



**Family Voices CARES**

**Telehealth Project**

FAMILY  VOICES<sup>®</sup>

Roseani Sánchez  
Project Director

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# Project Goals

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**Share best practices for serving families** via telehealth, especially families who are diverse, vulnerable, medically underserved and hard to reach

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**Identify strategies to overcome barriers to family participation** in telehealth services

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Ways to **promote family engagement** in telehealth

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Ideas and **resources for promoting family-centered telehealth**

# Project Overview

Mini Grants

Telehealth Academy

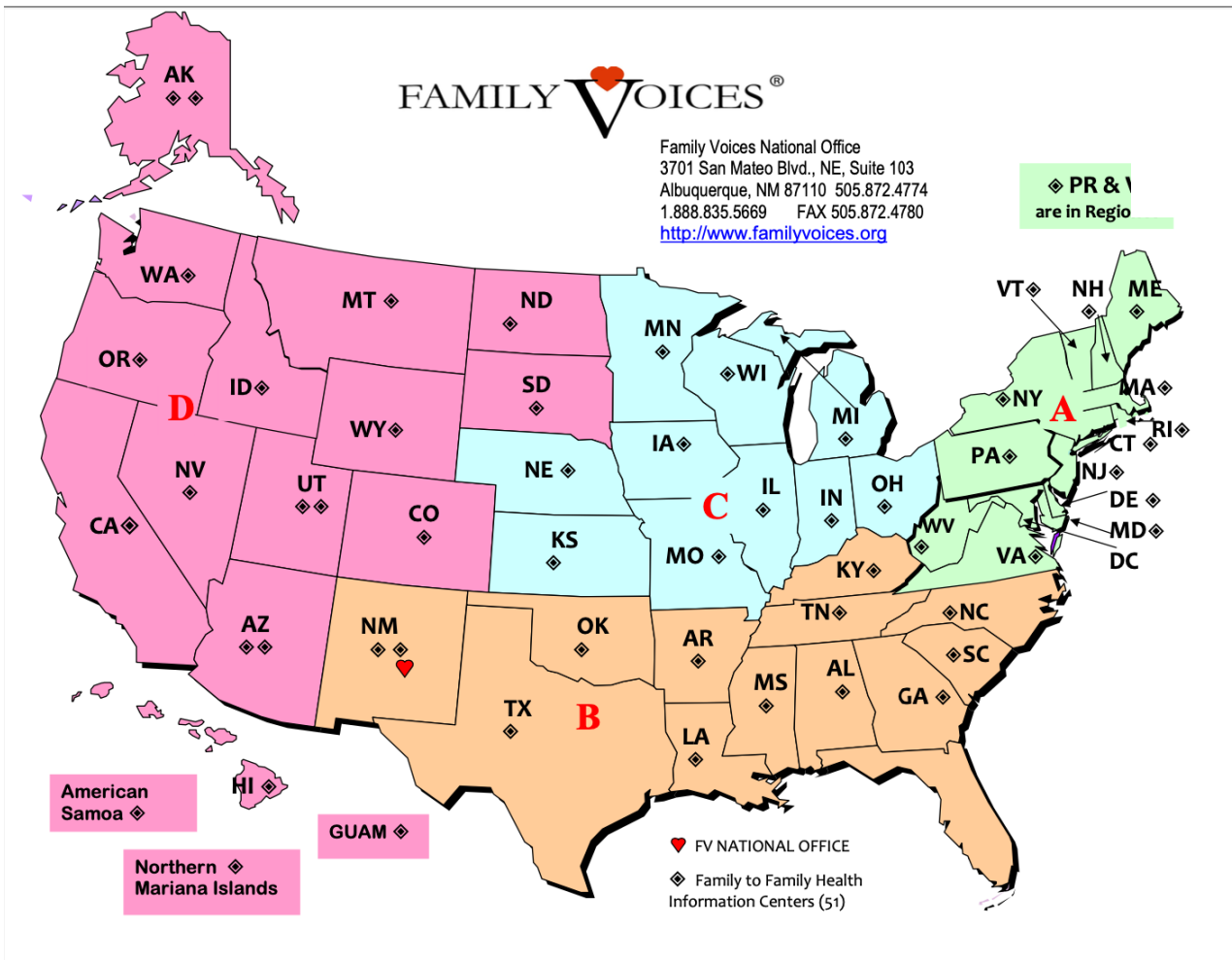
Nuts and Bolts of Telemedicine

Community of Practice

# FAMILY VOICES®

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◆ PR & VI  
are in Region



# Mini Grants Program



# Program Develop



**Are You Connected?**

**WEBINAR 1**



**Do You Have a Device?**

**WEBINAR 2**



**Can You "See" Your Provider?**

**WEBINAR 3**



**Your Family's First  
Telemedicine  
Appointment**

**WEBINAR 4**

## **Full List of Telehealth Definitions:**

**AMC Health:** Patients can send biometric data from FDA (Food and Drug Administration) approved medical devices through Bluetooth and patient dashboards that facilitate medication adjustments and other assessments.

