



## *Family Support Strategies during COVID-19: Creating Change for Lasting Effect*

*Massachusetts Department of Public Health  
Universal Newborn Hearing Screening Program  
Sarah Stone, Director  
Jennifer Fleming, Special Projects Coordinator*



# *Disclosures*

## Sarah Stone and Jennifer Fleming disclosures

- No financial or nonfinancial relationships relevant to the content of the proposals exist.

# *Learning Objectives*

- Participants will be able to describe family support efforts in MA during pandemic
- Participants will be able to identify developed resources that may be helpful for families in other states
- Participants will consider modifications to existing systems to better support families

## *Pre-pandemic: Setting the stage*

MA Universal Newborn Hearing Screening Program (UNHSP) described:

- Staff of 6, includes parents and consumers
- Funded by HRSA, CDC and the state
- 48 birth hospitals, audiologist required for each program
- 40 audiological diagnostic centers, approved by UNHSP
- 60 Early Intervention programs
  - All children who are deaf and hard of hearing (D/HH) are eligible for EI in MA

# Visual D/HH Resource Guide

## FROM THE ROOTS UP

### A Family's Journey Through Services for Children who are Deaf and Hard of Hearing

For links and information, please visit the  
**Universal Newborn Hearing Screening Program**  
[at mass.gov/universal-newborn-hearing-screening-program](http://mass.gov/universal-newborn-hearing-screening-program)  
 or contact us at 800-882-1435 in newborn.hearing@state.ma.us

**RESOURCES FOR YOUR FAMILY'S JOURNEY**

<p><b>Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)</b>        (Call 800-882-1155 and ask for the Children's Specialist in your area.)</p> <p><b>Massachusetts Family TIES Parent-to-Parent Program</b>        (Call 800-905-TIES(8437) to set up a telephone call with another family who has a child who is deaf or hard of hearing.)</p>	<p><b>Early Intervention (EI) Team/IFSP</b>        (Call 800-905-TIES (8437) and ask for the Early Intervention Program in your area.)</p>
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10/2012

### Services for Children who are Deaf and Hard of Hearing

#### Birth to three

**Early Intervention (EI) Team/IFSP**  
 An early intervention team, or EI Program, provides services to children with hearing and vision disabilities (including those who are deaf or hard of hearing). Team members work together to identify an individualized family service plan (IFSP) to address other concerns of the EI team. Your child will receive, in part, to help and other services will be determined.

**Speech Language Pathologist (SLP)**  
 A professional who assesses and provides oral and language instruction. Some have specialized training and certification in working with children who are deaf or hard of hearing.

**Specialty Service Providers**  
 These services include services provided from Specialty Service Centers. These centers are to provide specialized services for children with hearing and vision disabilities. These centers provide services such as hearing and vision services (TOD, SLP, and other EI Program), program, program, hearing, instruction, oral deaf and hard of hearing, and other services. Hearing and vision services are provided from these Specialty Service Centers.

**Teacher of the Deaf (TOD)**  
 A teacher of the deaf is a teacher of children who are deaf or hard of hearing. Individuals become a teacher of a variety of ages.

**Family Sign Language Program**  
 The goal of the Family Sign Language Program is to introduce family members to Sign Language, teaching them to communicate with their child or the child's age group.

**DHH Program Consult & Assessment**  
 Consultants provide assessment and services to develop individual plans and monitor progress over time.

#### Health Services

**Pediatrician**  
 Pediatricians are doctors who manage the health of a child, including physical, behavioral, and mental health issues. They also monitor for diagnosis and treat childhood illnesses, from minor health problems to major illnesses.

**Otolaryngologist / ENT**  
 Otolaryngologists are trained in the medical and surgical management and treatment of patients with disorders and conditions of the ear, nose, throat (ENT) and related structures of the head and neck. Some specialize in specific areas.

**Audiologist**  
 A health care professional trained to diagnose hearing loss, evaluate hearing levels and ability, recommend hearing aids and/or other hearing devices to needed, and fit a person with a hearing aid.

**Hearing Aids / Cochlear Implants (CI)**  
 A hearing aid is a device that amplifies sound. A CI is an implantable electronic device that provides the sense of sound by stimulating the auditory nerve directly. Both devices are used for children over the age of 21. Contact your hearing aids for children under the age of 21.

**Ophthalmologist**  
 An ophthalmologist is a medical professional who has a doctorate in medicine. They are trained in hearing and vision loss. Some focus on certain specialties. A referral to the eye doctor is common. Pediatric ophthalmology is available.

**Health Insurance**  
 Health insurance is a form of insurance coverage that pays for medical and surgical expenses.

**Geneticist**  
 A geneticist is a doctor who can be identified. A geneticist specializes in the diagnosis and management of hereditary disorders.

