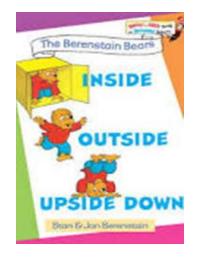
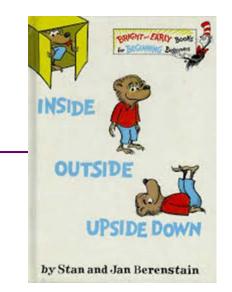
### Inside, Outside, Upside Down;

Infusing the EHDI System with Deaf and Hard of Hearing Partners and Parents



National EHDI Meeting
Pre-session
February 26,2017





# Inside Outside Upside Down

Paraphrased from The Bernenstain Bears book by Stan and Jan Berenstain in which Small Bear has an **epic adventure**.

In fifteen pictures and sixty-six words Small Bear goes into a box that gets dollied onto a truck and taken to town. The box falls off the truck, whereupon Small Bear climbs out and runs home shouting, "Mama! Mama! I went to town inside, outside, upside down!"

Inside, Outside, Upside Down was published by Random House in 1968 – by 2002 it had sold 3 million copies.

### Your Presenters:

- Have been inside, outside and upside down in various systems
- Parents
- Deaf/hard of hearing
- Professionals
- Committees/task forces
- Committed to the EHDI system

### Nan Asher

- Dx with M/S HL at age 4. (S/S now)
- Brother Dx with Profound Loss
- Center based classroom upon Dx
- Mainstreamed ½ day K-3. Fully M-S at 9
- BA in HA (honors) Masters in Liberal Studies
- Previously owned business in HAT
- Five time Gubernatorial appointment to DODBHH Advisory
- MI HLA member, on current advocacy board
- Past Executive Director of Michigan Assoc D/HH
- Administrator for Camp Chris Williams
- MI H&V member, Coalition for D/HH People treasurer
- Contract worker for MI-EHDI
  - Loss to follow up & Provider education in SE MI

### Karen Hopkins

- Identified at the age of five
  - Bilateral moderate hearing levels
  - Progressive
- No early intervention or parent support in Northern Maine
- Met first Deaf/HH peer at age 18
- New perspective:
  - Need for family support and Deaf/HH peer interaction for children and families
- Maine Educational Center for the Deaf and Hard of Hearing
- First EHDI & Hands & Voices Conferences
- Board Support
  - Hands & Voices
  - Maine's Foundation
  - Maine's EHDI Advisory Board





### Melinda Meyers

- Identified at age 3
  - Bilateral moderate hearing loss, aided
  - Progressive
- No Early Intervention or parent support
- John Tracy Clinic 3-5 (phone support)
- 1985 Developmental Therapist – ASL
- Parent Infant Specialist
- ASL Family Trainer
- Deaf Mentor Coordinator







### Karen Putz

- Founded the II Hands& Voices chapter
- Hands & Voices board since 2004
- Co-Director of HVD/HH Infusion withStephanie Olson
- Mom to three D/HH kids (adults!)
- Deaf Mentor in EHDI system since 2003



### Through the Door Diagnosis



### Lisa Kovacs

- Founded the Indiana Chapter of Hands & Voices 2004
- Guide By Your Side Coordinator Indiana 2009
- Guide By Your Side Coordinator H&V HQ 2012
- Director of Programs Hands & Voices HQ 2014

#### Various Roles within EHDI

- Parent
- GBYS Coordinator /IN model first point of contact
- EHDI Advisory Board Indiana
- Parent on IN NICHQ group
- AAP/EHDI Task Force
- AAP/EHDI QI Expert Group

....and this all started because I was a parent with a child who was diagnosed with a hearing condition in 2000 through UNHS





### Stephanie Olson

- Identified at the age of three, severe to profound hearing loss
- Early intervention/parent support did not exist
- Teaching/Social work
- EHDI-March 3-4 in Atlanta,GA 2005
- Hands & Voices HQ and H&V Colorado
- Early Intervention provider in Colorado
- Children's Hospital Colorado





