NCNC
North Carolina
Navigating Care

Train the Trainer Manual

ncfamilynavigation.org

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Project Overview

How and Why the Project Began:

This project (funded by HRSA# H6MMC33235) and the Navigation Guide were in response to critical needs in the state identified through regional meetings, surveys and focus groups with professionals, families*, and self-advocates. Two of the needs identified were for a central website of resources, and for navigational guidance for families. The resulting NC Family Navigation Guide website aims to be a source of information to improve access to coordinated and integrated care for young children with/at increased likelihood of a diagnosis of Autism Spectrum Disorder (ASD) or other Developmental Disabilities (DD). The website was primarily designed to support family navigation professionals while they engage families in identifying needed resources. It was also designed for families to use individually to support themselves and their children through different stages of development. We hope the Guide can build capacity and self-efficacy of families to recognize early concerns and advocate and navigate for their children with/at increased likelihood for ASD/DD diagnosis. *The terms "family/families/parents" will be used interchangeably throughout this Guide in a broad sense to represent those people (parents, grandparents, other caregivers) who surround the child and provide direct care for the child.

The website was designed using a decision tree model and a set of questions to help families identify where they want to start the Guide, depending on their needs. The first question is for families who may be concerned about their child's development and/or want to monitor their child's development. The second is for families whose child has been evaluated, but they still have questions or concerns. The third question is for families who are ready to identify needed services and supports for their child or family.

Steering Committee Contributions:

A Steering Committee was created to gain consensus on a decision tree model and to compile resources. The Steering Committee included representation from all the state agencies providing community-based navigation services and a diverse set of families. The Committee provided insights on accessibility and cultural diversity, and provided a breadth of knowledge on local and national resources that could be useful for families and other caregivers. Throughout the development of the Guide and website, our team worked closely with the statewide Committee.

A Letter from the Project Team

Dear Trainers,

On behalf of the NCNC team, we would like to thank you for helping to extend the knowledge and use of the NC Family Navigation Guide to navigators and families across the state. Through this "Train the Trainer" effort, we can continue to support child and family needs with tools that are relevant, user-friendly and sustainable. This work would not be possible without you.

Within this manual you will find the materials and instructions needed to train and empower those within your agency to use the Guide with families. We invite you to explore the website (ncfamilynavigation.org) for all the necessary tools in digital format under the "Training" tab.

We hope you will embrace this opportunity with enthusiasm – knowing that your impact on professionals and families is meaningful. If questions arise following the training, our contact information is located on the FAQ page. Finally, we wish you great success in your training endeavors!

With Gratitude,

NCNC Project Team

Training Set Up

1

Determine if you need additional facilitators. Whether you need additional trainers depends on the number of participants and your format (virtual or in person). While the training can be completed by one trainer, we recommend including other 'facilitators' for the breakout groups (case studies) if you have 15-20 or more participants (e.g., 1 facilitator for every 8-10 participants, if possible). Be sure facilitators are familiar with the case study they will moderate.

2

Get to know the training components. The training can be broken down into four components. Locate and become familiar with each of the four parts.

1. *Welcome and Introductory PowerPoint Presentation*. The PowerPoint (with embedded notes for additional content) can be found on the website under the Training Tab and in the Appendix of this Manual.
2. *Website Walkthrough of the Decision Tree model (Questions 1 and 2)*. You will need the website open to the home page on your computer. A script for the website walkthrough is available on the website under the Training Tab and in the Appendix of this manual.
3. *Overview of the Life Domains.* This is the resources section of the website. Step by step instructions for its use can be found on the website under the Training Tab and located in the Appendix section of this Manual.
4. *Practice with Case studies.* The case studies and step by step instructions for their use in small groups/breakout rooms are located on the website under the Training Tab and in the Appendix of this Manual.

Steps continued on the next page…

3

Be sure to practice going through each step before your first training! For the full training, we recommend reserving 2 hours since questions will arise throughout the session and timing may vary. You will also want to leave time for questions at the end. Suggested sequence and timing:

- Intro and annotated PowerPoint (20 minutes maximum)
- Website walk-through (20 minutes)
- Overview of Life Domains (Resource Section) with examples given for each domain (15 minutes)
- Breakout rooms and Case Studies (20 minutes)
- Wrap up and closure (10+ minutes)

4

Set up meeting and space (live or virtual) and gather training materials. Steps may include:

- Select delivery mode (live or virtual)
- Send out notice of training details and logistics; You may choose to use the flyer template in the Appendix of this Manual to help with advertising your training
- Send a reminder email 24 hours prior to the training
- Use the checklist in this manual to ensure you have the necessary training materials

Training Checklist

PLANNING

☐ Set a date and time for your training session

☐ Decide on a training location or virtual platform

☐ Send training link and promotional flyer to participants

☐ Confirm trainer/s, facilitators and roles for each

☐ Run a practice training and test web links

MATERIALS (All can be downloaded from ncfamilynavigation.org under Training Tab)

☐ Have annotated PowerPoint loaded on computer (with notes visible)

☐ Have the Website Walkthrough (Q1 & Q2) navigation script available

☐ Have the Resources Section Script available

☐ Have one of the case studies available to use for practice

☐ If multiple facilitators and break out rooms, each facilitator needs a case study available

☐ Send or give website flyer to participants

Frequently Asked Questions

We have addressed the most commonly asked questions that have come up during our previous NCNC Family Navigation training sessions. Please let us know if you come across others.

1. What does the term "navigator" mean?

A navigator is a broad term used to describe anyone who serves in the role of working with a family to help them identify support services. The term "navigator" was chosen because this is a statewide project that reaches organizations and agencies using a variety of names/titles for individuals serving in these types of roles (e.g., care coordinator, family support, care manager). Additionally, some other professionals may act in navigation roles on occasion and many managed care organizations are developing "navigator" training.

2. Is there a certification process for becoming a navigator?

In terms of this project, there is no specific training or certification for becoming a navigator. If you work with families and support coordinated care or access to care – you are already a family navigator!

3. Is the Guide for families to use or just for navigators?

The family navigation website was designed to support navigators in their work with families; however, we also know (and hope) that many families will continue to access the Guide once they have learned of its availability. We also anticipate that families will share this resource with one another and use it over time as their child reaches new stages of development.

4. Do you have a search box feature within the guide to help locate resources?

*Unfortunately, no. As a grant funded project, we were not able to financially support the IT infrastructure required to include a search box. If you are in a document or web browser, you can use "Control+F" (or "Command+F" on a Mac) as a **Find command.** Pressing the Cntrl key + the F key at the same time will bring up a search box in the top right corner of the screen. While we know this is different from being able to search the entire website, it may be a helpful tool to use when looking for specific information with or for a family. In addition, once you become more familiar with the website, we hope you won't need any additional help navigating. As part of our training package, we will also provide simple outlines of what content is available as the main headings under each Resource Domain.*

5. Is the guide just for families who have concerns about Autism Spectrum Disorder (ASD)?

No. The guide is intentionally designed to be a comprehensive tool that can meet the needs of families who have a child they are concerned about or who may have a higher likelihood for any type of developmental delay and/or disability. However, due to the ASD prevalence and emphasis within the HRSA grant that funded the website, the decision tree model contains a specific pathway for ASD concerns.

6. Who should I contact if I have questions about the guide?

The NCNC Project Coordinator is Julie Williams-Swiggett (juliews@email.unc.edu) and is a good contact for project or training related questions. After August 2025 (the grant's end), you may need to contact the Family Support Network and the UNC School of Social Work where the website is housed (Laurel Powell: powellm@email.unc.edu).

