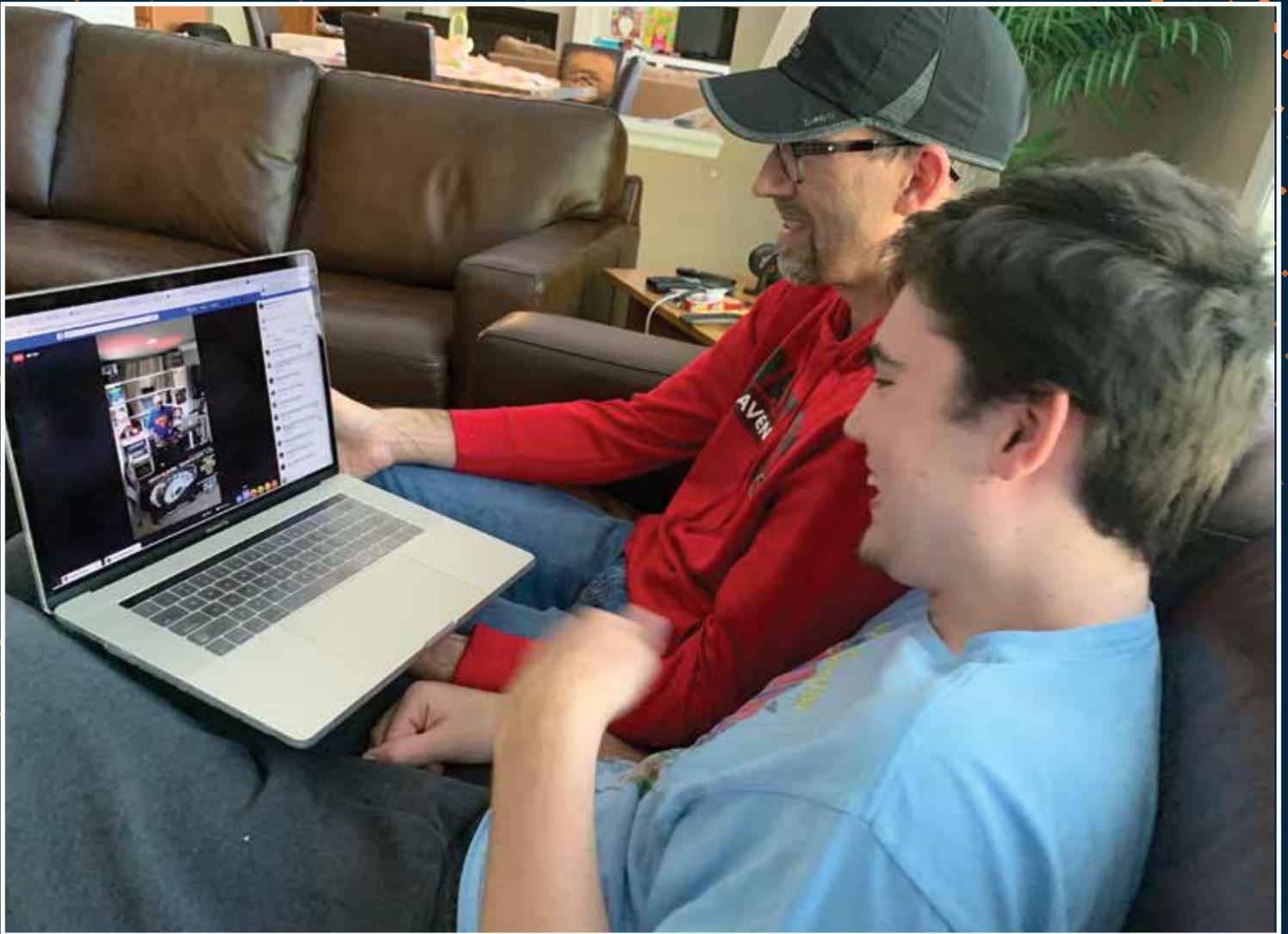


# breaking ground

NUMBER 102

MAY 2020



## Searching for Silver Linings

TN

Council on  
Developmental Disabilities

Dear readers,

We have all weathered some very unusual times these past few months. I have been reminded again of how important it is for the Council to stay deeply connected to our disability community across the state.

In this issue of *Breaking Ground*, you'll read about how that connection has allowed us to serve a unique role during the COVID-19 crisis. You'll also read about why your input is needed right now to help guide the Council's work for the next five years.

Times of crisis tend to clarify the things that are most important in our lives. I hope you have found a solid circle of support, even as we all stayed apart. I am more grateful than ever for the love of family, for the important work of the Council, for our amazing staff who make it happen through every challenge – and for each one of you.

The needs in our disability community have been great through this crisis. Many still face hardship as we work our way toward a new normal. Our community will be more important than ever as we look for ways to support each other. The Council will continue to listen and respond to the needs that emerge, as we also continue our critical, long-term work.

Thank you for being a part of this remarkable community.

Sincerely,

Wanda Willis  
Executive Director



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**On the Cover:** Aidan Vogus and his dad stay connected during social distancing. Aidan’s Ravenwood High Assistant Principal Reggie Mason puts on a Facebook Live DJ show each week during the quarantine to bring people together.

Learn more about the Tennessee Council on Developmental Disabilities.

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This project was supported in part by grant number 1901TNSCDD, 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.



Tennessee Council on Developmental Disabilities, Reauthorization No. 344067, March 2020, 12,000 copies. This public document was promulgated at a cost of \$1.69 per copy.

# How Your Input Can Shape the Council's Work for Change

By Jolene Sharp, Chief Public Information Officer, TN Council on Developmental Disabilities

Have you ever faced a problem with a disability service that was so frustrating, any solution felt impossible? Have you ever found a program that was so wonderful, you wished you could make it available everywhere?

