

Dear readers,

Every one of us has spent the past several months adjusting to change. That's looked a bit different for each of us. Some of us have weathered the times pretty well. Others have struggled with huge challenges.

This issue of Breaking Ground tells stories of change during a pandemic. What does adjusting to a new reality look like in Tennessee's disability community? There is a strong thread of good news:

- Agencies that serve people with disabilities have pivoted almost overnight to deliver key services remotely.
- Therapists have brought amazing creativity to remote support for our littlest ones.
- Our state's disability information and referral service has become a critical resource for the hard-hit Latino community.
- People with disabilities have used their voices to protect rights that were at risk in new ways.
- Organizations have worked together to address issues we'd never thought of pre-pandemic.

As I read these stories, I find hope. I am reminded that Tennessee has remarkable people working to serve and advocate across state government, at private organizations and non-profits, and in local communities.

People with disabilities have been uniquely affected by COVID-19. Many face extra barriers to getting the support they need during a crisis. These challenges will be with us for a long time. Yet even in the struggle, we prove again that this is a community that truly understands resilience and determination.

Stay safe and of good courage, dear readers.



Sincerely,
Wanda Willis
Executive Director

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On the Cover: Carl's lifelong dream was to have his own trailer home. DIDD's Enabling Technology program gave him tools - like the video doorbell - to stay safe while living on his own.

Learn more about the Tennessee Council on Developmental Disabilities.

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How the Pandemic Changed Pathfinder

By **Angelica Deaton, Statewide Multicultural Outreach Coordinator,**
and **Karen Mevis, Statewide Information and Referral Coordinator for TN Disability Pathfinder**

Tennessee Disability Pathfinder is Tennessee's statewide information and referral service. It was launched by and continues to be funded through the Council. Pathfinder offers a central source where individuals and families can search, find, and connect with the disability services they need.

Disability Pathfinder was not immune to the coronavirus. Big changes came in the wake of the arrival of the COVID-19. Those changes continue today.

Many things about Pathfinder's work shifted to meet the needs of Tennesseans with disabilities, their families, and the professionals serving them. Access to resources and the way we helped people connect to services changed over time. Our Multicultural Program struggled to help people who don't speak English address major health disparities or inequalities. Even our website changed to help people better understand COVID-19 and disability, with new health resources related to the pandemic. Life as we knew it changed. Just one thing did not change: our dedication to helping Tennesseans find resources for persons with disabilities.

Now we:

- Work remotely;
- Post the statewide COVID-19 resources at the top of the Pathfinder website homepage;
- Attend and host virtual meetings, trainings, and conferences;
- Make sure agencies are open before referring to them;
- Help people find COVID-19 test sites so they can go to a homeless shelter;
- Give people information about a resource they need and then help them figure out transportation, if needed;
- Find out if new rules mean people will wait in the parking lot of agencies they need to visit;
- Frequently ask if people have enough food;
- Explain and explore telehealth options;
- Find and give online resources when in-person resources are not available;
- Sometimes assist in translating vital health information for the Spanish-speaking community.



Within Nashville's Latino communities, the pandemic's negative economic impact broadened health disparities for people living with disabilities. Reductions in working hours and job losses hit people and families harder when there is no access to financial help. Additional barriers – like the lack of Spanish language resources and access to health care, working in public service jobs that do not provide health insurance or sick leave, and the fear of asking for help due to concerns about immigration status – result in families being unable to get housing, food, medications, equipment, therapies, treatments, or even COVID-19 testing. Furthermore, some people in these families must choose to go to work even if they are at risk, and even if they have been exposed to the virus, just to have enough money to survive.

Many of the stories we've heard are alarming. Some are heartbreaking. For example, Maria, a Latina mother of three children, including a child who has cerebral palsy, started to have symptoms like joint pain, headaches, and fever. She and other members of her family were uninsured and could not get a test to confirm COVID-19. (At the time, testing was not readily available.) The entire family lived under a fearful cloud of uncertainty, until it got worse. The only child with health insurance—the child with a disability—tested positive.

Maria's story reflects the challenging experiences of Latino families with members who have disabilities – families without access to health care, and without an option to quarantine and prevent the spread. Maria is now considering applying for Supplemental Security Income (SSI) for her child as the only way to provide for him. She knows that this may affect the possibility of becoming a permanent citizen in this country.

In response to the evolving pandemic and the changing, growing needs of Tennesseans, Pathfinder doubled down on its efforts to provide Latinos with more resources. One of the first steps we took was to develop a user-friendly webpage of COVID-19 resources in Spanish. Pathfinder gives all Latinos (with and without disabilities) easy access through Camino Seguro to resources available in Spanish.



In a world of remote meetings, Disability Pathfinder's staff continues the work to help Tennesseans find resources for people with disabilities.