7. Is there a Spanish version available?

Unfortunately, the project did not have the funds to translate the tool into Spanish; however, many of the resources and tip sheets throughout the website direct users to pages that are available in Spanish with the click of a button. We hope to contract with our web developer to launch a Spanish version of the Decision Tree Model in the fall of 2024 with grant extension funds.

8. How does the website support those with dual diagnoses and/or mental health concerns?

Resources and supports for dual-diagnoses and mental health concerns are embedded throughout the website. For example, in the Resources section under "Safety and Security," navigators and families will find information related to mental health emergency preparedness. In general, the guide acknowledges that children can be diagnosed with both a mental health challenge and a developmental disability (sometimes referred to as a co-occurring condition or dual-diagnosis) and encourages caregivers to partner with their local LME/MCO to find out what types of providers or services may be helpful for their family.

Appendix of Training Materials

ZOOM TIP SHEET
A few helpful tips for those hosting their training virtually with a zoom platform.

FLYER TEMPLATES
Templates for promoting your training and our NCNC website flyer.

POWERPOINT SLIDES WITH SPEAKING NOTES

WEBSITE NAVIGATION SCRIPT
A script, in table format, that trainers can follow to guide exploration of the Family Navigation website.

RESOURCE SECTION SCRIPT
A script, in table format, that trainers can follow to guide exploration of the Resource section.

BREAKOUT ROOM/SMALL GROUP INSTRUCTIONS
Instructions for facilitating small group/virtual breakout rooms with case study examples. Note that we have not included a script for this section. Facilitators of small group breakout rooms are encouraged to use case studies as a platform for identifying individual questions and concerns.

## CASE STUDIES FOR SMALL GROUPS
Three case studies for small group discussion and exploration. A facilitator copy (with answers) and a participant copy (without answers) are both included.

APPENDIX: Zoom Tip Sheet

A good resource for Zoom video tutorials can be found at https://learn-zoom.us/show-me. We recommend the tutorials "Screen Sharing" and "Basic Event Administration" for facilitators.

If you are wondering how to share audio on Zoom while sharing your screen, just open the Zoom application and start your meeting. Here's how to share computer sound on Zoom on Mac and Windows:

From the toolbar, choose the button "Share Screen".
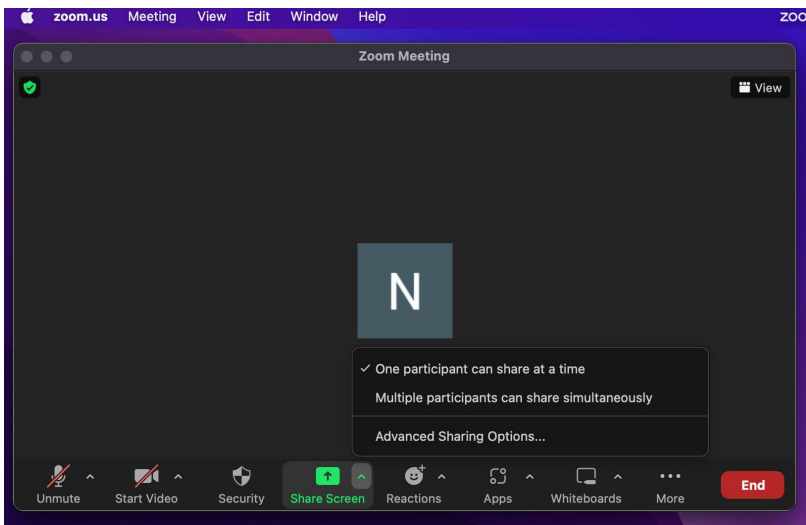
You will get a pop-up window wherein you will need to check a box appearing at the bottom in order to share your computer sound.

If you want to share video clips, check "Optimize Screen Share for Video Clip". Also, ensure your volume level is appropriate.
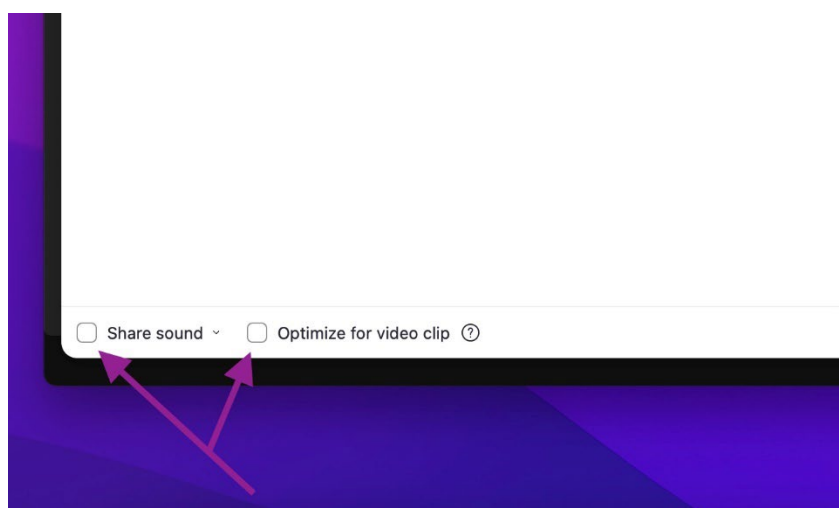
ncfamilynavigation.org

Introducing a new web-based tool designed to help families find information, resources and supports, with a focus on children with developmental delays and disabilities. This guide is organized in a series of questions to help you find what you need at this time.

NCNC
North Carolina
Navigating Care

Learn to track your child's development and what to do if you or someone else has concerns. If your child has been evaluated, determine if additional assessments, information, services or supports are needed.

Explore information and resources across six life domains to guide you in planning for your child and family.

FREE Training
for Family Navigators &
Support Personnel!

NCNC Family Navigation Guide

This free 2-hour training will provide an overview of a new online resource tool for family navigators and other professionals. It is primarily designed to assist families who have children with or at risk for developmental delay or disabilities answer common questions and find resources. Other families may find useful information, too.

Our interactive workshop will provide an overview of an enhanced family navigation service for NC and introduce the interactive NC Family Navigation Guide using website demonstrations and case examples. Although this tool was developed for navigators to use in collaboration with families, it is family-friendly and easy to use so families may also use it on their own.

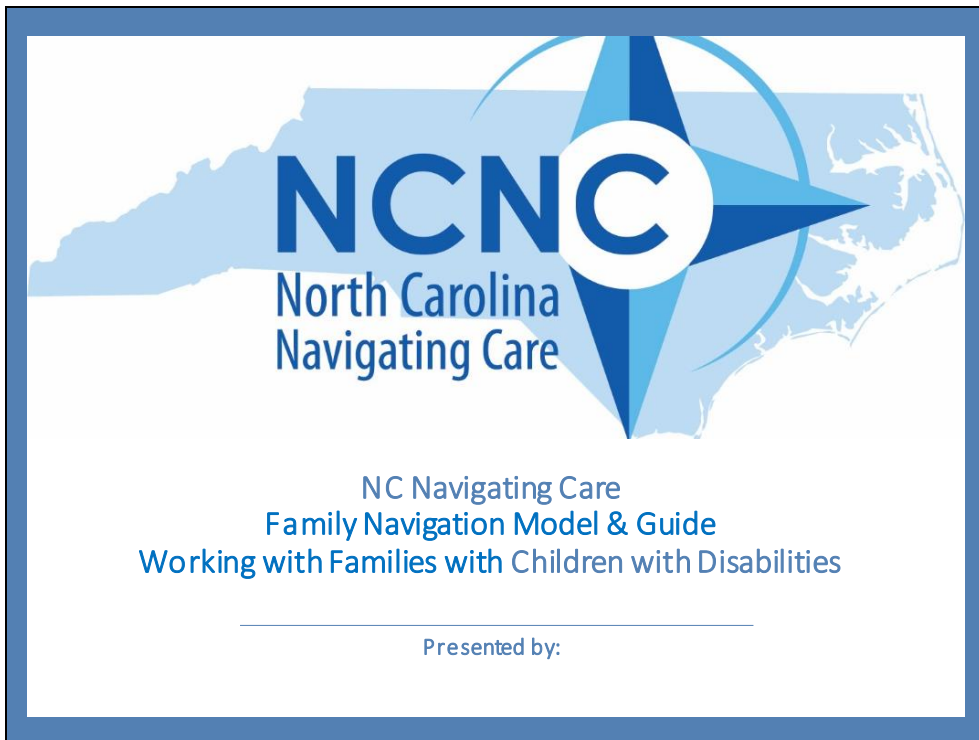We invite you to attend one of the workshops to learn about this new tool!