Progress for people with disabilities depends on stories like those. Finding and using supports to live a full life can be very hard work. It also gives every member of the disability community a powerful force for change: personal experience.

You aren't alone in finding how to turn those experiences into change. Many years ago, a law was written that would change the landscape for people with developmental disabilities and their families. The vision laid out in that law continues to take shape today – but it relies on your input.

## A Law with a Bold Vision

Councils on Developmental Disabilities, which exist in every state and U.S. territory, were created by the federal Developmental Disabilities Act (DD Act). The DD Act is a beautiful law that was largely written by families of people with disabilities.

The DD Act's stated purpose is to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that

promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."

The DD Act means you get a say in policies and practices that support people with disabilities to live the lives they want for themselves, as full members of their communities. The Act doesn't make empty promises. It includes concrete ways to make change happen. One of those ways is through state Councils on Developmental Disabilities.

How do councils like ours help make the DD Act vision a reality? The answer could fill many pages. We'll focus here on the tool that councils use for planning and tracking progress: the state plan.

## Putting the DD Act into Action

The DD Act gives councils the work of:

- supporting advocacy (making sure the voices of people with disabilities are heard),
- building capacity (growing the supports that are available),
- and systems change (making the disability services system better).

The Act then gives the structure for councils to use to do that work. It requires each council to write a new state plan every five years. The plan outlines major goals, and shorter-term, more specific objectives.

The state plan is our map for how

we will do the work given to us by the DD Act. It guides where we invest our efforts and funds, and how we know whether we're making progress. In fact, we send updates to the federal government every year to show our progress on state plan goals.

## We Need YOU

The Tennessee Council's current state plan began in 2017 and ends next year, in 2021. As you may imagine, we start working on a new state plan many months ahead of time.

The DD Act says our work must be guided by people with developmental disabilities and their family members. Before we can write a new state plan for the Tennessee Council, we need your input. This is where your experiences can help shape change.

For many months, Council staff have worked to create a public input survey. This survey will form the basis of our state plan. It's how we hear from the disability community all across Tennessee about what issues are most important.

### Take the Council Public Input Survey

Take our survey online today!  
Visit [bit.ly/PublicInput2020](https://bit.ly/PublicInput2020).

If you need help filling out the survey, call Council Director of Program Operations Alicia Cone at **(615) 253-1105**.

We need your voice. This survey gives you the chance to tell us what services and supports you use, how well they are working, and where there are gaps. You can tell us where we should focus our work, and what most needs to change. The more people who respond, the better our information will be as we plan our goals for the next five years.

Without your input, we won't know about that service that felt impossible, or the program that turned things around for you. Those are experiences only you can share.

### Building on Progress Together

The Council has been working for decades to grow opportunities for people with disabilities in Tennessee. We have seen – and helped create – great change in that time. As a result of our work:

- There are college programs and more full-wage jobs for people with developmental disabilities.
- Home ownership is a reality for many people with developmental disabilities.
- Child care resource centers help providers serve young children with developmental disabilities.
- Next Chapter Book Clubs have members in locations around the state.
- More than 600 Tennesseans have become advocacy leaders through our free Partners in Policymaking® leadership course.
- Council funding allows people to find and connect to thousands of services through Disability Pathfinder, the statewide disability services portal.

None of that would be possible without the guiding input of Tennessee's disability community. Your perspectives help us understand the needs and challenges of our system, and how our work can open new doors for people with disabilities. While we are proud of the progress we have made together, we know many challenges remain.

We look forward to the work ahead. Help us make Tennessee the place we all want it to be for people with developmental disabilities. We can't wait to hear from you! ■

Want to learn more about the Council's work? Read other examples of key projects over the decades in our online brochure: [bit.ly/TNCouncilOverview](http://bit.ly/TNCouncilOverview).

## The Council's Current State Plan (2017-2021)

### Goal 1:

#### Developing Leaders

Prepare Tennesseans to be leaders who influence policy and practice through scholarships, information, internships, and training.

#### Examples of projects

**under this goal:** Partners in Policymaking®, Council scholarship fund, other training and education opportunities

### Goal 2:

#### Impacting Policy and Practice

Improve Tennessee policy and practice through tracking key legislative activity, developing and nurturing collaborations, and providing resources for demonstration projects.

#### Examples of projects under this goal:

Employment Roundtable, Disability Policy Alliance, providing perspective on the impact of proposed laws, advising as requested on disability-related legislation. This includes all the Council's work on federal and state policy priorities. Visit the council website at [tn.gov/cdd](http://tn.gov/cdd) for more details.

### Goal 3:

#### Informing and Educating Stakeholders

Implement public information activities that increase Tennesseans' awareness of disability policies and practices.

#### Examples of projects

**under this goal:** *Breaking Ground*, e-newsletters, social media, Tennessee Disability Pathfinder

# The Council's Role In Times of Crisis

By **Jolene Sharp, Chief Public Information Officer, TN Council on Developmental Disabilities**

It's been a difficult several months for many in Tennessee, and around the world. As the COVID-19 virus reached our state in March, we found ourselves dealing with a situation we had never faced before. Many in our communities faced extra challenges unique to being a person with a disability during a public health crisis.

At the Council, we also found ourselves struggling to find our footing. Staff transitioned from the office to working from home full-time. We, like so many, were relying on virtual communication to stay connected. Our inboxes were flooded with information. We needed to answer the question: in a crisis unlike anything we have seen before, how can the Council best serve people with disabilities in Tennessee?

The answer took shape as we crafted a COVID-19 communications plan. The plan helped us think about how our larger agency role and goals apply during a crisis. It has helped us stay focused on the unique value we can offer during an unfolding situation.

