



# Supporting Families of Children with Hearing Loss

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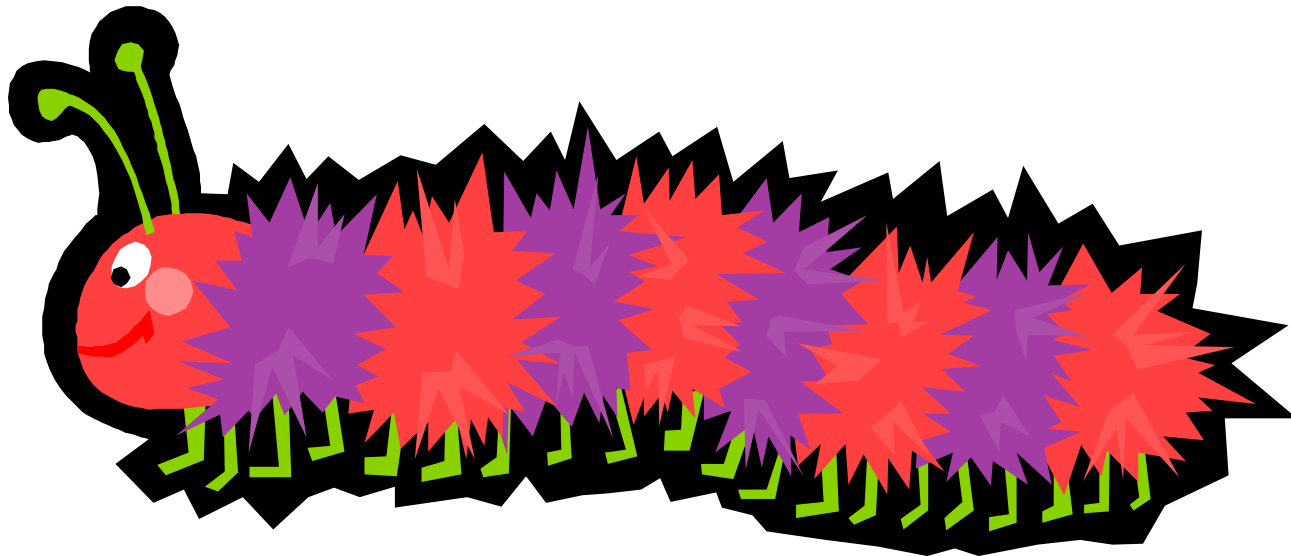


# Session Goals

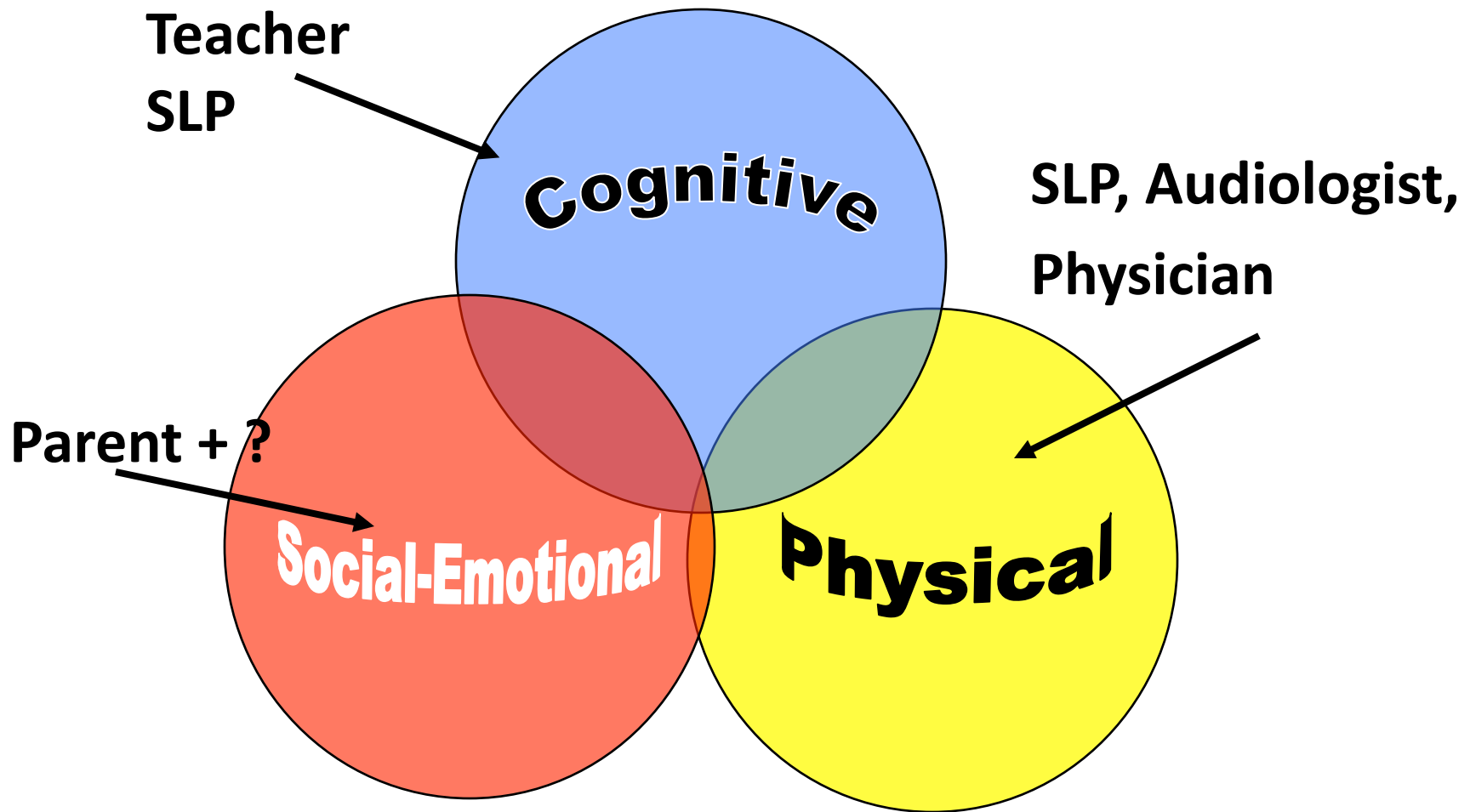
- Describe specific strategies for “delivering the diagnosis”
- Discuss “grief” and the emotions that often accompany the diagnosis of HL
- Share counseling guidelines that were designed to support families following the diagnosis of hearing loss

