



Advisory Committee on Heritable Disorders in Newborns and Children • May 13, 2021





# Agenda

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- AMCHP & Project Overview
- NBS Project Partners
- Lessons Learned & Next Steps
- Q & A

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# AMCHP

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AMCHP leads and supports programs nationally to protect and promote the optimal health of women, children, youth, families, and communities.

AMCHP envisions a nation that values and invests in the health and wellbeing of all women, children, youth, families, and communities so that they may thrive.



# Anti-Racism Commitment

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“We cannot fully achieve our goals unless we acknowledge that racism is a public health crisis and directly impacts the health outcomes of our communities and those we serve.”

- All-In Statement, June 23, 2020



# Project Overview

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- \$4M CARES Act grant from HRSA MCHB; May 1, 2020 – April 30, 2021 (NCE received in March)
- Support telehealth use in MCH public health systems as part of pandemic response

## Title V & CYSHCN

*Children & Youth with  
Special Health Care  
Needs*

## MIECHV

*Maternal, Infant, &  
Early Childhood Home  
Visiting*

## Newborn Screening

- EHDI  
*Early Hearing Detection & Intervention*
- **NBS & CCHD**  
*Newborn Bloodspot Screening; Critical  
Congenital Heart Disease Screening*

# National SME Partners

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## Telehealth

- Center for Connected Health Policy & Telehealth Resource Centers

## Lived Experience

- Parent to Parent USA, AYA

## Public Health Agencies

- ASTHO & NACCHO

## Home Visiting

- Rapid Response & ASTHVI

## EHDI

- NCHAM & Hands & Voices

## NBS & CCHD

- **APHL & Expecting Health at Genetic Alliance**



# Project Structure

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## National SME Partners

- Steering group, including RFP development & proposal scoring
- Provide technical assistance to MCH agencies & constituents
- Develop national resources, tools, guidance, etc. for MCH professionals, agencies, and families

## RFP Awardees

- Up to \$100k per jurisdiction
- One or more focus areas
- Awards began in October & November 2020
- Received TA, and peer support through virtual roundtables