As the practices of masking, social isolation, and self-quarantine stretched further and further into the future, we witnessed quickly increasing numbers of people looking for financial help. They needed new ways to cover essential needs. Our Multicultural Program broadened into areas where there was no one else to help. We helped with interpretation, and when individuals and families met the requirements, helped

with filling out applications for unemployment, Families First, Food Stamps (SNAP), and Family Support, to name a few. When opportunities were found, we referred and connected families in need with community partners.

Social media has been especially important during this time for the Multicultural Program. We share information from official sources in Spanish at our Camino Seguro Facebook page. We share the same information with a closed group for families who include someone with a disability. Families on our mailing list receive emails and text messages when relevant new information about resources and guidelines come out. They also get check-in contact notifications to help us stay in touch. Pathfinder has let Latino families know they can reach out to us with their resource needs.

Some of the most heartbreaking stories involve complex resource needs and requests. Untimely deaths of caregivers from COVID-19, for example, has left some people with disabilities alone, unable to live safely by themselves. When Ann didn't come home from the hospital, her adult son with autism was alone. Without any plans made for the future, his friends and family

Tennessee Disability Pathfinder

Your navigator on the path to community services.

DisabilityPathfinder.org

Helpline: 800-640-4636

Tennessee Disability Pathfinder is a project of the Vanderbilt Kennedy Center and the Tennessee Council on Developmental Disabilities, with additional support from the Tennessee Departments of Education, Health, Intellectual and Developmental Disabilities, and Human Services/Division of Vocational Rehabilitation.

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Growing Independence Through Technology

**By Cara Kumari, Assistant Commissioner of Communications and External Affairs,
TN Department of Intellectual and Developmental Disabilities**

The COVID-19 pandemic has brought challenges to the state, the nation, and the world. That includes changes to how we at the Department of Intellectual and Developmental Disabilities (DIDD) support people with intellectual and developmental disabilities in their homes and communities.

Our priority is to make sure that we support people with disabilities to live the lives they envision for themselves. But we must also balance the health and safety of the people we support. People with intellectual and developmental disabilities often have health conditions

that may put them at a greater risk of having complications from COVID-19. Because of this, in March when the governor declared a state of emergency, we moved to provide homebound services for people who receive Medicaid waiver services through DIDD. This gives people an option to stay home during the days to allow for social distancing and reduce the number of people they come in contact with daily.

However, there are still important supports and services people need, even when they are staying at home. DIDD was in a good position to come up with creative, out-of-the-box solutions to make sure those services could still be delivered in the COVID-19 pandemic.

When DIDD developed its Enabling Technology program two years ago, it was an opportunity to support people's independence goals at home, at work, and in the community. Enabling Technology allows us to use



Carl—who lives on his own with support through Enabling Technology—shows off his "associate of the month" key chain.



Gerald uses an automatic dispenser to help him keep up with his medications.

technology to support a person with disabilities to live as independently as possible.

We didn't know when we started Enabling Technology that it would be key during this state of emergency. The work that was already done and the results we had already seen allowed us to launch into action quickly once the pandemic hit to provide this technology to more people.

Here are some of the ways we did it:

- **Remote Supports and Sensors:** By using remote supports and sensor technology, a person can remain in their home independently, but have access to direct support staff. They do this through a camera or a sensor notification that staff respond to immediately. People can have safe supports and an emergency response through the technology, while limiting the need for in-person staff in their homes. This reduces the chance a person will be exposed to COVID-19 and helps limit spread of the virus through the community.
- **Telehealth:** In the past, people with disabilities were too often sent to emergency rooms for non-emergency reasons. Right now, people who are sick with COVID-19 are using emergency rooms. We want to make sure people with disabilities can get the treatment they need without having to make an unneeded visit to the ER. This is where telehealth can help. Telehealth allows a person to have remote access to a doctor around the clock. Through the use of a company called StationMD, people getting services through DIDD can reach doctors who are trained to treat people with intellectual and developmental disabilities. If a person still needs to see a doctor in person or go to the ER, the telehealth service will help coordinate that.
- **Virtual Services:** Important services called "Exploration" and "Discovery" help people explore jobs in the community. They learn how their skills and abilities might contribute to a job. Before the state of emergency, those services often involved in-person training and visiting different job sites. Now, DIDD is working to develop virtual reality lessons for people with disabilities. The virtual lessons will help them learn about different jobs, provide them with on-the-job scenarios, and help with other skills training. This will provide a private, less stressful environment to learn about work, while also reducing possible exposure to COVID-19.



Technology innovations allow people with limited movement and speech to drive wheelchairs with eye movements and communicate with family, friends, and staff.



Kenny uses technology on his iPad to help him safely use public transportation to get to and from work.