# Who am I?

CATIPIHLER *“CHOP’s Assessment and Treatment Implementation Program for Infants and toddlers with Hearing Loss - Enhancing (Re) habilitation”*



# Child Developmental Model



# Family Wellness Program



Louise Montoya, M.A., LPC, CSC

# Pediatric Counseling Guidelines

- Impact of diagnosis on a family
- Psycho-Social development
  - Erik Erikson's model of development
  - Development of self-concept (15 mos+)
  - Development of social skills

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# Impact of Diagnosis

- Sharing information
- Recognizing emotional reactions
- Promoting healthy attachment
- Positively impacting family systems

# Sharing Information

*Audiological Counseling Evaluation*  
*“ACE”*

Kris English and Susan Naeve-Velguth

<http://gozips.uakron.edu/~ke3/ACE.pdf>

# Informing Parents - A.C.E.

- Getting started
  - Privacy - no barriers - tissues - organized
  - Comfort - walked them into room, children - distracting?
  - Stated the purpose of the next part of the visit



# Informing Parents - A.C.E.

- Breaking the news
  - Connecting - eye contact, facial expression, body language
  - Terminology
  - Avoiding creating doubts about test results
  - **Wait for response after giving the news**

# Informing Parents - A.C.E.

- Assessing parent's understanding of and the reaction to the situation
  - **Acknowledge emotional reactions**
  - Let the parent guide the amount of information - detail and language
  - Let parents set the pace - check for understanding
  - Give information tailored to parent's concerns

# Informing Parents - A.C.E.

- Eliciting concerns
  - Invite questions
  - **Respond to both content and emotional aspects of concerns that are expressed**



# Informing Parents - A.C.E.

- Give a time frame for action
  - Describe the “next steps”
    - Follow-up appts
    - Connection with early intervention
    - Amplification
  - Invite to include others in next appt

# Informing Parents - A.C.E.

- Give suggestions for specific activities
  - Log of responses to sounds
  - Provide written/video information
  - **Offer connection with other parents**
  - Encourage parents to sustain bonding process
  - John Tracy clinic



# Informing Parents - A.C.E.

- General considerations
  - Show warmth - sense of commitment - convey hope
  - Competent and caring professional manner
  - Discussed painful topics sensitively
  - Tailor the pace to suit the parent
  - Effectively managed time

