Breaking Ground 111 - October 2022

Cover description: Text on the cover says “Breaking Ground issue 111 – The Path to Adulthood – Helping You Plan for A Successful Future.” Photo is of a young man, taken from behind, showing him sitting in an empty theater in red velvet seats wearing a blue cape. The cape has embroidered letters “S” and “J” and a lightning bolt. Cover also includes our Council logo.

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*Subscriptions to Breaking Ground are free and available through the Council website. Visit tn.gov/cdd to subscribe or contact us by phone or email with subscription updates or requests, and please include name and mailing or email address. This project was supported in part by grant number 2101TNSCDD, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.*

# Introduction by Lauren Pearcy, Executive Director, TN Council on Developmental Disabilities

Dear Readers,

As the school year begins for many of us, this edition of *Breaking Ground* will highlight stories about students with disabilities and different paths to adulthood. As I read the articles myself, I thought about the young people I’ve met recently on their own paths.

One young woman who stands out is a student at Access ETSU – the inclusive higher education program at East Tennessee State University. She gave me a tour when I visited in June. As we walked around campus, we talked about her academic focus in art and history. She explained that she is a third generation Buccaneer. In addition to taking academic courses, she interns in the campus museum where her grandmother’s art is on display. I asked her if she considered any other college. She shook her head no, vigorously. It struck me right then that without inclusive higher education programs like Access ETSU, my tour guide would have had a completely different life story, and family legacy, simply because of her disability.

We continued on. My tour guide pointed out places that made me nostalgic for my own college experience:

* where she and friends hang out in common places (including a long, epic slide down a hillside)
* where she studies alongside thousands of other students in the library (The library research assistant greeted her by name.)
* where she exercises in the state-of-the-art gymnasium

I saw that everyone on campus interacts daily with people who have intellectual disabilities, thanks to inclusive higher education. What a marked change from just a decade ago when these programs did not exist.

Before I left campus, I pointed out a huge poster of a student playing basketball. “He is one of the first graduates of Access ETSU,” my tour guide explained. I looked again and realized I recognized the young man. He is starting the Council’s Partners in Policymaking® leadership academy this fall. I smiled when I thought about how much these young people will do in their lifetimes, simply because we are (finally) giving them a chance to do so.

Wishing a great start to the school year to those of you in that season, and a great start to fall for all of us,

Lauren

Executive Director, TN Council on Developmental Disabilities

Image descriptions:

* Headshot of Lauren, a young white woman with long dark blonde hair, a blue dress and earrings
* Lauren poses with Amyra Perkins, an East Tennessee State University Access student and Lauren’s campus tour guide.
* A set of stairs on the ETSU campus celebrates values that are well-represented by the inclusive higher education Access program.
* A campus poster features Garrison Buchanan, one of the first graduates of Access ETSU – and a current scholar in our Partners in Policymaking® program!

# Education Watch: Issues we’re tracking this school year

*By Brian Keller, General Counsel and Director of Public Policy, TN Council on Developmental Disabilities*

Across the state, students are settling into a new school year. It’s not news to their parents that students with disabilities continue to face additional challenges in getting the education supports they need. In fact, it’s stories from many of you – parents advocating for your school-age children – that have informed three issues the Council is watching closely this year.

**First, a little about our role in education.**
The Council on Developmental Disabilities works to improve education for students with intellectual and developmental disabilities by:

* Providing reliable, accurate information
* Learning about new best practices for inclusion
* Engaging in solutions-focused advocacy

Our work is always informed by the real-life experiences of those living with disability. We work with state agencies and community groups to inform families and educators and create meaningful change for students with developmental disabilities.

**There are three key education issues we're tracking this year.**

1. **Tennessee Investment in Student Achievement (TISA)**
[TISA is the new education funding formula](https://www.tndisability.org/article/tisa-101-how-tisa-works%20) that will take effect next school year. Even though it won’t impact schools for another year, it’s a big deal. The way we fund public education in Tennessee hasn’t been changed for the last 30 years.

At the beginning of August, the TN Department of Education’s public comment period about the new funding plan closed. The Council provided comment based on input from our Governor-appointed members, who are Tennesseans with disabilities and family members of people with disabilities. (To read our comment, visit our email newsletter archive at tn.gov/cdd and read the August issue.)

Now, the Department of Education is reading through all the public comments and finalizing the regulations that will take effect in 2023. We’re waiting to see those final regulations to understand exactly how students with disabilities will be impacted. Stay tuned to our [weekly public policy news](http://eepurl.com/BDhsH) for more information.

**The personal view:**

A Council member has shared many times how hard she’s worked towards inclusion in a general education classroom for her daughter, who needs significant support due to her disabilities and complex health needs. Her story and others led us to recommend that the Department of Education commit to routine IEP audits to make sure funds are being used to support students in the “least restrictive environment,” as required by federal law.

1. **School staffing shortages**
We’re following stories about staffing shortages in schools, among teachers, paraprofessionals, and school-based therapists. There are hundreds of job openings across the state. We’re waiting to see how students with disabilities will be impacted once they get back to the classroom. Our hope is that districts can find a way to bring educators back and provide meaningful supports and services in the meantime – no small task.

