

Empowering Adolescents Who Are Deaf and Hard of Hearing

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The adolescent years are challenging for all kids. If hearing loss is added into the mix, the issues faced by these teens are quite complex and require some skill development in advocacy, empowerment, and independence. This article will explore the emotional journey of the individual and the family.

Children who are deaf and hard of hearing are often invisible to the rest of the world. These children may appear to know and understand all that is happening around them because they smile or nod. This is usually not the case. As children grow into adolescence, there is a critical need to transfer ownership of the hearing loss from the parent to the adolescent in order to foster self-advocacy and empowerment. Far too often, the parents of children who are deaf and hard of hearing become so overprotective that they do not allow the move towards independence. This overprotectiveness is based on fear that the child will be harmed physically, psychologically, or social/emotionally.

Two groups of children cope with hearing loss: children who are born hard of hearing or deaf and children who develop hearing loss later in childhood. While both groups encounter challenges, there are distinct issues for each group.

Children Born Deaf and Hard of Hearing

The first group are those babies who do not pass the newborn hearing screening test. When they receive the news of hearing loss, parents usually go through a grieving process. The initial reaction is shock; parents cannot believe this is happening to their new baby. The dream they had for their newborn is no longer possible. The typical emotional journey will take the parents from shock through denial, depression, anger, acceptance and, hopefully, advocacy. The family's emotional path may encounter obstacles along the way, often represented by transition points—entering kindergarten, middle school, high school, college—each of which can trigger the grieving process once again.

Approximately 95% of parents with a child born hard of hearing or deaf are themselves normal hearing [1]. Once a diagnosis of hearing loss is confirmed, 2 critical issues must be addressed. Will parents choose a communication modality of listening and spoken language or a visually-based

system such as American Sign Language (ASL) or Cued Speech? Will technology be utilized in the form of hearing aids, cochlear implants, or bone anchored devices? Since these parents are normal hearing, they tend to choose listening and spoken language as the communication modality for their child. There are also parents who are themselves deaf and communicate with ASL. In this situation, the natural language in the home is ASL, and the parents may choose that modality as the child's primary mode of communication. Most parents choose spoken language for the child who is hard of hearing or deaf while fewer families choose a visual communication system. All these families should be provided immediate services such as family support and early intervention. Fortunately, there have been amazing advances in both areas and a greater likelihood for success exists today than in any previous generation.

Children Who Lose Hearing Later in Childhood

The second group of young people with hearing loss are adolescents who were born with normal hearing, but develop hearing loss during childhood for whatever reason (eg, illness, genetics). These post-lingually deafened students have the advantage of developed speech, but have a very difficult transition from being hearing to non hearing. These students remember what it was like to hear and do not understand what is happening to them. Several inappropriate behaviors may surface. These adolescents, like their parents, will go through a grief process—shock, denial, depression, and anger, but will hopefully reach a level of acceptance and be able to move forward. The critical immediate issues are to determine if it is possible to restore any hearing and to ensure there is a communication system in place. In recent years, cochlear implants are often used to restore hearing function. Implants require a great deal of work on the part of the adolescent and the family to retrain the brain to receive a new signal for speech processing. After the technology is in place for the child, speech therapy,

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auditory training, and aural rehabilitation are necessary for success.

While parents are managers of a child's hearing loss from the initial diagnosis, it is critical that, as the child enters adolescence, a transfer of ownership of the hearing loss occurs from parent to child. Often this is a difficult transition for parents. For the child, understanding his or her own hearing loss, utilizing technologies for hearing loss management, and caring for and maintaining these technologies will greatly assist in the development of self-confidence and independence. This process should begin as early as possible. For the child who is born with hearing loss, assigning simple tasks related to the understanding of the hearing loss and related technology will empower the child to become the primary responsible person for managing these issues in the family and at school.

Empowerment Strategies

Creating a mentoring opportunity for the adolescent who knows and understands his or her own situation can be another step towards empowerment. Identifying younger children in the community and at school who have hearing loss and utilize hearing loss technology whom the adolescent can teach what he or she has learned will help both older and younger children become more self-confident.

Support groups for adolescents with hearing loss also play an important role. Many students with hearing loss find that they are the only person in their school "like them." Community support groups provide students with hearing loss to meet others like them. Connecting with other students with hearing loss can empower youth and build their confidence. Creating and supporting opportunities to bring adolescents with hearing loss together helps them create their own support communities. Today there are virtual platforms that can facilitate ongoing communication, which allows youth with hearing loss to stay connected to peers from support groups. Learning that you are not alone is a huge step towards empowerment.

Family Retreats

One strategy proven to be very successful with adolescents is the family retreat concept. The CARE Project, founded and operated by the author, provides emotional support opportunities for 10-12 families with children who are deaf and hard of hearing. This experience is based in a 3-day weekend retreat for the families and a group of volunteers. While parents are in educational seminars, children of all ages participate in activities and field trips with volunteer supervision. These activities bring adolescents together with their peers who also are deaf and hard of hearing. There is great power in having the children make new friends, some of whom will stay connected for years to come. The CARE Project also offers single-day retreat experiences for

families in local areas and, while perhaps not as powerful as weekend-long retreats, they do have a positive impact on all family members. The parents gather with many other parents who are at various places on their emotional journeys, while the children spend time together in structured activities, allowing them to get to know each other. The outcomes have been positive for all family members, as evidenced by post-retreat evaluations.

Deaf and hard of hearing adolescents who have attended family retreats are given opportunities to return for future retreats as staff volunteers and mentors. These experiences continue to empower these young people to be independent and to understand what it is like to help others who are like them. Their evolution as mentors gives these adolescents a true sense of reaching down to help pull up the next generation.

Regardless of the medium (local support groups, retreat weekends, day retreats), it is important to include young adults who are deaf and hard of hearing as mentors for adolescent participants. Not only does this give these teens/tweens role models with whom to identify, but it also gives the parents of these children a concrete vision of what may be possible for their own child. As mentioned earlier, most parents of children who are deaf and hard of hearing may not know anyone else who is "like their child." As the emotional journey takes families into uncharted territory, it is difficult to recreate the dream that the parents had for their children without meeting and getting to know successful young adults who are deaf and hard of hearing. Meeting these young adults from all walks of life will restore the ability of the parents and the adolescent to recreate the vision they had for the future, whether the young adults seek to become doctors, lawyers, photographers, audiologists, speech pathologists, teachers, firemen and firewomen, and any other vocation.

Conclusion

Everyone should have the same goal for children who are deaf and hard of hearing: As these children reach adolescence, they should all have a well-developed language. With a good language base and strong communication skills in place, each child turned adolescent will emerge into the teen years empowered, independent, and self-confident. **NCMJ**

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