### Our passion...

- move beyond asking deaf/hard of hearing people and parents to help at certain times
- move from personal to professional involvement
- ensure improved outcomes for ALL children who are Deaf/Hard of Hearing
- to work diligently with partners at all federal, state and international levels to make improvements for all children who are D/HH a reality
- timely

### Goals for Session

- Attendees will understand the importance of including deaf and hard of hearing staff members at every level in the EHDI systems: National, State, Territory and local teams
- Attendees will increase their understanding and ways that D/HH adults can positively impact EHDI systems
- Attendees will be able to state how to integrate the needs of parents and the availability of D/HH adults in the family's life
- Attendees will be able to state how collaboration between parent support programs and DHH Guide/mentor programs leads to cohesiveness

### EHDI and Hands & Voices

- EHDI has history; so does FAMILY and DHH INVOLVEMENT!
- our history and our own stories are woven throughout this presentation...
- growth of parent involvement
- growth of DHH involvement
- Today we will
  - recognize that we can learn from each other
  - process together
  - share a common goal

### H&V Mission/Vision Statement

#### **Mission**

Hands & Voices is a parent-driven organization that supports families with children who are deaf or hard of hearing without bias around communication modes or methodology.

#### **Vision**

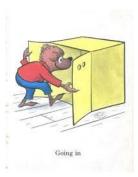
We envision a world where children who are deaf and hard of hearing have every opportunity to achieve their full potential.

#### **Motto**

"What works for your child is what makes the choice right"

## EHDI Under State Health Care Programs

- Early identification of children who are D/HH through universal newborn hearing screening and timely audiological evaluation
- Prompt and appropriate early intervention (medical, audiological, and developmental) and culturally competent support that results in the best possible outcomes for the infant or child
- Training providers: early childhood education, enhancing skills and knowledge of audiologists, early intervention specialists and health care providers
- Monitoring and evaluation of the EHDI system to improve its effectiveness and impact
- Research and tracking
- Legislation
- Financing
- Medical home model
- Parent support
- **1**,3,6



### Deaf and hard of Hearing Involvement Community

- NCHAM recognizes the value of connecting families and their deaf or hard of hearing child with deaf or hard of hearing individuals. Such individuals are typically adults who interact with the family and provide various types of assistance through one-on-one interaction. A variety of terms are used to describe such individuals:
- "deaf mentors"
- "deaf guides"
- "role models"
- "partners"

### Purpose and Goal (NCHAM)

- http://www.infanthearing.org/dhhadultinvolvement/technology.html
- The Learning Community is designed to learn more about expanding and improving existing opportunities for families of children who are D/HH to interact with adults who are D/HH. Sharing resources and networking with others is a key element in this process.
- A primary goal of the Learning Community is to keep in mind the shared passion of "supporting families of children who are D/HH."

### D/HH Involvement

- NCHAM uses "D/HH Adult Involvement" because
- It captures a broad range of service delivery models
- It is inclusive of supports offered to children who are hard of hearing as well as deaf
- Deaf/HH adult involvement can use a variety of communication modalities and a variety of assistive devices

### Example of programs listed:

- Arizona School for the Deaf/ Blind Contact Stacy Abrams
- Center for the Deaf and Hard of Hearing Education in Indiana Deaf Mentor Program Contact Jodee Crace
- Center for the Deaf and Hard of Hearing Education in Indiana Deaf Mentor Program Contact Billy Schwall
- Center for the Deaf and Hard of Hearing Education in Indiana Deaf Mentor Program Contact Meg Warnock
- Chicago Hearing Society Contact Karen Aguilar
- Doctorate of Education-Student, Deaf Studies, Lamar University Contact Beth Hamilton
- Hands & Voices Virtual Deaf/Hard of Hearing Guide Project Contact Janet DesGeorges
- Hands & Voices Virtual Deaf/Hard of Hearing Guide Project Contact Karen Putz
- MN Deaf Mentor Family Program, Lifetracks, Inc. Contact Danelle Gournaris
- MN EHDI Program Contact Nicole Brown
- National Association of the Deaf Contact Tawny Holmes
- NCHAM Contact Mandy McClellan NCHAM on Facebook
- New Mexico AmeriCorps Sign Language Teacher Program Contact Cindy Huff
- NM School for the Deaf, Deaf Mentor Program Contact Joanne Corwin
- Texas Guide By Your Side D/HH Guide Program Contact Pam Farley
- The Maine Educational Center for the Deaf and Hard of Hearing Early Childhood and Family Services/Deaf Mentor Program Program Contact Karen Hopkins ECFS
- The Maine Educational Center for the Deaf and Hard of Hearing Deaf Mentor Program Contact Melinda Meyers
- UT Deaf Mentor Program at UT School for the Deaf/SKI-HI Deaf Mentor Model Program Contact Paula Pittman
- Wisconsin Educational Services Program for the Deaf and Hard of Hearing Outreach: Deaf Mentor Program Contact Bonnie Eldred Wisconsin Program on Facebook
- Wisconsin Educational Services Program for the Deaf and Hard of Hearing