Upcoming training dates:

Registration/Zoom Link:

Presenters will be **INSERT YOUR NAME HERE**

APPENDIX: PowerPoint Slides with Speaking Notes

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

Presented by:

Welcome
Add your name / agency to bottom of slide

WELCOME!

Please sign in by putting your name, organization, and role/position in the chat

Leave your video on, if possible

Please keep microphones on MUTE

Raise hand for questions/comments
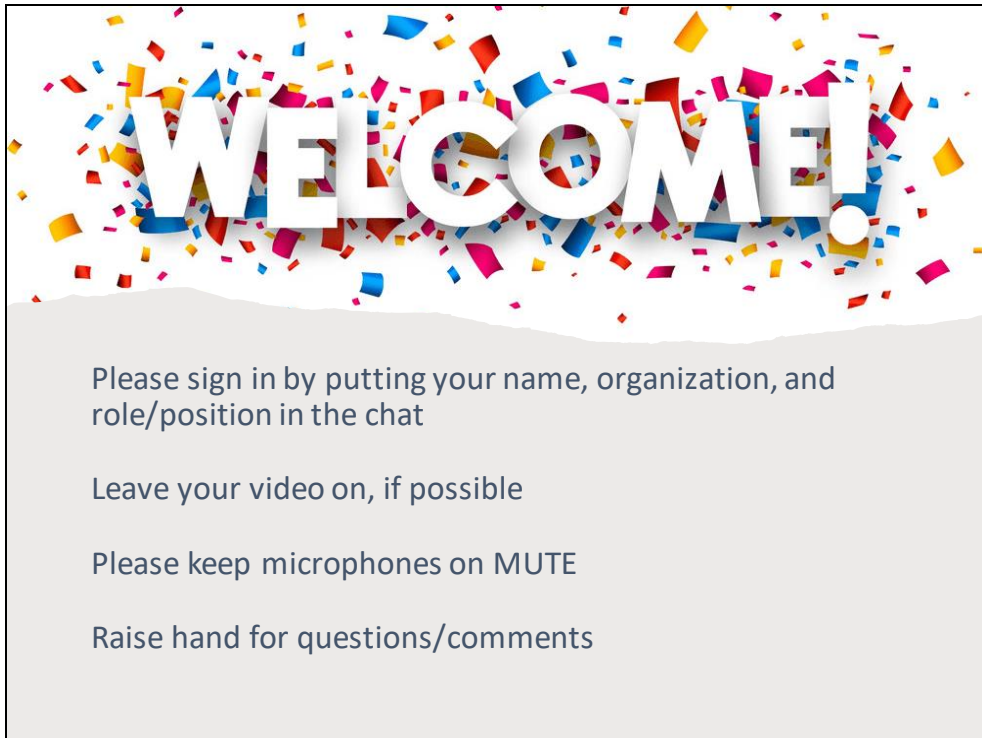
Use this slide if doing a virtual presentation.

If in person, delete the information and put your own introductory information.

Today's Purpose and Agenda

👥 Introduce NC Navigating Care Team

🧭 Provide Background Information on "Family Navigation"

🗂 Describe Development of the Guide

🗺 Overview of Family Navigation Model & Guide

Briefly go over the agenda for the training.

Before we start the training, we want to acknowledge the team who developed the Family Navigation Guide. The project was funded by HRSA and the team is listed on this slide.

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

- **Survey of 450 NC families of autistic children birth to nine** (Martinez, Thomas, Williams, Christian, Crais, Pretzel, & Hooper, 2018, *JADD*).

- **Focus Group study of 55 diverse NC families of autistic children birth to nine** (Crais, McComish, Kertchner, Hooper, Pretzel, Mendez, Villalobos, 2020, *Focus on Autism and Other Developmental Disabilities*).

Prior to this HRSA grant, Drs. Crais and Pretzel worked on another HRSA grant which set the framework for the focus on family navigation. We want to briefly mention two published studies that were conducted in NC. One was a large survey of 450 families of young children with ASD and the other consisted of a series of focus groups across the state with families who had a child with ASD.

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

This slide shows the primary findings from the survey of 450 NC families. The purpose of the study was to better understand the journey families undertake when seeking a diagnosis.

In the first box, it shows that fewer than half of the families reported having their child screened for autism by their primary care physician. We know from Medicaid data that more physicians were doing ASD screenings but it's clear that families weren't always aware that the forms they filled out were validated screening forms.

[Briefly mention the next 3 boxes]

All of these experiences led to a moderate amount of uncertainty among families and indicated a clear need for family navigation and guidance through this process.

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)
- Moving through multiple providers to get answers
- Limited resources
- Negative experiences with some providers
- Family and cultural beliefs
- **Biggest overall issue was need for "navigators" and "model" to guide family throughout process.**

The second study consisted of 8 focus groups (4 English speaking, 2 Spanish speaking, 2 American Indian) across NC of 55 family members of children with Autism ages 1 ½ - 9 years

They reported numerous barriers when seeking evaluation and diagnoses.

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

So, in addition to this previous research, we know that this is an important time to focus on family navigation.

The Medical Health Home model is key to future care. Studies have shown that individualized attention to whole-person care can offer improvement in physical and behavioral health, increase access to community-based social services, and assist in the management of chronic conditions. Addressing social determinants of health is key so that caregivers/families are able to even consider other services and supports their family member with disabilities may need.

The goal of upcoming Medicaid transformation and the transition to managed care is to improve the health of North Carolinians through an integrated and well-coordinated system of care that addresses both medical and nonmedical drivers of health. This will hopefully be accomplished through the Care Management model in which Family Navigation will play a role. The current target date for the roll out of the plan is October 2024.

Finally, by your presence here today, we can see that Family Navigation work in NC is important to you and a big part of your job.

Navigation Guide Steering Committee

- Included representatives from NC agencies providing navigation/care coordination for young children (birth to five) with disabilities.

- Included diverse family members of individuals with disabilities

- Committee met monthly for 2 years.

Getting back to the recent HRSA grant and the creation of the Family Navigation Guide, the Guide was the work of a large, statewide steering committee.

Principles of the Navigation Guide

- Heavy focus on ages birth to eight, but Guide can help family throughout child's life
- Family engagement and family guidance are key
- Every page has "Warm hand off" link to resources where families can talk to a professional
- Written primarily for navigators, but was also written for family members
- Not enough funds to translate materials into Spanish, but a number of sites have materials in Spanish (Coming 2024)
- Sustainability: chose well established websites and will be maintained by Family Support Network

This slide highlights some of the important principles of the Steering Committee as the Guide was developed.

