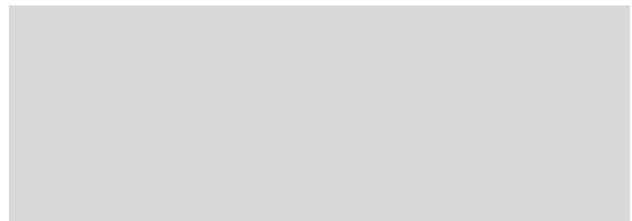




# Telehealth Family Resource Guide



## Table of Contents

<b>Introduction.....</b>	<b>4</b>
<b>What is Telehealth?.....</b>	<b>4</b>
<b>General Telehealth Resources.....</b>	<b>4-5</b>
<b>Advantages and Disadvantages of Telehealth.....</b>	<b>5-6</b>
<b>Telehealth Decision Making Guide.....</b>	<b>6</b>
<b>Additional Telehealth Decision Making Guidance.....</b>	<b>7</b>
<b>Equipment Needed for A Telehealth Appointment.....</b>	<b>7</b>
<b>Tips for Obtaining A Telehealth-Ready Device.....</b>	<b>7-8</b>
<b>Troubleshooting Technical Problems.....</b>	<b>8</b>
<b>Tips for Finding A Telehealth Provider.....</b>	<b>8-9</b>
<b>Telehealth Rights and Responsibilities.....</b>	<b>9-11</b>
<b>Parent Advocacy During Telehealth.....</b>	<b>11-12</b>
<b>Parent Training and Educational Resources.....</b>	<b>12</b>
<b>Telehealth Fatigue and Caregiver Self-Care.....</b>	<b>12-13</b>

**Telehealth Resources for Children.....13**

**Indiana-Specific Information.....13**

**Diagnosis-Specific Resources.....14**

**Legal Resources.....15**

**Indiana Family to Family Contact Information.....15**

## **Introduction**

This guide is intended to offer resources and information to support families with children with special healthcare needs and/or disabilities who reside in Indiana. This guide is not extensive, and the information is current at the time of update (July 2022). Families may contact us directly at 844-323-4636 or by emailing [info@inf2f.org](mailto:info@inf2f.org) for further support.

## **What is Telehealth?**

According to the Child Mind Institute, telehealth is “any treatment in which a practitioner provides care via technology instead of in-person appointments.

Options include:

- Live video calls
- Phone calls
- Text Chat
- Mobile health apps
- Electronic prescriptions

Like in-person... treatment, telehealth options can often provide treatment for families and groups as well as individuals.” ([2020 Children’s Mental Health Report Supplement: Telehealth and Children’s Mental Health Guide for Parents](#))

Family-Centered telehealth is when you and your provider are working together for the wellbeing of your loved one. Family-centered telehealth can help children and youth with special healthcare needs (CYSHCN) and families to access health care, improve experience, reduce stress, improve communication, and improve quality of life and well-being. ([Family Voices, Inc., The Nuts and Bolts of Telehealth, 2021](#))

## **General Telehealth Resources**

1. [Telehealth Resources](#) (Family Voices, Inc., 2021)
2. [“The Nuts and Bolts of Telehealth” Curriculum](#) (Family Voices, Inc., 2021)
3. [Telehealth Definitions](#) (Family Voices, Inc., 2021)
4. [Family-Centered Telehealth](#) (Family Voices, Inc., 2021)
5. [Family-Centered Telehealth SPANISH](#) (Family Voices, Inc., 2021)
6. [Telehealth Barrier Busters](#) (Family Voices, Inc., 2021)
7. [Telehealth for Kids](#) (Child Mind Institute, 2022)

8. [Telehealth: Providing Best Outcomes for Children During COVID-19](#) (Nationwide Children's, 2021)
9. [Telehealth Services Start with Your Pediatrician](#) (HealthyChildren.Org, 2021)
10. [Telehealth Tip Sheet](#) (Child Neurology Foundation, 2021)
11. [Telehealth 101: Get Plugged-In to Your Child's Health](#) (HealthyChildren.Org, 2021)