### EHDI with Deaf and hard of hearing individuals woven

into the fabric of EHDI Systems at every level Christie Yoshinaga Itano

In 2013, the Early Intervention Supplement to the Joint Committee on Infant Hearing Position statement 2007 was published

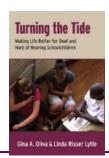
(http://pediatrics.aappublications.org/content/131/4/e1324.fullJCIH, 2007).

**Goal 3a**. (pg. e1328) Intervention services to teach American Sign Language (ASL) will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.

**Goal 10**. (pg. e1337) Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels. Their participation will be an expected and integral component of the EHDI systems

**Goal 11** (pg. e1338) All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH. This goal intends that families have access to meaningful interactions with adults who are deaf or hard of hearing who have the knowledge and skills to mentor, support, and guide families in culturally and linguistically sensitive ways and to serve as communication/language and social role models and mentors for deaf and hard of hearing children and their families.

### Research



Research demonstrates the benefits to families of connections with members of the deaf and hard of hearing community. Parents who have many contacts with deaf and hard of hearing adults exhibit a strong sense of competence in regard to raising their child (Hintermair, 2000).

Hearing parents identify deaf parents as one of the most important sources of support (after teachers, therapists, and spouses) (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003).

Children from families who received deaf mentor services made greater language gains, had considerably larger vocabularies, and scored higher on measures of communication, language, and English syntax than similarly situated children without deaf mentor services (Pittman, 1998).

Deaf community members are able to provide deaf children with something hearing parents cannot, experience as a deaf person.

The Book: "Turning the Tide- Making Life Better for Deaf and Hard of Hearing Schoolchildren" (2014) demonstrates how important it is that D/HH children are not educated alone.

"In the case of deaf individuals, the hearing culture is the majority culture. Glickman (1996) developed a model of culturally deaf identities in which he divided identities along a hearing world–deaf world spectrum where the highest level of identity development is a bicultural model."

### Effective Programs

Towards a New Model for the Deaf Infusion of Leadership in Early Hearing Detection and Intervention Services Christine Yoshinaga-Itano, Published by Deafness Forum of Australia: Libby Harricks Memorial Orientation June 2015

#### Effective Role Models have;

- 1. a written job description
- set appropriate expectations
- established policies and procedures
- 4. a strength based program, strong role models, strong families
- 5. a coordinator for the project
- 6. training and an awareness of biases
- 7. follow-up reports on effectiveness
- 8. communication and interaction with other US states who have a program currently to find out what works. Overcoming cultural barriers includes not only the diversity among deaf, hard of hearing, spoken language users, and American Sign Language communicators, but also includes training role models in cultural sensitivity to meet the needs of the non-English speaking and culturally/ethnically diverse families.

### Side by Side with Hands & Voices

Leveled Recognition Program required training components which includes training for DHH Guides

- Complete Initial GBYS Training
- We are Hands & Voices and Intro to GBYS
- Supporting Families Without Bias
- D/HH Guides: Initial GBYS plus 2 additional trainings:
- The Role of the D/HH Guide
- D/HH Guides; Working With Parents



### H&V DHH GUIDES

- DHH Guides share the "uncut" version of their own stories. It gives D/HH Guides an opportunity to learn from each other's stories (because of the diversity), safe space to tell the uncut version band guidance on sharing a story with families
- Training on the Leveled Recognition Program and selfevaluation process
- Parent Guides and D/HH guides work together to understand the different roles they play and how they are all part of a system of support to families.
- Protocols of how they will cross refer or work as a team to support families should be identified before the training and this time could be used to share those protocols.
- Local level systems training
- Program level expectations billing, program policies, etc...

