# Creating Cohesive Deaf and Hard of Hearing Leadership in EHDI Systems and Beyond

How Our Community Drafts a Blueprint for D/HH Leaders
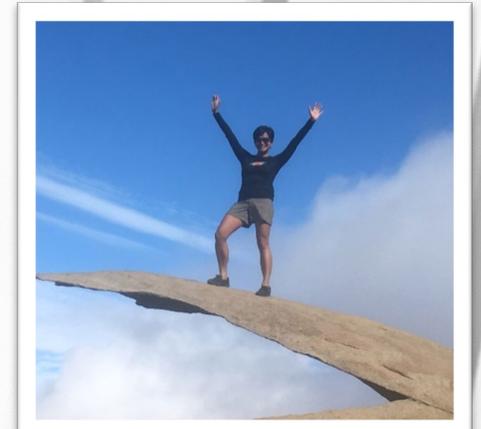
Candace Lindow- Davies

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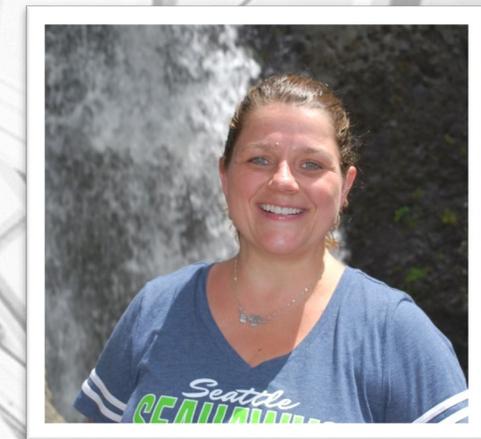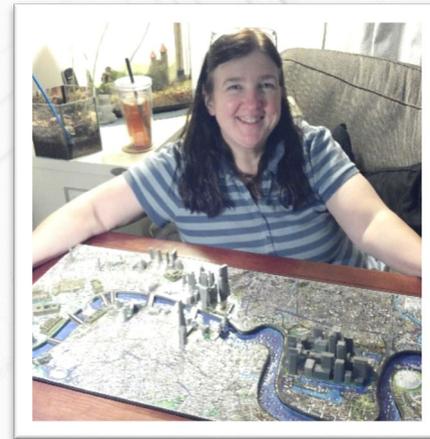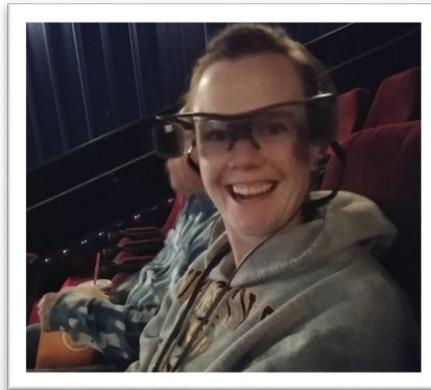
Allison Cunningham

Anita Dowd

Nan Asher

Emilie Wilding

Welcome!

http://handsandvoices.org/fl3

Goals and Objectives

1. Name three characteristics of an effective D/HH leader

2. Identify three examples of current practices and services supporting integration of leaders who are D/HH in EHDI systems

3. List strategies/changes that will increase family access to D/HH professionals/leaders in EHDI systems

Add-on objective:

Co-create strategies to ensure opportunities for growth of D/HH leaders in/from low resourced communities

Table Topic Discussion #1

- Briefly introduce yourself to your table
  - Parent/provider/DHH Guide/Mentor/role models/teachers…
 - What led you to attend this pre-session?

GO!

Share !

Are You a Leader?

BE AN "EVERYDAY LEADER"

Society commonly perceives leaders as individuals who make grand, world-changing decisions. Thus, the vast majority of people are reluctant or shy to identify themselves as leaders. But true leadership is about making the life of another person better, and most people do that everyday – perhaps without knowing it.

