

The *CARE* Project



Counseling, Aural Rehabilitation and Education

Developed by

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www.thecareproject.me

Sorrow

Mourning

Distress

Deep emotional outpouring

WHAT IS GRIEF?

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 GRIEF WITH FAMILIES?

**HOW DO
PARENTS/FAMILIES
HANDLE GRIEF?**



PARENT/FAMILY PERSPECTIVE

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

Kris English, Ph.D.

BREAKING BAD NEWS

The process begins

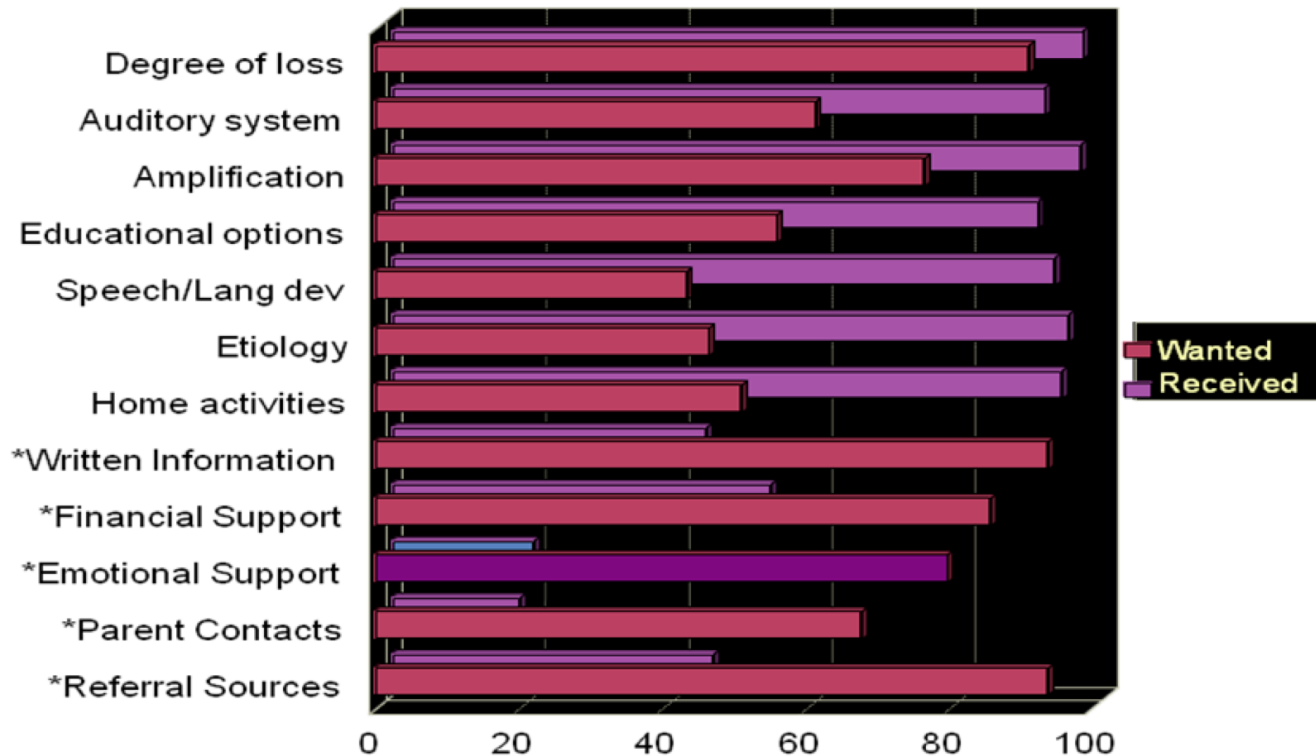
- Parents learn their child isn't "perfect"
- Professionals "dump" lots of information on the parents
- Parents are not usually allowed time to process emotional reactions
- Professionals feel uncomfortable/untrained and may not have the time to deal with emotions

Grief

**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.



**PARENTS AND
PROFESSIONALS MUST
BECOME PARTNERS**



GRIEF



**GRIEF COMES IN
DIFFERENT FORMS**

Grief

- A process
- A part of life
- Common to all people
- Comes and goes
- Affects people in different ways
- Impacts families AND professionals involved

Examples of Grief

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

Sexton, 2010; English, 2002; Kubler-Ross, 1970

STAGES OF GRIEF

Stunned to hear the news!