## **Advantages and Disadvantages of Telehealth**

According to the Child Mind Institute, some advantages of telehealth include:

- **Increased Access to Providers**  
Families may have increased access to medical providers and specialists due to telehealth, since they can more readily access providers that are not local to them.
- **Easier Scheduling with Providers**  
Families may find that scheduling with providers is easier due to telehealth, since they do not have to travel to and from their provider's office.
- **Increased Comfort**  
Families may be more comfortable during appointments when they are at home in a familiar setting. They may be more likely to speak freely and openly with their providers.

According to the Child Mind Institute, some disadvantages of telehealth include:

- **Provider Licensing and Billing Issues**  
Many state licensing requirements for telehealth have been loosened during the pandemic; however, the rules may change unexpectedly in the future and create issues for both families and providers.
- **Decreased Insurance Coverage**  
Not all telehealth services are covered under all insurance plans, and families may need to navigate this complex system with their medical providers, insurance company, and/or their employer's human resource department.

- **Technical Difficulties**

Issues with internet connection, devices, and/or telehealth software may cause problems for families and providers as they try to connect via telehealth appointments.

- **Decreased Privacy**

Some parents may find decreased privacy an issue in their homes if they have children present in the home during a telehealth appointment.

- **Trouble Building a Rapport Between Families and Providers**

It may be difficult for providers and families to connect and get to know each other when they are not able to meet and visit in-person.

[\(2020 Children’s Mental Health Report Supplement: Telehealth and Children’s Mental Health Guide for Parents\)](#)

## **Telehealth Decision Making Guide**

How can you decide if telehealth is right for your family? According to the Child Mind Institute, “Telehealth might be a good option for your child if:

- **It’s difficult to attend in-person sessions:** Whether it’s because of coronavirus-related restrictions, transportation issues, or scheduling difficulties, getting to in-person treatment sessions can be tough. If that’s the case for your family, telehealth might be a better option.
- **You’re having trouble finding the right provider:** Maybe there aren’t any specialists in your area, or you want to work with someone who understands your family’s culture and views on mental health. Telehealth can increase the odds of finding the right fit for your child.
- **You or your child aren’t comfortable with in-person sessions:** If you prefer not to visit a provider’s office, or if your child is especially shy or anxious, telehealth might be more comfortable for your family.

Telehealth isn’t for everyone. It can be particularly challenging for young children, those with severe developmental delays, or youth with severe mental health or behavior challenges. If you think your child might not be able to focus for the duration of a telehealth session or participate through technology, in-person session may be a better choice.” [\(2020 Children’s Mental Health Report Supplement: Telehealth and Children’s Mental Health Guide for Parents\)](#)

## **Additional Telehealth Decision Making Guidance:**

1. [Video Visits with Your Pediatrician: When Is Telemedicine A Good Option for My Child?](#) (Children’s Hospital of Philadelphia, 2020)
2. [Telehealth Services Start with Your Pediatrician](#) (HealthyChildren.Org, 2021)
3. [Can Telehealth “Video Visits” Be A Good Option for My Child? How Do They Work?](#) (HealthyChildren.Org, 2021)

## **Equipment Needed for A Telehealth Appointment**

### **1. Internet Connection**

### **2. A Device**

A device can refer to any electronic mechanism, including: laptop, desktop, tablet, or smart phone. Most devices and computers will have a built-in microphone and camera, which should work fine for your telehealth appointment. If your device does not have a microphone, you will need a separate microphone so that your provider can hear you. Earbuds and headphones can be used if they contain a microphone. If your device does not have a camera, you will need a camera so that your provider can see you. ([Family Voices, Inc., The Nuts and Bolts of Telehealth, 2021](#))

