

# The *CARE* Project



The Journey to Hope and Resilience

Johnnie Sexton, Au.D.  
Executive Director  
[www.thecareproject.com](http://www.thecareproject.com)

Ohio, Arkansas, Indiana, Kansas, Idaho, Utah, Pennsylvania...

# THE CARE PROJECT EXPANSION GRANT

# Just a few reminders....

- TURN YOUR CELL PHONES OFF!
- ALTHOUGH WE WILL TAKE A BREAK, GO IF YOU HAVE TO GO!
- TAKE TURNS.....RAISE YOUR HAND....I WILL CALL ON YOU!

# Johnnie Sexton

- Aware of deafness since birth
- 33+ years experience with individuals who are deaf and/or hard of hearing
- Pediatric/educational audiologist
- Design Team for EI Audiology system for North Carolina



# The CARE Project, Inc.

- The CARE Project
  - 501c3 public charity
  - Tool Kit
    - Devoted to helping families
      - Reach acceptance
      - Advocate/move forward
    - Help professionals understand the importance of processing emotions
    - Facilitate active listening between parents and professionals through use of shared experiences



# No Bias

- The *CARE* Project does not prescribe to any one philosophy or mindset
- All perspectives on deafness/hard of hearing, technology and methodologies are acceptable
- *CARE* is meant to raise awareness and facilitate the processing of emotions
- *CARE* is NOT a substitute for long-term counseling



CARE is NOT about communication and/or amplification choices

**THE CARE PROJECT IS  
ABOUT AN EMOTIONAL  
JOURNEY**

Use of the term “grief”

# THE ELEPHANT IN THE ROOM!



A large, curved, blue shape that resembles a stylized wave or a segment of a circle, positioned in the lower half of the frame. It has a gradient from a lighter blue at the top to a darker blue at the bottom.

Documentary film overview

# THE CARE PROJECT

A large, solid blue curved shape that starts from the left edge, curves upwards and then downwards to the right, filling the bottom half of the slide. It has a subtle gradient and a slight shadow effect.

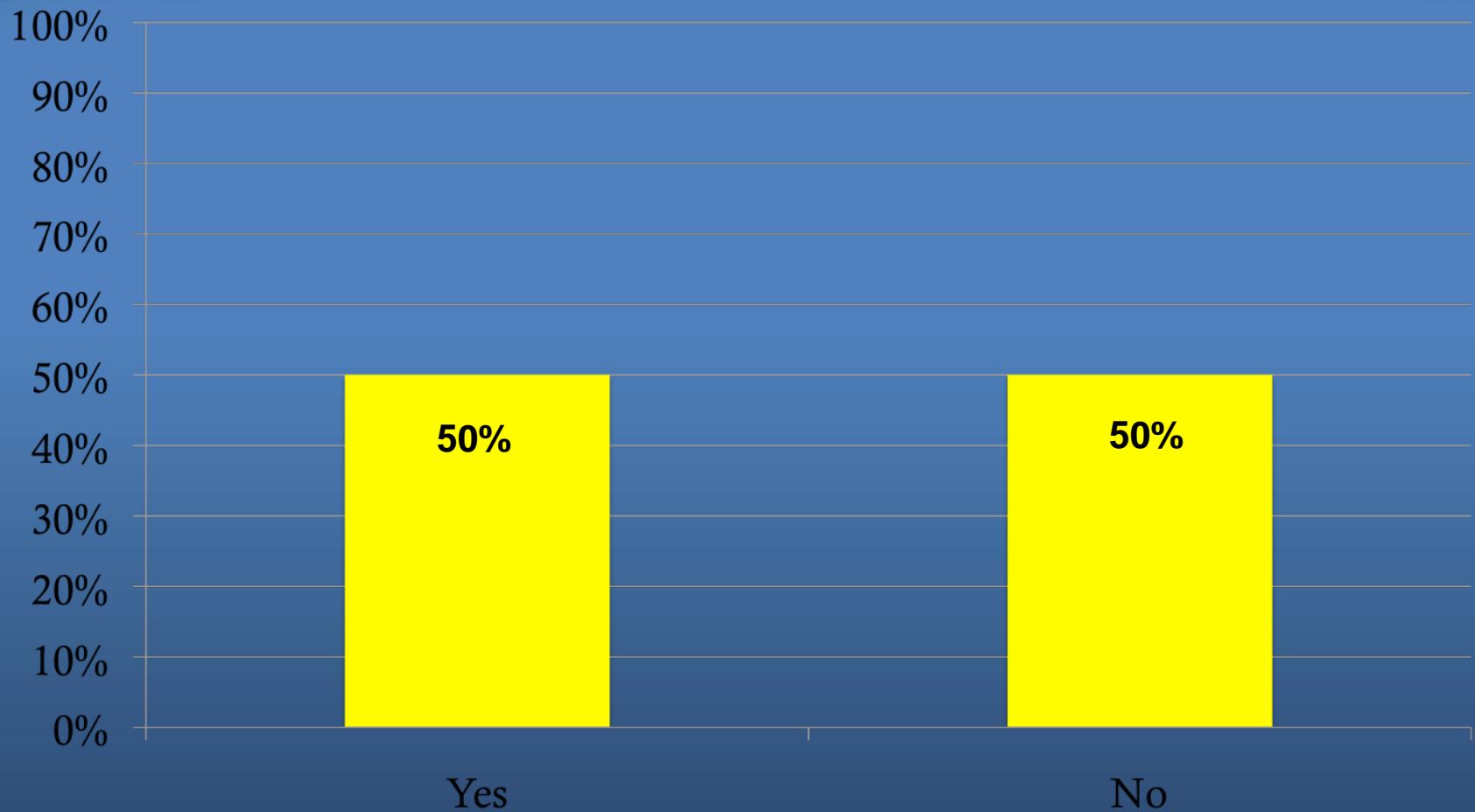
# PRE-WORKSHOP SURVEY

N = 624 (08-01-2015)

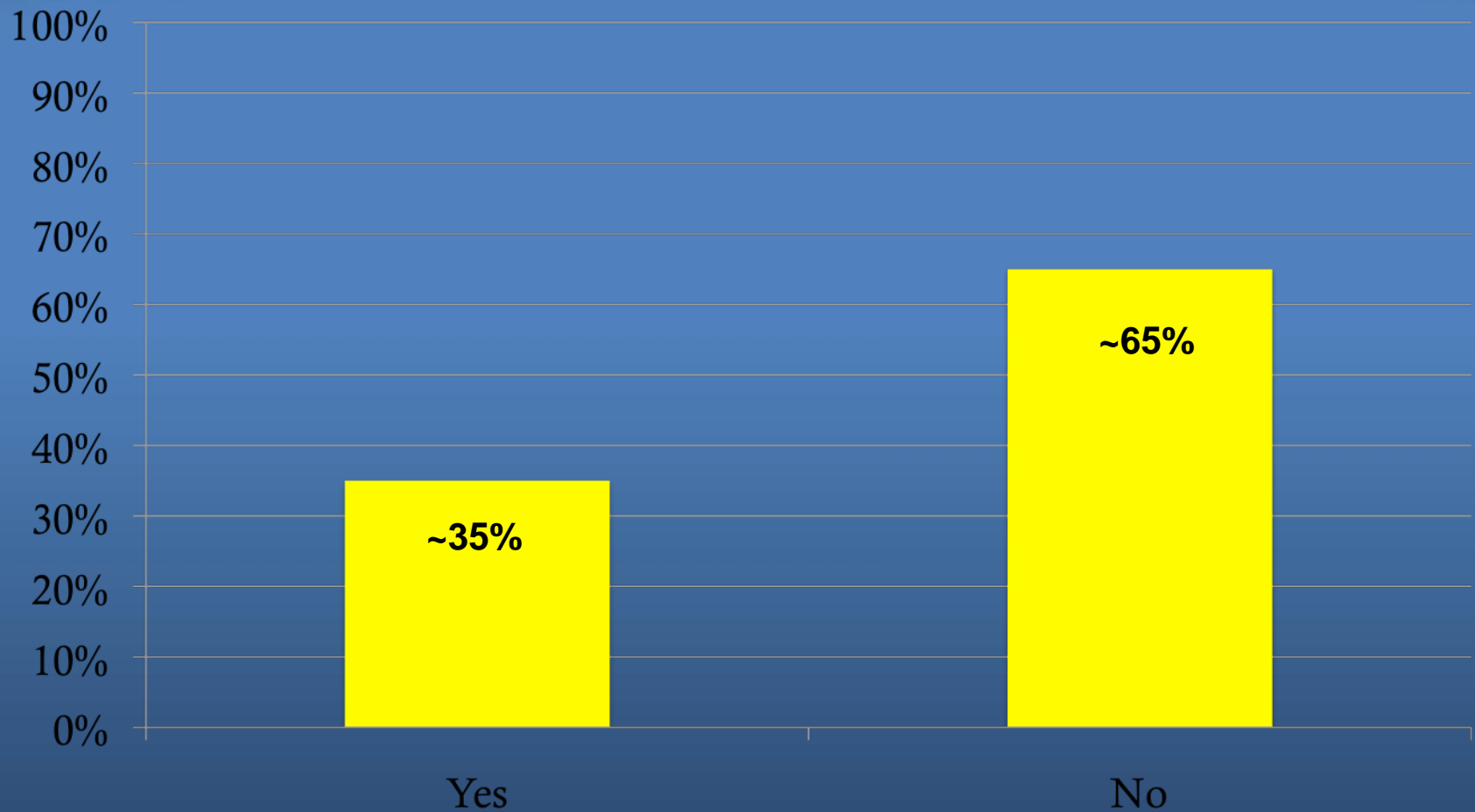
Pre CARE Project Workshop Survey Results

