

# Useful Decision-Making Tools that Assist Parents in Ensuring Successful Language and Communication Outcomes



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**PRESENTED BY  
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—  
HANDS & VOICES**

# Presented today by:



## Janet DesGeorges

- **Mom to Leah, Danielle, and Sara**
- **From the parent perspective (vs. theoretical research/professional applications)**



We all have a  
story to tell...



# My Professional Background



- Credentials: M.O.M. (*“mom, you wouldn't have a job if it wasn't for me”*); our family story
- Systemic involvement for over 15 years (medical, educational, community)
- Executive Director and Co-Founder, Hands & Voices Headquarters (over 50 chapters in the U.S. and abroad)
- Certificate of Completion at the University of North Carolina- Chapel Hill MCH Public Health Leadership Institute



# Today's Presentation



- Why we talk about the decision making process.
- Current trends and conversations.
  - Use of Semantics; Far From the Tree.
- The importance of 'process' in decision making.
- Tools that assist families.
- How we know we got it right – tying successful language and communication outcomes to the decisions.

# Inspiration for Today



- “When you come upon a wall, throw your hat over it, and then go get your hat.” – an Irish Proverb
- “I hate quotations.” - Ralph Waldo Emerson

# A quote on choice



*“...As I'm so completely filled with emotion, I look up and see the person who so flippantly made an insensitive, judgmental comment about her critical assumptions regarding our family's communication choice. She has just walked away and gotten on with her day, only to ruin mine. She doesn't realize, or worse still, maybe she does, that her five-word comment will resonate in my mind for the next week, if not forever. Not because it was helpful, but because it was harmful. I should not have to defend the communication choice that is best for our family, our child, and our life. It's working perfectly for us, and I don't expect anyone else to make the same choice we have unless it works for them!” – Cami Wright, “A Parent’s Right to Choose” *The Hands & Voices Communicator**

# The Buzz



- 2013 National EHDI Conference – number of presentations on the subject 5\*
- Number of presentations I've done on this topic: 10+
  - ✦ Including: “Please Just Tell me What to Do”; “The 5 W’s of Decision Making”; “The Parent Piece”; “How Families Make Decisions”; \**“The Parenting Journey: An Intimate Look at the Decision-Making Process from the Hands & Voices Perspective”...*
- Number of resources at H&V website on this topic
  - ✦ ‘choices’ – 149    ‘options’ – 163    ‘decisions’ – 165
- Books/Articles/Research on the topic
  - ✦ 6,740,000 (google search: ‘decisions in deafness’) – never a reliable number

# Participants in the Discussion



- **Researchers/Objective Testing**
  - “We can objectify the whole process and just take out the emotional turmoil of it all.”
- **Professionals**
  - “We are the experts.”
- **The Child**
  - “Wait and let the child decide/lead the way...it’s his/her life.”
- **The Family**
  - “This is OUR child.”
- **Deaf/Hard of Hearing Adults/Communities**
  - “This child is part of our community.”

# Why discuss decision-making?



- This is a big deal – *a life hangs in the balance*
- Leads to:
  - Improved and more thoughtful decisions
  - Self awareness of our own unique style of processing
  - Better understanding of other's beliefs
  - Increased scrutiny of presented information
  - More thorough exploration of all angles of a problem or its solution



# Current Trends and Conversations on the topic

# Semantics – what if we change the words we use?

- Options
- Choice
- Choices
- Decisions
- Approaches
- Considerations
- Opportunities

- Biased
- Unbiased
- Informed
- Non-Biased
- Objective
- Subjective
- Fluid
- Flexible
- Set in stone

At some point in time, a parent has to get up in the morning and 'do something'.



# Conversations



- Far From the Tree - by Andrew Solomon

- Vertical Community

- ✦ Hearing Parents in a Deaf World

- “I asked the family what their goals were for their child and that drove my support for their decision”

- ✦ This is our child

- Horizontal Community

- ✦ “I never thought of myself as a

- ‘hearing person’ til I met my wife”

- ✦ The beauty of the learning curve

- Decisions in context to my child



# Decision making as a ‘process’



- Time considerations

- For Parents

- ✦ System underestimating the timeline of ‘new parenting’
  - 2 Stories: the 6 day old; the 20 day old
- ✦ The learning curve
  - Getting info... **AND** processing it takes time.
- ✦ Emotional states
- ✦ Ownership of decisions

- Children

- ✦ Let the child lead the way -objective/subjective information over time
- ✦ “Not my decision anymore” – the transition of decision making

# Decision making Tools...what's available?



- **Support and information can be found from a multitude of sources.**



- The *Decision Guide for Communication Choices* is a tool, that was developed by parents for parents, with the guidance and support of professionals who work with children who are deaf or hard of hearing.
- This guide walks the parent/caretaker through the steps of making communication choices and decisions for their child and family. **This process is not always, or even usually, a one time thing.**
- It's meant to be shared with others and used to promote discussion.
- This guide is not meant to be used as a solitary activity, it should be provided to parents with a companion packet of national, as well as local information and resources available to families of children who are deaf or hard of hearing.

