

breaking ground

NUMBER 108

DECEMBER 2021

Forward Together
Celebrating Wanda Willis' Legacy



Council on
Developmental Disabilities

Dear readers,

I appreciate this opportunity to express a career's worth of gratitude here, in the Council's amazing magazine, *Breaking Ground*. Transitioning into retirement and leaving this great agency in the hands of the best team I have ever worked with is pure joy.

I fell in love with this work as a 21-year-old special education teacher. That was before the first federal law requiring public education for students with disabilities was passed. Over the years, I held many different positions, most in Tennessee state government. Working with the Tennessee Council on Developmental Disabilities has provided the greatest opportunity to work with others on a shared vision and make a difference. My truest mentors have been people with disabilities themselves – people from all walks of life, with all types of disabilities, at different stages of the lifespan, and with different goals. They show me every day that we continue to set the bar too low. Years ago, I threw the bar away.

Most people who know me are aware of my reverence for the Developmental Disabilities Act, written by families and passed by Congress in 1971. The Act created Councils to be a nucleus in state government where people with disabilities, family members, heads of government disability services, universities, and private agencies would come together. They work together on equal footing to prioritize needs and barriers outlined in a 5-year state plan. We *always* agree on our vision, and often disagree on how to get there! (That's how work for change goes.) However, if you read our annual reports, you will see that the Tennessee Council has accomplished so much. Together with our partners, the Council generates excitement and passion in every project we undertake.

I am overjoyed to be leaving the agency in the capable hands of Lauren Percy, whose vision, ability to connect to people, humility, and understanding of the DD Act and role of councils will take the agency forward in new and exciting ways.

Thank you for the honor of working alongside you for so many years. The Council has been a blessing in my life beyond all hopes and dreams.



Sincerely,

Wanda Willis
Executive Director

Table of Contents

4 In Their Own Words:
The Personal Side of Lasting Impact



8 Forward Together:
A 33-Year Legacy



10 The Art of Collaboration

12 Five Years of Impact:
Measuring the Council's Success



16 Big Solutions for Real Needs

17 The Next Frontier:
What will the Council work on for the next five years?

On the Cover: Council Executive Director Wanda Willis stands in front of the Tennessee State Capitol, representing the government she has served in for nearly all her career. Wanda will retire in January after 33 years as head of the Tennessee Council on Developmental Disabilities.

Photo by Dawn Majors, state photographer. Dawn has provided much of the cover story photography for this magazine over the past couple years. We so appreciate the skill she brings to her work, and the ways that adds to *Breaking Ground's* visual appeal.

Learn more about the Tennessee Council on Developmental Disabilities.

615.532.6615 | www.tn.gov/cdd | www.facebook.com/TNCouncilonDD | Tnddc@tn.gov

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.



Tennessee Council on Developmental Disabilities, Reauthorization No. 344067, December 2021, 5,300 copies. This public document was promulgated at a cost of \$1.41 per copy.

In Their Own Words

The Personal Side of Lasting Impact

Lynette Porter is the Deputy Director for the Tennessee Council on Developmental Disabilities. She has been with the Council for 21 years, since June of 2000.

Councils on Developmental Disabilities exist to create lasting change through a culture of innovation within the disability service system. Wanda leaves us with a legacy of long-term positive impact for Tennesseans with disabilities and their families for generations to come.

It has been an honor to watch the impact of groundbreaking programs the Council has established through the years under Wanda's visionary leadership. I've witnessed countless Tennesseans with developmental disabilities participate in higher education programs on college campuses, find careers in their chosen fields, own homes, participate in community book clubs, and use their advocacy skills developed in our training programs to make a difference in their communities, as well as impact policymakers.



Wanda chats at a 2019 Council meeting with members Sarah Kassas and Jennifer Coleman.

Having been a part of Council programs designed for individuals across the lifespan, I can't help but reflect on youth with disabilities that I met during our high school leadership trainings. I met many of them again at our post-secondary programs or Partners in Policymaking® Leadership Institute. I've seen those same people, now adults, meet with their legislators, participate in community advisory boards, and use the skills gained through the Council to become mentor/trainers to other people with disabilities. It is the best example of Wanda's legacy I know.

How do you capture the lasting

impact of the Tennessee Council on Developmental Disabilities under Wanda's careful guidance? We thought one way is through the voices of people who have been a part of programs created by the Council under Wanda's leadership. These ongoing programs have equipped thousands of individuals across the state with knowledge and tools to use their voices to impact policies and practices that affect all areas of their daily lives.

