

# Progressive Hearing Loss and Family Stress

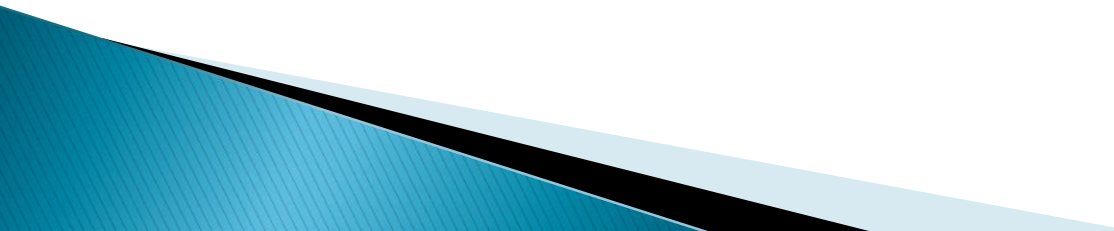
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# Status of Research

- ▶ No systematic research on families with infants/children with progressive hearing loss even though they account for about 15% of all preschool cases of SNHL (Hone & Smith, 2002)

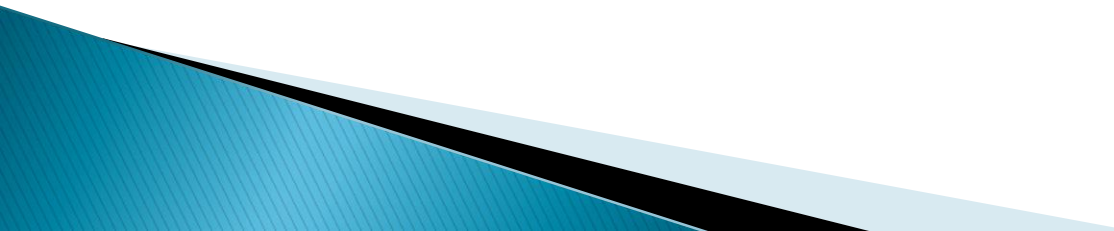
# Studying the Impact of Progressive Hearing Loss in Pediatric Populations

- ▶ Nearly all research on the impact of infant and childhood hearing loss on families is cross-sectional
    - Not well-suited to the study of progressive losses, and developmental and situational changes
    - BUT likely included children with progressive losses
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# Research Status – Hearing Loss Characteristics

- ▶ Most studies have focused on families with infants/children with severe-to-profound hearing loss
  - Deaf Children with Deaf vs. Hearing Parents
  - Children Fitted with Cochlear implants
- ▶ A growing number of recent studies have considered the impact of early identification, diagnosis and intervention
- ▶ Newer literature coming out on children mild, moderate and unilateral hearing losses

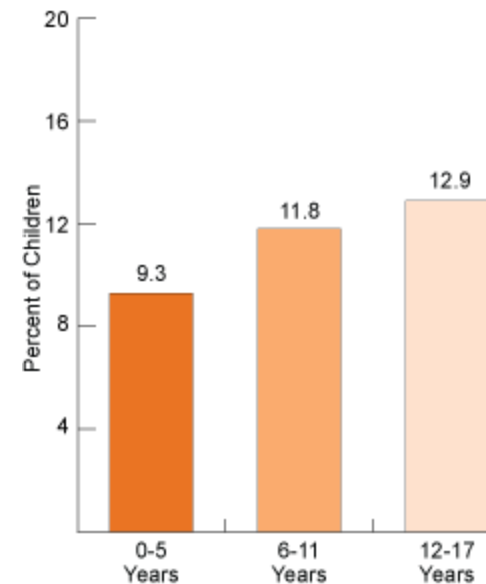
# Infants / Children with Progressive Losses are Heterogeneous

- ▶ **Etiology** (e.g., Connexin 26 vs. EVA vs Ushers)
  - ▶ **Onset**
  - ▶ **Time course**
  - ▶ **Severity and configuration changes over time**
  - ▶ **Treatment, therapeutic, and educational options and resources**
  - ▶ **Family characteristics and situations**
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# Things to Consider When Looking at Family Stress