The Council is the only disability-related state agency that doesn't offer direct services. We exist to improve services so people with disabilities can live self-directed lives as fully included members of their communities. We work for change from within government while staying directly connected to people with disabilities through our Council members. (We also stay connected through input from the broader Tennessee disability community. For more about that, see "How Your

Input Can Shape the Council's Work for Change" on page 4

Our grounding in that unique role helped us outline four key areas for our COVID-19-related work:

## Informing policymakers in Tennessee and Washington, D.C. – We focused on helping policymakers:

- Communicate critical information to people with disabilities, and
- Understand and meet the needs of the broad disability community – not just those already receiving services from state programs.

We surveyed our Council members to understand their greatest COVID-related concerns, questions, and needs, and then shared insights from their responses with the Governor's office and leaders of key state agencies. We tracked down answers to questions raised by Council members and others and shared those answers with the public through our email newsletters and social media.

We tracked and shared surveys from other agencies and organizations about COVID-19 needs, making sure the disability perspective is heard.

## Creating and sharing tools about COVID-19 specifically for people with intellectual and developmental disabilities –

In a crisis, it is still critically important to talk to people with disabilities rather than just about them. The Council began collecting the very best resources about COVID-19 specifically for people with disabilities. We have updated our Facebook and website lists often as new tools become available. Tools range from social stories for children to short videos by self-advocates to more detailed medical information for adults. When we saw gaps in the tools available, we created new ones. This included a visual symptoms checklist to help people who might not use speech to say how they are feeling. All of these resources

## What did the Council COVID-19 grants fund?

|   |   |
|---|---|
| <h3>Technology</h3> <ul style="list-style-type: none"> <li>• Tablets</li> <li>• Computers</li> <li>• Printers</li> <li>• Internet access</li> </ul> | <h3>Recreational Activities &amp; Educational Supplies</h3> <ul style="list-style-type: none"> <li>• Gardening and art supplies</li> <li>• Online arts and exercise classes</li> <li>• School supplies and tutoring</li> <li>• Indoor and outdoor play equipment</li> </ul> |
| <h3>Other</h3> <ul style="list-style-type: none"> <li>• Sensory toys</li> <li>• Therapy mat</li> <li>• Stroller and high chair</li> </ul>           |   |

have helped support people with disabilities in being informed and self-directed during the crisis.

The Council also provided concrete support for people with disabilities through new grants, announced in early April. The grants funded technology to support people with disabilities in staying connected and engaged during social distancing. Applications immediately flooded in. Priority was given to applications from rural areas, where families face extra barriers to staying connected.

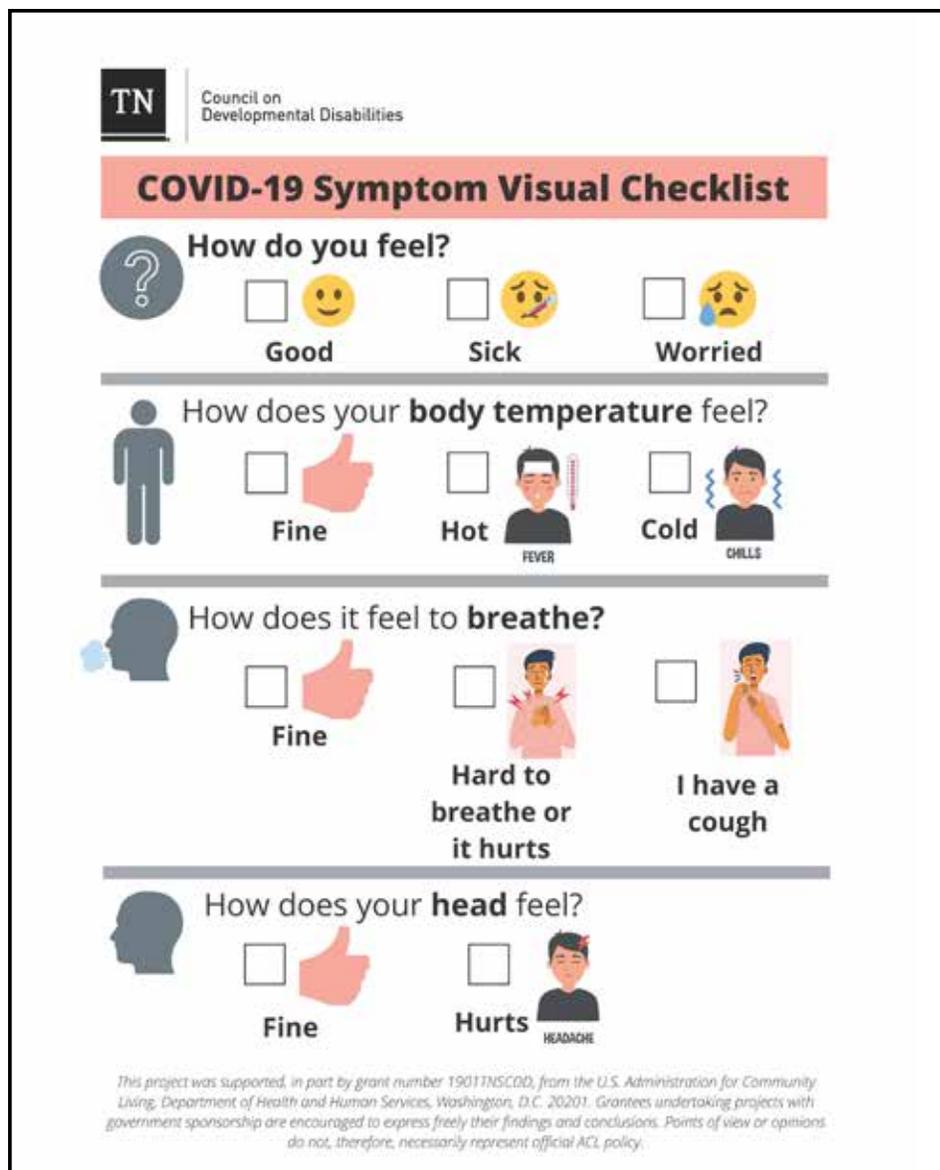
**Sharing national and state policy updates** – The Council’s role within government gives us close access to important information about national and state policy changes. During a crisis, policy can change very fast. The Council’s public policy newsletter has been a key tool to help people with disabilities get clear, understandable information about COVID-19-related policy changes. Updates from state agencies are often written for provider agencies or other professionals. Average citizens can have a hard time knowing how changes might affect their lives. We have worked closely with our contacts at state agencies and national policy groups to get up-to-date, accurate information in simple language to the disability community in Tennessee.

