

Council on Developmental Disabilities

Dear readers,

Those of us who work in the disability field are talking more than ever about technology. It's not just a trendy topic. Technology has reshaped how all of us connect and move through the world. While that brings challenges, it also offers opportunities. Changes in technology offer the chance for many people with disabilities to take back control and get rid of barriers in their lives.

In this issue of *Breaking Ground*, you'll read about how Rosie Dunn found belonging on social media – and now uses her platform to share disabled joy. You'll also get some practical tips on apps and tools that can support community inclusion and independence. You'll read about a podcast that explores the landscape of disability and points the way toward what's possible.

As technology keeps changing, the Council will keep pushing the conversation about how we can tap its potential for our Tennessee disability community. It's part of a bigger question at the core of our work: **How can we make sure people with disabilities steer their own lives as much as possible, getting the support and services they need for their vision of a good life?**

You'll see that theme in stories about projects the Council helped fund: the new Center for Decision-Making Support, and person-centered training for our state's biggest employment program for people with disabilities. You'll also see it in stories about how our extra funding to the Family Support program helped families during the pandemic.

Happy reading, everyone, and have a safe and healthy fall!



Sincerely,

Wanda Willis

Executive Director



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On the Cover: Rosie enjoys the boardwalk at Oval Beach in Saugatuck, Michigan.

Learn more about the Tennessee Council on Developmental Disabilities.

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How To Use Technology for Connection and Independence

By Evan Espey, Technology and Access Coordinator, Empower Tennessee



It's an obvious truth that the COVID-19 pandemic has changed our lives. The restrictions from most in-person interactions have highlighted the importance of different ways of connecting with the world. That applies to employment, education, or social lives.

Thankfully, technology provides ways to be less isolated and live more independently. Even before the pandemic, many people with disabilities relied on assistive technology (AT) to gain and expand their independence so they can live, work, and participate in their communities.

New ways to think about assistive technology

AT can be anything from very high-tech—such as a special computerized device to help you communicate—to

something as simple as a plastic hook on the end of a yardstick to grab items that are out of reach. AT can be purchased, or it can be a modified item you already own. The purpose is to make tasks, big and small, easier to manage.

Teaching and modeling safe, healthy, and smart ways to use technology to engage with the world and achieve your goals can be an important part of preparing children and young adults with disabilities for adulthood. Learning to use these tools can help young people get ready to live more independently.

Life in the 21st century is high-tech. Devices like smartphones, Amazon Alexa, and Google Assistant have



become common to automate tasks, from turning on the living room lights to ordering groceries. Technology can also be used to set reminders for medical appointments, to take medication, or to remove something cooking in the oven. Technology can be a great equalizer. It can be customized to meet different needs and abilities. The possibilities for using technology in creative ways for access and independence are practically endless.

The pandemic has also reminded us of the importance of internet access. You might connect through cellular hotspots, satellite subscriptions, or broadband access. An internet connection is essential for many of the ways we use technology to access the world. It's how we interact on social media, search for our favorite recipes, and attend all those virtual events. As a society, we should start thinking about internet access as a basic utility, like electricity and water.

Once you have the right equipment and connection, you may need software or apps to improve your independence. Screen readers and voiceover features can be a game changer for people who are blind or have low vision. Captioning empowers the Deaf and people who are hard of hearing. And text-to-speech technology helps those who do not have the ability to speak to express themselves. Smartphones, tablets, and other "smart" devices keep improving the built-in accessibility features for users with all types of disabilities.

These are just a few ways in which technology can help people with disabilities to live a life of their own choice.

Getting Help with Technology Access

So, how do we make sure all people with disabilities have access to the technology they need? Tennessee is fortunate to have two important networks to help.

- The Tennessee Technology Access Program is a network of AT centers around the state. The centers are a program of the Tennessee Department of Human Services' Vocational Rehabilitation Division. These centers can match you with the right technology and train and support you to use it. There are 5 centers that serve every county in Tennessee:
 - · Mid-South Technology Access Center
 - · The STAR Center
 - Signal Centers
 - United Cerebral Palsy of Middle Tennessee
 - SPARK (formerly East TN Technology Access Center)

Find your local AT Center at www.tn.gov/humanservices/ds/ttap.html.

Centers for Independent Living (CILs) are community-based centers focused on a person's goals for independent living. Assistive technology may be one way to help you live independently. That might include learning new ways to use everyday, off-the-shelf technology you already have. A CIL may be able to provide the technology you need, or the CIL might refer you to one of the AT centers already listed.

There are six CILs across the state:

- Tri-State Resource and Advocacy Corp.
- TARP Center for Independent Living
- · Jackson Center for Independent Living
- Empower Tennessee
- · Memphis Center for Independent Living
- disABILITY Resource Center

Contact your local CIL to find out what's available in your area: www.silctn.org/.

I serve as the Technology and Access Coordinator at Empower Tennessee, the Middle Tennessee CIL. We provide a broad range of assistive technology services like:

- Setting goals for living more independently
- Finding and navigating resources
- Getting financial help
- Loaning assistive technology or equipment to support independent living goals

We also offer a monthly Tech Talk Peer-to-Peer Group that currently meets virtually to discuss ways technology can make life easier.

In the face of our "new normal," let's make sure we all can stay connected to our family, friends, and community. It makes a positive difference to our physical, mental, emotional, and spiritual health. Technology can be the key to unlock those opportunities.

Be empowered. ■

Evan Espey joined Empower Tennessee as the Technology and Access Coordinator in 2020. In this role, Evan oversees the Assistive Technology (AT) program and resources to best help consumers reach their maximum independence through the use of AT. A recognized authority, advocate, and resource for Tennessee's community of people with disabilities, Evan brings over a decade of public policy, outreach, fundraising, community relations, and AT experience to Empower Tennessee. Much of this experience was developed during the six years he served on the Tennessee Council on Developmental Disabilities, and from graduating from the Council's Partners in Policymaking Leadership Institute in 2015.