~Drew Dudley, Everyday Leadership
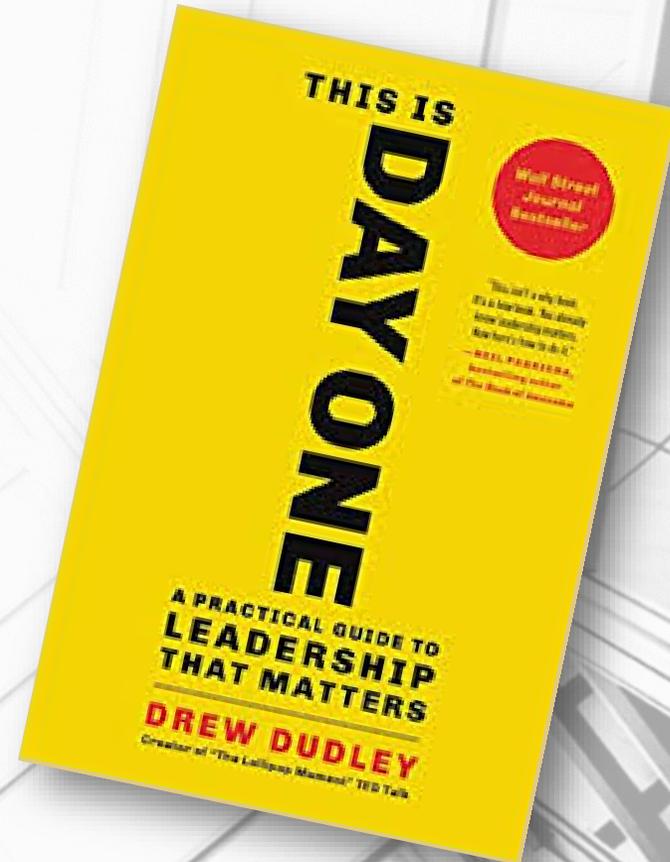
The Time is Now: Future Leaders

Youth Leadership programs – then what?

Share examples of leadership programs for D/HH professionals?

Thoughts:

- College training programs – part of EI training/certification

- EHDI

- Do leadership training programs need to be different for D/HH professionals?

Let's Start with: Skills, Traits &Qualities

101 Best Leadership Skills, Traits & Qualities – The Complete List in Leadership   By Brian Downard

101 BEST LEADERSHIP
SKILLS, TRAITS & QUALITIES

THE COMPLETE LIST

Top **10**

Qualities of a good leader

✓ Multicultural Sensitivity
✓ Focus
✓ Intelligence
✓ Ability to inspire
✓ Commitment

✓ Passion
✓ Ability to connect
✓ Willingness to make mistakes
✓ Vision
✓ Positive attitude

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Table Topic Discussion #2
Top Traits of D/HH Leaders

- What are the top five most important traits of an effective D/HH leader in EHDI Systems?

GO!

Share !