**Telling the stories of coping** – Our direct connections allow the Council to tell the stories of Tennesseans with disabilities. This continued to be important during the COVID-19 pandemic. Government and policy must be informed by the real experiences of citizens. Interviews with

Council members and others from the disability community help make the issues personal. At a time when we have all stayed apart, the stories of how others in the disability community are coping have helped us feel hopeful and less alone.

As we learn more in the coming

months about what life will look like after COVID-19, the Council will stay focused on the unique ways we can support people with disabilities in our state. If you have questions or suggestions about how we can help, please don’t hesitate to contact us: TNDDC@tn.gov, or 615-532-6615. ■



*As the Council found gaps in available information, we created new tools. This check list helps people who don't use verbal speech tell how they are feeling.*

**You can view, download, and print tools from our COVID-19 resource list.**

**On Facebook:** [bit.ly/CDDcovidFB](https://bit.ly/CDDcovidFB)

**On the Council website:** [bit.ly/CDDcovidWeb](https://bit.ly/CDDcovidWeb)

# A Will to Farm

## 150-Year Family Tradition Continues with TN AgrAbility

By Eileen Legault, TN AgrAbility Project, UT Extension Area Specialist and Jason Barber, Cattle Farmer

Those of us with sight might assume that farming depends on visual work. Unionville native Jason Barber is proving what is possible with limited sight. Using support and technology through Tennessee AgrAbility, Jason is continuing his family legacy of farming.

Tennessee AgrAbility is a USDA-funded project led by University of Tennessee (UT) and Tennessee State University (TSU) Extension. It is dedicated to improving the quality of life of farmers and agricultural workers with disabilities.

TN AgrAbility partnered with the TN Department of Human Services' Division of Vocational Rehabilitation and its Tennessee Technology

Access Program to provide the support and assistive technology\* Jason Barber needed to continue to work on his family farm.

### A 150-Year Legacy at Risk

Jason Barber is a seventh-generation Unionville, Tenn. farmer who manages a 100-acre beef cattle and hay farm. The Barber family has been farming since 1866, and would not think of doing anything else.

In 1998, Jason was diagnosed with Retinitis Pigmentosa (RP), a chronic and degenerative eye condition. His RP progressed to the point of legal blindness, with tunnel vision and night blindness, by 2008.

Farming with a visual impairment is a unique situation for a farmer. "I am grateful for my friends' and family's help," Barber said. "Farming can change at any moment, and decisions must be made on the fly, and in seconds, sometimes. RP affects my day-to-day operations, but I have learned to make the best of it. If farming was easy, everyone would be doing it! I will continue farming as long as I safely can."

Jason and his siblings are caregivers for Gale, his 75-year-old dad, who has Parkinson's and dementia. Gale is Jason's eyes and hands. Some days are more challenging, but they make a great team.

Gale has feared that as the years pass, he will become less able to help Jason. "It puts my mind at ease, knowing that the State of Tennessee is pitching in to help my son keep farming and keep the family tradition going," Gale said.

### Powerful Partnerships

Jason says fate intervened when Jessica Barber, his sister-in-law



Finis Stribling, TSU Area Specialist (far right), and John Teague, Bedford County Extension Director (2nd from left), discuss ideas with Jason and Gale Barber to help farmers keep farming.

\* Assistive Technology (AT) is any item, piece of equipment, or system used to help a person with a disability or long-term health condition to keep or improve functional abilities.



*Jason “sees” the cattle tags with his digital wand.*

who lives in Knoxville, met Eileen Legault, an AgrAbility specialist. Jessica asked if AgrAbility worked with farmers with disabilities across Tennessee. Eileen explained that yes, Extension offices are in all 95 counties.

Members of the TN AgrAbility team visited Jason to assess his farm, make recommendations, explain services, and find assistive technology solutions. The team’s recommendations built on the work Jason had done over the years to adapt his facilities so he could work by feel and memory.

Jason skillfully walks around

the farm without help, and “sees” things others overlook. He says his other senses are very alert now. Jason voluntarily stopped driving in 2008, when he knew his vision was decreasing. His biggest mobility challenge is depending on others to drive him.

The technology team focused on making use of his remaining vision to help Jason with everyday life. Their recommended solutions included a digital wand to help Jason tag and identify the cattle, and cattle chutes and gate options to help him navigate without being able to see contrasting colors.

AgrAbility saw the chance for more partnerships to fully support the Barber farming legacy. To help Jason pay for the assistive technology he needed, Eileen Legault referred him to the Division of Vocational Rehabilitation’s Blind and Visually Impaired Services.

Vocational Rehabilitation funded an iPad and the recommended digital cattle wand, called an “Electronic Identification Tru-Test Stick Reader.” The wand helps Jason “see” the cattle tags. It uses Bluetooth® wireless technology to share information to smart devices.

