Children with Hearing Loss and Special Needs [STUDY]

Counseling Families of Children with Hearing Loss and Special Needs

By David Luterman, D.Ed

Abstract
There is a paucity of research on counseling parents of children with hearing loss and additional special needs. Therefore, we must extrapolate from what we know of counseling parents of children with a single disability and provide information based on experience. The emotional aftermath of the diagnosis appears similar for both groups. Parents of the child with multiple disabilities struggle with feelings of isolation and alienation from mainstream programs for children who are deaf or hard of hearing. They also have the additional burden of trying to find a suitable program and of dealing with a large array of professionals. Because of the additional issues that need to be dealt with, parents of the child with hearing loss and additional special needs tend to remain in denial longer than parents of children with a single disability.

Introduction
A computer search of the literature under a variety of adjectives yields almost no data on counseling issues for the family of the child with multiple disabilities who is deaf or hard of hearing. This is a severely under-researched area which merits considerable attention. There is clearly a need for more information and research, which is why this article must be written from an anecdotal and experiential basis, borrowing heavily from what the field knows of counseling families with only one disability.

Recent surveys of the Gallaudet Research Institute (GRI) indicate that as many as 40% of children in programs for the deaf and hard of hearing have additional disabilities (GRI, 2003a,b). What that figure does not portray is the extent of the additional handicap. The actual percentage of children with multiple disabilities may be lower, however, as not all children who are mainstreamed were included in the survey, and it can be surmised that the majority of them are children with a single disability.

Counseling Families
For the past 38 years, I have been working with families who have just learned that their child is deaf or hard of hearing. The early intervention program serves children birth through 3 years of age and features a nursery, individualized therapy sessions, and a parental support group. Almost all parents have come into the program thinking that their child was “just deaf.” A review of files containing background information, indicates that approximately 15% of children enrolled in the program have or might have another serious disability. Many of these other disabilities were not diagnosed while the families were in the program, since almost all leave by the time the child is 3 years of age. There was often a suspicion on the clinician’s part that “something more may be going on here other than hearing loss” and the diagnosis of other disabilities was made in a subsequent program. Approximately one-third of these families came into the program knowing their child had additional special needs or discovered it while they were enrolled; that is, the diagnosis of the other disability was made before 3 years of age.

In counseling families, we first need to look at how parents of
the child with hearing loss come to terms with the diagnosis of deafness, and then we can look at some of the problems that are unique to the family with a child with multiple disabilities.

For all parents with normal hearing who have a child who is deaf or hard of hearing, the diagnosis represents a loss which must be grieved. The loss for which the parent grieves is of the dream that all parents have of how their child and how their life would turn out. Their dream does not include a child with disabilities, which is usually seen as a terrible loss by the parents. This loss has been compared to a death in the family (Tanner, 1980). However, the construct of equating a child with disabilities to a death in a family is a bit too simplistic. The grief engendered by the death of a family member is acute and terminal, bounded by ritual and vocabulary (Kubler-Ross, 1969). The grief experienced by the parent of a special needs child is chronic and unaccompanied by ritual. There is usually minimal emotional support within the parents’ domain, as most people have little or no experience with chronic grief. In an actual death, we bury the body. Chronic grief, however, is experienced on a daily basis. Parents are constantly reminded of their loss and there are many “trigger” events along the road of raising their child that remind the parents what they have lost. These trigger events may be as simple as a birthday party or family gathering. It is at occasions such as these that comparisons to children who are typically developed are made, and the family’s pain may be quite acute.

Usually family members and friends of the parents attempt to make them feel better. In doing so, they usually invalidate the parents’ feelings, which serves to further isolate and alienate the parents. What people in pain need most is to be listened to and have their feelings validated. This is counter-intuitive to most family members and friends who seek to take the pain away (Clark, 1990). It is when a group of parents can meet and share their experiences that validation occurs and the healing process can begin. This is the immense value of a support group. It is here, though, that the parents of the child with multiple disabilities feel their double alienation; not only are they “different” at home, they are also “different” within the program. It is hard, and at times almost impossible, for parents of a child with hearing loss and special needs to find an educational program where they feel affiliated and a support group where they can feel entirely comfortable. It is a formidable task for the group facilitator to tease out the “universal” in special needs, so as to make parents of children with multiple challenges feel connected to the group.

It is a challenge to raise a child to responsible adulthood. When there is a special need, the task of parenting seems overwhelming. This is doubly true for the parent of the child with multiple special needs. The feeling of inadequacy is so pervasive that parents often seek someone to rescue them from their feelings of inadequacy. It is often very hard for professionals not to mount a rescue. To do so often leaves the parents mired in their feelings of inadequacy, and they thus tend to not take responsibility for their child. By assuming responsibility, the professional is reinforcing the parents’ feelings of inadequacy. I have called this the “Annie Sullivan Effect” and it usually results in a poor outcome for the child (Luterman, 2002). Best results occur with independent parents who have high self-esteem (Schlesinger, 1992). The rescue scenario tends to create dependant parents who have learned helplessness.

Anger

Anger is a frequent concomitant of the grief process; it occurs whenever there is a violation of an expectation. For parents of children who are deaf or hard of hearing, it is the expectation that the child would have normal hearing and that they would have a “normal” life. The parent of the child with multiple disabilities has a very abnormal life, even within the realm of special needs, and therefore their anger is usually more intense. Anger also stems from a loss of control. A fundamental need for most people is to feel that there are unlimited possibilities to do what needs to be done in their lives to operate in their child’s best interests. A child who is deaf or hard of hearing may severely limit the parents’ options, and they acutely feel the restriction; the child with challenges in addition to hearing loss further limits the parents and generates even more anger. (“Why can’t he or she just be deaf?”) Anger also frequently masks fear. Boorstein (1996), a clinical psychologist, has noted that almost all anger in his practice is a mask for fear. This is true for parents of children with hearing loss.

