Center for Connected Health Policy

TELEHEALTH & MEDICAID: A POLICY WEBINAR SERIES

Telehealth & Patients With Disabilities
October 1, 2021

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is a non-profit, non-partisan organization that seeks to advance state and national telehealth policy to promote improvements in health systems and greater health equity.
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- Closed captioning is available.
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ABOUT CCHP

- Established in 2009 as a program under the Public Health Institute
- Became federally designated national telehealth policy resource center in 2012 through a grant from HRSA
- Work with a variety of funders and partners on the state and federal levels
- Administrator National Consortium of Telehealth Resource Centers
- Convener for California Telehealth Policy Coalition
Telehealth & Medicaid: A Policy Webinar Series

October 8, 2021: Permanent Policies

This webinar series was made possible by grant number GA5RH37470 from the Office for the Advancement of Telehealth, Health Resources and Services Administration, U.S. Department of Health & Human Services.
Today's Webinar

Ivanora Alexander
Executive Director
Office for the Children with Special Health Care Needs
Kentucky Cabinet for Health and Family Services

Jan Withers
Director, Division for Services for the Deaf and Hard of Hearing
North Carolina Department of Health and Human Services
KEY POLICIES

• Important Federal Laws
  – American Disability Act (ADA) – Must ensure *effective communication*
  – Section 504 of the Rehabilitation Act
  – Section 1557 of the Affordable Care Act

• Some states may have more stringent/other requirements

• Simply providing a specific mode of communication may not be effective for your patient
ACCESSING TELEHEALTH

Center for Connected Health Policy
Telehealth & Medicaid Policy Webinar Series
October 1, 2021

Ivanora Alexander, Executive Director
Office for Children with Special Health Care Needs
Louisville, KY
Today’s Agenda

• Overview of the Office for Children with Special Health Care Needs (OCSHCN)
• OCSHCN’s Telehealth Program
• Barriers and Solutions to Telehealth Visits
Office for Children with Special Health Care Needs

• Established in 1924

• Title V Maternal and Child Health Program with specific focus on children with special health care needs
OCSHCN Overview

Mission

To enhance the quality of life for Kentucky’s children with special health care needs through quality service, leadership, advocacy, education, and collaboration.
OCSHCN Overview

Vision

To be a visible leader in supporting the highest quality of life for Kentucky’s children with special health care needs and their families through collaboration and creation of a more accessible community based system of support.
OCSHCN Overview

12 Offices in 11 Districts + 6 Satellite Locations
Who are children with special health care needs?

“Children and youth, birth to age 21, who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

*Definition used by the Maternal and Child Health Bureau*
Office for Children with Special Health Care Needs

SERVICES

• Early Hearing Detection and Intervention (Statewide)
• Early Intervention Service Coordination
• Specialty Medical Clinics (18 locations across Kentucky)
• Care Coordination Services (Statewide/community based)
• Audiology and Hearing Aid Services (Statewide)
• Occupational, Physical, and Speech Therapy
• Medically Complex Foster Care Support (Statewide)
• Family to Family Health Information Centers
• Various Partnerships and Collaborations
Office for Children with Special Health Care Needs

SERVICES

Specialty Medical Clinics and Care Coordination

- Autism
- Cardiology
- Cerebral Palsy
- Craniofacial Anomalies

- Neurology
- Ophthalmology
- Orthopedics
- Otology
Telehealth Program History

• Initiated in 2013 for neurology clinics -- later expanded to autism clinics

• Increase access to pediatric specialists for patients in rural counties across Kentucky

• Families visit an OCSHCN office in their community and along with an RN Care Coordinator meet virtually with urban-based pediatric specialists
2020 Modification to Telehealth

• Expanded to patients in suburban/urban areas
• Expanded video-based services
  • Medical Complex Foster Care Program virtual home visits
• Additional clinics
• Early Intervention Service Coordination
• Speech, Occupational, and Physical Therapy
2020 Modification to Telehealth

Telehealth Visits In a 1-Year Period

- MAR 2019-FEB 2020: 836 visits
- MAR 2020-FEB 2021: 3571 visits
2020 Modification to Telehealth