We hope you enjoy these thoughts from people who have participated in Council trainings and programs through the years.



Wanda with Lynette's daughter, Hailey

OUR MEMBERS:

“My time on the Council enlightened me with wonderful new relationships, opportunities and experiences I will cherish for as long as the Good Lord allows me to stay on this earth.”

—Former Council Chair

“For me, being on the Council, I feel like I've learned a lot of tools, and even though I have been in the disability world for a long time, it's different on the other side of learning policy things and how we can affect change, and how important our story is. I think that's been really empowering for me.”

— Current Council member

PARTNERS IN POLICYMAKING® LEADERSHIP INSTITUTE GRADUATES:

“There are no words to describe how much Partners has helped me to realize that my life may never be the same as it was before my accident, but with my knowledge from Partners, I have hope.”

“Being a part of Partners has been a life-changing experience for me. Partners networking is incredible.”

“Partners in Policymaking taught us acceptance of all people with disabilities, taught us that there is hope for all those who have a disability, taught us that we are not alone and that one person can change the system, and then showed us how to plan to make those changes.”

“This is an amazing program, and I am truly thankful to have participated. My life and my family have been forever changed.”



The 2016 Expect Employment report presentation to then-Governor Haslam was held at the Grand Ole Opry, and featured Clancey Hopper, who worked there as a tour guide. Here, Wanda poses on the Opry stage with Clancey – now a member of the Council.

YOUTH LEADERSHIP TRAINING GRADUATES:

“What I especially liked and learned at the Forum was the feeling of independence, how to live on my own, and how to be more active in advocacy.”

“I have started thinking positively about my disability.”

“I am able to do a lot more than I thought I could.”

“I learned how to look at my disability in a different way. People say I'm limited, but here I feel like the possibilities are endless.”

SCHOLARSHIP FUND USERS:

“My experience with the conference was a great experience. I benefitted from the conference in the way that it would better help me understand the disability I am living with, be a strong voice in self-advocacy to others, and better gain knowledge and understanding of the many different types of disabilities in people across America and around the world.”

“We met several other families, made connections, learned about resources and services available to us. These skills/knowledge can be used for our child and also to help other families that we may encounter in the future. Educating ourselves is the key to being a successful advocate for our child.”

“I found resources to help me have a better life. Now I feel better about my future.”

**TN DISABILITY
PATHFINDER CALLERS:**

“I actually see a glimpse of hope.”

“I’m very happy to know about this service because it is something that is very needed and I will be calling it again.”

**OUR READERS
(EMAILS, MAGAZINE,
SOCIAL MEDIA, ETC.):**

“You are doing a great job and the information you share is incredibly valuable and important!”

“Love the weekly email newsletters! I read them from top to bottom every time. I am new to the disability world and the newsletters allow me to see all the ‘ponds’ that are available to cast multiple fishing poles into. I am casting as many poles as possible as fast as possible into as many ponds as possible to see what information I can catch — some helpful; some not helpful. The newsletter is the map to the ponds. Without the newsletter, I would have no idea where to start to seek information and help.”

“The Council’s *Breaking Ground* and newsletters focus/angle is so positive and shines the light on persons with disabilities (and when appropriate, their families or other care providers) and highlights the strengths and successes of living with a disability. The view is up close and personal and diverse in the coverage of all types of people with all types of disabilities. As a parent of a child with a disability, the information is helpful and encouraging, and I truly appreciate it.”



Wanda and members of the Council attend Disability Day on the Hill in 2017

OTHER PEOPLE IMPACTED BY THE COUNCIL'S WORK DURING WANDA'S LEADERSHIP:

"I like coming to book club and it is one of my goals to get out in the community. I like reading and having fun with everyone."
—Next Chapter Book Club member (local inclusive reading clubs started by the Council)

"The most important accomplishment for my children was developing empathy for others. They...talked about other club members and how they admired their positive attitudes regardless of their disabilities."
—Parent participant in an inclusion project at Chattanooga's Creative Discovery Museum



Wanda poses with Keri Dougherty at a Council youth training held at the TARP Center for Independent Living.



Megan Hart celebrates her graduation from Partners in Policymaking® in 2011 with Wanda and Ned Andrew Solomon, Director of Partners for many years. Megan is director of Tennessee Disability Pathfinder – more about Pathfinder later in this issue.

A 33-Year Legacy

Forward

Wanda Willis has spent more than three decades building the Tennessee Council on Developmental Disabilities into the agency it is today. Her leadership grew the Council from a tiny, poorly understood department to an effective, independent agency leading on a host of key disability issues. Today, the Tennessee Council is widely seen as one of the best in the nation.