# CDC Decision Guide to Communication Choices



## Decision Guide to Communication Choices

For Parents of Children Who Are Deaf or Hard of Hearing

*"I wish I knew when my son was little that the decisions I made for him were my decisions for that time. I wish I knew I could change course and that was okay. It would have taken a lot of pressure off. I wish I realized that as he grew older, he would become the decision-maker and I would become his consultant and biggest fan."*

Candace Lindow-Davie, Luke's mom, © 2008 MN - Hands & Voices

**This pamphlet will help guide you through the steps in deciding about communication.** The right choices are up to your family. Discovering what works for your child is truly a work in progress. Your child's needs, as well as your family's needs, will change with time and you'll want to review your choices regularly. The communication method you choose first may not be your last choice or your only one.

**The keys to making a good decision for your child and your family are:**

- Knowing all of the options that are available,
- Learning all you can about those options, and
- Not feeling pressured to make a decision until you have enough information and you feel ready to choose.

**Learn all you can about the different communication options.** You can get information from organizations that support children with hearing loss. You may also want to talk to professionals, other parents of children with hearing loss, and adults who have grown up with hearing loss. Books, journals and quality websites are good resources, too.

**This pamphlet will guide you through three steps, they are:**

1. Find your starting point for the decision,
2. Identify and explore your decision making needs, and
3. Plan your next steps.

## Step One: Find your starting point

**This step will help you describe your starting point in exploring communication options.** Please remember, this decision about communication involves the whole family.

**How far along are you with your decision?**

- I do not know what my options are.
- I am considering the options.
- I am close to making my choice(s).
- I have already made my choice(s).

**Are you leaning toward certain communication option(s)?**

- No
- Yes. Which option(s)? Why?

## Step Two: Identify and explore your decision making needs

**Now you know how far along you are in making your decision.** Step 2 will help you identify what support and knowledge would be helpful to continue the process. It will also help you evaluate the options and clarify the advantages and limitations of each option.

Experience shows that people that answer "No" to one or more of the following questions are more likely to:

- Delay their decision,
- Feel regret about their choice or
- Blame others for bad outcomes.

Therefore, it is important to focus carefully on your needs.

### A. Support

- Do you have enough support and advice from others to make an informed choice for your child and family?
- Are you choosing without pressure from others?

# CDC Decision Guide to Communication Choices



## Use this chart to further explore your needs regarding support

*You may use separate sheets if you need more space.*

From whom have you received support?	Name:	Name:	Name:
Which option does this person prefer?			
Is this person pressuring you?			
How can this person support you?			
What part of the person's background affects their opinion?			

The following questions refer to the "Comparison" table below.

### B. Knowledge

- Have you considered the advantages and limitations to each option for your family?  Are you in contact with others for more information?

**In the comparison table below.** List the options and the main advantages and limitations that you already know. Underline the advantages and limitations that you think you are most likely to experience.

### C. Values

- Are you clear about which advantages and limitations matter most to you?

**In the comparison table below.** Use stars (\*) to show how much each advantage and limitation matters to you. Five stars (\*\*\*\*\* ) means that it matters "a lot". No star means "not at all".

### D. Certainty

- Do you feel confident about the choice(s) you made?

**In the comparison table below.** Circle the option with the advantages that (1) matter most to you and (2) are most likely to happen.

## Advantages vs. Limitations Comparison Table

*You may use separate sheets if you need more space.*

This chart helps you work through your needs in the four categories (A, B, C and D) in Step 2 above.