OCSHCN’s traditional telehealth model was transformed. Traditionally, the patient and care coordinator were at an OCSHCN facility and they met virtually with a physician at another facility. The new model combined three locations — that of the physician, the care coordinator, and the patient from their home.
IDENTIFIED BARRIERS

1. Limited understanding of video-based visits
2. Inequity in technology — both in devices and accessibility of internet services
3. Not all specialties are represented in telehealth
ADDRESSING THE BARRIERS

Limited understanding of video-based visits . . .
Increase Understanding of Telehealth: Family Voices Series

- Family Voices CARES-Act Telehealth for Family Engagement Grant
- OCSHCN’s Family to Family Health Information Center provided telehealth education and support to families through video-based instruction
Increase Understanding of Telehealth: Pre-Visit Mailing & Call

• What is telehealth?
• How do these meetings work?
  • Prior to the meeting
  • Day of the meeting
• How do I prepare for the meeting?
• What if I need to cancel my meeting?
• Can I participate in other meetings?
ADDRESSING THE BARRIERS

Inequity in technology — both in devices and accessibility of internet services . . .
Tools for Families: Tablet and Network Access

OCSHCN LENDING LIBRARY
(Funded by AMCHP CARES Act)
• Tablets
• Protective Case and Stand
• Internet Connection
ADDRESSING THE BARRIERS

Not all specialties are represented in telehealth . . .
<table>
<thead>
<tr>
<th>ONSITE &amp; VIDEO-BASED</th>
<th>ONSITE &amp; DEVELOPING VIDEO-BASED PROGRAM</th>
<th>ONSITE ONLY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>Audiology</td>
<td>Ophthalmology</td>
</tr>
<tr>
<td>Neurology</td>
<td>Remote programming</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>Cardiology</td>
<td></td>
</tr>
<tr>
<td>Craniofacial Anomalies</td>
<td>Preference is onsite</td>
<td></td>
</tr>
<tr>
<td>Orthopedics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Otology</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ADDITIONAL BARRIERS?
Continuously monitored patient/family satisfaction via surveys . . .
<table>
<thead>
<tr>
<th></th>
<th>Count</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>204</td>
<td>60%</td>
</tr>
<tr>
<td>Good</td>
<td>119</td>
<td>35%</td>
</tr>
<tr>
<td>Fair</td>
<td>12</td>
<td>4%</td>
</tr>
<tr>
<td>Poor</td>
<td>2</td>
<td>1%</td>
</tr>
<tr>
<td>Very Poor</td>
<td>3</td>
<td>1%</td>
</tr>
<tr>
<td>Response</td>
<td>Count</td>
<td>Percent</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------</td>
<td>---------</td>
</tr>
<tr>
<td>Definitely</td>
<td>228</td>
<td>67%</td>
</tr>
<tr>
<td>Probably</td>
<td>71</td>
<td>21%</td>
</tr>
<tr>
<td>Possibly</td>
<td>32</td>
<td>9%</td>
</tr>
<tr>
<td>Probably Not</td>
<td>9</td>
<td>3%</td>
</tr>
<tr>
<td>Definitely Not</td>
<td>1</td>
<td>0%</td>
</tr>
</tbody>
</table>
What about the telehealth visits has generally gone well?

<table>
<thead>
<tr>
<th>Reduced risk of exposure to contagious illnesses compared to an in-person visit.</th>
<th>Reduced stress compared to having to travel for an in-person visit (e.g. finding day care, transportation, travel time and energy, parking.)</th>
<th>Our provider(s) have included other professionals in the visit (e.g., nutritionist, care coordinator, behavioral specialist, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received clear instructions before the visit(s), including what to do and/or who to contact with issues.</td>
<td></td>
<td>Reduced time missed from school and work compared to an in-person visit.</td>
</tr>
</tbody>
</table>
**SURVEY RESULTS**

What about the telehealth visits has generally NOT gone well?