**The personal view:**

A Council member shared with us her daughter’s story of how the lack of teaching assistants led to the class becoming so chaotic that her daughter was injured. The teacher was in tears over the incident. Other families have shared challenges with their students getting IEP services due to shortages of school-based therapists, or increased pressure for their children to spend more time in special education classrooms because of staffing shortages.

1. **Behavior supports for students**
We have heard countless stories from our Council members, as well as other community members, about difficulties in getting appropriate behavior supports for students with disabilities. We have also heard some amazing success stories about what happens when students get the right support.

This will be the first full school year that a new regulation from the Department of Education is in place. That regulation sets out guidelines for what must be included in a Functional Behavior Analysis (FBA) and Behavior Intervention Plan (BIP). ([Learn more on the TN Dept. of Education's special education behavior webpage at tn.gov/education/student-support/special-education/behavior](https://www.tn.gov/education/student-support/special-education/behavior.html).)

We’ve also been tracking several legislative proposals that would punish students who need behavior supports, including criminalizing the behavior of many students with disabilities. We’re concerned these proposals may unintentionally harm students and their families. We’ve also heard stories that some students with disabilities are being removed from their classrooms more frequently. Research shows us that when educators are supported with the right tools to deliver the right kinds of behavior supports for students with disabilities, many students thrive in inclusive classes with their peers.

**The personal view:**

A Council member who has a son with autism shared that behavior was affecting his son’s learning in school. This parent was struggling to access any behavioral supports through the school. Another parent reached out after her elementary school-aged son with autism was sent home for behavior issues nearly every day for weeks. The mother was struggling to get access to more support or information about how her son’s behavior plan was being used.

On the successful side, a Council member tells how help finding a medication interaction and access to the right therapy for her son with Down syndrome completely changed their family’s daily reality. The right supports have allowed her son to make huge progress in school.

If you have stories about behavioral supports for your child/student with disabilities, please share those with us. We want to hear both the positive and the negative stories:

* + problems with getting the services your child needs,
	+ being removed from their classrooms or dismissed early,
	+ AND successes where a student with disabilities is getting the right kind of support.

All these stories help us better understand what is going on in schools for TN students.

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**Help is available!**Every school year brings a new set of challenges, as well as opportunities, to be addressed by our community. Your stories help us better understand the issues and find the right policy solutions for students and families. Email us anytime at tnddc@tn.gov.

In addition to our newsletters and social media, connect with our partners who work on education issues for students with disabilities, like:

* [Transition TN](https://transitiontn.org/)
* [STEP-TN (Support and Training for Exceptional Parents)](https://tnstep.org/)
* [Family Engagement in Special Education (The Arc TN)](https://familyengagementtn.com/)
* [Disability Rights TN](https://www.disabilityrightstn.org/)
* [Vanderbilt TRIAD (Treatment and Research Institute for Autism Spectrum Disorders)](https://vkc.vumc.org/vkc/triad/home/)

# Autism at Work: Three Tennesseans Finding Their Paths to Success

*By Krystyne Brown, Deputy Director of Communications & External Affairs, TN Department of Intellectual and Developmental Disabilities (DIDD)*

**Editor’s Note:** October is National Disability Employment Awareness Month. In celebration, we are sharing these stories from DIDD and Tennessee’s Council on Autism Spectrum Disorder. The people in these stories have found job paths that fit their unique interests and strengths. Want to know more about how our state is working on employment for people with all kinds of developmental disabilities? [Visit Community Services > Employment First on DIDD’s website: tn.gov/didd](https://www.tn.gov/didd/for-consumers/employment--first.html).

## Juli Liske

Through raising her sons with autism, Juli Liske came to understand herself more. She was diagnosed with autism as an adult and learned to better advocate for her own needs and her family’s needs. “It was really life changing. It opened up not just understanding my children better but having a little more grace and patience for myself,” Juli explained. “There's no better employee than people on the spectrum for a lot of jobs. It has to be a way of life and a way of wrap-around-thinking in order for folks with autism to fulfill their greatest potential.”

Juli is now an author and dental hygienist. She wrote a book to help other families like hers called “In the Eye of the Hurricane – Finding Peace in the Storm of Autism.” Ben, her youngest son, is featured in the book. He is now 21 years old. He’s a teacher, musician, tutor, and was recently accepted into a doctoral program at a university in Georgia.

From 2008 to 2017, Juli opened and ran the Brown Center for Autism. The Center was an early intervention organization that provided many different services, including counseling, for families of children with autism in Tennessee. She says her current job in dental hygiene allows her to continue her work with families by helping autistic patients feel more comfortable in the dental chair. In addition, Juli is a board member for the [National Autism Spark Research Study](https://sparkforautism.org/). This role allows her to be a part of making change nationally that will improve independent living, employment, and community accessibility for people with autism.

## [Sydney Maitland](https://youtu.be/Scz85YbR7AY)

After trying out many different jobs, Sydney Maitland feels like he has finally found a career that calls to him. That job is just a few steps outside his backdoor at his home in Trenton, TN, where his farm stands. That’s where Sydney cares for three chickens for laying eggs, several dairy goats, and homing pigeons. He is working with [Vocational Rehabilitation](https://www.tn.gov/humanservices/ds/vocational-rehabilitation.html) and [Tennessee AgrAbility](https://agrability.tennessee.edu/) to create a business plan and get the training he needs to learn how to make a living off of what he loves: his livestock.

