

The *CARE* Project



The Journey to Hope and Resilience

Johnnie Sexton, Au.D.
Executive Director
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!**

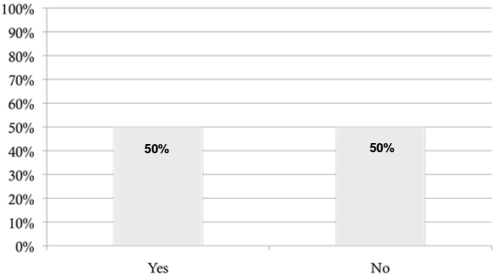
Documentary film overview

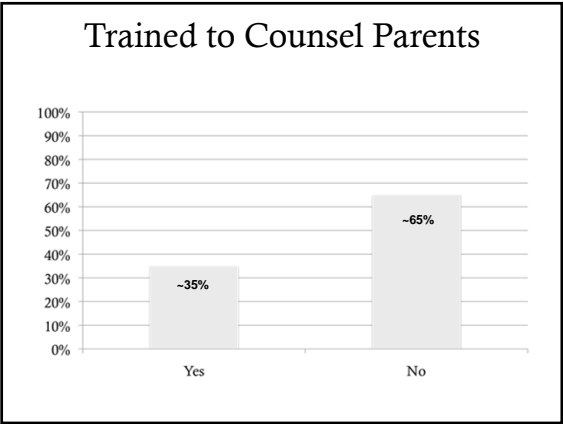
THE CARE PROJECT

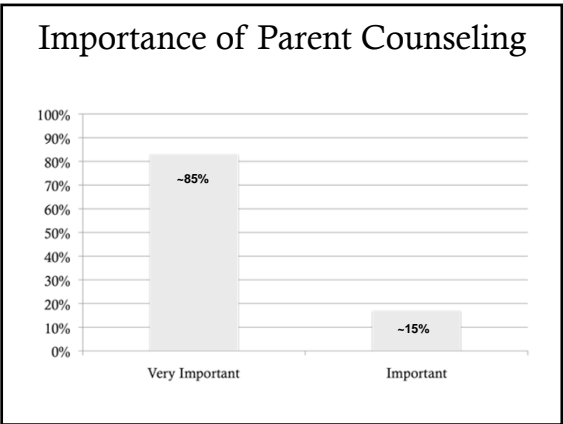
PRE-WORKSHOP SURVEY

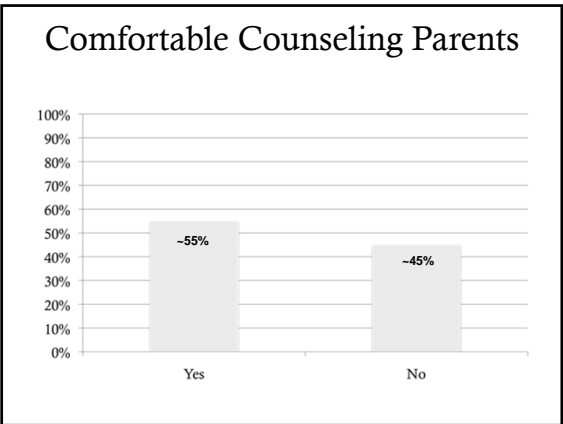
N = 624 (08-01-2015)
Pre CARE Project Workshop Survey Results
Evidence-based...we need data!