<table>
<thead>
<tr>
<th>#1</th>
<th>#2</th>
<th>#3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>My child and I weren't able to interact as well with the provider compared to an in-person visit.</strong></td>
<td><strong>We have experienced technical issues trying to connect, and/or lost the connection during a telehealth visit.</strong></td>
<td><strong>We have had trouble hearing and/or seeing the provider(s) during the visits.</strong></td>
</tr>
</tbody>
</table>
TOP SURVEY RESULTS

What about the telehealth visits has generally gone well? (Provider)

• High provider satisfaction due to care coordination and video conferencing setup/coaching prior to provider/patient interaction.
• Less time on technical issues; more time with patient as compared with non-OCSHCN telehealth visits
• Seeing the patient in their home environment enhanced care/recommendations
SUMMARY

• Expanded telehealth options in 2020
• CARES Act grant allowed increased accessibility to technology, education on use of technology and internet services
• Continuously monitor patient/family satisfaction via surveys
• Moving toward new telehealth services
• Technology has limitations -- monitor how many telehealth visits in succession
Thank you for your attention.
Communication Equity and Telehealth

Center for Connected Health Policy Medicaid Telehealth Webinar Series

Jan Withers, Director
October 1, 2021
Objectives

• Gain awareness of and recognize the importance of communication equity in health care

• Understand how to ensure policy, procedure and guidelines translate to effective practices resulting in communication equity

• Be able to access key resources designed to foster communication equity in telehealth as well as in other health care encounters

• Be able to contact and engage Subject Matter Experts to build capacity to ensure communication equity in telehealth and health care
Why It Matters

• **North Carolina In 2019**
  - State’s total population 10.49 Million
  - Black 2.25 Million
  - Hispanic/Latino: 1.02 Million
  - Deaf, Hard of Hearing, DeafBlind 1.20 Million
    - 33% growth rate until 2030 = 1.60 Million
    - 21% growth rate for general population

• **Age Groups with hearing loss**
  - 18-64 16.2% Population
  - 65-74 30% Population
  - 75+ 50% Population

• **Special populations**
  - Military Veterans
Why It Matters

Special populations and considerations

• **Military Veterans**
  - Hearing loss is the leading combat-related disability, with 60% of returning veterans experiencing hearing loss and/or tinnitus.

• **Older Adults**
  - Hearing loss is the third most chronic treatable health condition among older adults, after arthritis and hypertension.
  - Comorbidity: Diabetes, dementia, falls
Why It Matters

• A hidden disability that is often overlooked or misunderstood

• The Goal: Effective Communication
  – It’s a Simple Goal!
  – Achieving it is Complicated!

Deaf
• Most born deaf or became deaf prior to spoken language development.
• Primarily uses ASL

Hard of Hearing
• Most lose their hearing later in life and do not know ASL
• Some born hard of hearing or gradually lose hearing over time.

DeafBlind
• Various degrees of hearing and visual loss
• Communication methods will vary significantly depending on the onset, level, and type of hearing and vision loss
It’s Not One-Size Fits All

- Deaf, Hard of Hearing & DeafBlind patients have a wide variety of communication needs.
- For many Deaf patients, American Sign Language (ASL) is their primary language while English is their second language.
  - The grammatical structure is different from the one for English
- Most **Hard of Hearing** patients would benefit from CART (Communication Access Real-time Translation) captioning, while many **Deaf** patients may not.
- Most Hard of Hearing patients are likely not to have hearing aids but could benefit from various other tools for communication. Unfortunately, many are not familiar with or able to afford the tool(s) that work best for them.
- **DeafBlind** patients have an added layer of complexity depending on the degree and type of vision loss and hearing loss
Delays in Addressing Hearing Loss

7-year delay for the average adult
- Unaware of link between adult-onset hearing loss and overall health
- Hearing loss denial
- High cost of hearing aids
- Lack of access to information

Longer delays for veterans
- Stigma magnified by military culture

Slow boil effect
- It’s invisible and painless, therefore—
- I’ll deal with it later, but later never comes
- Poor self-advocacy skills

Over 90% of people with adult-onset hearing loss could benefit from hearing aids, but only 16% actually use them.

