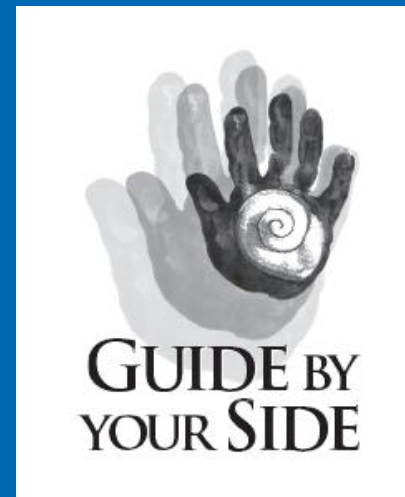


Impact of Hearing Loss on the Family



Lisa Kovacs
Indiana Hands & Voices



Guide By Your Side Coordinator
H & V GBYS National Coordinator

lkovacs@isdh.in.gov

317-233-7686

Hands & Voices...

what makes us tick

- **We are a parent-driven, parent/professional collaborative group that supports families without bias about communication modes and methods.**
- **We believe that there is no one communication choice that will work for all children** who are deaf or hard of hearing. We think families need access to good information that's free from a sponsoring agenda or ideology.
- We believe that **“What works for your child is what makes the choice right.”** ©
- **We get meaningfully involved** in early hearing detection and intervention programs, educational advocacy, and other systems to improve them from an end-user perspective.

Continued...

- We exist to help our children/students reach their **highest potential**.
- We believe our children have a **fundamental human right** of communication, regardless of their mode or method of communication.
- We believe **parent-to-parent support** is a cornerstone for families finding their way.

Diversity of our H & V Families

Hands & Voices supports families who have kids:

- **with mild, moderate, severe, profound, unilateral, conductive, auditory neuropathy, congenital, acquired, or age progressive hearing loss or deafness, deaf +**
- **who speak, kids who sign, kids who do both, kids who cue, kids who are aided or not aided, and/or kids who have cochlear implants**



Guide By Your Side

Hands & Voices Family Support Program

- Embodies the mission of Hands & Voices – providing unbiased support to families with children who are deaf or hard of hearing
- Guides are specially trained parents of children with deafness or hearing loss
- Unique support that comes from someone else who has walked this path and can share from direct support and wisdom





Benefits of GBYS



To Families

- Local family support early
- Research shows positive child outcomes when there is an increase in overall parent involvement
- Parents will be assured that information is shared in a timely and unbiased manner
- Contact with another parent who can “truly” understand

To The State

- A pool of trained parent leaders
- Embedding parent/professional collaboration into state systems
- Build sustainable capacity to support families statewide
- Statewide model of unbiased support

Impact of Hearing Loss on the Family



Diversity of our H & V Families

The reaction to the diagnosis:

140 individual family contacts

The majority have been hearing families





Family Stories

- One family found the news devastating; had questions like “will my child ever marry”, “will they have friends”, etc...this family was paralyzed by the news.
- Another family, grieved for a couple of days and then they were off and running. Looking into resources and research and really felt as if they were going to be okay.
- Yet another family, the parents were Deaf and they found it very offensive that the EI professionals were making such a big deal over the diagnosis. They felt they didn't need all the attention.
- And last but not least, a Deaf mother of 3 children who were Deaf but then she had hearing child. She said she didn't know what all the fuss was about until she had a hearing child.

Why Families Need Support

- 95% of all children who are deaf or hard of hearing are born into hearing families (Mitchell & Karchmer 2004)
- 90% of these families have no background in deafness or connections to the deaf community (Center for Demographic Studies 1984)

“The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives” (D. Luterman, 2006)

What should Parent Support look like ?