*Continued on page 15*

# Searching *for* Silver Linings

## *How the Vogus Family Navigates COVID-19*

By Jen Vogus

**A**s parents of two children (Aidan-18, Eleanor-9), my husband Tim and I were anxious about the demands of COVID-19 and the stay-at-home order. How could we balance working full-time from home, educating our kids, maintaining some semblance of household order, and keeping ourselves healthy AND sane? We grew more worried as the weeks turned into months largely confined to our home.

Our biggest concern being at home for a long period of time was for our son, Aidan. Aidan has physical and intellectual disabilities due to a novel chromosomal deletion (STXBP1), and for all his life he has had a strong dislike of being stuck at home, even for a weekend. Aidan strongly prefers a structured day with activities outside the home, especially activities with other people, and usually lots of them. His disability causes him to be functionally non-verbal, so without this structure, frustration, stimulatory behaviors, and yelling make their appearance. As a result, our weekends and holiday breaks are usually highly planned. Tim and I often laugh about how we never imagined going to so many air shows, motorcycle races, renaissance festivals, roller coasters, superhero movies, and Dave Matthews Band concerts! Despite the challenges Aidan faces, one thing he does not lack is enthusiastic interest in a variety of activities and events.

On top of this concern was also disappointment. This spring had big milestones and important events for Aidan. Aidan's 18th birthday and high school graduation were upcoming (in April and May). We were planning a big graduation party, with a large number of family, friends, and others from across the country who've mattered to Aidan. Besides those once-in-a-lifetime events, there was the planning for his transition program next fall, the Easter holiday that was usually spent with family, our trip to Disney World to celebrate graduation right after the school year ended, and multiple concerts that were getting canceled and postponed.

So what have we been doing to relieve our worry and



*Left: A go-to activity with Aidan is to walk to the train tracks.*



Sister Eleanor involves Aidan in her hands-on science experiments.



A trip back in time: Aidan and Ryan went to preschool together at Vanderbilt's Susan Gray School.

frustration and to acknowledge those special moments? How have we adjusted to a new way of daily life and managed to stay (mostly) happy together as a family? I'll share a few tips that worked for us.

### **Take a trip back in time to rediscover old things and make them new.**

We've gone through closets in search of clothes that are too small and explored boxes of memory items from years past. We even came across party hats from Aidan's first birthday! Aidan's sister, Eleanor, took it upon herself to add an eight to the one and declared it the perfect accessory for his 18th birthday!

Years ago, I taught high school earth science and have promised the kids I would get out my boxes of rocks and minerals that I stored away. We finally did, and they thought it was so cool. Eleanor involved Aidan in her hands-on science experiments, like the erupting volcano.

I am a photographer and was editing senior photos I took of a close friend's son. Aidan and Ryan went to preschool together at Vanderbilt's Susan Gray School, and

Aidan was so excited to see the photos of his friend. We've spent lots of time going through old photo albums and looking at pictures of when Aidan and Eleanor were little. They love hearing stories of when they were babies!

### Get out and go... safely!

When Aidan gets bored or frustrated, he is always happy to take a break and go outside. Our go-to activity with Aidan is to walk to the train tracks in hopes of watching one go by. If it does, the engineer usually honks and waves, which makes Aidan's day. The sunshine and fresh air is all Aidan needs sometimes. Other times, it's taking a drive to the railyard or the airport viewing area to watch from the car as trains or planes come and go. He is also content sitting on the deck, watching the bunnies, birds, and bees go about their business, or watching the neighbor's yard get mowed.

Taking a break is not important only for Aidan. Tim and I are both used to having daily time to ourselves. Going for a walk while listening to music or a podcast or even taking a walk into another room with headphones on makes a difference.

### Find creative ways to connect with others you care about.

One of Aidan's favorite people is Dr. Reggie Mason, an assistant principal at Ravenwood High School. Aidan loves stopping by his office to say hi as often as he can. Dr. Mason has put on a Facebook Live DJ show each week during the quarantine to bring people together to connect, enjoy music, and forget about their worries for a bit. Aidan thought it was so cool to see him scratching and playing old-school jams! And Tim loved it too ... rap music is his favorite.

Easter is usually spent with family, but we were able to make the best of it by FaceTiming with entire family scattered all over the country. We've never done this



*A new way to holiday: Celebrating Easter with family scattered all over the country.*



JENVOGUIS

*Aidan enjoys sitting on the deck, watching the bunnies, birds, and bees go about their business.*

before, but we will likely never have another holiday apart without it.

### Don't be too hard on yourself and appreciate those little things.

As important as all of this is, we realize that this is an unprecedented experience and is not easy. Despite what Facebook and Instagram show, it's OK just to get through it! But hopefully a little time traveling, getting out and about (safely), connecting (virtually) with a range of people and activities that matter, and showing ourselves a little compassion makes it doable as parents and people.

*Jen is the founder of AbleVoices, a non-profit organization that teaches photography to people with disabilities as a means for self-expression, empowerment, and advocacy. She is also a 2007 graduate of the Partners in Policymaking® Leadership Institute. Learn more about Jen and AbleVoices at [www.ablevoices.org](http://www.ablevoices.org). ■*

# Katie Beckett Waiver

## *What is it and what do families need to know?*

Content adapted from <https://www.tn.gov/didd/katie-beckett-waiver.html>

“Katie Beckett” waivers are Medicaid programs for children with disabilities and complex medical needs. The important aspect of many Katie Beckett programs: they include children who otherwise would not qualify for Medicaid because their family’s income is too high.

In 2018, Tennessee passed a law to create a Katie Beckett program just for children who otherwise would not qualify for Medicaid. Right now, Tennessee is waiting for the federal government to approve the state’s plans for the program. The program will be managed by the state’s Medicaid program, TennCare, and the TN Dept. of Intellectual and Developmental Disabilities (DIDD). Those agencies are getting ready to start the program as soon as possible once it is approved.