# Telehealth Defined

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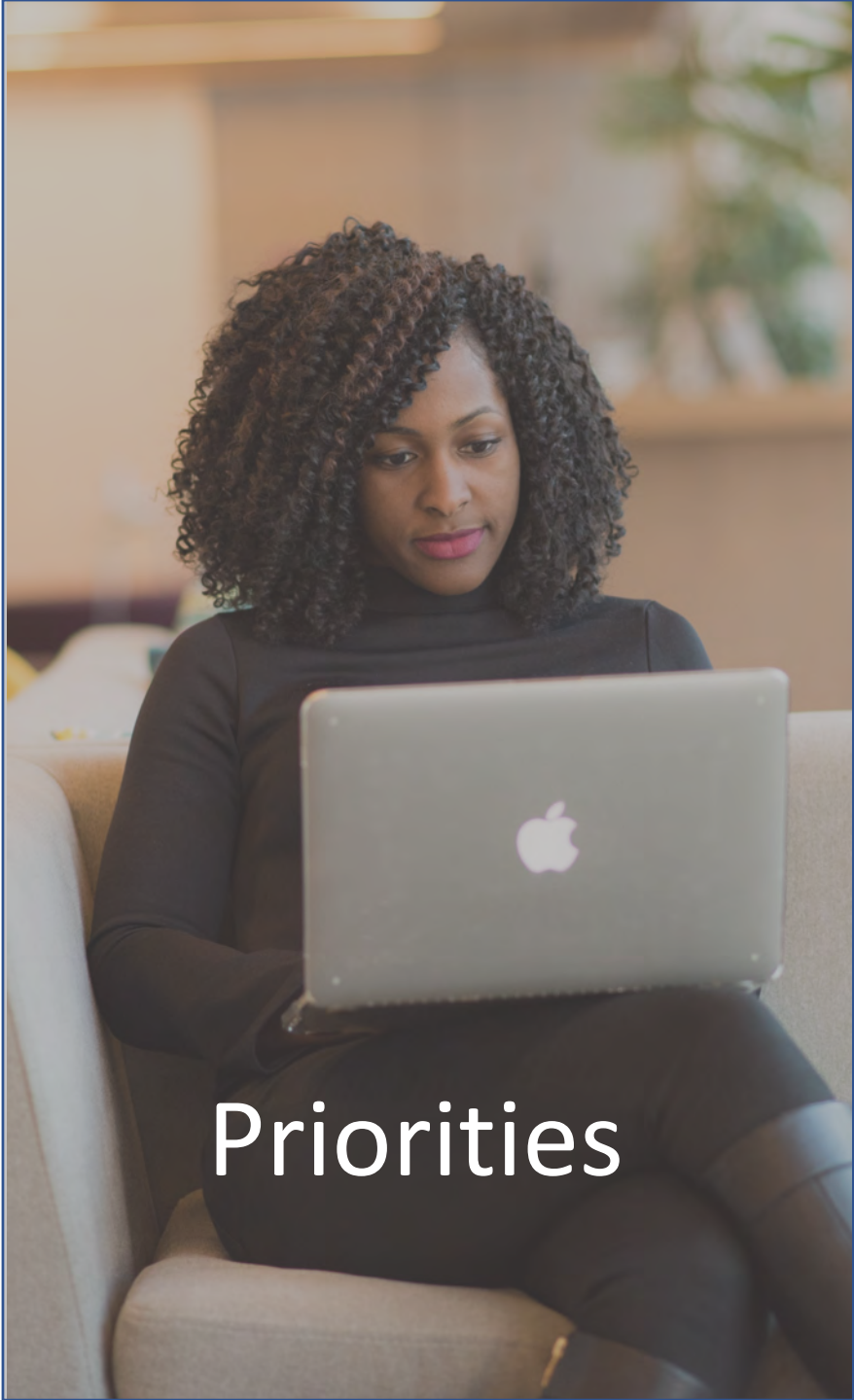
## Telehealth

- is the remote delivery of health care services and clinical information via telecommunications technology.
- can be synchronous, such as a video call with a peer support group, or asynchronous, such as a "store-and-forward" consultation between providers.

## Telehealth is not

- solely technology-based, such as health information technology (HIT).
- services that support telework for agencies, but not telehealth for families.