- Support that is unconditional
- It is listening first... not judging
- Support is not offering advice... it is offering guidance, a sounding board, ideas, ...
- Support to help families discover what they are feeling...not to make the feelings go away

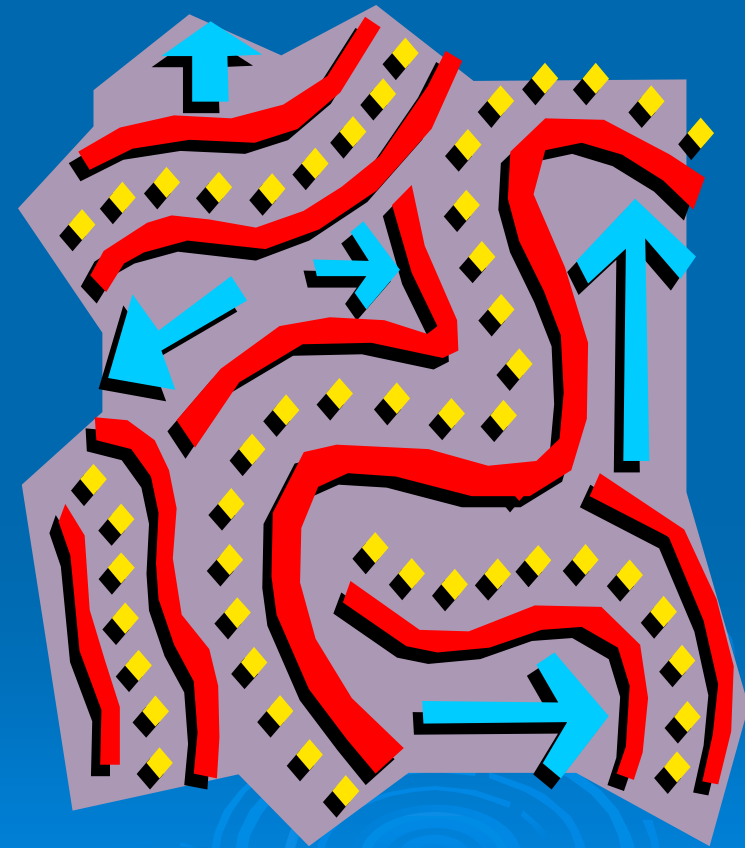


Parent Support to...

- **help families identify their options... not to tell them which options to choose**
- **discuss steps with a family... not to take the steps for them**
- **help families discover their strengths and realize their child's strengths... not to rescue them and leave them vulnerable**
- **help families discover that they can help themselves... not to take that responsibility for them**

It's the Families Journey

- Information needs to be meaningful to the family at the point in time in their journey
- Deliver the information to the family in a way that the family best learns or is easily understood by them
- Ask the family how they best learn, what are the burning questions they have.....
- Meet the Family right where they are in the process



Where Families Find Support

- Formal Parent Support Groups
 - △ Deaf Specific
 - △ General Disability
- Informal Parent Support

Parent-to-Parent

- Mentor
- Role Model

Adults Who Are Deaf/ Hard of Hearing

family

Information

- Internet Websites
- Brochures
- Books
- CDs/DVDs/Videos
- Resource Guides
- Curricula

Existing Communities

- Family
- Friends
- Neighborhood
- Places of Worship/Spiritual

Professionals

- Service Coordinator
- Parent Educator
- Early Interventionist
- Audiologist
- Medical Home/ Physician
- Speech/Language Pathologists
- Teacher
- Hospital Staff
- Communication Instructor/Specialist

Many opportunities for family support

How can all of us better support the families to “impact” the impact:

parent to parent

Audiologist

ENT

Early Intervention Provider

Teacher



What we can do:

- Respect the uniqueness of each family
- Do not judge
- Get to know the family
- Deliver information in a way they learn best
- Empower them to become the principle stakeholder
- Be a good coach
- Allow them to make decisions that feel right for their family and support their decisions

Let's take a closer look at each....

There is no “one size fits all”

Each Family is SO Unique

They come from differing
backgrounds,
experiences, and cultures

There is no “one size fits all”
approach to supporting
families

We must first listen to the
families!