Report back as a group

Leadership: Perspectives From Deaf Leaders and Interpreter Leaders

US and Canada, 50 leaders Deaf and Interpreter leaders

1. What characteristics do you value in a leader?

2. What do others value in you as a leader?

3. Describe one of your best leadership experiences.

4. What difference and/or similarities do you see among deaf leaders and hearing interpreter leaders?
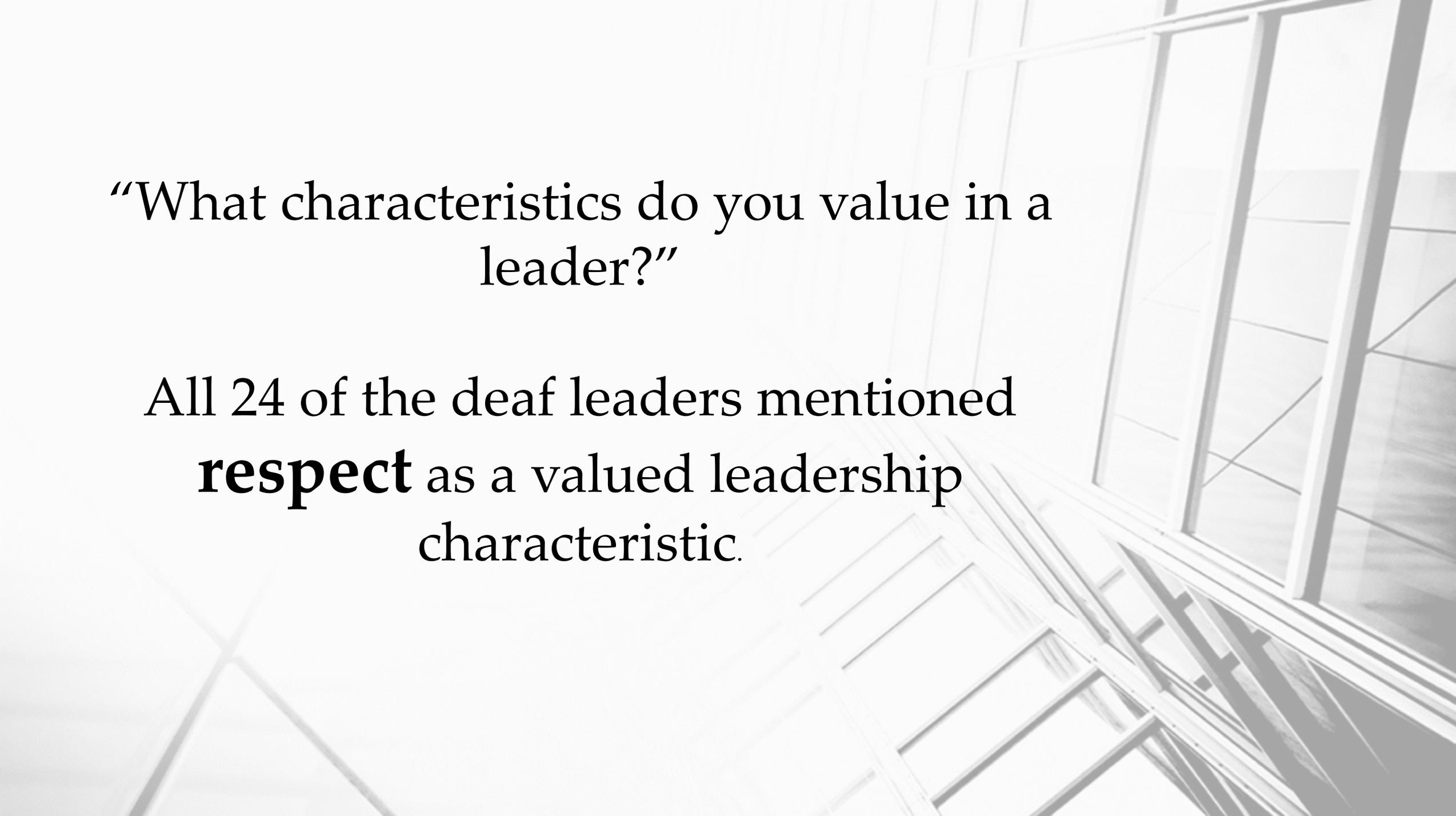
"What characteristics do you value in a leader?"

All 24 of the deaf leaders mentioned **respect** as a valued leadership characteristic.

In answering the question **"What do others value in you as a leader?"** deaf leaders reported:

- Being involved in the community (92%),
- Being a good listener (67%),
- Being responsible, (63%),
- Being fair (50%).

Systems

In one of the five themes, a higher percentage of interpreter leaders than deaf leaders reported "knowledge of how systems work."*

This may indicate either:

knowledge of how systems work was not perceived as important to deaf leaders as it was to interpreter leaders

or

deaf leaders were unaware of this difference

One interpreter leader shared "Hearing leaders have more access to resources and assistance than deaf leaders."

This comment could be because deaf leaders have generally not had the same level of access to communication as interpreter leaders.

*Sixteen (62%) interpreter leaders versus 10 (42%) of the deaf leaders

For Consideration

- If you become involved without truly knowing or understanding the systems and the families/children being served, you may do more harm than good

- Two things:
    we need a system that honors and
    includes D/HH adults in the services
  and
    we need D/HH adults who are trained to
    work with families

Traits of Confident Leaders
in the EHDI System and Beyond

- Authentic

- Open minded

- Sincere

- Embrace diversity

- Know what they believe in

- Always learning

- Positive attitude/outlook/vision

- GRIT!

Confident Leadership Comes from Being…YOU

Your story and your leadership is uniquely yours.

Recognize that you are a part of a movement…and a mission.

Know thyself and stand strong during challenges.

Positive "Self Talk"

Banish this:

- I'm not good enough to do this!

- What if I say/do this wrong?

- I'm gonna mess this up!

- I don't know enough!

- Everyone is better than me.

- Why did I agree to do this????

More of this:

- I know my story and I can speak it and lead with confidence.

- All the knowledge I need is within me. What I don't know, I will learn.

- My purpose is to connect, inspire, help, and share.

- I am enough.