	Advantages: Reasons to choose this option	How much it matters. Add * to *****	Limitations: Reasons to avoid this option	How much it matters. Add * to *****
Option 1				
Option 2				
Option 3				

PS

... continued on next page

## Step Three: Plan the Next Steps Based on Your Needs

**This final table will suggest specific steps that will help you feel confident about your decision.** Don't give up. Keep looking for the resources you need to get to a level of comfort with this process. You will begin developing an understanding of your long term goals for your child, which will in turn shape your decisions and provide motivation. *You can do it!*

If you are having difficulty	What you can do
Do you feel you do not have enough support?	<ul style="list-style-type: none"> <li>• Discuss your options with a trusted person</li> <li>• Find out what help is available to support your choice</li> </ul>
Do you feel pressure from others to make a specific choice?	<ul style="list-style-type: none"> <li>• Focus on the opinions of others that matter most to you</li> <li>• Share your guide with others</li> <li>• Ask others to complete this guide</li> <li>• Find a neutral person to help you and others involved</li> </ul>
Do you feel you do not have enough facts?	<ul style="list-style-type: none"> <li>• Find out about the advantages and limitations</li> <li>• List your questions and note where to find the answers</li> </ul>
Are you not sure which advantages and limitations matter most to you?	<ul style="list-style-type: none"> <li>• Review the stars in the balance scale to see what matters most to you</li> <li>• Find people who know what it is like to experience the advantages and limitations</li> <li>• Talk to others who have made the decision</li> <li>• Read stories of what mattered most to others</li> <li>• Discuss with others what matters most to you</li> </ul>

Are there other factors that make the decision difficult? If so, list them here:

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## Local Contact Information:



PHOTO: SHUTTERSTOCK.COM

# Projects completed by the CDC Parent-to-Parent Subcommittee include:



## • **Decision Guide to Communication Choices for Parents of Children Who are Deaf or Hard of Hearing**

- Questions You May Want to Ask Your Child's Audiologist
- Questions You May Want to Ask Your Child's Genetics Team
- Questions You May Want to Ask Your Child's Medical Professional
- Questions You May Want to Ask Your Child's Early Interventionist
- Questions You May Want to Ask Your Child's Ear, Nose and Throat (ENT) Doctor
- Questions You May Want to Ask Your Child's Speech Language Pathologist
- IFSP Communication Plan Guide
- ***In progress: The What Else Checklist?***

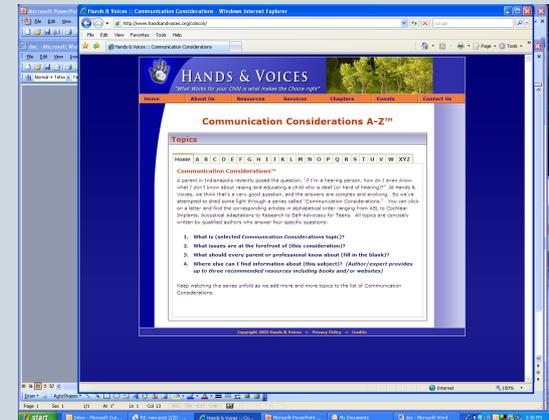
• **These can all be downloaded at: <http://www.cdc.gov/NCBDDD/ehdi/edmaterials.htm>**

# Hands & Voices Resources



- **Communication Considerations A – Z™**

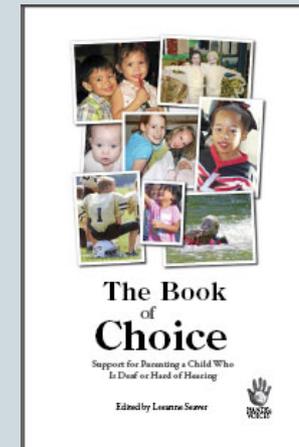
- ✦ “Will he talk? *Should he?* **How will we learn how to sign with her?** Where will she go to school? **How will we know the communication choice we’re making is right for our child?** Who can help? When should we decide about a cochlear implant? Can he attend our neighborhood school? **Will she have friends?** What don’t we know? whose philosophy is right? What if we make the wrong choices?”



- **The Book of Choice**

~ *Parents sharing what they know now that they wish they'd known from the start.*

These resource can be found at  
[www.handsandvoices.org](http://www.handsandvoices.org)



# Global tools



- **Basic Decision Making Strategy**
  - Define the question and/or issue, develop a goal
  - Become well informed; Identify options; Explore alternative solutions; Use diverse info sources
  - Consider objective & subjective measures
  - Weigh positives and negatives
  - Make a decision and go for it!
  - Measure progress; evaluate the outcome
  - Modify the approach, or recommit to the strategy

**Derived from: -Baldwin, R./D'Zurilla TJ, Goldfried MR. Problem solving and behavior modification. J Abnorm Psychol 1971;78:107-126**

# Successful Language and Communication Outcomes



*“The need and right to communicate is the most fundamental of human rights. To deny it is to harm the human spirit; to foster communication is to reveal all the possibilities of life.”*

**-L. Siegel**



“I got snow on my boots”



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