In Practice

By Babs Tierno, Executive Director, Autism Tennessee

Keeping the Peace with Google Home

About five years ago, I received a Google Mini Speaker as a prize at an event I attended. I was unfamiliar with the product, but I'm pretty tech-savvy. So, I took the speaker home and set it up.

That same week, my son had a therapy session. We talked about ways for the two of us to work together instead of against each other.

My son has autism, OCD, and anxiety. That can be an explosive situation when things don't go according to plan. We were noticing that my son often resisted when he felt I controlled a situation. We were trying to come up with ways for him to finish tasks without me holding him accountable. I recalled that the Google Mini had a "routines" option on the app. My son and therapist both thought that was worth a try.

I went home and made a list of all the things we do every single day. I listed what triggers the action, and when it happens. I came up with about 20 tasks. Then I got started programming the speaker.

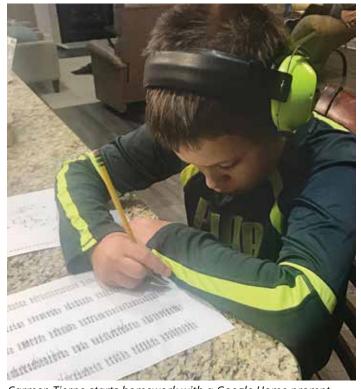
For each task, I set the speaker to "ding" at 70% volume to alert that a task is coming. Then, Google speaks aloud a task. Sometimes there is a timer associated with it. Sometimes the task is followed by music. The options are endless. We use Google Home routines to prompt all home transitions like:

- •meals
- •self-care
- bedtime
- •getting ready and leaving the home
- medication reminders
- chores
- •and more.

Here are a few examples of how we use this off-theshelf technology in our home.

•6:30 a.m.: Ding! It's wake-up time. (Kids Bop songs blare to wake him up.) If you are downstairs before 6:40, you get to choose what we watch.

•7:00 a.m.: Ding! It's time to brush teeth in one minute. Go to the bathroom and get your toothbrush ready with toothpaste. (Sixty seconds pass.) It is time to brush



Carmen Tierno starts homework with a Google Home prompt

teeth. Inside, outside, tops, and tongue; when I stop counting you are done. 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20. Rinse your mouth and your toothbrush. Great job!

•8:10 a.m.: Ding! It's time to leave for school. Please put your shoes on, get your backpack, and get in the car.

•4:05 p.m.: Ding! It's time for homework. Get your backpack and pencil, and sit down at the table.

•8:00 p.m.: Ding! It's time for bath. Rory, sit on the stairs for your turn. Carmen, go upstairs and get started. Dirty clothes in the hamper, use soap on all your parts. (This one turns on classical piano music to start the nightly bedtime calm-down routine.)

Using Google Home has made a real difference in the stress level of our home. Parents and caregivers went from adversaries to allies helping our son manage his day. I recommend this technology to any family who is struggling with routines!



Podcast Explores The Landscape of Disability

By Naveh Eldar, Long-Term Services & Supports Workforce Development Manager, BlueCross BlueShield of TN

Naveh Eldar has worked in the field of disability services for more than 20 years and is an expert in supported employment for people with disabilities. Now, he's using a new platform to talk with remarkable people about the issues he cares most about.

You can find his podcast, "The Landscape," on all podcast apps or at: www.tennesseeworks.org/the-landscape-podcast/.

What prompted you to create the podcast?

In my career, I have worked for two main populations within the disability community:

- People with a severe and persistent mental illness, and
- People with an intellectual and developmental disability.

Learning best practices for each population has really helped me see my work from more angles. It for sure made me better at my job. So, I decided to look for a podcast where I could learn about all types of disabilities, and be inspired by the work being done from every population.

I also tend to focus on all the wrong in the world. I wanted a show that would be uplifting and show all the great work and people that were out there. There are businesses with heart, and programs changing the world, and people who are examples of what is possible. I wanted to hear them all.

But when I looked, all the podcasts on disability issues seemed to be very niche. Many of the people I wanted to hear from were nowhere to be found. For example, I searched for an interview with Susie Rutkowski. She is a co-founder of Project SEARCH, which is an amazing internship program for students with intellectual and developmental disabilities. I happen to know Susie. When I didn't find an interview featuring her, I emailed her and asked if she'd ever done one. She told me that she had never heard of podcasts.

The same thing happened with another international program for people with disabilities I knew about. Then I decided, "Okay, these people need to be heard. These programs need to be spread wide and far and celebrated!" So...I decided to start my own podcast on people,

LANDSCAPE

with Naveh Eldar

programs, and businesses that are changing the landscape for individuals with any type of disability!

Who have been some of your most memorable podcast guests?

The cheesy thing to say, which happens to be true, is that I absolutely love all the guests I've brought on the show. I'm the one who invites them, so it makes sense that I invite those that interest me greatly. Having said that, Linda Murnane was my favorite interview. She's the only person that I gave two episodes to, because her story was so fascinating.

The first episode tells her story of fighting through all these obstacles to become a lawyer. She faced parents that wouldn't pay for her schooling because she was a female. The Air Force at the time kicked women out if they got pregnant and wouldn't put their child up for adoption!

Then, in the second episode, she rises through the Air Force ranks to become a lawyer, then all the way to becoming the lead judge over all of Europe. The highest point, though, was when she was later invited to be the head judge for the United Nations over war crimes in the former Yugoslavia. I listen to her story and I am humbled by her passion, humanity, and intelligence.