**Evidence-based...we need data!**

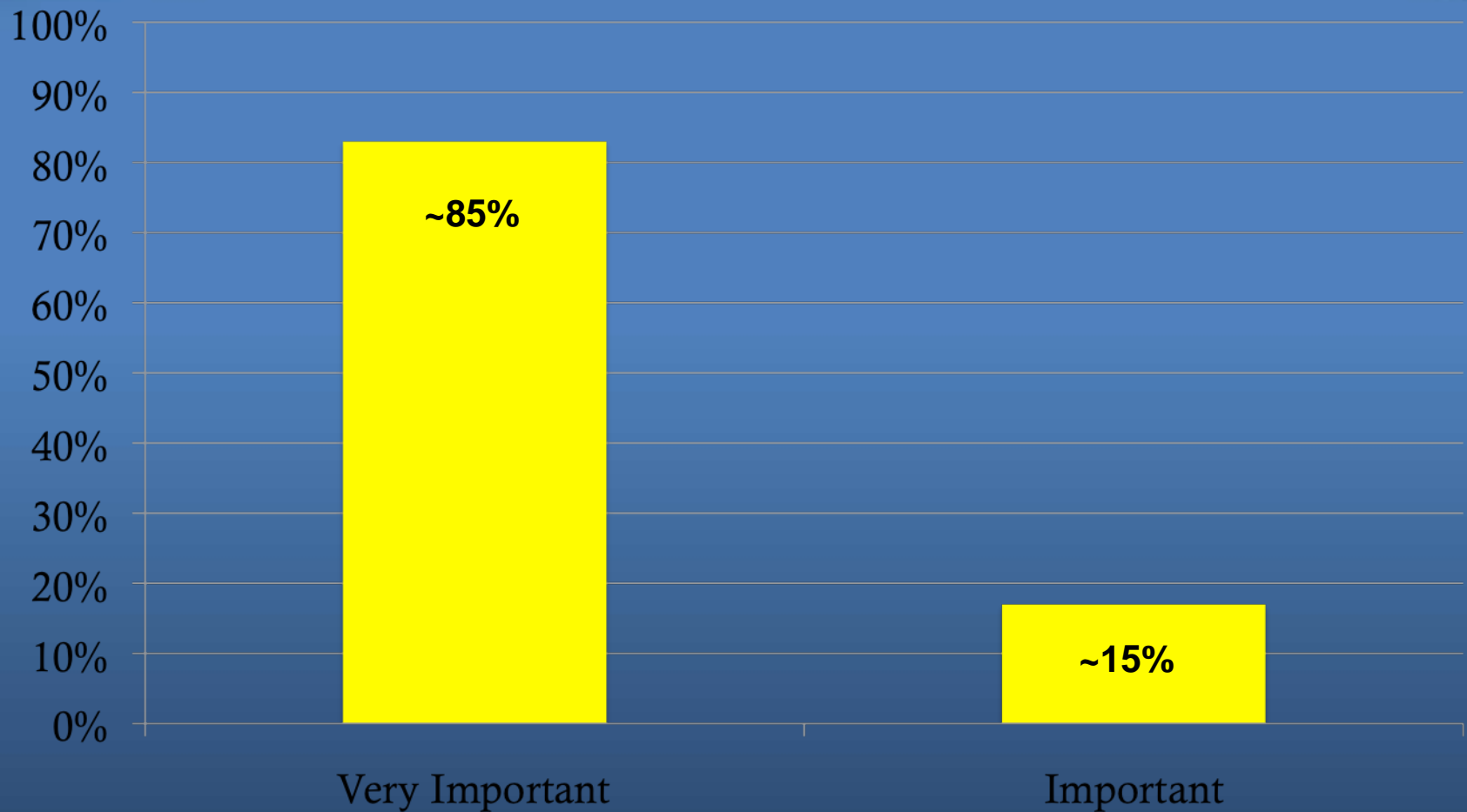
# Experience With Counseling



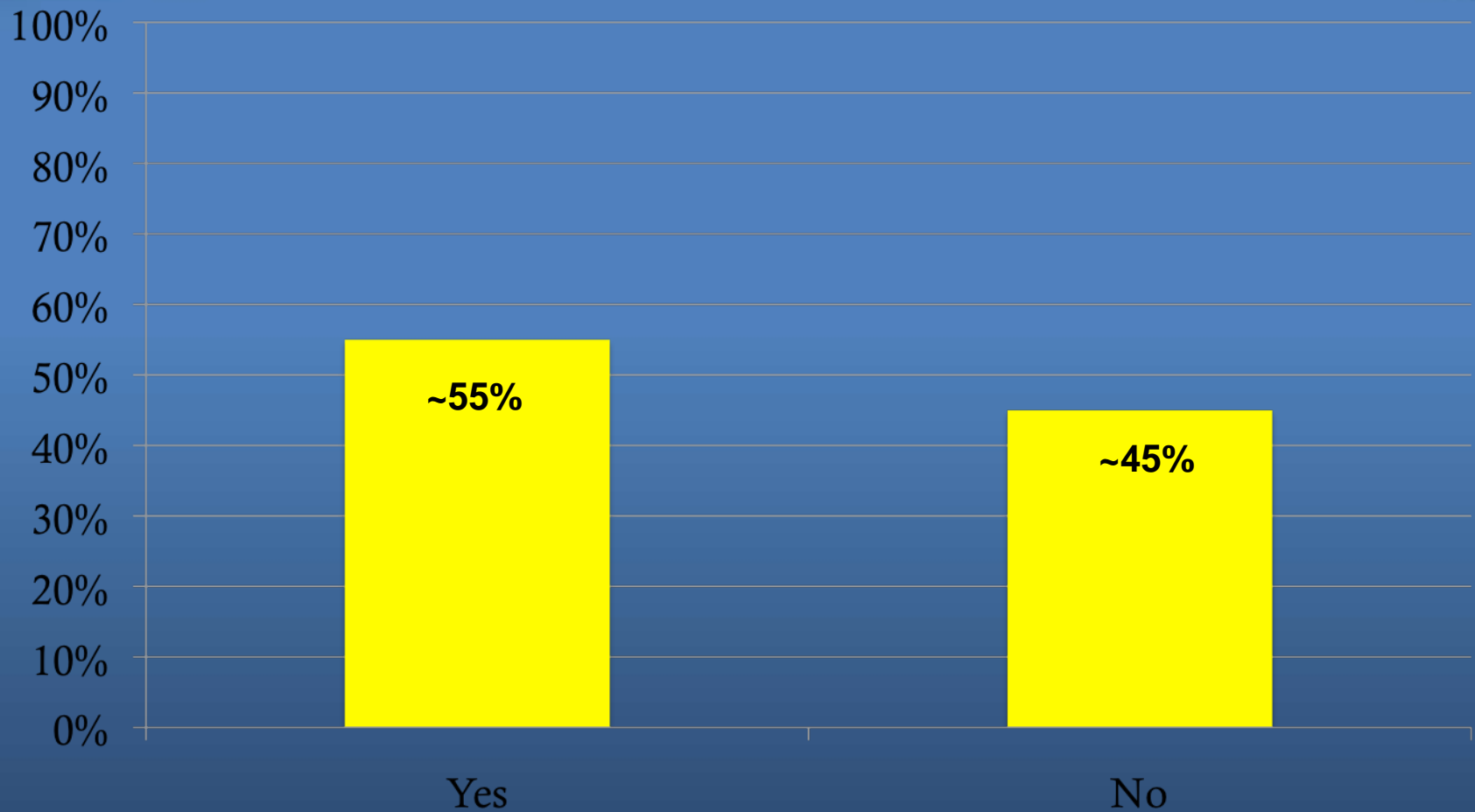
# Trained to Counsel Parents



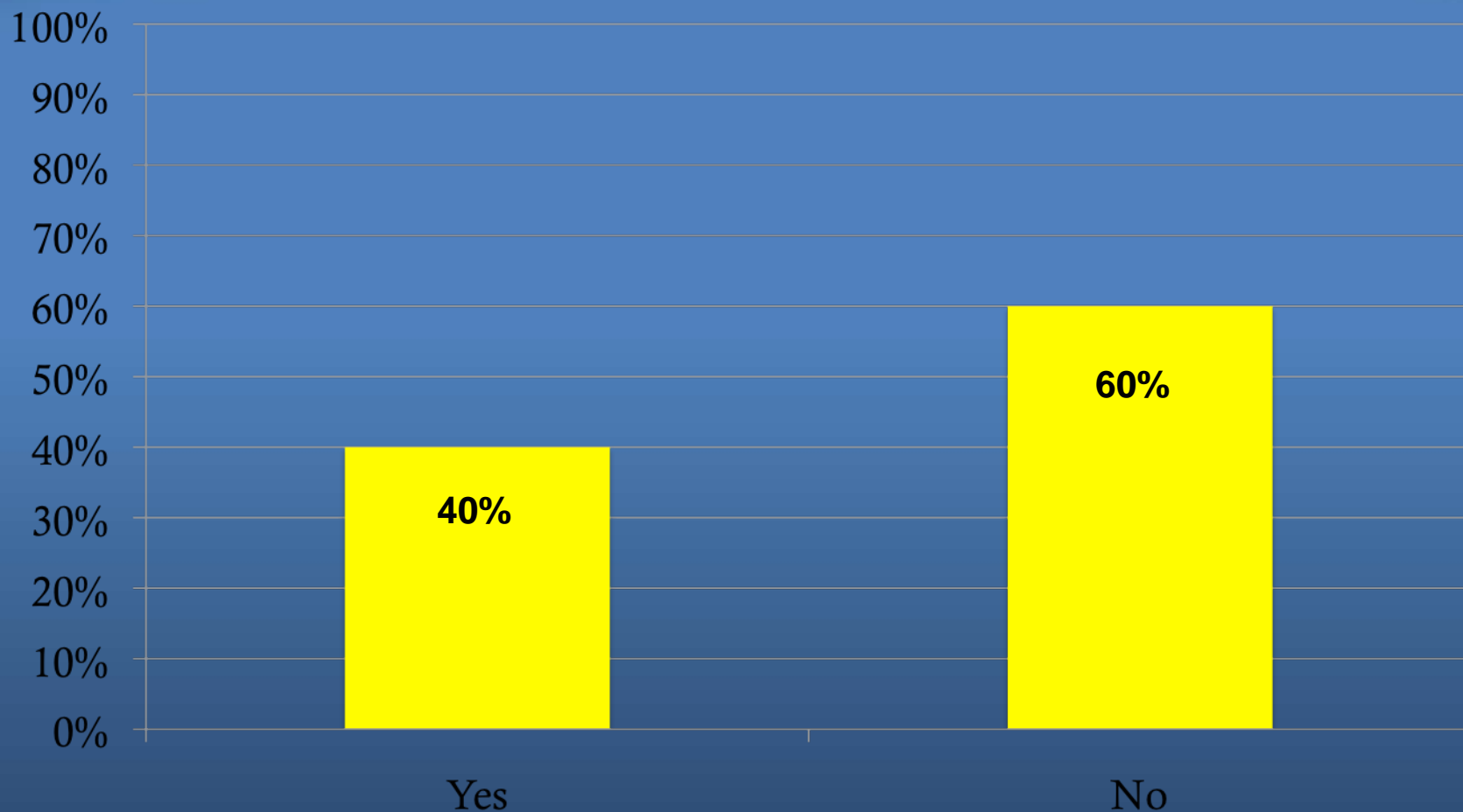
