

Vanderbilt Consortium LEND Care Navigation Concept Guide

What is Care Navigation? (*The Emerging Field of Patient Navigation, 2012*)

Patient navigation is a healthcare service delivery model built around the patient, and created to reduce barriers to care through the use of patient navigators

- Navigators work in a variety of settings – community, hospital, home, primary care, and tertiary care, for example – to guide patients through the treatment process and keep the healthcare team apprised of all facets of the patient’s care.
- Care Navigators ensure that barriers to care are resolved
 - Break down medical jargon of a diagnosis, assist in finding transportation to appointments
 - Reactive – seek solutions to a variety of problems
 - Versus proactive
 - Can be proactive in developing a rapport with the patient so when they face a barrier, they are comfortable seeking assistance
- Addresses individual patients – not entire healthcare systems

Role of Trainee as Care Navigator

Goals for trainee and what we hope they gain:

- To successfully participate in reduction of barriers to accessing healthcare for families
- To gain appreciation for the real-world struggles of families of children with complex healthcare needs as they relate to social determinants of health
- To become a competent care navigator with a working knowledge of the resources available to families that can help to reduce barriers to healthcare access
- To learn how to effectively liaise between diverse groups (physicians/ nurses on medical side, social workers/ community organization advocates on the community side, teachers/ school practitioners, etc.) toward the ultimate goal of reducing barriers to access for families
- To learn effective interviewing skills aimed at ascertaining a family’s barriers to access
- To foster rapport building skills in order to garner the trust of families served
- To learn strategies for effectively empowering families and to facilitate their independence

Goals for family and what we hope they gain:

- Significant reduction of barriers to accessing services
- Knowledge of the most helpful resources available to them as well as strategies for accessing those resources independently
- A broad understanding of the healthcare system and its operations in order to develop confidence while seeking out future healthcare services

Duties/ Responsibilities of Trainee Care Navigator:

- “Identifying all of the barriers—psychological, social, financial, and environmental—that affect the patient’s ability to adhere to treatments or maintain their health” (Families USA, 2013 The Promise of Care Coordination: Transforming Health Care Delivery article)
- Maintain consistent communication with the family to ensure their needs are being met
- Gain experience as a care navigator by providing guidance to quality and comprehensive care for the individual and their family members in a reactionary manner so that they may be empowered and encouraged to navigate services in a more autonomous capacity (referenced from the Center of Health Affairs Issue Brief on The Emerging Field of Patient Navigation: A Golden Opportunity to Improve Healthcare, see Core Module 1 for copy of brief).

Communicating with Families

- Building Rapport
 - <http://tuh7143yo1527qz2743fa3x7.wpengine.netdna-cdn.com/wp-content/uploads/2013/08/The-Navigation-Perspective.pdf>
 - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4029856/pdf/nihms563070.pdf>
- RESPECT Model
 - “Communication has been defined as ‘the transmission of information, thoughts, and feelings so that they are satisfactorily received or understood.’ Good patient communication involves recognizing and responding to the patient as a whole person – an approach frequently termed ‘patient-centered’ care. It also involves recognizing that in any provider-client interaction two experts are present: the provider who has the clinical knowledge and the client who has the knowledge of the individual and cultural factors that influence effective treatment and care. The RESPECT model, presented below, crystallizes the patient-centered approach to communication” (Joseph, 2012).

The RESPECT Model

Rapport

- Connect on a social level
- See the patient’s point of view
- Consciously suspend judgment
- Recognize and avoid making assumptions

Empathy

- Remember that the patient has come to you for help
- Seek out and understand the patient’s rationale for his/her behaviors or illness
- Verbally acknowledge and legitimize the patient’s feelings

Support

- Ask about and understand the barriers to care and compliance
- Help the patient overcome barriers
- Involve family members if appropriate
- Reassure the patient you are and will be available to help

Partnership

- Be flexible with regard to control issues
- Negotiate roles when necessary
- Stress that you are working together to address health problems

Explanations

- Check often for understanding
- Use verbal clarification techniques

Cultural competence

- Respect the patient’s cultural beliefs
- Understand that the patient’s view of you may be defined by ethnic or cultural stereotypes
- Be aware of your own cultural biases and preconceptions
- Know your limitations in addressing medical issues across cultures
- Understand your personal style and recognize when it may not be working with a given patient

Trust

- Recognize that self-disclosure may be difficult for some patients
- Consciously work to establish trust

- Words To Watch

- “Many people, even highly literate people, have trouble understanding words used in health care. In some instances, a word may be totally unfamiliar. In other cases, a word may be familiar, but the person may not understand it in a healthcare context.” (Joseph, 2012)
- Tables below are from Joseph, 2012.

