



**NCNC**

North Carolina  
Navigating Care

NC Navigating Care  
Family Navigation Model & Guide  
Working with Families with Children with Disabilities

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# Today's Purpose and Agenda



Introduce NC Navigating Care Team



Provide Background Information on “Family Navigation” Goal



Describe NCNC Project & Development of Guide



Overview of Family Navigation Model & Guide



Demonstrate Guide with Case Studies



THE UNIVERSITY  
of NORTH CAROLINA  
at CHAPEL HILL



# North Carolina Navigating Care Team

## HRSA #H6MMC33235

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**Community Partners: Kim Tizzard, Felicia Williams Brown & Kerri Erb**, Autism Society of North Carolina

## Current Project Built on Work of Previous HRSA Project (H6MMC26248)

- Survey of 450 NC families of children with Autism (Martinez, Thomas, Williams, Christian, Crais, Pretzel, & Hooper, 2018, *JADD*).
- Focus Group study of 55 NC families of children with Autism (Crais, McComish, Kertchner, Hooper, Pretzel, Mendez, Villalobos, 2020, *Focus on Autism and Other Developmental Disabilities*).



# Survey of Needs of Young NC Children with Autism (Martinez et al., 2018, JADD)

Conducted statewide survey of 450 families of young children with Autism:

- Children under 9 years of age
- Focus: Experiences & needs of families for services and supports
- 80/100 counties represented
- Demographics: 77% White, 13% Black, 13% Hispanic/Latino, 4% Asian, 2% American Indian; 32% below state income median

# Survey of Needs of Young NC Children with Autism (Martinez et al., 2018)

Less than ½ (47%)  
of children  
screened for  
Autism by PCP

25% told “not  
autism” by a  
professional before  
Autism diagnosis

54.3% diagnosed  
with other autism-  
related conditions

Almost ½ saw 3 or  
more separate  
professionals  
before diagnosis

Moderate amount  
of uncertainty  
among families



Focus Group  
Study with  
families of  
NC Children  
with Autism  
(Crais et al.,  
2020)

- 8 Groups (4 English speaking, 2 Spanish speaking, 2 American Indian) across NC
- 55 family members of children with Autism  
1 ½ - 9 years
- 69% White, 33% Hispanic/Latino, 16%  
American Indian, 5% Black/African  
American, & 2% Asian

## Focus Group Results: First Concerns

- 37/55 families were the first to notice concerns
- For 23/37 who raised concerns, physician often reassured (e.g., “He’ll talk when he’s ready.” OR “He is fine.”)
- Mean age diagnosis 3.74
- Non-Hispanic White children’s mean 2.55 years; Hispanic children’s mean 4.97 years, despite similar reported ages of first concerns
- Again, degree of uncertainty among families



## Focus Group Results: Many Barriers

- Not knowing who/where to go
- Conflicting advice
- Disagreements within and outside the family
- Uncertainty or “denial” (as described by family members)
- Moving through multiple providers to get answers
- Limited resources
- Negative experiences with some providers
- Family and cultural beliefs

# Focus Group Results: Facilitators, Concerns & Need

- Small minority noted professionals (e.g., physician, early care provider) or a family member first raised concerns and then linked them with professional services.
- Some found navigators who helped.
- **Biggest overall issue was need for “navigators” and “model” to guide family throughout process.**

# Representative Quotes Following Diagnosis

*Where do I GO and who do I CALL? Somebody on a post-it note would write down their person ..and it's like somebody in an alley handed me a phone number to call.*

*The other thing that's so hard is that now you have this [diagnosis] and you don't know where to start and you're like drinking from the fire hose... There's no quarterback to help you figure it out.*

# Why Focus on Family Navigation Now?

- Medical Home model is key to future
- Upcoming Medicaid transformation opportunities for family navigation
- Current family navigation work in NC



## 2019 HRSA Project Goal



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To implement innovative, evidence-based strategies (including Family Navigation and Provider Education) that improve access to coordinated and integrated care in North Carolina for young children with/at risk for Autism and other Developmental Disabilities and their families in medically underserved areas and populations.

## Two Primary Components

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Enhance developmental and Autism screening, referral, tracking, and follow-up in targeted pediatric practices.

Develop, implement, and provide training for a NC Family Navigation Guide and Model.

# Navigation Guide Steering Committee

- Included representatives from NC agencies impacted by and/or provide navigation/case management/care coordination for young children (birth to five) with disabilities.
- Included a number of diverse family members of individuals with disabilities (e.g., disability, age of child & parent, race, ethnicity).
- Committee met monthly for 2 years.



# Navigation Guide Steering Committee Process

- Committee reviewed guides from other states for elements we might want to replicate.
- Didn't want to "recreate wheel" Guide links to trusted & well-established existing sites.
- Used a decision tree model with a set of questions to help guide families.
- Answers immediate questions of family and can guide to next steps.
- It is not meant to provide medical advice, but guidance toward seeking medical advice.





# Principles of the Navigation Guide

- Family Navigation occurs in different ways in NC
- Different titles used: navigator, service coordinator, care manager
- Common roles: Support family, link with services
- The Guide can help family throughout life of child, but heavy focus on ages birth to eight
- Family engagement and family guidance are key
- Comprehensive Guide, but can't be all things to all people
- Every page has a link to “warm hand off” resources where families can talk to a professional

# Principles of the Navigation Guide

- Written primarily for navigators, but consideration given to varied reading levels of family members
- Unfortunately, not enough funds to translate materials into Spanish, but a number of sites have materials in Spanish
- Sustainability once project ends (recognized sites chosen who update their sites regularly; FSN will also update)
- Now that Guide and Model developed, project will use “train-the-trainer” method to reach representatives across all state agencies who offer navigation services

# Gated Guiding Questions & Process

Concerns and developmental monitoring

The evaluation process and results

Next steps after diagnosis and life course domains

Go to demo of site



# ACTIVITY: FINDING RESOURCES (Q3)

- Now it's time to practice using this resource!
- You will be assigned to a breakout room, please join!
- After joining the room, you will be introduced to a specific case study by a facilitator
- Minimize zoom (or use a different device) so you can access the website
- Log on to **[ncfamilynavigation.org](https://ncfamilynavigation.org)**
- At the bottom of the homepage, click on **Find Resources**
- The facilitator will use the case study to walk you through the domains and find resources
- If you finish your case study, explore the website
- Rejoin large group to discuss

# Questions and Discussion