Anger is usually the first emotion to emerge after the initial diagnosis and it frequently masks the feelings of inadequacy. Parental fears are related to their ability to cope and almost all have a fear that something else may be wrong with their child.
The deafness has activated feelings of vulnerability and many parents are waiting for the “other shoe to drop.” For parents of the child with additional special needs the “other shoe” has already dropped. One of the biggest fears of these parents is finding a suitable program for their child. The options are very limited.

Anger is a feeling that most people have difficulty dealing with. It is often equated with a loss of love and, since it seems to threaten the family homeostasis, families seldom deal with it directly. Thus, children are taught to repress their anger, which often becomes depression, or displace it onto people who are likely to be understanding. As adults, we carry the notion that anger is a bad thing. In actuality, anger is usually a marker that something needs to be changed - there is a great deal of caring in anger. Angry people usually get things done and this can be a useful energy if directed appropriately. For parents of children with special needs, the anger often is displaced on the professional. It behooves the professional to confront the parents’ anger and unmask parental fears. This usually results in a fruitful encounter, which benefits the child.

Guilt

Guilt is usually felt by parents of children with special needs. The mother’s guilt is often related to ‘cause’ and the father’s guilt is often related to his ‘failure to protect the family.’ Mothers have the responsibility of carrying a fetus for 9 months and delivering a healthy child. When the child has a disability, the mother feels she has failed in some way. Even when the cause of deafness is unknown, the mother often feels guilt. She goes over her pregnancy day by day to find something untoward that happened that she can focus on as the cause of the hearing loss. Fathers in a traditional family are acculturated to protect everyone. When someone in the family is hurting and the father cannot solve the problem, the father usually feels guilt.

Guilt very often translates into two kinds of behavior that are not helpful for the child. Guilt-ridden parents tend to overprotect their child (“I let something bad happen to you once, I am not going to let that happen again”); or, the guilt can lead to the super-dedicated parent (“I let something bad happen to you, and I am going to make it up to you”). Overprotection leads to a fearful child who has limited capacity to cope with the world on his or her own. The family with overly dedicated parents usually becomes dysfunctional as not enough energy has gone into family maintenance. Very often siblings are at risk and marriages break down when most of the energy within the family is devoted to the child with disabilities.

For parents of children with hearing loss and additional special needs, the task is even more difficult. For them, the child seems more vulnerable than the child with only a hearing loss. The line between overprotection and reality protection for a child with multiple special needs is often a thin one. In the same vein, the parents of the child with multiple disabilities often have to be proactive and a strong advocate in trying to locate programs or trying to create them for a unique child with special needs. So much energy needs to be expended in locating and maintaining programs that there is little left for family maintenance. These families may look very guilt ridden (and some are) when it is the “nature of the beast,” and the families are coping with a very difficult problem that requires large expenditures of energy. These families are under a great deal of stress, not the least of which is the large number of professionals they have to cope with. This often includes physicians, audiologists, physical and occupational therapists, speech-language pathologists, and special education teachers, each with their own objectives, and these families are often overwhelmed. What is needed is a careful coordination of the array of professionals working with the family, so that there is a unity in the recommendations and in the implementation of services. A case manager is a must for these families.
Denial

One of the primary emotion-based means of coping with stress is denial. In denial, there is no “owning” of the situation. People feel removed from reality. Denial enables people to function under extremely stressful situations. It is a marker that the person is not ready to face reality. At its core, denial is based on a parent’s anxiety of an inability to respond to the child’s needs. With the child with special needs who is deaf or hard of hearing, the hearing loss often seems to the parent the lesser of two evils. Hearing loss is a relatively concrete disability. There are ways to ameliorate it via hearing aids (and now cochlear implants), whereas many of the other disorders, such as developmental delay and infantile autism, are less tangible and less amenable to therapy. Often, the parent of a child with hearing loss and special needs clings to the diagnosis of deafness while denying the presence of another disability.

Denial is a coping strategy that the parent relinquishes when parental confidence is enhanced. Denial is emotion-based coping and reflects feelings of being overwhelmed. When parents can see problem-centered ways of coping are directly focused on the disability and are within their sphere of competency, denial can be relinquished. For professionals, assaulting denial directly is seldom effective; it tends to create the passive-aggressive parent who, on the surface, seems to accept the new reality, but in actuality does not follow through with the prescribed therapy. Parents need time and emotional support to accept that their child has multiple challenges. Confronting the denial directly leads to an adversarial relationship that delays acceptance.

Sensitive counseling that has a high degree of listening and emotional support can expedite the parents’ acceptance and move them from denial into productive, problem-centered coping. The hallmark of good counseling is careful listening and trusting that the parents will ultimately find the best solution for themselves and their child. Information should be given judiciously and parental confidence enhanced by emphasizing the skills and knowledge the parents already possess.

Summary

In summary, parents of children with hearing loss and special needs face the same emotional issues as parents of children who are deaf or hard of hearing. They must deal with their feelings of grief, anxiety, anger, guilt, and vulnerability. In addition, they feel more isolated and alone because of the difficulties in finding a suitable community for themselves and their child. Their feelings are intensified by their isolation, leading to a tendency to remain in denial much longer than parents of the child with the single diagnosis of deafness. The subject of children with hearing loss and special needs and the impact of the additional disabilities on families is severely under-researched.

Source: The Volta Review, 2004