### What inside connections do Deaf/HH adults have that other experts may not?

- Resources
- Social Identification
  - Dignity
  - Self-Esteem
  - Peer to Peer Networking
  - Deaf/HH professional networking
  - Cultural community involvement
- Real Life Model for families and the EI team

## What additional Voice Can Deaf/HH bring to EHDI and EI services?

- Deaf/HH professional perspective
- Positive perspective from personal experiences
- Positive perspectives from families experience
- Role Model
- Deaf Community/Cultural perspective
- Focus on Access

## What is the difference between Deaf and hearing parent's perspectives?

Sharing from Deaf families around the nation: Culturally Deaf families may also include CODA Parents:

- Deaf families may show happiness in having a deaf baby
- Hearing parents are typically shocked
- Both may experience grief Deaf parents tend to have a shorter grieving process – but pops up at various times
- Most Deaf parents are aware of Deaf Culture and communication choice
- Hearing parents often need more time to understand communication options
- Deaf parents usually know what they want for their deaf/hh children quickly
- Hearing parents do research on resources before making their final decision for communication-language plans

### Perspectives

- For Deaf parents the psychosocial-emotional development/support is often the priority for their deaf/hh children
- Hearing parents educational may view placements/audiological needs/language planning as priorities
- Deaf parents and Hearing parents have different cultural values, norms and social perspectives but they share similar home routines, interests and community involvement

## What about families "outside the box"?

- Deaf Plus
- Families with more than one language in the home
- Families across the hearing 'level' spectrum
- Deaf parents with deaf plus children or other disabilities.
- GLBT parents
- Teen parents

### Connections and Insights Audience Participation

- What inside connections and insight do adults/professionals that are D/hh have that other experts might not have?
  - Family goals vs. goals of the professionals
  - High Expectations
  - Diversity, flexibility, unique ideas
  - Connections within the organization and outside the organization
  - What true access looks like

## How does our personal history and experience impact systems?

- Ideas from the presenters...
- Ideas from participants
- Discussion
- Share

## How does our personal history and experience impact the family's journey?

- Ideas from presenters
- Ideas from participants
- Discussion
- Share

### Parental Involvement in the systems

- Parental involvement in EHDI: paved the way for D/HH involvement
- At the table, part of the process
- Creating change
- Families, babies and children
- Language
- Global
- Policies and legislation
- Future leaders

## The Evolution of Parent Involvement in EHDI

## Lisa Kovacs Director of Programs Hands & Voices

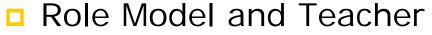
Can this be a model of involvement that can be used to enhance DHH involvement in EHDI?

### My "Consumer" experience influenced my ability to be a parent leader





- Diagnostics
- Medical Home
- Early Intervention
- IEP Team Member
  - Advocate



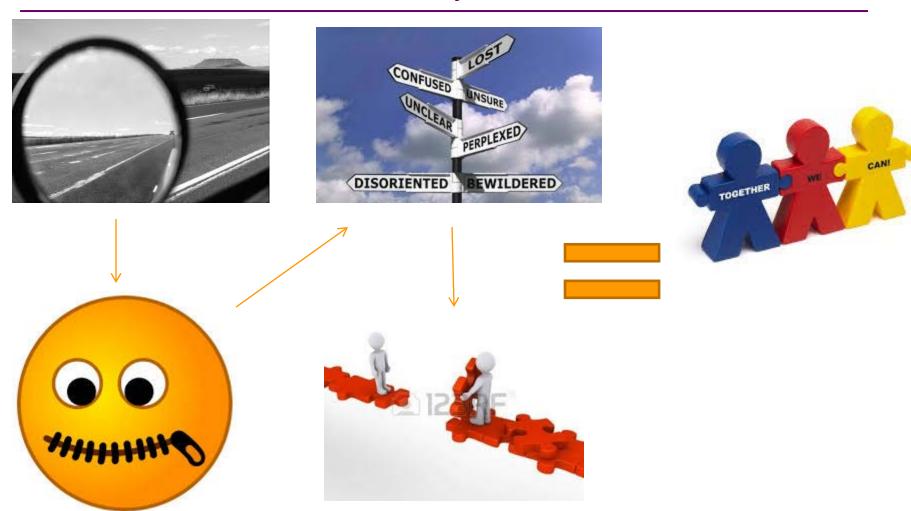
- Transition Expert
- Observer and Supporter