There is no doubt that all of us would like the world to "get back to normal." Many of us miss our extended families, our friends, our group activities, and our daily routines. We are all ready to see this pandemic in the rearview mirror. But in the meantime, we at DIDD still have a charge and a commitment to make sure we are supporting people with high-quality services every day. DIDD believes that some of new methods we've developed during this state of emergency are vital right now and will continue for years to come to give people opportunities to reach their goals and be more independent. ■

Tennessee has a New Crisis Care Policy, Thanks to COVID-19

By Brian D. Keller, Esq., Public Policy and Voting Attorney, Disability Rights TN

One of the many surprising things about the COVID-19 pandemic was learning that many states, including Tennessee, had hospital policies for emergencies that allowed for discriminating against patients with disabilities. This came to light last spring, when hospitals had to prepare for the worst: what to do if there are too many people in the hospital and not enough capacity to care for them. Who would get care, and who would be turned away? Who should get the hospital's limited number of ventilators? Of hospital beds? And so on.

Many states had protocols and guidance in place to address these impossible decisions. In Tennessee, such guidance had been drafted in 2016. Alarming, it included ways to prioritize patients that would allow discrimination against people with disabilities and other conditions. These types of policies are often referred to as "healthcare rationing."

Disability advocates across the country jumped into action. Before the end of March, national disability groups and Tennessee's advocacy community were working together to change the guidance and prevent discrimination during the pandemic. People with disabilities, including Council member Jean-Marie Lawrence (see next page), raised their voices. At least 10 other states filed similar complaints.

By March 28, 2020, Disability Rights Tennessee was working with:

- The Arc Tennessee,
- The Tennessee Disability Coalition and Civil Rights Education and Enforcement Center,
- Epilepsy Foundation of Middle & West Tennessee,
- National Kidney Foundation, and
- National Multiple Sclerosis Society.

The groups worked together to file a complaint with the Office of Civil Rights for the U.S. Department of Health and Human Services (OCR-HHS). The complaint aimed to change Tennessee's guidance. In the complaint,

DRT argued that Tennessee's guidance violated the Americans with Disabilities Act, because it recommended that hospitals discriminate against people with disabilities. We recommended that Tennessee use a "disability-neutral" system to decide who should get care in an emergency. A neutral system would not use disability as a reason to not give medical care to someone.

By June 2020, a resolution was negotiated between DRT, Tennessee, and OCR-HHS that resulted in new guidance for Tennessee that is free of discrimination. In fact, the new guidance is now considered a model for the nation for how to provide healthcare in an emergency.

Tennessee's new guidance includes the following elements to prevent discrimination:

- Uses a "disability neutral approach" to focus on the person's ability to survive the emergency, not their disability, as the main measurement for providing medical care;
- Clarifies that assessment tools used to predict a person's survival must be modified for people with disabilities; and
- Prevents a person's age and life expectancy after treatment from being used to decide who gets life-saving care.

The guidance also includes new language that goes above and beyond the original complaint. It says:

- Hospitals should allow visitors for people with disabilities who need a supporter because of their disability.
- Hospitals must provide effective communication to patients with disabilities during their care.

If you or anyone you know have issues with health-care rationing, visitor policies, or other issues related to COVID-19, contact DRT at 1-800-324-1660 or at GetHelp@DisabilityRightsTN.org.

All new parts of Tennessee's guidance are consistent with national best practice standards and the Americans with Disabilities Act.

The changes to Tennessee's guidance now protect people with disabilities from being treated differently during an emergency. Because of these updates, Tennesseans with disabilities will be afforded equal treatment during a medical crisis in the future. In a strange way, we can thank the pandemic for bringing light to these issues and the opportunity to change them. ■

Visit the Council's COVID-19 resource page for more easy-to-understand information about hospital policies and your medical rights. The page also has tools to help a person with a disability communicate with medical providers.

<http://bit.ly/CouncilCOVIDList>

Knowing My Worth

How I Used My Voice During COVID

By Jean-Marie Lawrence, Council member for the Southeast Development District

I'm an emergency management planner by profession; I prepare as best I can, limit the damage wherever possible, and react based on facts and what I can control. As the COVID-19 virus spread closer and closer to home, I was anxious, but confident in my ability to survive. What I didn't expect was how the pandemic would affect me as an activist, shining a light on civil rights issues many of us did not know existed.

Early in the pandemic, I learned many states had guidance in place in case hospitals had more patients than they could handle in an emergency and had to limit care. Some of this guidance allowed hospitals to deny treatment to people with certain health conditions or disability-related criteria. Tennessee had one

of these documents, written in 2016 by a state Department of Health workgroup.