- ▶ Just having children increases stress in families
  - Tends to increase with age and peaks in adolescence (HHS, 2014)
  - Increased stress with increasing numbers of children (Noh et al., 2017; Rodriguez-Jenkins & Marcenko, 2014)

Children Whose Parents Usually or Always Feel Stress, by Age

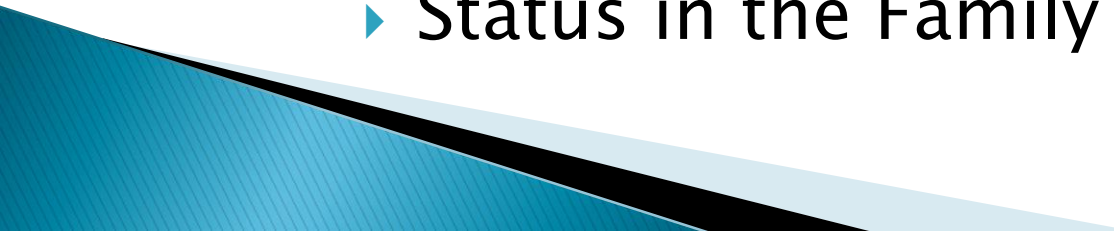


(HHS, 2014)

# Families with Hearing Children

- ▶ Families with hearing children and their situations are highly variable
  - Difficult to identify significant family issues in an individual family with an individual child
  - Influences are multidirectional, dynamic and transgenerational
- ▶ Wide-ranging effects
- ▶ Most families are doing the best they can and want the best for their children

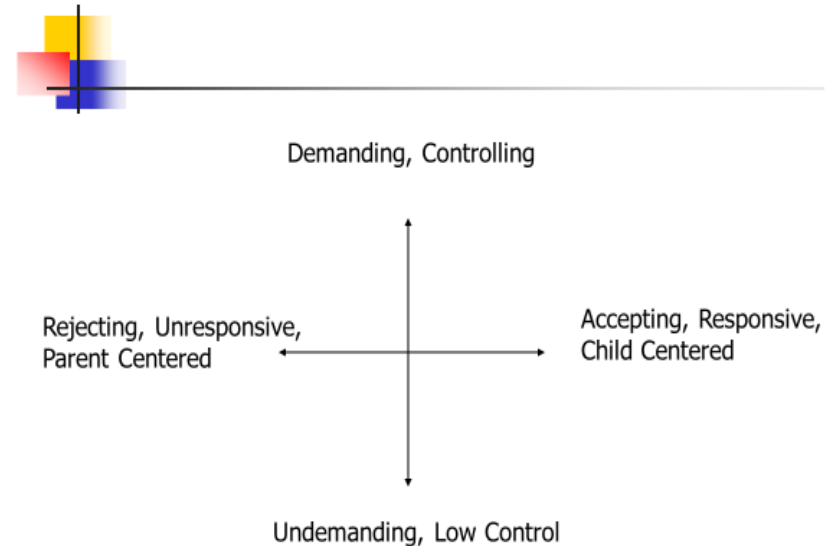
# General Parent–Related Predictors

- ▶ Maternal Education
  - ▶ Age
  - ▶ Income and Cost of Raising a Child
  - ▶ Work Demands
  - ▶ Urban vs. Rural
  - ▶ Social Support Network
  - ▶ Parenting Style
  - ▶ Social–Emotional Skills
  - ▶ Status in the Family
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# Parenting Style