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#### Pre-school and beyond

**Preschool**  
 An educational institution or learning space offering early childhood education to children between ages 3 to 5. Operational program for DHH children only.

**Elementary School**  
 An elementary (or primary) school is a school in which children receive education in their primary school years (age 5 to about age 10), before leaving their preschool and before secondary school.

**Aide**  
 A person whose job is to assist someone. In children who are deaf or hard of hearing, this is often a hearing aide.

**Teacher of the Deaf (TOD)**  
 A teacher of the deaf is a teacher of children who are deaf or hard of hearing, specializing in one or more of a variety of ages.

**Hearing Assistive Technology (HAT)**  
 Devices that can be used to assist someone. In children who are deaf or hard of hearing, this is often a hearing aid. Also referred to as assistive listening devices, HAT can be used with traditional hearing devices or without hearing aids to assist a hearing-impaired person.

**Individualized Education Program (IEP)/504 Team**  
 School staff and parents work with a team to develop an individualized education program (IEP) to help the student. Individualized Education Program (IEP) is the least restrictive environment, accommodations, services, and supports for students with disabilities. The IEP is developed by members of the school's special education group.

**Educational Audiologist**  
 The Educational audiologist will assess their practice in supporting students who are deaf or hard of hearing as an educational benefit by providing the student's hearing, hearing, and/or other program, identify how can affect their academic, social, communication abilities and educational and learning.

**SEPA (Special Education Parent Advisory Council)**  
 A parent organization that works with the school system. Its primary is to provide, through the use of the school system, information and resources for parents of children with special education needs.

**Speech Language Pathologist (SLP)**  
 A professional who assesses and provides oral and language instruction and is responsible for working with children who are deaf or hard of hearing.

**Federation for Children with Special Needs**  
 The Federation for Children with Special Needs provides information, support, and resources for parents of children with disabilities, their professional partners, and their communities.

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**Universal Newborn Hearing Screening Program (UNHSP)**  
 The UNHSP helps families get the services they need. Services include Family support, outreach and educators, parent-to-parent support, information and referral, medical, educational, information, and resource services.

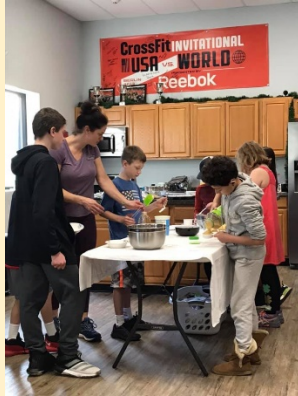
**MA Commission for the Deaf and Hard of Hearing (MCDHH)**  
 MCDHH is a special authority, created under state law, to serve the Deaf, oral deaf, deaf-blind, and hard of hearing individuals of all ages and their families and service providers. MCDHH provides services to parents and families statewide.

# *Pre-Pandemic: Parent Support Groups*

Parent support organizations help connect parents with children who are deaf and hard of hearing. Examples include:

- Hear Together
- Family TIES
- Hear My Dreams
- AG Bell
- Universal Newborn Hearing Screening Program
- Specialty Service Providers
- Hands & Voices
- Facebook/Social media groups

# Pre-Pandemic Parent Support Activities



- Parent Forum
- Social Events
  - Zoos
  - Play spaces
  - Baseball games
  - Museums
  - Cooking classes



# *Family Support during COVID-19*

What changes do we need to make to ensure families are supported?






# Newborn Screening and COVID-19

## NEWBORN SCREENING AND COVID-19


COVID-19 SHOULD NOT STOP SCREENING  
PLEASE CONTINUE TO SCREEN



### BLOODSPOT SCREENING

Collect between 24-48 hours of age  
OR before TPN or RBC transfusion  
OR immediately prior to discharge if before 24 hours.


**Questions:** [NBS@umassmed.edu](mailto:NBS@umassmed.edu) (non urgent)  
Tel: 774-455-4600



### HEARING SCREENING

Complete prior to discharge. Babies who do not pass  
require a follow up hearing test, but it may occur  
outside of the three week time frame.


**Questions:** [Newborn.Hearing@State.MA.US](mailto:Newborn.Hearing@State.MA.US)



### CCHD SCREENING

Complete pulse oximetry at 24-48 hours of age.  
Early screening before 24 hours increases the risk of  
false positive or false negative results. If releasing early,  
make arrangements for screening to be done 24-48  
hours of age.

