

# Better Together: Lessons Learned from a Community-Engaged Research Study



March 19, 2024  
EHDI Conference  
Denver, CO



# ASHA and AAA Disclosures

## **Jacob Holzman**

- Salaried faculty at University of Colorado
- Grant-supported researcher (NIH)
- Unpaid ad hoc reviewer for academic journals

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- Salaried project director at University of Kentucky

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- Salaried Director of Programs, Hands & Voices Headquarters
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- Grant reviewer (NIH)
- Member of Editorial Board, *Perspectives of the ASHA Special Interest Groups*
- Unpaid ad hoc reviewer for academic journals

## **Lori Travis**

- Salaried Audiology Services Administrator and audiologist, Kentucky Office for Children with Special Health Care Needs (OCSHCN)
- University of Colorado, University of Arkansas for Medical Services, and University of Kentucky subawards to OCSHCN

# Learning Objectives

1. Describe the gap in previous research that this study addresses.
2. Describe how community and academic partners collaborated to develop this study.
3. List basic aims and principles of the field of implementation science.

To view a copy of these slides and a poster presented at the conference:



# The Project: Behavioral Parent Training for Families with Deaf and Hard of Hearing (DHH) Preschoolers

- Preschool-aged DHH children have at least the same prevalence of challenging behaviors as their hearing peers
- Behavioral Parent Training (BPT) has 40+ years of evidence that it improves child behaviors and parenting behaviors
- BPT is not part of the array of services typically offered to caregivers of DHH children
- DHH children have been excluded from the studies providing the evidence base for BPT



# Adapted Behavioral Parent Training: FCU-DHH

## The Family Check-Up Model

- Positive behavior support
- Limit-setting and consequences
- Relationship building



(Dishion et al., 2008)

## ***PLUS...***

Family Management Training:  
Everyday Parenting Curriculum

Brief & Tailored  
Family Management

Family Management  
Weekly Meetings

Family Management  
Parent Groups

Community  
Resources & Support

- Delivered by another parent of a DHH child
- Session content, role-plays, and homework tailored to situations described by caregivers of DHH children
- 3 additional sets of resources:

Child Development Toolbox  
Communication Toolbox  
Advocacy Toolbox

# Our questions

## Does it work?

- Inclusion and exclusion criteria
- Randomization
- Standardized data collection
- Standardized time line
- Research-y “rules”



Zamurovic Brothers, [thenounproject.com](http://thenounproject.com)

# Our questions

Do caregivers like it?

Do parent coaches like it?

What kind of coach training and supervision are needed?

Will caregivers sign up? Come to sessions?

What parts of the intervention are used most? Least?

What does it cost to deliver?

Is it feasible to deliver outside of a research project?

Could it fit into services already offered? Which ones?

What would be needed for an agency or organization to take this on?