Alongside other disability advocates in Tennessee, I began speaking out immediately. I channeled my anger into action: I read the document carefully, highlighting the areas that violated my civil rights. I re-read the Americans with

Disabilities Act. I contacted every federal and state representative I had. I made sure other Tennesseans with disabilities were educated and informed about the document and their rights.

The document was soon removed from the state Department of Health website and disavowed

by the current Governor's administration. The U.S. Department of Health and Human Services issued a bulletin that same week, the last week in March, emphasizing that states and hospitals are not allowed to violate civil rights of people with disabilities during a pandemic.

I was able to share my story as part of the Office of Civil Rights complaint filed by Disability Rights Tennessee on this issue.

My actions helped make sure the

rights of people with disabilities and health conditions were protected in our state.

In a time when I felt powerless to be the person I usually am and face conflict in person, head on, I found a way to use my voice. Ignoring what society said my life was worth, I demanded the worth I knew was mine.





Council on
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SKILLED AND ESSENTIAL

Stories of Working during the Pandemic



A global pandemic changed many things, including how we work. While many people with disabilities have faced job loss or shorter hours, others have been able to keep working. We asked several people who are working during the pandemic: What has changed for you? What's been positive? What's been hard? What have you learned?

These are their stories.

James ("Jimmy") Moore

Van Ayer Senior Living and Rehabilitation

I work two days a week at Van Ayer Nursing Home in Martin, Tenn., in the dietary department. I stock all food and supplies: dry and canned food for the pantry, frozen food, and fresh food. My duties include purging rotting produce and out-of-date stock. I also do clean-up in my area – sweeping, wet mop, trash removal.

Since COVID-19, personal protective equipment (PPE) is enforced at all times. We are distancing in dietary as much as possible in a kitchen. We all make maximum effort to keep persons and work areas sanitary.

In my life, I have much less social interaction, shopping, going out to eat, church. I like home but want to get out



Jimmy is tested for COVID at least weekly, and wears his mask during his work shifts.

more. I go to work two days a week and the rest of the time am watching TV or listening to the radio. It has been boring at times, and lack of exercise has made it hard when I have to work. I have enjoyed being around my roommates. We try to make the best of the situation.

I have learned that by working at Van Ayer, I am surrounded by staff and coworkers who truly care about my well-being and the people they serve – all true professionals. The administration follows all safety guidelines to the letter. My SJCS [St. John's Community Services – a provider agency] staff and administrators have done their best in this serious environment to take care of us and keep us safe. We are kept up to date with Relias online training: how to work and be safe at work, how to work and be safe at home. When working at Van Ayer, every time we work, our temperature is taken. A series of questions about our recent activity and contacts is logged. I am tested every Tuesday for COVID-19. It is my thought SJCS and Van Ayer have done a thorough job of keeping clients, consumers, and staff safe.



Clancey Hopper,

*Mid-Cumberland Development District Council member,
United Healthcare*

My job situation changed significantly as COVID-19 spread throughout Tennessee. The Grand Ole Opry, where I worked as a tour guide, was shut down. I came home on March 16 from my job at United Healthcare and started working from home on March 17. I have been working from home ever since then!

My living situation has changed, as well, as a result of the pandemic. I moved out of the home I was living in and now live happily with my family in Lebanon, Tenn. I manage my workflow quite well from home! I am very disciplined in my work and have created a productive work environment for myself. I only work three days a week.



Clancey Hopper has been able to continue her office job remotely.

The things that have been good about this time are being able to spend quality time with my family, a few friends, and rest more! The things that have been hard about this time for me have been dealing with anxiety, missing family and friends, and sadness. I have learned that it's okay not to be okay. This is a strange and scary time we are living in. I have also learned more about self-awareness and how beautiful the breath truly is, and another day of life. The final and most important thing I have learned during this time is I have a greater appreciation and a deeper love for those I love, and time is a precious gift!

L'Mya Muhammad

Blue Cross Blue Shield, Fulfillment Department

As COVID-19 began to spread, I went from part-time to full. There were lots of schedule changes. We were short of staff and supplies. There was more social distancing, and I had to work with a lot of different people. I got to learn new tasks to help cover what was needed.

Things that have been hard are mainly struggling with transportation, since bus routes change and are not running as often. Also, new scheduling of work.

I have learned that I can do more than I thought I could before.



L'Mya moved to a full-time schedule after COVID.



Eric learned new safety procedures before going back to his 11-year career at Publix.

Eric Wilson, with mom Gina Wilson

Publix

Eric: I work at Publix, and I bag groceries and take people out to their cars.

Gina: He's been at Publix for 11 years now, and it has been a growing process. To make sure that he learns all training, I take all classes with him. He can learn anything but maybe not at the pace of the training presentations. We practiced bagging at home for the first year or so and practice any new procedures at home, too, to prepare him for his job.