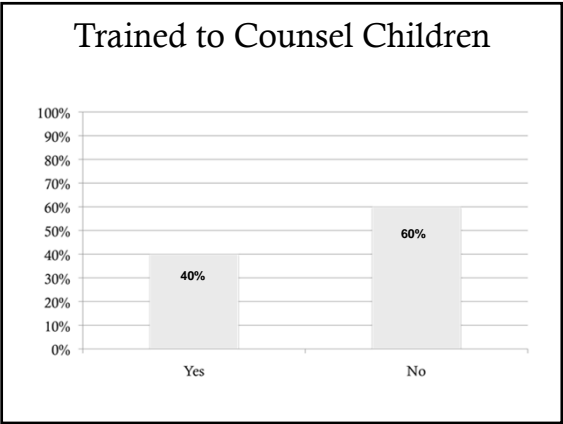
Experience With Counseling

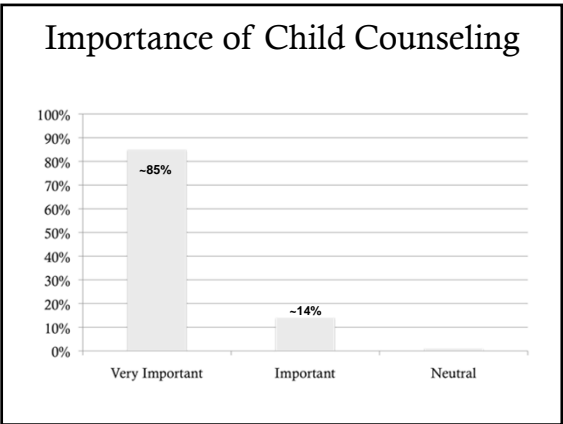


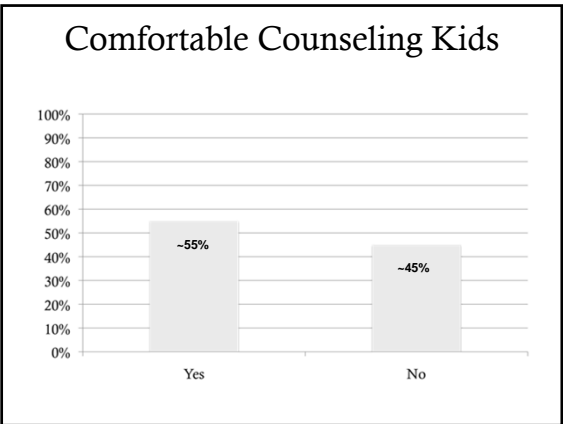




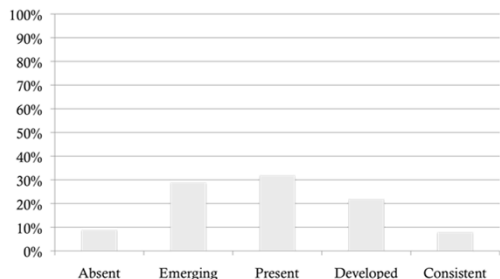








Counseling Skills Ratings



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*

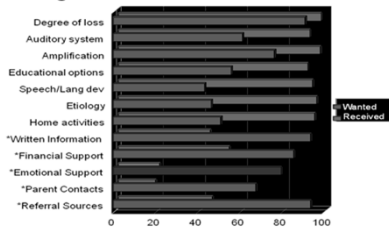
Is there a gap between what we are expected to do and what we are trained to do?

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.

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 Luterman, 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

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

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?**

Sexton, 2010

EMOTIONAL STAGES

Stunned
Traumatized
Upset
Numb

Jolted
Hysterical
Thrown a curve ball
Blown away

SHOCK

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

ANGER

Irritated
Displeased
Bitter
Outraged

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

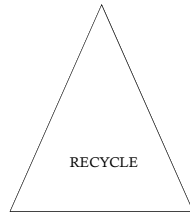
May not go through all stages

No one "exits" the process, never to return

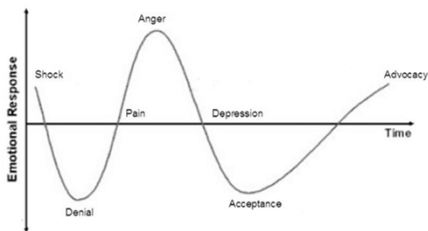
RECYCLE

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 (Madsen, 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?

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

Brzeziski, 1998

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

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

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

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

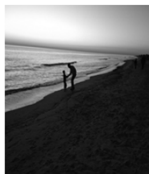




IMPLEMENTATION

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

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

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 | • Implement |
| • Listen | – Retreats |
| • Probe | – Journaling |
| • Connect | – Community events |
| • Share | – Workshops |

So, What is The CARE Project?

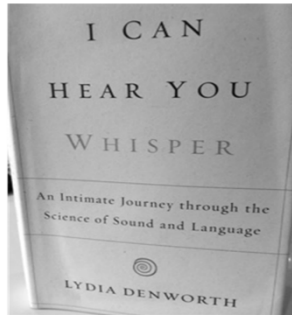


POST-WORKSHOP SURVEY

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)

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

Find us on Facebook