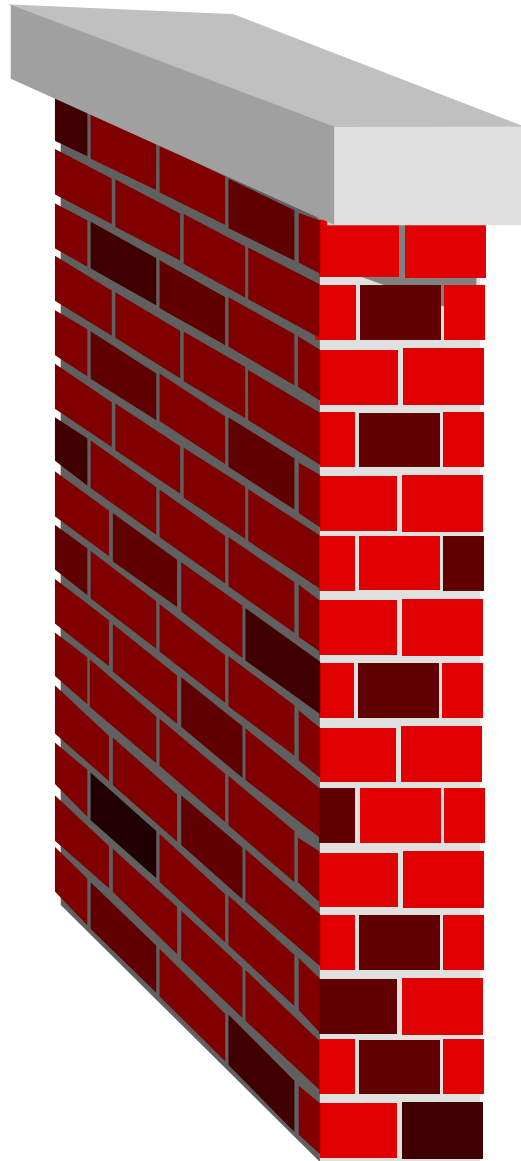
# Impact of Diagnosis

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“I don’t remember anything  
you said that day after you  
told me that my daughter has  
a hearing loss.”

**Information**

**Support**



**Shock**

**Anger**

**Sadness**

**Grief**

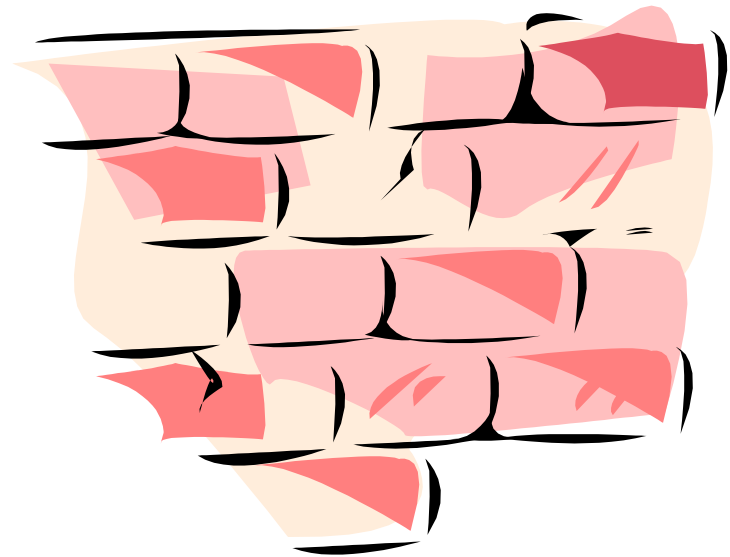
**Denial**

**Guilt**

# Recognizing Emotional Reactions

## Feelings Involved with Grief

- Shock/Denial/  
Numbness
- Anger/Fear/Panic
- Sadness/Hopeless
- Guilt/Bargaining
- Healthy acceptance



# Grief

- **Good grief:** Core pain can't be taken away.
  - It must be acknowledged, expressed in a safe, caring environment.
  - Some emotions have an important purpose in helping parents adjust to the diagnosis
- **Strong feelings of inadequacy**
  - Many parents happy to turn over their child to “the experts”
  - Professionals eager to rescue

Luterman, (1999)

# Feelings Involved with Grief

- Shock/Denial/Numbness
  - Numbness to protect parents from deep pain
  - Allows parents to build up energy for the work ahead of them

# Feelings Involved with Grief

(continued)

- **Deep anger:** Parents feel cheated. Anger hides their fear
  - Many professionals are very afraid of the anger and respond defensively
  - Helps parents get things done
  - Need to help parents capture and direct their energy effectively

Luterman, (1999)

# Feelings Involved with Grief

(continued)