### I remember the days when...



## Parent Involvement Evolution over the past 20 years

**Started** being required through grants and projects

Typically as volunteers

The start of paid parent positions

Required Parent Involvement

Suggested **Parent** Involvement NICHQ, pepnet, JCIH, Advisory

**Parent** training curriculum to address leadership skills

Parents in

Leadership Roles

Committees

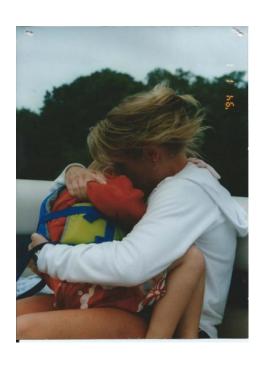
New idea parents were "seen but not heard"

#### Where does parent expertise come from?

#### ex·pert



having or showing special skill or knowledge because of what you have been taught or what you have experienced.

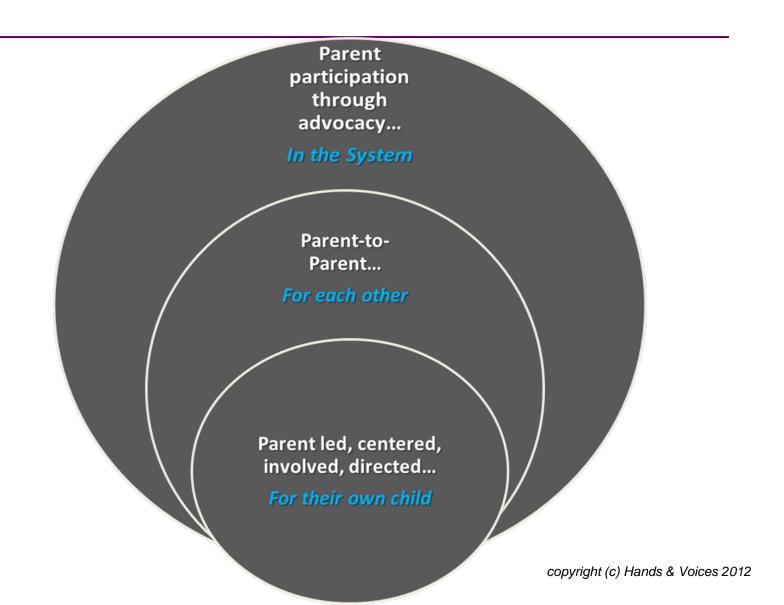


"I'm just a parent"

**TRAINING** 

Parent Leader

#### Who can parent Leaders represent?





Parent-to-Parent...

For each other

Hands & Voices
Guide By Your Side
Support



#### Guide By Your Side ™

is a Hands & Voices program that embodies our strong values for direct peer connections and networking.

It promotes self efficacy and hinders isolation by exploring our common bond, shared experiences, challenges, wisdom and insight.



#### Hands & Voices Parent Leaders

Parent participation through advocacy...

#### In the System

- Ability to share insights and information about their experiences in ways that others can learn from
- See beyond their own personal experiences and represent the needs of other families
- Families with other communication modes, special needs, medical/cultural viewpoints
- Respect the perspectives of others
- Speak comfortably in a group with candor
  - Work in partnership with others

#### How Personal Stories can Impact the System

"Universal Newborn Hearing Screening, Diagnostic Audiology Testing, Parent Concerns, and Management of Risk Factors for Hearing Loss are not just a check box on an Electronic Medical Record (EMR) or something that we need to try and remember to discuss with families on a routine visit. These are factors that can greatly impact the outcomes of children like Anthony".