Sydney was a premature twin and was diagnosed with autism as a child. He graduated high school with honors, but he didn't know what he wanted to do after graduation. He’s always loved animals and the outdoors, so his parents decided to build him the farm behind their house. He says it’s now where he feels most like himself. He’s excited to see how his business will take off. “I just want to say to the people who have autism, if you have a dream or a goal in life just go for it. People with autism, they're capable of doing things just as well as any other person. It rather means you just have to do things a little bit differently.”

## Jacob Collins

With the cape on, Super Jacob is a crime-fighting, comedic superhero ready to take on the toughest of villains in the name of love and community. With the cape off, Jacob Collins is a movie theatre employee who’s passionate about entertainment. “Oh yes, I am glad to be myself,” Jacob said. “I am glad to be the good way God made me. I like showing people some funny stuff. It makes me feel very proud.”

Jacob works at Forge Cinemas in Pigeon Forge, where he likes to talk to customers, take their tickets, and tell them about all the voices behind their favorite characters. When he’s not working, he’s often writing. He has been writing about his character, Super Jacob, for years. He now has a notebook full of 183 seasons of adventures and heroics. The stories all feature the man dressed in a white karate gi (karate uniform) and a brilliant blue cape with the letters S.J. on the back. The first season became a comic book called *Super Jacob Saves a Rose*. Jacob’s dad and a local community theatre helped Jacob turn that story into a play. *Super Jacob Saves a Rose* was performed in front of a full audience at the Creative Theatre in 2019.

Jacob is ready to get back in front of the stage lights. He says he’s already working on the sequel script for *Super Jacob and the Impractical Joker*. He dreams of being a voice actor one day.

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Image descriptions for “Autism at Work” article:

* Juli Liske and her son, Ben; white woman with short blonde hair, jeans and a black sweater sits on a couch with her legs curled up next to her and her arm around the shoulders of a young man, her son Ben, who is wearing glasses, a plaid button up shirt, and khakis
* Sydney Maitland cares for livestock on his family farm. He is a young white man with brown hair and glasses and a black T-shirt reaching down to feed a brown and white goat.
* Jacob Collins, also known as Super Jacob; young white man sitting in red velvet seats in an empty theater; wearing glasses and a blue cape
* Jacob Collins shows off his first comic book; young man with short brown hair and sunglasses and a blue cape, holding up a comic book

# 5 Ways to Help Your Child Get Ready for Adulthood

*Lesley Guilaran is a former Governor-appointed member of our Council. She is also the parent of children with disabilities, a long-time special education teacher, and now a school district transition coordinator. She shared with us her thoughts about what makes for a successful transition to adulthood for young people with disabilities, based on her personal and professional experience.*

**1. Practice, practice, practice.**

Learning to make decisions takes practice for all of us. Getting our kids with disabilities ready for adulthood can’t start when they are about to turn 18. As early as you can help them practice making decisions, the better! That might look a little different for our kids with disabilities, but they can build these skills over time. We started practicing decision-making with our son, Angel, from a very early age. Some things that help Angel make decisions:

* **Offering 2 or 3 options.** Too many options can be overwhelming. Narrowing it down to a few choices helps Angel feel ready to choose.
* **Using plain language.** We explain decisions in simple, concrete terms. We might give a lot of examples or write a list of pros and cons. Once we know he understands his options, we respect his choice.

**2. Talk about the future.**

We talk about jobs a lot in our house to create that expectation. When Angel asks, “When can I have a phone?” the answer is, “When you have a job!” We tie lots of consequences and our narrative about adulthood to having a job. Angel knows that learning skills will help him be able to work. And he knows work is the door to more independence – and being able to buy things he wants!

**3. Do the front-end work.**

Teaching our kids with disabilities how to be independent can take a lot more work than it does for kids without disabilities. Sometimes as parents, we do FOR instead of allowing our kids to do for themselves. It’s easier, and we’re tired! But our kids can do so much more than we give them credit for. Practice independence and self-care skills as early as possible.

We’ve learned some strategies that help build independence at home.

* **Give prompts, then fade them out.** Angel struggled with choosing appropriate clothing. He would get overwhelmed and couldn’t pick out what he needed on his own. So, I made him a list of steps, with pictures: pants, shirt, socks, etc. Now, he can do it by himself. He might ask questions for reassurance, but over time, his independence is increasing, and he needs less support. We’ve done this in many areas. When Angel was learning to take a shower, we put visual steps in plastic in the shower for him to follow. Now, he doesn’t need the visual.
* **Use your child’s natural interests.** Angel started cooking at age 11 or 12. It made us nervous at first, but now he browns our meat. He’s my sous chef! He’s started learning all the spices and how to follow a recipe. It helps him with understanding how to read instructions, how to measure ingredients… He also helps me with cross-stitching and sewing. When he was younger, we got monthly TinkerCrate engineering kits. He learned to follow the instructions and put something together on his own.
* **Teach siblings and other family members to allow maximum independence.** Our son Xiao Yu sometimes assumes a caregiver role. We have to tell him, “Hey, let Angel do it himself. Let him practice independence.”
* **Teach money management.** Allow kids to use their allotted money on whatever they want.We’re still working on money skills. But Angel knows that he has a set amount of money that he can spend however he wants. A while back, he had a toy phone he wanted to buy. We talked about how long he would need to save to buy it. He knew when that day came, and he asked to go get that phone. Parents might want to tell their kids, “No, you don’t want to waste your money on that.” But making those mistakes is how our kids learn.