Medical Word Examples: Words frequently used by doctors and in health care instructions.

Problem Word	Consider Using
Ailment	Sickness, illness, problem with your health
Benign	Will not cause harm; is not cancer
Condition	How you feel; health problem
Dysfunction	Problem
Inhibitor	Drug that stops something that is bad for you
Intermittent	Off and on
Lesion	Wound, sore; infected patch of skin
Oral	By mouth
Procedure	Something done to treat your problem; operation
Vertigo	Dizziness

Concept Word Examples: Words used to describe an idea, metaphor, or notion.

Problem Word	Consider Using
Active role	Taking part in
Avoid	Stay away from; do not use (or eat)
Collaborate	Work together
Factor	Other thing
Gauge	Measure; get a better idea of; test (dependent on context)
Intake	What you eat or drink; what goes into your body
Landmark	Very important (adj.) Important event; turning point (n.)
Option	Choice
Referral	Ask you to see another doctor; get a second opinion
Wellness	Good health; feeling good

Value Judgment Word Examples: Words that may need an example or visual to convey their meaning with clarity.

Problem Word	Consider Using
Adequate	Enough <i>Example (adequate water): 6-8 glasses a day</i>
Adjust	Fine-tune; change
Cautiously	With care; slowly <i>Example: making sure to hold on to handrails</i>
Excessive	Too much <i>Example (bleeding): if blood soaks through the bandage</i>
Increase gradually	Add to <i>Example (exercise): add 5 minutes a week</i>
Moderately	Not too much <i>Example (exercise): so you don't get out of breath</i>
Progressive	Gets worse (or better)
Routinely	Often <i>Example: every week; every other day</i>
Significantly	Enough to make a difference <i>Example (smoking/heart disease): 2 times the chance of having heart disease</i>
Temporary	For a limited time; for about (an hour, day...) <i>Example: for less than a week</i>

- People First Language

<https://www.thearc.org/who-we-are/media-center/people-first-language>

(Scroll down to the section **The Power of Words: People First Language.**)

https://www.cdc.gov/ncbdd/disabilityandhealth/pdf/disabilityposter_photos.pdf

Communicating with the family when you aren't sure of the answer

What happens when the family asks you something you don't know the answer to?

- Do NOT make anything up in fear of appearing uneducated to the family.
- Make a clear statement to the family that you do not know the answer to their question, but also make a commitment to the family that you will research this topic (if appropriate) or you will contact additional resources.



TENNESSEE CARES NETWORK

at Vanderbilt University Medical Center

LEND Family Navigation: Background and Script

Introduction:

We are so pleased to have your assistance with our Family Navigation project. This project is funded through the Health Resources and Services Administration (HRSA), part of the Maternal and Child Health Bureau – the same federal agency that funds LEND!

You will be talking to parents/caregivers after their young child (< 5 years old) has had an appointment with a TRIAD clinician and received a diagnosis of Autism Spectrum Disorder (ASD). This appointment may have happened through the medical center or a research study. Some families had a telehealth appointment and others had in person appointments.

Most families have had some preparation for our call. They received an email introducing Family Navigation, and/or the clinicians mentioned it during the appointment. Even with that, some families will not be expecting our calls. *This service is optional. If families do not have any questions or do not want to be contacted again, they are allowed to make that choice. Just let Nina Harris know.*

Remember that families may feel overwhelmed by their child's recent diagnosis and the amount of information they received. Diagnostic appointments may be fairly brief (an hour or two). Because of this, families may not have had a chance to review a report or look at materials by the time of our first phone call. *Please don't try to take responsibility for that – if they have questions about clinical findings or have not received the report, let Nina Harris know.*

We are very grateful that they have a team of Family Navigators to follow-up with their patients. It means a lot to them that we are able to continue to support these families, especially in a time of COVID, when families have less face-to-face contact during diagnostic visits.

