Tennessee Cares for Autism Spectrum Disorder Navigation Network Report



In 2019, the Vanderbilt Kennedy Center (VKC) Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) at Vanderbilt University Medical Center created the *Tennessee Cares for Autism Spectrum Disorder Navigation Network*. The purpose of the network was to connect rural or medically underserved families of children with suspected autism or developmental delays to community resources and providers. Funded by the Health Resources & Services Administration (HRSA) and the Autism CARES Act, the network provided:

- 1. **Family navigation**, sharing information to empower families and close gaps between the diagnostic experience and post-diagnostic care; and,
- 2. **Provider education and support**, increasing community medical and early intervention providers' knowledge of autism care.



Family Navigation: Connecting Caregivers to Resources

Families were sent for **Family Navigation** by their primary care providers, early interventionists, and community partners.

- Our navigation team connected families to information and resources in their communities. We reviewed those resources with each of the families with whom we connected (Table 1).
- We created a resource list using input from important partners, including the Tennessee Early Intervention System (TEIS), Tennessee Disability Pathfinder, Meharry Medical College, and the Tennessee chapter of the American Academy of Pediatrics. Our resources emphasized supporting families from different backgrounds, including in rural areas.
- To help families access care after the grant ended, we trained other community partners in how to help families find information and care. Partners included primary medical providers, early intervention providers, and community care navigators through groups like Tennessee Disability Pathfinder and the Title V CHANT network.
- 4. On a national level, we shared the navigation framework through a partnership with the Vanderbilt Consortium LEND program and the Association of Maternal & Child Health Programs (AMCHP) database, where the framework is available for download (Table 2).

Table 1: Family Demographics

3,264 total children from 89 counties Male (71.3%) and Female (28.7%)



Racial/Ethnic Background: White (60.4%), Black (18.9%), Asian (2.4%), American Indian / Alaska Native (0.4%), Native Hawaiian / Pacific Islander (0.3%), Two or more races (2.5%), Hispanic or Latino (16.4%)



Languages Spoken: English (87.9%), Spanish (8.2%), Arabic (2.5%), Other (1.4%)



Insurance: Medicaid (76%) Uninsured (1.2%)

Table 2: Practices in AMCHP Innovations Database

Click a title below to view

ASD in Primary Care Education (ASD-PRIME)

Early Intervention Caregiver and Provider Support Services (EI-CAPSS)

LEND Trainees as Family Navigators

STAT-MD: Early Identification of ASD for Pediatric Health Providers

TELE-ASD-PEDS (TAP) Telehealth Evaluation Model

"Our providers were great and it was awesome that my daughter's TEIS team was able to be involved."

– Parent

Provider Partnerships in Primary Care

We provided **Primary Care Outreach and Training** to help community medical providers support children with autism within primary care. Training included withinpractice screening and diagnosis, how to connect families to resources, and evidence based best practices for autism follow-up visits (Figure 1).

We also created an online **Community of Practice** through which medical providers attend didactic sessions, review complicated cases, and learn about local resources. The goal of this community is to improve care of children with autism and other disabilities within the medical home. This community, operated now by a physician partner, also supports workshops, educational events, and online learning modules.

Our focus on supporting medical providers as leaders and clinical champions earned our group the Vanderbilt Nursing TEAM Award, which recognizes provider teams that come together to improve a process and positively impact patient care.

Since 2020 We Have

Trained **150+** practicing clinicians to use specific diagnostic tools within different settings

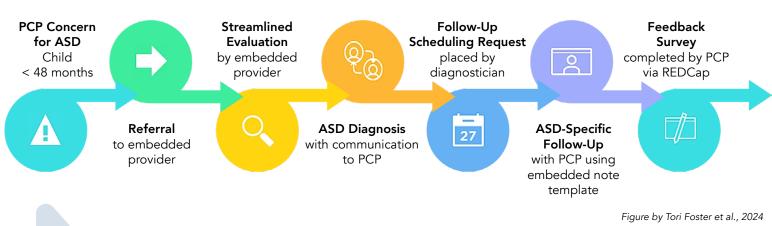
Trained **200+** pediatric residents in enhanced screening, diagnostic, and care coordination protocols

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Supported diagnostic evaluations for **700+** children

Supported autism-specific follow-up appointments for

350+ children



"I am grateful for the grant, which has supported my professional development and improved my autism-related teaching skills." – Participating Pediatrician

Figure 1: Primary Care Supports-from concern, to evaluation, to follow-up

Provider Partnerships in Early Intervention

Some Tennessee communities do not have easy access to pediatricians or other medical providers.

We partnered with our state's Part C Early Intervention Program (TEIS) to train the early interventionists that visit children's homes, even in our most rural and underserved regions. This training, called the **Tennessee Early Assessment and Mentorship Opportunity (TEAM Opp)**, empowered early interventionists to talk with families about autism, connect them to diagnostic visits over telehealth, and provide them with evidence-based follow-up care. This was accomplished through direct teaching and supervision, group trainings, online learning modules, and a **Community of Practice**.

By 2026, this program will be available to TEIS providers in every district of Tennessee.

Since 2020 We Have

Connected **900+** children to telehealth evaluations for autism

Hosted **27** Communities of Practice across the states

Increased the number of collaborating agencies from **5 to 19**

Increased the number of early interventionists involved from **12 to 212**

Online Trainings

We continue to offer the Families First program. This learning series, which happens in person and live via online platforms, targets the needs of families of young children with autism and communication delays. We also offer Brief Online Trainings (BOTS) for families, early interventionists, and medical providers. These trainings, available free of charge, offer information on evidence-based care and strategies to be used within the home.

"This experience was great to see how we can all better collaborate and support individual needs of the child and family." – Participating Early Interventionist

Publications

- Weitlauf, A., Miceli, A., Vehorn, A., Dada, Y., Pinnock, T., Harris, J., Hine, J.F., & Warren, Z. (2023). Screening, Diagnosis, and Intervention for Autism: Experiences of Black Families Seeking Care. *Journal* of Autism and Developmental Disorders, ePub ahead of print.
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- Foster, T., Bahrami, L., Miller, C., Miller, H., Muccilli, K., Warren, Z., & Hine, J.F. (2024, January 30). Diagnostic and Care Management Resources for Medical and Other Pediatric Providers. <u>triad.vumc.</u> <u>org/provider-portal</u>
- Weitlauf, A., Vehorn, A., Miceli, A., Pinnock, T., Dada, Y., Hine, J.F., & Warren, Z. (2022). Black families' experiences of developmental screening: Review of well-child visits to inform enhanced ASD risk assessment. *Journal of Autism and Developmental Disorders*, 43: 503-510.
- Hine, J.F., Wagner, L., Goode, R., Rodrigues, V., Taylor, J. L., Weitlauf, A., & Warren, Z. E. (2021). Enhancing developmental–behavioral pediatric rotations by teaching residents how to evaluate autism in primary care. *Autism*, 25(5), 1492-1496.
- Hine, J.F., Allin, J., Allman, A., Black, M., Browning, B., Ramsey, B., Swanson, A., Warren, Z., Zawoyski, A., & Allen, W. (2019). Increasing access to autism spectrum disorder diagnostic consultation in rural and underserved communities: Streamlined evaluation within primary care. *Journal of Developmental and Behavioral Pediatrics*, 41(1):16-22.



Resources available at <u>triad.vumc.org/tncares</u> For more information email <u>tncares@vumc.org</u>

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