North Carolina Navigating Care

NCN

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

Today's Purpose and Agenda

Introduce NC Navigating Care Team



Describe NCNC Project & Development of Guide

Overview of Family Navigation Model & Guide

Demonstrate Guide with Case Studies





North Carolina Navigating Care Team HRSA #H6MMC33235

Elizabeth Crais, Division of Speech and Hearing Sciences, Rebecca Pretzel, Carolina Institute for Developmental Disabilities, Wanqing Zhang, Health Sciences; Kori Flower, UNC Pediatrics; Julie Williams-Swiggett(Project Coordinator), Medical School; Laurel Powell, & Barbara Leach, Family Support; Social Work, Web developers at Frank Porter Graham Institute, University of North Carolina at Chapel Hill

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





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

- <u>Survey</u> of 450 NC families of children with Autism (Martinez, Thomas, Williams, Christian, Crais, Pretzel, & Hooper, 2018, *JADD*).
- <u>Focus Group</u> 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: <u>Experiences & needs</u> of families for services and <u>supports</u>
- 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 autismrelated 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
 1½ 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



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.

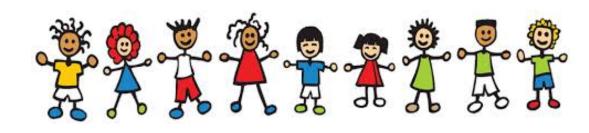




Enhance developmental and Autism screening, referral, tracking, and follow-up in targeted pediatric practices.

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
- 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