Thank you again for your participation!

Amy S. Weitlauf, Ph.D.
Program Lead
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Nina Harris, M.Ed.
Family Navigation Lead
nina.harris@vumc.org

Procedures:

You will be assigned to call at least one and no more than two families as part of this project.

Before you call the family, you will be given the following information. It will be found in your HIPPA compliant Box folder.

All of this information is protected health information (PHI) and must be treated as strictly confidential.
This means that you should not talk about it with anyone outside of LEND/TRIAD or email about it.

When you call a family, you will know the following information:

Child's Name
Date of Birth
Date of Evaluation with TRIAD Clinician
Clinician Name
Parent Name and Contact Information
Diagnosis (All children followed as part of this program will be confirmed as having ASD)
Additional notes as needed

Please note: After each call, you will need to keep your own personal notes to be able to do this. Information that you share in the REDCap survey will not be available to you at a later time. Keep your notes in a secure location. Use family initials or a number code instead of names.

Always remember, it is okay not to know the answers to family's questions. Just share that you will work to find the answer and call the family back. Follow through in this way is what means the most to families!

First phone call (to be made immediately when contact information is shared)

Introduce yourself: "Hi, my name is _____. I'm calling from Vanderbilt as part of the Family Navigation team that works with (Clinician's name). May I please speak to (caregiver's name)?"

(If you have not reached the designated caregiver, STOP and ask if there is a better time to call back. Don't talk about things like autism or appointments with anyone but the person named in the information you received.)

(If you have reached the designated caregiver, continue below)

"Again, I'm part of the Family Navigation team. We follow-up with families whose children have new diagnoses of autism. We make sure they got their diagnostic reports and see if they need information about any of the recommended next steps.

Is this an okay time to talk for a few minutes?"

IF NO – "That's alright. Is there a better time to call back?"

IF YES – "Wonderful. I wanted to check in and ask you a few questions about how things have been going since your visit.

Did you receive a copy of your child's diagnostic report?"

If NO – "I'm so sorry to hear that. I'll check on that for you and make sure it gets in the mail. Can you confirm your street address for me?"

If YES – "Great. I have a few resources that I would like to review with you. First, though, do you have any questions about what the report recommends?"

PLEASE NOTE: IF THE FAMILY HAS SPECIFIC EVALUATION QUESTIONS, THOSE NEED TO BE ANSWERED BY THE PSYCHOLOGIST. PLEASE SEND AN EMAIL TO NINA HARRIS LETTING HER KNOW TO CHECK NOTES IN REDCap AND SHE AND THE PSYCHOLOGIST WILL FOLLOW UP WITH THE FAMILY. DO NOT INCLUDE CHILD NAME OR OTHER IDENTIFYING INFORMATION IN THE EMAIL TO NINA.

LET THE FAMILY KNOW THAT YOU WILL BE HAPPY TO HAVE THE FAMILY SERVICES COORDINATOR REACH BACK OUT WITH ANSWERS. DO NOT ATTEMPT TO ANSWER THESE QUESTIONS YOURSELF.

To guide the rest of your conversation, please use the below to understand the common resources and service recommendations that the psychologists share in each written report:

If the family has questions about the report – "Okay. I've made a note of those and will forward them on to our clinical team. If somebody does not contact you within one week, you can call our Lead Navigator, Nina Harris, at 615-322-7565 to be sure they got your message."

“I want to be sure that you are aware of a few resources that we recommend to all families after a visit. I’m going to check in and see if you’ve been able to look into these yet and if not, connect you with these agencies.

Remind me of your child’s age?”

For children 33 months and under, involvement with Tennessee Early Intervention (children under three): “Okay. Have you heard of the Tennessee Early Intervention System?”

If child is enrolled, you can stop. If not, “Do you want more information or would you like us to make a referral?” If referral needed, email Nina and ask her to check REDCAP notes for family you completed survey for. Please DO NOT send child’s name or other identifying family information in the email.

For children over 33 months, involvement with the Preschool Special Education Services in the School System (children over three). “Have you heard of the preschool special education program that’s offered in your school district?”