“Under Wanda’s leadership, the Council has worked diligently to affect change for people with intellectual and developmental disabilities, their families, and communities through leadership at state and national levels,” says Donna Meltzer, CEO of the National Association of Councils on Developmental Disabilities. “The Tennessee DD Council has been a leader through national initiatives as well as through policy advocacy. Wanda herself has been a true leader for our entire network, serving on the national Board of Directors and even as the President of the Board of NACDD. Wanda’s calm, steady, and smart leadership has made her a mentor to many – myself included – in the DD Council network. Through her leadership, she has made her Council and our national organization better in every way.”

A career of such breadth and depth is hard to summarize. But if you want to understand what drives



Wanda holds her 2018 lifetime achievement award from the Association of University Centers on Disabilities. She is pictured with the leadership of Tennessee’s Developmental Disabilities Network agencies, AUCD Executive Director Andy Imparato (far left) and 2018 AUCD Awards Committee Chair Celia Feinstein (to Wanda’s left).

Wanda’s impact, there is only one place to start: the federal Developmental Disabilities Act.

Every staff member will tell you reading that Act was their first assignment on joining the Council. Wanda speaks often about the wisdom of the people with disabilities and families who helped craft that law more than 50 years ago. Wanda has proven that its core vision and values still offer a formula for lasting, positive change.

Wanda’s genius has been her ability to use the Developmental Disabilities Act as a blueprint for bringing people together to act on real solutions. In work that can often be confrontational, Wanda invites people in. She listens to understand. She digs deeper. She disarms defenses. She is undaunted by obstacles. Her passion and leadership keep everyone invested and working together until there is a way forward.

Wanda understood early on that the Developmental Disabilities Act gave councils a unique role: positioned within state government, with an eye on the entire service system, but guided by citizen Council members living the disability experience. She saw that on the Council, leaders of key disability services could sit at the table with people who needed and experienced those services. She built up a staff that could grow those con-



Aaron Bishop and Jennifer Johnson of the federal Administration on Community Living visit the Tennessee Council in 2015 – pictured here with Wanda and Council staff Alicia Cone.

Together

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

nections between services and citizens and use them to chart a path to real change.

The Developmental Disabilities Act did not create councils alone. It created two other arms of this work that join councils to form a state Developmental Disabilities Network. Protection and advocacy agencies form the legal arm of the network (Disability Rights Tennessee in our state). University centers of excellence in developmental disabilities form the research and training arm (two in our state: the University of Tennessee Center on DD and the Vanderbilt Kennedy Center of Excellence on DD). Councils are the systems change arm.

Wanda saw that this three-part network could do much more together than any one part could do alone. The result is a Developmental Disabilities Network that works more closely together in Tennessee than in any other state. Wanda also saw Centers for Independent Living as

close partners and led work to bridge that statewide network with the Developmental Disabilities Network.

Leadership from the Administration on Community Living – the federal agency that funds and oversees all Developmental Disabilities Act programs and Centers for Independent Living – visited Tennessee three different times to see these partnerships first-hand. The national Association of University Centers on Disabilities chose Wanda for its lifetime achievement award in 2018. The award was a recognition of her role in strengthening the work of the Developmental Disabilities Act, reaching far beyond Tennessee or even councils nationally.

Andy Imparato was executive director of the Association at the time of Wanda's award. (He is now executive director of Disability Rights California.) "For me, Wanda Willis embodies the spirit of the DD Act envisioned by

Continued on page 11

Julie Hocker, former U.S. Commissioner of the Administration on Disabilities (center front), visited in 2019 to hear from citizens with disabilities and their families about the Council's work, and to learn about Tennessee's close DD Network partnership.



By Lisa Primm,
Executive Director,
Disability Rights Tennessee

The Art of

I first met Wanda Willis 9 years ago when I was applying to become the Executive Director of Disability Rights Tennessee (DRT). Wanda was a DRT board member and part of the Executive Director search committee. At the time I had family connections to the disability community, but I had worked mostly in mental health and public policy. As I embarked in a career leading a statewide organization which impacts a diverse community of people with disabilities (yes, she gave me the job), I realized that I had much to learn!

Wanda immediately took me under her wing. She was my greatest supporter, my fountain of knowledge, and my shoulder to cry on. She introduced me to the wider disability community, from leaders in Tennessee state government to heads of other statewide disability organizations. Wanda helped me in any way she could so that we could collaboratively have the greatest

positive impact on Tennesseans with disabilities. Also, she did this just because that is who Wanda Willis is—always a team player.