Believe me, I know this takes time and can be hard. But the earlier you can start to practice those skills, and create the expectations, the easier it makes this longer-term. We hold Angel to high expectations, and he rises to those.

**4. Build job-related skills.**

Work is good for everyone’s soul and is a critical part of all of our lives, whatever our job looks like. Since students with disabilities can stay in school until they are 22, more and more school districts are moving to a transition model. With that model, once students graduate, they can attend a transition program to help them learn job skills. Take full advantage of those programs!

We also focus on job-related skills at home. I use a website called [The Autism Helper](https://theautismhelper.com/). It focuses on learning work tasks. I print out the tasks, and Angel does them. It has really made me start thinking about, “What tasks can he do?” If he CAN do them, he should be doing them.

Angel sorts silverware, does his own laundry, and folds our towels. Those are tasks that relate to a lot of jobs. One of the Project SEARCH rotations focuses on laundry. (See more on that below!) We worked over the summer on doing consecutive tasks – back-to-back tasks without needing guidance. Angel finished three tasks without needing help. These are all skills that tie directly to employment.

**5. Help your child self-regulate.**

Teach self-control, self-regulation, and tools for de-escalation. Temple Grandin talks a lot about this, about her struggles with her temper. We tie it back to a job. I’ll say to Angel, “What would happen if you said that to a boss?” And he’ll say, “I’d get fired.” We talk a lot about self-control. He’s learned tools to calm himself down.

## 5 Programs and Resources to Know About

**TN Center for Decision-Making Support** – Provides easy to understand, accurate information about all decision-making support options for people with disabilities, all in one place. The Center can help families have important conversations and find the right support options as a child turns 18 and becomes a legal adult. You can learn about supported decision-making, powers of attorney, conservatorship, and other options. Visit [tndecisionmaking.org](https://www.tndecisionmaking.org/).

[**Project SEARCH**](https://www.tn.gov/humanservices/ds/vocational-rehabilitation/transition-services/project-search.html) – A program available in many school districts across the state. It provides students with an internship year at a worksite in order to help them gain work skills. Many Project SEARCH graduates go on to permanent employment after the internship is over. Bonus fact: The Council helped launch the first Project SEARCH site in Tennessee more than 15 years ago! (Read more: [Breaking Ground 97 - Project SEARCH: A path to the future (tn.gov)](https://www.tn.gov/cdd/engage-with-us/breaking-ground/breaking-ground-97/breaking-ground-97---project-search--a-path-to-the-future.html)) For more information, ask your IEP coordinator or email VR.TransitionServices@tn.gov.

**Vocational Rehabilitation (VR)** – Provides a variety of services to people with disabilities to help them be ready for employment. Some of their services include:

* Counseling and guidance
* Training
* Transition services from school to work
* Job Placement
* Personal Care Assistance
* Rehabilitation Technology Services
* Independent Living Services
* Supported Employment
* Services for the Deaf/Hard of Hearing and for people who are blind/visually impaired

It is really important to enroll your child in VR (sometimes referred to as Voc Rehab) to obtain these services. [Visit tn.gov/humanservices/ds/vocational-rehabilitation.html](https://www.tn.gov/humanservices/ds/vocational-rehabilitation.html).

Another VR program is called [**Pre-Employment and Transition Services (Pre-ETS)**](https://www.tn.gov/humanservices/ds/vocational-rehabilitation/transition-services/pre-employment-transition-services.html). This is a school-based program for students with disabilities between ages 14-22. The program prepares students for the transition from high school to a career path, which could include post-secondary education, training, or employment. Ask your school about how to participate!

**Employment and Community First (ECF) CHOICES** – Tennessee’s program for home and community-based services for people with intellectual and developmental disabilities. These services through TennCare can help with employment and everyday living in the community, including support from paid staff. [Visit tn.gov/tenncare/long-term-services-supports/employment-and-community-first-choices.html.](https://www.tn.gov/tenncare/long-term-services-supports/employment-and-community-first-choices.html)

**Transition Tennessee** – [TransitionTN.org](https://transitiontn.org/) is Tennessee’s online home for training and resources on preparing students with disabilities for life after high school. Their goal is to improve transition outcomes for youth and young adults with disabilities by sharing research-based practices and policies. The website is organized into different sections for educators, for providers, and for students. Each includes free video-based lessons, ideas, resources, and more.

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IMAGE DESCRIPTION:

* The Guilaran family, left to right: Fonsie, Xiao Yu, Lesley, Angel and Aden; family photo of Guilaran family with their 3 teenage and young adult sons, Lesley and her husband seated in their living room

# An Insider’s View of Inclusive Higher Education

As a loyal reader of *Breaking Ground* magazine, you’ve heard a lot from us about inclusive higher education. You may know that:

* Students with intellectual disabilities have access to college programs across Tennessee.
* These programs exist on a growing number of community, state, and private college campuses. (Visit [TNIHEAlliance.org](https://tnihealliance.org/) for a full list of programs.)
* Graduates of inclusive higher education programs have much higher rates of employment than people with intellectual disabilities who do not attend college. (88% of graduates from the 2017 and 2018 classes in Tennessee were employed 90 days after graduation, according to the [TN Inclusive Higher Education Alliance](https://tnihealliance.org/).)

