Parental Decision Making and the Choice of Communication Modality for the Child Who Is Deaf

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Background: Early intervention decisions for a deaf or hard of hearing child are difficult to make, partly because of the lack of definitive proof of the superiority of any particular communication approach.

Objective: To compare the relative importance of the child’s hearing loss and parental attitudes, beliefs, values, and aspirations in the decision process.

Methods: Eighty-three parents were surveyed about decision factors that may have affected their choice of communication modality, including resource availability, attitudes and beliefs about hearing loss, values, trade-offs, and goals. Parental preference ratings on hypothetical outcomes were also collected in 4 domains: communication, academic performance, social functioning, and emotional well-being.

Results: The child’s extent of hearing loss was the most influential decision factor ($P < .001$). Beyond the extent of hearing loss, logistic regression further showed that parental cognitive-attitudinal factors were important in the inclination to favor an oral approach—if they believed that deafness can and should be corrected and if they desired the child to be able to speak ($P = .03$ and .04, respectively). Technology that aims at improving the child’s ability to speak (eg, cochlear implants) had no significant impact on the decision to choose oral only training.

Conclusions: Professionals who work with deaf children and their parents should recognize the presence of many relevant issues beyond the extent of the child’s hearing loss. Interventions may be most effective if aimed at balancing parental beliefs and aspirations and audiologic considerations.


By the end of 2001, 37 states had passed legislation mandating newborn hearing screening. As a result, it is estimated that hearing loss will be identified in 1.5 to 6.0 of every 1000 neonates born in the United States. Lobbying groups are pushing for newborn hearing screening, despite a recent independent report questioning the cost-effectiveness of such routine screening programs and an extensive literature review showing limited clinical benefits. Accompanying the trend toward the earlier diagnosis of hearing loss is a need for earlier decision making by parents about the best interventions and training for their child. Immediately after the identification of hearing impairment, parents must quickly evaluate numerous options in communication, education, and habilitation in the absence of an evidence base and with limited information about the expected outcomes of the interventions.

One of the earliest decisions that parents must make is the choice of communication modality, usually categorized, but not limited, to 3 approaches: oral-aural habilitation (auditory verbal training, oral training, lipreading, cued speech, etc), visual-gestural or manual communication (eg, American Sign Language), or a combination of speech and sign language (eg, Total Communication). Previously, professionals have typically based their recommendations on the child’s residual hearing, because this is believed to be directly correlated with the amount of speech information available to the child and, therefore, his or her speech potential. Technological advances, such as digital hearing aids, and cochlear implants, that provide more auditory information to the deaf child have complicated the decision. Moreover, implantation is increasingly being performed on younger children, toddlers and infants, all without the benefit of long-term outcome data. The implications of these national trends may have considerable impact on the choice of communication modality.

Families of deaf children may receive plausible but often speculative or incomplete information about various interven-
tions. There remains no definitive evidence establishing the connection between long-term outcomes, child (and family) characteristics, and recommended communication and amplification modality, despite 200 years of debate between the proponents of the oral and manual modalities. Information that families receive is likely to be influenced by the opinions, beliefs, and attitudes of health professionals and educators and by the availability of specialists and educational and habilitative resources.

In the absence of conclusive medical evidence, parents may rely instead on their beliefs, values, and goals, which are often polarized among people who take opposite stances. At one extreme are those who see deafness through a medical prism, as a disorder or condition to be ameliorated or fixed. At the other extreme are those who view deafness as a culture, to be honored and preserved. These contrasting viewpoints translate into divergent approaches to the habilitation of the child who is deaf.

This article assesses the impact of several decision factors on the parents’ choice of communication modality for the child who is deaf or hard of hearing. We hypothesized that parental decision making was affected by several factors, including the recommendations of professionals and other family members, assistive devices used (eg, cochlear implants), the parents’ goals and values in raising the child (including the importance of speech vs sign language), the parents’ attitudes and beliefs about deafness, resource availability, and the cost of interventions and services. To test this hypothesis, we compared the relative contribution of these factors in making decisions regarding communication modality for a deaf child.

**METHODS**

A survey instrument was developed to collect data, including the child’s sex and age, the extent of the child’s hearing loss, the use of assistive devices, resource availability, and values, trade-offs, goals, attitudes, and beliefs about hearing loss. The study design was approved by the Institutional Review Board of The Children’s Hospital of Philadelphia.

The items in the survey were reviewed independently by a panel of professionals who care for deaf children, including a child psychiatrist (A.G.S.), a science writer (L.B.), an audiologist, a pediatrician/epidemiologist, and a counselor who works with families of deaf children. The panel reviewed the contents and response scales regarding relevance of study construct, clarity, friendliness, and readability.