Wanda's collaborative style has been demonstrated time and again, but most notably in her role as my Developmental Disabilities Network partner. Together with Bruce Keisling of the University of Tennessee Center on Developmental Disabilities and Elise McMillan of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, we are the "DD Network" in Tennessee. And Tennessee's DD Network is undisputedly the best one in the entire country. Tennessee has been cited numerous times as the gold standard for what a strong Network should be.

I have also worked closely with Wanda as part of the TN Disability Policy Alliance, where Wanda created a unique space for statewide disability agencies with

Lisa presents Wanda with Disability Rights Tennessee's Freedom Award in 2018.



Collaboration

national representation to join together for candid conversations about policies impacting the populations we serve. Wanda and her colleagues have also collaborated with DRT on important issues like supported decision-making. In that project, Wanda brought subject area experts like Jonathan Martinis to the collaboration, which ultimately lead to the creation of the TN Center for Decision-Making Support.

Most recently, we worked together on in-home access to COVID-19 vaccines. This project was largely the brainchild of Wanda. When she learned of the state's work to connect Tennesseans with disabilities to COVID-19 vaccines, she knew this was the perfect opportunity for our community to protect some of our most vulnerable citizens. She began talks with leaders in the state and connected all the partners so that we could join forces. With Wanda's ability to gather community support and collaborators, we have been able to offer vaccination across the state to people with disabilities and supporters in their own homes.

I share these examples to illustrate the incredible mark that Wanda has left on the disability community. She is a true collaborator. Under her leadership, the TN Council on Developmental Disabilities, a small but mighty organization, has honed the art of collabora-

tion to yield far greater results than their budget and staff members could have accomplished alone. Wanda possesses a unique ability to bring people together. She sees the strengths in everyone and understands how they can best contribute. And ultimately, she has always understood that we are stronger and more impactful together. In her work as a great connector, she has laid the groundwork for success in our community for years to come, and for this I will always be grateful. ■

Lisa Primm joined Disability Rights Tennessee as the Executive Director in December 2012. She previously served for four years as Policy Director for the Tennessee Alliance for Legal Services, and before that she was employed as Director of the TennCare Partners Advocacy Program. Lisa has pursued social justice for oppressed and disenfranchised populations throughout her career, focusing primarily on client advocacy, health care policy, mental health treatment, and civil legal services. She holds a master's degree in social work from the University Of Tennessee College Of Social Work in Nashville (1998) and a Bachelor's Degree in Psychology from Alma College in Michigan (1989). She has been a Licensed Advanced Practice Social Worker since 2010.

Forward Together *Continued from page 9*

Elizabeth Boggs, Eunice Kennedy Shriver, and other key shapers of the law and the network. Wanda is strategic, collaborative, visionary, and values-driven, just like the DD Act. I am grateful for her leadership, her impact, and her legacy in Tennessee and beyond."

Wanda is the first to admit that change is often much harder and takes much longer than anyone wants. In a career crowded with successes, the losses still sting. She knows there is much more work to be done. But her optimism is contagious as she talks about her retirement in January and this transition for the Tennessee Council. She leaves the agency positioned to be a force for change long into the future.

That forward momentum can be seen in the per-

spectives of our Developmental Disabilities Network partners, which follow. They will highlight some of the recent and ongoing work our agencies have done together, under Wanda's vision and guidance. These projects show the real-world impact across our state. The approach to each project bears her imprint: listen to the voices of people with disabilities and families, understand the need and opportunity, gather partners, and take action together.

That formula is Wanda's legacy, born in the Developmental Disabilities Act and brought to life over 40 years of service. It is also this Council's road map to continued positive change for people with disabilities and their families in Tennessee. ■

Our Center was tasked recently with doing a study on the outcomes of the Council's work over the last five-year state plan. I knew it would be a good opportunity to summarize the Council's broad impact across all programs and services. I didn't know that it would also become an important way to understand Wanda's legacy as she retires.

Our job was to look at all Council activities from 2017-2021. The key question: did the Council meet its state plan goals? Those goals were:

- Growing and empowering leaders
- Impacting disability-related policy and practice
- Informing and educating stakeholders (people connected to disability)

What we saw in our analysis is an effective agency that is making the lives of people across the state better. I want to share a few of the highlights from each of the three goals. They illustrate the reach of the Council – and the lasting impact of its executive director.