Eric: After COVID, I have to wear a mask all of the time, and it's irritating. I have to wash my hands more and use hand sanitizer.

Gina: Eric's dad and I decided to pull him from Publix in March, and we kept him home for two months before allowing him to return. We kept in close contact with Publix during that time. At home, we practiced over and over proper hand washing (which he just needed a reminding about how to do) and how to wear the mask, including putting it on and off. We practiced NOT touching our face and speaking louder so that customers could hear him through his mask.

Eric: COVID ruined my golf game, potluck bingo, and vacations. I don't get to see my friends or my grandparents as much. We have to wear masks all the time, and we don't get to go out to eat – my favorite.

Gina: He FaceTimes with grandparents and really misses eating out.

Eric: I mostly work and stay home now. My family likes to walk and bike a lot.

Gina: Typically, he has about one activity a day outside of work, including Special Olympics (power lifting, golf, basketball, football, bowling, skiing, swimming), Faith Friends (a weekly Bible study), social hour at the rec center, and book club. His dad, John, and I have allowed him to return to his photography lessons, since they are now all outside and the teacher is awesome at keeping him safe.

Eric: The hardest part of COVID is not seeing friends and grandparents, no Bible study, and no potluck bingo. I can't go out to eat yet, and I miss that.

Gina: We watch him closely to make sure he's not lonely or getting depressed because of the isolation. We keep him busy, which is best for him.

Eric: One good thing about this time is I've lost some weight from not eating out, and from walking a lot. I spend a lot of time with mom and dad and have time to watch a movie. One thing I have learned is that wearing a mask is not fun, but it helps make COVID go away.

Manases Gonzalez

Blue Cross Blue Shield, Outgoing Mail Department

After COVID-19, my schedule changed. I had earlier shifts because they grouped us into two groups. I



Manases now works longer shifts in the outgoing mail department at Blue Cross Blue Shield.

worked longer hours, waking up earlier. I worried some when others got COVID.

Everyone is wearing masks and keeping social distancing. It has slowed down the spread. This time has not really been hard for me, but for others that were exposed, it was hard.

I have learned that I can keep going, regardless. ■

New TN Center for Decision-Making Support

Introducing Tennessee's new Center for Decision-Making Support: a website, call center, and dedicated team to help Tennesseans with disabilities make an informed choice about the support they need for making decisions about their own life with help from people they trust.

The Center will be Tennessee's first resource dedicated to hosting information about decision-making – from using informal support from friends and family to seeking to petition for or reverse a conservatorship – in one place. The Center's goal is to make that information easy to navigate and understand.

Learn more and contact the Center for Decision-Making Support:

By phone: 615-248-5878 or 800-835-7077 X 322

By email: sd@thearctn.org

Website coming soon!

This project is a collaboration among The Arc Tennessee, Disability Rights Tennessee, and the Council on Developmental Disabilities. The development of the Center has been funded by the Council.



Council on
Developmental Disabilities



What Does Virtual Early Intervention Look Like?

By Lauren LeGate, Public Information Officer (TN Early Intervention System), TN Dept. of Intellectual and Developmental Disabilities (DIDD)

*Tennessee's Early Intervention System (TEIS) provides services for children from birth to age three who have disabilities or developmental delays. On July 1, 2020, TEIS moved to DIDD from its previous home with the Department of Education. Since the pandemic began, TEIS staff and therapists have had to re-think how to safely and effectively serve children and families. That has often involved using teletherapy. Telehealth or teletherapy is a way to provide services and therapies, like early intervention services, remotely via phone or computer. TEIS shared a couple of great success stories with **Breaking Ground** to show how this option is working well for many children and families.*

ARRGGGHHH you loving teletherapy?

We know our coordinators, early interventionists, and therapists are going the extra mile during COVID-19 for the families we serve. At Pediatric Therapies in Franklin, Occupational Therapist Hilary Boucher is captivating the attention of the children she works with by choosing a different theme for each day. For one of her themes, she dressed like a pirate and came up with pirate-themed therapeutic activities. Hilary says the children she works with are responding well and are very engaged. Shiver me timbers, we have some amazing therapists!

Telehealth with an Interpreter

Telehealth visits look different for every family. Sixteen-month-old Sophia visits weekly with her early interventionist, Tiffani Dixon, and her interpreter, Gisella Morales-Cameron. Sophia has been receiving TEIS services for about a year through Emory Valley Center and is continuing to make progress through virtual visits.

Sophia's mom, Elena, says Sophia has been so happy to see familiar faces. During her first teletherapy visit, she smiled, waved, and showed off her new babbling skills. Elena was able to work with the early interventionist to help Sophia sit up independent.



Pirate teletherapy!



On Sophia's first teletherapy visit, she was lying in her crib.