- **Sadness/Hopelessness**
- When parents begin to feel safe, they begin to feel **guilty**:
  - Fathers for not protecting the family
  - Mothers because she secretly believes she's at fault for the hearing loss
  - Comes between the marriage, family becomes unbalanced (Mother+child, father+work)
  - Danger is overprotection of child. Conveys helplessness to the child

Luterman, (1999)

# Parents with Unresolved Grief Can Be:

- Emotionally overwhelmed
- Stuck in anger
- Frequently suppressing their emotions
- Depressed or passive
- Unrealistic or stuck in denial
- Disorganized, confused
- Actively searching for the cause of the hearing loss

Yoshinaga-Itano, (2001)

# Professionals Can Help Parents Resolve Grief by:

- Providing immediate, appropriate support
- Having appropriate counseling skills
- Having expert knowledge and experience with living with hearing loss
- Actively listening
- Not judging the family
- Build parental self-esteem, self-confidence

Yoshinaga-Itano, (2001)

# What can we help parents understand:

- The etiology, emphasizing that cause was not parents' intention
- Their child is not fragile.
- Their child can do anything, but, may have to do some things differently.
- That taking good care of themselves and their marriage = taking good care of their child.

Luterman, (1999)

# Parents who Positively Resolve Their Grief:

- Report a change in their emotions since initial diagnosis
- Can move on in life, and suspend their search for the reason
- Can provide accurate representations of their child's abilities

Yoshinaga-Itano, (2001)

# Healthy Acceptance

## Parents:

- Acknowledge their preference that their child not be deaf/hard of hearing
- Accept the permanence of the hearing loss
- Understand and have entire family **take consistent action** to make necessary changes create accessible/effective communication environment for deaf/hard of hearing child



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# Healthy Attachment

## *Between Parents and Children*

- Deep enduring connections established between child and caregiver
- Occurs between birth and age 3
- Learned ability
- ***Result of ongoing reciprocal interactions*** characterized by ***protection, need fulfillment, limits, love*** and ***trust***

# Healthy Attachment Can Lead to Development of:

- Basic trust and reciprocity
- Self-regulation of affect and behavior
- Healthy identity = healthy self-worth + autonomy
- Morality based upon empathy, compassion and conscience
- Resourcefulness and resilience for response to future stress
- Stimulating experiences required for healthy brain development

# Potential Consequences of Insecure Attachment:

## Self-regulation deficits:

- Impulse control
- Self-soothing
- Initiative
- Perseverance
- Inhibition
- Patience

# Potential Consequences of Insecure Attachment:

Development of problem behaviors:

- Impulsiveness
- Hyperactivity
- Inattention
- Seeking stimulation
- Poor self-image
- No friends
- Oppositional and defiant
- Disruptive
- Manipulative
- Blames others (internalized helplessness)

# What can you do?

- Inform parents that:
  - Teach parents about the importance of healthy attachment
  - Support them through the feelings associated with grief
  - Help them understand the impact hearing impairment has on communication – avoid misunderstanding communication difficulties

