Confronting Deafness in an Unstilled World

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Man was born free, and he is everywhere in chains. With this call in *The Social Contract*, Rousseau may be said to have launched the Romantic, not to mention the French, Revolution. To Rousseau, society was the enemy: convention, ostentation, the clever chatter in the salons was false: society constrained the freedom of the individual to live and speak honestly and virtuously, just as chains then constrained the residents of mental institutions. The theme of society and the individual dominates the experience of deafened adults; but to most, society is paradise lost, the false friend who betrays and ejects them from their accustomed place. As their sense of exclusion grows, they may come to feel, like Rousseau, that society is indeed the enemy and that peace can be found only in solitude.

The adjustment of adults to progressive hearing loss can be viewed as a conflict between their drive for continued sociability and their need for the relief that solitude offers from the tensions and blows that sociability now brings. I shall review some of the common feelings about and adjustments to hearing losses of varied severity and age of onset reported by some 1,500 members of Self Help for Hard of Hearing People (SHHH), the large American voluntary organization of hearing-impaired persons. Their accounts were obtained by a four-page questionnaire inserted in the January-February 1984 issue of *Shhh*, the bimonthly magazine distributed to all SHHH members. I will try, in part, to summarize these comments and, in part, to depict and interpret the emotional and social dynamics of increasing deafness in formerly hearing persons, as reflected in this material. All unidentified quotations in this article are drawn from these questionnaires, and each in a series of quoted passages represents a different individual.

Most quotations come from responses to five open-ended questions: "How has your hearing loss affected your personal life (e.g., family, social life, leisure activities)? How has your hearing loss affected your working life? Who and what has best helped you adjust to your hearing loss (e.g., spouse, friend, hearing aid)? What could be done to help you now? We welcome any other comments you wish to make about your hearing loss and any suggestions you have for SHHH activities or articles." Only one page was allotted to replies, but many members attached additional pages of comment; some even enclosed a copy of their audiogram.

The questionnaire was prepared jointly with Kathryn P. Meadow-Orlans, Research Scientist at Gallaudet University, in cooperation with SHHH President Rocky Stone and Vice President Patricia Clickener. Michael Karchmer, Susan King, and other staff of the Gallaudet Research Institute undertook the computer programming and statistical analyses; the project was authorized by Raymond Trybus, Dean of the Institute, and financed by Gallaudet.

Questionnaires were received from 1,670 persons, 28 percent of the 6,000 SHHH members. Seventy respondents (audiologists, teachers, counselors, and other professionals working with hearing-impaired persons or family members of a hearing-impaired person) had normal hearing. The number and quality of responses to specific questions varied: 1,518 persons replied to the question about the effects of bearing loss on their personal life, 1,415 to the question about its effects on their work, and 1,069 offered suggestions for SHHH activities. The average age of respondents was sixty-two: 30 percent were seventy or older and only 11 percent, under forty: 62 percent (and 70 percent of those under sixty) were women. In this preponderately elderly, female population, only 22 percent were employed full-time and another 9 percent, part-time: 48 percent were retired: 18 percent classified themselves as housewives and 5 percent, as unemployed.

Most respondents had a major hearing loss. The difficulty of assessing the severity of loss by a series of graduated questions (the Gallaudet Hearing Scale) was evident: nonetheless, as estimated by this method, which a good many respondents criticized, 53 percent had a loss of 56 decibels or more and another 34 percent, of 41-55 deci-
bels, in their better ear. Nineteen percent said that they had lost some or all of their hearing by the age of nine or earlier; and from 11-14 percent, during each succeeding decade (their teens, their twenties, and so on, up to and including their sixties).

These SHHH members are heavy users of hearing aids: 89 percent owned one or more, often, two, and most wore one or both “all the time.” The remaining 11 percent included some with a small loss and some who refused to wear an aid, but most were evidently too deaf to benefit from one and some could not endure the excruciating noise.