**Accommodations:** The adjustments or changes made to a system to make it work for a child or family's unique needs.

**Apps:** An application that can be downloaded to a mobile device

**Attachment:** An attachment is a computer file sent along with an email message. One or more files can be attached to any email message, and be sent along with it to the recipient. This is typically used as a simple method to share documents and images.

**Audio (turn on/off):** In computers, audio is the sound system that comes with or can be added to a computer.

**Bits and Bytes:** Bits (written with lowercase “b”, such Mbps megabits per second) are smaller and are used to measure and describe the speed of an internet connection. Bytes (8 bits= 1 Byte, written with uppercase “B” such as MBps) are bigger and measure the size of data and space for that data on your computer. Bits (speed) and Bytes (file size) determine download time. The higher the bits and bytes in your broadband, the better your connection.

**Broadband [over power lines (BPL)]:** The delivery of broadband over the existing low- and medium-voltage electric power distribution network. BPL speeds are comparable to DSL and cable modem speeds. BPL can be provided to homes using existing electrical connections and outlets.

**Broadband:** A high-speed internet connection that is faster than dial up. Cable modems and DSL (Digital Subscriber Lines) are the two technologies that are most commonly available to provide access.

# Glossary



## I can't do my telemedicine visit because...

### I DON'T HAVE A PHONE OR DEVICE



#### WHAT DOES THIS MEAN?

It means that you do not have access to a device (phone, tablet, laptop, or computer) to connect to broadband or cellular signal to have a telehealth or telemedicine appointment.



#### WHO CAN HELP?

- Family members or neighbors with a device
- Libraries
- Community organizations
- Your Family-to-Family Health Information Center
- Your child's school
- If the individual or family is eligible for Medicaid, they can get a phone with monthly minutes, data, and texts from Lifeline.



#### WHAT ARE MY NEXT STEPS?

- Call the Family-to-Family Health Information Center in your state, territory, or tribal nation who can help you with the application process.
- Call a community-based or other organization that helps you understand and access the supports that are available to you and your children with special health care needs.



#### WHERE CAN I LEARN MORE?

- Family Voices' Nuts and Bolts of Telemedicine Webinar: Are You Connected
- Human-I-T reuses and recycles unwanted electronics and provides it to those in need at no cost. Assistance and applications are available in English and Spanish.

# Barrier Busters

- What does this mean?
- Who can help?
- What are my next steps?
- Where can I learn more?



# Family- Centered Telehealth

## What is Family-Centered Telehealth?

Family-centered telehealth is a way of providing services through a variety of digital platforms that assures the health and well-being of children and youth with special health care needs (CYSHCN) and their families through respectful family/professional partnerships. Although this way to deliver health care is not new, the use of telehealth platforms for providing health care and related services to CYSHCN is unprecedented. Therefore, it is necessary to ensure that telehealth is not simply reactive or a temporary substitute for in-person care, but actively uses the core concepts of family-centered care to enhance the delivery of healthcare services and meet the needs of CYSHCN and families. The core concepts of family-centered care, detailed below, relate to dignity and respect, information sharing, participation, and collaboration. Family-centered telehealth can help CYSHCN and families access health care, improve experience with healthcare, reduce stress, improve communication between all team members and across systems, and improve quality of life and well-being.

## Core Concepts of Family-Centered Telehealth

### Dignity and Respect

Ask for, listen to and integrate the strengths, cultures, traditions, and expertise that CYSHCN, families and professionals bring to the telehealth visit. Families define themselves and determine who and how they will participate in their children's care, decision-making and telehealth visits. Build on family strengths and acknowledge the family as the constant in the child's life. Support CYSHCN in learning about, self-managing and participating in his/her care and decision-making.