In a later teletherapy photo, Sophia is active and engaged in her therapy visit, showing her great progress.

dently. You can see Sophia's progress in the progression of pictures taken over continuing visits. On her first visit, she is lying down in her crib. In a later visit, she is sitting on her mom's lap, interacting with Tiffani and Gisella.

Elena says that besides the early interventionist and interpreter, Sophia has five siblings who love to be included. Since the early interventionist can't be in their home, she says the children have been very helpful during the telehealth visits, helping Sophia practice different strategies. Whether it's through tele-intervention or face-to-face visits (once they start again), we can't wait to see all of the things Sophia and her family have been working on!

Teletherapy Captures an Unforgettable Moment

Malachi, a toddler who has received TEIS services since May 2019, was born 11 weeks early. That made him automatically eligible for TEIS services. Malachi has been receiving developmental therapy through Support Solutions of the Mid-South. Malachi's mother, Rene, was determined to continue therapy during social distancing because of all the improvement that she was witnessing with her son.

During one of Malachi's teletherapy sessions, Rene was asked what motivated Malachi to stand up. She said, "Elmo videos on TV!" Early Interventionist Kristina Scott asked mom to turn on Elmo to see



Malachi brought tears to his therapists' eyes when he met a major milestone on camera.

if Malachi would stand. When that happened, Malachi took his first steps! Motivated by Elmo, he took three steps, briefly paused, and then took seven more.

It's an emotional moment for any parent, but especially mom, Rene, who has been working with her son for months. It's also a moment early interventionists don't always get to witness, so both Rene and Kristina ended the call with tears in their eyes.

If you or someone you know needs early intervention services, 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. You can download it wherever you access mobile apps. You can also fill out the referral at https://stateoftennessee.formstack.com/forms/teis_referral. ■

TN Commission on Aging and Disability *Meeting Needs in a Pandemic*

By Jim Shulman, Executive Director, Tennessee Commission on Aging and Disability

Tennesseans have witnessed a swift, strong, and kind response to the unprecedented challenge of the pandemic.

Overnight, the Tennessee Commission on Aging and Disability (TCAD) created new programs to serve the state's older citizens. Like a barn raising, it did so with the selfless support of its partners, neighborhoods, and volunteers who showed up with their tools and good cheer to serve those in need.

For instance, a small business support effort linked emergency federal funding with a group of 100 local restaurants in towns across the state. The restaurants needed the business, and thousands of older adults needed the meals.

In a few short weeks, TCAD saw the number of meals provided to older Tennesseans climb from 8,000 a day to more than 14,000.

New policies and trainings, matched with recruiting plans and background screenings, produced a Care Through Conversations program. The program put volunteer callers in touch with people at home alone.

Often those conversations were about the essentials: Do you have enough food? Do you need anything from your doctor? The pharmacy?

Other times, those phone calls were about something equally essential. People missed seeing their friends. Their barbers. Their fellow worshippers.

The phone calls were lifesavers.

And while the TCAD pandemic response heartened thousands, it continues to be a challenge. Federal, state, and local officials work every day to overcome the disease and all of the disruptions and heartache that come with it.

For instance, how should Tennessee reopen its senior citizens centers, closed to keep the coronavirus at bay? Although TCAD does not control the centers' operations, the

questions for advice and guidance continue to arrive.

On behalf of the state's oldest citizens, TCAD is determined to stay at the center of those non-stop conversations — and to get the job done. ■



How the Pandemic Changed Pathfinder... *Continued from page 5*

were left to desperately seek options to help support him – but few options exist. Pathfinder specializes in information and referral, but we sometimes wish we could create the resources that are missing.

Many callers seem to feel better just from talking to a real person. We hear that a lot, and that has not changed at Pathfinder. Callers can still talk to a person on the phone. People who email us asking for help get responses as soon as possible; and people who want to search by themselves on our user-friendly site can. One of our new-

est staff members is continually updating our information and improving our website. We all are still dedicated to giving you the best information and resources we can find – before, during, and after the pandemic.

Pathfinder includes a website with a searchable directory of Tennessee agencies and services and a call center providing information and referral. Learn more at disabilitypathfinder.org/ or call Pathfinder at 1-800-640-4636. Find Spanish-language resources at <https://vkc.vumc.org/vkc/CaminoSeguro/>. ■

Pressing On: *Technology and the Pandemic*

By Jennifer Cunningham, OTR/L, Vice President of Client Services, STAR Center, Inc.

Have you thought about what life would have been like if there had been a worldwide pandemic 20 years ago? Everything would likely have looked very different than it does today. Information from the U.S. Census Bureau reports only about half of homes had a computer just 20 years ago. Even fewer had internet access.

