Tennessee Council on Developmental Disabilities Annual Report 2020 – Disability Means Building a Legacy of Change

# Introductions

The past year was one of huge challenges and major milestones. The Council has responded to the effects of a global pandemic. We have seen important results in our work to improve services for people with developmental disabilities. We celebrated 30 years of the Americans with Disabilities Act and 100 years of Vocational Rehabilitation.

This year also marks 50 years since the signing of the federal Developmental Disabilities Act (DD Act). The DD Act established a Developmental Disabilities Network in every state and U.S. territory: University Centers of Excellence, Protection & Advocacy Systems, and State Councils on Developmental Disabilities. State Councils like ours connect the disability services system directly to people living with disability in order to create change. The goal of every Council on Developmental Disabilities is to improve disability policies and practices in their state. We are all guided by principles of greater inclusion, independence, and self-determination for people with lifelong, significant disabilities.

In Tennessee, we celebrate 50 years of progress and look to the future, knowing the DD Act continues to represent a vision and purpose that unites us all.

-Wanda Willis, Executive Director

I have always loved that the DD Act was largely written by people with disabilities and family members. As the mom of a fantastic young man with autism, I am grateful for those who came before us. They saw a vision for a better future. Today, my son benefits.

As Chair of the Tennessee Council on Developmental Disabilities, I am proud of the accomplishments of our Council. Seeing the progress of the last 50 years gives me hope for the next 50. The Council works to make sure the voices of people with disabilities are helping to shape the future of our state. Because those voices are heard, the next generation of people with disabilities will have greater inclusion, independence, and self-determination. Thank you for your support as the work continues.

-Tecia Puckett Pryor, Chair

## Featured quote

“I have had the honor of serving on the Council twice, and over my terms, two accomplishments stand out for me. The Council was a driving force for the creation of Tennessee Disability Pathfinder’ a multi-lingual, cross-disability information database for people with disabilities.” -Stephanie Brewer Cook, Former Council Chair

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# A Legacy of Change: Snapshots of the Council’s Impact

Tennessee’s Council on Developmental Disabilities has been fulfilling the vision of the Developmental Disabilities Act since 1975. We don’t deliver direct services but exist just to create change. We are the only state agency with an objective, bird’s-eye view of the entire disability services system. We have trusted relationships within state government, and we are connected directly to people living with disability through our Council members. This allows us to see clearly what’s working and what’s not, and where different pieces of the system are working on related issues. We’re able to bring that work together, making it more effective and guiding with new ideas and best practices. The result: lasting, positive change for people with developmental disabilities.

1. **1975** – **The** **Council on Developmental Disabilities is established in TN** by governor order after the creation of councils in the DD Act five years earlier.
2. **1985** – **Council launches first supported employment programs** for Tennesseans with I/DD through a national employment grant.
3. **1989** – **Begins supporting** **People First of Tennessee**, a statewide self-advocacy group for adults with intellectual and developmental disabilities. This group goes on to lead major change, including the closing of state-run institutions for people with developmental disabilities.
4. **1993** – **Launches Partners in Policymaking® Leadership Institute** for Tennesseans with disabilities and family members. Nearly 600 people graduate from Partners and have a huge impact across our state. Partners graduates influence everything from national and state policy to more accessible local communities. The 2021 class is the Council’s 27th.
5. **1995** – **Launches “Home of Your Own”** to increase home ownership for Tennesseans with developmental disabilities. Banks and lenders are educated on supporting home ownership for people with I/DD. During the project, 132 people buy their own homes, 73 move from institutions into the community, 185 units of affordable and accessible housing are made available, and 240 people with disabilities receive training on home ownership.
6. **1995** – **Founds Childcare Resource and Referral Centers** to increase quality childcare options for families of kids with disabilities. The 10 centers are now run by the Dept. of Human Services. They educate childcare providers about best practices and inclusion of children with disabilities, giving families more quality childcare options.
7. **1997** – **Builds** **TN Disability Pathfinder**, the state’s central source for disability information and referral. Pathfinder is operated by Vanderbilt Kennedy Center. It offers a website and multilingual hotline to search, find, and connect with disability services. A few years later, the Council launches a Spanish-language version of Pathfinder, called “Camino Seguro.” Today, the Departments of Health, Intellectual & Developmental Disabilities, Education, and Human Services also help fund Pathfinder.
8. **2003** – **Holds the first** **TN Disability MegaConference**. Mega Conference continues annually and is the largest cross-disability, statewide conference. People from across the state learn about disability issues and resources and connect with each other.
9. **2005** – **Launches TN’s first** **Project SEARCH** **site** at Vanderbilt Children’s Hospital, which continues to operate today. Project SEARCH is a nationally known internship program for young adults with disabilities. There are now 17+ Project SEARCH sites across TN, offered through a partnership of several state agencies. Dozens of young people are prepared for full-time employment through the program each year.
10. **2006** – **Funds TN’s first inclusive higher education program** for students with intellectual and developmental disabilities,Next Steps at Vanderbilt. There are now 5 more college programs at Lipscomb, Union, UT Knoxville, ETSU, and University of Memphis. Graduates of these college programs have dramatically higher rates of employment than the general I/DD population. Learn more with this video: <https://youtu.be/KYkRdNQmAGg>
11. **2007** – **Starts “TN Adult Brothers and Sisters” (TABS)**, a peer support network led by siblings of people with disabilities. Today, TABS continues to offer information, learning opportunities, and emotional support to siblings of all ages.
12. **2017** – **Launches an education campaign on supported decision-making**, an approach that supports people with disabilities to make as many decisions about their own lives as possible. That work leads to the state’s first Center for Decision Making.