### **How will the program work?**

Tennessee’s Katie Beckett program has two parts.

#### **Part A (Managed by TennCare Managed Care Organizations)**

- Will serve up to 300 children with the most significant disabilities or complex medical needs.
- Will enroll based on a thorough assessment of needs and Medicaid eligibility process.
- Children in Part A will be enrolled in Medicaid, which means they will have access to full Medicaid benefits like home health, private duty nursing, durable medical equipment and supplies, and occupational, physical, and speech therapies - in addition to the services in the Katie Beckett program.
- Children in Part A will also get up to \$15,000 a year in home and community-based services. These are non-medical services that help families care for children in their homes, like respite for caregivers and home/vehicle modifications.

#### **Part B (Managed by DIDD)**

- Will serve up to 2,700 children with disabilities or complex medical needs who do not qualify for Part A.

- Will enroll on a first come, first served basis when the program opens.
- Children in Part B will not be enrolled in Medicaid.
- Children in Part B will get up to \$10,000 a year in home and community-based services, with flexibility to choose any or all of the following services within their budget: help paying insurance premiums, a healthcare savings type account, respite, or different types of services from a community-based provider.

### **When and how can families sign up?**

TennCare and DIDD have been collecting forms from people who are interested in applying for the program. This is not an official application for the program and does not put you “in line” for a spot. But if you fill out an interest form, DIDD and TennCare will let you know when sign-ups start and will share other information about the program.

To fill out an interest form, call your DIDD Regional Office at:

- West Tennessee Regional Office: (866) 372-5709
- Middle Tennessee Regional Office: (800) 654-4839
- East Tennessee Regional Office: (888) 531-9876

Not everyone who fills out an interest form may qualify for the program. Katie Beckett will serve as many eligible children as program funding will cover.

### **Where can I find updates and more information about the program?**

To stay up-to-date on the Katie Beckett Program, go to [www.tn.gov/tenncare/long-term-services-supports/katie-beckett-waiver.html](http://www.tn.gov/tenncare/long-term-services-supports/katie-beckett-waiver.html) or [www.tn.gov/didd/katie-beckett-waiver](http://www.tn.gov/didd/katie-beckett-waiver).

You can also follow the Department of Intellectual and Developmental Disabilities and TennCare on Facebook and Twitter. ■

# True Accessibility Means Dignity in Public Restrooms

By Chrissy Hood, Council on Developmental Disabilities member, South Central TN Development District

Having two older and active sisters, our daughter Alaina has been on-the-go since she was a baby. We call her our social butterfly, because she loves to be around people. She enjoys attending Martin Methodist Redhawks volleyball, soccer, basketball, and softball games, and going to the mall to people-watch.

Alaina also has autism, cerebral palsy, epilepsy, and a disability called Phelan McDermid Syndrome, along with other complex medical needs. Being out in her community has gotten harder as Alaina has grown. One of the main barriers is one not many people think about: access to appropriate and accessible changing tables.

Approximately 200,000 Tennesseans (4% of the population) needs help with one or more activities of daily living. Help with toileting is a common need for adults who are aging or have disabilities and

other conditions. Many adults and children need access to changing spaces that are larger than a baby changing table. Everyone deserves a safe, dignified, and clean toileting experience.

Though the need exists widely, most communities do not have any adult-sized changing tables. We have had to lay Alaina on the nasty bathroom floor, take her to our van to change her on the floor, or simply stay at home and keep her from being a part of her community. It affects the entire family. There have been many times we had to tell Alaina's sisters we could not go to a specific event or place because we had nowhere to change Alaina.

This is not in line with civil rights and disability laws like the Americans with Disabilities Act and the Olmstead Act. Most people are not aware of the problem. That's why I know it is important for me to tell

my story. When I spoke to my legislators at Tennessee's Disability Day on the Hill, I realized that people will support this issue once they hear our personal stories.

Would you want to change your loved one on a dirty bathroom floor or keep them isolated at home?

Accessibility is about more than being able to physically get into the restroom. Truly "universal" changing spaces are height-adjustable, adult-sized changing tables. This means the table is the length of an average adult when they lie down and can also go up and down so the person does not have to be lifted. This is safer for the person and their supporter.

Other states are starting to pass laws requiring universal changing tables in public spaces. In Arizona, a new law requires publicly-funded renovations or new buildings to include an adult changing table in family restrooms. Florida is considering a law that would require many public areas to have an enclosed, assisted-use toilet area. Similar bills have been proposed in California, Georgia, Maryland, Michigan, New Hampshire, New York, Ohio, Oklahoma, Pennsylvania, and Wisconsin.

There are bright spots of progress right here in Tennessee. For example, Alaina enjoys playing Miracle League accessible baseball. Our field in Lawrenceburg, Tenn. was organized through Abigail's Plan, a nonprofit started by Tommy Lee Kidd (former Chair of the TN Council on Developmental Disabilities). During construction of the



An example of a full-size, height-adjustable changing space.

field, I talked to Tommy Lee about the need for a universal changing table. He immediately got on it, and one was installed in the third base bathroom. This is a huge blessing to the players and families. Earlier this year, Nashville International Airport installed a universal changing table that is height adjustable. This was a huge victory for many people with disabilities and their families who use the airport.

Policymakers, businesses, and advocates need to hear more stories to understand the need and the policy options to address this problem. The Centers for Disease Control estimates 30% of the population has a disability. Many of us will, at some point, support a loved one who needs care. Disability is the one minority population that any of us could join at any time. We can acquire a disability because of disease or an accident; if we are lucky to live long enough, many of us will likely age into disability. Disability issues are the responsibility of us all. Let's make the world



*The Hood family*

accessible and dignified for all of us.