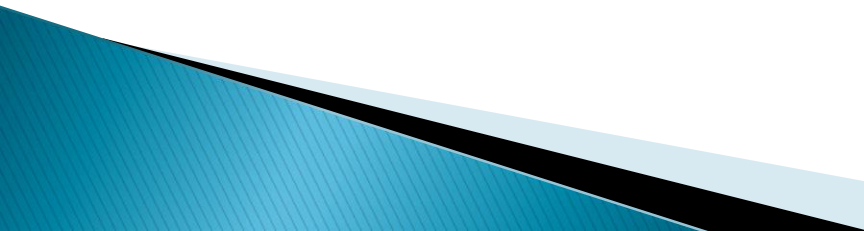
- ▶ Baumrind (1967, 1971)
  - 2 dimensions
  - Demanding, Controlling vs. Undemanding, Low Control
  - Accepting, Responding, Child Centered vs. Rejecting, Unresponsive, Parent Centered



# More Recent Framework

- ▶ **Three dimensions** (Kawabata et al., 2011; Ketelaar et al., 2016)
  - **Positive Parenting Style**
    - Sensitivity, warmth, responsiveness, interact in a positive and meaningful way, set standards but responsive to child needs
  - **Negative Parenting Style**
    - Strict rules, punitive discipline, inflexible
    - Interferes with healthy social–emotional development
  - **Uninvolved Parenting Style**
    - Ignoring, disregarding, unpredictable
    - Associated with aggressive behavior in children

# General Child-Related Predictors

- ▶ Age
  - ▶ Sex
  - ▶ Language/communication skills
  - ▶ Social-emotional development (e.g., temperament, emotional regulation, empathy, resilience)
  - ▶ Behavior
  - ▶ Literacy and school performance
  - ▶ Physical skills and appearance
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# Impact on the Family with a Infant/Child with Hearing Loss

- Emotionally fragile at screening and diagnosis (Russ et al., 2004)
- Extreme levels of stress initially
- Mourning process can vary
- Parents often overwhelmed by the decisions that they have to make quickly that have long-term consequences (Fitzpatrick et al., 2016; Hyde 2010)
- Overwhelmed by the technology (Fitzpatrick et al., 2016)

# Consequences

- ▶ Can impact the overall health of the family (multidirectional)
- ▶ Can interfere with involvement in timely intervention and treatment (Fitzpatrick et al., 2014; Ingber et al., 2010)
- ▶ But timely and effective intervention reduces overall stress levels
  - Early intervention and cochlear implants have had a substantive impact

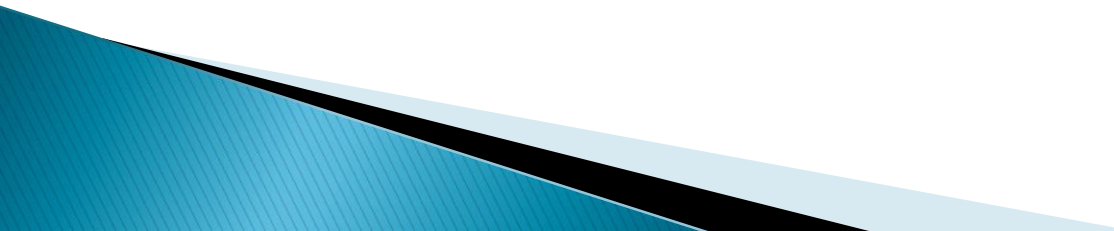
# Influencing Factors

- ▶ Age of onset
- ▶ Age of identification and intervention
- ▶ Nature and extent of the hearing loss
- ▶ Appropriate fitting and use of sensory devices
- ▶ Availability, access and soundness of the peri- and post-fitting (re)habilitation
  - Rural vs. Urban
- ▶ Medical conditions
- ▶ Other co-morbid handicapping conditions
- ▶ Social support network
- ▶ Emotional status of family