[Important to highlight the 'warm hand off' and the upcoming Spanish translation.]

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
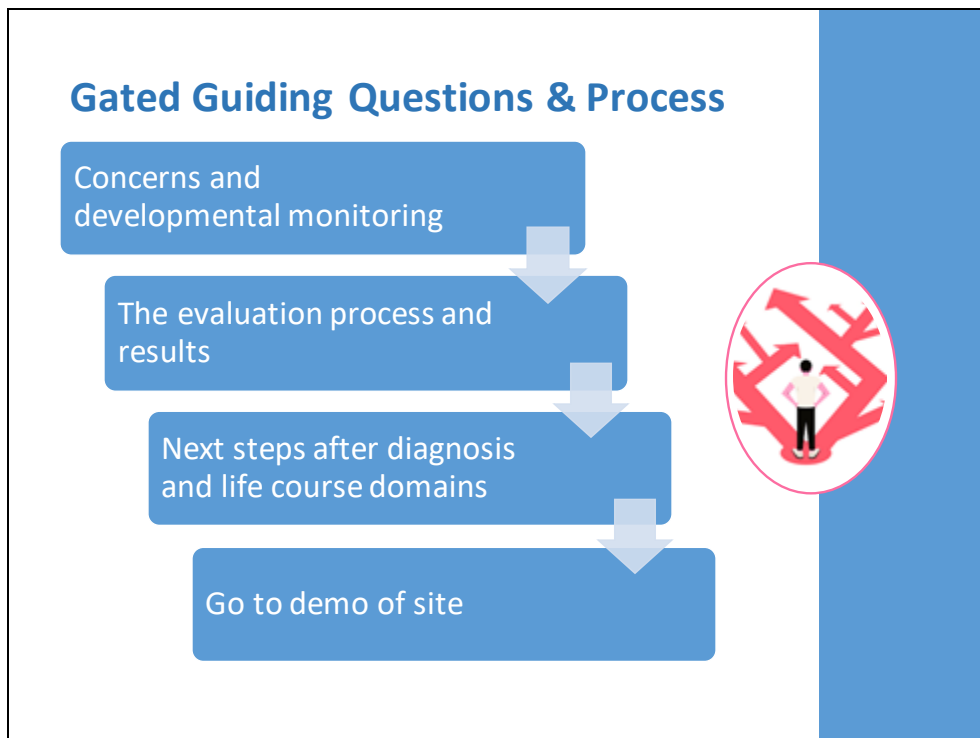
We are going to go carefully through the online Family Navigation Guide but it's important to understand that it is laid out using 3 Gating Questions. These questions help families select the best starting point.

We will now guide you through the site and introduce you to our 3 gating questions.

ACTIVITY: FINDING RESOURCES (Q3)

- Now it's time to practice using the Guide!
- 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

You may use this slide if doing a virtual training and using breakout rooms.

Questions or Comments?
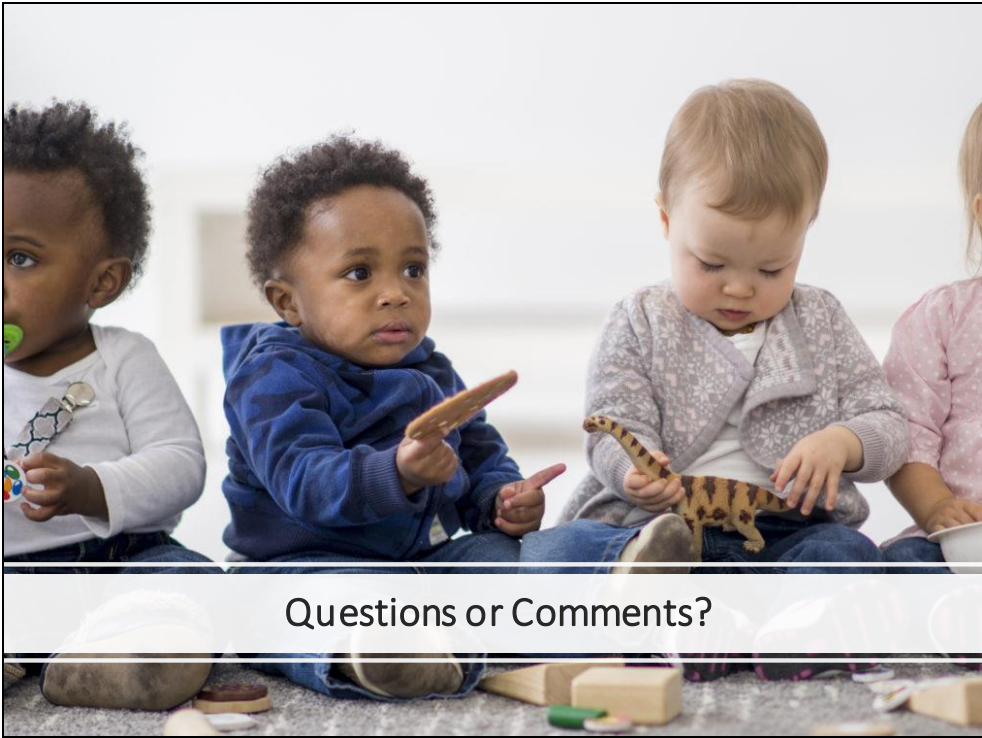
APPENDIX: Website Navigation Script

#	Action on Screen	Script
1	*Stop Sharing Screen to PowerPoint; Transition to screen share of ncfamilynavigation.org home page*	"For the next little bit, I will be sharing the website and the decision tree model, that can be used with any family who may have concerns about their child, is simply interested in monitoring their child's development, or has already had their child evaluated. Once we have reviewed the site and decision tree, I am going to walk you through a case example."
2	*Scroll Over the Screen*	"This is the landing page of the website for NC Navigating Care Project. Because many websites that families interact with regarding their children tend to be text heavy, the project has tried to share information about the website through short blurbs and with videos. Let's look at the introductory video now."
3	*Play Video on Landing Page*	
4	*Scroll to Top of Page and Hover over Individual Tabs as You Speak*	"Now, let's review the tabs at the top."
5	*Hover over Who We Are Tab*	"The first tab lets you know who was involved in developing the website, including a list of the steering committee members.
6	*Click on the Who We Are Tab and Scroll Down to Steering Committee List*	"You can see this list covers many organizations and agencies plus family members who helped us develop a comprehensive tool."
7	*Scroll Back to Top of Webpage. Hover over the Monitoring Development Tab*	"The second tab, Monitoring Development, is one place you can click to get to the

		decision tree, but we will come back to that in just a minute."
8	*Hover over Resources Tab, but Do Not Click*	"Under resources, we find information on services and supports based on six life domains. These are the domains, but we will wait on this part of the site and hear more about it later in the training."
9	*Hover on Helpline*	"Finally, we have the Helpline Tab, which gives a list of what we call "Warm Handoffs".
10	*Click on Helpline to Open*	"These are for anytime the family or you want to call or click to go directly to an agency's website. We have a paragraph and a table to give families a glimpse of these eight longstanding resource agencies who have a statewide presence."
11	*Slowly Scroll Down the Page to View Agency Contact Info*	You can see that this section gives a list of ways the agency may support the family. This list of Helplines is for families AND navigators, and can also be useful for new people at your agency or those new to North Carolina resources. Finally, I will just add that these agencies were involved in our website development and are aware of their status as a warm handoff touch point."
12	*Click on NCNC Logo to Return to Homepage.* *Scroll Slowly Toward Bottom of Landing Page*	"Scrolling down from the top of the page, you see a paragraph on the role of parenting and, below that, there are two sections."
13	*Stop at First Section on Page*	"If you click the 'Get Started' button here in this first section, it will send you to questions 1 and 2, where the navigator will have an opportunity to guide families through developmental milestones, identify

