

## The Impact of Deafness on Family Life

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Deafness can have a profound effect on family life, or it can be viewed merely as a minor inconvenience. The impact created and the adjustments required differ at each stage of the life cycle and are related to the cause of deafness, age at onset, and previous experiences of family members. In this paper, three "family types" will be described, illustrating a range of reactions and responses: (1) families with hearing parents and an infant who is deaf; (2) families with Deaf parents and an infant who is deaf or hearing; (3) hearing families in which one spouse becomes deaf in mid-life or later.

**Parents hearing, child deaf.** At least 90% of children who are deaf are born to two hearing parents, most of whom have no prior experience with deafness or reason to think that their child might be deaf. Thus, the first impact of deafness for these families can be a suspicion that something is amiss. Typically, profound deafness is identified when a child is about 15 months old, whereas a moderate to severe hearing loss is likely to be discovered at about age 22. (1)

Often, a confirmed diagnosis evokes prolonged grief and mourning for the loss of an idealized "perfect" child: (2) "I put on 30 pounds. . . I spent months crying and eating;" "When we first discovered she was deaf, I completely turned away from God—I was brought up to believe the sins of the parents were visited on the children;" "We were at a loss to know what to do."

However, if the child has other conditions linked to a difficult or premature birth or if parents had feared mental retardation or autism, deafness becomes a less significant problem: "I was relieved to know why she didn't make an attempt to talk, why she didn't respond to those noises. . . From that time on we had some direction to go;" "I thank God that's all she has. . . . So she is deaf—That's something we can cope with and something we can help her with. . . we're thankful we have her."

Regardless of parents' feelings about deafness—their grief or relief—the central impact of deafness soon becomes apparent: how to communicate with a young child who relies primarily on vision, not sound, for language and meaning. Communication issues have a long-term and wide-spread impact on all members of the immediate and extended family.

Until 1970, only a handful of children with hearing parents were exposed to a visual/manual language before the age of 13. All communication at home and at school was oral: parents and teachers spoke and the child was expected to use residual audition with hearing aids to support speechreading (lipreading). Today, more than half of deaf preschoolers are exposed to sign language—English-based signs with simultaneous speech (total communication) or American Sign Language (a language with its own syntax, grammar, and idioms). In the 1970s and 1980s, the communication controversy in deaf education focused on the relative merits of oral-only vs. oral-plus-English-based sign. In the 1990s this controversy expanded to include American Sign language as a bilingual/bicultural option.

Whether families utilize one of the visual language forms or an oral system, they are expected to spend many hours and much effort in learning a new language system and/or in training their child. Frequently the mother becomes intensely involved in these special needs and the father takes

a less active role. Thus, family structures are dramatically or subtly modified. Hearing aids, tutoring, and therapy can be very expensive; some families move to a different location in order to meet the special educational needs of the child who is deaf.

In the past decade, cochlear implants have been approved for young children with moderate as well as profound deafness. A recent survey showed that 10% of 6- and 7-year-old deaf children had received the devices. Thus, parents face an additional choice or dilemma as they decide to pursue this alternative.

Many hearing parents believe that their family's life has been enriched by their contacts with the Deaf Community, through attendance at social and cultural events conducted in sign language, and in their meetings with other families who have deaf children. Whatever the family's communication method, deafness will affect their lives. Hearing siblings often become sign language interpreters, with a special bond to a deaf sister or brother. However, they may also feel neglected and resentful of the attention given to and accommodations made for a deaf sibling. Feelings of rivalry and jealousy can emerge on both sides. Deafness influences most family interactions and relationships.

Parents Deaf, children deaf or hearing. For families with two Deaf parents, the situation may be almost the reverse of that described above. Deafness in a newborn infant can be expected and welcomed, as expressed by this Deaf parent-to-be, "I am very excited about becoming a father. I hope to have a deaf child. The doctor told us that we could never have a deaf son because my deafness is X-linked through my mother. But maybe we can have a daughter." (3) These parents perform informal hearing tests soon after an infant's birth and are not surprised if there is no response to sound.

Having found hearing aids of limited help to themselves, many Deaf adults resist providing them for their children, despite the recommendations of educators and audiologists. Cochlear implants are anathema to the more militant members of the Deaf community, as symbols of the non-acceptance of a Deaf identity.

