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MCH Innovations Database Practice Summary & Implementation Guidance



LEND Trainees as Family Navigators

A structured introduction to family navigation for future professionals that connects families of young children with ASD to community care while promoting compassion, awareness, and understanding of family experiences for care providers.



Location

Nashville, Tennessee



Topic Area

Family/Youth Engagement,
Service
Coordination/Integration



Setting

Clinical



Population Focus

CYSHCN, Families, Health
Care Providers



NPM

NPM 11: Medical Home



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Section 1: Practice Summary

PRACTICE DESCRIPTION

Our “LEND Trainees as Family Navigators” program emerged from the need for a shared care coordination experience for LEND trainees spread across eight institutions and two cities. With the guidance of the former (Tyler Reimschisel, MD) and current (Evon Lee, PhD) Vanderbilt Consortium LEND directors, in addition to participating faculty, LEND long-term trainees were matched with families that had received a diagnosis of Autism Spectrum Disorder (ASD) from affiliated providers within the Vanderbilt University Medical Center’s Center for Child Development. The goal was twofold: to provide families with needed assistance in navigating complex health care and associated systems, while also providing LEND trainees the opportunity to experience care navigation and become familiar with health care systems, social determinants of health, and community services.

In parallel to the LEND program, the TN Cares for ASD Navigation Network at the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) was developed as part of an ongoing HRSA-funded grant that empowers families of young children with developmental delays or ASD by connecting them to community care. The Network developed a Family Navigation framework that attempted to standardize important resources for all families of children < 5 years newly diagnosed with autism spectrum disorder or global developmental delay within targeted regions of our state. This framework includes points and methods of contact, as well as important content related to: Part C agencies, public school Child Find contacts, disability advocacy partners (Tennessee Disability Pathfinder, Autism Tennessee), a list of evidence-based therapies that every family should be aware of when making care planning decisions, and respite or mental health resources.

As LEND faculty members transitioned and patient care navigation needs increased, our teams decided to formalize the LEND trainee navigation role through a partnership with the TN Cares Network. We worked together to create the framework for a sustainable, replicable introduction to the navigation experience that was capable of growth, that could be applied across settings or geographies. This program reflects the shared understanding that families of young children (birth to age 5 years) with ASD often struggle to access community care after their diagnoses. Although this is partly due to a lack of available service providers, especially in rural and medically underserved regions, it may also be due to fractured care systems – the diagnosing provider, the early intervention system, primary care providers, disability advocacy groups – that exist side-by-side but may not talk to each other.

Our merged model, described in this document, therefore attempts to increase family knowledge of these groups and services, while also providing a hands-on practicum experience to the future interdisciplinary providers who might one day care for these families. This emerging practice is a framework through which other LEND sites could help trainees understand not only what resources are available, but also give opportunities for direct contact and conversations with families to deepen their understanding of family experiences during this critical post-diagnostic window.

CORE COMPONENTS & PRACTICE ACTIVITIES

The goal of our program is to give LEND long-term trainees a practicum in which they execute the following core components: 1) Attending a training session in which core resources are presented by a lead Family Navigator and the program is explained; 2) A review of the training packet, including resources commonly available to and



recommended for families of children with ASD (birth to 5 years) in Tennessee; 3) Up to three points of phone contact with three families of newly diagnosed young children, including review of standardized resources list and a framework for taking relevant notes, and 4) Experience in care coordination by sharing notes and updates back with the lead Family Navigation team. Importantly, each of these components can be easily modified to reflect the resources of different states to increase portability.

Core Components & Practice Activities		
Core Component	Activities	Operational Details
Session	Attend training session with Family Navigator	Attend an in-person/Zoom training session where an experienced Navigator provides information about the program and its rationale, including its focus on increasing family competence while giving trainees important insight into the lived experiences of families.
Packet	Review packet of training materials	Review packet of information explaining rationale for program, timeline of activities, sample scripts for speaking with families, recommended resources, and resource contact information to share with families.
Phone Call	Call a family of a young child with a new diagnosis	Call up to 3 families enrolled in Navigation program, no more than 3 times each, to: assess needs, make notes, share information related to what families request, and identify areas that need follow-up with Lead Navigator or diagnosing provider.
Care coordination	Share care notes back with Navigation team	Use HIPAA compliant document storage and survey sites to share notes with lead Navigator, who provides feedback on content, makes recommendations for next phone call, and models further care coordination activities related to follow-up with providers.