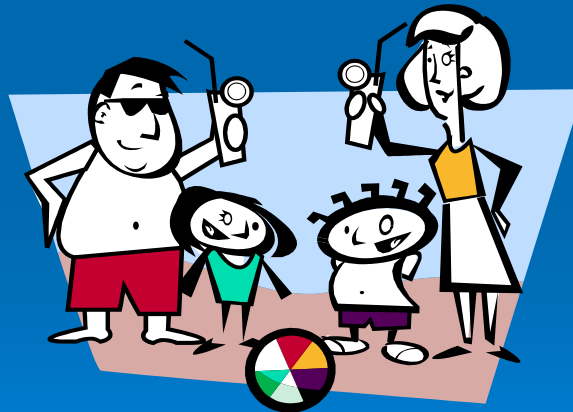
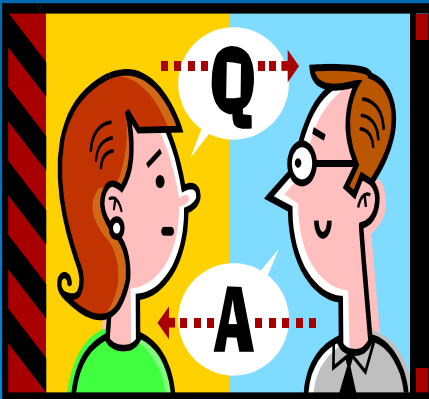
Clean Slate



Importance of not judging the families

Getting To Know the Parents

Take the time to get to know the uniqueness of every family



We all learn differently



You just received a brand new cell phone:
How would you learn to use it?



Identifying Learning styles

Would you...

- You open box and just start pushing buttons
- You read the manual from cover to cover
- You skim the manual and then start pushing buttons
- You ask many questions to the sales person and then you talk with others who have the same phone

Understanding different learning styles

DYNAMIC LEARNER

You prefer “hands on”, not afraid to take risks. You jump in and do by trial and error. Your favorite question is: What if?

ANALYTIC LEARNER

You prefer to know what the experts think, read the manual cover to cover, Your favorite question is: Why?

COMMON SENSE LEARNER

You prefer basic facts first then pull up your sleeves for hands on experimenting. Your favorite question is: How?

IMAGINATIVE LEARNER

You prefer to bring own experience into the process. You listen, discuss and enjoy consulting with others. Your favorite question is: Why?

Job Description for the Parent

The principle stakeholder who has both subjective and objective expertise in the context of the whole child as well an intimate knowledge of the family's dynamic, lifestyle, culture, values, and goals for their child.



Teaching Parents to be the Principle Stakeholders

Coaching	Traditional Therapy
Family centered	Child centered
Focus on the parents skills	Focus on the child's skills
Parents get hands on practice in real life situations	Parent is given instruction
Parent is the key to implementation	Professional is the key to implementation
The professional is in the wings	The parent is in the wings

A Good Coach

- Is always moving and improving
- Sees the potential in every parent or caregiver
- Is an improver
- Helps families move from point A to point B
- Never accepts the status quo
- Identifies gaps and gifts
- Inspires
- Sees the big picture and clarifies the steps necessary to achieve the parent's desired outcome