"360 Degrees" of Support

- Bring in others who have the expertise that you don't
- Expand your own knowledge
- Connect with other D/HH people with different experiences/skills
- Ask the family what they would like to explore/learn
- Learn WITH the family
- We don't know what we don't know…Blind spots

Leading from Within

Ask yourself:

Am I focused on the needs of the families?
How am I empowering the family to make their own decisions?
Am I giving "360 support"?
Am I creating value?

Beginning with Families:

@HandsandVoices

Great things are done by a series of small things brought together.
Vincent Van Gogh

Respecting a Family's Journey

Beyond What We May Know

- Microtia - atresia

- Auditory neuropathy

- Deaf/HH Plus

- Unilateral or mild hearing loss

- Deaf Culture

- Cued Speech

- Listen and Spoken language

- Technology

- **Can you support other perspectives?**

The Family's Journey and Yours...

My journey does not define your journey

A lifetime commitment

To be unthreatened by difference of communication choices

the impact of family priorities and values

Every family is different, every journey is different

Responsibility

We can't predict the twists and turns on the journey

Accountability

Panel Discussion

- Nan Asher
- Anita Dowd
- Emilie Wilding
- Allison Cunningham
- Elle Mendolia

Panel Questions

- Tell us about your experience of becoming a leader. What helped your success?

- How does your state system support D/HH adult leadership? And how do families access them?

- What advice do you have for D/HH youth interested in becoming leaders in EHDI Systems?

- Best advice, support and resources that have helped you in your leadership role…

- Questions from the audience

What Connects All of Us

- We must build resources and programs TOGETHER that benefit families and support D/HH children
- No time to waste!

What is the "Power of Story"?

- Puts a face on the issue

- Creates "relational triggers"

- Invokes a possible connection

- Can demonstrate empathy

World Storytelling Day logo by Mats Rehnman

Art of Sharing *Your* Story

- Share stories that apply to the family's situation

- Maintain a balance in the conversation

- Respond meaningfully

- Refrain from using a story to manipulate an outcome

- Represent all families in systems (beyond your story)

One D/HH Person Does Not "Represent"

The Basis of Meaningful Involvement:

- Families feel supported and have access to resources that work for their child
- D/HH adults provide support/resources without bias
- D/HH adults recognize and honor the family's journey which can change at any time—and provide support for that change

Table Topic Discussion #3
Meaningful Involvement of DHH Adults in EHDI Systems

- What does "Meaningful Involvement" mean?

- What does it look like in early intervention?

- What does it look like beyond early intervention?

- Share examples of meaningful involvement

GO! Share !

Connecting with D/HH Adults: What are the Challenges?

Not relatable -adults that are in the role are so much older that the birth to three parents/Past experiences may not reflect today's reality

Families may not be ready after identification-need to offer at different times in the journey/ Families with newly identified babies are overwhelmed and may not be able to take advantage of D/HH Mentors/Guides/Role Models