# Importance of Parent Counseling



# Comfortable Counseling Parents

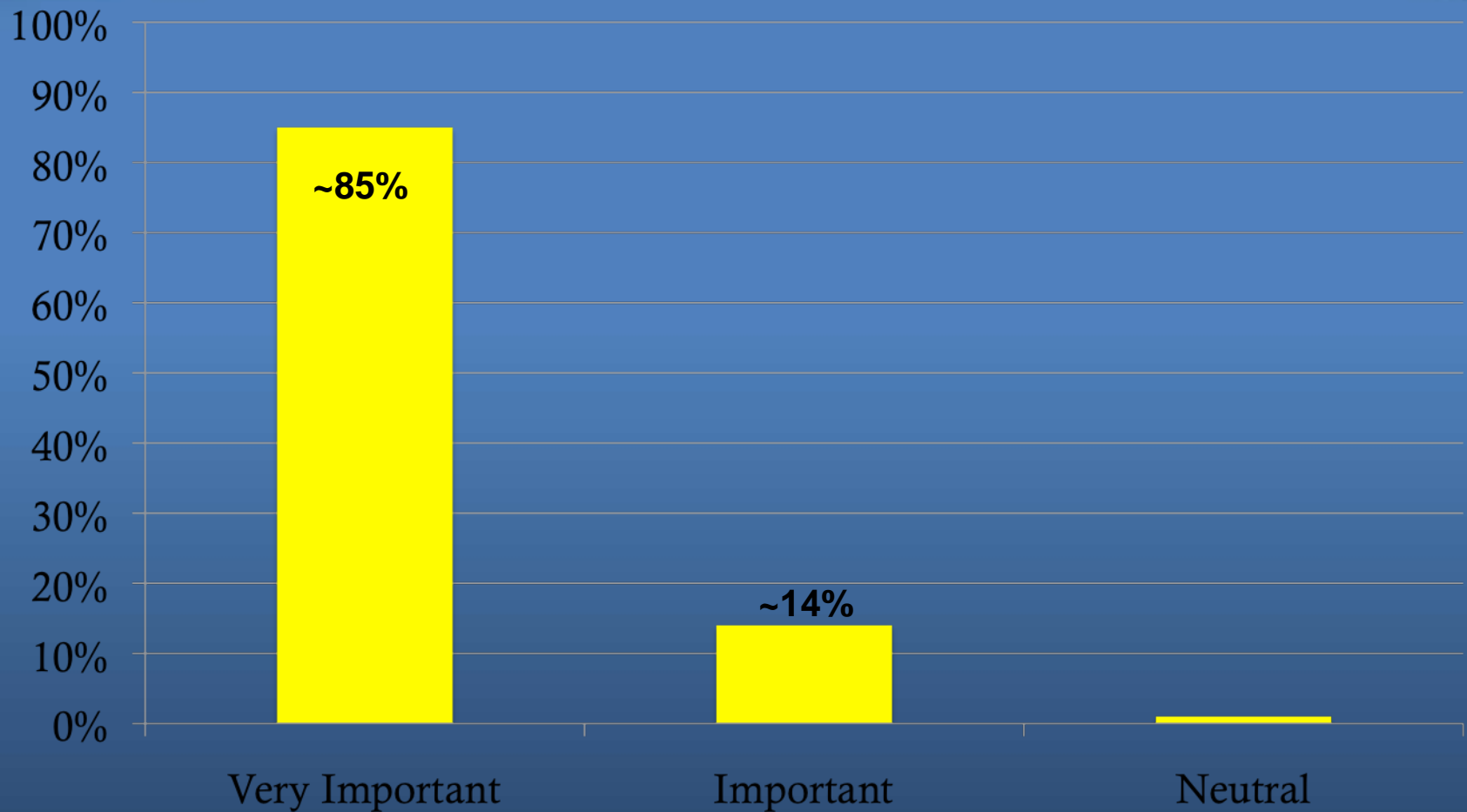


# Trained to Counsel Children

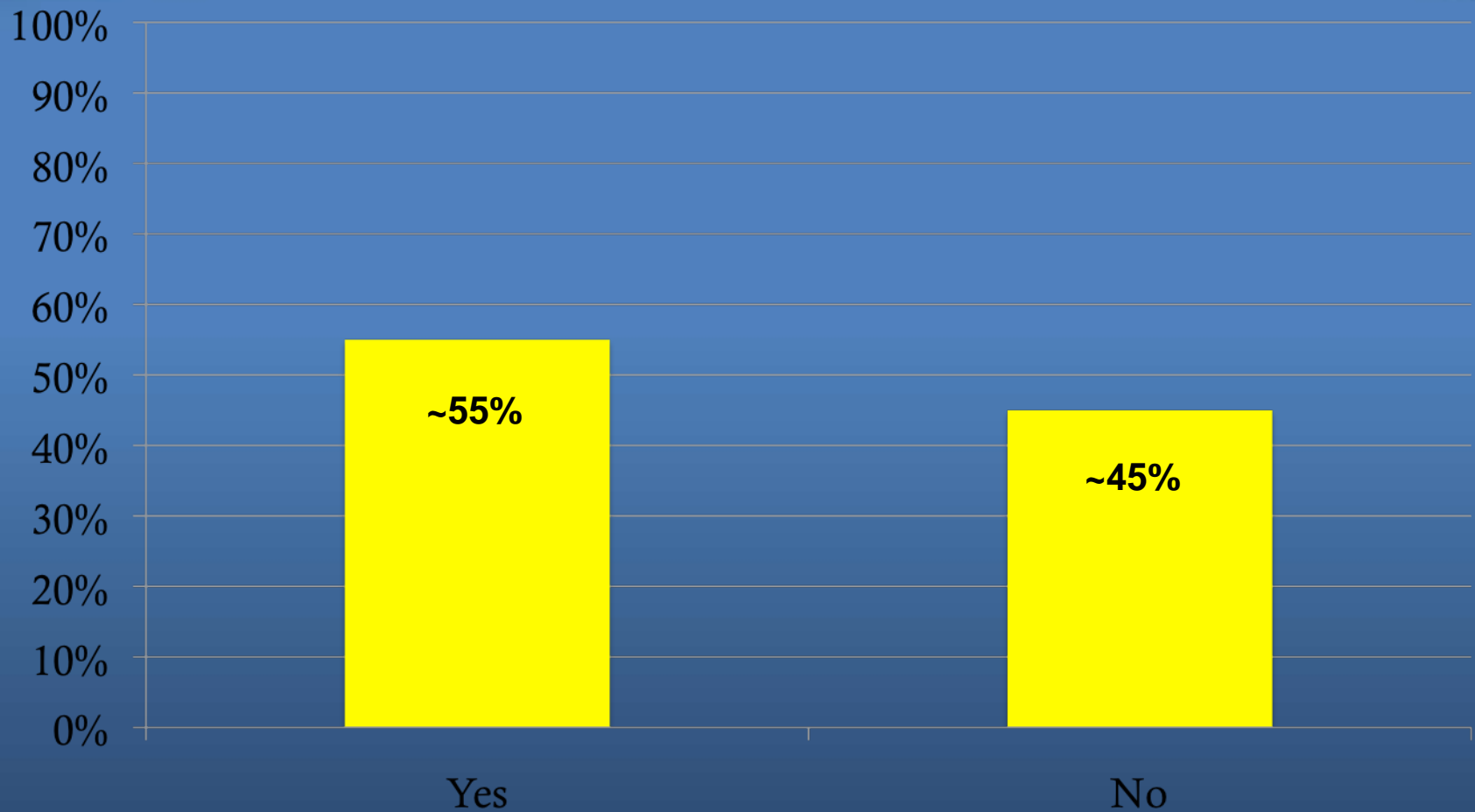




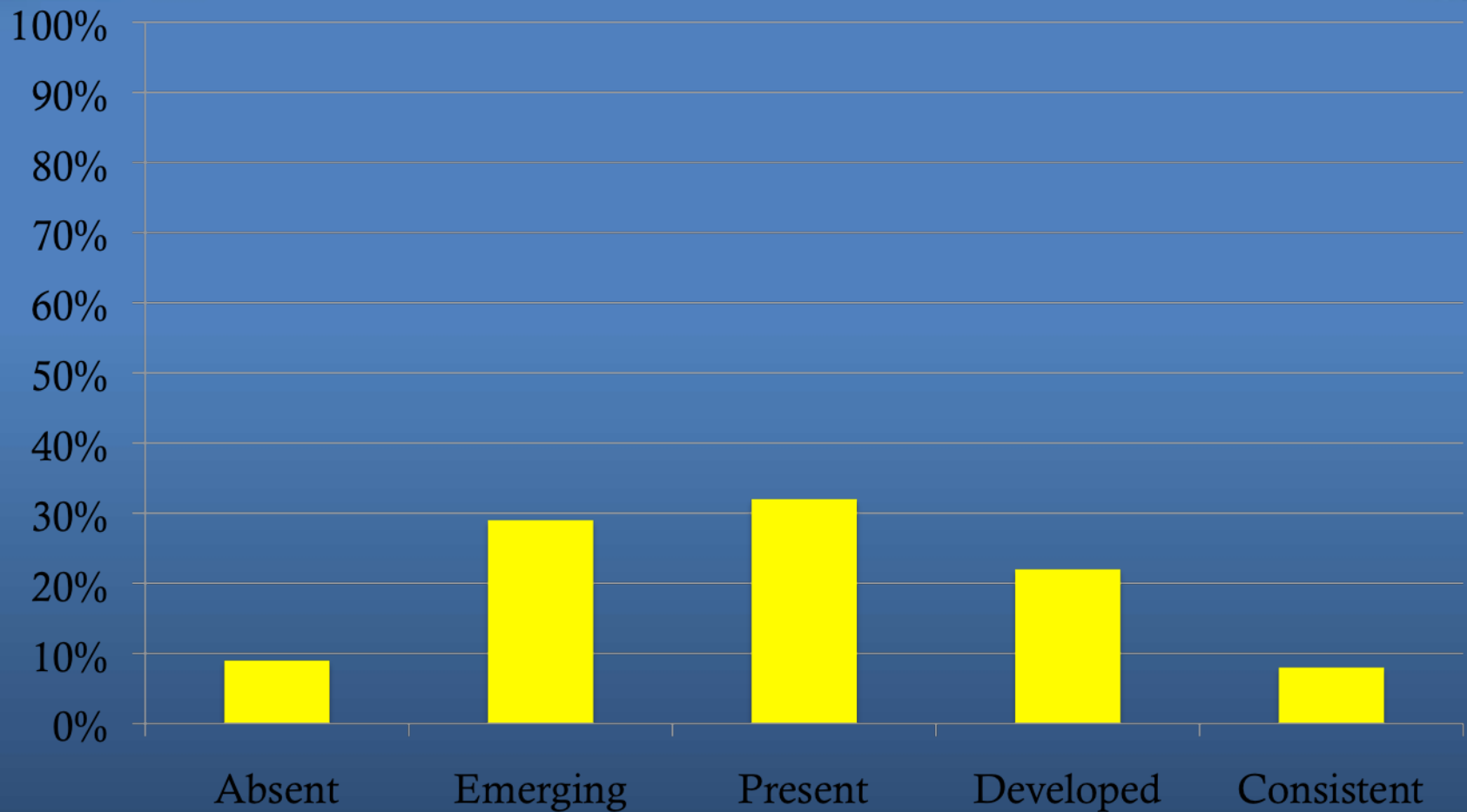
# Importance of Child Counseling



# Comfortable Counseling Kids



# Counseling Skills Ratings



# Your Role in Counseling

- Informational: traditional role and usually great at it
- Adjustment: new/expanded role and often not trained or comfortable with it