The first section of the survey consisted of questions about the child and the family, including the child’s hearing loss; the use of amplification, assistive listening devices, and cochlear implants; the communication approach used; and the nature of interventions obtained. For training, we asked if the child had been exposed to one or more of the following communication programs: speech alone, auditory training, sign language, cued speech, or other. Parents’ choice of training in communication was categorized into oral only (speech alone or with auditory training), sign only (sign language only, without any speech or auditory training), and oral and sign (a combination of oral and manual training).

**DECISION FACTORS, HEALTH BELIEFS, AND ATTITUDES**

The next section contained 11 items, including 5 derived from the literature to represent the most common factors that influence early intervention decisions: recommendations of professionals, recommendations of friends, cost of services, availability of services provided by the local school district, and availability of services close to home. These items were asked by prompting (‘‘which of the factors listed below most influenced the decisions you have made?’’) and were rated on a 4-point scale (‘‘very important,’’ ‘‘somewhat important,’’ ‘‘somewhat unimportant,’’ and ‘‘very unimportant’’).

Six attitude items were adapted from an instrument designed to measure parental attitudes and goals regarding how deaf people integrate into mainstream society, the appropriateness of sign language, and a deaf child’s language development, communication mode, and school placement. A 4-point response scale was used (‘‘strongly agree,’’ ‘‘agree somewhat,’’ ‘‘disagree somewhat,’’ and ‘‘strongly disagree’’).

**QUESTIONS REGARDING PARENTAL VALUES AND TRADE-OFFS**

In the next part of the assessment tool, we used a multiattribute utility procedure to assess parental preferences for hypothetical functional outcomes in children with hearing loss. The domains were derived from what parents consider important in developing family-centered interventions. They were also modeled after health outcome domains important in assessing health-related quality of life in children and adolescents.

Hypothetical outcomes were described in 4 functional domains: the child’s academic performance, ability to communicate with hearing and deaf people, social experiences, and emotional well-being. Table 1 shows the range of hypothetical outcomes in these domains. These outcome statements were constructed so that they approximated a range of mutually exclusive outcome states from success to struggle and failure.

Functional outcomes for each domain were printed on a single sheet of paper with a vertical ruler ranging from 0 (least desirable) to 1 (most desirable). Parents were instructed to first identify the least and most desirable outcomes and assign them 0 and 1, respectively. They were then asked to draw a line connecting each remaining functional outcome to a point on the scale that indicated its desirability compared with the best and worst outcomes. The age of 18 years was selected for the scenarios because it corresponds to standardized academic achievement goals in reading and mathematics and because, by then, major effects of the education and socialization processes would likely be apparent.

Differences in the ratings were used to measure parental preferences for their child’s potential outcome. For example, to measure the parents’ aspiration that their child be able to speak only rather than to sign only, we report the difference in ratings assigned to the corresponding statements describing these 2 outcomes. Differences in ratings, rather than the actual numeric values, are thought to better reflect the respondents’ relative preference to contrasting outcomes. The differences were chosen so that the corresponding statements make a reasonable and unambiguous contrast between 2 representative hypothetical outcomes within a domain. For example, in the academic domain, we report the difference in rating between the statements, ‘‘At age 18 years, your child reads at a third-grade level and does math at a sixth-grade level.’’ This compares age-appropriate reading and math proficiency with a lower reading and math level that is more typical of deaf children. This contrast represents by how much a parent desires academic excellence that exceeds what is normative for the population. Similar contrasts were calculated for social functioning and emotional well-being.

We also used the same rating scale to assess parents’ preferences regarding educational options typically available in the
Table 1. Functional Domains and Outcomes in Preference Assessment