# Priorities

Improving the family's experience

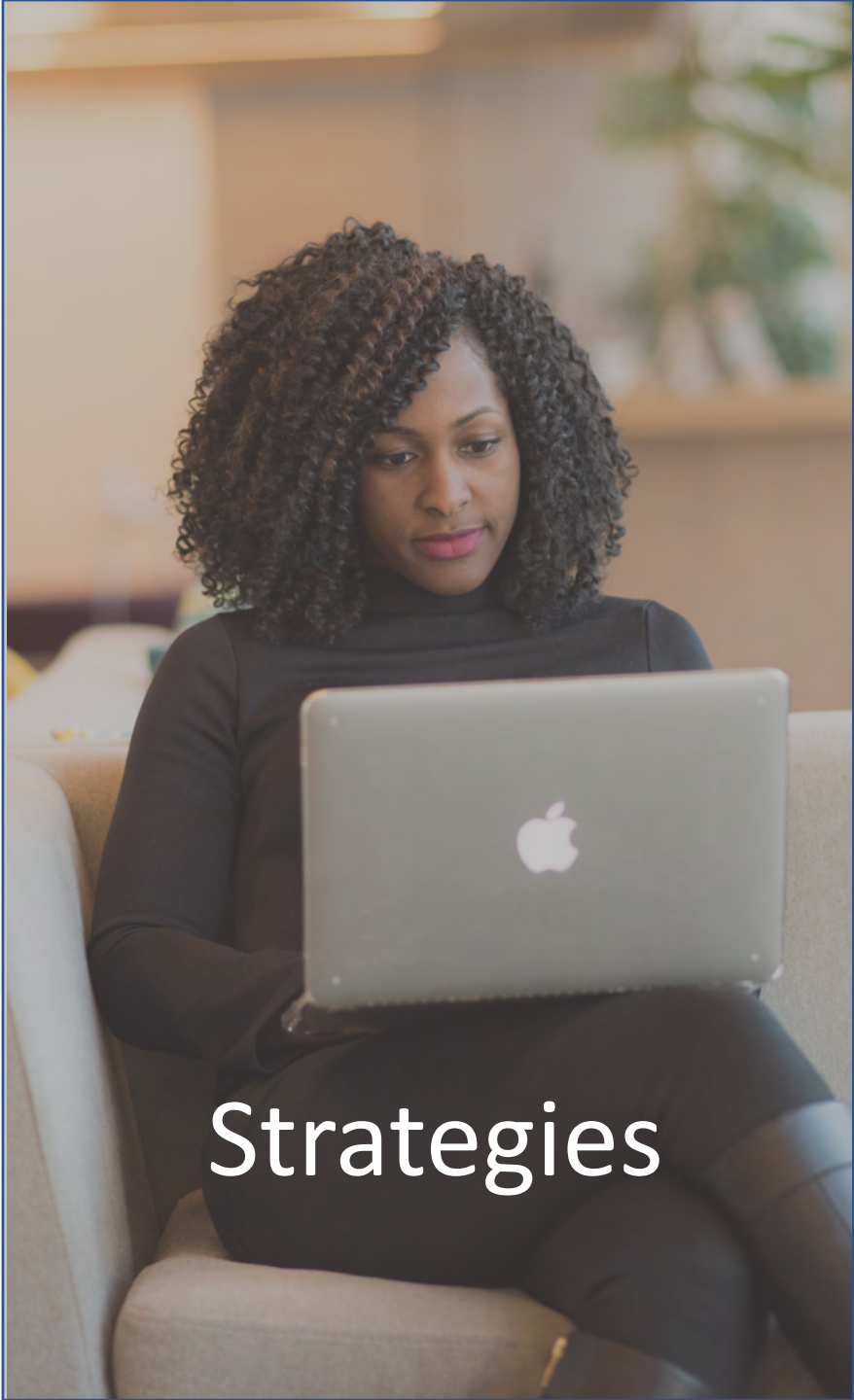
Increasing health equity

Expanding access to services

Collaboration across systems

Full family engagement

Innovation in telehealth use



## Strategies

Engagement with family-led org

Focus on families not well served *prior* to the pandemic

One proposal per jurisdiction

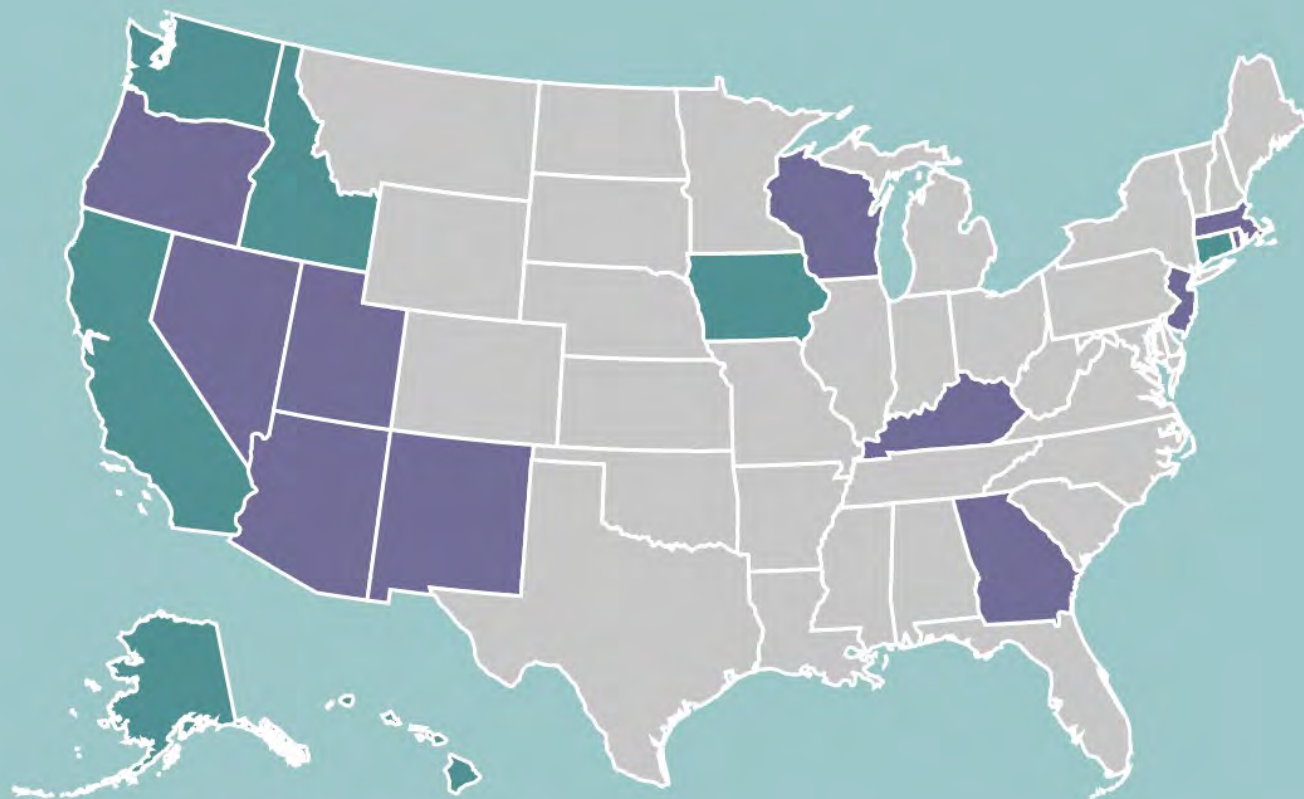
Encouraged local collaborations

Offered TA & 2 cycles during RFP window

Alternative procurement & contracts

# RFP Awardees: 21 Projects

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- 18 states
- 3 territories
- 2 tribal nations
- 1 freely associated state

GU AS MP PW MH FM

TM PSF PR VI

# NBS Projects

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## NBS-Focused

- Connecticut
- Puerto Rico
- Alaska (partial award)

## NBS-Associated

- Iowa
- Hawaii-led project with California, Idaho, and Washington as part of WSRGN



# Presenters

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- Supporting & engaging families virtually

**Natasha Bonhomme, Expecting Health at Genetic Alliance**

- Improving access to subspecialty care through telehealth

**Dr. Sulay Rivera, University of Puerto Rico**

- Expanding services offered to NBS families via telegenetics

**Ginger Nichols, Connecticut Children's Medical Center**

# Challenges & Lessons

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- Timeline & competing priorities
- Sustainability planning
  - Funding
  - Reimbursement parity
- Data service options for families – no ‘great’ choices
- Flexibility and adaptability are essential
- Family & community engagement improves programs
- The ‘impossible’ can be done



# NBS Challenges & Lessons

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- Lab capacity & staff reassignments
- Telework versus telehealth
- Direct services to families are often largely in the private sector
- More decentralized than other MCH program areas
- Telehealth provides opportunities to address known systems issues





# Next Steps

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- Continued funding through MCHB NCE and supplemental award from CDC NCBDDD
- New team name: Clinical & Community Collaboration
- Ongoing technical assistance available to *any* MCH program exploring virtual services
- Supporting data collection & evaluation efforts of funded projects
- Opportunities for peer sharing





# Questions & Contact

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