		concerns, and assess whether a child has been evaluated. If a navigator feels these questions are important at this time and the family agrees, that's where they would start. You would click here and walk through the decision tree together. Or, you could click on 'Monitoring Development' on the tab at the top of the page, which we will do in just a moment."
14	***Scroll Down and Stop at Bottom Section of the Page*** ***(Don't click on Find Resources yet!)***	"This last section takes you to question 3 and the option to move directly into looking for resources and supports through six life domains. Sometimes you will work with families who already have and agree with a diagnosis for their child and they are searching for resources; navigators can help them do that by clicking the Find Resources button."
15	***Scroll to Top of the Website and Click on Monitoring Development Tab***	"Let's move back to the Monitoring Development Tab. When we click here, we are initially shown the three gating questions that were referenced earlier. Let's click View Questions and start the decision tree."
16	***Click View Questions***	"Once you begin using the Decision Tree, you might see this black screen here like mine with the option to resume or restart. This was intentional so that navigators and families have the option to leave the Decision Tree and they can resume where they left off. Others may see a Legend page. For our purposes today if your screen is black, click "Restart".
17	***Click Restart (for those with the Black Screen)***	If you are not seeing the black screen, the first thing you see is the Legend page with a list of three icons which appear throughout the decision tree. This first one allows you

		to start over any time you need to. The second one (the icon with the person) takes you directly to the warm handoffs. The last one just lets you know there are tip sheets available on some of the pages."
18	***Click Begin***	"Now, let's enter the decision trees by clicking Begin. Here's where we start with the three gating questions to help the navigator and family figure out where to start. Before we look at the questions, I want to point out the green writing you will see on this page and others. The website is intentionally written with a reading level that is widely accessible for all website visitors. These green phrases are here to provide a brief description of terms caregivers may hear throughout their child's development. Highlighting these terms empowers them by improving their health literacy and giving them the knowledge they need to feel more confident talking with their providers at their medical home."
19	***Read Questions on the Right Hand Side of the Screen***	Now, back to our 3 questions, they are **Read questions** You can ask the family to choose which one is most applicable to their situation. For today, let's say you're meeting with a family who has some concerns about their child's development, but has not had a formal evaluation. In this case you could start with Question 1 where you might help them figure out next steps."
20		"As you click, the website will move you along to the next question in the decision tree. Notice that the questions sometimes give examples to assist families and navigators in choosing the best response for

		their situation. There are also several options on the right for answers for the family. For example, here the choices are (Yes; No or I'm not sure; I do not have concerns, but someone else does; and Yes, and developmental screening has been done). Right now for this family they do have concerns, so we will click Yes."
21	*Click Yes*	"Before we answer the next question, did you notice the icon on top? You can click here to be taken straight to the list of warm hand offs. Some families may want to continue the decision tree, but others may prefer just to talk immediately to a warm hand off agency."
22	*Click Warm Handoff Icon*	"You can see when I click on the Warm Handoff icon, this is what the resources look like. Same agencies, but a slightly different format."
23	*Click X in the top right corner of the Warm Handoff Pop Up to go back to where you were*	"The next question says, 'Have you talked to your child's doctor or nurse about these concerns?' We bring up the doctor/nurse throughout the decision tree so we can remind families about being engaged with their doctor and medical home to encourage good lines of communication. When asked, the family said they did bring up concerns with their doctor and the doctor had concerns too, so let's click 'Yes. I talked to my child's doctor or nurse and we both have concerns." You can also mention it was a great place to start.
24	*Click "Yes. I talked to my child's doctor or nurse and we both have concerns."*	"Now the question asks, 'Did your child's doctor/nurse do a developmental screening?' At this point, the family said the doctor did a developmental screening, so let's click yes again."

25	*Click Yes*	"When we click Yes, you can see we have a question and another green word description, this time defining developmental delay. We also see that another icon we learned about has popped up. This icon is meant to let us know that there is a tip sheet available."
26	*Click Tipsheet Icon*	"When we click the icon, another window opens, which is helpful because that means we will not lose where we were in our decision tree by choosing one of these icons. This one takes us to the NC Infant-Toddler Program website. Here, families and navigators will learn more about the Children's Developmental Services Agency (CDSA) system and the North Carolina Infant and Toddler Program in case a positive screening occurs.

"Let's close this website and get back to our decision tree." |
| 27 | *Go to the very top of your computer and you'll see a tab for North Carolina Infant-Toddler Program. To Close this Tipsheet, click on the X, and Return to Decision Tree* | "Now we return to the question, 'Did the results show a developmental concern or risk of developmental delay?' The family does say the doctor had concerns about development too, so let's click 'Yes.'" |
| 28 | *Click Yes* | "When we click yes, we see that the green words come up again, this time to remind parents that all children should receive a routine autism screening at 18 and 24 months. Because of the increasing prevalence of autism, we make sure to ask all families about autism characteristics when there are any developmental concerns. The tip sheet icons on this page |

		take us to 3 different websites about identifying characteristics of ASD."
29	**Click the 3rd Tip Sheet Icon labeled "Signs & Symptoms Tip Sheet"**	"I am going to click on this 3rd tip sheet to show you an example of a resource that can offer support for families who may have concerns about ASD. This tip sheet can also help families who would benefit from resources in languages other than English. The tip sheet is from the CDC and tells us more about what Autism might look like or the signs and symptoms of Autism. You can click right here under the title to access a Spanish version of the same information."
30	**Close CDC Website and return to Decision Tree**	Now I am going to head back to our Decision Tree question, to answer "Are you or your child's doctor or nurse concerned that your child has behaviors that may suggest autism?" The family said that their child's childcare provider had mentioned ASD so let's click 'Yes.'
31	**Read the script, then click 'Yes.'**	"Now we are asked 'Did your child's doctor or nurse screen for autism?' This is another way to prompt families to remember what happened at their doctor's appointment. Let's assume the family says yes because they brought up the care provider's concern and we will click 'Yes.'
32	**Read the script then click on the Tip Sheet.**	"Now, the green words give families a description of Autism and the tip sheet icon takes us to the Autism Society of North Carolina (or ASNC) website to see another local resource and some statistics regarding autism."
33	**Slowly Scroll through the ASNC Tip Sheet as you read the script.**	"Looking at the ASNC website gives families the ability to see a local organization and statistics regarding autism. Just like the CDC

		website we explored previously, the ASNC website is also an example of a resource that is well vetted with consistently updated information. For example, this website has already been updated to reflect the recent ASD changes to published statistics. Now let's close this website and return to our Decision Tree"
34	**Close this Tipsheet by clicking on the X and Return to the Decision Tree to Read the Script**	"Back in our decision tree, we are asked if the findings of the screening showed a risk for Autism."
35	**Click "Yes"**	"Let's click Yes, because the family said the screening showed some characteristics of ASD."
36	**Read the Script**	"We find more green writing and more opportunities for tip sheets about developmental evaluations and developmental delays. The question asks, 'Did your child's doctor or nurse suggest you seek an evaluation?' The Mom at this point begins to cry and says the doctor said let's wait a bit to refer him. The parents are anxious to know, so let's say 'No, but I would like to seek an evaluation. We know sometimes this happens, as medical professionals may not be familiar with early signs of ASD, and let's see how we could support this family in seeking an evaluation."
37	**Click "No, but I would like to seek an evaluation."**	"Choosing 'No" will send us to information about the two service systems in NC and guidance on how to make a referral based on age. This provides families with access to the information they would need to build their knowledge and to help them make an