<table>
<thead>
<tr>
<th>Domain 1: Communication</th>
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<tbody>
<tr>
<td>Communicates freely with hearing people and with people who sign</td>
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</tr>
<tr>
<td>Struggles but can communicate with hearing people and communicates freely with people who sign</td>
<td></td>
</tr>
<tr>
<td>Communicates freely only with people who sign</td>
<td></td>
</tr>
<tr>
<td>Communicates well only with close family</td>
<td></td>
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<tr>
<td>Does not make himself or herself understood even with close family</td>
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<th>Domain 2: Socialization</th>
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<tr>
<td>Has rewarding friendships and many social activities separate from school</td>
<td></td>
</tr>
<tr>
<td>Has rewarding friendships in school but few social activities separate from school</td>
<td></td>
</tr>
<tr>
<td>Has numerous casual acquaintances at school but few social activities separate from school</td>
<td></td>
</tr>
<tr>
<td>Struggles to make acquaintances even at school; has no social activities separate from school</td>
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<tr>
<td>Is alone most of the time, even at school; has no friends</td>
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<th>Domain 3: Academic Achievements</th>
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<tbody>
<tr>
<td>Excels in all subjects at school</td>
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<tr>
<td>Works at school at the level expected for his or her age</td>
<td></td>
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<tr>
<td>Works at school at a sixth-grade reading level and a ninth-grade math level</td>
<td></td>
</tr>
<tr>
<td>Works at a third-grade reading level and a sixth-grade math level</td>
<td></td>
</tr>
<tr>
<td>Is unable to read or do simple math</td>
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<th>Domain 4: Self-esteem and Emotional Well-being</th>
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<tr>
<td>Generally feels proud of self, happy, and free of worry</td>
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<tr>
<td>Usually feels good about self, but occasionally becomes upset</td>
<td></td>
</tr>
<tr>
<td>Sometimes feels bad about self, angry, worried, or sad</td>
<td></td>
</tr>
<tr>
<td>Almost always feels bad about self, angry, worried, or sad</td>
<td></td>
</tr>
<tr>
<td>Feels worthless and extremely angry, worried, or sad</td>
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United States—if the child attends (1) a local school for the deaf, (2) a deaf class in a public school, (3) a residential or boarding school for the deaf, and (4) a regular class in a public school. Each parent’s most preferred school setting was identified.

SUBJECTS

The survey instrument was distributed to 88 parents, either self-administered during an in-person interview to 49 or administered by mail to 21 at their request. In an effort to capture a diversity of opinions, the survey was also distributed to 18 parents attending a workshop of the American Society for Deaf Children, which is a national organization of families and professionals supporting full communication access, particularly through the use of American Sign Language. Five of the surveys collected at the national workshop were excluded because they were answered by deaf parents (n = 2), a grandparent (n = 1), or the parent of a child older than 18 years (n = 1) or because the survey was incomplete (n = 1). We aimed at recruiting hearing parents of deaf children younger than 18 years, and did not include parents whose child had known medical or developmental conditions that could affect cognitive development. The analyses were based on 83 returned surveys.

ANALYSIS PLAN AND STATISTICS

The analyses were performed in 2 steps. The first was to determine if each decision factor was individually associated with the parents’ actual decisions. Next, factors that show a statistically significant association were combined in an exploratory logistic regression model to compare their relative importance. Of particular interest was how important the behavioral decision factors were compared with the severity of the child’s hearing loss. That is, the model compared how parental goals, beliefs, and attitudes affected the decision, after controlling for the extent of the child’s hearing loss.

Nonparametric statistics were applied because of the skewed response distributions in the actual parental choices and in many attitude questions. The 4-point scale was dichotomized because of sparse cells in the cross tabulations. The Fisher exact test was used whenever appropriate. Missing data were omitted in the analyses.

The raw ratings of the hypothetical functional outcomes were scaled relative to the rated best and worst outcomes so that the best outcome always has a scaled rating of 1.0, and the worst, 0.0. Comparisons between ratings were primarily performed by independent sample t tests without assuming equal variance.

A stepwise procedure was used in the logistic regression to rank order the relative contributions of the decision factors in predicting the probability of a parent undertaking only oral training (the oral only group) vs some or all signing (either sign only or oral and sign). Comparisons between groups were primarily performed by odds ratios, with summaries of relative risk whenever appropriate. The fit of the model was evaluated by the Nagelkerke R², the area under a receiver operating characteristic curve, and the Hosmer-Lemeshow goodness-of-fit test.

RESULTS

Table 2 summarizes the children’s age, sex, race, and extent of hearing loss. Also listed are the parents’ actual decisions in communication modality and the prevalence of cochlear implants. More than half of the respondents chose a combination of speech and sign for the child, followed by oral only; a few chose sign only. Most children had severe to profound hearing loss, and, at the time of the survey, 20 had received cochlear implants. The 3 sources of data yielded similar distributions of hearing loss: 57% (27/47) of the children in the interview group had profound loss, while 71% (15/21) and 67% (8/12) of the mail-in and the American Society for Deaf Children groups had profound loss, respectively. There was no overall statistical difference among the 3 groups in their beliefs and attitudes.