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Project Search The Place for Opportunity

By Mikey Newton, intern at Project Search: Wilderness at the Smokies

Project SEARCH is an international model for helping people with disabilities learn job skills through internships at community businesses. Mikey Newton is an intern at Project SEARCH: Wilderness at the Smokies Waterpark Resort and Family Adventure Center. Mikey is enjoying his role as a lobby attendant for his first internship at the resort and thinks he may like to work at the front desk next.

Jennifer Jeffers, Program Director at the Project SEARCH site in Sevierville, TN at the Wilderness of the Smokies Waterpark Resort and Family Adventure Center, shared: "This is the third year of this program. Our interns are between ages 18-21 when the school year starts. Wilderness at the Smokies is a hospitality location that has 4 water parks, 743 guest rooms, 3 retail shops, 8 food service areas, and a variety of opportunities to help our interns become marketable employees. We have been honored to have 10 interns participate over the first two years of the program. Nine of them are currently employed in a variety of settings (one young man is not able work right now due to the pandemic). We are excited about the 5 young men who began working in their first internships this September. Our county is going to gain 5 great employees thanks to this partnership between Wilderness at the Smokies management and staff, Sevier County School District, and our partners at The Access Program and Vocational Rehabilitation."

Though I've only been attending Project Search for a little over two

weeks now, already we've done so many things together. We've done fun activities, learned about each other, and even toured River and Stone Lodge! Surprisingly, I had only learned that Project Search was a global organization last week. I've made some new friends, explored some interesting places, and overall, I couldn't be happier. After all, this is much better than high school, that's all I can say!

But what does this project mean to me? Well, it's a great opportunity for me personally because without this, it would've been much harder for me to find a good-paying job. Even if I don't find a job I want here, the great people of Project Search promised that they would ensure we all have jobs before letting us go, so I'm confident my future is sealed. The job I'm looking at for my first internship is lobby attendant, but dishwasher could also be something I might enjoy doing. As for my third internship (if I do a third one), it will most likely be front desk. I know those don't seem like outlandish jobs, but for me, it's perfect.

One of my favorite things about Project Search is how nice all the staff are here. They take things slow, they make sure we're following along with what they're telling us, and they make sure to answer all of our questions with integrity and kindness. There are lots of reasons to get involved with Project Search: You could be a disabled guy or girl looking to get a good job in the future. You could be a parent want-



ing to make sure your child is taken care of when you pass away. You could even be a staff member wanting to help the new generation work our future jobs.

In any case, Project Search was made for you! They have everything here: kind and just instructors, spacious facilities, and great jobs! Some of them are hard, but you can't be successful without hard work. Trust me, trying to take the easy way out is never a good way to get things done. They're also getting us used to presenting and hosting meetings.

Remember, Project Search is a fine organization with teams ranging across the world! Every intern you see at work represents trials and errors of work, and just know, ANY-ONE can work if they're willing to put in the effort to at least try.



Transformation at Every Level

Change Comes to Vocational Rehabilitation

The Tennessee Department of Human Services (TDHS) is on a journey of transformation. Changes began a couple of years ago. The vision: center everything on providing customers with the best experience possible. Those customers include people with disabilities served through the Vocational Rehabilitation (VR) program – the state's largest program supporting people with disabilities to find jobs and launch careers.

At every level of leadership, the Division of Rehabilitation Services – which oversees VR and other programs – has taken a fresh look at who, how, and why they serve. The Council has supported the work of transformation in a couple of ways:

- Investing in a year-long, nationally recognized personcentered training for ALL division staff, from front-line counselors to top leadership. Experts from Griffin Hammis Associates focused staff on helping every person find the right job with the right supports to thrive and meet their personal goals.
- Working together with Griffin Hammis and VR leadership to review and update policies to embody a person-centered approach. These changes help VR put into practice an approach that focuses on strengths and helps all customers work toward their dreams.

Together, these concrete changes make sure the experience of the customer with a disability guides all VR policies, practices, and decisions.

What does transformation really look like in practice, for the people delivering VR services every day? Below, several staff from the Division of Rehabilitation Services share what they've learned.

In Their Own Words: What has person-centered training meant for you?

Kristen Martin, VR Counselor: "There was a line one of the trainers said that went something like 'getting to know individuals rather than just getting to know what job they want,' and I felt like that was a perfect summary of our role as VR counselors. I was reminded that it isn't just about getting them 'a job' and moving on, but rather working with them and discovering what job would best fit their personality and individual gifts and talents."

Lucy Crider, VR Counselor: "The take-aways I learned from person-centered training include—appreciate the customer's culture and serve them holistically."

Nicole Dawson, VR Counselor: "The training reminded us that in many cases, people experiencing disabilities can feel a loss of autonomy... and that VR counselors should repeatedly express to the customer both verbally and by their actions that they (the customer) are the authority on their own lives and have the right to choose their path.

The person-centered training helped to refocus my practices. I became more intentional about engaging in extensive conversations with the customers about their short and long-term employment goals. One recent customer who is experiencing both blindness and mental illness comes to mind. As I was developing his individual plan for employment, the customer continually experienced challenges related to his mental health. That required that I engage in multiple conversations to allow him time to process and decide upon his employment goals. He outlined his concerns, and I used counseling and guidance to help him to plan for challenges that he might face. After the customer decided on his goal, it was important to find a provider with whom he felt comfortable. The customer expressed his gratitude that his desires were honored at every step and stated that in his past experiences searching for employment, this had not been the case. All these steps were necessary to assure that the customer remained the driver in his own life and that his personal autonomy was reflected."