		informed decision about how they want to proceed.
		If they choose to move forward with seeking an evaluation, there is contact information and directions for starting that process here."
		This point completes Question One.
38	*Read Script and then Go Back to the homepage of ncfamilynavigation.org; You may be able to click on the tab to the left of your current browser window. The screen will show you the 3 questions.*	"Now speaking of evaluations, let's head back and explore the Question 2 pathway for just a minute. We are going to get back to those gating questions by clicking on this tab to my left."
39	*Click "View Questions"*	"Remember to get started, we will click 'View Questions.'"
40	*Click "Restart" and then "Begin"*	"And then we will Restart our Decision Tree Pathway by clicking Restart and then Begin."
41	*Read Script, and then Click "Has Your Child Already Been Evaluated?"*	"We just walked down the pathway for Question 1 and explored those resources and options for families who have developmental and/or ASD concerns. Now let's get a glimpse into what the pathway looks like for a family who has already had an evaluation by clicking here on Question 2, "Has your child already been evaluated?"
42	*Click Yes, for Developmental Concerns*	"And because we have already seen several resources for Autism, let's click yes for developmental concerns this time."
43	*Read Script, and then Click on "What is a Disability" Tip Sheet*	"Now the question is asking us, Do you have questions about your child's evaluation or the diagnosis?" We know that so many families have questions at this point or they may identify questions in

		time. We also know that it is sometimes hard for families to move forward (for example, believe that their child has a disability, begin an intervention) if they still have questions about the evaluation or diagnosis. So, we have 3 really helpful Tipsheets for both families and navigators focused on asking and answering those questions. I'll be able to show you these two on the right in our upcoming case study, so let's click on, 'What is a Disability Tip Sheet'"
44	***Click on the What is a Disability Tip Sheet, then scroll down to blue/green highlighted section "Related Conditions"***	"This takes us to another CDC website that is a great starting point for understanding disability definitions and getting some common initial questions answered. This blue section here links to a variety of specific diagnoses and their hyperlinks will take you to information specific to those conditions."
45	***Close this Tipsheet by clicking on the X and Return to the Decision Tree***	"Now let's close this Tipsheet." Once you have helped address their concerns about the evaluation and come to the end of Question 2, you may then guide them to Question 3: the Resource Section to help them identify services and supports they may need.
46	***Go Back to the homepage of ncfamilynavigation.org; You may be able to click on the tab to the left of your current browser window***	"Before we take a deeper dive into the Resources Section, let's think about a real-life scenario that you may face. I want to show you how we can use this tool with a family who really doesn't know if they should be concerned about their child's development. I'm going to provide a case scenario and guide you through the process. So, let's go back to the homepage and start fresh."

47	*Read Script*	Ok, here's the scenario: "**Marcie, a 20-year old, single mother is beginning to worry about her son Noah's development. He just turned 2 and is her only child. She isn't exactly sure what he should be doing at this age but wonders if he should have some words by now.** You and Marcie are going to sit side by side while you introduce her to the Family Navigation Guide and website."
48	*Read Script and then Click on Monitoring Development*	"After you have walked her through the first page, click on Monitoring Development at the top."
49	*Click View Questions; Click Begin*	"Then click on View Questions. We will restart this time because we are working with a new scenario. You would review the icons with Marcie, then click 'Begin' and look at the three questions together when prompted to "Pick the starting point that best applies to you and your child."
50	*Read the 3 gating questions and then Click the top Question*	"In Marcie's case, we would click on the top question because we are most interested in tracking Noah's development and helping Marcie learn the developmental milestones Noah should be reaching since he just turned two."
51	*Read Script and then click No or I'm not sure*	"Read over the 4 response options. Remember, Marcie doesn't know what Noah should or should not be doing, so together, we would click, "No or I'm not sure" and see what resources the decision tree can lead us to for Marcie and Noah."
52	*Read script and Click "Complete a milestone checklist"*	"This brings us to some wonderful information and resources that you can review with Marcie about what's typical at each age of development.

		Let's click on Complete the Milestone Checklist to see what we could review with Marcie. You may want to look over this page to see what's available. For now, we could help her compare Noah's development to the milestone checklist for 24 months and also download the Milestone Tracker app."
		"Now I am going to head back to the decision tree."
53	*Close out the CDC website. Click Previous button two times*	"Now let's imagine that we are back seeing Marcie for a follow up visit and here's what's new with her: **Noah has started day care and his teachers have mentioned that he is quiet and likes to play by himself. They often report that Noah gets frustrated easily and has temper tantrums at times. Marcie has completed the CDC checklist in the milestone tracker app that she downloaded with you at your last visit. She noticed that Noah was not meeting all his speech and communication milestones. She tells you she wants to get him some help, but she doesn't know what to say to their pediatrician."** "So clearly things have changed a little bit for Marcie and Noah and now other people are having some concerns about Noah, too."
54	*Read Script and then Click on the Top Question*	"So, we are going to go back to the gating questions and ask Marcie to 'Pick the starting point that best applies to you and your child.'" Click on the top response again to indicate that Marcie now has some concerns for Noah's development."

55	*Click Yes*	"Now we will click on Yes again, because Marcie and the teachers both have concerns about Noah."
56	*Click "No, but I want to."*	"And now our question asks, "Have you talked to the doctor?" and after reading the response options, we will click "No but I want to" because that is what Marcie has shared with us at this particular visit."
57	*Click on How to Get Help for the Child* *Scan over the sheet slowly to show what kind of information is provided*	"After walking through the decision tree this time, we now have access to some encouraging words and a resource to help Marcie feel more confident and comfortable talking to Noah's doctor – which is exactly what she needs to feel empowered to take the next step."
58	*Close out the How to Get Help website and then click the Previous Button three times*	"Now let's go back and visit with Marcie one more time. **Noah is now 34 months old. He recently had an evaluation at a nearby clinic and was diagnosed with broad Developmental Delay. Marcie knows that the clinic team spent the morning with her and Noah, but she doesn't think that Noah was feeling well and he didn't respond to them like he might have at home or at his childcare center. Marcie wonders if the diagnosis could be wrong, but you aren't quite sure what to tell Marcie at this point**."
59	*Click "Has Your Child Already Been Evaluated?"*	"This time we will click gating question 2: "Has Your Child Already Been Evaluated?" and then "Yes for developmental concerns."
60	*Click Yes, for developmental concerns*	"This is where we want to bring up the third tip sheet, which was designed specifically for navigators."
61	*Click on Tip Sheet for Navigators*	"This tip sheet is a valuable resource as it helps navigators move through the sometimes-difficult waters of a family's

	Scan through the Tip Sheet to show a few of the items addressed	reaction to a diagnosis, which can look different for every family. This information is relevant and applicable across diagnoses – including developmental delay, hearing loss, Down syndrome, Fragile X, etc. Once you have had time to talk with Marcie about her concerns and perhaps helped her take some action (observe him with other children, talk to his childcare teachers, etc., Marcie may be more ready to move ahead with the recommendations made for him.
62	*Read the Script, Close Tip Sheet.*	"Marcie tells you that Noah will be starting at a public preschool at Lincolnwood Elementary in 2 months. She wonders if he will be able to get special education services from the school system such as speech and occupational therapy. To help her find the answer, it is time for Gating Question 3: Resources."
63	*Read Script then navigate back to the ncfamilynavigation.org website or by clicking the tab at the top of the navigation bar. Then, click on Resources at the top of the home page*	"So, that was a brief demonstration of how the decision tree components of the website work. Let's head back to the resources tab and explore what's there."
	TIME – 20:02	