Excerpt from an article in the EHDI Email Express

#### How to Identify Parent Leaders

- Desire to help others
- Ability to see beyond their own story
- Ability to share insights and information about their experiences in ways that others can learn from.
- Understanding of common challenges faced by families
- Ability to speak with candor
- Motivation to impact systems
- Capacity to engage and maintain involvement

Ensure a diverse group of parents are identify to capture the variety of experiences. Think socio-economic status, culture, language, etc.

## Training for Professionals on - How to make families feel comfortable to share the





- Articulate to families the value of their experience
- Explain what you will do with the information they provide
- Share an example of how a parent experience/story has made a change in your work/practice
- Consider easy access

## Examples of H&V parent involvement at all different levels

- Local and state level special education advisory councils
- State EHDI advisory boards
- Parents participating in legislative efforts
- Parents co-authoring or authoring publications
- Local Early Intervention councils
- American Pediatrics medical home and EHDI
- Speakers at conferences and workshops
- Quality Improvement efforts

## Transition of Leadership - Parent to Young DHH Adult Involvement

- Speaking to other parents
- Mentoring younger children
- LeadershipOpportunities
- Legislative
- Speaking to AuD students
- Serving on Boards



## In a Perfect World, some of the "H&V kids and early the intervention kids will lead EHDI into the next generation!





### Outside the system in Michigan:

- Michigan-EHDI has always had D/HH advisory members, (Stakeholders) started with agencies who sent D/HH staff (2-3).
  - Nan represented Michigan Association for Deaf and Hard of Hearing People
  - Currently have: deaf physician, Deaf H&V mentor and MDA member
- MADHH was also the fiduciary for MI-Hands & Voices
  - When Michigan's largest United Way changed their mission, it no longer funded any D/HH agencies.

## Moving "Inside" Michigan EHDI

- Hired as a contract worker for:
  - Loss to follow up.
  - Provider education.
- Requirements:
  - Phone calls to parents and Drs. (Bluetooth)
  - Face to face visits with PCPs.
- Different perspective:
  - Importance for full access for conferences.
  - Early on Resource guide: "Deaf people feel." \*

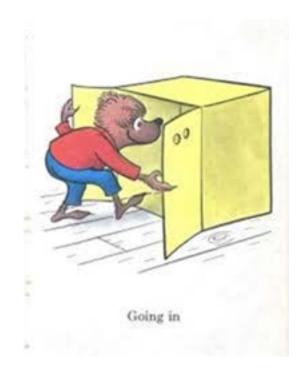
## Turning it upside down

- Spearheaded the Midwife project
- State conferences & Family Matters
- Hands & Voices support as D/HH adult
- Support Camp Chris Williams for D/HH youth
- Occasional one-one conversations with parents
- Give perspective input in Early-On, Family notebook, Lions resource guides

### Inside Looking Out:

- Pending Legislation
  - Miss Michigan-2014: KT Maviglia: Hearing Aid for Children Bill (SB 449) stalled until 2020
  - Deaf Child's Bill of Rights
  - Lead K Bill
    - Concerns on language delay, while valid, but might not necessarily be addressed by these bills.
      - 175 babies ID'd in MI. Should be 300+
      - High lost to follow up: 600 kids a year
      - Early On enrollment of D/HH children is only 50%
- Family Matters! Workshop

# Outside....going in with a positive attitude....one example



"We are far more effective on the inside looking out than on the outside looking in"

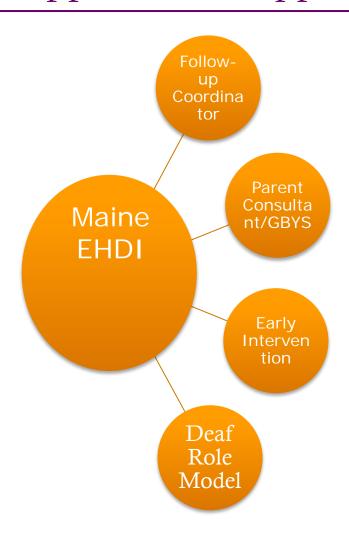
Helen Lynch



# Maine's Process for bringing everyone together

- Memorandum of Understanding Dept of Education and Maine Educational Center for the Deaf
- Support for Maine EHDI
  - Parent Consultant
  - Parent Follow Up Coordinator
- Deaf Mentor Program
- Hands & Voices
  - GBYS Parent Coordinator
  - Events
  - Conference