No funding/No funding/No funding

Let's discuss…
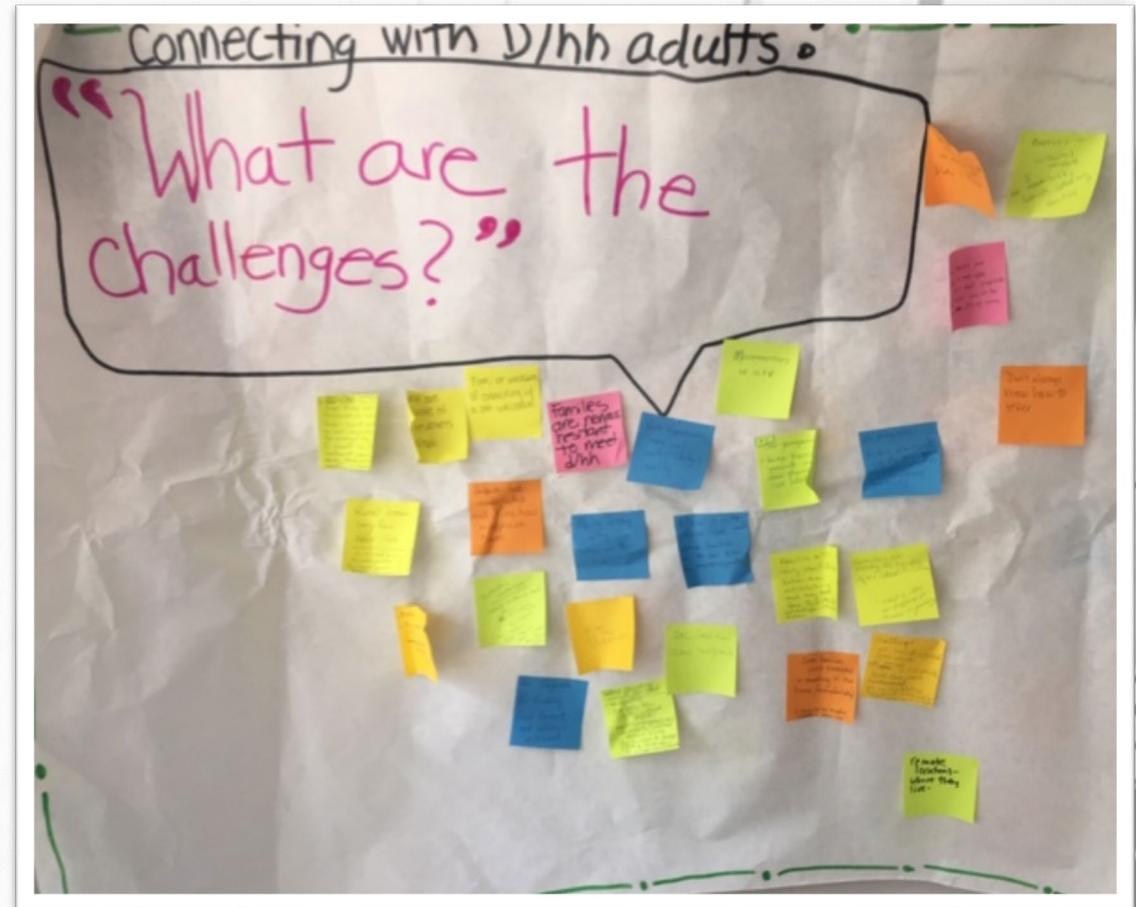
How Can We Implement Change?

Create better connections to families after child is diagnosed

Have D/HH at every family event and more events in various regions

Collaborate with organizations to promote the use of Guides/Role Models/Mentors

Improve training to reflect new inclusive language: sign, cue, spoken

Improve funding/ more funding

Let's discuss…
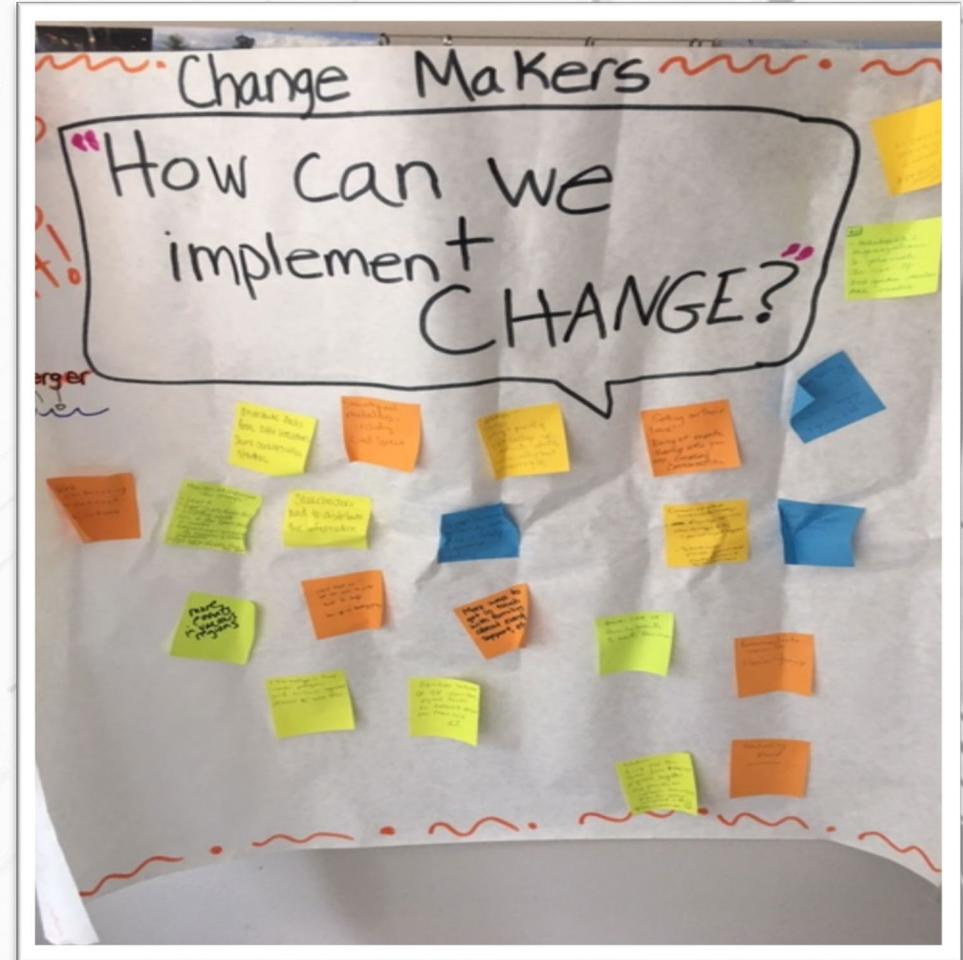
The Power of Collaboration without Competition