# The Work Continues: Our Impact in Fiscal Year 2020 July 1, 2019 – June 30, 2020

In the past year, the Council saw measurable impact under every goal area. Keep reading for more information about each goal’s activities and impact.

* Goal 1 – Developing Leaders
* Goal 2 – Impacting Policy and Practice
* Goal 3 – Informing and Educating Stakeholders

### Featured quote:

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.  A few of highlights are:

* Dental policy and awareness: A fellow Council member shared his story of going to the dentist and not being able to communicate exactly what his issue was. The Council teamed up with the other disability networks and some dentists to make some policy changes so dentists were better trained to meet the needs of patients with disabilities.
* Community Conversations: The Council worked with other disability organizations to hold wonderful meetings across the entire state with employers, promoting the benefits of employing people with disabilities.
* Post-secondary education: The Council funded college education opportunities for people with disabilities.
* Washington advocacy: The Council allowed me and my family to be part of a Tennessee delegation to go to Washington, D.C. to the National Disability Policy Seminar and speak with our Senators and Congressmen about disability policies.

-Tommy Lee Kidd, Former Council Chair

# Goal 1: Developing Leaders

The Council creates change by equipping Tennesseans with disabilities and their family members to become leaders in their own communities and across our state.

Participants in all Council **leadership programs this past year** reported they had an:

* Increased ability to advocate – 98.3%
* Increased knowledge of disability topics and issues – 97.9%
* Increased ability to access resources – 97.1%

An independent evaluation of 25 years of the Council’s scholarship fund showed long-term benefits. More than 75% of people who responded said the scholarship fund:

* Increased their ability to advocate (speak up for myself or others) – 80%
* Increased their ability to participate in activities that change the way that services are provided – 80%
* Increased their ability to find and use more resources in their area – 80%
* Helped them explore and use more of their communities – 79%

### Featured quote:

“Through the Council’s scholarship fund, I was able to attend the National Federation of the Blind convention. I learned more of how to live and succeed as a blind individual in our country. I have also been able to serve on several boards throughout my state and local organizations.” – Scholarship fund participant

The Council responded to the COVID-19 crisis by offering **special grants for FY20** to help people with disabilities and their families stay engaged and connected during quarantine. 100% of people who received grants said the money helped them feel less anxious and alone during COVID-19.

What did the Council COVID-19 grants fund?

* Technology like tablets, computers, printers and internet access
* Recreational activities and educational supplies like gardening and art supplies, school supplies and tutoring, backyard play equipment, and online arts and exercise classes
* Other needs like sensory toys, special highchairs and strollers, and therapy mats

# Goal 2: Impacting Policy and Practice

The Council creates change by improving disability policies and practices. We do this by connecting policymakers with the real-world perspectives of people experiencing the system.