## Maine EHDI Four-Pronged Approach to supporting families



#### Memorandum of Understanding Maine's Early Intervention Program



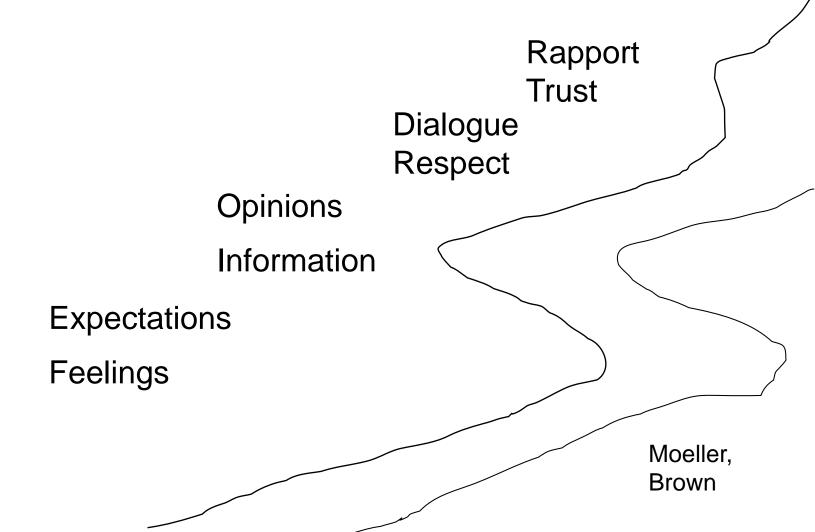
"To develop one family-centered early intervention process for families who have deaf or hard of hearing children throughout Maine."



## Where we begin.....



#### Process





#### Maine's 6 Visit Communication Opportunities Exploration Process

- □ All families statewide
- Ensures all perspectives are supporting families
- Collaborative approach
- Families lead the way

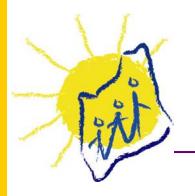


# Communication and Language Opportunities

□ The concept of "informed choice" reflects the fundamental belief that families need comprehensive, meaningful, relevant and evidence-based information from professionals in order to make decisions that are most appropriate for their child." (Young et al., 2006)



- Role of Deaf and Hard of Hearing Children and Adults is critical – Deaf and Hard of Hearing Partnerships
- □ Role of parents of Deaf and hard of hearing children is critical



## Opportunities to Learn From Deaf Adults



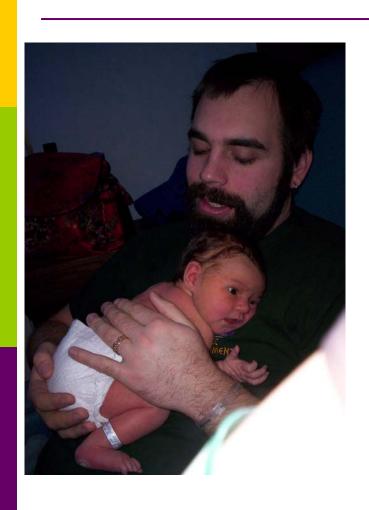
- Deaf Role Models
- Parent Infant Program
- ASL Family Training
- ASL for Families Program
- Deaf Mentor Program
- Hands & Voices Events

## Opportunities to Learn From Parents of Deaf and Hard of Hearing Children

- EHDI Parent Consultant
- Parent Guides
- Parent Infant Program
- Board participation
- Hands & Voices Events



# Deaf and Hard of Hearing Adults and Parents Supporting Early Intervention ...Strength Based Connections



- □ Tell me about your baby.
- Tell me about your family.
- □ Who gives you support?
  - Friends, neighbors, church
- □ What are your interests, jobs, or hobbies?



### Maine's Certified Deaf Mentors Ready to Support Families



The Deaf Mentoring Program provides children who are deaf or hard of hearing and their families with opportunities to interact with, and learn

from, a Deaf or Hard of Hearing adult.



