

#### *Telehealth & Patients With Disabilities* October 1, 2021



#### **CENTER FOR CONNECTED HEALTH POLICY (CCHP)**

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.

# **Disclaimers & Friendly Reminders**



- Any information provided in today's webinar is not to be regarded as legal advice. Today's talk is purely for informational and educational purposes.
- Always consult with your organization's legal counsel.
- CCHP has no relevant financial interest, arrangement, or affiliation with any organizations related to commercial products or services discussed in this program.
- Today's webinar will be recorded and slides presented here will be made publicly available as resources at cchpca.org.
- Closed captioning is available.
- Please refrain from political statements or advertising commercial products or services during this webinar.



# **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







## NATIONAL CONSORTIUM OF TRCS

#### TelehealthResourceCenter.org







© Center for Connected Health Policy/Public Health Institute

# **Telehealth & Medicaid: A Policy Webinar Series**



October 8, 2021: Permanent Policies

Image source: American Psychological Association

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.



© Center for Connected Health Policy/Public Health Institute

#### loday'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





© Center for Connected Health Policy/Public Health Institute

# **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





CABINET FOR HEALTH AND FAMILY SERVICES

— Office for —

Children with Special Health Care Needs

#### **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





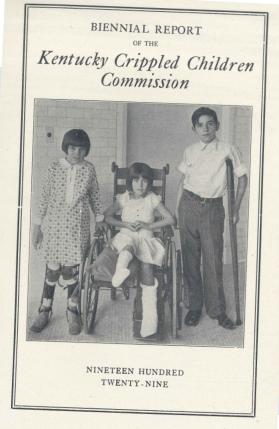
# Today's Agenda

- 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**

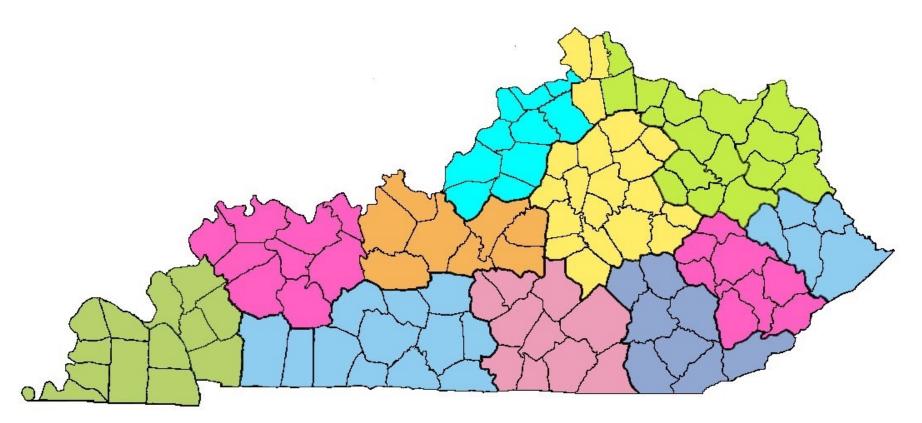
## Vision

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



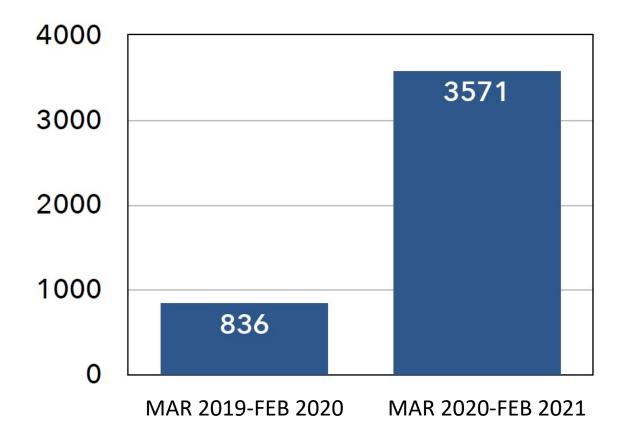
## **2020 Modification to Telehealth**

- 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



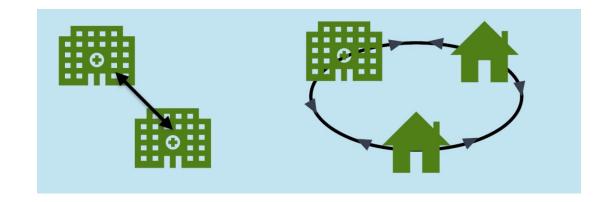
### **2020 Modification to Telehealth**

**Telehealth Visits In a 1-Year Period** 





### **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 videobased 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 . . .