# Support

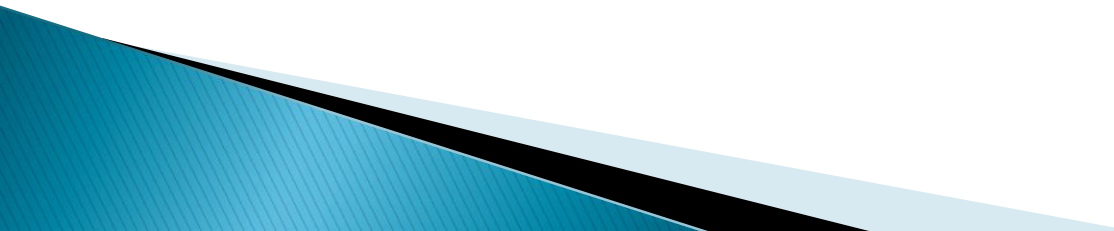
- Support networks affect stress levels and tend to become more restricted for families who have a child with hearing loss (Quittners, 1991, 2010)
  - However, the level of support is more critical than the size of the support network

# Impact of Increased Family Stress

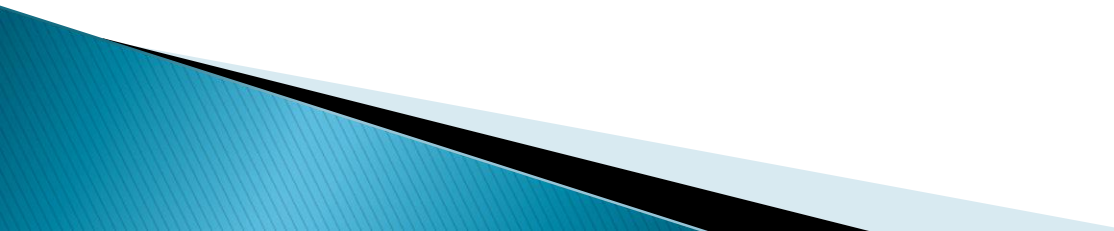
- ▶ Can interfere with timely diagnosis, intervention and education
  - ▶ Stress levels impact parent–child interactions and may impact cognitive and language development
  - ▶ Can impact social–emotional skill development (Hintermair, 2006; Mulier–Nix et al., 2004)
  - ▶ Increases risk for poor parent–child attachment (Hamner & Turner, 1990; Greenberg & Marvin, 1979)
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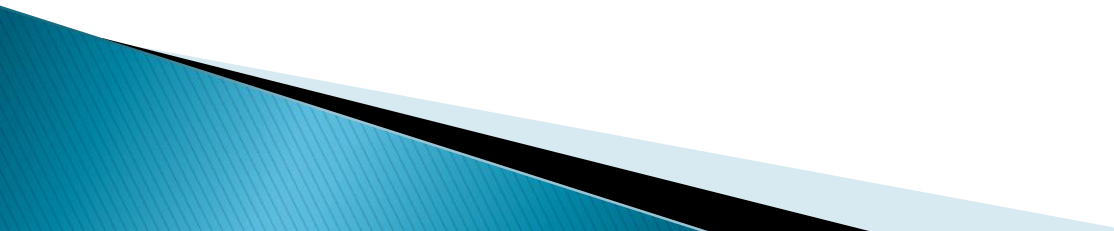
# Global Stress

- On measures of global stress mothers and fathers are similar
  - In some studies parents of children with hearing loss do not significantly differ from parents of hearing children
    - Situational differences
    - Child differences
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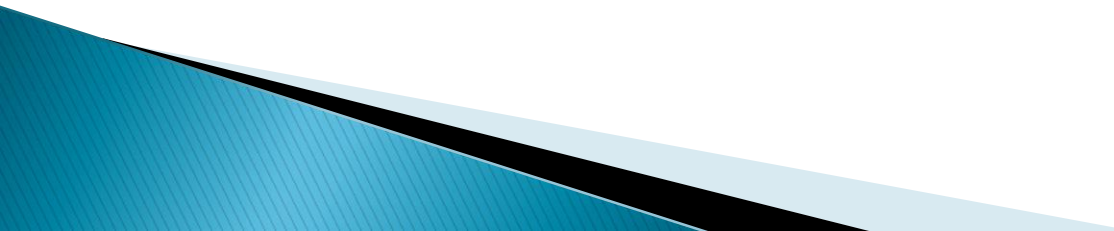
# Mothers