PREDICTORS OF COMMUNICATION CHOICE

Table 3 summarizes how patient characteristics, resources, and parental attitudes, beliefs, goals, and aspirations contributed separately to the choice of communication modality. Decisions were not associated with the child’s age, but were strongly associated with the extent of the child’s hearing loss. Among those 18 parents whose child had moderate to moderately severe losses, 14 chose oral only and 4 chose oral and sign as communication for their child. Conversely, children who had profound hearing loss were less likely to have received only oral training. Of the 50 children with profound loss, only 10 chose oral only, while 33 chose oral and sign and 7 chose sign only as the communication modality.

The use of advanced technological devices did not seem to be associated with the acceptance of the oral ap-
Several respondents in the oral and sign group did not answer the question regarding factors that influenced the decisions they have made. These were omitted in the calculations. Thus, the percentages and cross tabulations for these particular decision factors were based on 70 available responses, with 30 valid responses in the oral only group, 32 in the oral and sign group, and 8 in the sign only group. Approximately 90% of the respondents considered the recommendation of a professional important or somewhat important. Parents rated a friend’s recommendation as important in only 47%, 59%, and 43% of the 3 respective groups. Services provided by the local school district and cost were important for approximately 20% to 50% of the parents. There were no statistically significant group differences. Judged by the percentages of parents considering the decision factors important, the recommendation of a professional was the most important factor of all, followed by services close to home, services provided by the local school district, recommendation of a friend, and the cost of services.

A parent was more likely to choose oral only training if he or she thought that “all deaf children should go to ordinary schools” and “all deaf children could learn to speak if enough time and effort was put into teaching them.” Also, parents who chose the oral only approach were less likely to agree that “children should be taught sign language so they can talk to deaf people” and “although sign language may be useful, it is not really a proper language.” The choice of communication modality was also related to the parents’ preferred educational setting for their child. Of the 30 parents who chose oral only training, 19 preferred a “regular class in a public school” for their child, while only 1 of the 8 parents who chose sign only communication preferred this mainstream setting. Most of the parents in the sign only group favored the local school for the deaf.

PARENTAL PREFERENCES IN HYPOTHETICAL OUTCOMES

Table 4 summarizes the parents’ preferences in enabling their child to be flourishing in communication, academic performance, social functioning, and emotional wellbeing. For each group, we calculated the average ratings in the functional contrasts in the 4 domains.

In the communication domain, a preference score of 0.57, as seen in the oral only group, means that on a scale of 0 (total failure in communication) to 1 (complete success), these parents rated the ability to speak 0.57 more desirable than the ability to sign. For parents in the oral and sign group, however, the preference was only 0.14. Parents in the sign only group had a preference of −0.07, suggesting that they valued signing slightly more than speech. Compared with the oral and sign group, parents in the oral only group rated speech more than 4 times as desirable as sign (0.57−0.14=0.43, P<.001). There were no significant differences among the 3 parent groups on preferences for academic performance and social and emotional functioning. Parents in the oral and sign group gave emotional functioning a 0.73 desirability, which is slightly higher than the 0.69 and 0.67 ratings from the other 2 groups. The differences were not statistically significant.

In comparing the relative importance of the significant factors, Table 5 summarizes the results of the logistic regression model predicting the probability of choosing oral only as opposed to some form of signing. The independent variables included the child’s extent of hearing loss (2 dummy variables contrasting “severe” and “moderate to moderately severe” with “profound”), parental preference ratings in the child’s ability to speak as opposed to sign, and 4 dummy variables representing the agreement to attitude questions. The Nagelkerke $R^2$ ($R^2=0.75$) and the area under the receiver operating characteristic curve (0.95) suggest reasonable model fit. The Hosmer-Lemeshow goodness-of-fit test also showed that the model’s predictions were in concordance with the observed training choices.

The child’s extent of hearing loss was the most important decision factor in parental decisions to favor the oral only approach. The odds for parents of a child with moderate loss to choose oral only communication were 176 times higher than the odds for a child with profound loss; at the lower bound of the confidence inter-
val, the odds ratio remained almost 7-fold higher. We also converted the odds ratio of 176 into relative risk. Not shown in Table 5, the model intercept of −5.16 represented the estimated log odds for a profoundly deaf child receiving oral training only, controlling for other independent variables. By applying the inverse logit transformation, it translated to an estimated risk of 0.0057. Similarly, being moderately deaf entailed a log odds of 0.012, which translated to a risk of 0.503. Therefore, a moderately deaf child was 88 times (0.503/0.0057) more likely to receive oral training compared with a profoundly deaf child similar for other independent vari-
Parental decision making regarding communication approaches for a deaf child is affected by the child's easily measured audiometric findings and the parents' more elusive cognitive-behavioral processes. One can distinguish families' choices based on the assessment of parental beliefs and attitudes about deafness, parental valuation of the child's future ability to speak and sign, and the child's extent of hearing loss. Among those factors, the extent of the child's hearing loss seems to be the most important. This may derive from the recommendations of professionals, given that parents have few means of interpreting the results of hearing tests immediately on identification of the hearing loss and when the initial course is charted. The conventional criteria of audiological findings remain dominant, despite recent technological advances that ameliorate the functional severity of the hearing loss.