SHOCK

This can't be happening to us

Not my child

It can't be true

They must be mistaken

DENIAL

Realizing the truth
A state of anguish

PAIN

Mad

Blaming

Lashing out

ANGER

It sinks in

It is true

You feel really, really bad

DEPRESSION

Embrace the truth

Begin to find peace within

Begin to find peace with others

ACCEPTANCE

Move beyond acceptance

Ensure the child has every opportunity

Strive to have a successful and happy life

ADVOCACY

Grief may return over the lifespan

May not go through all stages

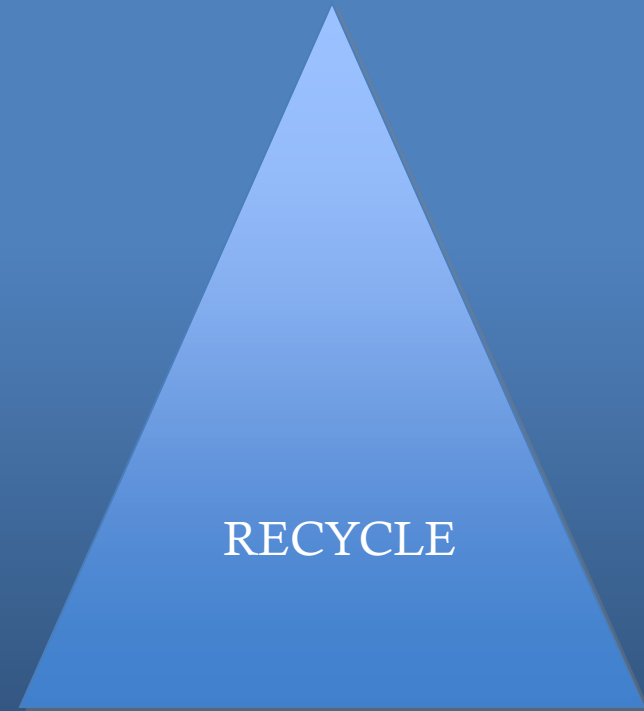
No one “exits” the process, never to return

RECYCLE

Emotional Stages of Grief

Sexton, 2010

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



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

CARE focuses on 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
- Be active in listening
- Don't create co-dependencies

CARE...shared experiences

- Each person has a story to tell/share
 - Individually/one on one
 - Organize groups/pair up strangers
- Ask them to share the story with each other
- Report back to the group
- Use those key points to facilitate group discussion
- Creates a sense of community/connectedness/comfort in others

CARE Documentary Film: Different Perspectives

- Culturally Deaf Adult
- 7 year old identified through NHS
 - his parents
 - his grandmother
- Hard of Hearing Adult with Hearing Aids
- Deaf Adult with Cochlear Implant
- Hearing Daughter of deaf adult
- Hearing Son of deaf parents
- Teacher/counselor
- Mother of deaf/blind child

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.

The CARE Project Status

- Phase One completed and launched
 - March, 2010
- Initiate pilot project (schools, universities, hospital/clinics, EI programs, etc.)
 - Winter, 2010
- Establish Living Journal
 - Winter, 2010
- Documentary film premiere events
 - East Coast (Fall, 2011)
 - West Coast: San Francisco (Spring, 2011)

To date, over 100 people have contributed to The CARE Project process and the work continues in the United States. In 2011, CARE will be established in other countries.

IT TAKES A VILLAGE

Thank You!

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