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Building Bridges to the Future

*The Council on Developmental Disabilities in Fiscal Year 2022*

What is the Tennessee Council on Developmental Disabilities?

I thought a lot about how to explain our role during my years as Director of Public Policy for the Council. I have thought about it even more in my first year as Executive Director.

The Council has a very broad mission, given to us by the federal Developmental Disabilities Act: **We work to improve supports and services to make life better for people with lifelong disabilities and their families.**

But what makes us different from other disability organizations with a similar mission?

To me, it’s WHO we are (why we exist) and HOW we work that make us special. **We are the bridge between two groups that are often disconnected: professionals in a large disability system and the people they serve.** Councils on Developmental Disabilities are designed to have one foot squarely in each camp, so to speak.

Our [members](https://www.tn.gov/cdd/who-we-are/council-members.html) are from both groups:

* people personally experiencing disability
* professionals from government and disability agencies

When we come together, we bridge the system with the people.

# Bridging systems and people with disabilities

Historically, government systems – and all of society – have misunderstood, underestimated, and underrepresented people with disabilities. Councils on Developmental Disabilities were created in every state to change that. In Tennessee, we are dedicated to understanding, honoring, and elevating [the estimated 160,000 people who have developmental disabilities in our state](https://www.tn.gov/cdd/who-we-are/tn-disability-data.html). We operate [from core values established in the DD Act by Congress](https://www.tn.gov/cdd/who-we-are/values-and-best-practices.html).

That’s WHO we are.

Here’s HOW we do things:

* We operate from inside state government, making us a sister state agency with the departments that offer disability services. From this position, we can create change from the inside. **We are change makers.**
* We are guided by citizens affected by the disability system. [Our citizen members, appointed by the Governor, represent every district of the state and the vast diversity of the state](https://www.tn.gov/cdd/who-we-are/council-members.html). These perspectives show the gaps between how the system *should* work and how it *does* work. When those perspectives come together with policymakers, the system improves. **We are bridge builders.**
* We are the only entity that takes a system-wide approach to disability services. We collect information across government about disability services. [Our role is to build connections across the 150+ disability services in Tennessee and help them work together](https://www.tn.gov/cdd/who-we-are/state-plan-and-goals/state-disability-services-snapshot-2019.html). **We are dot connectors.**

# Moving past problems to solutions

The most important ingredient of real, lasting change is the ability to move past problems and find solutions. No entity can do this alone with sheer will (although many of us wish we could)! I am convinced that Councils can only do this because of the people we are able to bring together: citizens who understand the problems and professionals who can act on solutions.

Councils use a framework called the [state plan](https://www.tn.gov/cdd/who-we-are/state-plan-and-goals.html) to turn ideas into action.

* Image description: overlapping Venn diagram with 3 circles with the 3 state plan goals:
  + Goal 1: developing leaders
  + Goal 2: improving policy
  + Goal 3: informing the public
  + Connections between goals 1 and 2 -preparing leaders to improve disability policy; ensuring leaders learn about current policy issues impacting disability community
  + Connections between goals 2 and 3 – telling stories to build awareness and change attitudes to improve policy; informing people about policy issues and advocacy opportunities
  + Connections between goals 1 and 3 – teaching leaders how to inform their communities; keeping leaders updated about important information

The work of Councils is often slow. We are often in the background – planting the seeds that other organizations sustain. This is by design. Councils have small budgets and are careful not to duplicate work. Instead, [we start and grow new ideas](https://www.tn.gov/cdd/who-we-are/our-impact-over-time.html).

In this report, we share stories and data that show what this work looked like in fiscal year 2022: July 1, 2021 – June 30, 2022. Each of the stories shows how our work for change crosses state plan goal areas, linking leadership development, public policy, and communications. The thread consistent throughout these stories is connecting citizen experiences to government solutions. This is why Councils exist. It is how we continue building bridges to the future more than 50 years after Congress created us.

It’s a privilege and a great responsibility to do this work. We hope you will feel that as you read this report.

-Lauren Pearcy, Executive Director

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# Jackie Kancir: Helping Emergency Rooms Better Serve People with I/DD

It started with a bad experience. So much of our work does.