Jordan Herald, Regional Supervisor: "One of the most important concepts I took away from the training was that it is okay to fail. We have all failed at one point in our lives. It is okay if our customers go down an employment path that they have chosen and don't excel (at). I believe that our counselors do everything they can do to keep our customers from experiencing those difficult situations. Sometimes, our intent to help by blocking someone from a painful experience can hinder that person from getting an experience that they are entitled to - good or bad."

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Need employees?

VR business services match employers with ready workers

By Breona Washington, MS MRC, Gregory Ouellette MS, and Carol Croney, MBA TN Department of Human Services Rehabilitation Services Division

The Tennessee Department of Labor's Jobs4TN website listed more than 400,000 job openings across the state for August 2021. You've likely read headlines about businesses struggling to find workers. There is good news: a program from Tennessee's Department of Human Services (TDHS) can connect businesses with willing, passionate, trained, and qualified workers. This ready workforce can help meet the labor needs in Tennessee.

TDHS Division of Rehabilitation Services helps businesses hire and keep employees with disabilities.

Business Employment Consultants help match the needs of Tennessee businesses to people with disabilities actively looking for work.

The Business Services Unit can help to:

- train employers about disability issues
- work with partners to address reasonable workplace accommodations
- increase accessibility for customers with disabilities
- lower costs by keeping valued employees whose jobs are affected by illness, injury, or disability

All these services are free to employers.

Keith's story: A business partnership opens the right door

"I'm a paraplegic. Who will hire me?" These were the words that Keith Saltkill, a hard-working Tennessean, found himself asking after health challenges interrupted his career in law enforcement and horticulture. However, Keith found new purpose and hope through partnership with the Tennessee Department of Human Services (TDHS) Rehabilitation Services Division.

Keith started his career in law enforcement. He loved working as a police officer and later became the security officer for the Roane State Community College campus in Crossville. In this role, he improved campus security by "closing" at night, escorting teachers to their cars, making

sure students were safe, and closing the campus during weather emergencies. While working at the college, Keith decided to take some horticulture classes at the University of Tennessee in Knoxville and opened a side business in landscaping. Things were going well until Keith became diabetic. He eventually lost both of his legs and some of his eyesight and hearing. After many surgeries and years of rehabilitative services, he was ready to secure a part-time job. But that question kept bothering him: "Who will hire me?"

Keith found the confidence he needed through the help of his TDHS Business Employment Consultant (BEC) and Vocational Rehabilitation Counselor. They assured him that plenty of employers would be glad to have someone with his abilities and skills. Thanks to a growing business relationship with Lowe's, the consultant and counselor were able to connect Keith to just such a job.

Today, Keith enjoys working at Lowe's. He loves to talk with customers and said that his work at Lowe's gives him purpose and a reason to get up every day. The job also allowed him to purchase more reliable transportation. A Lowe's employee scholarship is paying for Keith to take online management classes at his local community college and university.

A broad impact

Keith is just one of many employees to be celebrated this October for National Disability Employment Awareness Month. This is a time to acknowledge the contributions and passion of employees like Keith. It's also a time to show businesses that hiring people with disabilities not only promotes inclusion and diversity – it builds our state's economy.

In 2019-2020, TDHS Division of Rehabilitation Services helped more than 1,400 Tennesseans with disabilities meet their employment goals while making full wages in inclusive work settings. These qualified, ready-to-work employees are helping to meet the labor needs of businesses across Tennessee.



For more information

If you know a business owner who needs employees, or if you would like to connect Tennesseans with disabilities to employment resources and training, the Department of Human Services would like to hear from you.

Tennesseans with disabilities (or advocates) who want to learn more about employment and training opportunities can visit https://www.tn.gov/humanservices/ds/vocational-rehabilitation.html or contact TDHS **Vocational Rehabilitation Services** at 615-313-4891 (TTY# 615-313-5695 or long distance TTY# 1-800-270-1349).

Businesses interested in learning more about how the TDHS Business Services Unit can help find and retain employees can visit www.tn.gov/humanservices/ds/vocational-rehabilitation/vr-business-services or contact the Business Services Unit Program Manager in their area as listed below:

East
Grand Region
Breona Washington
Office: 423-296-2344
Cell: 423-736-2511
Breona.Washington
@tn.gov

Middle Grand Region Trish Farmer Office: 615-313-4907 Cell: 615-663-6963 Trish.Farmer@tn.gov

West Grand Region Amanda (Mandy) Board Office: 901-348-3947 Cell: 901-355-7191 Mandy.Board@tn.gov

Transformation at Every Level Continued from page 9

Annalise Romeiser, VR Field Supervisor: "The personcentered training was valuable to me and all of my staff. In our group discussions, we were able to really dive into the importance of community contacts and doing what is best for the customer as opposed to maintaining a caseload and just going through the motions. One of my staff told me that it radically changed his approach to intakes and gathering information and getting to know a person's support system and what the customer values. I have also seen changes in the way that we do business on the whole. No longer are we solely focused on quantity of services, but instead on the quality of the services we provide. Sandra Ray, Regional Supervisor: "I realize that those of us in Vocational Rehabilitation can no longer make assumptions. We have to understand our own biases, even though we may not feel that we have any. We have to maintain self-awareness. We have to respect our customers' cultural/religious beliefs and work preferences. Counselors are no longer the leader of the team. They need to be co-facilitating the meeting with the customer. The customer decides who they want at their team meeting, not us. We have to learn to actively listen to our customers and practice patience while talking with them. Too often in the past, we have tried to hurry through the various VR processes and have not actively listened to what the customer is actually saying to us. We need to discuss each step of the VR process with the customer and anyone they choose as part of their team to ensure they are fully involved in the decision-making process. Always, ALWAYS remember we are part of the customer's team! We are a support and the customers need to make their decisions."