HEALTH EQUITY



Our practice derives from the family-centered LEND approach and our TN Cares activities, which specifically focus on increasing knowledge and competence for families from rural and medically underserved communities. Families of racial, ethnic, and linguistic diversity experience significant delays in accessing diagnostic care (Constantino et al., 2020; Wiggins et al., 2020; Zuckerman, Chavez, & Reeder, 2017; Zuckerman, Chavez, Regalado Murillo, Lindly, & Reeder, 2018; Zuckerman et al., 2013). Race-based disparities persist regardless of insurance coverage or socioeconomic status (Constantino et al., 2020). Many existing developmental assessment models have been developed based upon the input of primarily White providers and patient families (Shaia, Nichols, Dababnah, Campion, & Garbarino, 2020) and do not reflect content that is actually relevant, important, or accessible to diverse groups (Harris, Coffield, Janvier, Mandell, & Cidav, 2021; Vanegas, Magaña, Morales, & McNamara, 2016; Windham et al., 2014).

Our Navigation team is advised by, and has partnered with, two community groups that have been instrumental to our efforts to engage in an approach that is mindful of, and attempts to combat, these care disparities. This stakeholder feedback happens in an ongoing manner and is resulting in ongoing, direct changes to our Navigation procedures that in turn are incorporated into the framework proposed.

The first is Meharry Medical College, one of the oldest historically Black medical colleges in the United States. Theodora Pinnock, MD, Developmental Behavioral Pediatrician, attends a regular meeting with our team that focuses on raising our awareness of care disparities, implicit and explicit racial bias, and new opportunities to connect specifically with families of color in our region, including important community spaces and leaders. She has also modeled for us, and provided resources on, how to engage in conversations about bias with trainees and raise awareness amongst our team of structural racism and its impact on the disability community.

Our community resources are also informed by our collaborations with Tennessee Disability Pathfinder regarding those deemed most appropriate, accessible, and helpful to Spanish-speaking families. We are advised by Latinx providers from Camino Seguro, the multicultural outreach team of Tennessee Disability Pathfinder, a service that provides free information, referral sources, and help with navigating services via phone, email, and website to families across our state. Camino Seguro staff provided our team with trainings in cultural competence as well as supervision to our own bilingual Navigator. This includes significant revision and re-translation of some of our materials, a Spanish language version of our website, ongoing awareness-raising of how resources may not be accessible to families without transportation or insurance, and opportunities to connect with community spaces and leaders previously unknown to or not considered by our team.

Finally, our team has recently been joined by an experienced family service provider who also speaks Arabic. Our goal is to apply lessons learned from our Meharry Medical College and Camino Seguro partnerships and use that framework to better support families that speak Arabic over time.

EVIDENCE OF EFFECTIVENESS

Our evaluation plan consists of two surveys sent to LEND trainees via REDCap to collect quantitative data about confidence and comfort communicating with families. Prior to beginning their care navigation practicum, trainees are asked to complete a three-question survey assessing their initial levels of comfort and confidence communicating with families. After completing the practicum, trainees are sent a post-practicum survey with the same three questions to re-assess their comfort and confidence levels. An additional question asks trainees if they have increased their knowledge and/or skills as a result of the practicum. Trainees can provide qualitative feedback on specific care coordination experiences in their notes that are shared with the Navigation team or directly to the Navigation Lead at any time.



Practice effectiveness is measured by comparing trainee responses to the pre- and post-practicum survey to determine changes in confidence and comfort levels. The surveys ask trainees: their confidence finding information about autism and autism-related services; their comfort level discussing autism and autism-related services with families; and their confidence that they can help families get access to appropriate services and supports.

During the first year of this practice, we collected qualitative data from the trainees. The responses to the questions, “What did you learn about the process of care navigation?” and, “How will what you learned inform your role as a care navigator going forward” showed initial successes. Trainees learned that it is not always easy to get in contact with families; that being prepared for contacting caregivers is important; sometimes caregivers need someone to listen as much or even more than they need a resource; calls to second families went more smoothly showing that practice makes perfect; follow through shows integrity; all caregivers handle the diagnosis of autism differently; and that it was a really good learning experience to have these difficult conversations (see Table 1). Through these comments, trainees showed growth over time and higher confidence levels in their own abilities to speak with caregivers and guide them to resources and supports.

Table 1

Examples of Qualitative Feedback from LEND Trainees

I feel as though my role in the call was to make sure that [the family] was in connection with the resources they need and be a listener to any concerns they may have about the services their child is receiving. I think now that we have established some rapport, the next phone call will go even better.