# ONSITE & VIDEO-BASED

- Autism
- Neurology
- Cerebral Palsy
- Craniofacial Anomalies
- Orthopedics
- Otology

ONSITE & DEVELOPING VIDEO-BASED PROGRAM

- Audiology Remote
  - programming
- Cardiology Preference is onsite

#### **ONSITE ONLY**

#### Ophthalmology



# ADDITIONAL BARRIERS? Continuously monitored patient/family satisfaction via surveys . . .



How do you rate OCSHCN's telehealth doctors visit compared to a typical in office doctors visit?	Count	Percent
Excellent	204	60%
Good	119	35%
Fair	12	4%
Poor	2	1%
Very Poor	3	1%



Based on your experience with OCSHCN's telehealth services, would you like to be able to access other types of telehealth?	Count	Percent
Definitely	228	67%
Probably	71	21%
Possibly	32	9%
Probably Not	9	3%
Definitely Not	1	0%



#### **TOP SURVEY RESULTS**

# What about the telehealth visits has generally gone well?

Reduced risk of exposure to contagious illnesses compared to an inperson visit.

Reduced stress compared to having to travel for an in-person visit (e.g. finding day care, transportation, travel time and energy, parking.

Our provider(s) have included other professionals in the visit (e.g., nutritionist, care coordinator, behavioral specialist, etc.)

Received clear instructions before the visit(s), including what to do and/or who to contact with issues.

Reduced time missed from school and work compared to an in-person visit.



#### SURVEY RESULTS

**#1** 

# What about the telehealth visits has generally NOT gone well?

**#**2

11 <b>±</b>	π∠
My child and I	We have exp
weren't able to	technical
interact as well with	trying to c
the provider	and/or lo
compared to an	connection
in-person visit.	telehealt

have experienced echnical issues ying to connect, and/or lost the nnection during a celehealth visit.

We have had trouble hearing and/or seeing the provider(s) during the visits.

#3



#### **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.



CABINET FOR HEALTH AND FAMILY SERVICES

> Office for Children with Special Health Care Needs

Ivanora Alexander 310 Whittington Parkway, Suite 200 Louisville, KY 40222 (502) 429-4430 x2065 Ivy.Alexander@ky.gov chfs.ky.gov/agencies/ccshcn



Office for Children with Special October 2021





NC Department of Health and Human Services Division of Services for the Deaf and Hard of Hearing

# **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**

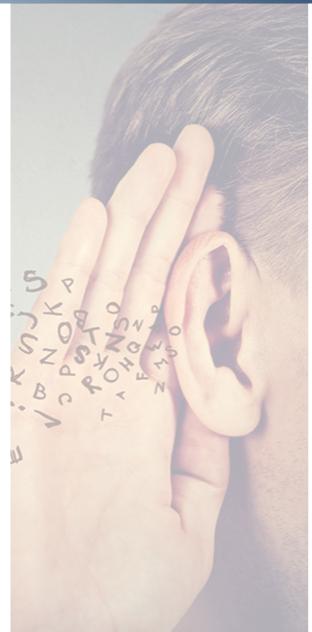
- North Carolina In 2019
  - State's total population 10.49 Million
  - Black 2.25 Million
  - Hispanic/Latino: 1.02 Million
  - Deaf, Hard of Hearing, DeafBlind 1.20 Million
    - 33% growth rate until 2030 = 1.60 Million
    - 21% growth rate for general population
- Age Groups with hearing loss
  - 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 <u>Simple Goal!</u>
  - Achieving it is <u>Complicated!</u>

#### 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

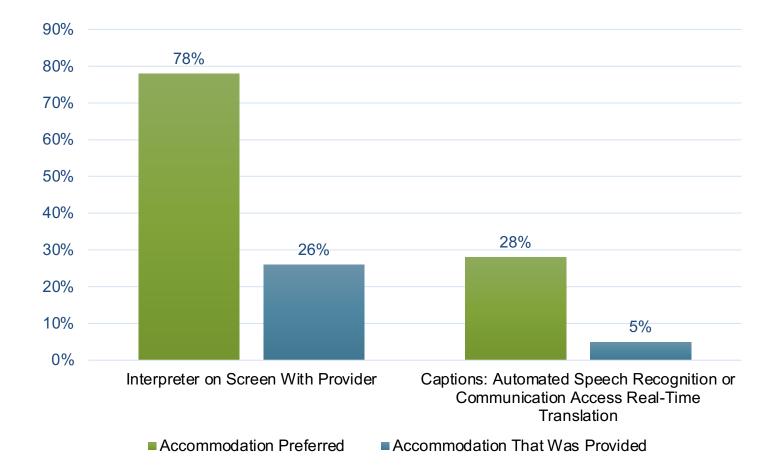
- Advocacy Exhaustion
- Distrust of System