One lesson learned

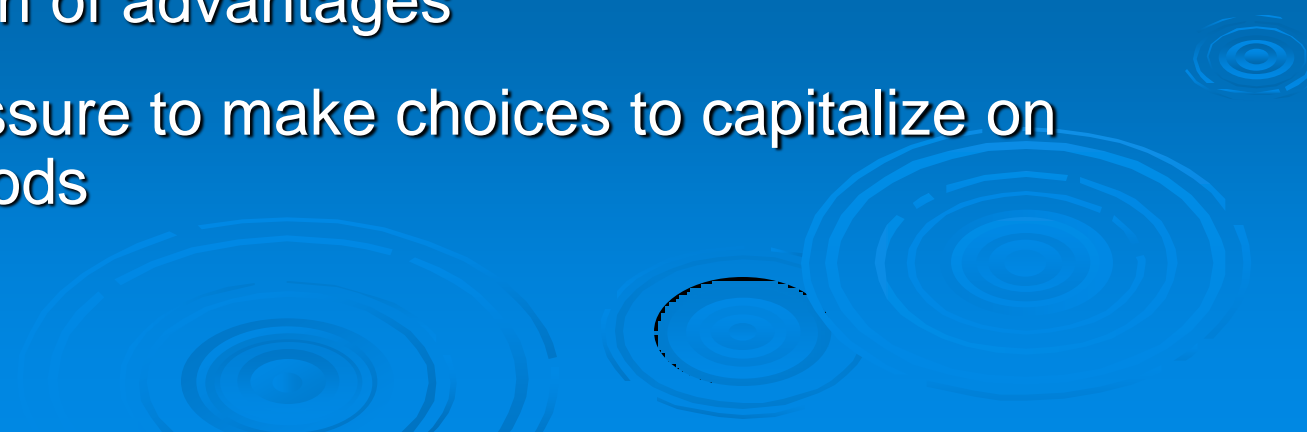
Coaching
others
positively
impacts the
coach. It
improves the
“COACH’S”
own game.



Decisions...decisions...what's a family to do???



To Complicate Matters...

- Families face complex decisions at a time of intense adjustment demands and a schedule to keep
 - Many types of decisions...much to learn...and we all want the best for our children
 - Lack of consensus among professionals can lead to confusion & uncertainty
 - Advancing technologies with some lags in documentation of advantages
 - Sense of pressure to make choices to capitalize on sensitive periods
- 

Look at the complexity of the issues ?

- **Age of Identification**
- **Onset of Hearing loss**
- **Degree of Hearing loss**
- **Benefit from Hearing Aids**
- **Family Dynamics:**
 - Lifestyle
 - Siblings & Extended Family
 - Bilingual issues
 - Culture & Values
 - Attitude & Commitment
 - Finances
- **Multiple Issues or Labels**
- **Family Support System**
- **Urban or Rural**
- **Availability of Resources**
- **Technology**
 - Parents can choose sound
 - Validity of testing
- **Society issues**
 - Beliefs about Disability
 - Social Isolation
- **Child's Innate Abilities:** learning style, personality, development, inclinations
- **Peers & Social Outlets**
- **Educational Options**
- **Long term Goals**
- **Validity of information**
- **Flexibility and fluidity of choice-making process**
- **and more...!**

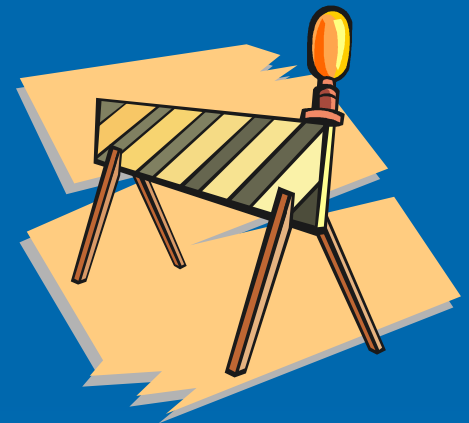
Guiding Principle



Families should have access to information on the full range of options AND the knowledge that there is no single approach that is best for all children who are deaf or hard of hearing

Barriers

- Provision of biased information
- Withholding information about some options
- Unequal weight given to certain options
- Attitudinal biases about some support options
- Limited range of service options in local programs



Choices

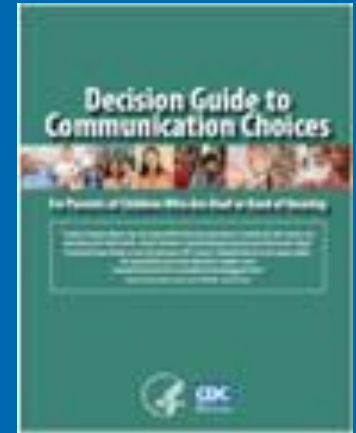
Ensure that parents know that their choices can change over time.