APPENDIX: Resource Section Script

#	Action on Screen	Resources Section Script
1	*Navigate to ncfamilynavigation.org home page; Hover over the Resources Tab at the top of the home page*	"The Resources section, or Question 3, can be accessed several ways. First, you can click on the Resources Tab at the top of the home page."
2	*Scroll to bottom of page; hover over Find Resources button*	"Alternatively, you can scroll down to the bottom of the Home Page and click on *Find Resources*."
3	*Click on the Monitoring Development Tab at the top of the page; then click View Questions; Click Begin; Click question 3 "Do you have questions about next steps for your child and family?"*	"The third way is to enter the website and, at the 'gating' or starting point slide, view the three questions and choose question 3 (*Do you have questions about next steps for your child and family?*)"
4	*Scroll down to the middle of the page to highlight icons*	"After clicking question 3, you'll see colorful icons and brief descriptions for each of the six life domains covered in the Resource section."
5	*Scroll to the bottom of the page*	"Scrolling down this page, you'll see a reference for the Charting of the LifeCourse Framework developed by Dr. Michelle "Sheli" Reynolds at the University of Missouri – Kansas City, on which the six domains are based."

		"As you can see, the six life domains include: Healthy Living Daily Life and Education Community Living Safety and Security Social & Spirituality Advocacy & Engagement"
6	***Go to top of website landing page and click on Resource Tab***	"Although you can click on any of the colorful icons to enter a domain, we'll use the Resources tab at the top so it's easy to navigate across them as we take a closer look at the resources in each domain."
7	***Click on the Health Living Domain; Scroll down the page so participants can see the range of questions***	"The first domain is Healthy Living. This domain helps answer many common questions and concerns about general health and how to access and navigate medical and health services and supports."
8	***Click on Social/Emotional Well Being***	"Let's click on **Social/Emotional Well-being** (something families may be hearing more about but are less familiar with) and you'll see a brief description of what social/emotional well-being covers."
9	***Scroll down and click on the video for Tantrums, Defiance Play it for the first 20 seconds.***	"Now let's go to the second link that talks about young children's emotions. When

	Then go to the top of your computer page and click X on the Tantrum tab.	possible, videos are included in the resource section."
10	*Go back to the Resources Tab at the top and click on Daily Life and Education.*	"Now we are going to look at the Daily Life and Education domain. This domain looks at services and supports your child may need to help develop daily living and early learning skills. Families may also have questions about early intervention, preschool, special education, or financial support for a family's day-to-day living."
11	*Click "What Services and Supports are available to help my family in our daily life?"*	"Let's click on the question What Services and Supports are Available to Help my Family in our Daily Life?"
12	*Scroll down the list to show links*	Scrolling down the list, you'll see links to child care and early education resources, plus information about respite care, care coordination, Innovations waivers, and personal and cultural support."
13	*Go back to the Resources Tab and click on Community Living*	"The third domain is Community Living. Community living is not just about where we live, but about how we access and are involved in our communities. This section of the website provides resources for improving living conditions at home and in the community

		such as housing and home modifications, technology, transportation, food and other everyday needs for the families you are supporting."
14	*Click "How can we meet transportation needs for my child?" and Scroll slowly down the page*	"Let's look at a commonly asked question and click on How can we meet transportation needs for my child?" You will see that this area was answered broadly from Medicaid funded transportation services to school transportation as a related service. Additional resources and services are also included here as well such as vehicle adaptations, car repairs and other needs."
15	*Go back to the Resources Tab and click on Safety and Security; Scroll down the page to show the many options*	"Next let's look at Safety & Security. Safety is always a priority when it comes to our children and families and is often a concern for the families with whom we work. Helping caregivers and individuals know their options in addressing needs associated with safety and security provides a strong foundation that leads to lifelong lessons. This might include preparing for emergencies, considering guardianship and alternatives, and addressing legal, financial,

		and insurance options that can help ensure security in the future."
16	***Click "What Can I do to help my child stay safe?"***	"Let's look at the first question - What can I do to help my child stay safe at home and in the community? You'll see several resources but let's look more closely at the section on "How can I teach my child about safe touch"
17	***Click "How can I teach my child about safe touch?"***	"In our work supporting families it can be often difficult to know how to broach a sensitive topic. Using a tool like this guide is a great way to bridge that gap and start crucial conversations."
18	***Click on article from Michigan Health***	"The second article from Michigan Health is beautifully done with really nice talking points."
19	***Go to the top of your computer screen and X out of 7 Ways to Talk.***	
20	***Go to the Resources Tab and click on Social & Spirituality; Scroll down the page to show the four questions***	"The fifth domain focuses on Social & Spirituality issues. Connections are so important to us, and isolation is often a huge challenge for families. Social and Spiritual connection is a major component to our well-being; creating room for acceptance, self-discovery, and expression. It's something families need and often

		struggle to find. This domain provides guidance and resources for how to connect with inclusive communities, how to find opportunities for children to socialize with their peers, and ways to join faith groups."
21	***Click on "Where can I find a welcoming faith or spiritual community?" and Scroll down the page to show resources available***	"Let's click on Where can I find a welcoming faith or spiritual community?"
22	***Hover over link to ToolKit***	"This is a list of faith communities that have special needs ministries and offer inclusiveness for our families' unique needs. This list includes a variety of faiths and the first link leads to a helpful toolkit full of information through the Autism Society of NC. The toolkit describes about how to start a disabilities ministry or to help your faith community be more responsive to persons with disabilities"
23	***Go to the Resources Tab and click on "Advocacy and Engagement" and Scroll down the page to show participants the questions listed***	"The last domain is Advocacy & Engagement. For a lot of families, after receiving a diagnosis, it takes a while to find their voice to advocate for their child and family needs. It's not uncommon to rely heavily on the professionals and their recommendations until families

		realize they have a say and a powerful seat at the table as well. Families also often feel they have to be their child's voice; however, many children have their own voice and it's the families' job to teach them how to use it. These resources are designed to help families feel empowered to speak up for themselves and to teach their children to do the same. Not only for themselves, but to help other families learn to speak up too."
24	*Click on "How can my child learn to speak-up and make decisions?"*	"Let's click on How can my child learn to speak-up and make decisions? Advocating for what we want is not limited to verbal ability. Here, families can learn how to teach their children the skills needed to make their wants, needs, and preferences known."
25	*Click on Churchill resource*	"The first link, the Churchill resource is a great step by step guide to encourage self-advocacy."
26		"We've now briefly reviewed the six domains in the Resources section. We encourage you to spend some time on your own to familiarize yourself with the wealth of resources offered here."