Growing and Empowering Leaders

The Council supports many different leadership and advocacy trainings for Tennesseans with disabilities, family members, and professionals who serve the disability community. These programs include the Partners in Policymaking® Leadership Institute, advocacy training for high school students with disabilities, and the state Leadership Academy for Excellence in Disability Services. The goal of these programs is to help people learn more about disability issues, help them find and use resources, and prepare them to advocate for themselves and others.

More than 6,300 people participated in activities through these training programs, the Council scholarship fund, and grassroots advocacy projects over the past five years. Participants have consistently rated these learning experiences as meeting or exceeding their expectations. When we followed up with people years after their training experiences, they told us they



Above: Partners in Policymaking graduates Clancey Hopper, Jeanne Buckman, and Sharon Stolberg enjoy meeting up at a reunion.

Right: Young artist Rainbow Moshu used Council COVID-19 grant funding to buy new art supplies to express herself during a hard time.



of Impact

By Bruce Keisling, Executive Director, University of Tennessee Center on Developmental Disabilities



Council member Martez Williams joined the Governor for the signing of the Precious Cargo Act earlier this year. The bill was amended to reflect concerns Martez shared about the intersection of policing, race, and disability.

continue to engage in disability-related activities in their communities. They now hold officer positions, memberships, research roles, program planning duties, and fundraising responsibilities across more than 75 national and state disability organizations.

Impacting Disability Policy and Practice

The Council knows that improving policy and practices that affect the lives of people with disabilities is a collab-

orative effort. They have built strong relationships with a wide variety of partners, including:

- members of the legislature and their staff
- disability organizations
- public agencies
- community organizations
- people with disabilities and families
- the media



Council member Chrissy Hood testified at a state legislative hearing about a bill to increase access to adult-size changing tables. The Council continues to support Chrissy and others across the state in sharing their stories and educating on this issue.

The Council has led two critical statewide policy and practice groups for more than a decade:

- The Tennessee Disability Policy Alliance
- The Employment Roundtable

These groups coordinate work on common issues across dozens of agencies. In addition, the Council participates in two disability-related legislative events each year: the Disability Legislative Reception and Disability Day on the Hill. These events help people with disabilities connect directly with legislators. Council members and others who attend consistently say they are very valuable advocacy experiences.

The Council has worked with more than 50 national and state groups on policy and practice efforts that impact people with disabilities and their families. It is important to the Council to be a “go-to” resource for the disability community to learn about public policy. They also work to be a trusted resource for elected and state officials about disability issues. To that end, the Council has tracked as many as 150 federal and state bills each year. They prioritize 3-8 bills for each legislative session, often working directly with bill sponsors. Legislators

routinely ask the Council for help or to give testimony about disability issues related to their bills. Council staff and citizen members regularly participate during public comment periods and formally (and informally) consult on hundreds of topics each year.

Over the past 5 years, Council staff produced:

- Several position papers on public policy issues
- 50+ products on policy and best practices
- 120+ disability policy presentations

The Council staff and members participated in hundreds of public policy meetings across the state. Over 90% of bills prioritized by the Council move forward or pass within the state legislature!

Informing and Educating Tennesseans

The Council uses many different public information activities to educate Tennesseans with disabilities, their family members, policymakers, professionals, and the public. During the past 5 years, Council members and staff led around 80 presentations a year at local, state, and national training events. They are routinely asked to add disability information to content from other state agencies. We estimate that over the last five years, the Council has reached at least 2,000 people with disabilities, 5,500 family members, and 5,000 professionals through these types of activities to inform and educate.

Council communications platforms:

- The Council's magazine, *Breaking Ground*, is published four times a year and reaches at least 5,900 subscribers. In a recent survey, 75% of surveyed readers reported directly using the information found in this publication, and 90% said that the disability-related content in the magazine is relevant to them.
- Around 20,000 people visit the Council's website each year. Their weekly email newsletters reach over 2,300 email subscribers.
- The Council's social media presence includes more than 4,400 Facebook followers and 1,200 Twitter followers. The Council has released more than ten videos about the Council and sharing stories of Tennesseans with disabilities.



PHOTO BY MATTHEW PARBOTT

Left: Former Council member Serina Gilbert joined a local TV broadcast to talk about employment for people with disabilities.



A newspaper insert helped the Council reach the state's rural communities with disability stories and resources.

A major focus of the Council has been outreach to rural communities. The Council developed a newspaper insert about the Council and disability resources that was distributed in more than 200,000 rural newspapers.