### **3. Software**

Telehealth Software is a secure platform that will allow you to have a virtual visit (via video and audio interaction) with your provider. There are many free versions of telehealth software, such as: Doxy.me, Zoom for Healthcare, Microsoft Teams, and Provider-Specific Portals. ([Family Voices, Inc., The Nuts and Bolts of Telehealth, 2021](#))

### **4. An Appointment with Your Provider**

## **Tips for Obtaining A Telehealth-Ready Device**

If you do not own a telehealth-ready device (laptop, desktop, tablet, or smartphone), there may be options in your community to assist you in finding one. These options may include:

- Community-Based Organizations, such as [Indiana Family to Family](#).
- Indiana’s University Center for Excellence in Disabilities (UCED) Program: [The Indiana Institute of Disability and Community \(IIDC\)](#).
- Community-Based Private Foundations, such as Easter Seals: [Central Indiana](#) or [NE Indiana](#).
- Your Local Public Library
- Your Local Public School System
- Your Local Healthcare System
- Medicaid-Issued Cell Phones

Additional tips on obtaining a telehealth ready device can be found at Family Voices, Inc.’s [Telehealth Barrier Busters](#) webpage.

## **Troubleshooting Technical Problems**

If you are having trouble accessing your scheduled telehealth appointment with your provider, you can:

1. Contact your provider directly.
2. Call the nurse advisory line or helpline for your health provider, and let them know that you are having difficulty accessing your appointment.
3. Seek help in your community. Contact a friend, neighbor, or community health organization for help troubleshooting.
4. Look for online videos and tutorials.

Additional resources for troubleshooting technical problems associated with Telehealth can be found at Family Voices, Inc.’s [Telehealth Barrier Busters](#) webpage.

## **Tips for Finding A Telehealth Provider**

According to the Child Mind Institute, “There are lots of ways to find a qualified telehealth provider:

- **Evaluators:** If your child has already had a formal psychological evaluation, you can ask the evaluator for recommendations.
- **Current Providers:** If you or your child already sees a provider, you can ask if they offer remote options or know of any colleagues in their field or related ones who might.
- **Pediatrician:** Your child's pediatrician is always a good first stop. They may keep a list of local providers you can check with.
- **Your Insurance Provider:** Often your insurance provider will have a searchable database of in-network providers. Some even have the ability to filter by providers who offer remote services.
- **Universities and Teaching Hospitals:** Many telehealth programs are run through universities and teaching hospitals, so it's worth taking a look at some of the big ones in your state.
- **Internet Search:** Try searching for the kind of provider you want plus the word "remote" and your state to see what pops up.
- **Online Parent Groups:** There are groups based on location as well as groups for parents of children with every diagnosis under the sun.
- **Professional Organizations and Nonprofits:** Search for professional organizations and nonprofits associated with the type of care you're looking for. Many offer directories of providers. No matter how you find your provider, remember that a high standard of care and a good fit with your child are key." ([2020 Children's Mental Health Report Supplement: Telehealth and Children's Mental Health Guide for Parents](#))

Additional resources for finding tips on selecting a telehealth provider can be found at Family Voices, Inc.'s [Telehealth Barrier Busters](#) webpage.

## **Telehealth Rights and Responsibilities**

- [Telehealth Rights and Responsibilities](#) (Family Voices, Inc., 2021)
- [Telehealth Rights and Responsibilities SPANISH](#) (Family Voices, Inc., 2021)

### **Rights:**

- **Care via Telehealth**

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.

- **Plans of Care**

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.

- **Questions**

You have the right to ask your provider or the appropriate office staff any questions about logging on to, and needing assistance with, the platform. You have the right to share information or symptoms and ask questions during a telehealth visit as you would during an in person visit.

- **Documentation**

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.

- **Vision, Hearing, and Speech**

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

- **Family Support**

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

- **Interpretation**

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

- **Stop a Visit**

You have the right to stop a telehealth visit with the provider if you feel uncomfortable at any time. Some examples of things that may make you feel uncomfortable: If the provider is eating, taking another call, or talking with someone off camera.