APPENDIX: Breakout Room / Small Group Instructions and Case Studies

FINDING RESOURCES (Q3) DEMO (Speaking Notes in Purple)	Facilitator Notes
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 and log on to **ncfamilynavigation.org.**	This part will be done in the large group and the **slide** will show the directions. It is also helpful to put the website in the chat.
At the bottom of the homepage, click on **Find Resources** or you can use the drop down from the Resources tab at the top of our homepage. Now I am going to share a case study with you. And (Share screen with participant copy of the case study) and as I read I want you to think about where you could go within the Resources section to help a family locate a relevant resource. Let's work together and share the process. This is meant to be collaborative and exploratory to help you become more familiar with the contents of this section of the website.	Participants will be in breakout room and the facilitator will start the activity. Allow for introductions, if appropriate. **Facilitator will share screen to show case study** The *Find Resources* button will have been demonstrated in the overview but folks may need to be redirected to it. If they use the dropdown tab at the top of page, they will have to pick a specific domain. The button at the bottom of the homepage takes them to the page with all six domains.
	Read the first paragraph of the case study and go to the first question. Tell them which domain they should look in to find a resource. Give time and ask them to speak up if they find a resource. *Note, the case study goes through each domain in order. **Go to the next question and suggest the domain they should look in. Continue throughout the case study with paragraphs but have them explore on their own and report back.**
If you finish your case study, feel free to explore the website. Share any comments or ask any questions.	**If your group finishes early, have them continue to explore Q3 (or encourage them to go to the decision tree from the homepage).**
Welcome back. Let's wait for everyone to return and we will debrief as a large group.	Once all participants are back together, ask for comments, feedback, questions.

Case Study #1

Facilitator Copy

Benjy (4-year old boy with Down Syndrome)

Mr. and Mrs. Daniels are the parents of an almost 5-year-old Benjy who was diagnosed with Down Syndrome at birth. Benjy is an active, curious and friendly child and his parents dote on him. He received one hour per week of speech therapy and 30 minutes of physical therapy through early intervention. Due to the pandemic, his family stopped all services. Now it's time to send him to kindergarten. Mr. and Mrs. Daniels know that Benjy hasn't been evaluated since his transition to preschool. How do they request an updated evaluation and determine appropriate services when Benjy enters kindergarten?

Q3 > Daily Life and Education > Transition from Preschool to K-12

Although Benjy has been relatively healthy with the exception of frequent respiratory infections, he has been diagnosed with a mild hearing loss. They are concerned that this may affect his learning and development, particularly in a classroom setting.

Q3 > Healthy Living > Hearing Development -> What should I know about my child's hearing development? > Effects of hearing loss on development

Although Mr. and Mrs. Daniels can understand a lot of what Benjy says, his speech is still quite unintelligible to those who don't know him well. Other children often move on quickly rather than trying to listen and understand him. His parents have heard that there might be some assistive technology that could help him express what he is trying to say. They don't really know what assistive technology is and want to learn more.

Q3 > Community Living > What is Assistive Technology

Benjy's parents (and his grandparents) would also like to start an account to help cover expenses for some of Benjy's activities, extra therapy sessions and future needs. Mr. and Mrs. Daniels aren't sure what kind of account(s) they should consider and wonder if they should talk to a financial advisor or someone else who knows about these things.

Q3 > Safety and Security > What legal arrangements should my family consider for the security of my child? How do I make future financial plans for my child with disabilities?

Benjy has not had a lot of experience playing with other children, especially in groups. When he has been around his two cousins, he can be a bit rough when trying to get their attention. His parents feel he is doing this to initiate play but know it is probably not appropriate and this behavior may get him in trouble at school. They would like to find some specially designed group activities where he could learn and practice new social skills.

Q3 > Social and Spirituality > How can I find social and recreational activities for my Child?

Mr. Daniels' job takes him out of town a few days each week. Mrs. Daniels knows that she will be the primary parent attending school meetings and advocating for her child. She is a bit anxious about how best to do this yet still maintain a good relationship with his teacher and others at the school. Where can she learn about Benjy's educational rights and learn the skills she needs to advocate for him?

Q3 > Advocacy and Engagement > What rights for services does my child have and how can I speak up to get what he needs?

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Case Study #2

Foster Care/Adoption (Joseph, age 7 and Jack, age 5)

Joseph and Jack moved into foster care with Mr. Smith after their mom was incarcerated two months ago. Prior to foster care, the brothers moved often, did not attend school regularly and were often left alone. Both Joseph and Jack have been through a lot and Mr. Smith wonders about their overall well being and how best to support the boys. His first concern is making sure that the boys are healthy and he has been asked to find a "medical home" for them. He is not really sure what that means.

(Q3 - Healthy Living Section - Navigating and Managing Health Care – What is a medical health home?)

Joseph has a lot of energy and is unable to focus in school. When confronted about his behavior, he gets angry and combative. The past two weeks, the school has been calling Mr. Smith to come pick him up and have said he may be suspended for his behavior. Mr. Smith is wondering what can be done to help Joseph and keep him in school. He knows that Joseph has an IEP for "developmental delay" but needs to know what that means in terms of services and supports at school.

(Q3 - Daily Life and Education – What services are available for my child with an I/DD or Delay – Services for children older than 5: What are School-based services?)

Mr. Smith was able to take time off when the boys came to live with him but is now back at work. Joseph has had difficulty riding the bus to school and the driver has said his behavior is a safety risk to himself and other students. Mr. Smith needs to find transportation to school for Joseph since he cannot drive him each morning.

(Q3 – Community Living – Transportation – How can we meet transportation needs for my child – Public School Transportation)

Mr. Smith lives near the coast and understands the threat of hurricanes and flooding. He wants to create an emergency / disaster plan for the family but doesn't know where to start.

(Q3 – Safety & Security – How do I prepare our family for emergencies – What should I plan for in case of disasters?)

Jack is 5 years old and has mild cerebral palsy which causes some difficulties running smoothly, catching and throwing balls. However, he loves physical activities and wants to be on a soccer or basketball team and be around other children. Are there recreational activities available for him?

(Q3 – Social and Spirtuality – How can I find social and recreational activities for my child?)

Mr. Smith really loves Joseph and Jack and is hoping to adopt the boys. However, he knows that both boys have many issues that require attention and he will need to learn to find services and seek supports now and in the years to come. He would love to find support and help so that he can be the best advocate for Joseph and Jack..

(Q3 – Advocacy & Engagement – What rights for services does my child/ren have and how can I speak up to get what they need?) We might also mention the warm hand off here.

Case Study #2

Participant Copy

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Case Study #3

Danielle 17-year-old young lady with IDD

Mr. and Mrs. Davis reached out to the Practice Navigator, Ms. Coleman, at their daughters General Practitioners office. They realized that they would need to research appropriate options for their daughter as she will be turning 18 in just 6 months. This topic was brought up during a Parent/Teacher Conference with their daughters Occupational Course of Study lead teacher. The teacher recommended that they explore both Guardianship and applying for Social Security. Danielle has been participating in her IEPs and self-advocating for herself. The parents thought that this means that they did not need to explore these options. They are looking for guidance.

Safety and Security>What is adult guardianship and alternatives to guardianship (supported Decision making) AND > What is Supplemental Security Income…

Mrs. Davis reports that she has not organized Danielle's medical records in a way that she can access them quickly. Ms. Coleman expressed that this will be important for her to have materials close at hand as she will need this when applying for services.

Healthy Living>How can I keep track of my child's medical records

Danielle has expressed interest in working at the beauty salon where she gets her hair done. Mr. and Mrs. Davis don't know where to start to figure out if that's possible.

Daily Life and Education>How can I help my child learn important daily living skill…>connect to VR and/or other agencies listed there

Mrs. Davis admits that the idea of Danielle leaving high school soon is overwhelming for her and her husband. She is nervous about Danielle's future and indicates that she could use some support from other families who know what they are going through. She wonders if Ms. Coleman knows of any support groups they could tap into.

Social and Spirituality>Where Can I find a Support Community

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