#### Disconnect Between Patient and Provider

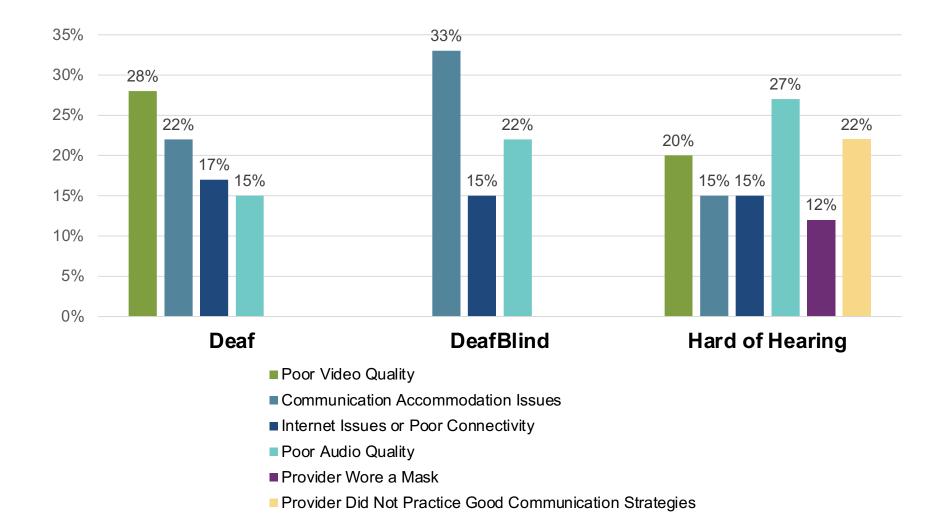
- North Carolina Institute of Medicine
  - <u>2020 Task Force Report</u>: Assuring Accessible Communication for Deaf, Hard of Hearing, and DeafBlind Individuals in Health Settings
- Journal of Health Communication
  - February 2021 Article on Disparities Affecting ASL Patients in North Carolina



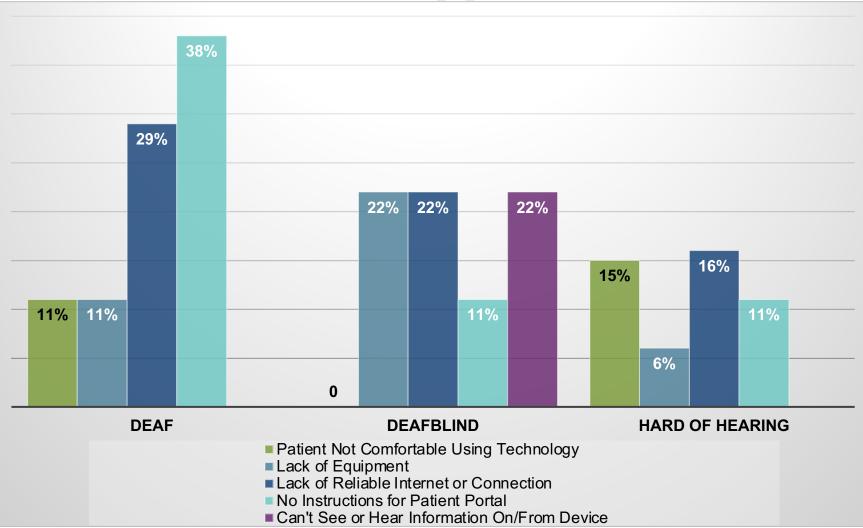
### Access to Preferred Communication Accommodations During Telehealth Visits (Deaf)