- ▶ On specific issues, mothers show greater levels of perceived stress than fathers
  - ▶ Worry about the impact of the hearing loss on themselves and their family
  - ▶ Reduced free time
  - ▶ Inadequate support from spouse
  - ▶ Depression
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# Fathers

- ▶ Stress related to child acceptability
  - ▶ Demands on emotional, physical, and economic resources
  - ▶ More denial
  - ▶ Less likely to develop constructive coping strategies
  - ▶ Less active involvement BUT respond well to interventions and counseling if engaged
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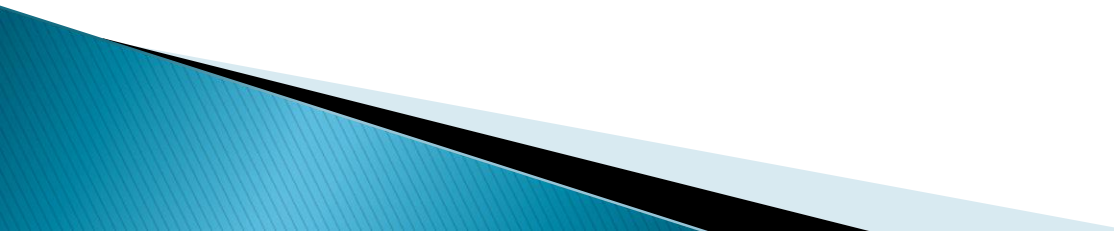
# Income

- ▶ Families with lower income show higher levels of stress
  - ▶ Combination of low income and living in a rural area is a substantive barrier to receiving services
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# Age of Identification and Intervention

- Very intense parental stress levels with early identified babies, and children with sudden onset -- but the duration is shorter (Russ et al., 2004)
- Infants receiving early identification, diagnosis and intervention show more typical auditory, speech and language development, which ultimately reduces family stress and normalizes family interactions
  - Quittner et al. (2010) found that language delays and behavior problems were strong predictors of parental stress in hearing parents of deaf children

# Age of Identification and Intervention (cont)

- The sooner support services are received after identification the more likely parent–child interactions will be normal
  - However, progressive losses in young children might be late–identified if hearing was normal at screening
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# Remain at Risk for Delays in Speech and Language Development

- ▶ Vohr et al. (2009) found that although very early intervention (< 3 mos) was associated with improved language development, by 12 to 16 months of age most infants with moderate–profound hearing loss demonstrate delays in both oral and signed language
- ▶ Fitzpatrick et al. (2007) found that parents express regret (guilt) over the gaps between age and speech and language development

# Milder Hearing Losses


- ▶ Infants/children with mild, minimal and unilateral hearing losses tend to not demonstrate marked delays
- ▶ Inconsistent responsiveness can cause family stress
- ▶ Also can result in academic and behavioral issues that can cause stress
- ▶ Inconsistent treatment approaches and down-playing the impact by professionals can exacerbate family stress (Fitzpatrick et al., 2015)



# Other Child Characteristics

- Additional handicapping conditions increase the level of stress in the family
  - Health
  - Cognitive
  - Behavioral\*
  - Social-Emotional\*
  - Motor
  - Speech and Language\*

# Availability and Soundness of Services

- Federal, State and Local Guidelines and Dictates
  - Case Managers
  - Medical Professionals
  - Audiologists
  - Speech–Language Pathologists
  - Educators
  - Social Workers
  - Psychologists
  - Parent Training Programs and Support Groups
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# Availability and Soundness of Intervention Programs

- With young children general stimulation and parent training approaches are common
  - SKI\*HI
  - State designed programs
  - Sunshine Cottage
  - Muenster Parental Program
- Individualize and specialized schools
- Regular school-based services
- Tailored parent counseling and instruction
- Family and online support groups
- Telehealth