Across all these public information activities, the Council demonstrates yearly increases in the number of Tennesseans with disabilities, family members, and others who report:

- a greater ability to advocate for themselves and others
- increased understanding of service systems
- a greater ability to access resources

A broad and lasting impact

The information above gives just the highlights of the very broad reach of the Council's work in the past five years. It stood out to me that people who access Council programs report benefits even many years later.

I have worked closely with Wanda through our DD Network partnership. The research our Center did for the Council gave me an even greater appreciation for Wanda's leadership. Her time as Executive Director has led the Council to ever-increasing engagement with Tennesseans experiencing disability. The answer

is clear: under Wanda's leadership, the Council met its state plan goals.

It's been a pleasure to work with Wanda and her staff over the last several years. I look forward to seeing her remarkable legacy continue! ■

Bruce Keisling is the Executive Director of the UTHSC Center on Developmental Disabilities and holds the Shainberg Professorship in Developmental Pediatrics in the College of Medicine. He directs the center's University Center for Excellence in Developmental Disabilities (UCEDD), which, along with the Tennessee Council on Developmental Disabilities, is part of the Tennessee Developmental Disabilities Network.

Snapshots of Impact

Data from the UT Center for Developmental Disabilities evaluation show the Council making a difference in the lives of real people.

At least 90+% of people who participated in Council leadership trainings said the trainings helped them:

- Increase their knowledge in disability topics - including policy and practices
- Identify and access needed resources
- Advocate for themselves and others in their community
- Have a greater sense of control of their lives
- See lasting gains in self-confidence and empowerment, knowledge, advocacy skills, professional and social networking, community inclusion, and quality of life

Over 90% of the bills chosen as priorities by the Council moved forward or passed within the state legislature.

More than 90% of people surveyed said that the Council's policy and practice work has increased their:

- Ability to advocate
- Knowledge of disability topics
- Knowledge of and ability to access available resources

75% of surveyed Breaking Ground readers said they directly used information found in this magazine.

Big Solutions for

So much is changing for people with disabilities in Tennessee. In many cases, that positive change can be traced back to the leadership of Wanda Willis and the Tennessee Council on Developmental Disabilities.

The area of need may change, but the key ingredients of Wanda's leadership of the Council are the same:

- Hear from individuals and families about a persistent need in Tennessee.
- Bring partners together.
- Work with partners toward a common goal that addresses the need.
- Stay involved to support, advocate, collaborate, and succeed.

At the Vanderbilt Kennedy Center, we have had the wonderful opportunity to work with the Council and the Tennessee Developmental Disabilities Network on many projects. Two that stand out and show the unique role of the Council are:

- Founding and growing inclusive higher education in Tennessee, and
- The continuing growth and impact of Tennessee Disability Pathfinder.

College for all

Before 2010, there were no inclusive higher education programs for students with intellectual and developmental disabilities in Tennessee. Wanda began meeting with a small group of leaders to address this challenge. The group brought people and organizations together and visited other states to learn more. We offered conferences to help the community learn about this educational opportunity that was growing in other parts of the country but not yet catching on in most of the Southeast.

The Council worked with the Vanderbilt Kennedy Center and another partner to fund the first program at Vanderbilt University. Wanda and the Council have stayed very involved in the Tennessee Alliance for Inclusive Higher Education (tnihealliance.org), with the goal of adding more inclusive college programs across the state. The Council has been involved in each of the six college programs now serving students across Tennessee. The Council has stayed connected with the Tennessee Department of Intellectual and Developmental Disabilities (DIDD)



Inclusive higher education programs at six campuses across the state make college dreams come true for students with intellectual disabilities.

and the Tennessee Higher Education Commission on a new project named "Tennessee Believes" that will fund more opportunities for these programs across the state.

Making it easier to find resources

In 1997, Wanda and the Council partnered with the Vanderbilt Kennedy Center to launch Tennessee Disability Pathfinder (www.tnpathfinder.org), the state's center for finding disability information and services. Since then, Pathfinder has helped thousands of people with disabilities, their families, educators, and other professionals find and access resources, support, and services.

In the beginning, the project included two staff members, a toll-free call number, and printed directories of information and services. With Council support, Pathfinder grew its staff, launched a website, and added a multicultural program to serve families from diverse backgrounds.