But maybe you’re still wondering: What do these programs really look like? What do students learn? And maybe most importantly: what should students with intellectual disabilities do to get ready for college?

A recent research study gives the parent perspective on skills that are important for future college students to learn (see sidebar). Parent and educator Lesley Guilaran offers her personal advice on how to build skills for independence in her article on page 8. But we also wanted to offer insight from another group of experts: current inclusive higher education students.

Below, you’ll hear from three students who give us a window into their college experiences.

## Amyra Perkins – Access ETSU

*What helped you the most in getting ready to attend college?*

I am a second-year arts and science student at East Tennessee State University. I think the summer orientation was helping me get ready for going (to college). Also, because my mom and grandmother graduated from ETSU, I know the campus. I am proud to get to go to the same college as them. I always wanted to go to college and was so happy when I got to go.

*What has been the best part of your college experience so far?*

The best part of going to college is all the things I get to do: classes, dances, CPA (Center for Physical Activity) time, movies, and my work at The Reece Museum. I learned last year that I like working in the museum setting. So this year, I am working with Access ETSU to find a job in a museum or event center. I am so glad that ETSU accepted me, because I like going to college very much.

## Rachel Williams – Next Steps at Vanderbilt

*What helped you the most in getting ready to attend college?*

In high school, I was able to attend preview day. It helped me to understand the Vanderbilt campus more, helped me to understand that there are peer mentors, and that we are one community all together. Also, it showed me different classes we can take. Also, attending the Next Steps Summer Institute the summer before I came to Next Steps helped me to find new friends. It helped me to know what Next Steps is like, and to not be scared to advocate for myself.

*Is there anything you wish you had known or practiced more before starting college?*

I wish I learned to advocate for myself before starting college. I wish I learned how to communicate better with others. I wish I was better prepared to speak to a class and have the confidence to do so.

*What has been the best part of your college experience so far?*

The best part of my college career is participating in the apprenticeship program, getting the opportunity to work with young children at the Vanderbilt preschool (Acorn School). It has shown me ways to be a teacher and has given me the opportunity to help little children learn and grow.

## Christian Rice – University of TN-Knoxville FUTURE program

*What has your college experience been like so far?*

I'm a 3rd year student in the UTK FUTURE Program. FUTURE is a program where people with intellectual and developmental disabilities get the college experience and eventually get a job at the end. It also teaches you how to be independent and learn to be independent in an apartment or dorm or what have you. The end goal is to get a job but also you get to meet new people like other FUTURE students and mentors.

(Mentors) help you with emotional support if you need it. They also can take you to lunch or baseball games, football games and basketball games. FUTURE also has events called Fun Fridays where mentors and FUTURE students get to hang out and do exciting events like go to the zoo or go bowling or just have field day.

Here are some fun classes I've done so far:

* American Sign Language
* Volleyball
* Animation
* Soccer

And here are the FUTURE classes that we have to do for the program to help us:

* Digital literacy
* Career and life planning
* Life skills

*Can you tell us about your internships?*

I started off with working at VolDining. And it wasn't the right fit for me. There just wasn't enough people my age there and the job was just too tedious. The next one was Knoxville Community TV and that one was fun. I got to do interviews and edit them and post them on TV, which was cool, and it got my name out there.

And then I was a student worker for the FUTURE program itself. There I helped with office work. I scanned stuff. I helped with scheduling mentors and I checked the mail in the mail room and I got to welcome some FUTURE students to the program, which was awesome. That was one of my favorites.

*What are some things you have learned at college?*

Thanks to FUTURE, I live on my own in an apartment and meet so many friends. It's crazy. We go out, hang out, eat out, enjoy football games, baseball games, and basketball games. We cruise in a friend’s car, ride scooters, make funny jokes in ASL.

I enjoy college so much. It's on the FUTURE staff members to help us along the way. I can't wait for this new semester – so many adventures to come. This should be a fun time.

## Recent study lists skills that will help students get ready for inclusive higher education

A recent study offers a list of the skills parents say are most important to help students get ready for inclusive higher education. The parents surveyed all had children who had attended an inclusive program. The top 9 skills they most agreed on were:

1. Follow instructions or directions
2. Ask for help or clarification in a variety of settings
3. Manage medications independently
4. Demonstrate basic hygiene skills without regular prompting
5. Accept responsibility for their actions
6. Demonstrate resilience
7. Show kindness to themselves and others
8. Demonstrate personal safety awareness, understanding “stranger danger,” how to navigate safely in a new environment, know who to contact in an emergency and what to do when feeling unsafe
9. Show time management skills like tracking time on a watch or phone, following a schedule without prompts, and using a planner

[The study was published in the *Journal of Inclusive Postsecondary Education*](https://journals.gmu.edu/index.php/jipe/article/view/2947). A full list of 30 skills is included at the end of the published study.

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IMAGE DESCRIPTIONS:

* Photo of Amyra Perkins – she is a light-skinned young woman of color with her hair pulled back, wearing a black sweater and clear-rimmed glasses, seated at a table holding her phone and a bouquet of flowers next to her
* Photo of Rachel Williams – a black and white selfie photo of a young white woman sitting in her car; she has long light hair and glasses
* Photo of Christian Rice – a young white man with brown hair wearing an orange University of TN and jacket, holding up his student ID

## Supplement to previous article - Preparing for Inclusive Higher Education and Adulthood - 20 Powerful Strategies to Prepare Your Child for Inclusive Post-Secondary Education - Created by Karla Wade, Ph.D.