# Family Counseling

- Emotional counseling
  - Informational counseling
  - Referrals
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# Levels of Emotional Support

- ▶ Providing an accepting and **supportive** environment
  - Professionals are considered a significant source of support (Lederberg & Golbach, 2002; Meadow-Orlans & Steinberg, 1993)
  - Total levels of professional support, over time and across sources, has a cumulative and positive effect on the behaviors of mothers and hearing-impaired infants/children (Meadow-Orlans & Steinberg, 1993)

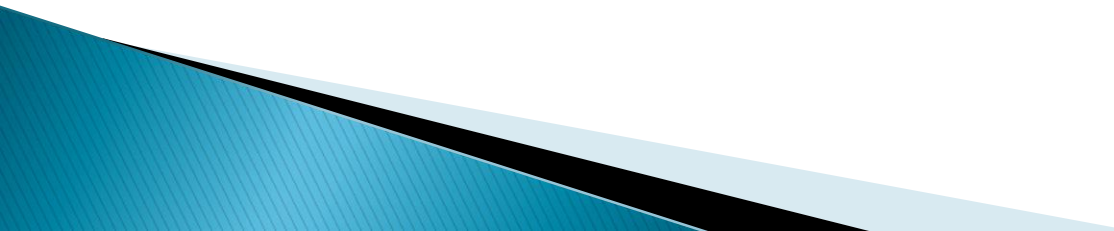
# Family-Centered Counseling

- Provide information and feedback in an empathetic manner
  - Avoid being directive, narrowly child-focused
  - Don't be afraid of providing emotional support
  - Yet be straightforward and truthful about severity and potential impact, even in cases with mild and unilateral losses

# Family-Centered Counseling


- Allow families to inform you of their needs and their child's needs
  - Adopt an open-ended questioning style, allowing the parents to have input
  - Promote parental expression of feelings
- Help families identify hassles of daily living that increase stress and strategies to reduce those stressors (Pipp-Soegel et al., 2002)

# Providing Information

- Provide information as the parents want and need to know it
    - Family needs assessment questionnaires
    - Provide appropriate and timely Information about resources
    - Provide information about rights to services
    - Balance between providing enough information and overwhelming families
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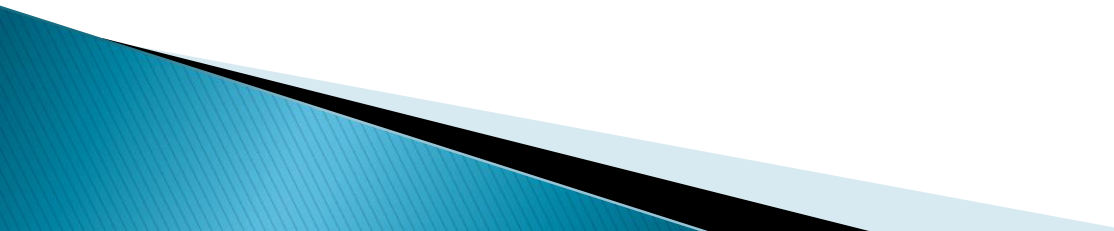
# Providing Information

- Be aware that informational needs change over time as does the specificity with which information should be presented
  - Parents need and want repetition of information over time
  - Supplementary information in multiple forms can be helpful
    - Handouts
    - Links to informational websites
    - Links to parent and professional forums
    - Audio and video recording of sessions
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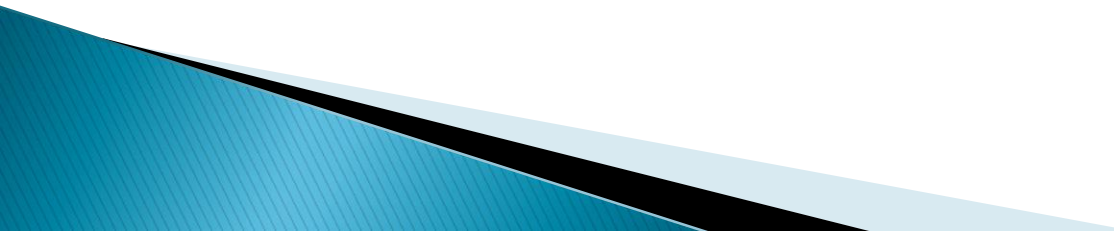
# Service Provision