### Featured quotes from policymakers:

"I can trust the Council to give me neutral, fact-based information about disability issues and the needs of Tennesseans with disabilities. They are always reasonable, always willing to listen to other perspectives. I consider them essential to discussions about disability." - Tennessee Representative Darren Jernigan (D-Old Hickory)

“I consider the Council a key partner when I am working on disability issues at the state legislature. They are always quick to research a topic and get back to me. Most recently, we worked together on an accessible transportation bill. Thanks in large part to data provided by the Council and powerful testimony from Council members living with disabilities, the bill passed unanimously.” – Tennessee State Senator Becky Massey (R-Knoxville)

## Examples of our impact:

### Decision-Making:

* Fiscal year 2017 – Set this as a priority – Council partners with TN organizations and national expert to learn more.
* FY18-19 – Inform and Educate – We work with partners to reach thousands of Tennesseans and further develop our approach
* FY20 – We fund the first in the nation Center for Decision Making – Solve a key barrier, an information gap for families, found during FY17-19
* FY20 outcome – Efforts move from education and relationship building to action. The Council funds a first-in-the-nation Center for Decision Making, a place where individuals, families and professionals can find easy to understand, reliable information about all kinds of decision-making tools. The Center helps people make informed decisions about what is best for them.

### Transportation

* FY18 – Bring together partners – the Council starts a workgroup to address accessible transportation
* FY19 – Legislative effort begins – Workgroup asked to help legislative leaders; Tennessee Accessible Transportation and Mobility Act introduced
* FY20 – Tennessee’s first Office of Accessible Transportation created – we solve a key barrier, the need for state level coordination of accessible transportation efforts, found during FY18-19
* FY20 outcome – A bill to create a new Office of Accessible Transportation within TDOT passes unanimously. TDOT’s member of the Council transportation workgroup is named to lead the new office. More information at <http://www.tennesseeworks.org/tennessee-creates-state-office-for-accessible-transportation/>.

### Employment

* FY19 – Partner with DHS for System-Wide Transformation – Council asked to partner with the Department of Human Services on disability aspects of a department-wide transformation effort to become more customer-centered
* FY20 – Launch two large-scale training projects – Reach Tennessee’s largest employment systems with training in disability best practices and person-centered thinking
* FY20 outcome – the Department of Human Services and the Council launch two projects:
  + A year-long person-centered training for all employment-focused staff
  + An update of the annual disability training for American Job Centers using person-centered thinking and best practices
  + Together these efforts result in major change across systems that help with employment for people with disabilities

# Goal 3: Informing and Education Stakeholders

The Council creates change by equipping the statewide disability community with clear, engaging information about key disability issues, policies, and resources. Information is power; an informed and engaged disability community will be heard wherever policies are made that affect their lives.

### Featured quote:

“There is always great information! A lot of information has helped my family. Especially right now, all of the COVID-19 updates are really helpful with understanding rights, laws, and going back to school or medical care. I attend webinars, when I can, that are listed and applied for the much-needed Pandemic EBT [school meal program]. Thanks to you!” -Parent of a child with a disability

## FY20 Communications activities and outcomes:

* COVID FAQs: *Filled an information gap* with easy-to-understand updates about policy changes and disability issues during COVID-19. This information was based on real questions and issues brought to us by Council members.
* #DisabilityMeans: *Drove diverse representation* *of people with disabilities* through a year-long social media campaign.
* Led outreach that *doubled public input* for a new, five-year state plan that guides our work. This input included increased responses from people who are Latinx, Black, and LGBTQ+. The input helps us identify needs and service gaps in the disability community.
* *Reached more people than ever before* with disability information and resources, including in rural areas:
  + 20+ events hosted and exhibits sponsored (shifting to virtual for most of the year)
  + 30+ mentions of Council work and members in press and other publications
  + 60+ presentations by Council members and staff
  + 47% increase in Facebook followers
  + 40% increase in Twitter followers
  + 32% increase in unique website visitors
* In a focused survey:
  + 100% of people said that Council communications *helped them better understand disability issues and public policy*.
  + 100% of survey respondents said our Council communications *helped them learn about disability services and resources that can help them*.

# What’s Next: Fiscal Year 2021

The Council has identified several focus areas for fiscal year 2021. Those include:

* Using your public input to guide our focus on priority areas like respite services, housing and financial assistance.
* Increasing our connection to underrepresented groups, including Black, LGBTQ+, rural, immigrant and Latino communities.
* Exploring new ways to equip youth with disabilities for leadership.
* Promoting inclusive higher education opportunities in community colleges and technical schools.
* Promoting the use of “plain language” to make disability information easier to understand.