### Parent Infant Toddler Program



- □ 8 Week sessions
- Deaf/Hearing Team
- Follows Early
   Intervention Model of
   Routines Based
   Intervention
- Parent to ParentConnections

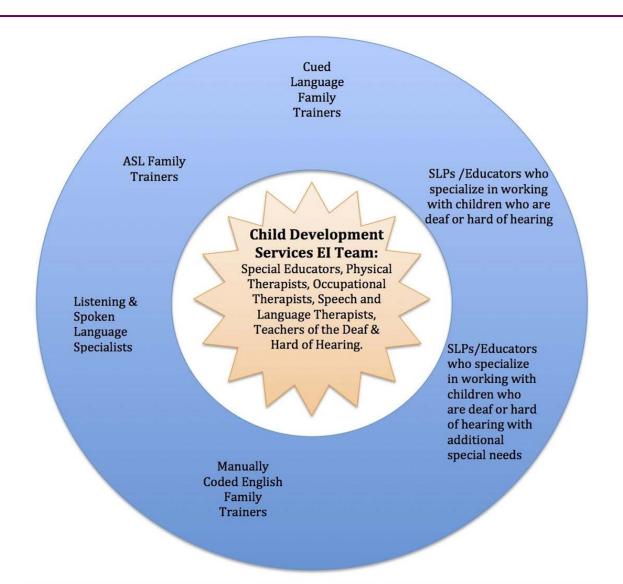
## Deaf Mentor Program Objectives

- Enhance the family's communication with their deaf/hard of hearing child.
- Serve as a positive role model for the deaf child
- Support families as a language model in the family's chosen methods of communication
- Share personal experiences growing up as a deaf person
- Model with a variety of fun and educational language activities
- Provide information on assistive technology (auditory and visual) for deaf/hard of hearing individuals
- Serve as a link to local resources for
- individuals who are deaf or hard of hearing.

## Community of Practice



#### Team of Providers



# What are your next Steps for infusing Deaf and Hard of Hearing Adults and Parents into your EHDI system?



## Turning it all upside down: Changing the Paradigm



## Deaf and Hard of Hearing Infusion

How do you provide support without bias?



## Providing Answers

- Can my child learn another language?
- Can my child fly a plane?
- Can my child serve in the military?
- Can my child scuba dive?
- Can my child...



# The Impact of D/HH Adults in the EHDI System and in LIFE!

#### Deaf Fire Chief



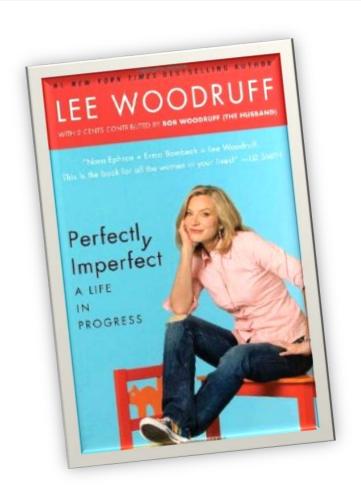
He may be the first deaf fire chief in the country. Mark Kite has taken over leadership duties at the Yukon Volunteer Fire Department in South Huntingdon, Pennsylvania. That puts him in charge of 75-fire fighters. It's a family tradition for the Kites. Mark's grandfather, father, brother and even his son have all served the community in this way.

#### Deaf Family Physician



Dr. McKee is a family medicine physician with clinical and research expertise in disability health. As a physician with a hearing loss, he is especially interested in advocating for the rights of Deaf and hard of hearing patients to obtain equitable health care. His research focus includes health disparities for individuals with various disabilities, health information accessibility, health literacy, and telemedicine applications. He services on Michigan Early Hearing Detection and Intervention Advisory Board. Dr. McKee is the current president of the Association of Medical Professionals with Hearing Losses (AMPHL).

# Lee Woodruff: The Gift of a Different Ability



"In those long-ago days I saw a daughter with a disability.

Now I see a beautiful, engaging person with a different ability, one that has blessed her with extra gifts and special perceptions."

#### A final thought from a parent...



"What we really want, really need as parents, is opportunities to contact other families with deaf children, help in making regular contact with adults who are Deaf and Hard of Hearing, information that is accurate, honest, unbiased, and fair, and then the emotional support from our early interventionist to make the decisions that are right for us and our child."