The Landscape of Disability Continued from page 7

Other favorite episodes have been:

- ESPN on their relationship with Special Olympics.
- The episode with David Quilleon, who is a Senior VP with Best Buddies International, because we are very alike in many ways.
- Briony May Williams, who was born with no fingers on her left hand and was a semi-finalist on The Great British Bake-Off, which is one of my favorite shows! I was a total fanboy in that episode.

How have your guests and their stories changed you?

This podcast has impacted me in every way imaginable. It has helped with my mental health. I have learned things that help me do my job as an employment specialist helping people with disabilities. It has helped me lessen my bias, because we ALL have biases, so not working on that isn't very productive. And it has brought me into the wider disability community, which is where we all should be.

Advocates often get frustrated when others know so little about whatever they are advocating for. An example is: if you are an advocate for cerebral palsy, you are amazed at how little others may know about CP. But ask yourself how much you know about cystic hygroma, Ehlers-Danlos Syndrome, or schizophrenia? No one can know everything, but we should make an effort to learn about others.

Like I said earlier, this podcast is about people, programs, and businesses changing the landscape for people with any type of disability. The goal is for it to be entertaining, uplifting, and educational. ■

Rosie Roaming

Have Wheels, Will Travel

By Rosie Dunn

As a wheelchair user, growing up I never saw myself represented in the media. It wasn't really something that concerned me or something that I thought about often, until I joined social media and finally found the representation I had been lacking.

Through Instagram, I have been able to meet others like me, and truly connect with other wheelchair users – mostly women – on a level I have rarely been able to before. Through seeing them travel the world, go to school, work, get married, have children, and live with confidence and style, it has inspired me to do the same – both in my daily life and online.

In 2019, I started my blog and Instagram page, "Rosie Roaming." Travel is one of my favorite things to do, even though it can be challenging or look different as a wheelchair user. So far, I have been to 36 states and 7 countries, with my goal being to visit all 50 states and as many countries as I can! I started Rosie Roaming to share my experiences traveling as a wheelchair user, to connect with other wheelchair users, and to show how it can be done in a chair.

One great travel experience I had recently was a day trip I took to Saugatuck, Michigan with some friends. The reason the trip was so great for me (aside from the



amazing company of my friends) was because of one simple thing: a boardwalk. The beach is a place that has traditionally been full of logistical nightmares for me. If you have any experience with sand and wheelchairs, you know that they do not mix. When a wheelchair is the way you move about the world, that makes navigating a place that is so alluring and relaxing for most into a frustrating and calculated experience. At most beaches, my options are to be carried across the beach or to use a beach wheelchair - both of which rely on several specific factors in order for the option to be on the table at all.

Until this beach trip, I had not been on a beach with a boardwalk, which allowed me to go onto the beach in my chair independently. This boardwalk at Oval Beach in Saugatuck extended onto the actual beach, and allowed me to go about halfway down the beach, then park my chair next to the boardwalk and lay on the sand. During the second half of the day, I actually stayed in my chair on the boardwalk, on the side so I'd be out of the way of the people heading back to their car, while sitting next to my friends who were on the sand beside me. This boardwalk is such a simple thing, yet it made all the difference for me.

Although I love to travel, it isn't something I do in my everyday life, especially in the age of the pandemic and being a full-time college student. However, I still want to share my experiences, so I have started sharing more of my daily life, too. I think this will be helpful to keep the page going as I continue throughout my life, wherever I may go.

My favorite part of this journey is finding a vibrant, passionate community. Life with a disability can be really hard, and it has been life-changing to find others who can relate to my struggles, because they have experienced them, too. When one of us is discouraged or facing a challenge, the others are always here to lift us back up. On the other hand, when one of us celebrates something joyous,



Rosie on a visit to Chicago, Illinois

the community is there to cheer right alongside. Disabled joy is something that is hardly represented in the media, yet it is thankfully a reality for me and many of us in the disability community. This community has helped me find my voice and helped spark a new passion for disability inclusion and advocacy.

One area of injustice that my community has been facing lately has been the treatment of wheelchairs by airlines. In the past three months, I personally know at least 12 people who have had their wheelchairs lost, damaged, or destroyed while traveling on an airplane. This experience is often really traumatizing and puts a halt on their life. A broken wheelchair can take months to fix or replace, with the bill often being thousands of dollars. Even if this bill is paid for by airline companies, wheelchair users are still stranded until their chair is fixed or a replacement is provided to them. Wheelchair users like myself rely on our wheelchairs to connect us to the world. Without mine, I would be stuck in bed. My wheelchair is absolutely essential to my independence, health, and livelihood. It is customized to fit my specific needs and is not easily replaceable. Although I personally have not experienced a damaged wheelchair as a result of airplane travel, it is becoming an increasing



concern of mine as I see it happening repeatedly to my community. Reports from the U.S. Air Travel Consumer Report show that in 2019, an average of 29 wheelchairs were lost, damaged, or destroyed every single day. Airlines need to start treating disabled passengers and our wheelchairs, which are extensions of our bodies, with the respect and dignity we deserve.

I hope to carry my advocacy work and internet presence into the healthcare field as a Physician Assistant. I plan on attending Physician Assistant school in a couple of years, after finishing classes and obtaining the patient care experience needed to apply. Physically disabled people are extremely underrepresented in healthcare. I hope representation will increase in the future as part of important diversity movements. I believe people with disabilities are capable of providing excellent care to patients, and provide unique perspectives, often having had many experiences as patients themselves.

Representation, I've learned, is essential for envisioning a future where you belong. I hope by sharing my experiences on my Instagram and blog, I can help contribute to the representation of disabled joy and belonging for others.