From all the evidence provided, Kathryn Meadow-Orlans and I attempted to assess the adjustment—the degree of personal acceptance and contentment or bitterness, anger, and dissatisfaction—of each respondent. Of the 1,388 persons we ventured to classify, we judged the adjustment of 33 percent to be “poor,” 31 percent as “good,” and 36 percent as intermediate or average. On a five-point scale, we classified the adjustment of 7 percent as “poor,” 31 percent as “good,” and 36 percent as intermediate or average. On a five-point scale, we classified the adjustment of 7 percent as “very poor”: 26 percent, “poor”; 36 percent, “average”: 23 percent, “good”; and 8 percent, “very good.” The proportion classified as “poor” was higher among women, those with a severe loss, and those who were divorced or separated as compared with those who were either living with their spouse or widowed. Relatively fewer of the oldest respondents (those over seventy) were classified as poorly adjusted: old age brought a greater degree of either peace or weariness and a disinclination or inability to protest.

Undetected Loss

Hearing loss is not only invisible, a fact often lamented as adding the burden of disclosure to that of the condition. It may go undetected by those with the loss. Adults who suffer a sudden loss are, at least, inescapably aware of that traumatic event. If awareness is the first step in the long process of adjustment, that step is thrust upon them. It would follow, as some argue, that their adjustment is earlier or, at any rate, quicker than it is for the person with a gradual loss. Both the theoretical point and the empirical facts are debatable. One can also argue that a great deal of adjustment proceeds unconsciously and that the perfect marriage between consciousness and reality exists only in the minds of some intellectuals.

Certainly, some hearing loss can go undetected at all ages: in infants and children, because they have never experienced any other kind of hearing, and in adults, because their loss is so slight it can be misinterpreted. After all, to miss a word, especially in a noisy place, is entirely normal. Who can hear anything in a disco? Many people with a “good” ear live so completely in the hearing world that they are seldom considered, and do not consider themselves, “impaired.”

If hearing impairment is the most prevalent disease [one respondent writes], I wonder why I meet so few who have it. I go to a spa, to classes, to clubs. Occasionally someone says he or she is hard of hear-

The answer is that most have a loss that is functionally insignificant. If the line between an insignificant and a significant loss is drawn between “having difficulty only with faint speech” and “frequent difficulty with normal speech” (which the National Center for Health Statistics places between the 40 and 41 decibel levels), in 1981 roughly 3.1 million or 1.5 percent of the United States population had such “frequent difficulty,” while over 11 million or 5 percent had a lesser loss in one or both ears. Thus, the population with some hearing loss fades into the hearing population much as the population with some loss of hair fades into the population with a full head of hair.

That is both the opportunity and the aggravation of adults who, as puzzling episodes, miscues, and misadventures mount, finally realize that something may be wrong with their hearing. “I couldn’t figure out how the other kids heard what they did,” a twenty-two-year-old girl, who evidently had some hearing loss since infancy, writes: “after high-school graduation, it ‘clicked’ in my mind.” Similarly, a girl of twenty, also with an early loss, for many years “didn’t realize how much I was missing.” How can you know everything that you do not hear?

How can you be aware of everything that you do not hear?

Passing and Bluffing

A loss not noticed by the person who has it can also be overlooked by friends and family, who may attribute the nonresponsiveness they observe to personality, not physiology. “During school years, before I knew I had a hearing loss, my friends always complained that I was stuck up and thought I was better than anyone. They said I never answered them when they spoke to me!”

Passing, or being taken, for someone with normal hearing but not normal conduct—“unfriendly, uncooperative, stupid, no personality”—is common. Indeed, it is unavoidable in casual encounters in public places, crowds, and social gatherings; for, whether a hearing aid is worn or not, few people are as alert to the presence of hearing loss as the person who has it; and the opportunity to disclose it may not arise. Thus, be it vigilant or, as the years go by, dulled and weary, the deafened person’s passage through the hearing world, oblivious to much that transpires, is characteristically guarded and