### Information Sharing

Communication goes in both directions, between CYSHCN and families and their health care teams, and is open and honest. All members of the health care team, including CYSHCN and their family, receive timely, complete and accurate information in order to foster shared decision-making and effectively participate in telehealth. Discussions are not limited to symptoms, concerns, needs and clinical information, but also celebrate successes and involve other aspects of child and family life.

- What is family-centered Telehealth?
- Core concepts of Family-Centered Telehealth
  - Dignity and respect
  - Information sharing
  - Participation
  - Collaboration

# Rights and Responsibilities

## Telehealth Rights and Responsibilities



### CYSHCN and Family Rights and Responsibilities for Telehealth

#### RIGHTS

*You have the right to receive considerate, respectful and compassionate care* through telehealth regardless of your age, gender, race, national origin, religion, sexual orientation, gender identity or disabilities.

*You have the right to receive safe and high-quality care* within the range of services that telehealth provides.

*You have the right to ask your provider or the appropriate office staff any questions about logging on to, and needing assistance with, the telehealth platform.*

*You have the right to accommodations for vision, hearing and speech* to be able to access your telehealth visit.

*You have the right to access a telehealth visit in your primary language* with effective and adequate interpretation services.

*You have the right to have a family member, support person, or other individual present* with you during your telehealth visit.

*You have the right to share information and ask questions* during a telehealth visit as you would during an in-person visit.

*You have the right to receive the same type of information*, such as test results or diagnosis, during telehealth as you would during an in-person visit.

*You have the right to discuss and collaborate in making plans of care* during a telehealth visit as you would during an in-person visit.

*You have the right to disagree with any plans or ask for review or changes to the plan of care* in a telehealth visit just as you would during an in-person visit.

*You have the right to request an in-person visit* if you feel that the telehealth visit will not meet your child or family's needs.

*You have the right to stop a telehealth visit* if you feel uncomfortable at any time.

*You have the right to share a concern or grievance* about your telehealth visit verbally or in writing with your provider and/or office staff.

# Preparing for a successful Telehealth Visit

## Preparing for a Successful Telehealth Visit

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*This guide will help you prepare before your visit with your service provider.*

Provider's Name: \_\_\_\_\_



### BEFORE THE VISIT

Select as applicable and briefly explain in the notes:

- Since your last visit, is there any information you want to share with your provider?
  - Celebrations  Concerns  Challenges  Other
- Any new changes, observations or updates to share about:
  - Doctors  Behaviors  Symptoms
  - Medicines  Treatment  Labs  Imaging  Other
  - School  Therapies  Socialization
- Plan of Care:
  - Any updates from other providers/specialist or changes to the plan of care



NOTES:



### DURING THE VISIT Who, How and What?

- Who will participate in the visit- either joining virtually or in person?
  - Child
  - Parent, family member, or other caregiver
  - Home health aide
  - Others
- How do you want the visit to flow or proceed? What will be discussed:
  - How comfortable are you helping with the physical exam?
  - Do you want to demonstrate or share information about any home routines, supplies, or equipment?
  - Would your child like to share any information during the visit?
- Did you notice anything during the exam that your provider did not notice that you want to share?  
Describe in the notes:



NOTES:

# Social media Tool kit

**Your Family's First  
Telehealth Visit!**



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**#FamilyCenteredTelehealth**

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## The Fab 4

For a Family-Centered Telemedicine Appointment

#1

Are You  
Connected?

#2

Do You Have  
a Device?

#3

Can You  
"See" Your  
Provider?