If you're interested in following me, my Instagram is @rosieroaming, and my blog can be found at www. rosieroaming.com.

Rosie Dunn is a Nashville native, full-time manual wheelchair user, and a paraplegic due to a spinal cord injury. She is currently a senior at the University of Notre Dame. In the future, she hopes to become a Physician Assistant and continue growing her blog to connect with others with disabilities.



Rosie and her mom, Carol, pose in front of Kylemore Abbey on the west coast of Ireland.



Who makes decisions about my life?

New Center for Decision-Making Support can help you know your options

By Dara Bacon, The Arc Tennessee & Kelsey Loschke, Disability Rights Tennessee

Tennessee is the first state in the nation to offer people with disabilities and their families one place to learn about decision-making options: https://www.tndecisionmaking.org/. The Center for Decision-Making Support is a onestop-shop for learning about ways to get help with making financial, healthcare, or other kinds of decisions. You'll learn about tools like:

- powers of attorney
- · advance directives
- special needs trusts
- ABLE accounts
- having someone manage your Social Security benefits ("a representative payee")
- conservatorship
- · and more.

The Center offers helpful resources and staff to talk one-on-one about your options and to refer you for legal consultation, if you need it.

"The Tennessee Center for Decision-Making Support is an incredibly valuable resource for the disability community. Individuals and families can access accurate, easy-to-understand information on topics like special needs trusts, conservatorship, and more. It's all in one place." says Heidi Haines, Executive Director of The Arc Tennessee.

Finding the right decision-making supports for your life shouldn't be hard. You shouldn't have to be able to afford a lawyer or know the right people. You should be able to find help to make as many choices about your own life as possible.

The Center offers the LifeCourse "Exploring Decision-Making Supports" Tool to get you started. The LifeCourse tool will help you think about areas where you make your own decisions and areas where you need help. For example, you'll write down how much help you need for decisions about daily life, staying safe, where you live, and your social life. You might make some decisions all on your own, and you might need some help for others. Maybe there are some decisions you need someone else to make for you.



Scott's colleagues and board members of The Arc Tennessee are an important part of his daily life. Scott has a designated circle of support team that offers support when he needs it. Pictured: Scott Finney, Ashley Coulter, Robyn Lampley, and Rick Guiden.

The Center's website is organized to match the levels of support on the LifeCourse Tool. That makes it easy to find information and tools to fit the kind of support you need.

The website also offers accessibility and language options for people who need them. In fact, visitors can translate website content into any of 100 different



languages with one click. People with visual impairments or learning disabilities can change the visual layout of the site to make it easier to use. For example, you can change the background color, have content read out loud, enlarge the font size, and more.

THE CENTER'S STORIES:

Making Decisions about Our Own Lives

The Center's website features many stories to show how different people get support to make decisions. One story features Scott Finney, a nationally recognized self-advocate with Down syndrome. When Scott turned 18, he began making decisions about his life as a legal adult. His parents still supported him with decisions, and after their death, his sister and colleagues now offer him support when he needs it.

"I discuss my wants and needs with my sister and circle of support. We are a team," says Scott, who makes most of his own decisions and has been employed with The Arc Tennessee for 33 years. "I know I can call upon my sister and circle of support for any reason, at any time."

Scott is part of People First Tennessee, a disability rights group led by self-advocates. People First is a primary way Scott shares information about the Tennessee Center for Decision-Making Support. "When I share about my life, I like telling others about the Center and decision-making options because it's so helpful. I'm really glad I get to work, make decisions for myself, and be part of things that are important to me," Scott says.

Helping with Difficult Issues

In the first month of its launch, the Center took more than 1,000 questions from Tennesseans. Many of the situations involve complex issues, like abuse and exploitation with no easy way out of the legal arrangement like conservatorship. These situations show serious issues with the current system. The Center will be working with judges and lawyers to better understand and begin addressing these difficult issues.

How We Help

"The transition from school to adulthood is a common time when families begin really exploring decision-making tools," explains Penny Johnson, who serves as the Center's Program Coordinator. "It's important for individuals and families to know that the Center is an unbiased, easy-to-navigate resource for all ages."

You can contact the Center for any issue related to decision-making, even if you don't know where to start. The Center sometimes gets calls from people who just

want to share their story, and this helps us learn. Here are some examples:

Caller: "Hello, we have a conservatorship in another state and are wanting to move to Tennessee. Can you help us?"

Center for Decision-Making: "Yes, we can refer you to the court in your new county. Be sure to check out the Center for Decision-Making page on conservatorship best practices: https://www.tndecisionmaking.org/conservator-ship-lev4/. "

Caller: "Hello, I am a teacher. A student and their family have asked me about getting conservatorship. How can I help them?"

Center for Decision-Making: "We encourage everyone to start by taking the LifeCourse Tool for Decision Making as a self-assessment first. It helps you learn about the areas where the person wants and needs support: https://www.tndecisionmaking.org/wp-content/uploads/CtLC-ExploringDecisionMakingSupports_2020.pdf. From there, you can refer them to us and we can work through the options that best fit the student's life."

Caller: "Hello, I know I need some legal help with decision-making. Can you help me?"

Center for Decision-Making: "We have a directory of lawyers across the state who practice law in this area. Based on your county, we can give you a list of lawyers in your area to try."

How to contact the Center

- Visit: https://www.tndecisionmaking.org/
- Call: (800) 835-7077
- Email: ds@thearctn.org
- Note: if you want to recommend a lawyer for our directory, please visit: www.tndecisionmaking. org/contact/.

Dara Bacon is the Director of Communications & Public Awareness for The Arc Tennessee. Officially joining the staff in January 2020, Dara manages all online resources for The Arc Tennessee, including the Tennessee Center for Decision-Making Support.