Familiarity with deafness and its special communication needs have prepared these deaf adults to care for a child with the same needs. They are fluent in sign language and are members of a Deaf community that provides a rich support network. Most Deaf adults feel quite capable of providing warm and nurturing home environments for their deaf children. Studies show that these children have no more behavioral problems or linguistic deficiencies than those reported for the general population. In fact, many studies show that deaf children of Deaf parents perform better, socially and academically, than deaf peers with hearing parents, even though Deaf parents had fewer social and financial resources. Family problems are likely to be related to the lack of educational or employment opportunities rather than to hearing or communication. Nevertheless, Deaf adults are often discriminated against by uninformed adoption workers. There have been cases (fortunately rare) where social agencies have tried to remove children from Deaf parents solely because of their deafness.

On the other hand, deaf parents may question their own ability to provide a good home environment to a hearing child. After the birth of her hearing infant, one Deaf mother thought, "Oh, my God . . . What on earth am I going to do with her? I don't even know how to talk to her" (Preston, 1994: 17). However, the (hearing) Children of Deaf Adults (CODAs) report interesting and happy, if unusual, family lives. (See books by Preston, Sidransky, and Walker listed in the bibliography). Sign language is usually their first language, with spoken English, acquired from hearing relatives, family friends or the media learned as a second language. They often serve as interpreters for Deaf family members, sometimes in sensitive and inappropriate circumstances. However, this practice has declined in recent years, since the Americans with Disabilities Act requires that interpreters be

provided in many situations.

Deafness in later life. The incidence and prevalence of deafness rises dramatically with age. More than three-quarters of the deaf population lost their hearing after they were 19 years old. (4) More than 60% of those who "at best can hear shouted speech" are aged 65 or older. (5) Those who are born deaf rightly point out that their hearing was not "lost" since that which was never possessed cannot be lost. However, to a person who has heard and spoken for many years, the sudden or even gradual loss of hearing can be traumatic, forcing a re-assessment of identity, of work and family relationships. One woman notes the variation of responses in this poetic way, "We deafened people have two lives: the years with ears and the years without. We pass from one to the other over a bridge of sighs or on stepping-stones of self-determination. It all depends." (6)

Jack Ashley, who lost his hearing soon after being elected to the British House of Commons, illustrates both the "bridge of sighs" and the "stepping stones of self-determination" when he says, "On one day I could hear fairly well. . . . A few weeks later I was virtually totally deaf. The plunge from a normally hearing world into one of almost total silence meant the plummeting of my happiness, aspirations, and hopes for the future." (8) Nevertheless, his determination enabled him to continue to represent his district successfully for many years. His wife's assistance and his own courage, ebullience, and talent were important to his continuing ability to perform this very public role.

Few people deafened as adults manage hearing loss so well. Depression, withdrawal, irritability, isolation, and fatigue are common. Many dread meeting new people. One study found much "suffering, fear and loneliness." (Cited in Meadow-Orlans, 1985: 41) Deafened persons have special difficulty with children; teenagers and daughters can be especially impatient with deafened parents. Deaf spouses report that conversations are "often conducted without them." Clearly, deafness places a strain on both deaf and hearing members of the family. (Meadow-Orlans, 1985: 45)

Relief from communication difficulty is rarely sought through sign language in this population, although a few families may learn rudimentary fingerspelling. Hearing aids and other assistive devices are the more usual techniques investigated, and increasing numbers of deafened adults consider a cochlear implant.

Conclusion. Deafness changes the lives of families in many ways. For hearing parents with deaf children, the cause of deafness, the circumstances surrounding its identification and early professional advice cushion or exacerbate the situation. Deaf parents with deaf children rarely see childhood deafness as a disability or handicap. Rather, it is a familiar, readily accepted condition. When profound deafness occurs late in life, families must modify lifelong habits and expectations.

Conflicting opinions about the best communication mode continue to plague the hearing parents of children who are deaf. Their use of American Sign Language is a recent development; little is yet known about its relative effectiveness. The same is true of cochlear implants. The increasing visibility of the Deaf community and the greater public acceptance and respect for sign language reduce the negative effect of deafness on the hearing parents of young deaf children.

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#### Endnotes

1. Various percentage estimates related to deaf children are based on a national survey of 404 parents of 6- and 7-year-olds reported in Meadow-Orlans et al., 1997.

2. The following quotations are from unpublished interview data.

3. Cited in Meadow-Orlans (1995: 68).

4. This is calculated from 1994 data reported by Schein (1996: 26).

5. From 1971 data reported by Reis (1985).

6. Cited in Meadow-Orlans (1985 : 35).

7. See Ashley (1985: 60).