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# Healthy Family System

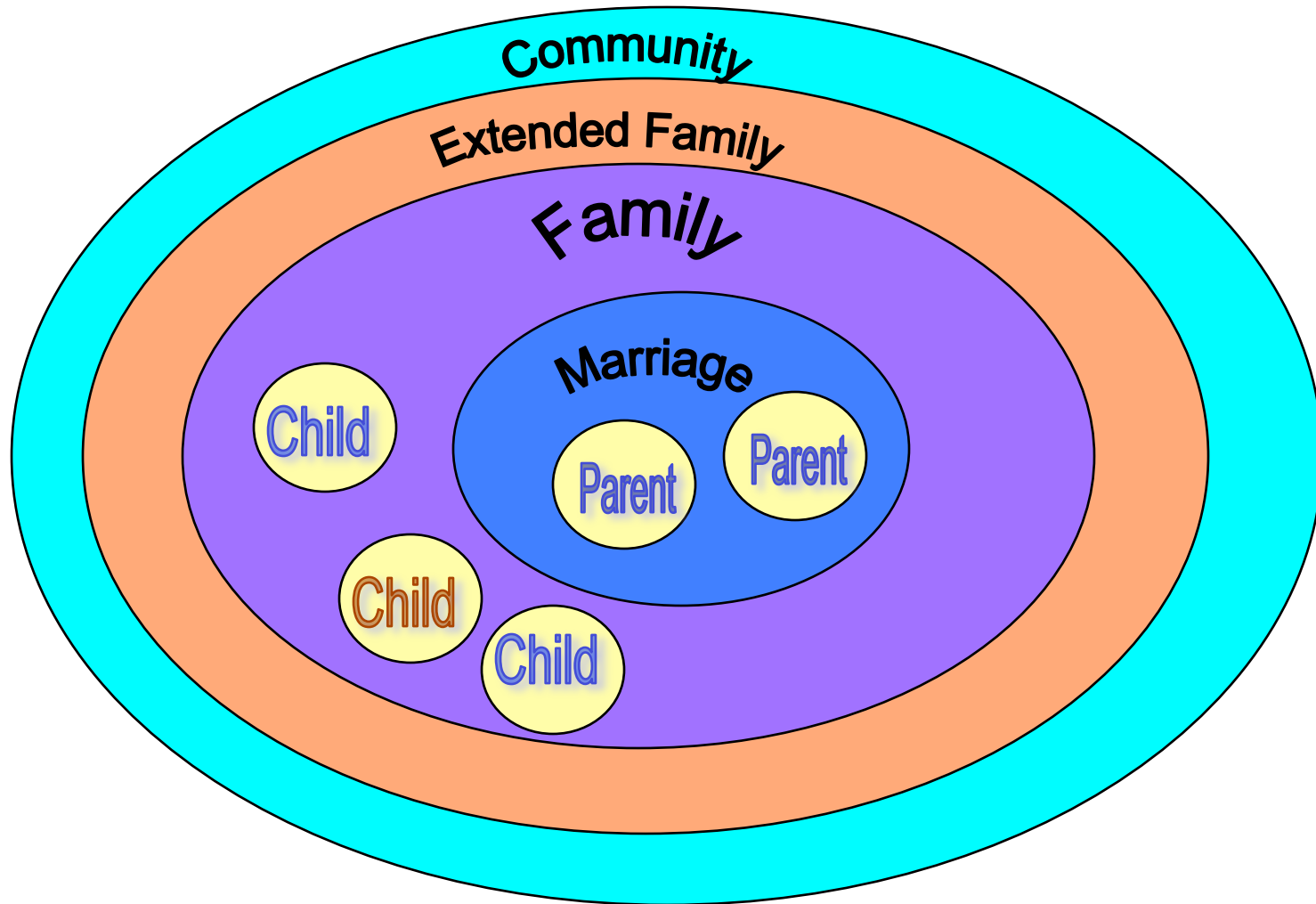
- Feels empowered
- High self-esteem (especially for the mother)
- Feeling that burdens are shared
- Achieved healthy acceptance of the diagnosis