This year, life changed for all of us due to the COVID-19 virus. The increased number of computers in homes allowed work and school to continue as places began to close. Some with disabilities had more difficulty moving to this new way of life. Many students who had access to assistive technology in the classroom or college library were suddenly without those tools. Those who had custom solutions at work began working from home. Still others were suddenly laid off or out of work as businesses tried to figure out how to move forward.

At the STAR Center, we hear stories from our clients with disabilities, assist them through difficulties, and help them look to the future. Meeting people where they are and helping them to move forward during the pandemic has had its challenges. Through technology, we have been able to continue to make a difference for those we serve. The services we provide have not stopped as the pandemic has taken over many parts of our lives. However, the way we provide services has had to change.

Throughout our history, our work with people with disabilities across West and Middle Tennessee has mostly happened in person. Recently, we have had to change the way we do things by using video communication, phone calls, and email to continue to serve those in need. Without these tools and this flexibility, people served by the STAR Center would still be waiting for help, in many cases.

With our new ways of service, lives continue to be changed. The nurse with hearing loss was able to keep treating patients using a stethoscope with a wireless connection to her hearing aids. A teenager with difficulty talking learned to socialize using her communication device and smartphone. The music producer with vision loss received updated technology as he moved to work from home. A college student studying sign language



A display shows some of the technology the STAR Center can provide to help people meet their goals, even during a pandemic.

was provided with a video studio to keep up with his classes. The young child with many medical issues was loaned a simple communication device to use as he works with his speech therapist online. Many other Tennesseans with all types of disabilities were provided daily living aids (e.g. shower chairs, wheelchairs, walkers, and vision aids) to stay independent in their own homes.

The dreams of people with disabilities in West and Middle Tennessee may have changed during the pandemic, but they haven't gone away. With the ability to change, and through the use of technology, we have been able to press on to make a difference for those we serve.

The STAR Center was started by Margaret and Chuck Doumitt in 1988, when their two children began to lose their vision. They looked all over the nation to find solutions for their children. The only resources available were in large cities that were far away. The Doumitt family chose to stay in Jackson, Tenn. They formed a support group of parents and specialists in West Tennessee. In 2019, the STAR Center began providing Assistive Technology services in Middle Tennessee through partnerships with Vocational Rehabilitation Services and the Tennessee Technology Access Program.

The STAR Center's mission is to help any person with any disability to realize their potential. We served over 3,000 clients in 2019. This year we celebrate our 32nd year of standing in the gap for individuals with disabilities. For more information about our services, please visit star-center.org. ■

Supporting Siblings During Challenging Times

By Emma Shouse Garton, Public Information Specialist, TN Council on Developmental Disabilities

Emma Shouse Garton, in addition to her role as Council Public Information Specialist, helps lead TN Adult Brothers and Sisters – “TABS.” She has two younger brothers, Evan and Brendan. Evan has autism and other disabilities.

For most of us, our sibling relationships are our longest-lasting ones. We know our siblings long before we meet our partners or have children. Often, our siblings are in our lives after our parents pass on. For siblings of people with disabilities, these relationships have a lifelong impact. Many siblings eventually take on some level of caregiving for their brother or sister. Some siblings find themselves providing support to aging parents, siblings with disabilities, and their own children – all at once.

For more than a decade, the Council and Vanderbilt Kennedy Center have supported Tennessee Adult Brothers and Sisters (TABS). TABS is a statewide support and information network of siblings of people with different types of disabilities. For many years, TABS hosted conferences for adult siblings. TABS also promoted “Sibshops,” events that offer fun and peer support for siblings ages 8-13.

At TABS events, we hear over and over from participants what a big relief it is to be around other people who “get it.” We’re often meeting people who never knew that a network for siblings of people with disabilities existed. They finally feel like they found people who understand some of the unique joys and challenges of growing up with and supporting a brother or sister (or multiple siblings!) with disabilities. It’s



Emma and Evan share a sweet moment.

also a safe space to tell all the funny stories that can come with growing up as the brother or sister to someone with a disability. (My go-to story is that time a very young Evan yelled out “Kill the beast!” during a solemn prayer at church – a reference to his *Beauty and the Beast* phase!)

TABS had a few activities planned for the spring. Then the pandemic began and turned life upside down. Many siblings were thrown into new support roles for our brothers and sisters with disabilities. Some TABS members moved their sibling into their own home due to worries about the health risks of living with older parents or in group settings. Some members were unable to see their siblings due to provider agency or group home visitor rules. Other siblings were overwhelmed with worry as they were unable to travel to brothers and sisters living many states away.

Many TABS members expressed concern and heartache at how the change in routine led to increased anxiety, depression, loneliness, and behavioral concerns for their siblings. As with all people with disabilities

and family members, we worried about our siblings’ extra health concerns. We wondered what would happen if our brother or sister had to be hospitalized.