# Roles & Responsibilities of Hearing Health Professionals (Adjustment Counseling)

- Adjustment Counseling....
- ASHA (2008) - *Guidelines for Audiologists Providing Informational and Adjustment Counseling to Families of Infants and Young Children With Hearing Loss Birth to 5 Years of Age*
- ASHA (2007) - *Scope of Practice in Speech-Language Pathology*

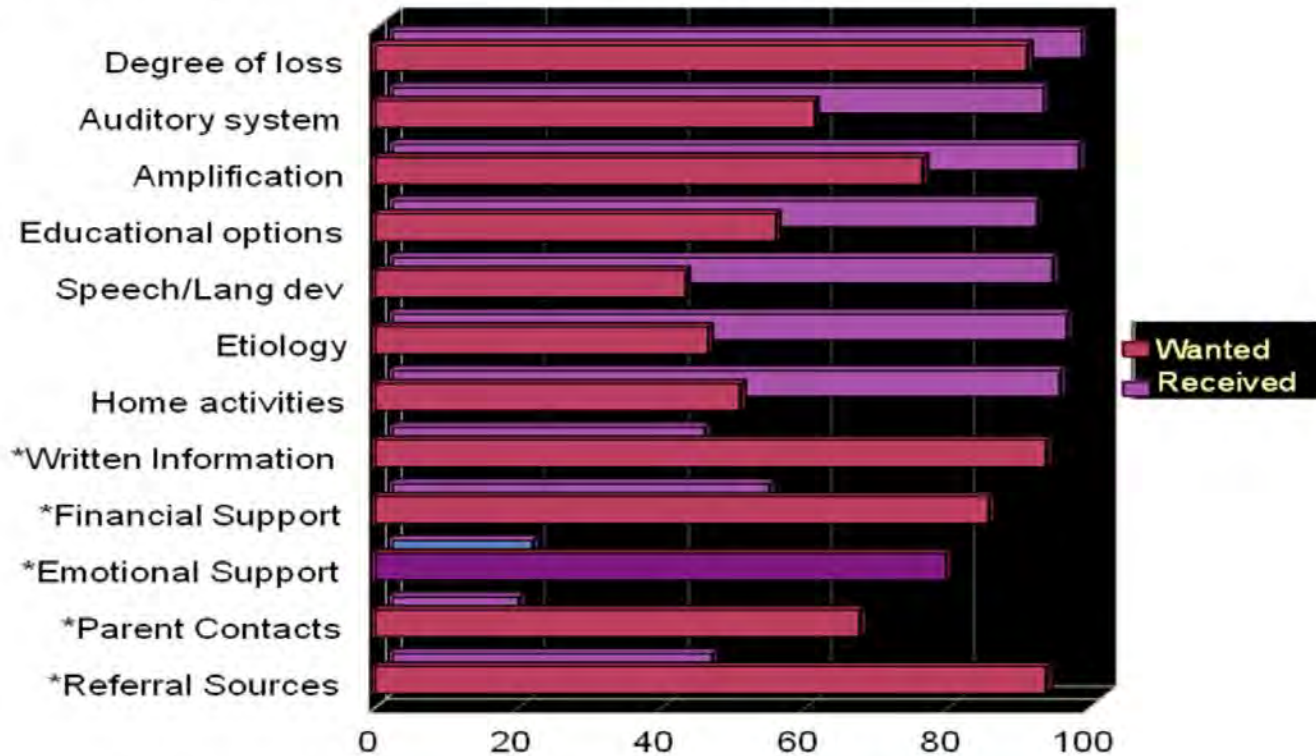
*Is there a gap between what we are expected to do and what we are trained to do?*

90-95% of parents who have children born deaf and hard of hearing are normal hearing themselves.

# PARENTS WANT EMOTIONAL SUPPORT

# What Parents Want vs Receive

## Information Wanted vs. Received by Parents at Hearing Loss Confirmation



Martin, George, O'Neal, & Daly (1987); \*Sweetow & Barrager (1980)

Slide provided by David Luterman via Karen Anderson.

A large, smooth, blue curved shape that starts from the left edge, arches upwards, and then curves back down towards the right edge, creating a wide, shallow arc. It has a slight gradient, being darker blue at the bottom and lighter at the top.

The journey is lifelong.....

# THE JOURNEY BEGINS



# Attachment (Bowlby, 1986)

- Bond is established before birth between parent and child
- Expectation that the baby will be
  - Perfect
  - Normal
  - Wonderful
  - Disability free
  - Disease free

# Until the Baby is Born

- David Luterma n, 2013 Lecture
  - Cloak of invincibility
  - “Nothing happens to us”
    - But if you live long enough, something will!
    - If not, then something already did!
- \*Is this true as the child grows up?
  - EI, PreK, Elem, Middle, High School, etc.???



The unexpected....

# BREAKING THE NEWS

# The process begins

- Parents learn something different than what they expected
- Professionals “dump” lots of information on the parents (it’s our job!)
- Parents are not usually allowed time to process emotional reactions
- Professionals feel uncomfortable/untrained and may not have the time to deal with emotions

# Flight or Fight

- When faced with shocking news, humans go to a different place in the brain
- Memory function shuts down
- Information is not processed
- Yet professionals tend to overwhelm parents with information
- This, in turn, can lower self-esteem

David Luterman, Lecture, 2013



Sorrow

Mourning

Distress

Deep emotional outpouring

**Initial responses....**

Suppress

Avoid

Spousal conflict

Cry

Communicate

Seek counseling

Isolate

**HOW DO  
PARENTS/FAMILIES  
INITIALLY HANDLE  
FEELINGS?**

Information “dumping”

Avoidance

Dismiss it

Nervously talk

Tell them how to feel

Tell them what you would do

“It could be worse”

“Everything will be fine”

# HOW DO PROFESSIONALS HANDLE EMOTIONS WITH FAMILIES?



# Professionals' Responses

- Professionals cannot be successful with parents/clients' feelings if unable to deal with parent/client feelings
- Feelings just “ARE”
  - Cannot be controlled
  - Behavior CAN be controlled
- NEVER feel sorry for your clients
- Grief is a part of the human experience



# Impact on Professionals

## JANE MADELL, PH.D.



**PARENTS AND  
PROFESSIONALS MUST  
BECOME PARTNERS**



GRIEF

# Grief

- A process
- A part of life
- Common to all people
- Comes and goes
- Can have a positive outcome
- Affects people in different ways
- Impacts families AND professionals

A large, solid blue curved shape that starts from the left edge, curves upwards and to the right, and then curves back down towards the right edge, creating a wide, shallow arc that occupies the bottom half of the slide.

When the unexpected happens!

# GRIEF COMES IN DIFFERENT FORMS

# When the Unexpected Happens

- Critical illness diagnosis
- Loss of a pet
- Inability to have children
- Body image issues
- Divorce
- Failure at school/Failure at work
- Loss of job
- Learning your child has hearing challenges

# News of Hearing Status

- NHS: pass, refer, follow up
- Getting a confirmed diagnosis: how long can this step take?
- Rapid transition to early intervention: must make a lot of decisions quickly
- Immediate use of hearing technology
  - Short term
  - Long term



# Hearing Technology: Emotional?

- Hearing aid choices
- Ear molds
- Batteries
- Accessories
- Assistive technology (FM, etc.)
- Maintenance, care and repairs
- Longevity of devices
- CI

A large, solid blue curved shape that starts from the left edge, curves upwards and then downwards to the right, creating a wide, shallow arc that fills the bottom two-thirds of the frame. The top of the arc is slightly irregular, suggesting a hand-drawn or layered effect.

MEET BELINDA CATTRELL

# Parent Reactions to Technology

- Overwhelmed
- Confused
- Frustrated
- Happy
- Relieved
- ????

# Triggers and Transitions

- Service models
  - Changing agencies: EI to PreK to School
  - Changing schools: Elem to Middle to High
- For the student
  - Early years: more parent focused
  - Teens/tweens: more individual focused
- For the audiologist
  - Transfer ownership of HL from parent to child
  - Develop trust with student

Men

Dads

Couples

Women

Moms

Siblings

Individuals

Deaf Culture

Extended Family

Cultural Ethnicity

**ARE THERE  
GENDER/SPOUSAL, FAMILY  
AND/OR CULTURAL  
DIFFERENCES?**

A large, solid blue curved shape that starts from the left edge, curves upwards and then downwards to the right, creating a wide, shallow arc that fills the lower two-thirds of the slide. It has a slight gradient and a soft shadow effect.