It's a journey, and they will learn along with their child “what works”

Hands & Voices Motto

“what works for the child is what makes the choice right!”

Decision Guide to Communication Choices



Step One: Finding your starting point

How far along are you with your decision

Step Two: Identify and explore your decision making needs

Do you have others supporting you and can help you make an informed choice for your child and family?

Are you feeling pressure from others?

Advantages and Limitations list of options – Comparisons

Step Three: Plan the next Steps Based on Your Needs

Do you feel you have enough facts?

Do you know what help is available to support your choice?

Determine what matters most to you!

Empowering Parents EARLY



- Parents Dreams for Their Child
- Parents Concerns
- What They Want To Learn
- Parents Priorities
- Family Goals

The parent's dreams and goals don't need to change for their child – The journey to get there is just going to be different!

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Tips for Empowering Families

- Converse from the beginning; be both positive and proactive in interactions with families.
- Offer help in response to family-identified needs (let them set the agenda).
- Permit the family to decide whether to accept or reject help.
- Frame questions in a way to promotes a thoughtful response “would you consider?” “Would you be willing...”
- Promote the family member’s ability to see themselves as active participants in making good choices.

Empowerment

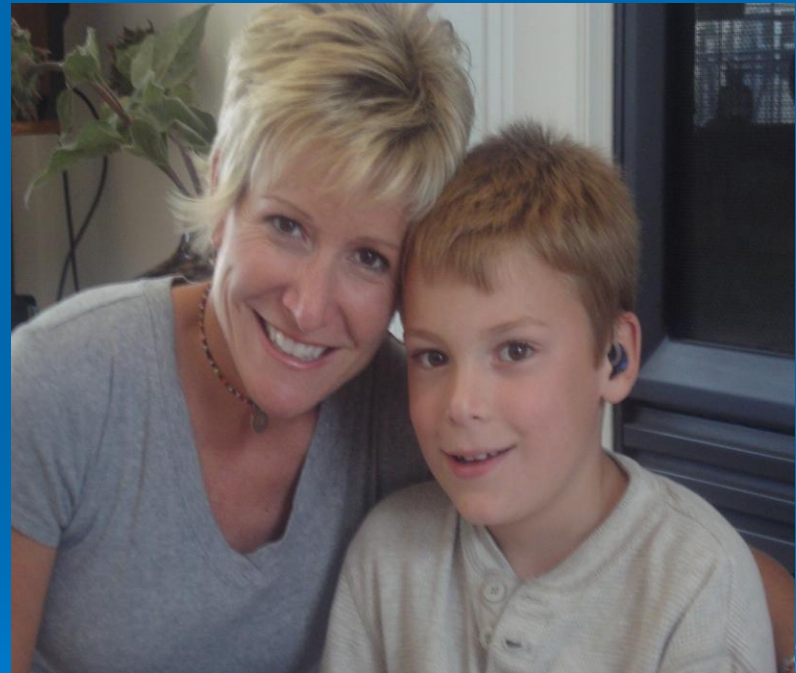
“families are seen as possessing the wisdom to ultimately make good decisions for themselves, and the professionals are seen as people who have the specialized knowledge to help illuminate the possibilities for them....”

Luterman 2001



The “BLIND SIDE”

No limitations!



*Never underestimate the POWER of a parent's
love for their child*

Keeping Our Eyes on the Prize

- A Strong Family
 - Getting productive good communication at home
 - Healthy attitudes towards deafness & hearing loss
- An Effective Education
 - Early ID/ Early Intervention
 - Communication access
 - Maintaining standards-based achievement
 - Academic & social success
- A WASK: Well Addressed Successful Kid
 - A result of good decisions
 - Success is success



Hands & Voices

www.handsandvoices.org



Thank you!