If child is enrolled or family has started evaluation process, you can stop. If not, “Would you like me to help you find this information so you can start that process now? We can also talk about this on our next call, if you prefer.”

If family needs information to get involved, search online for the specific county school system and offer to share preschool special education contact number with the family. You can do this through Tennessee Disability Pathfinder search engine by searching for “special education” and then the family’s county.

Families have to call themselves and ask how to start the process. It is a long process in which a family is sent a packet of paperwork to complete, then has a school system eligibility evaluation (schools must do this to receive federal funding). If the child is eligible (NOT EVERY CHILD WITH A DIAGNOSIS OF AUTISM QUALIFIES), a program plan will be written and the family is a part of writing that plan. The plan will determine what services will benefit the child based on the child’s strength and needs.

If families have questions about school systems, the best resource is Support and Training for Exceptional Parents, or STEP: www.tnstep.org, (800) 280-STEP.

Caregiver Training: “TRIAD offers several caregiver trainings. These include online workshops as well as handouts that I could email to you. Would you like to hear about those trainings today?”

If yes, you can review:

Families First: Call (877) ASD-VUMC to register or visit <http://vkc.mc.vanderbilt.edu/vkc/triad/fam/> to learn about upcoming workshops.

Online Caregiver Trainings (These are free, but families have to sign up and register as a user before they can access them): <https://triad.vkclearning.org/>

VKC Handouts: <https://vkc.mc.vanderbilt.edu/vkc/resources/autism/>

Autism Speaks Toolkits: <https://www.autismspeaks.org/tool-kit>

Other therapies: “Finally, sometimes children with new diagnoses of autism are eligible to receive different kinds of therapies, like speech therapy, occupational therapy, or ABA therapy. If these were recommended, or if you are interested, have you talked to anyone about this yet?”

If yes, skip to next section.

If no, “Okay. Sometimes it can take a while to get set up and find a provider. We recommend that you talk to your child’s pediatrician and your insurance company to find out who is located in your area and accepts your insurance plan. Sometimes children can also get these through TEIS or the school district.”

If families want to know more about ABA, we recommend these handouts:

ABA Tip Sheet: <https://vkc.mc.vanderbilt.edu/assets/files/tipsheets/abatips.pdf>

Selecting a Behavioral Services Provider:

<https://vkc.mc.vanderbilt.edu/assets/files/tipsheets/behservicesprovidertips.pdf>

ATN/AIR-P Guide to Behavior Analysis:

<https://www.autismspeaks.org/tool-kit/atnair-p-parents-guide-applied-behavior-analysis>

ALTHOUGH ABA IS HIGHLY RECOMMENDED, IT CAN BE HARD FOR FAMILIES IN TENNESSEE TO FIND AND TO PAY FOR IT. Many families ask for agencies in the area they live that provide these services; you should direct them back to their child’s pcp for assistance.

You don’t have to bring this up when you call, but some families will ask you about:

Respite services: You can find these on Tennessee Disability Pathfinder by county. Families can also call the caregiver support websites listed below:

Caregiver Support Groups:

Mid-state: Autism Tennessee; you can refer families to their website at <https://autismtennessee.wildapricot.org/>, their HELP Line at 615-385-2077, or their email at SUPPORT@autismtn.org

Southeast: Chattanooga Autism Center: <https://www.chattanoogaautismcenter.org/>

West TN: ARMS Jackson: <https://autismresourcesmidsouth.org/>

Financial Needs (email Nina Harris alerting her to see your most recent REDCap notes to help a family with financial needs. Nina will reach back out to the family to assist)

At the end of the first call: Thank family for their time, let them know you will call back in about one month to check in again. If the family seems to think they may need support sooner than the next check in point, please give them contact information for Nina Harris at 615-322-7565.

Once call is complete, send email to family with any resources, information or links you promised to send. Make notes for yourself so you can review prior to the second phone call. Complete redcap survey to document this call.

Second Call: One month after the first call, please reach back out to the family.