#4

Your Family's  
First  
Telemedicine  
Appointment

**#FamilyCenteredTelehealth**



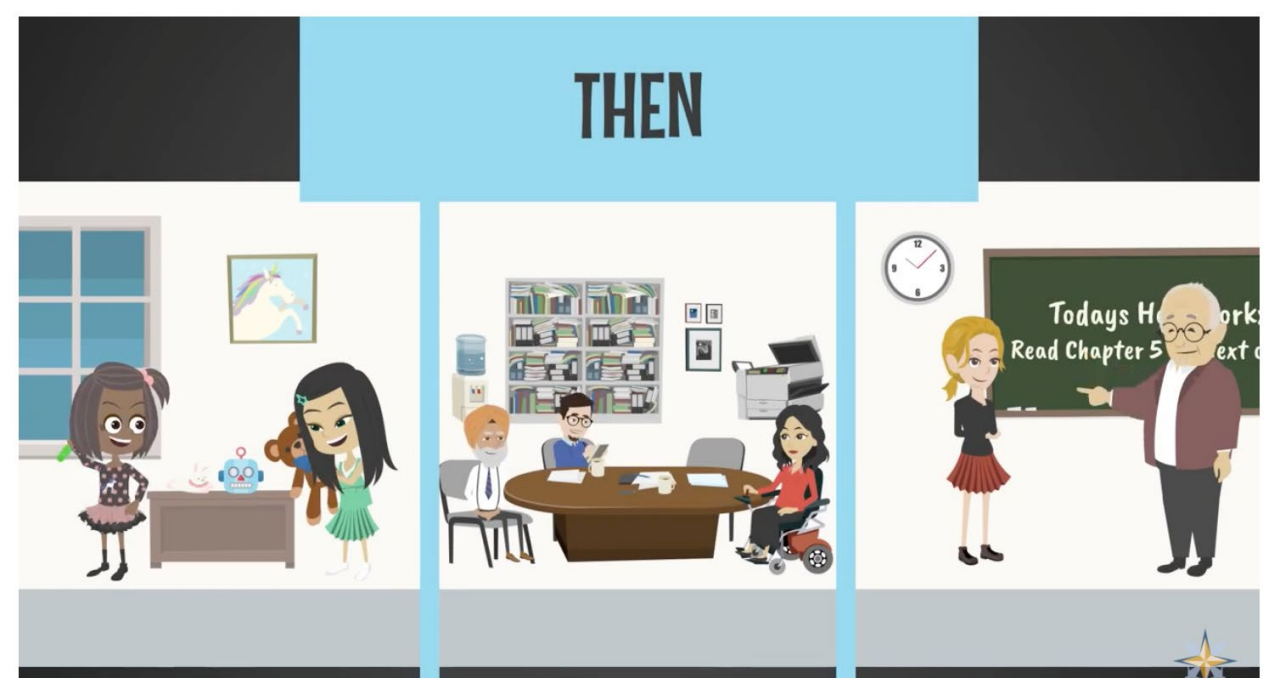
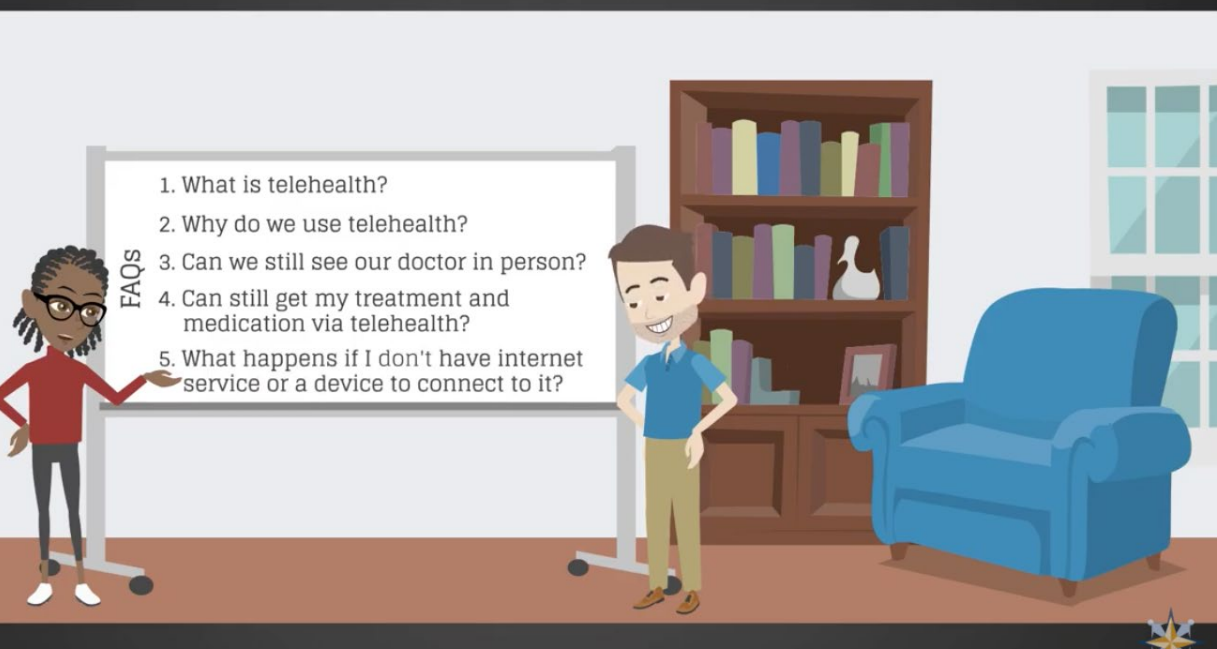
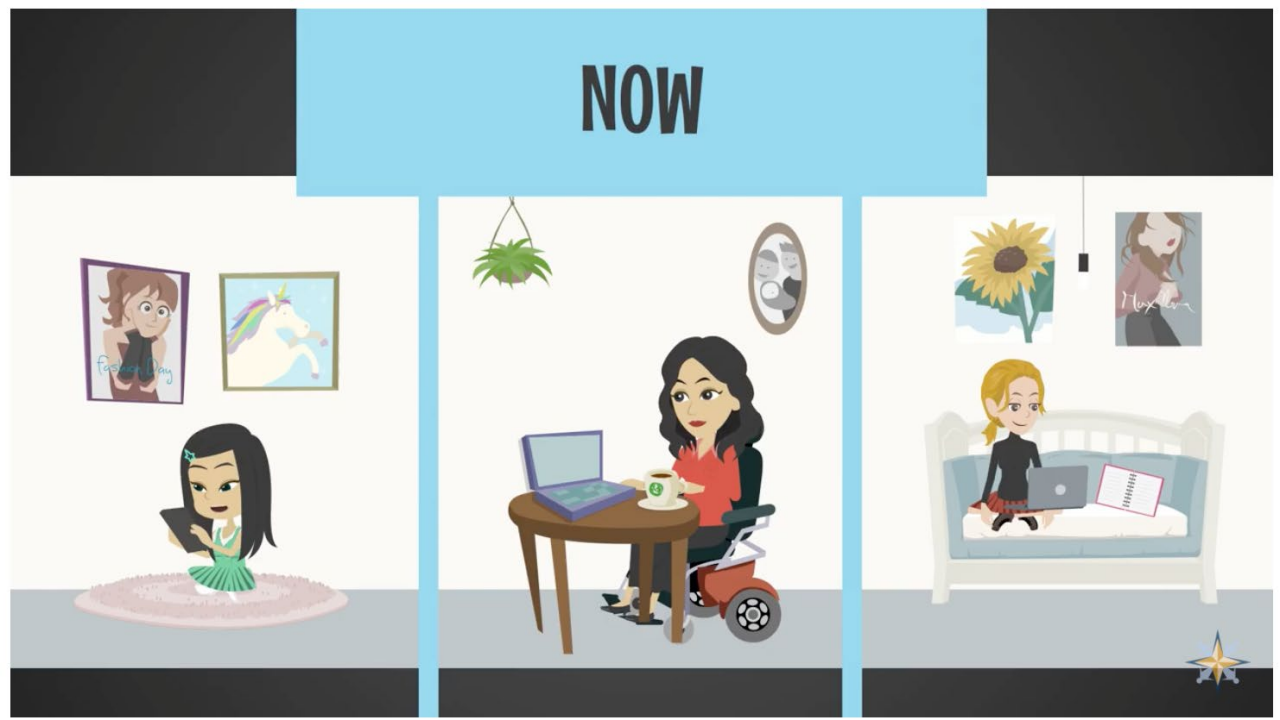
**#FamilyCenteredTelehealth**

**Barrier Busters!**



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**#FamilyCenteredTelehealth**



A teal-colored circle is centered on the page, containing the word "RESOURCES" in a white, bold, sans-serif font. A thin white horizontal line is positioned directly below the text. The background of the entire image is a blurred stack of books with various colored spines, including shades of brown, red, and white.

# RESOURCES

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[ABOUT FAMILY VOICES](#)

[PROGRAMS & PROJECTS](#)

[PUBLIC POLICY](#)

[RESOURCES](#)

[NEWS](#)

[EVENTS](#)

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# Telehealth



[MINI-GRANTS](#)

[TELEHEALTH ACADEMY](#)

[CURRICULUM / CURRÍCULO](#)

[PARTNERS](#)

[YOUTH](#)

[FAMILY RESOURCES/RECURSOS PARA FAMILIAS](#)





# Community of Practice

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- ❑ **Objectives:**
  - ❑ Share telehealth best practices
  - ❑ Identify and begin to overcome barriers
  
- ❑ **Key Tools and Strategies:**
  - ❑ Regional Coordinators
  - ❑ FV staff member for each region



# Engaging Underserved Communities

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We hired nine (9) participants that represent different cultural points of view and necessities, creating the Culturally Responsive Committee.



**THANK YOU**