I think it's helpful to remember that every family is going to be different-some families may feel confident in their own skills, abilities, and knowledge and not feel a need for a lot of support. This doesn't mean we don't offer support and check in but understanding that families bring their own background and experiences to these conversations is helpful.

I learned that, for my next call, I will have even more resources prepared, although I felt I had more than enough for this call. I want to know more about the TEIS information. I feel more confident to call this family back - even excited.

Having had this experience, a first opportunity to speak with any family about autism, makes me more prepared for how to handle future calls.

I felt more prepared for this call than my initial call with them. It was helpful to have notes from the previous call to refer back to.

Because I made a list of resources and practiced the script beforehand, I felt very prepared speaking with this family. During the call, I felt as if my primary role was being a listener and providing support for the family member as they were going through a difficult time. The family member also seemed happy to know that I would be able to share a list of resources. Having spoken with this family member, I feel much more confident speaking to them the next time.

While I am a little sad our next call will be the last, I think I have made an impact on this family for sure.



Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

We have partnered with several community organizations that have advised us on available resources, family perspectives, cultural competence, and effective partnerships with medical providers.

Practice Collaborators and Partners		
Partner/Collaborator	How are they involved in decision-making throughout practice processes?	Does this stakeholder have lived experience/come from a community impacted by the practice?
Parents of children with autism spectrum disorder or developmental delay	Parents complete surveys after each point of contact about changes in competence and knowledge	Parents are the primary care providers for the children receiving services in this program. Parents of children with SHCN are also represented on our Navigation team and within our LEND program.
Camino Seguro	Ongoing consultation on care provision for Spanish speaking families; shared ownership of Navigation activities related to complex care referrals	Camino Seguro represents the interests of Spanish-speaking and Latinx families affected by disability care coordination and barriers to such within English-speaking systems.
Meharry Medical College	Ongoing consultation on care provision for families of color, specifically Black and African-American persons; input on Navigation content for appropriateness and accessibility	Partners at Meharry Medical College represent the interests of Black and African-American families and providers that are disproportionately affected by structural racism within our medical system and community care options.
Vanderbilt University Medical Center pediatric social workers	Targeted consultation and shared care coordination for multi-stressed families	The pediatric social workers within the medical center advise us on complex cases in addition to educating our team on available community resources related to housing stability, financial assistance, and safety planning, particularly for families also cared for by medical providers in the hospital.



Tennessee Chapter of the American Academy of Pediatrics	Represent pediatricians throughout the state of TN, including those in rural and underserved areas	Results of Navigation efforts are regularly communicated to TNAAP leadership and to primary care providers of children receiving care. Strengthening family-pediatrician partnerships is emphasized in our program.
Autism Tennessee	Represents families of, and people with, ASD in the mid-state	Autism Tennessee is a community organization that provides family support and navigation. We send every family that participates in our Navigation experience to them for additional ongoing care and emphasize their role to our trainees.

REPLICATION

This practice has not been replicated in any other location.

INTERNAL CAPACITY

This practice requires collaboration between programs and the support of Faculty Directors and support staff. Our family navigators and our LEND Consortium both have the same home department. This made working together simple. We gathered several times as a large team to determine goals and feasibility. Once that was accomplished, support staff took over daily practice needs. Staff currently involved made time in their schedules to make this practice possible. No new staff was hired or needed. Please refer to the practice timeline tables for number of hours staff spent working on the project year one. Many hours were reduced in year two.

PRACTICE TIMELINE

The practice timeline shows the total hours of faculty and staff time needed to plan for implementation of the practice in year one. Most planning and pre-implementation hours were not needed in year two.

Trainees have five months to complete the family navigation practicum experience. This includes training, learning about community resources, and providing navigation services to three families. Staff needs (hours committed to project) are higher during the initial five months and much lower for the remainder of the calendar year.