But Wanda and the Council continued to hear from people with disabilities and families about the struggles of finding good information about the disability services system. More was needed. Wanda worked for several years to bring in six other state agencies to invest in Pathfinder:

Real Needs

By Elise McMillan, Co-Director,
Vanderbilt Kennedy Center
for Excellence in
Developmental Disabilities

- Department of Education
- Department of, Intellectual and Developmental Disabilities
- Department of Mental and Substance Abuse Services
- Department of Health
- Department of Human Services/Division of Rehabilitation Services
- Tennessee Commission on Aging and Disabilities

These agencies have worked together with Pathfinder Director Megan Hart to expand the Pathfinder staff and launch a new website. The updated site offers new features that make it easier to find resources based on the specific need.

Wanda saw an opportunity to learn even more about what Tennessee's disability community needed. In Fall 2020, the Council partnered with Vanderbilt University,

Continued on page 19

Snapshots of Disability Experiences

More than 3,000 Tennesseans connected to disability answered questions about what is important to them and how they get information about services. The study provides a large amount of data. We will share just a few highlights.

What experiences are most important for people with disabilities?

Experiences rated important by the most people with disabilities:

- Having good mental health (95%)
- Making their own decisions (94%)
- Pursing personal growth (92%)
- Being physically healthy (92%)

Experiences rated as important by the most parents of younger children with disabilities:

- Learning social and communication skills (95%)
- Having good mental health (95%)
- Learning daily living skills (94%)

Experiences rated as important by the most parents of youth and adults with disabilities:

- Having good mental health (95%)
- Being physically healthy (95%)
- Making friends (90%)

Do people know who can help?

The most people with disabilities were unsure who could help them with:

- Dating (37%)
- Finding or keeping a job (33%)
- Advocating for others (33%)

The most parents of younger children with disabilities were unsure who could help their children with:

- Attending summer camps/programs (47%)
- Having friends (45%)
- Participating in recreational activities (44%)

The most parents of youth and adults were unsure who could help them with:

- Having their own place to live (58%)
- Dating (49%)
- Finding or keeping a job (44%)

What is your biggest disability-related question or need right now?

People with disabilities:

1. Employment
2. Financial help
3. Medical care

Families (parents, siblings, other family members):

1. Financial help
2. Finding services
3. Respite or homecare (help caring for a loved one so caregivers can get a break)

Professionals (people working in disability-related fields, like special education, adult services, etc.):

1. Finding services
2. Financial help
3. Transportation

The study includes much more data that Pathfinder, the Council, and other agencies will be using to help us meet the needs of our statewide disability community.

The Next Frontier

What will the Council work on for the next five years?

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

The Council officially began working under a new five-year state plan on October 1. Why does that matter?

Every state council like ours is required to write a new state plan every five years. The state plan is our map for how we will do the work we've been given by the federal Developmental Disabilities Act:

- Supporting advocacy (making sure the voices of people with disabilities and their families are heard)
- Building capacity (growing the disability supports that are available)
- Systems change (making services better for people with disabilities)

The new plan is based on your input!

Hundreds of you responded to our public input survey last year. That survey is a key part of creating our state plan. Your responses helped us know what is important to Tennessee's disability community. For example, you told us that the most important areas for services are:

- health and wellness
- money and finance
- employment

You also told us that **it is hard to learn about services in the areas that are important to you**. That feedback is guiding an important new area of the Council's work – more on that in a minute.

The Council also gets ready for a new state plan by doing a "comprehensive review and analysis" of Tennessee disability services. This helps us understand all the services that already exist. We learned that Tennessee has **154 disability services** across **23 different state agencies**. This shows how complex the system is – and why it can be so overwhelming for people with disabilities and their families.

What we did with your input: the Council's new five-year state plan!

Our plan has three broad goals. Under the goals, objectives tell the concrete ways we will meet the goal. We'll also share some examples of current projects under each goal.

Tennessee Council Five-Year State Plan 2021-2026

Goal 1: Developing Engaged Leaders

- Objective 1.1: Provide leadership learning and development programs to Tennesseans with disabilities and their family members to increase advocacy skills and engagement.
- Objective 1.2: Support grassroots self-advocacy in Tennessee through three training and program development activities to increase advocacy skills and engagement.

Example projects: Partners in Policymaking®, Council scholarship fund, youth trainings, supporting self-advocacy groups

Goal 2: Improving Policy and Practice

- Objective 2.1: Track, summarize in plain language, and share information with Tennesseans about policies that impact people with disabilities. Position the Council as a top resource for Tennesseans to learn about policy affecting people with disabilities.
- Objective 2.2: Ask for and study the perspectives of people with disabilities to identify system barriers and make sure those perspective influence policy changes.
- Objective 2.3: Measure progress toward inclusion, self-determination, and independence.