# Being part of the “real world”!



Communities Harnessing and  
eMpowering Parenting Strengths



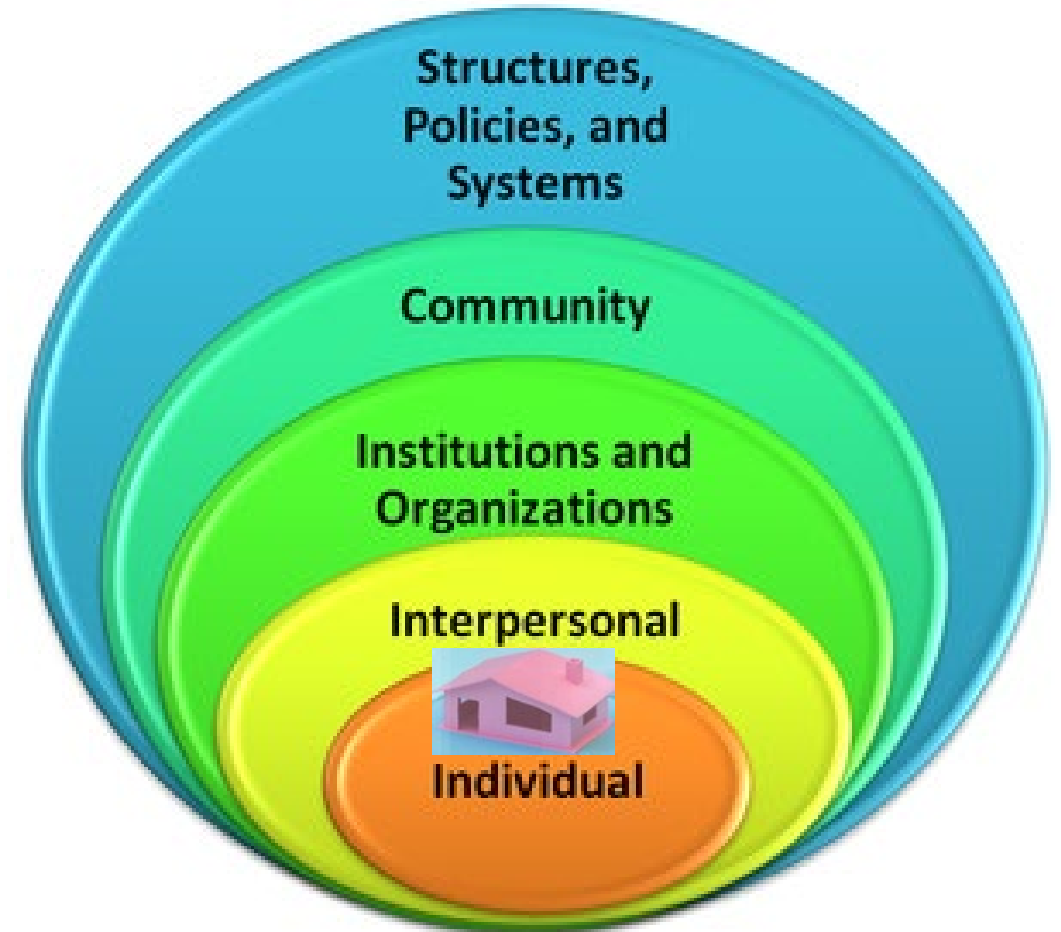


# Being part of the “real world”!



**CHAMPS**  
DHH

Communities Harnessing and  
eMpowering Parenting Strengths



Which brings us to....

# Implementation Science

Different outcomes than traditional health-related research:

- Acceptability
- Feasibility
- Appropriateness
- Adoption
- Reach
- Fidelity
- Adaptations
- Cost
- Sustainment

...and Effectiveness!

# Implementation Science

Some principles of implementation research:

- Engage with stakeholders in a meaningful way
- Understand the context
- Adapt to make the intervention “fit”
- As much as possible, reflect the real world in who is involved and how the intervention is delivered
- Think about sustainment from the beginning

# Community-Academic Partnerships!



FUNDING SUPPORT: R01DC016957



ACCORDS

ADULT AND CHILD CENTER FOR OUTCOMES  
RESEARCH AND DELIVERY SCIENCE

UNIVERSITY OF COLORADO  
CHILDREN'S HOSPITAL COLORADO

# Hearing & Behavior Community Advisory Board

Parents of DHH children

KY Office for Children with Special Health Care Needs

KY Department for Behavioral Health, Developmental, & Intellectual Disabilities

KY Commission for the Deaf and Hard of Hearing

Kentucky School for the Deaf

First Steps

The Hearing and Speech Center

Kentucky Hands & Voices

Centerstone Behavioral Health Services

Southeast Audiology

UK Healthcare



Lessons  
learned



# Lori Travis

## Audiology Services Administrator

Office for Children with Special Health Care Needs  
Kentucky Cabinet for Health and Family Services

### Study roles:

- Community Advisory Board member
- Identification of eligible children
- Encouraged audiologists to refer parents to the study

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- Reaching families: When services are limited or not accessed, research can offer another option for families
  - Unique resource: Families are less likely to initiate contact from study flyers, advertisements; EHDI can facilitate direct contact with families and audiologists/other providers
  - Red tape: Persistence and patience needed
  - Relationships: Partnering on one project leads to another, collaboration over time to expand and improve services



# Sarah Roof

Executive Director

Kentucky Hands & Voices

## Study roles:

- Community Advisory Board member
- Collaborated in FCU adaptation process
- Coordinates H&V parent coaches' employment, pay, logistics
- Matches coaches to families

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- Challenges: Coordination is complicated, study activities are part-time and sometimes sporadic, competing demands
  - Research requirements: Rigidity in some study aspects that is different than usual H&V practices (e.g., time limits, dual relationships, confidentiality)
  - Rewarding experiences: Family feedback, connecting to resources
  - Surprises: Willingness of many families to attend FCU sessions that they are not compensated for

# Jacob Holzman

## Assistant Professor

Division of Child & Adolescent Mental Health  
University of Colorado School of Medicine

### Study roles:

- Family Check-Up training and clinical supervision with parent coaches
- Contacts and assesses participants flagged for possible elevated risk
- Data analysis and manuscript writing

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- Training and supervision: Experiences supporting parent coaches versus clinical trainees in academic medicine setting
  - Positionality: Learning about families of DHH children from parent coaches and participants who are all parents/caregivers of DHH children
  - Gaps in care: Heightened appreciation of limitations in current system in which mental health service providers lack training and experience with DHH individuals