Sexton, 2010

# EMOTIONAL STAGES

Stunned

Traumatized

Upset

Numb

**SHOCK**

Jolted

Hysterical

Thrown a curve ball

Blown away

This can't be happening to us  
Not my child  
It can't be true  
They must be mistaken

Rejection  
Disbelief

**DENIAL**



Realizing the truth

A state of anguish

Ache

Hurt

**PAIN**

Tortured

Wounded

Suffering

Undone

Mad

Blaming

Lashing out

Furious

Irritated

Displeased

Bitter

Outraged

**ANGER**

It sinks in

It is true

You feel really, really bad

# DEPRESSION

Desolate

Gloomy

Sense of hopelessness

Embrace the truth

Allow

Realize

Admit

Acknowledge

Begin to find peace within

Begin to find peace with others

Recognize

# ACCEPTANCE

Move beyond acceptance  
Ensure the child has every opportunity  
Strive to have a successful and happy life

Move forward  
Support  
Advance

# ADVOCACY



Grief may return over the lifespan

May not go through all stages

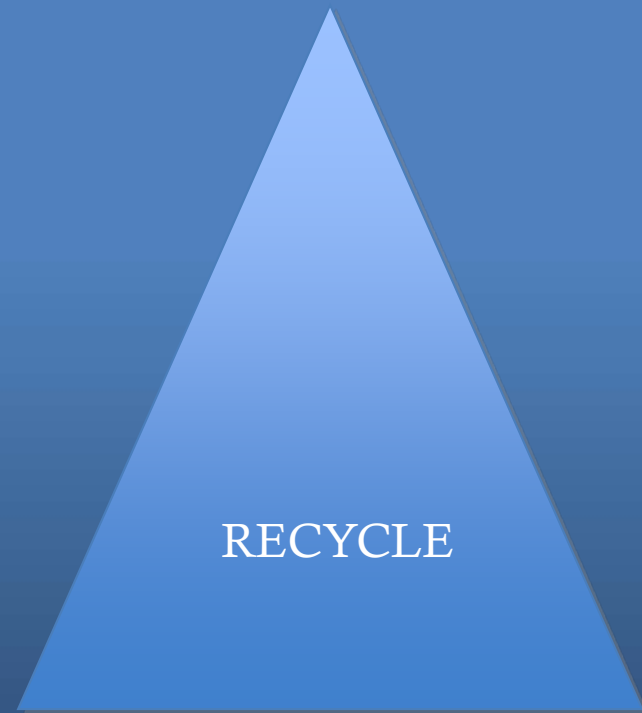
No one “exits” the process, never to return

**RECYCLE**

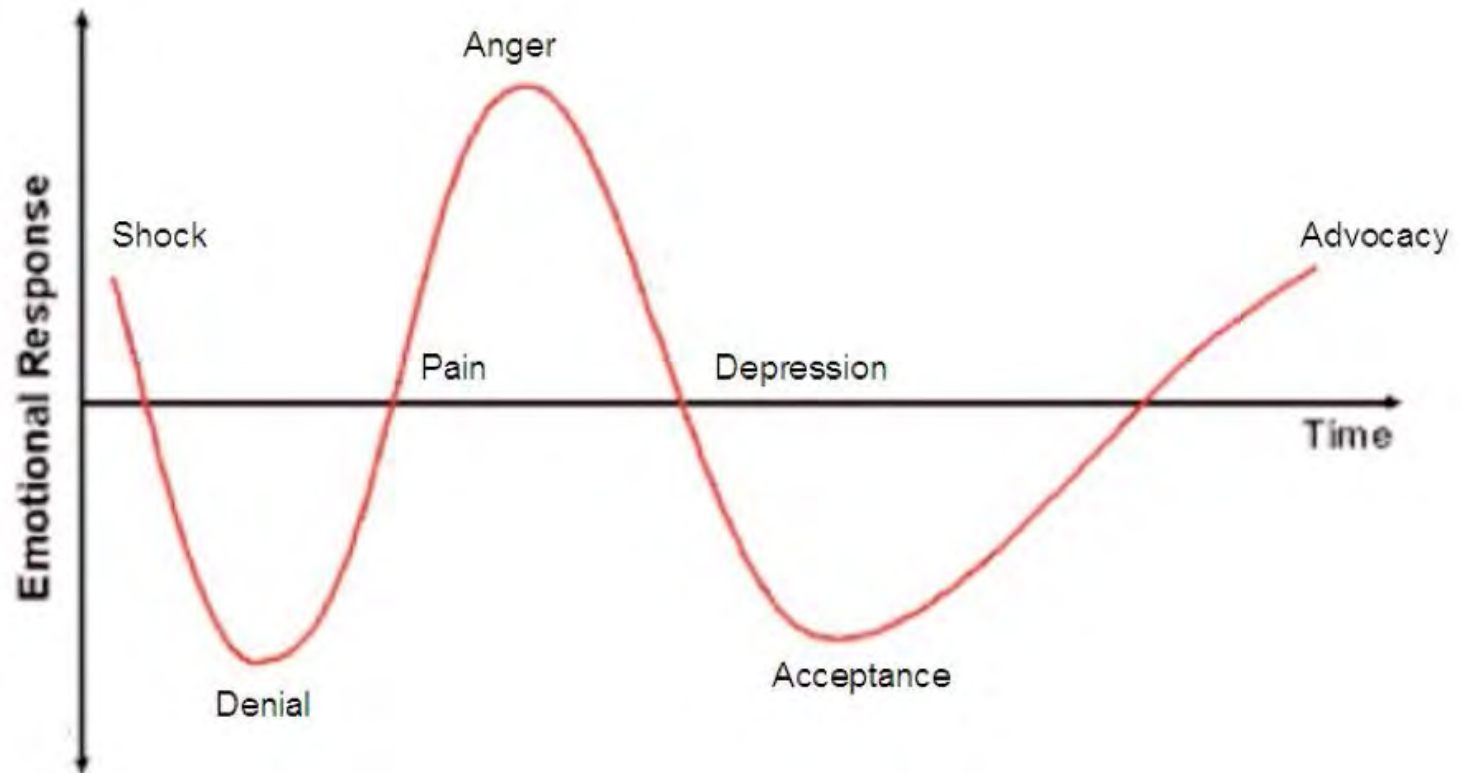
# Emotional Stages

## Sexton, 2010

- Shock
- Denial
- Pain
- Anger
- Depression
- Acceptance
- Advocate



# Emotional Responses





# Other words?

- Guilt
- Confused
- Frustrated
- Ambushed
- ????



From Pain Comes a Lot of Growth

**FROM GRIEF COMES  
RESILIENCE...**

Kenneth Frazier, NBCC & NC Licensed Counselor

**“IF YOUR DREAM DOESN’ T  
COME TRUE.....  
CREATE A NEW DREAM!”**

# Resilience

- The positive capacity for people to cope with stress and adversity (Masden, 2009)
- *A process*, not a trait (Rutter, 2008)
- Hardiness, mental toughness, resourcefulness
- Positive adaptive behavior when faced with stress or trauma (Luthar et al, 2000)



WHAT CAN WE DO?

A blue curved banner with the word ENCOURAGE in white serif font.

ENCOURAGE

# 10 Ways to Build Resilience/ APA

- Maintain good relationships
- Avoid seeing stressful events as unbearable problems
- Accept circumstances that cannot be changed
- Develop realistic goals
- Develop self-confidence
- Look at the bigger picture

# 10 Ways to Build Resilience/ APA

- Take decisive action in adverse situations
- Look for opportunities of self-discovery
- Expect good things and visualize positive outcomes
  - Vision boards
- Take care of one's mind and body





Enhance Listening Skills

**LISTEN**



Focus on Active Listening and Shared Experiences

# The CARE Project



“I have learned a great deal from listening carefully.  
Most people NEVER LISTEN.”