We know we can’t “pour from an empty cup.” If we are needed to provide support to our siblings, parents, and our own families, we must take care of ourselves, too. So, TABS decided to begin offering informal virtual meetings every month as a safe place for siblings to gather to comfort and connect with one another, share fears and frustrations about our families and lives, and learn about resources that can help us.

We’ve held meetings monthly since May, and the response has been wonderful. Each meeting has attracted about a dozen or so siblings. Those include familiar faces, folks that TABS had lost touch with

Tennessee Adult Brothers and Sisters (“TABS”) is a statewide network that aims to empower and educate siblings of individuals with all types of disabilities by providing information and peer support. TABS is led and supported by the Council, Vanderbilt Kennedy Center and sibling volunteers across the state. For more information on Tennessee Adult Brothers and Sisters, visit the TABS webpage at <https://vkc.mc.vanderbilt.edu/vkc/tabs/> or follow TABS on Facebook. TABS is the Tennessee state chapter of the national Sibling Leadership Network. Learn more at sibling-leadership.org.

in recent years, and many brand new people we've been delighted to meet and befriend. We're also reaching some younger siblings in their late teens and early twenties, who may feel more comfortable connecting to a new group from the comfort of their home instead of at a conference or meet-up.

Each meeting begins with a presentation or discussion on a specific topic. So far, we've held panel discussions or hosted presentations on:

- Supporting your sibling's health-care and medical needs, and resources for your sibling's doctors iddtoolkit.vkcsites.org/
- Person-centered planning and the Charting the LifeCourse framework and tools lifecoursetools.com/
- Public policy issues related to COVID-19 and disability

- Emotional health, self-care, setting healthy boundaries, and managing family conflict

Then, we go around the virtual "room" and check in with one another. How's your week going? What's been the biggest recent challenge? What's been a bright spot? How can we help? What do you need?

My favorite part of these meetings – and most sibling gatherings in general – is how siblings who are further along in their life journey are eager to give lots of reassurance, wisdom, and advice to younger siblings. The younger siblings are often uncertain about how their role as a sibling to someone with a disability fits into their plan for the future. The siblings who have been supporting and caring for their brother or sister for decades constantly remind these younger

folks that they need to live their own lives and take care of their own wellbeing, in addition to providing love and support to their siblings.

TABS welcomes anyone who identifies as a "sib" or is interested in learning more about sibling issues. We have participants whose siblings have passed away, those whose siblings were born with their disabilities, those whose siblings acquired disabilities later in life, and with a whole spectrum of different needs and diagnoses. We're sometimes joined by "siblings-in-law" (partners of siblings), who often become key supporters of our siblings.

If you are interested in connecting to TABS, you can email emma.shouse@tn.gov or follow TABS on Facebook. Look for ongoing posts with resources for siblings and information about future gatherings. ■

Call for Artwork: *Breaking Ground* 2021 Arts Issue

Did you know the Council creates an annual issue of *Breaking Ground* dedicated to art by and about Tennesseans with disabilities and their families?

If you write short stories, creative essays, or poetry, send us your work! If you paint, sculpt, draw, take photographs, or create other visual art, we want to see what you've made!

Breaking Ground magazine invites Tennesseans with disabilities and their family members to contribute to our 2021 Arts issue. We will consider:

- fiction, creative essays, and poetry up to 1,000 words,
- photos and all other forms of visual artwork.

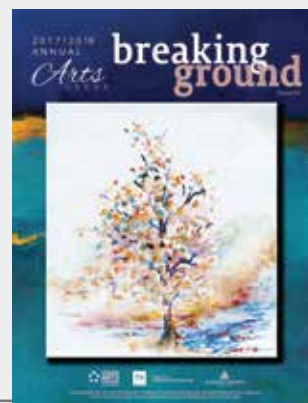
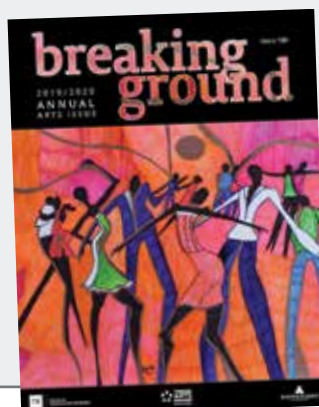
We also welcome stories about arts programs in Tennessee that involve or are led by people with disabilities.

The arts issue will come out in early 2021. If your work is chosen,

your name, a short bio, and the title of the artwork will be featured in the magazine. You will also get copies of the printed magazine to keep and share.

Please include your full name, the best way to contact you, and a one- or two-sentence bio with your submission. Please limit submissions to three (3) per person. Submission deadline is **Dec. 31, 2020**.

Send submissions electronically to tnddc@tn.gov. Questions? Please call (615) 253-8778.



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