- Services shouldn't be a secret to families
  - Knowledge of resources and appropriate timelines reduces parent stress levels (Hintermair, 2006)
  - When parents of hearing-impaired children are underserved they often direct their frustration toward professionals such as physicians and audiologists
- ▶ Devote time to knowing available resources, appropriate professionals and where to make appropriate referrals
- ▶ Coordinate with other professionals

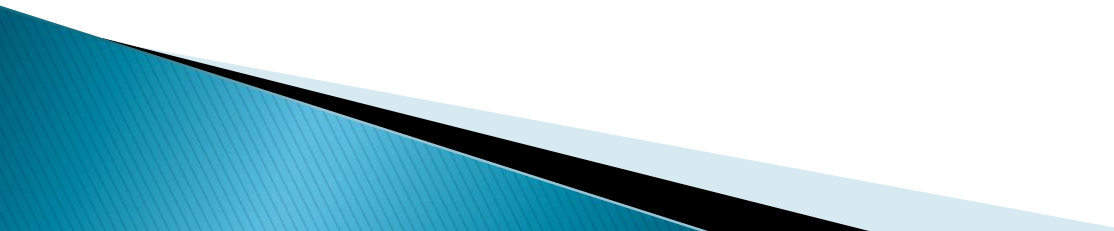
# Child Counseling and Instruction

- Self-esteem
  - Self-acceptance
  - Friends and social network
  - Place within the family
  - Cultural issues
  - Focus on strengths
  - Seriously consider feelings and beliefs
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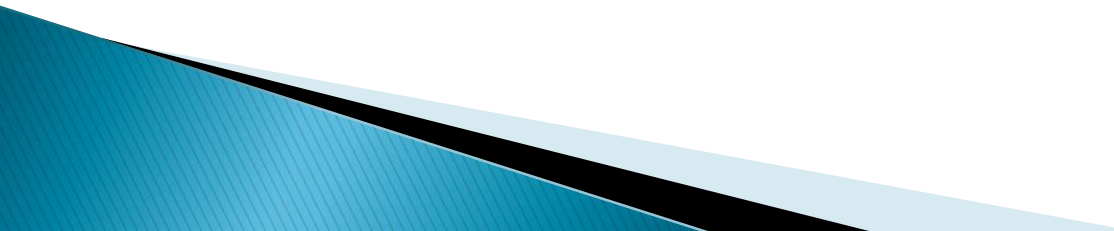
# Goal Development

- Facilitates the counseling and instructional process
  - Opens the (re)habilitation process to greater parental involvement
  - Provides a starting point, an anchor for the family and professionals
  - Provides markers to judge progress
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# Setting Goals

- Look beyond the audiogram and the hearing loss
  - Establish goals that relate to function of the whole child within his/her environment
  - Establish goals that relate to the integration within family and community
  - Consider seriously the parent's, larger family and child's needs, goals and expectations
  - Because needs change over time goals should be fluid
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# Multidisciplinary Approach

- Play an active role in the development of the IFSP and IEP when feasible and appropriate
  - Maintain communication with family and case manager
  - Actively communicate with all of the rehabilitation specialists working with the child
  - Seek/provide information and feedback about the appropriateness of the hearing aid/cochlear implant fittings and rehabilitation services
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# Impact of Family Counseling

- ▶ Lower levels of family stress
- ▶ More positive interactions
- ▶ Parents communicate with their children more consistently and fluently
- ▶ Empowerment
  - Mothers who believe they can stimulate language skills in their young children tend to have children with higher language skills (DesJardin, 2006)
- ▶ Improved child developmental outcomes
- ▶ Improved family health status