- How can you learn even more about the EHDI system and serving families in your state?

- Who can you reach out to?

- Is there a group you can get to know better?

- Is there a place on your state roadmap for D/HH adults to connect with families?

Supporting Families in Low-Resource Areas

Let's talk about this…

What are strategies to ensure low-resourced families have access to D/HH adults?
What strategies can help D/HH youth from low-resourced families become leaders?

"The first responsibility of a leader is to define reality. The last is to say thank you. In between, the leader is a servant."

—Max DePree

We have to remember who we are serving…
our families.

Call to Action: Commitment to Empowering New Leaders

- How can you make a difference in your community, your sphere of influence?

- How can you cultivate new D/HH leaders/service providers within the EHDI system?

Resources

- Supplement to the JCIH 2007 Position Statement Principles and Guidelines 2013: http://pediatrics.aappublications.org/content/131/4/e1324

- 2015 Towards a New Model for Deaf Infusion Leadership Christie Yoshinaga-Itano PhD: https://www.deafnessforum.org.au/wp-content/uploads/documents/research_publications/2015_lhmo.pdf

- NCHAM Learning Community: http://www.infanthearing.org/dhhadultinvolvement/index.html

- FL3: http://handsandvoices.org/fl3/
  - Tips for Meaningful Participation by Parents and Adults who are Deaf and Hard of Hearing Serving in Early Hearing Detection and Intervention (EHDI) Systems: https://www.handsandvoices.org/fl3/fl3-docs/Final-DHHadults-in-EHDI_8-30-2018.pdf
  - Needs Assessment Report Family Leadership in Language and Learning (FL3) http://handsandvoices.org/fl3/resources/needs-assessment.html

Example of D/HH in the EHDI System
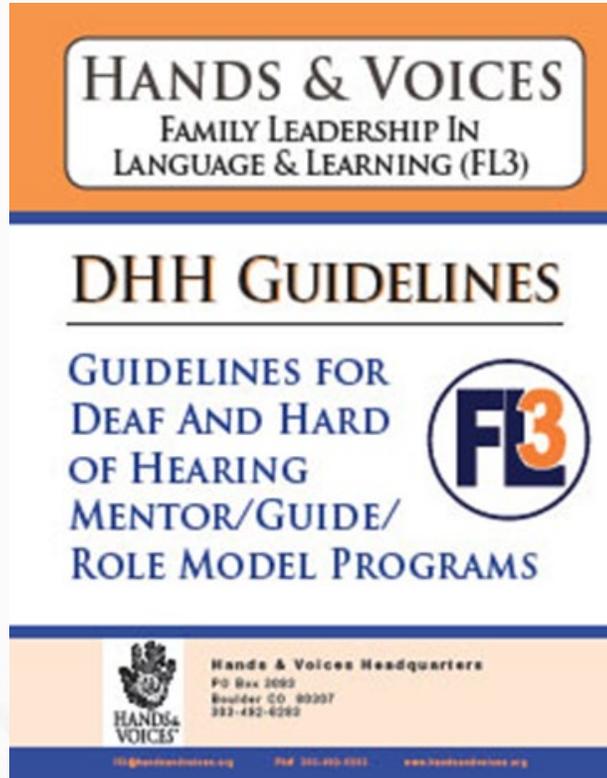
- Recruiting

- Onboarding

- Ability to work with parents and professionals

- Creating confidence in professionals

- Meaningful involvement

Fl3 DHH Guidelines: http://handsandvoices.org/fl3/fl3-docs/DHH-Guidelines.pdf