[\(Family Voices, Inc., The Nuts and Bolts of Telehealth, 2021\)](#)

### **Responsibilities:**

- **Come with Information**

You have the responsibility to come to the telehealth visit with information and updates about your child's health, such as celebrations in your child's life since the last visit, concerns, symptoms, treatments or hospitalizations since the last visit, medications, updates from other providers, and any other information you think your provider might need to know.

- **Ask Questions**

You have the responsibility to ask questions when you do not understand information or the plan of care. Take notes of any questions or concerns you have, or of any orders, plans, and/or action items discussed during the telehealth visit.

- **Participate**

You have the responsibility to actively participate in the telehealth visit. Offer your child the same opportunity to actively participate in the telehealth visit, when appropriate.

- **Assist**

You have the responsibility to assist with any physical examination of your child or demonstrate issues with your child's care, such as problems with supplies or equipment, during the telehealth visit.

([Family Voices, Inc., The Nuts and Bolts of Telehealth, 2021](#)).

## **Parent Advocacy During Telehealth**

When considering your rights and responsibilities during a telehealth appointment, remember that it is always acceptable to advocate for yourself, your family, and your child. A few things to remember when advocating for your family:

- It's okay to decline services.
- It's okay to tell your provider if you or your child are feeling uncomfortable.
- It's okay to say "no" to something that you or your child feel uncomfortable with.
- It's okay to tell your provider that you would like to end the appointment early for any reason.
- It's okay to ask your provider to take additional time to listen to what your child's needs are.
- It's okay to ask your provider to reschedule the appointment if it seems like they are too rushed or not able to listen effectively.
- It's okay to ask your provider to reschedule the appointment if they do not provide appropriate accommodations for your family (for example, an interpreter or closed captioning services).

- It's okay to give suggestions to your medical provider.
- It's okay to question your child's plan of care.
- It's okay to change providers at any time, for any reason.
- It's okay to disagree with your provider's treatment plan.
- It's okay to be firm with your medical provider.
- It's okay to follow up with your medical providers and hold them accountable for their part of your child's treatment plan (for example, making sure that referrals are sent in a timely manner).
- If you are having technical difficulties, it's okay to ask for a back-up plan (for example, switching to a phone call) or ask to reschedule your appointment.
- It's okay to tell your provider that you are uncomfortable with telehealth and that you'd prefer to be seen in-person.

As the parent or legal guardian, you are in charge of your child's medical care team. You are in control. It's okay to remind your providers that medical treatment is "teamwork", and it's always okay to remind your medical provider that your and your child's voices matter.

### **Parent Training and Educational Resources**

- [How to Have a Productive Video Visit with Your Child's Provider](#) (CHOP, 2020)
- [The Nuts and Bolts of Telehealth Curriculum](#) (Family Voices, Inc., 2021)
- [Telehealth Etiquette Video Series](#) (South Central Telehealth Resource Center, 2021)
- [Telehealth Best Practices for Children with Behavioral Challenges: Tips and Tricks to Make Visits More Successful- Webinar](#) (Child Neurology Foundation, 2021)

### **Telehealth Fatigue and Caregiver Self-Care**

- [Advice for Caregivers of Children with Disabilities in the Era of COVID-19](#) (American Psychological Association, 2021)
- [Coping with Stress During the 2019-nCoV Outbreak](#) (World Health

### Organization, 2021)

- [Parent/Caregiver Guide to Helping Families Cope with the Coronavirus Disease 2019](#) (The National Child Traumatic Stress Network, 2021)
- [Guía de ayuda para padres y cuidadores para ayudar a las familias a enfrentar la enfermedad Coronavirus 2019](#) (SPANISH) (The National Child Traumatic Stress Network, 2021)