- Ask the family how they are doing, if their child is participating in any new services, how those may be going, if they need help accessing information at this time.
- Follow up on information shared during the first call using your personal notes from the previous call.
- Let the family know you will call back one additional time in a couple of months. If the family seems to think they may need support sooner than the next check in point, please give them contact information for Nina Harris at 615-322-7565.
- Once again, email any informational flyers (NOT PERSONAL HEALTH INFORMATION) you promised to send to the family based on second call and keep notes for yourself for call number three. Complete REDCap survey to document the call.

Third Call: Prior to the end of February, call the family one additional time.

- Ask about their child, how things are going and if they have any further needs.
- Let the family know this will be your last check in.
- Please share contact information with the family for Nina Harris at 615-322-7565 if the family needs any additional supports or resources in the future. Complete REDCap survey to document the call.

SAMPLE LANGUAGE FROM PSYCHOLOGICAL REPORTS

The text below shares many of the exact service recommendations and resources that families receive from the psychologist in the written report. **You do not need to go through each with the family.** This is simply a guide for you to be aware of what has been sent and offered.

Service Coordination for children under age of three: It is strongly recommended that the caregivers share this report with those currently involved in their child's care (i.e., pediatrician, therapists) to further facilitate appropriate service delivery and interventions. It is also highly recommended that the caregivers share this report with the Tennessee Early Intervention System (TEIS) to develop and facilitate services until age three and to aid in the evaluation and potential implementation of an Individualized Educational Program [IEP] prior to the third birthday as appropriate.

Service Coordination for children over the age of three: It is strongly recommended that the caregivers share this report with those currently involved in their child's care (i.e., pediatrician, therapists) to further facilitate appropriate service delivery and interventions. It is also highly recommended that the caregivers share this report with the Preschool Special Education Department in their county of residence. The child may qualify for educational services and programming.

Applied Behavior Analysis (ABA) Services / Behavioral Consultation / Parent Training: Implementing behavioral and educational strategies for bolstering social and communication skills and managing challenging behaviors at home, intervention settings, and school will likely prove beneficial. As such, the caregivers, teachers, and service providers are encouraged to implement ABA techniques targeting effective ways to increase social and communication skills across settings. The use of visual schedules and supports within this plan is recommended. In order to create, implement, and monitor the success of such interventions, ABA services and supports (e.g., embedded techniques in the classroom/intervention settings, behavioral consultation, individual intervention, etc.) are recommended for consideration in creating the educational plan as appropriate. Caregivers should also consider bolstering these services by accessing a private ABA therapist and/or parent trainings where resources allow

Speech and Language Intervention: It is recommended that your child's intervention program include intensive speech and language intervention that is aimed at enhancing functional communication and social language use across settings. As such, it is recommended that speech/language intervention be considered for incorporation into your child's early intervention plan and eventual school plan on an ongoing basis. Directed consultation with caregivers should be provided by the speech/language interventionist so that they can employ productive strategies at home for increasing the skill areas in these domains.

Occupational Therapy: Your child could also benefit from ongoing occupational therapy to promote development of his adaptive behavior skills, functional early preschool classroom skills, and address sensory and motor vulnerabilities/interests. Such services should be considered for inclusion in your child's early intervention plan and potential future school plan as appropriate.

Educational/Classroom Placement: Your child would likely benefit from educational services targeting his specific social, communicative, and behavioral vulnerabilities. Therefore, the caregivers are encouraged to discuss potential educational options with their early intervention team and educational providers on an ongoing basis. It is recommended that your child participate in an appropriately structured developmentally focused school program (e.g., developmental preschool, blended classroom, center-based) where your child can receive individualized instruction, programming, and structure in the areas of socialization, communication, imitation, and functional play skills. The ideal classroom for your

child is one where the teacher to student ratio is low, where he receives ample structure, and where the teachers are familiar with children with autism and associated intervention techniques. I would like your child to attend school as many days as possible and developmentally appropriate in combination with the above services over time.

Caregiver Support/Advocacy: It can be very helpful for caregivers of children with autism to establish relationships with caregivers of other children with autism who already have expertise in negotiating the realm of intervention services. In this regard, your family is encouraged to contact Autism Speaks (<http://www.autismspeaks.org/>) and Autism Tennessee (<https://autismtennessee.wildapricot.org/>). The STEP (www.tnstep.org) program may also be a good resource for learning about legal and educational rights over time.