Jackie Kancir was a member of our 2022 [Partners in Policymaking® class](https://www.tn.gov/cdd/engage-with-us/partners-in-policymaking.html). Her daughter has a rare genetic disorder that sometimes lands the two of them in the hospital emergency room (ER). After a particularly bad visit, Jackie’s Partners connection led her to ask us: How can we help ER staff be better prepared to care for patients with intellectual and developmental disabilities (I/DD)?

Council staff got to work. We reached out to our trusted partners at the Department of Intellectual and Developmental Disabilities. With Jackie’s help, our combined teams drafted an ER Stabilization Protocol. It lists dos and don’ts for hospital staff when treating a patient with I/DD. [The ER Stabilization Protocol is now a part of the Vanderbilt Kennedy Center I/DD Toolkit for medical providers](https://iddtoolkit.vkcsites.org/er-idd-stabilization-protocol/).

The Council communications team featured the new protocol across our communications platforms. Now, anyone headed to the ER can have the [ER Stabilization Protocol for Individuals with I/DD](https://iddtoolkit.vkcsites.org/er-idd-stabilization-protocol/) to share with hospital staff. We’ve since heard from members of the community who have done just that.

Council expertise and trusted partnerships helped create a real solution from Jackie’s bad experience.

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# What the numbers say about FY22 outcomes under Goal 1: Developing Leaders

*Provide learning and development opportunities to Tennesseans with disabilities and their family members in order to increase their engagement in systems advocacy and systems change.*

* Provide access to learning and leadership opportunities
  + Partners in Policymaking Leadership Institute
    - Partners in Policymaking is the Council’s free leadership and advocacy training program for adults with disabilities and family members of people with disabilities.
    - Data highlights: 23 Partners scholars; 9 persons with disabilities, 14 family members; 12 virtual sessions
    - 95% reported increased knowledge of resources; 100% reported increased ability to address a barrier or resolve a problem; 95% reported increased leadership skills; 100% reported increased ability to access services; 100% reported increased sense of being connected to others with a similar experience; 90% reported increased ability to say what I want and what is important to me
  + Leadership Academy for Excellence in Disability Services
    - LAEDS is a leadership development program for state employees whose work has a direct impact on Tennesseans with disabilities and their families. The goal is to ensure that leaders who work in state government programs that serve Tennesseans with disabilities operate from a shared set of values, goals and principles.
    - Image description: pie graph showing how many participants from the following agencies were in the 2021-22 class: TennCare (6); Department of Human Services (4); Department of Correction (3); Department of Safety and Homeland Security (3); Department of Intellectual and Developmental Disabilities (2); and 1 each from Department of Environment and Conservation, Department of Health, Education and Veterans Affairs; There are currently 23 participants representing 10 state agencies
    - Link to LAEDS video: <https://youtu.be/IFjg6nPWy7g>
  + Scholarship Fund
    - The Scholarship Fund accomplishes two outcomes. First, it helps Tennesseans with disabilities and their families, especially people from diverse cultural backgrounds, to attend leadership coalition meetings, disability conferences, and disability trainings held in TN and across the U.S. Second, it helps organizations offer educational opportunities for Tennesseans with disabilities. The Council set a goal of supporting 6 organizations this year.
    - Image descriptions: logos for the following agencies: United Cerebral Palsy of Middle TN; Chattanooga Autism Center; Special Olympics of TN; TN Adult Brothers and Sisters; AbleVoices; and TN Adaptive Sports Association.
    - The Council supported three times more people with disabilities than it set a goal to during FY22. The Scholarship Fund was fully obligated in FY22.
    - Data highlights: people with disabilities supported by Scholarship Fund (goal 75) – current – 220; family members supported by Scholarship Fund (goal 150) – current= 112; total stipends provided – (goal 50) - current 25
* Support grassroots self-advocacy in TN
  + Advocates in Motion
    - The Council supported the organization Advocates in Motion to train people with developmental disabilities to mentor their peers to advocate for themselves with a focus on service planning meetings. In addition to training people with disability, AiM trainers trained 83 professionals in the field.
    - Data highlights: support advocates in motion through 8 trainings; goal – 40 people with disabilities trained by AiM trainers; actual – 31 trained
  + Data highlights across Goal 1:
    - Participants in Council learning and leadership opportunities reported …
      * 96% said they had increased knowledge and became more informed about resources and services
      * 100% said they had better ability to track down and access information and resources
      * 100% said they had increased ability to access services
      * 99% said they were more connected to others with a similar life experience
      * 97% said they had increased independence and self-determination
      * 99% said they engaged in increased advocacy
      * 99% were satisfied with their experience in leadership development activities

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# Chrissy Hood: Leading the Way on Adult-Size Changing Tables

It started with a story. So much of our work does.