## **Telehealth Resources for Children**

- [COVID-19 Social Stories to Explain Changes](#) (Autism Society, 2021)
- [Pandemic Social Stories](#) (Carol Gray Social Stories, 2020)
- [Telehealth Social Story](#) (ACES, 2020)
- [Telehealth Social Story](#) (Rachel Ashcraft, 2020)
- [Video: What is Telehealth?](#) (Beech Brook Kids, 2020)

## **Indiana-Specific Information**

Information on telehealth policies and procedures for specific healthcare systems within the state of Indiana can typically be found on their website or by contacting the hospital's main phone number or your provider. Some examples of telehealth policies and procedures, include:

- [Beacon Children's Hospital Connected Care](#)
- [Community Health Network Virtual Care](#)
- [Lutheran Children's Hospital Telehealth](#)
- [Peyton Manning Children's Hospital \(Ascension St. Vincent\) Online Care](#)
- [Riley Children's Health \(IU Health\) Virtual Visits](#)

Explore a state-wide directory of services, programs and helpful articles for the disability community via [Indiana Disability Resource FINDER](#).

## **Diagnosis-Specific Resources**

- **Deaf or Hard of Hearing**
  1. [Telehealth Visits for Children Who Need Hearing or Vision Help](#) (HealthyChildren.Org, 2021)
  2. [Video-Based Telehealth Accessibility for Deaf or Hard of Hearing Patients](#) (National Association of the Deaf)
- **Developmental Disabilities**
  1. [How Can I Help My Child, Who Has a Developmental Disability, Cope During COVID-19?](#) (HealthyChildren.Org, 2021)
- **Down Syndrome**
  1. [Covid-19 and Down Syndrome Resources](#) (Down Syndrome Indiana, 2021)
- **Epilepsy**
  1. [Covid-19, Epilepsy, and Telehealth Visits](#) (Epilepsy Foundation, 2021)
  2. [Epilepsy Telemedicine Checklist- ENGLISH](#) (Epilepsy Foundation, 2020)
  3. [Epilepsy Telemedicine Checklist- SPANISH](#) (Epilepsy Foundation, 2020)
- **Genetic Conditions**
  1. [COVID-19 Resources](#) (Global Genes, 2021)
  2. [National Organization for Rare Disease: Telehealth Principles](#) (NORD, 2021)
  3. [Telehealth 101: Webinar](#) (Immune Deficiency Foundation, 2021)
  4. [Telehealth Access Expanded in Response to Coronavirus](#) (Immune Deficiency Foundation, 2021)
  5. [Telehealth Offers Families Medical Care Options](#) (Immune Deficiency Foundation, 2021)
- **Mental Health**
  1. [How Telehealth Can Enhance Mental Health Care](#) (HealthyChildren.Org, 2021)
  2. [Mental Health Amid the COVID-19 Pandemic](#) (Active Minds, 2021)
  3. [Mental Health During COVID-19: Signs Your Child May Need More Support](#) (HealthyChildren.Org, 2021)

- **Spina Bifida**
  1. [Cincinnati Children's Hospital Covid-19 Guidelines for Spina Bifida Patients](#) (Cincinnati Children's Hospital, 2021)
- **Vision Impairment**
  1. [Telehealth Visits for Children Who Need Hearing or Vision Help](#) (HealthyChildren.Org, 2021)

## **Legal Resources**

[Indiana Legal Services](#) may address COVID-19 related telehealth issues.

## **Indiana Family to Family Contact Information**

- To view this Telehealth Resource Guide in digital format, please visit our website at: <http://inf2f.org>
- For additional resources and up-to-date information, please follow our blog at: <http://inf2f.blogspot.com/>
- For more creative ideas, including: social stories, child resources, and self-care ideas, please follow our Pinterest at: <https://www.pinterest.com/INFamily2Family>
- Indiana Family to Family can be contacted-
  - By phone at: 844-323-4636
  - By email at: info@inf2f.org
- Additional Indiana Family to Family social media is available at:
  1. Facebook: [Indiana Family to Family](#) and [Familia a Familia Indiana](#)
  2. [Twitter](#)
  3. [Instagram](#)