Pediatric Follow-up: Continued regular pediatric follow-up is recommended. I recommend you discuss the findings of the current report with your pediatrician and other medical care providers to garner expertise regarding local resources and interventions.

Resources: The following books and websites are recommended for your family to learn more about effective interventions with children with autism spectrum disorders.

- Autismparenting.net is a wonderful online resource that helps parents learn the behavioral strategies that support the development of social communication and play skills.
- An Early Start for Your Child with Autism: Using Everyday Activities to Help Kids Connect, Communicate and Learn by Rogers, Dawson, & Vismara
- Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life by Lynn Kern Koegel & Claire LaZebnick has information about parenting a child with ASD and includes chapters about working with the school system, managing challenging behaviors, and teaching communication and other prosocial skills from the perspectives of both a parent of a child with ASD and a behavioral clinician/researcher.
- The Autism Mom's Survival Guide (for Dads, too!): Creating a Balanced and Happy Life While Raising a Child with Autism by Susan Senator

Web-Based Resources: You can access many resources for families of young children with autism spectrum disorder at the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) website: <https://vkc.vumc.org/vkc/triad/home>

Additional Web-Based Resources:

- Tennessee Disability Pathfinder is a clearinghouse of local resources for families: 1.800.640.4636 or <http://vkc.mc.vanderbilt.edu/vkc/pathfinder/>
- The Vanderbilt Kennedy Center provides a list of printable resources addressing topics such as toilet training and communication. That list is available here: <http://vkc.mc.vanderbilt.edu/vkc/resources/printable/>

TRIAD Caregiver Training: TRIAD has developed online training, including videos and informational handouts for parents who have young children with autism spectrum disorder. Go to: <https://triad.vkclearning.org/> and create an account by clicking on "Register". You will create a free username and password that you will use to log in any time you use the website after that. After logging

in, click on “Caregivers”, then click on the training you want to watch (such as “First Steps after ASD Diagnosis”)

Families First Program: The caregivers are encouraged to participate in family trainings wherever possible to learn more about effective interventions for children with autism. Please call (877) ASD-VUMC to register or visit <http://vkc.mc.vanderbilt.edu/vkc/triad/fam/> to learn about upcoming workshops.

PERSONAL NOTES SHEET

Family Identifier: _____

Date of contact: _____

Notes:

HRSA Family Navigation LEND Trainee Experiences:

The experiences below are to share with you information that is always shared with families during the evaluation and typically again during navigation calls. We think it will be super helpful for you to be familiar with this information so you can best share it with families and encourage them to take advantage of all the resources.

1. Learn more about Autism Spectrum Disorders. Please read this brief guide published by LEND: <https://vkc.vumc.org/assets/files/resources/apgtoddler.pdf>. All the families you contact will be given this guide as a support. Submit 5 to 7 sentences on how this information will help you guide conversations with families.
2. Learn more about TRIAD. <https://vkc.vumc.org/vkc/triad/home/>. Go to the TRIAD Website and visit the “for families” section. Spend time becoming familiar with Families First and Printable Resources. Be prepared to share information from these sections with families you speak with for navigation services. Make a list of three supports or offerings that you plan to share with families during calls.
3. Learn more about TRIAD’s Brief Online Trainings (BOTs). Go to <https://triad.vkclearning.org/> and create a free account to access the TRIAD Brief Online Trainings. Once you create an account, go to the “for Caregivers” section and watch two different trainings of your choice. Pick topics of interest to you. Please let submit which two you chose to view.
4. Learn more about Autism Speaks Toolkits. Autism Speaks has many, many great print resources for families. The website, <https://www.autismspeaks.org/>, is sometimes difficult to navigate. Please hop on it and become familiar with it. Look for the First 100 Day Toolkit as well as other toolkits that may be useful to families who have children under the age of 5. Name three toolkits you think you may share or you have shared with families receiving navigation services.
5. Learn more about Tennessee Disability Pathfinder. Go to: <https://www.tnpathfinder.org/>. Briefly review the website and then click on the Find Supports and Services Here button. Choose a specific search in a specific county. Follow the prompts on the website. Share what service you search, which county you searched and three service providers you found. This tool may help you answer questions about services families may need near their homes.