**Questions:** [Eirini.Nestoridi@State.MA.US](mailto:Eirini.Nestoridi@State.MA.US)



Massachusetts Department of Public Health  
[mass.gov/dph](https://mass.gov/dph)

- Focus on core responsibilities
- Provide clear guidance and support to birth hospitals and diagnostic centers regarding policy and data
- Monitored early discharges and missed screens

# *Family Outreach and COVID-19*

## Family outreach after screening:

- Phone calls/texts/letters sent to families
- Expanded outreach to infants who missed screen
- Letters sent to pediatricians, missed appointments
- Diagnostic appointment availability limited
  - 7 out of 40 centers open during early periods
- Families needs varied as areas of the state were impacted differently
  - Transportation, Health Insurance
- Frequent communication with providers

**More intense follow-up was needed to assist families through the process of screening and diagnosis. Achieved 70% success rate in contacting families whose baby did not pass the hearing screen!**

# *Family Outreach and COVID-19*

## Family outreach after identification:

- Phone calls/texts/letters outreach to families
- EI services disrupted resulting in decreased service utilization
- Assist families with transition to tele-practice for EI services
- Include pediatrician in support of families, sharing resources and encouraging EI enrollment
- Supporting partner programs through social media, promoting programs and resources for families
- Increase Facebook presence

# *Leveraging existing relationships*

Partner with The Decibels Foundation, a non-profit organization designed to support families that have children who are deaf and hard of hearing:

- Brainstorm options for family support/connections and creative solutions to family issues and challenges
- Survey families to assess needs during COVID-19
- Reach out to professional partners for feedback/vetting of resources for families
- Provide and distribute resource list to families and providers  
[https://www.decibelsfoundation.org/what\\_we\\_do/remote-learning-resources.html](https://www.decibelsfoundation.org/what_we_do/remote-learning-resources.html)

# *Boston Children's Hospital Partnership*

- Work with Boston Children's Hospital (BCH) Deaf and Hard of Hearing Program and Middle School Group to create bilingual read aloud program for young children who are deaf and hard of hearing
- Middle schoolers led two read aloud evenings for children



# *Educational Videos for Family Support*

Educational Videos were created with professional partners to assist families. Videos are shared on UNHSP Facebook site:

- Self Care Tips for Parents and Caregivers
- tVISITs and tele-intervention
- Family TIES, family-to-family support
- What to expect during COVID-19 for child's audiology appointment
- Shared Reading Saturdays
- MA Family Sign Language Program
- Willie Ross School for the Deaf Specialty Service Program

[www.facebook.com/MassNewbornHearingScreening](https://www.facebook.com/MassNewbornHearingScreening)

# *Parent to Parent Support Virtual Gatherings*

Disruption to traditional services led to creation of UNHSP parent to parent virtual gatherings. Key components include:

- ZOOM platform used to unite families
- Led by UNHSP staff parents
- Safe, supported space
- Sessions not recorded for privacy
- Focused on accessibility: Interpreted, captioned
- Families with children of all ages participated
- Themed sessions planned with and without invited guests
- Consolidated list of resources shared by email post meeting

# *ZOOM...COVID-19 Impact on Families*

- How do we support each other?
- Challenges currently being faced
- Creative solutions
- Remote service options
- Fatigue considerations
- Masks
- Technology

**You are not alone!!  
We are in this together**





# ZOOM...Self Care



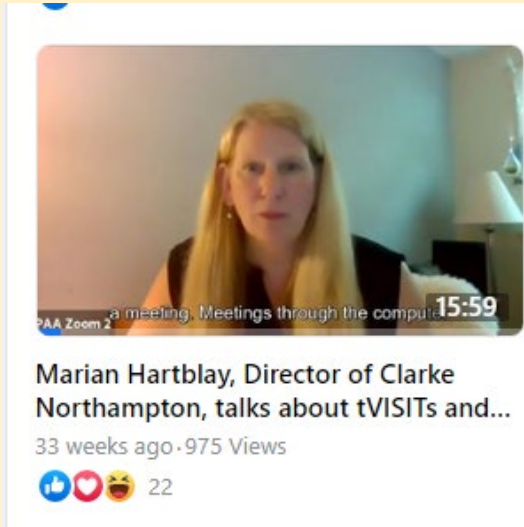
Ashley Cameron shares self care tips for parents and caregivers

39 weeks ago · 1.2K Views



- Ashley, parent, licensed massage therapist shares strategies
- To take care of others, need to take care of self first!
- Favorite self care strategies shared by group

# ZOOM...Remote Services



- Clarke Schools for Hearing and Speech share tele-practice expertise
- Best practices for remote EI services discussed
- Strategies for working with different EI providers
- Family experiences shared
- State education guidelines presented
- Equitable access factors discussed

# ZOOM...MCDHH

- General overview presented
- Four Child Specialists introduced
- Breakout rooms assigned for child/situation specific discussions
- Accessibility success: ASL, captioning, breakouts
- Reconvene as large group
- Connections made for long-term family support



# ZOOM...ASL Resources



- Share American Sign Language (ASL) resources
- Family Sign Language Program shares remote service options
- Shared Reading Saturdays
- National and state resources to learn ASL

