first time together because of the all-terrain wheelchair," said DIDD Commissioner Brad Turner, pictured with wife Rebecca and daughter Kinsley.

Tennessee State Parks recently launched a new webpage where citizens can view specific accessibility options: tnstateparks.com/about/accessibility. Tennessee State Parks will update the page as new offerings are made available.

View a 2:26 video about new accessibility features at TN State Parks



About Tennessee State Parks: Tennessee State Parks were established to protect and preserve the unique natural, cultural and historic resources of Tennessee. The public interest is served by promoting stronger communities and healthier citizens through diverse recreation while conserving the natural environment. For more information about accessibility visit: tnstateparks.com.



An Ocean Away, but Not So Far Apart

By Jolene Sharp, Chief Strategy Officer, TN Council on Developmental Disabilities

Children with Down syndrome took to the stage to dance, and the room filled with clapping and celebration.

Eleven years ago, I stood in a dark neonatal intensive care unit (NICU) room. It was the wee hours of the morning, and I had just finished feeding my newborn baby. I was exhausted as only a new mother can be.

I was also grieving. Tears streamed as I lifted my face in prayer.

Lina was born September 13, 2012. Her post-delivery diagnosis of Down syndrome was a shock. She spent 10 days in the NICU learning to feed. It was on one of the very first nights there that I laid my bruised heart open to God.

And then, I felt a response: "I know you're scared. You have longed for purpose. Here it is. Trust me."

In the following years, I have had countless reasons to thank God for the gift of Lina. Her big brother has since received his own set of diagnoses. Both my children are every day becoming more of who they were meant to be. It is my greatest privilege to learn who that is and support them on their path. Through advocacy for my kids, doors have opened in my community and here at the Council to work for belonging and opportunity for so many others. I have found joy in a purpose shared with

a broader community.

Still, I wasn't prepared for the phone call I received earlier this year from friends in Nashville. Their invitation seemed to come out of nowhere: "Would you consider traveling with us to Uganda to share your story with parents of children with disabilities?"

These friends have established ties to a university in central Uganda. They train, mentor, and support students to become leaders in communities across East Africa. Through their local contacts, they learned that two sisters were forming a new disability organization for parents in the area and were looking for support.

I was overwhelmed by the opportunity. What did I really have to offer? Would my experiences here in the U.S. be relevant to families half a world away? Would I be able to bring anything to the situation that would be of lasting value?

I asked a lot of questions. I researched. I prayed. The answer came back in words I'd heard before: "Trust me."

I said yes.

The power of a network

As I began to prepare for my trip, I needed to answer one big question: What disability resources already exist in Uganda?

Working for the Council has taught me the importance of connecting with existing resources. Sustainable support for a new organization would need to include local partnerships wherever possible. I had no idea where to start. I should have known our Council network would deliver.

A member of staff sent me information about a virtual conference for disability organizations in East Africa, which offered a wealth of information. Another contact linked me with the Association of University Centers on Disability, which sent a request to its national network for information about work in East Africa. Through those responses, I connected with leaders at some of the largest disability organizations in Uganda. And through those contacts, I also connected with a parents' organization in the very district I was visiting. The dots were beginning to connect.

New sights, familiar magic

On May 21, I joined four other Americans on a 30-hour journey to Uganda. There is really no way to convey the joy and sensory overload of the week that followed. Anything I say will only be a caricature of the vivid sights and the warm and affectionate people. The food was delicious, heavy on fresh bananas, mango, pineapple, and jackfruit, with Indian influences like rice and chapati. I now crave groundnut (peanut) sauce over rice – a Ugandan staple I haven't yet learned to make at home. The rolling equatorial landscape was high-contrast, lush green against bright red soil. In-town traffic was choked with crowded buses and boda bodas (small motorcycles) weighed down with impossible-looking loads. Everywhere, I saw beautiful children – evidence of Uganda's very young population.

Beyond the pleasures of a new cultural experience, there was work to do. On my second full day in Uganda, I met with the women behind Blessing Maama Uganda Development Association.

I found kindred spirits in Lydia Bantira Kibombo and her sister, Roy Baagala. Grief over the death of Lydia's 1-year-old daughter, Blessing, led Roy to suggest reaching out to other parents of children with Down syndrome – like Blessing. The effort grew beyond the two women's expectations. By the time I arrived, they had connected with dozens of families of children with Down syndrome and other disabilities, all in need of information and support.

