Module 7: Parenting a Child Who is Deaf or Hard of Hearing

Section: Initial Reaction and Range of Feelings



Activity 7.1: Facilitating Discussion on Initial Feelings and Experiences About Raising a Child Who is Deaf or Hard of Hearing

- A. Take the following points into consideration during the early weeks and months after a child is identified as deaf or hard of hearing:
 - It is important to provide information and support in a flexible, empathetic manner and to "meet people where they are." Seek to create natural opportunities for families to express their questions and/or concerns. It is important to pay attention to: a) what is most pressing for the family at any given time, b) how the family is coping, and c) how to support the family in a way in which they are not overwhelmed with too much information.
 - Each person is different in his or her desire and ability to process information. One family may want all of their questions answered and welcome resources from the first visit, while others may prefer to gather information over time. Either way, most information will probably need to be revisited in later visits as it becomes relevant to that child and family. While a provider may feel he or she has important "first responder" information to share, keep in mind that there is time. (To learn more about the varied learning styles of families: Parent Counseling in the Information Age: The Rules & Roles Have Changed.)
 - One point in the module that can't be emphasized enough is the importance of
 encouraging families to enjoy their child as a whole person with unique needs,
 personality, developmental skills, and joys. Especially during the early months when
 so much discussion about the child focuses on the ears, hearing, and communication
 options, it is important for families to simply enjoy being parents, to celebrate new
 skills, and to appreciate the blossoming of the adorable new person who has
 entered their life.



For more considerations for "first responders," see chapter 6 (Getting Started: Hearing Screening, Evaluation, and Next Steps) in <u>Early Intervention for Deaf and Hard-Of- Hearing Infants</u>, Toddlers, and Their Families.

- B. Follow up with the family's "first experience" finding out that their child is deaf or hard of hearing. Some families may have had the news shared in a way that conveyed a dire situation while others may have had the news shared in a more positive light. Provide a safe environment for families to "debrief" on their feelings and thoughts about this experience. This can guide your approach to intervention.
- C. Acknowledge that families will react in different ways when their child is identified as deaf or hard of hearing (e.g., shock, denial, guilt, fear, anger, resignation, acceptance, hopefulness, awe, grief, concern). Allow families time to process their thoughts and feelings. Identify where a family may be in the process of accepting this new information to best plan how to work with the family. Let them know that it is okay to be angry or frustrated one week and happy or excited the next; emotions will evolve as the child grows. Discuss the importance of early bonding with their child. (See Activity 1.2.)
- D. Support the family in dealing with the many professionals who have become a sudden part of their life (e.g., early intervention provider; audiologist; deaf mentor; ear, nose, and throat doctor; speech-language pathologist; physical therapist; occupational therapist). Review the varied roles of the professionals. When possible, seek to coordinate the many appointments and specialists so the family is not overwhelmed and services are streamlined and collaborative. (See Activity 1.1.)
- E. Take the following points into consideration in your work with families:
 - Deaf babies are typically born to hearing parents (90 percent) who may have no
 prior experiences with deaf people, the Deaf community, or the concept of someone
 not being able to hear. Lack of familiarity may lead to fear about a child's future.
 Families may wonder such things as whether the child will be able to go to school,
 grow up to be a working citizen, or get married and have children. Deaf families may
 celebrate that their child is born deaf.
 - Parents may be getting pressure from extended family members and friends on
 what language and communication approaches to use with their child. Families may
 feel stress about making quick decisions. Guide families in understanding the
 journey of identifying supports and services to meet the characteristics of their child
 and family as opposed to making a quick decision to choose one specific set of
 supports and strategies over another.



- Having a child who is deaf or hard of hearing may place strain on family dynamics and communication. Connect the family with other families for parent-to-parent support. If warranted, consider referring families for counseling to process their thoughts and emotions on having a deaf child.
- When families are faced with having a child who is deaf and the recommendation is made to learn American Sign Language, some may feel overwhelmed at the thought of learning a new language, learning about a new culture, and interacting with the Deaf community. (See Activity 4.6 to learn more about deaf mentors and role models and their role in early intervention.)
- F. Guide the family to resources to support them after the child is first identified:
 - Connect the family of a newly identified baby with established support group organizations (e.g., <u>Guide By Your Side</u>).
 - Seek out possible parent-to-parent grassroots support networks that may be available in your area. Before you connect a family with someone from the group, you may want to make the initial contact yourself.
 - Identify possible deaf mentor/deaf role model programs in your area. (For more about this, see Activity 4.6.). Consider finding role models/mentors with similar hearing characteristics as the child.
- G. Identify parenting books on raising a child who is deaf or hard of hearing that match the family's learning style. Review the books on your own and identify which books/parts of the books may be appropriate for the family with which you are working. Share and discuss real-life challenges and solutions highlighted that could be relevant to the family. Two books to consider for this activity:
 - <u>The Parenting Journey, Raising Deaf and Hard of Hearing Children</u> (Karen Putz)
 - I Can Hear You Whisper: An Intimate Journey Through the Science of Sound and Language (Lydia Denworth)
- H. Review the <u>Hands & Voices library of articles on family perspectives.</u> Identify articles to suggest to the family that represent a perspective that may forward their journey. (There are many to review!) Discuss and have parents share their views on the various journeys identified. These discussions can provide insight into the family's own journey.



- I. You may only see one of the parents for most of your early intervention visits. Make it a point to ask about how the other parent is doing. Inquire about the reactions of both parents to resources you may provide to help guide continued sharing of resources. Ask such questions as "Did you each find _____ helpful? What was most helpful? What rang true to each of you?"
- J. Take the following into consideration for families of a child with identified disabilities:
 - Which do they see as primary—the child not being able to hear or the child's physical or cognitive disability?
 - What are the family's emotions/feelings about having a child who is deaf and has additional disabilities?
 - Are there resources and support for families with deaf children with additional disabilities in your region?
- K. Take the following into consideration for families speaking a language other than English:
 - Are there any cultural connections to the emotions/thoughts related to the family's reaction to the child being deaf that are different from other families.
 - Is there access to support groups or counseling in the family's native language?

Additional Resources:

- Parenting a Deaf Child—Parenting Tips (National Deaf Children's Society-England)
- Early Beginnings for Children Who Are Deaf or Hard of Hearing: Guidelines for Effective Services
- Early Intervention for Deaf and Hard-Of- Hearing Infants, Toddlers, and Their Families
- BEGINNINGS for Parents of Children Who Are Deaf or Hard of Hearing, Inc.

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