Phase: Planning/Pre-Implementation

Activity Description	Time Needed	Responsible Party
Meetings between LEND Faculty and Staff and HRSA Family Navigators to prepare for trainee practicum	10 to 15 hours	Lead Family Navigator and LEND Trainee Practicum Supervisor
Developing materials to share information about autism, our family navigation model, working with families, and very specific scripts to guide trainees through the practicum	20 hours	Family Navigation Team
<p>REDCap Survey Development: Survey One measures trainees' comfort and competency pre- and post- practicum</p> <p>Survey Two captures specific information from the trainees about navigation services they provide to individual families and collects qualitative data about the trainees' experience.</p>	10 hours	LEND Practicum Supervisor with input from Lead Family Navigator

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Orientation with trainees	2 hours	Family Navigators and LEND Faculty
Work with trainees to assign specific families via the HIPAA	Time varies depending on the number of trainees. We spent a	Family Navigators and LEND Faculty



compliant document storage, answer questions, monitor progress, and follow up with the families as needed	total of five to eight hours a week supervising 15 to 20 trainees.	
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Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Ongoing quality improvement activities	3 hours	LEND Faculty and Staff and Family Navigation Team
Review of previous year and planning for the following	3 hours	LEND Faculty and Staff and Family Navigation Team

PRACTICE COST

Portions of this work were supported by the Tennessee Cares for ASD Navigation Network, which is funded by the Health Resources & Services Administration (HRSA) and the Autism CARES Act: Innovations in Care Coordination for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities Program, Grant # H6MMC332360100.

This project is also supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Grant # T73MC30767, Vanderbilt Consortium LEND.

There are no direct costs associated with this practice outside of faculty and staff effort. For more information on practice costs, please contact Nina Harris at nina.harris@vumc.org.

LESSONS LEARNED

Although many LEND trainees are initially hesitant to reach out to families, their feedback indicates they find it a rewarding experience. We found that the trainees need encouragement to make the initial calls and reassurance that they do not need to know all the answers to families' questions. Because the trainees come from a variety of professions, they also need some upfront training to become familiar with the resources available to families and children with ASD, as well as commonly recommended therapies and supports.



Because the practicum involves two entities, there were some initial challenges in determining oversight of the trainees with respect to following up with different elements of the practicum. To address this issue, we clarified which responsibilities belong to the practicum as a LEND experience (e.g., completing practicum "homework") and which belong to TRIAD-specific activities (e.g., contacting families). Those belonging to the practicum are overseen by a LEND staff member, while those directly associated with TRIAD are overseen by TRIAD leadership.

During the first year of the practicum, we discovered that trainees needed more direct guidance in how to follow up with families and what to do when they could not reach a family. To help address these issues in our second iteration, in addition to allowing more time in the initial session to cover these topics, we re-designed the reporting tool to include specific instructions regarding next steps after completing calls. This included providing trainees with scripted suggestions for starting conversations, querying family needs, and deferring to other team members.

To help the interprofessional trainees become more familiar with available resources, in the second year, when following up with a family, trainees are required to write an annotated list of appropriate resources to be sent to the family. This both allows them to become acquainted with these resources while ensuring the family receives a detailed list of resources tailored to their needs.

This program is being developed and refined in an ongoing and iterative way across two distinct but related programs of family navigation and interprofessional training and education. In hindsight, we would have clarified different scripted portions of the navigation process upfront for trainees. We also would have collected quantitative data more immediately in order to measure change. We have not yet identified components of navigation itself that should be changed, but we recognize the importance of community partnerships as well as internal partnerships to the success of the effort.

NEXT STEPS

We plan to continue this partnership indefinitely, making annual iterative improvements based on trainee feedback. Our trainees represent professions from across Middle and East Tennessee. Because it depends upon stakeholder and trainee input, we will make changes to recommended resources as those systems of care change. However, the framework itself is designed to be portable and flexible depending on the region in which it is implemented.

In the preliminary trainee presentation given by our Navigation team to the potential LEND practicum students, our next concrete step is to more deliberately discuss structural racism within autism identification practices and the multifold contributions to families not being able to access care. We feel that this step is especially important when offering navigation to identified families from medically underserved or rural regions, who may face explicit or implicit bias on the part of care providers.

RESOURCES PROVIDED

- Excel spreadsheet template
- Sample PowerPoint training
- Sample training script



- Sample REDCap surveys
- Sample trainee experiences
- Vanderbilt Consortium LEND Care Navigation Concept Guide

APPENDIX

- Vanderbilt Consortium (LEND) Leadership Education in Neurodevelopmental Disabilities: <https://vkc.vumc.org/vkc/lend>
- TRIAD: Treatment and Research Institute for Autism Spectrum Disorders: <https://vkc.vumc.org/vkc/lend>
- Tennessee Cares Network at Vanderbilt University Medical Center: <https://vkc.vumc.org/vkc/triad/tncares/>
- Vanderbilt Kennedy Center: <https://vkc.vumc.org/vkc/>