# Extended Family

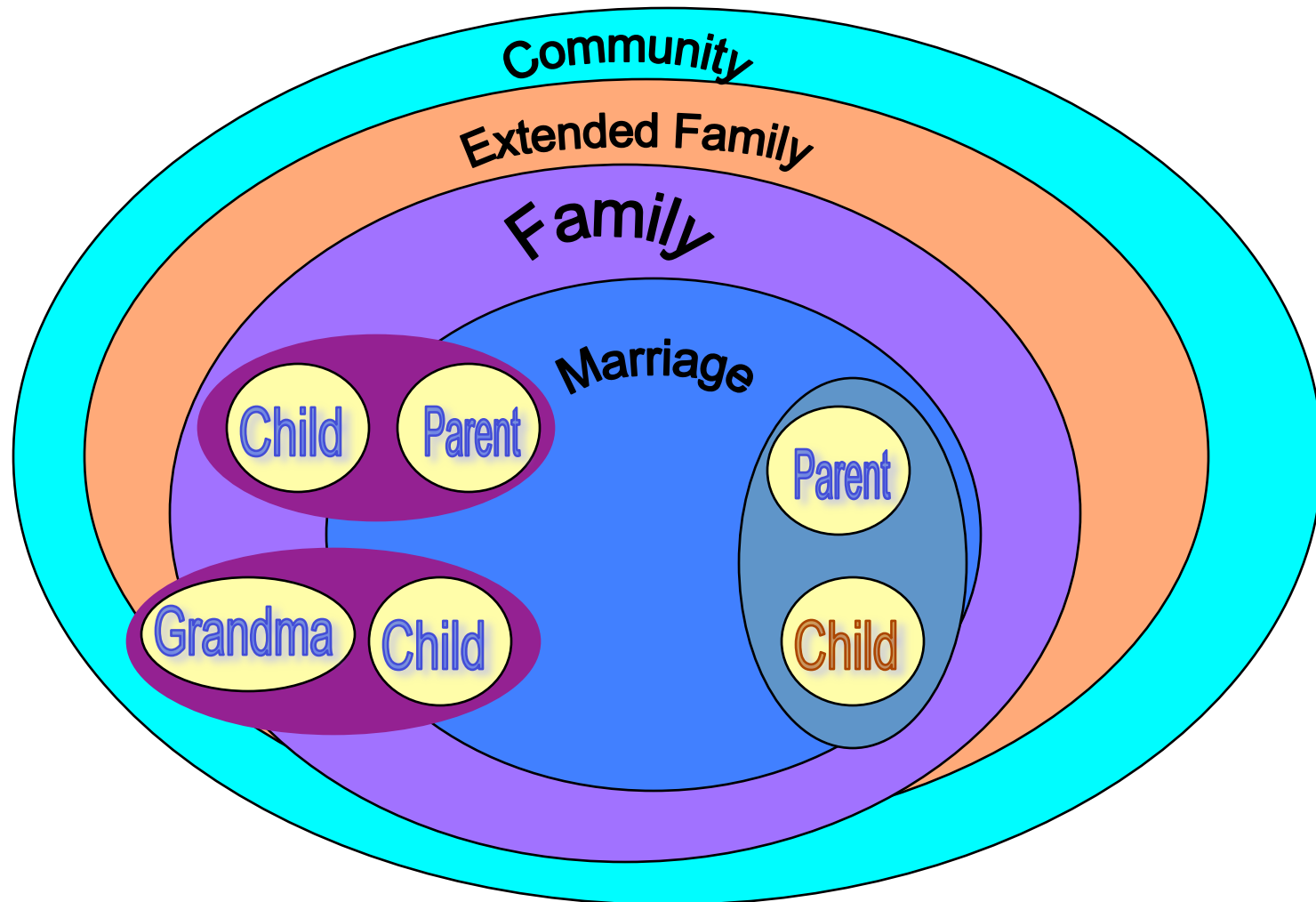
- How can family-centered care involve:
  - Parents
  - Siblings
  - Grandparents



# Healthy Family System



# Unhealthy Family System



# What can you do?

- Inform parents
- Be a sounding board
  - Listen
  - Coach
  - Acknowledge
  - Brainstorm
  - Support
  - Model strategies
- Refer to professionals when needed

# What can you do?

Help families understand:

- The etiology, emphasizing that cause was not parents' intention
- Their child is not fragile
- Their child can do anything, but, may have to do some things differently
- That taking good care of themselves and their marriage = taking good care of their child

# What can you do?

## Inform parents that:

- Children with congenital and pre-lingual onset of hearing loss do not experience grief until sometime between 7 – 9 years of age
- Parents need to keep their grief away from child. Child will misunderstand and misattribute parents' grief
- Child has best chance of resolving their initial grief if parents have positively resolved their initial grief

**Center for Childhood Communication  
The Children's Hospital of Philadelphia**

*3405 Civic Center Blvd.*

*Philadelphia, PA 19104*

*V: (800) 551-5480 TTY: (215) 590-5960 Fax: (215) 590-5641*

**Pediatric Audiology  
Counseling Guidelines: Birth - Adolescence**

**Guidelines for working with families/caregivers**

**At diagnosis:**

- Allow families to "tell their story"
- Show kindness, empathy
- Be honest
- Express hope and confidence

Parent should leave with:

- written information (info packet)
- a plan
- phone number (to call whenever clarification is needed)
- next appointment scheduled asap in writing

**Within 4-6 months of diagnosis:**

- Recognize/acknowledge the emotional responses
  - Facilitate healthy attachment between child and caregivers
  - Acknowledge imbalance and support work toward re-establishing a healthy family system
  - Actively involve family in intervention choices - avoid "rescuing" – convey hope with all communication methods/educational settings – convey that there are no failures
  - Support involvement of extended family – siblings/grandparents – direct contact with audiologist with parental consent
  - Connect to other families with children of same age/similar hearing loss and to veteran families
-

# PA Resources

## Care Coordination Plan

*Important Things To Do in the Next Month:*

<u>Area of Need</u>	<u>Date Discussed</u>	<u>Date Completed</u>
Early Intervention		
MA Application		
Obtaining Hearing Aids		
Medical Workup and Clearance: ENT		
Medical Workup and Clearance: Genetics		
Medical Workup and Clearance: Ophthalmology		
Information on Communication Options		
Family Connection		

<http://www.paearyhearing.org>