Read more and get involved at <https://dignifiedchanges.org/>.

*Chrissy Hood lives in Pulaski and is the mother of a teenage daughter with Phelan McDermid Syndrome, autism, epilepsy, cerebral palsy, and various complex medical conditions.*

*Passionate about increasing access to information in rural communities for families who are impacted by disability, Chrissy founded a parent support group in her community. She is the Chair of the Giles County Special Needs Support Group and also serves as Family Liaison and volunteer for the Unlimited Special Needs Ministry. ■*

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## **WILL TO FARM...** *Continued from page 9*

The OrCam MyEye 2, also funded by Vocational Rehabilitation, allows Jason to turn visual information (like text, faces, products, and colors) into audio information. This has obvious benefits for increased independence and farming tasks, like reading the labels on animal medicines.

For an updated record-keeping system, Eileen referred Jason to Kevin Ferguson, Extension Area Specialist in Farm Management with the UT MANAGE Program.

Meredith Bailey with STAR Center and Tara Janssen, an Occupational

Therapist, also worked together to help Jason continue farming safely. STAR Center recommended Zoom-Text to magnify and read everything on his computer screen. Access to the computer helps Jason with his farming business tasks, such as working with Excel spreadsheets and databases, and YouTube research.

### **A Will to Farm**

Jason loves technology and continues to learn new features. He spends time online, researching ways to help himself and other farm-

ers. In fact, he has been in communication with Tru-Test developers in New Zealand, in hopes they will add more features to their digital wand to aid low-vision and aging farmers.

We can't wait to see what new solutions Jason finds. He is a living reminder of the farmer's saying: "Where there is a will to farm, there is a way."

Contact TN AgrAbility for more information: [AgrAbility@tennessee.edu](mailto:AgrAbility@tennessee.edu) or 865-200-4527. Visit [www.agrability.org](http://www.agrability.org) and follow us @TNA-grAbility on Facebook. ■

# Learning about Disability Policy Will Make Me a Better Special Ed Teacher

By Lauren McCabe

This past year, I have been grateful to be the public policy intern with the Tennessee Council on Developmental Disabilities under Public Policy Director Lauren Pearcy. This experience increased my understanding and appreciation for all the committed people working at the state level to ensure Tennesseans with disabilities and their families have the opportunity to live the lives they choose.

My interest in disability policy came from my experiences as a peer mentor with Next Steps at Vanderbilt, the inclusive higher education program for students with intellectual and developmental disabilities. I saw how the Higher Education Opportunities Act and other systems paved the way to higher education for these students who wanted a college experience. The power of policy to transform opportunities for people with disabilities moved and inspired me.

From my experiences with Next Steps, I decided to study special education at Vanderbilt. My education focused specifically on students with intellectual disabilities, autism, and multiple disabilities. I especially focused on older students and post-secondary adults. I wanted to increase my knowledge of disability policy, and the Tennessee Council on Developmental Disabilities was the perfect fit. Through this internship, I had the opportunity to learn about disability policy work at the statewide level through many hands-on and research experiences.

I am thankful for the numerous shadowing opportunities Lauren Pearcy provided me during legislative sessions, policy workgroups, and Disability Day on the Hill activities. These hands-on experiences gave me a real look into the whole “team” of people it takes to develop effective policies.

I was grateful for the willingness of Council members



*Lauren McCabe finished her internship at the Council and graduated with a Master's in Special Education from Vanderbilt's Peabody College in May. We know how lucky her new students in Chicago will be to have her.*



*Lauren McCabe and Council Public Policy Director Lauren Pearcy*

to share their successes and challenges with the disability service system. Pairing a disability policy issue with a real person and story motivates us to create effective policies that solve problems. There are many personal stories of experiences with the special education system, accessible transportation, supported decision-making, and voting accessibility that I will carry with me into my professional future.

The COVID-19 pandemic has also created an interesting new layer to disability policy. It has opened my eyes to how important it is that the voices of people with disabilities are heard when responding to nationwide challenges.

My main research project while interning with the Council was working on their Comprehensive Review and Analysis (CR&A). The CR&A is a critical function of state councils. It is a snapshot of state disability systems and services - usually the only analysis of its kind. For each Tennessee state department, I researched if and how their programs support people with disabilities, statewide.

I was able to look deeper into programs I am more familiar with and to research programs that were new to me. I believe many professionals are not aware of the programs and services at the state level that sup-

port people with disabilities and their families. When I first began my internship, one of my goals was to better understand how state government supports people with disabilities. This project helped me reach that goal.

After I graduate with my Master's in Education in Special Education from Vanderbilt's Peabody College in May, I hope to return home to the Chicago area to carry out my passion for working with older students with intellectual and developmental disabilities and teach high school special education. My interest and work in policy will cer-

tainly not stop after my internship ends. I believe it will only grow as I work with my students and their families in preparing them for their next step beyond high school.

The immense knowledge, hands-on experiences, and individual relationships formed with Council members and staff will greatly impact my ability to provide my students the education and preparation they deserve. I highly recommend that future special educators and disability professionals expose themselves to the dis-

*Continued on page 19*

# Five Things That I've Learned about ADVOCATING FOR MYSELF

**By Jasmyn Cheatham, with support from Tonya Bowman**

1. It's ok to ask for help. My mom always helps me. My brothers, my teachers, my Bridges for the Deaf and Hard of Hearing family, my nana, my Brentwood Deaf Church family, and others help me.
2. Let people know what you need. They can help you if they know what you need.
3. Sometimes adults don't have all the answers and that's ok. They will do the best they can.
4. It feels good to have what you need. When my hearing aids are working and I have my interpreter with me at school, it is a good day.
5. You can help others by telling people about your need. They might need the same thing. We have to help each other.