Chrissy Hood is our Governor-appointed member from Pulaski and a graduate of Partners in Policymaking®. She is also the public face of Tennessee’s work for adult-size changing tables.

Chrissy didn’t know that’s where she was headed when she was appointed to the Council in 2019. That’s when she first shared her story with Council staff. She spoke powerfully about how the lack of adult-size tables affects her teenage daughter, Alaina, and their whole family. She talked about it as an issue of community access and basic dignity. As staff brought the issue to the full Council, other members shared how they were also affected or had seen the issue in their communities.

Over the next two years, staff brought expertise and resources to support a huge education effort. Members met with legislators, community leaders, and businesses. They [appeared in videos](https://youtu.be/HCSHn50_JV0). They [wrote op-eds](https://www.tennessean.com/story/opinion/2022/01/10/adult-size-changing-tables-provide-access-people-disabilities/9132009002/) and [talked to TV reporters](https://newschannel9.com/news/local/its-about-dignity-new-tn-bill-aims-to-promote-disability-inclusion-in-public-restrooms?fbclid=IwAR2BhkKZXrfQNT5fbBdYUfiO35nM2OOE9ML3JZCL1Y--t7uowS7tC5qvnnM). They researched details and brought us new ideas for outreach. The Council [took out billboards](https://www.facebook.com/photo/?fbid=285872623575714&set=a.240906878072289) and wrote a one-pager that spread across the state. The work was picked up by many of our Partners in Policymaking® scholars and alumni. Other disability organizations joined the effort.

A bill was introduced in 2021, sponsored by our members’ House and Senate representatives. The contents of the final bill passed in 2022 as part of the state budget. [A new grant program for height-adjustable, adult-size changing tables is open NOW](https://www.tn.gov/didd/for-consumers/adult-size-changing-tables.html). Businesses and local governments can apply through June 30, 2023, for $5,000 grants to help install adult-size tables.

Council expertise and trusted partnerships helped create a real solution from Chrissy’s story.

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# What the numbers say about FY22 outcomes under Goal 2: Improving Policy and Practice

Goal 2 Infographics – *Assure that Tennessee's disability service system is responsive to the needs of people with disabilities and promotes inclusion, self-determination, and independence.*

* Track and give input on policy - The Council tracks and gives input on policies that affect Tennesseans with disabilities. While FY22 saw a decrease in number of polices tracked, the Council exceeded its goal of policies created or changed as a result of its work.
  + Examples of policies tracked and input given (goal – 50; actual include:
    - TennCare III (Centers for Medicare and Medicaid Services)
    - TN education funding reform (TN Dept. of Education)
    - Benefits counseling (TennCare)
    - Guardianship (US Congress)
    - State as a model employer (TN Dept. of Human Resources)
    - Home- and community-based services funding (US Congress)
    - Mental health block grant (TN Dept. of Mental Health and Substance Abuse Services)
    - Youth detention (TN Dept. of Children’s Services)
  + Examples of policy improved or changed (goal 3; actual – 13) include:
    - Universal changing tables legislation
    - Tennessee education funding reform
    - Medicaid Alternative Pathways (youth transitions)
    - Teacher assault bill
    - Vocational Rehabilitation transformation
    - Katie Beckett policy changes
    - Changing tables:
      * TN Dept. of Environment and Conservation
      * TN Dept. of Transportation
      * Nonprofit organizations (Adventure Science Center, MaxAbility)
    - The Council’s weekly policy news offers up-to-date information about key policies impacting Tennesseans with disabilities. During FY22, the Council published 46 weekly policy newsletters, connecting with 1,623 subscribers.
* Identify barriers and increase input
  + Citizens and policymakers call on the Council for help navigating the disability system and highlighting barriers they face in accessing these systems
    - 44 inquiries from citizens
    - 34 inquiries from policymakers
    - 6 Council members ignite policy change
    - Example: TN Center for Decision Making Support – Since its creation the Center for Decision Making Support has directly served hundreds of Tennesseans in need of support. The center received over 200 calls or emails requesting direct support on cases, has worked on 27 of these cases, reversed 3 conservatorships, and modified 3 conservatorships. The center is processing 1 additional conservatorship reversal and has a waiting list of cases to support.
    - Image description: adult size changing table billboards that the Council funded in several communities across TN to raise awareness of the issue