Lydia and Roy had invited other important contacts to our meeting. The head of the Down Syndrome Founda-

tion of Uganda was there. So were medical staff at the biggest hospital in the district. Leaders with the district parents' association I had connected with were also there.

As the meeting unfolded, it began to feel familiar. People in the room shared needs and opportunities they were seeing, and themes emerged. Organizations who hadn't known about each other talked about how they might work together.

I realized: this feels like so many meetings I've attended for the Council! An ocean away, the same magic was happening. People across organizations were connecting the dots on shared work toward common goals. The room was full of the power of common purpose.

Joy in disability

The following day, more than 20 families gathered for a Blessing Maama-hosted event. A roster of speakers, including local leaders, addressed the gathering. The leader of the district parents' association shared information about health services for children with disabilities – welcome news for the audience.





A parent event offered a sense of hope and community to families who were gathering together for the first time.

As I sat at the front table, looking out at the crowd, my mind traveled back to that dark NICU room 11 years ago. I couldn't have dreamed that the path from there would lead to East Africa, to a room full of families finding hope and community. When I stood to speak, the message that poured out of me was one of shared purpose – of finding that together, our path forward is one of joy.

Not long after, the stage was crowded with dancing children, the parents videoing and clapping along. Most of these families had never before been together with others who shared their experience. Very few had experienced celebration associated with disability. As I have returned home, this is the moment that has stayed with me – families laughing and clapping together as their children with disabilities danced.

The work continues

In my final days in Uganda, I met with several other key disability contacts. I gave a talk to a roomful of university students about how they can become disability advocates in their own communities, from South Sudan to the Democratic Republic of Congo to Rwanda and Zambia. Since my return, I have stayed in touch with my new contacts, researching resources and working toward continued partnership.

The needs are familiar: a shift in attitudes and expectations, access to education, improved healthcare and support services. As with all work for change, the barriers can feel overwhelming. When I start to feel discouraged, I pull up pictures of children dancing as their parents clap along, and I remember the joy of purpose shared across the miles.

New Resource from TN Disability Coalition: Disability Etiquette Guide

By Hannah Kehrer, Communications Coordinator, Tennessee Disability Coalition



People with disabilities are just like everyone else. We deserve dignity, respect, and the opportunity to be treated equally. But sometimes it can be difficult to know how to interact with people with disabilities if you lack experience.

We get it. Knowing what to say and how to act can be challenging. That's where the Tennessee Disability Coalition's "Disability Etiquette Guide" comes into play.

The goal of TDC's Disability Etiquette Guide is to help equip and empower everyone; whether you're a part of the disability community or not. Don't let the fear of striking out stop you from getting to know us...because people with disabilities are pretty cool!

While our Disability Etiquette Guide is not a comprehensive list of what to do when interacting with people with disabilities, it is a great introduction to our diverse community. Inside, you'll find helpful guidelines to keep in mind as you navigate interactions with people with disabilities in everyday life.

Why are we releasing a Disability Etiquette Guide? The way we speak about, and to, people with disabilities matters. Life for people with disabilities has greatly improved, but some things take longer to change. That includes things like attitudes, perceptions, and the language we use. When folks use outdated language to describe people with disabilities, it can not only be offensive, but also perpetuates old, untrue, and harmful stereotypes.

Every person with a disability has a unique experience. In fact, even people with the same disability have individual needs and experiences. So, with the unique nature of the disability community, and the fact that language is ever-evolving, it would be impossible to cover everything. But everyone has to start somewhere!

Disability is NOT a bad word. Disability is part of our identity, and we are proud to be a part of the disability community. So, take a breath, flip through our guide, and remember that cultivating diversity in your community means including people with disabilities.

Visit our website to access the TDC's Disability Etiquette Guide: <https://www.tndisability.org/materials>

Free help for public schools serving students with disabilities through TN-TAN

The Tennessee Technical Assistance Network (TN-TAN) is a program from the Tennessee Department of Education that offers free help to schools and families to support students with disabilities, ages 3-22. The network provides targeted, intensive supports in the areas of:

- Assistive technology
- Autism
- Intensive behavior issues and supports
- Preschool and early childhood
- Response to Instruction and Intervention (RTI²) for Academics and Behavior
- Coming soon: Family Engagement and High school transition

TN-TAN launched in July 2021. It is part of the Tennessee Department of Education's (TDOE) strategic plan, called Best for All. TN-TAN came out of the department's work to improve the use of Individuals with Disabilities Education Act (IDEA) funds. TDOE wanted to use the funds to increase supports to schools and families for the benefit of students with disabilities across the state.