Kelsey Loschke is the Director of Community Relations at Disability Rights Tennessee. She has worked with diverse disability groups throughout her career, including individuals with intellectual and developmental disabilities. Her experience includes communications, public relations, voting rights, and systemic advocacy.

Stories from Family Support

In early 2021, the Council on Developmental Disabilities contributed \$300,000 in new funding to expand the Tennessee Family Support program to help more families during the COVID-19 pandemic. The Council has been active in promoting and supporting the Family Support program since it was created in 1992. We're excited to share a few stories of how Tennessee families benefited from these extra funds during a very hard year.

"We know the pandemic has had a heavy impact on people with disabilities and their families," Council Executive Director Wanda Willis said. "We are so grateful to our close partners at DIDD and the local agencies for helping us get these funds into the hands of the families who needed them most."

Marielle

"I work as an Early Interventionist for Emory Valley Center. I get to see firsthand the amazing things the Family Support Program provides families in our community. I have countless stories I can tell about the funding provided to help families on my caseload meet their child's needs. Throughout my career of helping families with applying for this program, I never realized that the Family Support Program would also help my own child and family one day.

Marielle started showing delays in her motor skills when she was a baby. When she was 22 months old and still was not walking, we realized it was time for an early intervention referral. She was



Tiffani Dixon and daughter Marielle enjoy laughs together at a therapy session.

later diagnosed with Congenital Hypotonia and Sensory Processing Disorder. We attended physical and occupational therapy at Blount Memorial Hospital. Marielle gained strength and new skills from attending regular therapies.

Then, the pandemic hit, and we had to pause therapy. THEN, Marielle turned 3, and she aged out of TEIS services that helped provide these therapy visits. Marielle needed to continue therapy, but our co-pay was too high for our budget.

We applied for the Family Support Program, and she was approved to receive funding! This program was a HUGE blessing for Marielle and our family! She was able to continue therapy, and also enroll in aquatic therapy and gymnastics so she could have more opportunities for strengthening her muscles and socialize with peers. It helped provide equipment that we use at home, such as a balance board, the Nugget cushions for climbing, exercise ball, and supportive shoes to fit over her orthotics. Words cannot express the relief we feel to return to therapies and provide the support our daughter needs. She is thriving and making great progress!"

—Tiffani Dixon of Maryville, TN

Reed

[Thanks to Family Support funding ...] "Our son Reed just finished a week of camp at DownsideUp. Theresa Nix (owner and operator of DownsideUp) has created the most inclusive, welcoming, safe, fun, and versatile place for the campers. During the camp week, Reed was surrounded not only by his peers but also by loving and compassionate adults. He was exposed to many fun activities every day and was eager to return for more the following day.

This camp has enriched Reed's



Reed experiences making slime during a week of camp at DownsideUp.



summer break in more ways than one. We wouldn't trade this experience for anything and are already looking forward to the next time we can return to DownsideUp."

—Yekaterina of Chattanooga, TN

Jeffery

"My son Jeffery is 39 years old and was born with Trisomy 14 chromosome abnormality. He also has a compromised immune system and many allergies that can be life-threatening. We have been so



Jeffery Lambdin

blessed to get approved for the Family Support program to purchase supplies that help us keep his environment safe and healthy. We have used Family Support funds to buy medical items, air purifiers with UV light, vacuums, sheets, and other things that keep our home clean to make sure my son stays well."

—Anita F. Lambdin of Claiborne County, TN

Kelsey

"I have a beautiful daughter, Kelsey, who is 30 years old. She has Down syndrome and a heart defect. She lives with me and depends on her dad and me for all of her needs. Kelsey loves spending time outdoors and is always ready to explore! She isn't afraid of anything and loves meeting new friends.

Kelsey currently attends a program in Memphis called Thrive, which provides social, recreational, and continued educational activi-



Payne shows off artwork made at Thrive, a program she attends every day.

ties. It's a daily program and costs about \$400 per month. The Family Support funds can pay for about four months out of the year, which is a great help! Funding has also helped in the past years with personal assistance, transportation, and summer camps."

—Kimberly Payne of Toone, TN ■

WHAT IS THE TN FAMILY SUPPORT PROGRAM? HOW DOES IT WORK?

- It is run by the TN Department of Intellectual and Developmental Disabilities (DIDD), through 16 local disability agencies that give out the funding in their local communities. These 16 agencies serve all 95 counties of the state.
 - * Find your local Family Support agency here: www.tn.gov/didd/for-consumers/family-support/family-support-contractagencies.html. Each agency has their own application process; contact your local agency to learn more.
- It is funded with state dollars.
- It provides money (no more than \$4,000) to help Tennesseans with disabilities and their families who do not get any long-term services and supports (like Medicaid waiver services through the 1915c DIDD programs or the Employment and Community First CHOICES program). People who get these services are not eligible for Family Support funding.
- A local Family Support Council in each area decides which families who apply get the funding and the amount they will get, based on need and how many

- families apply. A majority of each local council is made of up people with disabilities or family members who live in the area.
- Family Support dollars can be used for many different kinds of disability costs and services.
 Examples include respite care, equipment/supplies, nursing, counseling, housing costs, personal assistance, health-related needs, summer camps, and more.
- Learn more about the TN Family Support program at www. tn.gov/didd/for-consumers/family-support.html.

ENABLING TECH PAVES a Path to Independence

Introduction by Council staff; stories contributed by Steven Stock (Vice President, AbleLink Smart Living Technologies) and Kerri Pinger (Marketing & Communications Manager, CreateAbility Concepts, Inc.)