*Jasmyn Cheatham is a 2020 senior at Hillsboro High School and a member of the State Youth Advisory Council. She likes to advocate for people with autism and be involved with her community, family, and friends. Jasmyn lives in Nashville with her mom and brothers.*

*Tonya Bowman is the Statewide Family Resource Specialist for Family Voices of Tennessee. She is the mother of Jasmyn and two sons, Jeffrey and Jacob. Two of her children have special healthcare needs. Tonya loves working alongside other people who are passionate about serving children and families. She uses her voice to share the parent perspective across various councils, committees, and boards* ■



*Jasmyn Cheatham and mom Tonya Bowman*

# New Vanderbilt Centers Prepare Youth, Parents for Life after High School

By Elizabeth Turner

Vanderbilt Kennedy Center (VKC) researcher Erik Carter, Ph.D., has started two new Rehabilitation Research and Training Centers (RRTCs). The RRTCs focus on supporting youth with disabilities and their parents in the transition to adulthood, employment, and adult services.

"This work is part of VKC's emphasis on employment, which is a key part of our work as a Center of Excellence in Developmental Disabilities (UCEDD)," said Elise McMillan, VKC UCEDD Director. "These new RRTCs allow us to do more research, training, technical assistance, and information sharing."

Erik Carter said, "Many of us know firsthand the impact a good job can have on our lives. Through our UCEDD work with Tennessee-Works and Transition Tennessee, we have seen so many examples of people with intellectual and developmental disabilities (IDD) flourishing because of the income, relationships, and sense of purpose that comes from having a job they love. But too many Tennesseans with disabilities struggle to connect to these important experiences."

Statistics show that most youth and young adults with IDD have goals of working in their community alongside people without disabilities. Yet, integrated employment



Erik Carter



Jason Van Wulven finds joy in working hard at a great job.

is still not widespread. In Tennessee, only 16 percent of working-age adults with IDD are employed. Most adults with IDD live with their parents. Only 25 percent are able to get long-term services and supports (like Medicaid waivers) to help them with employment and other goals. This means that for many adults with IDD, their parents are the most important sources of support and guidance in their lives.

Yet most parents say they lack the information and support they need for early adulthood. In a recent study with almost 2,000 parents of Tennesseans with IDD, 57 percent said they were not at all familiar with programs for employment for people with disabilities, and 23 percent were only a little familiar.

Erik Carter will work closely with Elise McMillan and Julie Lounds Taylor, Ph.D., Associate Professor of Pediatrics and Psychiatry & Behavioral Sciences, to lead the two training centers.

"We pursued these two projects because we wanted to identify effective ways of connecting more people to employment," said Carter. "Also, we wanted to develop approaches that could be used widely across the state and around the country."

Each of the centers has a different, specific focus:

## Employment of Transition-Age Youth with Disabilities

Carter and his team are using this training center to look at how paid work during high school affects youth

with severe disabilities after they leave school. The end goal is to:

- better understand the impact of employment on students.
- develop practical, free resources to help schools around the country put the best ideas into practice.

In this project, high school students with severe disabilities will be randomly assigned to one of two study groups:

1. Those whose school transition program will involve them in paid work. The program will use a supported employment approach during their final year of school.
2. Those whose school transition program will work on career preparation and exploration without paid employment.

Staff for the center will support school teams and program participants by helping with:

- employment-related assessments,
- person-centered planning with family members,
- job development,
- on-site support,
- skills training in the classroom,
- and other resources.

This spring, Carter and his team held focus groups and an advisory

council meeting. The groups helped plan how the Center will help students, schools, and families, and create needed materials. The input helps the center make sure the program will be doable in most schools.

“We will be recruiting participants in waves over three years,” Carter said. “We will be partnering with schools, agencies, and disability organizations in Middle Tennessee to ensure we have a strong and diverse sample.”

For more information about this transition training center, visit <https://transition.vcurrctc.org>.

### Employment of People with Intellectual and Developmental Disabilities

The second new training center will develop a mentor program. Parents whose family member with IDD has been successful in employment will mentor parents whose family mem-



Julie Lounds Taylor

ber with disabilities has not yet found a job. The center will also share information with parents whose family member wants to find a job. Through mentoring and sharing information, families can get the help they need for their family member to find a job they love.

This spring, the Center’s team listened to the stories and advice of more than 50 parents through interviews and focus groups. They also met with an advisory council for advice on how to design the program so it can make a real difference for families.



Elise McMillan

Next fall, the Center will pilot a first version of the program focused on the expectations, knowledge, and goals families have for integrated employment. Families who participate in the program will get accessible and relevant information about the benefits of integrated employment and the path to work. Participants will then be matched to one or more mentors who have personal experience supporting a family member with IDD in finding integrated employment. Mentors will receive training, resources, and ongoing support from the project. This will equip them to provide encouragement and direction for the parents they are mentoring.

For more information about this employment training center, visit <https://idd.vcurrctc.org/>.

Elizabeth Turner is the associate director of VKC Communications. ■

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## Learning about Disability... *Continued from page 15*

ability policy world. This will help us escape some of the silos we sometimes find ourselves in and instead create a system of collaboration and understanding.

Even if you are not someone who is directly developing public policy, disability policy issues impact all

other areas of the disability service system. I am very thankful to the Council and, in particular, Lauren Percy for helping me improve my ability to support and advocate for students within the special education and greater disability service system.

Lauren McCabe received her M.Ed. and B.S. in Special Education at Vanderbilt’s Peabody College, with specific interests in high school and postsecondary-aged people with intellectual disability at the school-based and public policy levels. ■

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