* Source: <https://thinkcollege.net/resource/transition-planning/20-powerful-strategies-prepare-postsecondary-education>

20 strategies:

1. Make sure your child is a regular attendee at an over-night, sleep-away camp
2. Have your child become comfortable with electronic communication, including email and attachments.
3. Empower your child to manage a schedule using a cell phone (calendar, timers, reminders, etc.)
4. Strategize a system for independent medication management.
5. Help your child practice talking about disability characteristics, best learning styles, and needs.
6. Sign up for a drama or improv group.
7. Have your child call and make appointments for doctor/dentist/advisor.
8. Give your child a budget for clothing. Step back from the selection process.
9. Support choice making.
10. Let your child fail, and talk through making a different choice next time.
11. Fill your life with interests other than the social/sports/activity schedule of your child. (i.e. Get your own life.)
12. Start a savings program for college.
13. Help your child become comfortable with down-time and using time constructively.
14. Support your child in volunteering for a cause or organization. (Excellent work experience!)
15. Build expectations for postsecondary life (working, living independently).
16. Use public transportation, even if YOU don't live on the bus line.
17. Dignify your child's desires with high expectations.
18. Open a bank account with your child. Give your child the debit card and train responsible use of money.
19. Encourage moderation strategies around food and money.
20. Use Family Support dollars to pay for inclusive camping experiences and extend that use for postsecondary programs.

# Have you seen it yet? Tennessee website for finding disability services gets major upgrade

Tennessee Disability Pathfinder, the state’s central source for free disability information and resources, went through some exciting changes last year. An overhaul of Pathfinder’s website makes it easier for people with disabilities to find needed services. The statewide portal can be found more easily at [TNPathfinder.org](https://TNPathfinder.org). Updated, interactive features match users anywhere in Tennessee with disability resources, service providers, and community events.

[Tennessee Disability Pathfinder](https://TNPathfinder.org) is a project of the [Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities](https://vkc.vumc.org/vkc/ucedd), part of Vanderbilt University Medical Center. It has been mainly funded by the Tennessee Council on Developmental Disabilities, which also led funding for the upgrade.

Pathfinder helps people with disabilities, family members, caregivers, educators, and other professionals find and access community resources, support, and services to meet their needs. Users can get help through:

* a toll-free helpline,
* online directory, and
* regularly scheduled community workshops across Tennessee.

Pathfinder’s diverse staff can help people of all ages, types of disabilities, and languages spoken. Many staff members have disabilities or family members with disabilities.

**New features of the Pathfinder website**Visitors can access more than 3,500 disability providers and resources from across Tennessee on the new website. Searching for information is more customized. Users can search based on:

* *Stage of Life***:** Choose from Prenatal/Infancy, Early Childhood, School Age, Transition/Young Adult, Adulthood, or Aging
* *Topic of Interest:* Twenty service categories to select, with a text box to type keywords
* *Diagnosis:* Type of disability or health condition
* *Benefit/Payment Options:* Forms of payment accepted by the agency provider, such as health insurance, government program, private pay, or no cost
* *Service Area:* Select counties where services are provided

Pathfinder’s website is still open for anyone to use without creating an account, but there are new features for users who create a profile:

* bookmark resources
* save past searches
* submit new agency resources and website links to be added to the site
* post events on the Pathfinder Events Calendar

The updated Pathfinder website also includes added accessibility features. An accessibility menu offers tools to adjust color contrast, magnification, and font styles. Users are also able to translate the website into one of eight different languages.

The updates to Pathfinder’s website have been a big success. In the past year, more than 8,000 users have visited the site, resulting in more than 105,000 page views. The most frequented topics of interest include:

* financial assistance,
* basic needs,
* social inclusion,
* education, and
* housing.

Here is what some users had to say after visiting Pathfinder’s website:

*“I am so happy that I found this website because I was able to get my daughter the services she needed.” – Sent anonymously via June 2022 website feedback survey*

*“Love the new organization and layout of the site so much! Pathfinder is improving all the time.” – Family member via June 2022 website feedback survey*

*“To have a site with these resources listed is very helpful. I appreciate that it is available.” – Person with disabilities via June 2022 website feedback survey*

*“I highly recommend Pathfinder’s free online portal. It’s basically a search engine for health-related needs in Tennessee. I have used it both personally and professionally – it’s quite comprehensive.” – Jack Read, Respite Voucher Program Manager, Tennessee Respite Coalition*

According to Pathfinder’s June 2022 website feedback survey, 73% of users have registered for an account with Tennessee Disability Pathfinder, 68% have searched for a program using the website, and 49% were able to connect to a resource in the community after using the website.

“This upgrade has allowed us to keep the important parts of Pathfinder’s website while adding new features that allow users to better access and save information,” said Pathfinder program director Megan Hart. “We could not be happier that it has been received with such enthusiasm and positivity.”

Pathfinder is also now available through the State of Tennessee’s app, “MyTN.” MyTN provides a single point of access to a growing list of government services. You can download the MyTN mobile app from any app store.