In addition to direct supports, TN-TAN has a coordination team (managed by the University of Tennessee Center for Literacy, Education and Employment – UT-CLEE) that ensures network partners are working together to best support students, families, and schools. There's

also an evaluation team (managed by the University of Kansas and the University of Kentucky) to measure the effectiveness of the network and its individual partner and network goals.

Data from the most recent quarter indicate that TN-TAN supported 125 school districts across TN through response to referrals, training and consulting between April 1 and July 31, 2023.

Families and schools can learn more and access help at tn-tan.tnedu.gov. On the website, you'll find:

- A "Request Assistance" button
- Details about the services available through TN-TAN
- A calendar of TN-TAN events
- Resources related to the focus areas listed above

To follow the network on social media, follow the TN-TAN on X (Twitter) at @Tennessee_TAN. For general questions, contact TN-TAN@utk.edu.

SCAN TO VISIT THE TN-TAN WEBSITE



Topics inside our Disability Etiquette Guide include:

1. Meeting a person with a disability.
2. Interacting with a person who uses mobility aids like walkers, wheelchairs, etc.
3. Meeting a person with a disability that affects their speech.
4. Communicating with someone who is Deaf or uses an assisted hearing device.
5. Interacting with someone who is neurodivergent.
6. Meeting someone with intellectual and developmental disabilities.
7. Interacting with someone who lives with a mental illness.
8. Engaging with someone who is blind or has a disability that affects vision.
9. Service animals.
10. Making your events and meetings more inclusive for people with disabilities.
11. Using appropriate language.

(EDITOR'S NOTE: If any of the terms above are unfamiliar – read the Coalition's guide to learn more!)



The Tennessee Disability Coalition is an alliance of organizations and individuals across Tennessee who work together to improve the lives of Tennesseans with disabilities.

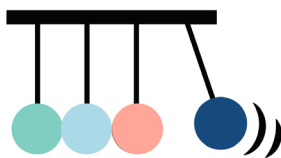
Text TEAMWORK to 72690 to receive Tennessee disability policy updates and alerts sent directly to your phone! Message & Data rates may apply. Avg. 1-4/ message per week.

Hannah Kehrer joined the Tennessee Disability Coalition in October of 2021. In her role, she supports the communications team with outreach, engagement, and storytelling. She's also responsible for TDC's social media presence, video production, and digital content. Hannah previously worked with advocates at the state and federal levels to fight for causes like Medicaid expansion and keeping youth from being criminally tried as adults. She's a fierce, passionate social justice advocate and is excited to work with the TDC to support and empower Tennesseans with disabilities. Hannah is originally from Texas and will be sure to let everyone know! She graduated from Belmont University with a Bachelor of Social Work.

Healthy Behavior Check-In



Council on
Developmental Disabilities



Supporting Well-being for People with Disabilities

Behavior is communication. It can be hard for people with disabilities to say when their needs aren't being met. Sometimes, unmet needs show up through behavior. Sometimes, behavior is a symptom of a medical problem (like a seizure or a urinary tract infection). Supporting well-being for a person with a disability means working to understand what the person's actions and non-verbal cues are telling us they need.

Autonomy & Independence

- Does the person have as much say as possible over their own life? Are they given meaningful choice whenever possible? Are they getting support to understand and make decisions?
- Are supporters and caregivers speaking directly TO the person? Are they paying attention to the person's responses (verbal or non-verbal) and wishes?
- Does the person have space to take reasonable risks and make mistakes?
- Does the person have time to be alone/do their own thing without direct supervision (as developmentally appropriate)?

Need help in this area?
Visit the **TN Center for Decision-Making Support** for information and tools.

Mental health

- Does the person have professional support for mental health? Do other family members/supporters?
- Are there mindfulness or other mental wellness tools that could be helpful?
 - Are there signs that a more complete mental health evaluation is needed?

Physical health

- Is it possible the person is not feeling well?
- Are they experiencing pain they can't explain (for example, a urinary tract infection or dental pain)?
- Are they getting recommended preventive, medical, and dental care?

Medication

- Is medication being taken as prescribed?
- Have medication dosages been checked recently?
- Has a doctor checked for possible interactions between different medications the person is taking?
- Do any of the person's medications have possible negative side effects? Are there other alternatives to try?

Finding the root cause for behavior can sometimes take some real detective work. Learn about a new tool to help people with intellectual/developmental disabilities and their supporters think about the needs behind behavior.

AVISO: Subtítulos disponibles en inglés y español.



SCAN TO VIEW
VIDEO