Example projects: Tracking opportunities to impact policymaking, weekly public policy e-newsletter, offering input and recommendations on policy changes, trainings on best practices

Goal 3: Informing the Public

- Objective 3.1: Use a wide range of communication tools/platforms and partnerships to:
 - Increase accessible disability information and resources for people with disabilities and their families.
 - Build understanding and engagement on disability issues relevant to Tennesseans.

- Increase engagement with historically underrepresented groups – including Black, Hispanic/Latinx, LGBTQ+, immigrant, refugee, and rural communities.
- Objective 3.2: In fiscal year 2022, work together with the Tennessee Developmental Disabilities Network communications team to increase access to healthcare information for LGBTQ+ Tennesseans with disabilities. Example projects: All Council communication platforms (like social media or this magazine), community events, partnerships to share information with other agencies or groups

What's really new in this plan?

The plan's structure is similar to the last five-year state plan. It leaves room for our specific work to grow and change. But there are a few important themes we want to point out. These areas are the new frontier of the Council's work.

1. **Leading on "plain language."** Plain language is information our audience can understand the first time they read or hear it. Our unique role allows us to serve as an information bridge. We can help sister state agencies share important information with our statewide disability community. And we can make sure the disability community gets clear, easy-to-understand information about the issues and services that matter to them.
2. **Connecting with underrepresented and marginalized communities.** People with disabilities who are also marginalized in other ways face many extra barriers. The Council is expanding who we are hearing from, and who we are reaching with information and resources. This means building new relationships. It means hearing and sharing stories of people from widely diverse experiences and backgrounds. It means sharing information in new ways to reach people who are not already well-connected.
3. **Increasing engagement.** We don't just want to push information out. We want to have more conversations. We want to bring more people into our work. We want YOU to be at the table where important decisions are made.

The Tennessee Council is pushing forward the work of the Developmental Disabilities Act. We count on you to help us. Your feedback tells us when we're getting it right – and when we're not. Your stories and perspectives are the real force for change. Come along with us. There is great work to be done! ■

Big Solutions for Real Needs *Continued from page 17*

Dr. Erik Carter, and the Pathfinder team to launch a one-year study to learn what matters most to the disability community and professionals in the disability field.

Over the last year, the research team surveyed more than 3,000 Tennesseans with disabilities, family members, educators, providers, agency staff, and healthcare workers to answer questions like:

- What are your most pressing needs and questions?
- Where are Tennesseans looking now for information and resources?
- What are your best recommendations for improving Pathfinder's reach and impact?
- How do these answers vary based on who is asked, what they do, and where in the state they live?

All this information is being used to inform the ongoing work of Tennessee Disability Pathfinder. It is also useful for the many state agencies, disability organizations, and schools in Tennessee who work to connect people with disabilities and their families to needed information and resources.

This report provides an in-depth look at the insights shared by so many different people from across Tennessee. It offers practical recommendations for addressing lasting needs related to information and services that enable people with disabilities to flourish. It can also be used by state agencies and organizations as they reflect on their own service delivery and information efforts.

Wanda's commitment to improve the lives of people with disabilities, their families, and the greater community has remained firm throughout her time as Council Executive Director. I am personally grateful to have worked so closely with her, and to have learned from her over so many years of partnership. I know that her impact will continue through the ongoing work of the Council. ■

Elise McMillan, JD, is Co-Director of the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities, Senior Associate in the VUMC Department of Psychiatry and Behavioral Sciences, and VKC Director of Public Policy and Community Engagement. She holds leadership positions with TennesseeWorks, Tennessee Disability Pathfinder, Next Steps at Vanderbilt, and the Tennessee Alliance for Inclusive Higher Education. She and her husband are parents of three young adults, including a son with Down Syndrome, and grandparents of five.

Tennessee Council on Developmental Disabilities

Davy Crockett Tower, 1st Floor
500 James Robertson Parkway
Nashville, TN 37243
Return service requested

PRSR STD
US POSTAGE
PAID
NASHVILLE, TN
PERMIT NO. 983

Call for Entries: *Breaking Ground* 2022 Arts Issue

Would you like your art to be featured in our 2022 *Breaking Ground* magazine arts issue? Tennesseans with disabilities are invited to send us your works.

We will consider:

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

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

The arts issue will come out in early spring 2022. If your work is chosen, your name, a short bio, and the title of the artwork will be featured in the magazine. You will also get copies of the printed magazine to keep and share.

Please include:

- your full name
- the best way to contact you
- and a one- or two-sentence bio with your submission

Limit submissions to 3 per person.
Submission deadline is Jan. 15, 2022.

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