#### **Reasons for Poor Telehealth Experience**

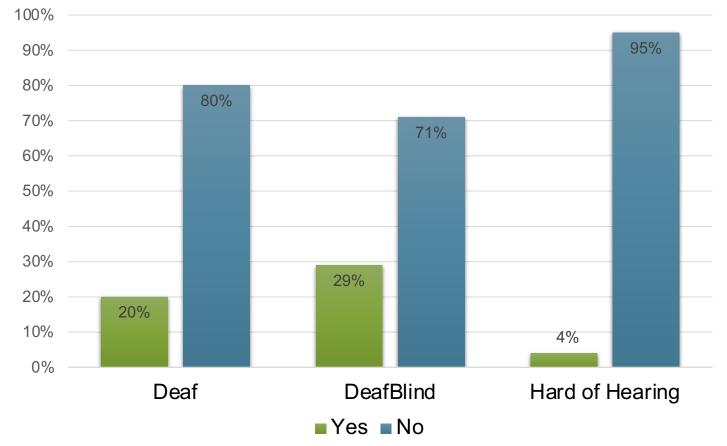


#### **Technology Barriers to Accessing Telehealth Appointments**

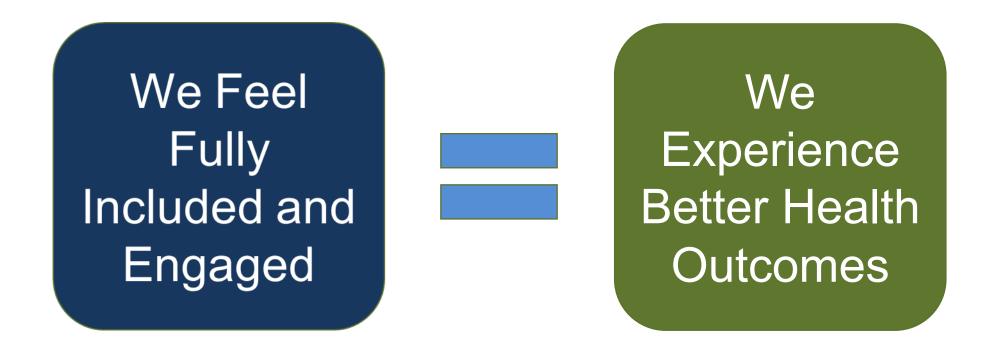


#### **NCDHHS, Division of Services for the Deaf and Hard of Hearing**

#### Percentage of Respondents Using Patient Portal to Request ASL Interpreters, CART or Other Accommodations



#### The Communication Equity Experience



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

#### **General Telehealth**

- Building Accessible Telehealth for Patients with Disabilities from the Ground Up
- <u>COVID-19: Guidelines for Healthcare Providers Video-Based Telehealth</u> Accessibility for Deaf and Hard of Hearing Patients

**NCDHHS, Division of Services for the Deaf and Hard of Hearing** 

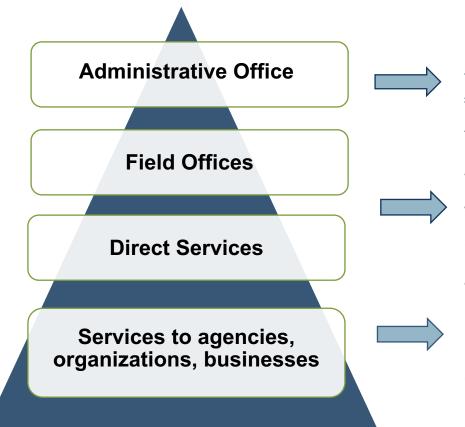
#### **Health Policy Level Considerations**

- 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



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







#### **Contact Us**

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

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

**Facebook** 

# Panel Q&A

Please submit questions using the Q&A function.



### **THANK YOU!**



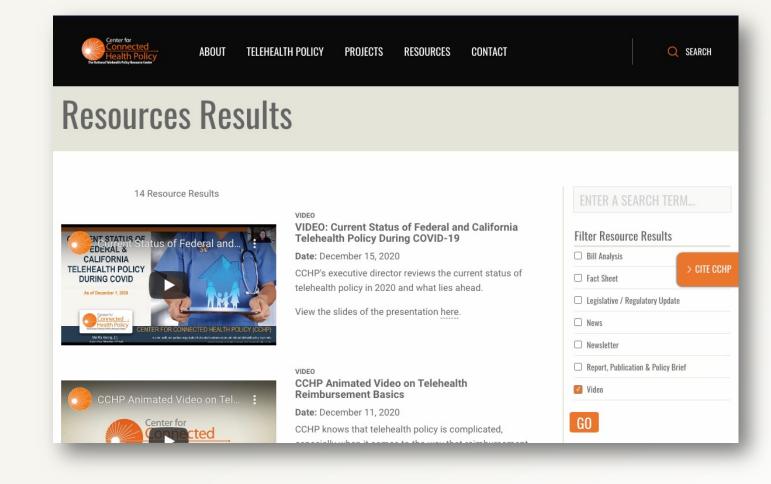
Ivanora Alexander Executive Director Office for the Children with Special Health Care Needs Kentucky Cabinet for Health and Family Services

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





## Webinar Recordings and Resources



Subscribe to CCHP's email listserv or stay tuned to CCHP's resources page for recordings of this webinar and presentation slide decks!



#### Join us Uctober 8, 2021 for *Permanent Policies*



Lori Coyner, MA Senior Medicaid Policy Advisor Oregon Health Authority

> Shannon Dowler, MD Chief Medical Officer North Carolina Department of Health and Human Services





Sara Salek, MD Chief Medical Officer Arizona Health Care Cost Containment System



# **EVALUATION FORM**

# Please don't forget to fill out your evaluation form!

# Thank you and have a great day!