Source: Quick Statistics About Hearing, March 2021
Two Major Barriers

1. Many Deaf, Hard of Hearing, and DeafBlind patients lack the knowledge and resources to effectively advocate for themselves, especially for accessible communication, in all areas of their lives.

2. Health care providers lack the knowledge and resources to ensure Deaf, Hard of Hearing and DeafBlind people have the same access to their services and resources as the general population.
The Deaf, Hard of Hearing, and DeafBlind Experience

Common assumptions related to scheduling and attending an appointment:

- The scheduler or provider has no experience working with people with hearing loss; therefore, accessibility has not been considered.

- “The scheduler assumes that it is my responsibility to provide my own accommodations.”

- “I will have to wait to show up at my appointment to see if accommodations will be provided.”

- “I will have to explain and cite federal accessibility laws to convince the scheduler/provider that they are obligated to provide accommodations and then guide them in the process of obtaining accommodations.”
The Deaf, Hard of Hearing, and DeafBlind Experience

- Hypervigilance
- Advocacy Exhaustion
- Distrust of System
Disconnect Between Patient and Provider

• North Carolina Institute of Medicine
  – **2020 Task Force Report**: Assuring Accessible Communication for Deaf, Hard of Hearing, and DeafBlind Individuals in Health Settings

• Journal of Health Communication
  – **February 2021 Article** on Disparities Affecting ASL Patients in North Carolina
Access to Preferred Communication Accommodations During Telehealth Visits (Deaf)

- 78% prefer Interpreter on Screen With Provider
- 26% prefer Captions: Automated Speech Recognition or Communication Access Real-Time Translation
- 28% prefer Accommodation That Was Provided
- 5% prefer Accommodation That Was Provided
### Reasons for Poor Telehealth Experience

<table>
<thead>
<tr>
<th></th>
<th>Deaf</th>
<th>DeafBlind</th>
<th>Hard of Hearing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor Video Quality</td>
<td>25%</td>
<td>33%</td>
<td>20%</td>
</tr>
<tr>
<td>Communication Issues</td>
<td>17%</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Internet Issues</td>
<td>15%</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Poor Audio Quality</td>
<td>15%</td>
<td>22%</td>
<td>15%</td>
</tr>
<tr>
<td>Provider Wore Mask</td>
<td>28%</td>
<td>27%</td>
<td>20%</td>
</tr>
<tr>
<td>Provider No Strategies</td>
<td>17%</td>
<td>12%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Legend:
- Poor Video Quality
- Communication Accommodation Issues
- Internet Issues or Poor Connectivity
- Poor Audio Quality
- Provider Wore a Mask
- Provider Did Not Practice Good Communication Strategies
Technology Barriers to Accessing Telehealth Appointments

<table>
<thead>
<tr>
<th></th>
<th>DEAF</th>
<th>DEAFBLIND</th>
<th>HARD OF HEARING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Not Comfortable Using Technology</td>
<td>11%</td>
<td>22%</td>
<td>15%</td>
</tr>
<tr>
<td>Lack of Equipment</td>
<td>11%</td>
<td>22%</td>
<td>16%</td>
</tr>
<tr>
<td>Lack of Reliable Internet or Connection</td>
<td>29%</td>
<td>11%</td>
<td>6%</td>
</tr>
<tr>
<td>No Instructions for Patient Portal</td>
<td>38%</td>
<td>22%</td>
<td>11%</td>
</tr>
<tr>
<td>Can't See or Hear Information On/From Device</td>
<td>0%</td>
<td>0%</td>
<td>11%</td>
</tr>
</tbody>
</table>
Percentage of Respondents Using Patient Portal to Request ASL Interpreters, CART or Other Accommodations
The Communication Equity Experience

We Feel Fully Included and Engaged = We Experience Better Health Outcomes
Health Programs Offered through Technology Must Be Accessible

• Electronic information technology (EIT) is often designed without regard to people with disabilities
  – “Failure to ensure that the services provided through (EIT) are accessible”...may constitute discrimination under Federal civil rights laws.