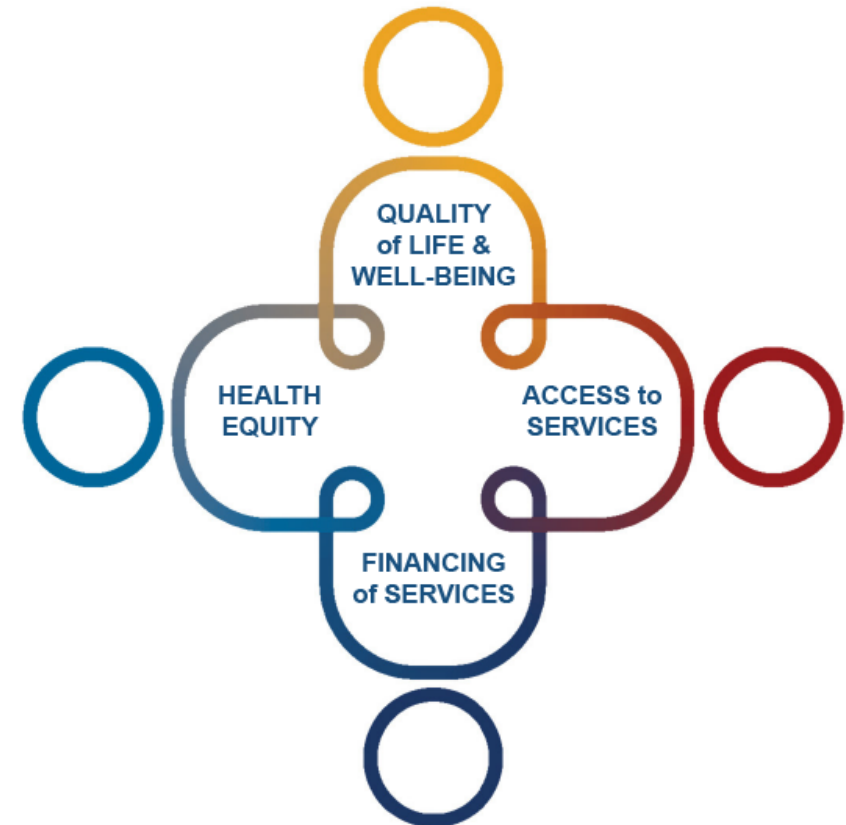
# Lisa Kovacs

Director of Programs  
Director, FL3 Center  
Hands & Voices Headquarters

## Roles:

- Advocacy training for parent coaches
- Recommended and shared H&V parent resources for toolboxes
- Facilitated study's national expansion
- H&V Guide By Your Side contact

- Connections between the study and practice:  
The MCHB CYSHCN Blueprint for Change
- Two-way learning: Families enrolled in the study vs. families typically engaged with H&V, Guide By Your Side
- Benefits of community-academic partnerships



Critical Areas for a Well-Functioning System

# Tina Studts

**Principal Investigator (PI)**  
**Associate Professor, Pediatrics**  
**University of Colorado School of Medicine**

# Julie Jacobs

**Site PI**  
**Project Director**  
**University of Kentucky College of Medicine**

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- Things rarely work the way you thought they would – learn from mistakes and failures
  - Transparency, humility, and flexibility
  - Learn from criticism and do better
  - Learn to recognize meaningful engagement vs. tokenism
  - Relationships take work and are the best part of community-academic partnerships

Your  
thoughts,  
ideas,  
questions?



# Acknowledgements

- The many caregivers who shared and keep sharing their stories and ideas
- Our **parent coaches** from Hands & Voices
- **The Hearing & Behavior Community Advisory Board**
- **Shelley Moats**, Little Ears Hearing Center/Norton Children's
- Additional co-investigators: Matt Bush, Liza Creel, Joneen Lowman, Phil Westgate
- Research assistants: Mallory Antel, Meghan Barnhart, **Laura Bellnier**, Diana Bigler, Cady Cornell, **Madi Fields**, Emily Goble, Anthony Mahairas, Allie Merritt, Callihan Moraska, Meagan Pilar, and Marissa Schuh
- Data collectors: **Melinda Ashworth-French, Laura Schuhmann, and Jennie Willson**

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Funding for this research provided by the University of Kentucky and by the National Institutes of Health: NIDCD (R01 DC016957-01) and NCATS (UL1TR000117 and 8KL2TR000116). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

# Thank you!

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To learn more about  
the CHAMPS-DHH study:



<https://medicine.uky.edu/departments/ent/champs-dhh>