**ERNEST HEMINGWAY**

# Engage In Active Listening

- Don't respond with information
- Be the “other adult”
- Acknowledge/validate what is said by parents/family
- Guide towards discussion
- Don't lecture
- Don't tell what you would do if it were you
- Don't create co-dependencies....families need to take ownership of what is happening

# Nonverbal Listening Strategies

- Be quiet
  - Let the other person talk
- Maintain eye contact
  - Look at the person
  - No distractions: cell phones, computers, etc.
- Display openness
  - Body language

Brzeziski, 1998

# Nonverbal Listening Strategies

- Listen without response
  - Let them finish
- Send acknowledgement
  - Give signals that you hear what they are saying

# Verbal Listening Strategies

- Feed back meaning
  - Paraphrase
  - Summarize
  - Restate
- Listen beyond words
  - Observe body language and comment
  - Encourage parents to relax in meetings



PROBE



# What Do Parents Need Help With?

- Do you know your child's hearing status?
- Do you understand your child's technology?
- Do you have good resources for support?
- Can you talk about your child and needs with others (i.e., teachers, neighbors, etc.)?

# What Do Teens Need Help With?

- Understanding and managing their own technology
- Understanding their own hearing loss
- Socialization

A large, solid blue curved shape that starts from the left edge and curves upwards and to the right, filling the bottom half of the image. It has a slight gradient and a soft shadow effect.

CONNECT

# Connect With the Community

- Share information from parents with community service providers
- Set up a network for resources
- The CARE experience can create connectedness beyond the group and into the community

A large, solid blue curved shape that starts from the left edge, curves upwards and to the right, and then curves back down towards the bottom edge, resembling a stylized wave or a large parenthesis. It occupies the lower half of the page.


SHARE

# Sharing Family Stories

- Each person has a story to tell/share
  - Individually/one on one
  - Groups
  - At home as a family
- Share those stories
- Results in group discussion/interaction
- Ultimately creates a sense of
  - Community
  - Connectedness
  - Comfort

# Take the Lid Off the Box!





Describe a time in your life when the unexpected happened  
Don't put your name on it  
Paying it forward

**It's your turn**



A large, solid blue curved shape that starts from the left edge, curves upwards and to the right, and then curves back down towards the bottom right corner, creating a wide, shallow arc that frames the text.

# SETTING THE STAGE

Film segments

**HEARING IS ONLY ONE  
AMONG OTHER LIFE ISSUES  
WITHIN A FAMILY**



Using the Grid

# ACTIVE LISTENING



The Hosley Family  
Wylene, Robin, Tanner, Mark,  
Luci, Ella, Bob

# Who is The CARE Project for?

- Parents/families
  - One on one meetings with parents
    - Share filmed stories of others
    - Private time to discuss feelings and insecurities
  - Parent groups
  - Family activities for home
- Professionals/Pre-professionals
  - Sensitivity Training/Staff Development
  - Audiologists, speech language pathologists, teachers, counselors...all professionals who work with these families

# The CARE Project Tools

- Brings
  - a family together
  - families together
  - communities together
  - professionals together
- Options
  - Retreats
  - Journaling
  - Community events
  - Workshops





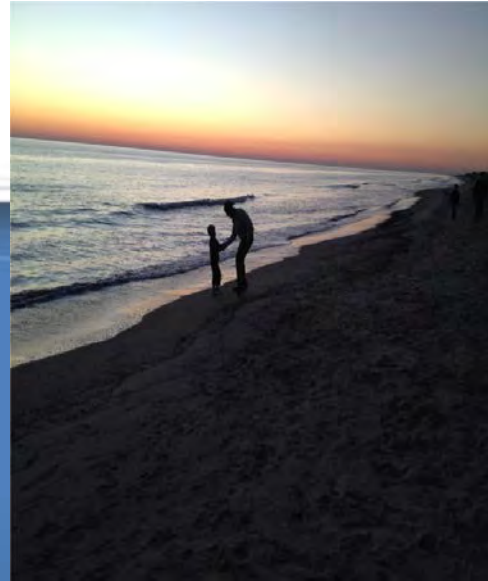
# IMPLEMENTATION



# Adjustment Counseling

- One on one with parents
- Parent to parent
- Support group for families
  - Families, Dads, Moms, Teens, Younger children, siblings, etc....
- Professional staff development and sensitivity training
- Parents and Professionals together





# PARENT SUPPORT GROUPS

# Key Points

- Involve leader parents
- Find a reason to meet
- “Feed them and they will come”
- Utilize filmed parent stories to start each meeting
- Give them a reason to talk: ice breakers
- Give them a reason to return

# Use Ice Breakers



- Tell us your name
- Why are you here?

# Use Ice Breakers

- Small groups of 2 people each
- Separate from your own family member
- Within each group
  - Pair up
  - Ask each other to share 3 things about his/her family
  - Report to entire group



# RETREATS

# Retreat Mission

- Families work through the emotional process
- Families share their journey with others
- Help parents reach acceptance
- Encourage advocacy with compassion
- Allow kids who are deaf and hard of hearing to connect with each other



# Retreat Experiences

- Family Retreat Experiences
  - Bring families together for a few days to share.
  - Volunteer staff (Audiologists, SLPs, Teachers, Grad Students)
  - Families
    - Core families: early in the process
    - Mentor families: further along in the journey

# Retreat Agenda

- Social
  - Free time for families with children
  - Dads' group
  - Moms' group
  - Teens/kids' group
  - Sibs' group
  - Family picnic without staff (bonding time)
  - Group dinner with all staff and families



# Retreat Agenda

- Educational Seminars (parents only)
  - Counseling/Journaling
  - Audiology
  - Speech-Language Pathology
  - Technology
- Planned children's activities
  - Field trips
  - Learning songs (video)
  - Art activities

# Retreat Agenda

- Filming family stories
  - Parents sign up
  - Voluntary
  - Meet in the afternoon with Media Director
  - Private opportunity to share
  - Major emotional breakthroughs occur



# RETREAT VOLUNTEER EXPERIENCE

# Retreat Volunteer Experience

- Professionals
- Young adults who are deaf and hard of hearing
- Parents/families with life experiences
- Counseling experts
- Camp leaders for activities
  - Chef for cooking lessons
  - Surfing coach
  - Artist



# JOURNALING

# Journaling

- Journaling: Journals to Resilience
  - Video
  - Written/Virtual
  - Benefits
    - Record thoughts
    - Review those thoughts
    - Helps solve problems
    - Gain clarity
    - Verify progress over time

# Journaling

- Journaling
  - Guidelines for writing
    - What happened?
    - How did you feel about it?
    - What did you do about it?
  - Have parents send you journal entries
    - Allows review and interaction
    - Stimulates discussion
    - Creates a stronger bond between parent and professional

# Journaling

- Sharing your journal entries
  - In-person review of journal entries
  - Virtual sharing....emailing journal entries and providing feedback
  - Video journaling....review video segments and provide feedback/comments





The Fergusons, Rachael Sievers, The Haleys

# VIDEO JOURNAL STORIES

# THE CARE PROJECT



*World Premiere Documentary Film Event*

**EXTRAVAGANZA**

Tickets for sale at  
[www.brooklynartsnc.com](http://www.brooklynartsnc.com)

6:30 P.M.      SEPTEMBER 23, 2011  
BROOKLYN ARTS CENTER  
516 N. 4<sup>TH</sup> ST., WILMINGTON, NC



## COMMUNITY EVENTS

# Community Events

- Film “premieres”
- Partner with community arts events
  - Theatre productions
  - Art openings
- Create your own event
  - Fundraisers
  - Awareness campaigns
  - Marathons/walking, running



A large, solid blue curved shape that starts from the left edge, curves upwards and then downwards to the right, filling the bottom half of the slide. It has a subtle gradient and a slight shadow effect.