**New Pathfinder funding partnerships**The new Tennessee Disability Pathfinder website was also made possible through expanded State of Tennessee funding partners. The Council has worked for many years to increase partnerships to support Pathfinder in serving more Tennesseans. New partners include:

* Tennessee Department of Education
* Tennessee Department of Mental Health & Substance Abuse Services
* Tennessee Department of Human Services, Division of Rehabilitation Services
* Tennessee Department of Transportation

These join existing funding partners:

* Tennessee Council on Developmental Disabilities
* Tennessee Department of Health
* Tennessee Department of Intellectual and Developmental Disabilities

For more information about Tennessee Disability Pathfinder or to check out the new website, visit [TNPathfinder.org](https://TNPathfinder.org).

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# Have you heard about MAPs?

Medicaid Alternative Pathways to Independence (MAPs) is a new Tennessee program coming November 1, 2022. MAPs will help people with intellectual or developmental disabilities live, work, and travel independently in their communities. MAPs is a different approach to supports for independence and work skills. It uses technology as a foundation. The program is offered through the TN Department of Intellectual and Developmental Disabilities.

**Who is MAPs for?**

MAPs is for anyone who has an intellectual and/or developmental disability AND

* Will leave high school in the next three years OR
* Has already left the high school OR
* Is going to an inclusive higher education program OR
* Is waiting for long-term services in a program called Employment and Community First (“ECF”) CHOICES

**Why is MAPs needed?**

This program will offer services that help answer the question, “What is the plan after high school?” It will use technology and person-centered support to help the member grow their skills at home, at work, and in the community. The program will offer services for 3 years to help the member build their independence.

**How does MAPs work?**

The program will provide technology and supports like:

* A cell phone and apps, including a personal map. The map will give step-by-step directions to help the member get to important places in their community (like work, home, or places they visit with family and friends) without needing someone’s help.
* Other technology as needed to help the member stay safe at home or get help if they need it.
* Peer mentoring to help with learning new skills.

The program will focus on goals for independence at home, at work, and in the community. Those might be things like:

* Managing money
* Taking medications correctly
* Finding a good job
* Getting promoted
* Building relationships in the community
* Finding fun local places to go

MAPs services will last for 3 years. They will be provided by agencies who sign up to offer the program. People who are getting vocational rehabilitation (VR) services can still sign up for MAPs.

**How can I learn more?**

This short video from DIDD explains the MAPs program: <https://youtu.be/i_7AOi0T8cs>.

For more information about MAPs, visit [tn.gov/didd/for-consumers/maps](https://www.tn.gov/didd/for-consumers/maps.html). The website has a presentation with more details about the program, a one-page flier, and answers to frequently asked questions. You can also contact DIDD Youth Transition Director Jay Camperlino directly at: Jason.Camperlino@tn.gov.

The online application for MAPs will go live on November 1, 2022 – watch DIDD’s website and social media accounts for news.

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*Information adapted from DIDD’s website and family/persons supported presentations*

# DIDD grant program graphic for adult-size changing tables

Text of graphic: Ready to install an adult-size changing table at your business? Apply for a $5,000 grant at tn.gov/didd!

Best practices:

* powered and height-adjustable for safety of person and caregiver assisting
* placed in single occupancy restrooms, universal to gender
* room size of at least 10x14.6 feet. This allows for a turning radius of 60 inches for the wheelchair in the middle of the room and 36 inches of space at one end of the table.
* Clear signage at the entrance of the building.

# Precious Cargo Act: Privately Disclose Your Disability to First Responders, Law Enforcement

*By Council on Developmental Disabilities staff*

## Sidebar: How to Privately Disclose a Disability to Law Enforcement and First Responders

*Did you know that Tennesseans can privately disclose their disability for use by law enforcement and first responders? If you want to disclose your disability and need for help, fill out the “ Application for Precious Cargo Designation on a Tennessee Registration” form on the TN Dept. of Revenue’s website (*[*https://www.tn.gov/revenue/title-and-registration/forms.html*](https://www.tn.gov/revenue/title-and-registration/forms.html)*) and take it to your county clerk’s office.

If you need an accommodation or have questions, contact**revenue.support@tn.gov**.*

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One of our “at-large” Council members, Martez Williams, lives in Nashville. He was appointed to the Council by Governor Haslam in 2016 and was reappointed for a second term by Governor Lee in 2019. He is also a 2017 graduate of Partners in Policymaking®, our leadership development program for people with disabilities and family members.

Martez uses a wheelchair and needs canes to transfer in and out of his vehicle. “What happens if I get stopped by the police and ordered to get out of the car? If I reached for my canes, would the police officer think that I was reaching for a weapon?” As a Black man with a disability, the concern has plagued Martez, who did not want a public display of disability on his vehicle.

When Martez first brought these concerns to the Council in 2020, we supported him to share his perspective in an op-ed published in *The Tennessean* and with his legislators. In 2021, during a meeting with his representative, he learned of a bill already under consideration (HB0040/SB00110). The bill would allow people with communication barriers to disclose their disability to law enforcement through the vehicle title and registration system. Martez worked with the bill’s sponsor to add language about drivers needing “assistance exiting the vehicle” to the legislation. The “Precious Cargo Act” was passed during the 2021 legislative session. Martez was proud to attend the bill signing event with Governor Bill Lee and others who advocated for this issue.