Photo credit: CDC

# *ZOOM...Education during COVID-19*

Educational Audiologist from The Learning Center's Public School Partnerships Program joined parents to discuss:

- Video resource developed for educators
- Considerations for deaf and hard of hearing students during COVID
- Remote and distance learning instruction challenges
- Tips to ensure accessible, equitable education
- Teacher of the Deaf vs. Educational Audiologist, Wright's Law
- Acoustics/Technology considerations



[https://www.youtube.com/watch?fbclid=IwAR2j6OJhLRSDs\\_Rrk5cHYScpgpFXfA P0xt8Av-TWErshQqqLi9eXoAKR9s4&v=7aCF5fOSGws&feature=youtu.be](https://www.youtube.com/watch?fbclid=IwAR2j6OJhLRSDs_Rrk5cHYScpgpFXfA P0xt8Av-TWErshQqqLi9eXoAKR9s4&v=7aCF5fOSGws&feature=youtu.be)

# *ZOOM...Family Activities During COVID-19*

- COVID-19 friendly summer plans
- How can we create fun?  
Ideas to find the joy.



# ZOOM...*Gifts and Gadgets*



- Bring your favorite craft/activity/gift idea
- How to celebrate holidays differently during pandemic
- Supporting deaf-owned businesses
- New traditions
- Parent to Parent support: Ideas for 2021

# ZOOM...Family Rights and Disability Laws



The MA Universal Newborn Hearing Screening Program presents a

## Free Online Event

An Afternoon Chat With

# Caitlin Parton

February 4th at 4pm



Caitlin Parton is an attorney and advocate for people who are deaf and hard of hearing. Caitlin will talk about the Americans with Disabilities Act (ADA), as well as the rights covered by the Individuals with Disabilities Education Act (IDEA), setting goals and protecting the rights of our children using tools such as a 504 plan and Individualized Education Program (IEP). Please join us!

*For a link to this FREE online event, please RSVP to: Sarah Stone at [sarah.stone@mass.gov](mailto:sarah.stone@mass.gov) or (617) 624-5912*

*ASL interpretation will be provided. Additional languages may be available upon request.*



If you are Deaf or hard of hearing, or are a person with a disability who requires accommodation, please contact Sarah Stone at (617) 624-5912 or [Sarah.Stone@state.ma.us](mailto:Sarah.Stone@state.ma.us)

- Deaf adult and role model for our families
- Americans with Disabilities Act (ADA)
- Individuals with Disabilities Education Act (IDEA)
- Individualized Education Program (IEP)/504 Plan
- Family Rights



# ZOOM...Author and Art Event



The Massachusetts Universal Newborn Hearing Screening Program presents an event for families who have a child who is deaf or hard of hearing:

## Family Event

On-line with Authors and Illustrators  
Debbie, Grace and Brynne Blackington

Saturday  
February  
20<sup>th</sup>  
10-11AM



**FREE  
EVENT!**  
Registration is required

Please join us on Zoom for this **FREE** fun caregiver/child event! Learn how a book is created and then make your own art. Basic craft supplies like paper and crayons **will be required.**

Space is limited.

To receive the link, please RSVP to:

Sarah Stone

[sarah.stone@mass.gov](mailto:sarah.stone@mass.gov)



If you are deaf or hard of hearing, or are a person with a disability who requires accommodation, please contact:  
Sarah Stone | (617) 624-5912 | [sarah.stone@mass.gov](mailto:sarah.stone@mass.gov)

- Debbie, Grace, and Brynne Blackington
- Bringing a book to life
- Art project designed for children
- Caregivers and children event
- Books mailed to families

# Results

UNHSP listened to parents, worked with partners, and developed new programs to support families.

- New families introduced to UNHSP and resources available
- Increased access to families with younger children
- Increased attendance/participation for educational programs
  - Educational videos/parent to parent support gathering
- State wide presence: Reducing geographical disparities
- Increased accessibility focus: ASL, Captioning, Language Interpretation

## *Conclusion*

**Family Support Activities have changed as a result of the pandemic. UNHSP's commitment to families has not.**

**Support activities such as virtual family to family support, videos for families, and Facebook efforts will continue beyond COVID-19.**

# Contact Us!

Sarah Stone, Director, UNHSP

[Sarah.stone@mass.gov](mailto:Sarah.stone@mass.gov)

Ph. 617-624-5912

Jennifer Fleming, Special Projects Coordinator, UNHSP

[Jennifer.Fleming@mass.gov](mailto:Jennifer.Fleming@mass.gov)

Ph. 876-851-7261x4045

<https://www.mass.gov/universal-newborn-hearing-screening-program>

[www.facebook.com/MassNewbornHearingScreening](http://www.facebook.com/MassNewbornHearingScreening)

Thank You!