

Supporting Children with Disabilities: Lessons from the Pandemic

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LEARNING OBJECTIVES

At the conclusion of the presentation, participants should be able to:

1. Identify strategies to help families of CYCHSN overcome barriers to telehealth.
2. Share resources that help increase access to and prepare families of CYSHCN for telehealth visits.
3. Connect families of CYSHCN to family-led organizations for additional telehealth information & other supports.

About Family Voices

- National family-led organization of families and friends of children and youth with special health care needs (CYSHCN) & disabilities
- Connect a network of family organizations across the US that provide support to families of CYSHCN
- Promote partnership with families at all levels of health care—individual & policy decision-making levels—in order to improve health care services and policies for children
- Home to 30+ projects

2020 CARES Act Telehealth Award

1. Support the national network of family-led organizations that support families/caregivers of CYSHCN to build their telehealth capacity to provide education, guidance, and support to CYSHCN and their families.
2. Identify, develop, and disseminate information and curricula on patient and family/caregiver's engagement and adoption of telehealth for partnering with pediatric health providers
3. Establish partnerships to provide education, training, and technical assistance to patients/family caregivers related to telehealth.
4. Support communities of practice of family support organizations and pediatric health professionals in coordination with the CARES Act – Pediatric Care recipient to share knowledge and strategies.

Strategies to Help Families Overcome Barriers to Telehealth

- Watch the Family Voices Nuts & Bolts of Telemedicine: Essentials for a Family-Centered Experience (available in English and Spanish). Customize and share with families in your state, territory, and Tribal nation.
- Share the Family Voices Barrier Busters (available in English and Spanish) to help families overcome barriers to accessing and participating in telehealth services.
- Collaborate with other partners, such as the Telehealth Resource Centers, to increase knowledge of telehealth technology for organizational staff.
- Partner with libraries, technology loan programs, schools, universities, and telecommunications companies to increase family access to devices and internet services for families.
- Address issues of confidentiality and privacy up front to reassure families the information they share is secure.

The Nuts & Bolts of Telemedicine: Essentials for a Family-Centered Experience



Are You Connected?

WEBINAR 1

Having access to a cellular or WiFi signal is often needed to have a video visit or #FamilyCenteredTelehealth appointment with your provider. Learn more about getting and improving your connection in this webinar.

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Do You Have a Device?

WEBINAR 2

Computers, Laptops, Tablets and Smartphones are all devices that can be used for a telemedicine or #FamilyCenteredTelehealth appointment. Learn if your device is "teleready" in this webinar!

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Can You "See" Your Provider?

WEBINAR 3

Learn what the 4 KEYS are that will help you unlock the doors so you and your provider can have a successful #FamilyCenteredTelehealth appointment in this webinar.

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Your Family's First Telemedicine Appointment

WEBINAR 4

Watch this webinar to learn some of the tips and tidbits that will make it a successful one! You won't want to miss the bloopers!

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Barrier Busters

1. I don't have the accommodations I need
2. I don't have a phone or device
3. I'm not on the internet
4. I don't have a signal
5. I am not comfortable being on camera
6. I can't find a private or quiet place for my appointment
7. I don't trust my information will be secure
8. No puedo pagar un plan o minutos
9. Mi hijo no participará
10. No tengo un correo electrónico
11. No sé cómo hacer esto con mi médico
12. Mi seguro médico no cubre la telemedicina
13. Necesito servicios de interpretación
14. No sé cómo iniciar sesión

**I can't do my telemedicine visit because...
I DON'T HAVE THE ACCOMMODATIONS I NEED**

 <p>WHAT DOES THIS MEAN? English may not be your first language, or you may have a disability or special health care need that makes it hard for you to communicate with your provider without special accommodations for you or your child. These accommodations could include an interpreter, special software, or extra assistance. The Americans with Disabilities Act requires that health care providers give devices, equipment or services necessary for effective communication between a person who has a vision, hearing or speech disability and one who does not.</p>	 <p>WHO CAN HELP?</p> <ul style="list-style-type: none">• Your provider• Your Family-to-Family Health Information Center• Local disability organizations• Local department of health
 <p>WHAT ARE MY NEXT STEPS?</p> <ul style="list-style-type: none">• Talk to or plan with your provider about what devices, equipment and services you may need to communicate. Be specific and feel empowered by your rights.• Contact your Family-to-Family Health Information Center.• Find your state or territory Disability Network Center• Find your state or territory Protection and Advocacy Center	 <p>WHERE CAN I LEARN MORE?</p> <ul style="list-style-type: none">• Accessible healthcare fact sheet**• A guide to disability rights laws• FamilyVoices: Family-Centered Telehealth Rights and Responsibilities document• COVID-19 Communication Rights Toolkit <p><small>**NOTE: Includes links to printer-friendly, large print and Spanish versions.</small></p>

FAMILY VOICES® www.FamilyVoices.org/telehealth

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Infographics



Infographic: Telehealth – What Is It?

[English](#) | [Spanish](#)

FAMILY-CENTERED TELEHEALTH

What Is It?

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.

Infographic: Family Centered Telehealth – What Is It?

[English](#) | [Spanish](#)



Infographic: Rights

[English](#) | [Spanish](#)

Checklists for Families to Navigate Telehealth


Preparing for a Successful Telehealth Visit

FAMILY VOICES®


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:**

NEXT STEPS

Before the visit is over, you and your provider can:

- Discuss the plan of care. **PAUSE** Are you comfortable and confident with the care plan?
- Discuss if you will need or will be provided:
 - ☐ Referrals ☐ Prescriptions ☐ Orders for supplies, therapies or medical care
- Clarify: Who is responsible for key parts of care plan, communication and care coordination?
- Discuss next appointment: will an in person or virtual visit work best for your child?
Consider the follow in this discussion:
 - ☐ Preference for the day and time that works best for your child and family
 - ☐ Discuss the safety and risks of each of the options (face-to-face and virtual)
 - ☐ Share your child's and your family's needs
- Any other needs or concerns that were not discussed?

 **NOTES:**


List additional achievements, concerns, or challenges you want to discuss:

FOLLOW-UP NOTES:


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Resources for Youth




Steps for a successful Telehealth visit



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Steps for a successful Telehealth visit



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<https://familyvoices.org/telehealth/youth/>

Strategies to Reach Diverse Families

- Use data sources to understand the demographics of the population in your state and territories.
- Use snail mail, radio announcements, and announcements in multiple languages in local newspapers to reach families who represent the race, ethnicity, language, and geography of the country.
- Create partnerships with community leaders, cultural liaisons, food banks, WIC programs, and other community services to reach families.
- Co-create telehealth materials with cultural liaisons and other community leaders to ensure they are culturally and linguistically appropriate.

Best Practices to Engage Families in Telehealth Services

- Send appointment reminders to families.
- Help families understand releases and telehealth technology.
- Help families prepare for telehealth visits by sharing the Family Voices telehealth resources in English and Spanish (i.e. Family-Centered Telehealth; Telehealth Rights and Responsibilities, and Preparing for a Successful Telehealth Visits) to ensure the telehealth appointment addresses the needs of the child and family.
- Follow up with families to see how the visit went.
- Continue to offer telehealth options even after COVID.
- Connect families with the Assistive Technology Project in their states.

*Thank
You*