• Accessibility Laws
  – Title II of the Americans with Disabilities Act of 1990
  – Section 504 of the Rehabilitation Act of 1973
  – Section 1557 of the Affordable Care Act of 2010
    • “Collectively, these Federal laws prohibit covered entities from giving individuals with disabilities an unequal opportunity or providing an aid, service or benefit that is not as effective as those provided to others.”
Health Services Offered through Technology Must Be Accessible

• For more information on the health care provider’s legal obligations:
  − HHS Office for Civil Rights Release 2016
  − Information and Technical Assistance on the American with Disabilities Act
  − This website also provides a way for patients to file complaints

• For general telehealth questions
  − CMS Point of Contact at CMS Regional Offices

• For situations involving telehealth equity technical assistance
  − CMS Office of Minority Health (OMH)
Additional Telehealth Resources

For Providers
- Telehealth and Disability: Recommendations for Providers (Fact Sheet)

Telemedicine in Medicaid
- Medicaid and CHIP COVID-19 Summaries
- State Medicaid & CHIP Telehealth Toolkit (Policy Considerations for States Expanding Use of Telehealth)
- States Expand Medicaid Reimbursement of School Based Telehealth Services Report
- Technology Innovation in Medicaid: What to Expect in the Next Decade
- CMS List of Services Payable Under The Medicare Physician Fee Schedule when Furnished Via Telehealth

General Telehealth
- Building Accessible Telehealth for Patients with Disabilities from the Ground Up
- COVID-19: Guidelines for Healthcare Providers – Video-Based Telehealth Accessibility for Deaf and Hard of Hearing Patients
Health Policy Level Considerations

- Contracts, policies, procedures, guidelines: Avoid boilerplate language and be sure to list different communication accommodation options
- Training at all levels
- Ensure that all Health Plans, Medicaid and other health providers
  - Understand and use best practices
  - Create communication accessible environments and materials
  - Mail/email correspondence that is accessible and easily understood
- Provide accessible avenue for appeals/complaints
- Build into budget funding for communication access
- Designate representative at the table whose primary goal is communication equity
Health Provider Level Considerations

- Patients understand types of communication access services available
- Accessible mail/email/website correspondance
  - Large Print, Braille, ASL Assistance
- Accessible applications, appeals & explanations
- Staff appropriately trained to handle telephone calls
  - Relay Service: Videophone, Captioned phone, TTY
  - Hard of Hearing callers
- Alternative communication methods established
  - Chat, text, email
Building the Capacity of Health Policy Makers and Providers to Foster Communication Equity

Administrative Office

Field Offices

Direct Services

Services to agencies, organizations, businesses

National Association of State Agencies of the Deaf and Hard of Hearing (NASADHH)

We are NOT stand-alone agencies that duplicate the services of other agencies and organizations

Technical assistance such as training and consultation on policy, cases, and best practices for staff, including decision-makers and front-line workers
Take-Aways: What You Can Do

Decide communication equity is health equity and therefore critical

• Have a place for Deaf/Hard of Hearing/DeafBlind Subject Matter Expert at the table
  
  – Contact your sister agency through NASADHH. If you are in a state that does not have a NASADHH member agency, contact the nearest one for assistance in locating a non-profit agency or an appropriate contact in your state

• Connect boots on the ground to field staff serving Deaf, Hard of Hearing, DeafBlind people

• Incorporate communication access in policy, procedure & practices
Regarding Other Disabilities

Decide that a fully-accessible experience means health equity

• Have a place for a person with a disability as Subject Matter Expert at the table
  - As a State agency, there is a very high likelihood you have sister agencies or programs that target specific disability groups. Contact them and develop a network of partners.
  - Recognize that different disability groups have different experiences, needs and solutions.

• Connect boots on the ground to field staff serving people with disabilities

• Incorporate accessibility in policy, procedure & practices
Questions?
Contact Us

Jan Withers, Director
North Carolina Division of Services for the Deaf and Hard of Hearing

[link]www.ncdhhs.gov/dsdhh
or call us at (800) 851–6099

Like us on Facebook
Panel Q&A

Please submit questions using the Q&A function.
THANK YOU!

Ivanora Alexander
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Join us October 8, 2021 for *Permanent Policies*

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Chief Medical Officer  
Arizona Health Care Cost Containment System

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