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# Martez Williams: Improving Information Sharing with Law Enforcement

It started with a worry. So much of our work does.

Governor-appointed Council member Martez Williams – also a graduate of Partners in Policymaking® – reached out to staff in response to George Floyd’s death. Martez uses a wheelchair and needs canes to transfer out of his vehicle. His worry: “What happens if I get stopped by the police and ordered out of the car? If I reach for my canes, would the police think I was reaching for a weapon?”

[Council staff supported Martez in writing an op-ed](https://www.tennessean.com/story/opinion/2020/07/29/police-interaction-fearful-for-black-people-disabilities/5531805002/) and in meeting with his state representatives. Martez learned there was a bill already in progress – the Precious Cargo Act – that would allow people with communication barriers to privately disclose their disability to law enforcement. The “Martez amendment” made sure “assistance exiting the vehicle” was added to the bill. Now, people with disabilities could let first responders know about their needs through the vehicle registration system.

But the bill wasn’t the end of the story. When Martez tried to use the new system, he ran into barriers. His local police department wasn’t aware of the new option and didn’t know how to direct him. Martez again reached out to Council staff.

The Council brought together the TN Dept. of Revenue, State Highway Patrol, and several local police departments. The Dept. of Revenue manages the vehicle registration system. They shared the new process for disclosing disability under the Precious Cargo Act. [The Council then shared that information with the disability community. Law enforcement agencies shared the information through their internal channels](https://www.tn.gov/cdd/engage-with-us/breaking-ground/breaking-ground-111/breaking-ground-111---precious-cargo-act.html).

Council expertise and trusted partnerships helped create a real solution from Martez’s worry.

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# What the numbers say about FY22 outcomes under Goal 3: Informing the Public

Goal 3 – Equip Tennesseans with disabilities, their families, policy leaders, and the community with information that promotes inclusion, self-determination, and independence.

* Increase accessible information
  + Data highlights for communications platforms and products with bar graphs to show progress:
    - E-news subscribers: goal:2,613; current: 2,485
    - E-news open rate: goal: 21%; current: 21%
    - Facebook page followers: goal: 6,240; current: 4,753
    - Facebook engagements: goal: 11000; current: 14,166
    - Twitter followers: goal: 1,616; current: 1,319
    - Twitter engagements: goal: 1,200; current: 1,378
    - Website unique visitors: goal: 27,600; current: 22,563
    - Breaking Ground subscribers: goal: 6,025; current: 6,128
* Build engagement in disability issues
  + Image of word cloud with varying topics covered in communications from the Council
* Lead statewide partnership: TN Disability Pathfinder
  + In partnership with 6 sister state agencies, the Council continues to support operation of the state’s only disability information and referral service, TN Disability Pathfinder; logos shows show agency partners, including:
    - TN Dept. of Human Services
    - TN Dept. of Intellectual and Developmental Disabilities
    - TN Dept. of Education
    - TN Dept. of Health
    - TN Commission on Aging and Disability
    - TN Dept. of Mental Health and Substance Abuse Services
* Increase engagement with underrepresented groups
  + Link to Spanish language YouTube video public service announcement about in-home vaccines for COVID-19 for people with disabilities and caregivers: <https://youtu.be/rfYI5RXC3HQ>
  + The Council led and produced two public service announcement videos to share information about the state’s accessible COVID-19 in-home vaccine program. These animated videos in English and Spanish were shared widely and targeted underrepresented communities in Tennessee.

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# The Work Continues in Fiscal Year 2023

[Visit our website](https://www.tn.gov/cdd) to follow our current priorities and engage with us. If you have a need or story to share, please contact us! We want to hear from you.

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