# WORKSHOPS

# Workshops

- Create local family support groups
- Create local teens/tweens support group
- Provide professional continuing education opportunities
- Bring families AND professionals together for a workshop event



# Summary

- Encourage
- Listen
- Probe
- Connect
- Share
- Implement
  - Retreats
  - Journaling
  - Community events
  - Workshops

# So, What is The CARE Project?





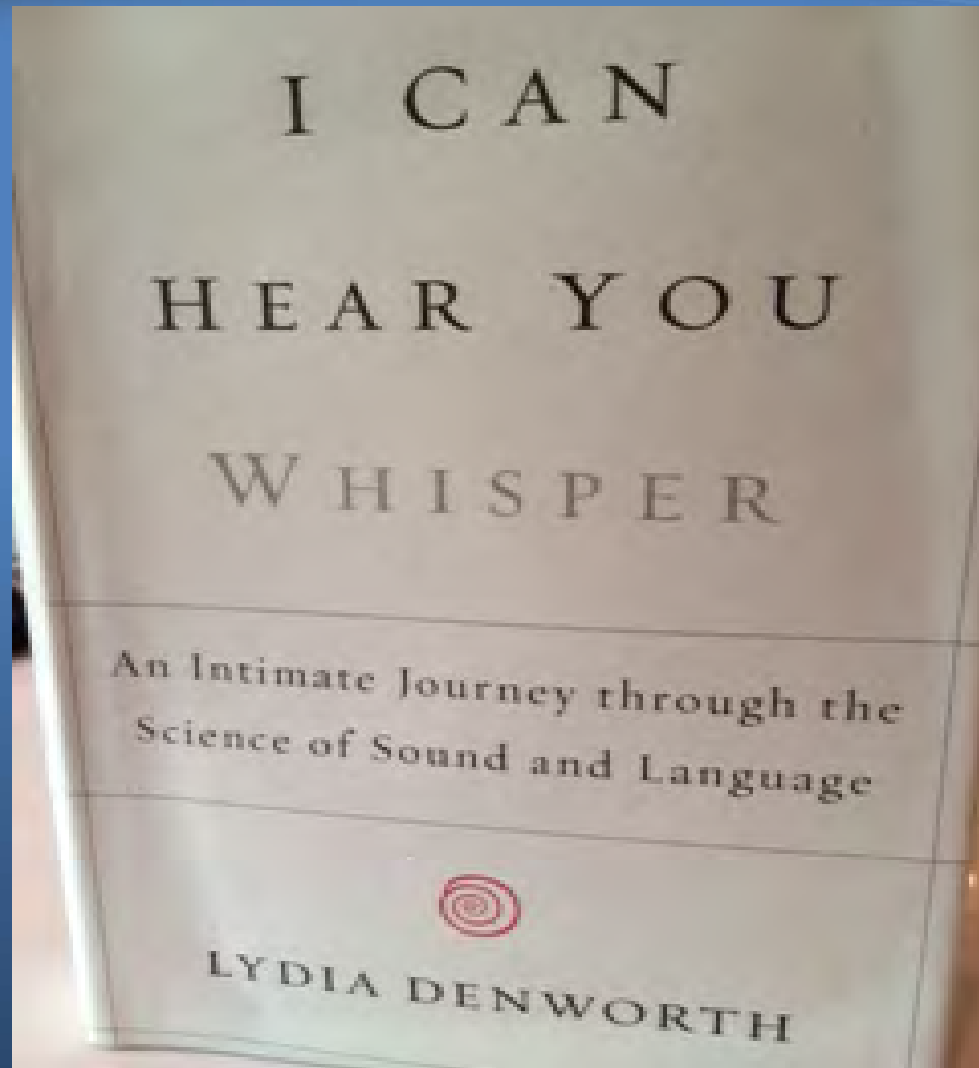
A large, solid blue curved shape that starts from the left edge, curves upwards and then downwards to the right, forming a wide, shallow arc that occupies the lower half of the slide. The top of the slide is white.

# POST-WORKSHOP SURVEY

# CARE Partnerships

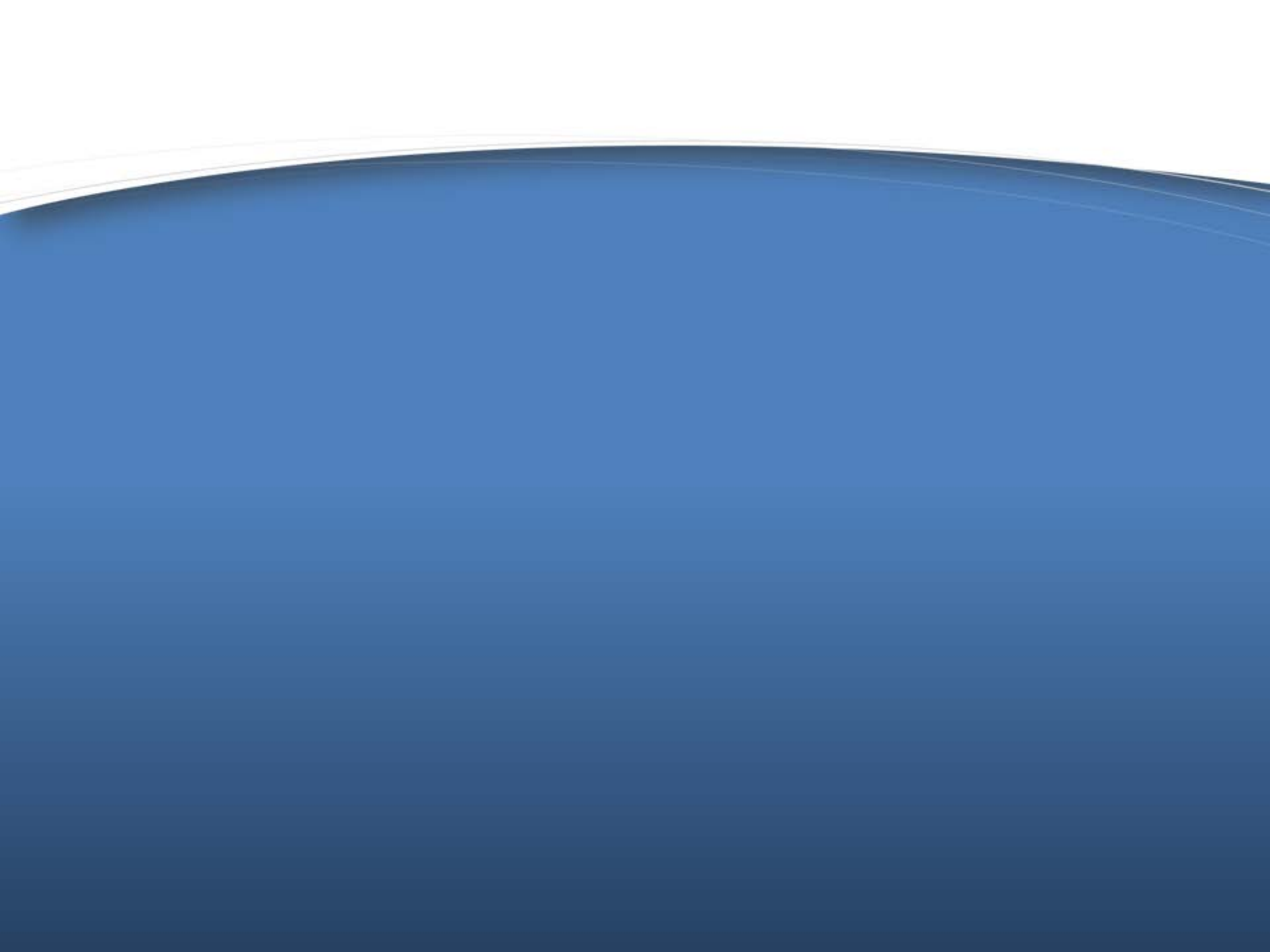
- EHDI Programs
- School Districts
- Early Intervention
- Part C
- NHS
- Universities
- Hospitals
- International

# Resources



# Resources

- “Counseling-Infused Audiologic Care”
  - John Greer Clark
  - Kris English
- Hands & Voices
- AG Bell Chapters
- NCHAM ([www.infanthearing.org](http://www.infanthearing.org))



# Role of Service Coordinator

- Refer families to community resources for counseling supports
- Connect families with Hands & Voices Guide By Your Side
- Offer connections to other community resources
  - Special Kids Network
  - Elks Home Service Program
  - Parent to Parent of PA
  - Community Support Group
  - Hands & Voices of PA
  - National organizations – American Society for Deaf Children, AG Bell, National Cued Speech Association
  - PA Deaf-Blind Project



Remember.....

**HEARING IS ONLY ONE  
AMONG OTHER LIFE ISSUES  
WITHIN A FAMILY**

# *CARE* is a Beacon of Hope for Families and Professionals

Sheds light on emotional issues of hearing loss and its impact on families, caregivers and professionals



Artwork: “Baldydelic” by Xris Kessler, acrylic on canvas, 2009.



# Thank You!

johnnie@thecareproject.com

[www.thecareproject.com](http://www.thecareproject.com)

Find us on Facebook