Because Martez spoke up, and because policymakers listened, change is happening to help first responders know the specific needs of Tennesseans with disabilities. Now, Martez is working to get the word out about how Tennesseans with disabilities can apply for the new Precious Cargo designation.

The Council is here to make sure that voices like Martez’s are heard by policymakers. Councils on developmental disabilities were created so that people with disabilities and their families help shape the policies and systems that affect their lives.

# Meet our new Governor-appointed members

## Kimberly Boyd, Northwest TN Development District

Kimberly Boyd was recently appointed by Gov. Bill Lee to represent the Northwest Development District on the Council. She has a 12-year-old son, William, who goes by “Ty.” Ty has autism and is the recipient of a kidney transplant. Kimberly works for Amerigroup as the Employment and Community First CHOICES member advocate for the west TN region. She first became involved in the disability community when working as an Independent Support Coordinator in 2007.

Kimberly and Ty live in Martin with their toy poodle, Sophie. Kim's main areas of interest related to disability are increasing access to appropriate public education, support services, and health insurance. Right now, she also serves on councils related to the [TARP Center for Independent Living](https://www.tarp1.org/) in Paris, TN. She loves decorating, traveling, and spending time with family and friends.

## Sara Miller, Southwest TN Development District

Sara Miller was recently appointed by Gov. Bill Lee to represent the Southwest Development District on the Council. Sara was born Deaf and says she became an active participant in the disability community when she began her teaching career in Deaf Education in 2008. In 2019, Sara founded her business, Language Priority, to design apparel and merchandise focused on ASL (American Sign Language) and the Deaf community. She also teaches online ASL classes.

Sara and her husband, Bryce, live in Jackson with their 2 dogs, one of whom is also deaf. She is passionate about accessibility to information, education, and communication. She shared, “I want to be a part of the change on behalf of the disabled community in Tennessee. I hope to use my lived experiences and those of others to help make changes for the better!”  Sara loves reading, drawing, and creating designs for her business.

## Bliss Welch, Southeast TN Development District

Bliss Welch was recently appointed by Gov. Bill Lee to represent the Southeast Development District on the Council. Bliss became a self-advocate during her teen years when diagnosed with Limb Girdle Muscular Dystrophy 2B/R2. During her reign as Ms. Wheelchair Tennessee 2013, she said she “developed a greater understanding of the need to advocate for change in policies so individuals with disabilities are viewed and treated as equals in society.”

Bliss and her 10-year-old daughter, Annabelle, live in Harrison, TN. Bliss works as an Accounts Specialist at Island Cove Marina & Resort. For the past decade, she has served as a volunteer for the Ms. Wheelchair Tennessee organization to empower other wheelchair-mobile women to find their voices and advocate. She also serves as the Chairwoman for the “[Harvesting Inclusive Play](https://harvestinginclusiveplay.com/)” committee in Chattanooga, a group partnering with the City of Chattanooga and the Kiwanis Club of Chattanooga to raise funds for a universally inclusive playground.

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# Back cover: Membership and Staff

Tecia Puckett Pryor, Council Chair - Smithville

Ryan Durham, Vice Chair - Lawrenceburg

Lisa Johnson, Leadership Committee Chair - Greeneville

Sarah Cripps, Public Policy Committee Chair - Smithville

Edward Mitchell, Communications Committee Chair - Jackson

Alicia Hall, Audit Committee Chair - Cordova

Kim Boyd - Martin

Alison Bynum - Smyrna

Shontie Brown - Memphis

Jody Cheek - Johnson City

Roddey Coe - Ooltewah

Kezia Cox - Knoxville

Will Edwards - Knoxville

Diamond Grigsby - Murfreesboro

Chrissy Hood - Pulaski

Clancey Hopper - Lebanon

Sara Miller - Jackson

Brigham Scallion - Bells

Bliss Welch - Harrison

Brent Wiles - Nashville

Martez Williams – Nashville

STATE AGENCY REPRESENTATIVES

Commissioner Brad Turner, Department of Intellectual and Developmental Disabilities

Commissioner Penny Schwinn, Department of Education

Assistant Commissioner Kevin Wright, Department of Human Services, Vocational Rehabilitation Services

Commissioner Marie Williams, Department of Mental Health and Substance Abuse Services

Interim Commission Dr. Morgan McDonald, Department of Health

Chief of Long-Term Services and Supports Katie Moss, Division of TennCare

Executive Director Richard Kennedy, Commission on Children and Youth

Executive Director Ralph Perrey, Tennessee Housing Development Agency

Executive Director James Dunn, Tennessee Commission on Aging and Disability

UNIVERSITY CENTERS FOR EXCELLENCE REPRESENTATIVES

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

Bruce L. Keisling, Ph.D., Executive Director, UT Center for Developmental Disabilities

PROTECTION & ADVOCACY

Lisa Primm, Executive Director, Disability Rights Tennessee

NONPROFIT ORGANIZATION

Allie Haynes, Membership Manager, Rural Health Association of Tennessee

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Lauren Pearcy, Executive Director

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Ashley Edwards, Assistant to the Executive Director

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Brian Keller, General Counsel (Public Policy)

Jolene Sharp, Chief Public Information Officer

Emma Shouse Garton, Public Information Specialist

Cathlyn ("Cat") Smith, Director of Leadership Development