Since 2017, our friends at the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) have been developing their "Enabling Technology" program. DIDD defines enabling technology as "the use of ... devices and technology to support a person with disabilities to live as independently as possible."

DIDD's program has mainly focused on helping disability service providers use technology in creative ways for the people they serve through Medicaid long-term services and supports. But there is good news for people not getting those services: anyone can use technology tools to become more independent!

We know from national data that less than 1 in 5 people with intellectual and developmental disabilities are getting paid disability supports. That means many Tennesseans with disabilities may need some support to live good lives in their homes and communities but are not getting formal services. Technology can be a great resource for those people with disabilities and their families.

We asked for stories from two of DIDD's Enabling Technology vendor companies: AbleLink Smart Living Technologies and CreateAbility. We wanted their best examples of how their apps can help Tennesseans with intellectual and developmental disabilities live self-determined, independent lives. Below are the stories they shared.

Note: Some of these products are designed with provider agencies, job coaches, or support workers in mind – but anyone can purchase the tools through the companies' online stores.

TECHNOLOGY FOR TRANSPORTATION AND EMPLOYMENT SUPPORT

Wayfinder (AbleLink)

In Chattanooga, Kenny wanted to be able to get to his job at Barger Academy without relying on his support staff for a ride. His support team at Orange Grove Center decided to purchase AbleLink's "WayFinder" app through the DIDD Enabling Technology Community Inclusion Pilot Project.

WayFinder provides GPS-based multimedia prompts to help people independently navigate fixed bus routes. Working together, staff from the Chattanooga Area Regional Transportation Authority (CARTA) and from Orange Grove traveled the route from Kenny's front door to the front door of Barger Academy. They set GPS waypoints and recorded instructions for Kenny to follow. Cues helped Kenny remain confi-

- "Walk down the street past McDonald's to get to your bus stop."
- "This is not your stop, Kenny, do not get off here."

dent and focused during his trips:

 "You are almost to work, Kenny, it's time to pull the bus cord."

WayFinder displays pictures of landmarks and other key points along his route to work for further support to help Kenny know that he is in the right place. Kenny is very proud of his newfound travel independence and is looking forward to learning new bus routes with help from WayFinder.

Endeavor (AbleLink)

When Anita started her job at a local Taco Bell, she got daily support from a job coach – a person to help teach her the job duties. This left Anita feeling micromanaged and frustrated, so a new plan was needed. Her supporters from Core Services of Northeast Tennessee decided to use DIDD's Enabling Technology program to access the AbleLink "Endeavor" app to help Anita become more independent at work.

Endeavor is a research-based, accessible, multimedia scheduling system designed specifically for people with cognitive disabilities. Her support staff looked at Anita's job duties and schedule at Taco Bell. They then



re-created her schedule using the Endeavor app, with familiar, personalized audio and visual reminders. Anita began using the system by strapping her phone to her upper arm and accessing the automated schedule via her Bluetooth headphones so that her hands remained free to do her work.

Now, Anita is now usually able to perform all duties during her six-hour workday without any help from her job coach, which means the world to her. Because of her efficiency, she has received additional job duties that are more challenging, and she is growing personally.

Employment Pathfinder (CreateAbility)

their talents, strengths, passions,

For Jordan and Mindy, two people with disabilities served by Madison Haywood Developmental Services (MHDS) of Jackson, TN, the idea of "independence" includes having a job and making their own money. Rance Thetford, the Supported Employment Manager at MHDS, knew that helping them find the right job needed to start with learning about

and interests. This process is often called "exploration" and "discovery" in disability employment services. Rance decided CreateAbility's Employment Pathfinder app, designed for people with intellectual disabilities, would be a good tool to use for this first step in their employment journey.

Jordan worked through the Employment Pathfinder assessments with his job coach, using the voice feature to help navigate the questions. Mindy chose to take the assessments from her home, downloading the app to her phone and taking the assessments by herself, in her own time.

After the assessments are done, the app creates a report for each person with helpful information that supporters can use to:

- Develop the right job coaching strategies for that person.
- Learn next steps for finding a job in the right field.
- Explore tools and technologies to support the person at work.

Employment Pathfinder provided for Jordan and Mindy a list of career options that were not only jobs they could do, but careers they could both excel at and enjoy doing. Currently, they are applying for careers in the fields suggested by Employment Pathfinder. They are hoping to take the next step in their journey – getting a job that's right for them!

Employment Pathfinder is one of several technology options in CreateAbility's Employment Suite of programs and tools. It also includes:

- MeMinder technology for task prompting and instruction so that people can feel more confident and productive while working.
- Evalu8NOW Avatar-led "check-ins" that ask people about their job satisfaction and well-being.

Explore and learn more

Learn more about how disability programs are using enabling technology to support Tennesseans with disabilities on the Tennessee Department of Intellectual and Developmental Disabilities website: https://www.tn.gov/didd/for-consumers/enabling-technology.html

AbleLink Smart Living Technologies, founded in 1997, has been working closely with the Tennessee Department of Intellectual and Developmental Disabilities on a variety of projects to provide personal technology for people with cognitive disabilities. Current efforts include a pre-employment technology pilot project featuring AbleLink's JobQuest service and an expansion of the WayFinder project in Chattanooga. Visit https://www.ablelinktech.com/ to learn more about their technology solutions.

CreateAbility has been building technology solutions for individuals with intellectual disabilities and traumatic brain injuries since it was created in 2001. Most of the enabling technologies they have developed are the result of research-based evidence and funded by agencies such as the NIH, USDA, and NIDILRR, who believe that technology should be an affordable solution for all. Visit *https://createabilityinc.com* to learn more about their technology solutions. ■



Tennessee Council on Developmental Disabilities

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