Among parents who prefer the oral approach to communication, parental valuation in the child's ability to speak rather than sign was the second most important predictive factor after the severity of the child's hearing loss. These were parents who seemed determined to help their child acquire speech so that he or she could communicate with hearing people and be educated in a mainstream educational environment. Many of them believed that all deaf children could learn to speak if enough effort was expended.

The lack of strong association between cochlear implants and the oral only choice is interesting. Given that 66% of the children were younger than 5 years, their parents might have been advised to choose both oral and sign training while the child developed speech. The eventual goals might be to move toward an oral only modality. This signifies the importance of studying the changes of communication mode over time.

There are several applications of these findings. In addition to thinking about the child's potential, typically estimated by the extent or severity of the hearing loss, professionals can play an important role in systematically helping parents examine their own preferences. Given the absence of evidence-based guidelines to assist in clinical decision making and the initiation of early intervention services, preference analysis in using hypothetical outcome scenarios may help parents focus on evaluating options that are most consistent with their goals and desired outcomes. Pediatricians who typically have a longer-term relationship with the family than do otolaryngologists and audiologists are in a better position to consider the parents' hopes and values and help them evaluate their options. Educators and health care professionals alike may benefit from these concepts in discussing intervention decisions and in the informed consent process with parents.

This study is limited in generalizability and causality; it does not have sufficient information to describe a shared decision process made by couples and the health professionals who advise them. We did not, because of survey length, include detailed inquiries regarding the

| Table 5. Logistic Regression Analysis Predicting the Decision to Choose Only the Oral Approach Rather Than the Oral and Sign and the Sign Only Approaches |
|---------------------------------------------------------------|---------------------------------------------------------------|
| Decision Construct                                           | Variables in the Logit Model                                  | Odds Ratio (95% Confidence Interval) |
| The child's hearing loss                                      | Severe vs profound                                           | 4.47 (0.53-38.05)                     |
|                                                              | Moderate to moderately severe vs profound                     | 176.33 (6.67-999.99)                  |
| Parental preferences and goals                               | Ability to communicate orally*                               | 38.15 (1.22-650.01)                   |
| Parental beliefs and attitudes                               | Agreement to "all deaf children could learn to speak if enough time and effort was put into teaching them" | 8.56 (1.19-61.51)                     |
|                                                              | Agreement to "deaf children should go to ordinary schools"   | 9.34 (0.60-145.92)                    |
|                                                              | Agreement to "children should be taught sign languages so they can talk to deaf people" | 0.23 (0.04-1.48)                     |
|                                                              | Agreement to "although sign language may be useful, it is not really a proper language" | 0.56 (0.05-5.80)                     |

*How much more desirable if the child "can communicate only with hearing people" vs "can communicate only with people who sign."
With infant hearing screening soon to be conducted universally, intervention decisions for a child who is deaf or hard of hearing will be made at an earlier age and without a clear evidence base or outcomes research. This article describes the effect of several decision factors on the parents’ choice of communication modality, underscoring the importance of parental values, beliefs, and preferences. Understanding these decision factors may better prepare a clinician to provide appropriate guidance, information, and referral resources for parents who are under the stress of making crucial intervention decisions that affect the lifetime of a child who is deaf.

Professional advice received. Professional advice is bound to influence the parents’ opinions about deafness and may be the most important decision factor of all. Future research will be directed at determining how professional advice may affect parental attitude and vice versa.

Our respondents were predominantly middle-class, well-educated, white families, who may have little in common with underserved families in terms of access to care for their deaf child. This study did not examine the origins of parental beliefs, values, and goals or the prospective impact of professionals’ opinions and guidance. Many of the beliefs and attitudes may have been shaped by the actual decision(s) made. Addressing the evolution and relationship of these factors was beyond the scope of this study. The logistic regression model is also limited in its generalizability because of the small number of events per variable.

Despite the limitations, our results have implications for health care professionals and educators who provide and/or refer parents for hearing screening, early intervention after newborn screening, and specific interventions, such as cochlear implantation, during infancy and early childhood. To provide more appropriate guidance, information, and referral resources, these professionals should routinely inquire about parents’ needs, values, beliefs, and preferences. Referrals made in the context of parental preferences will likely yield improved compliance with treatment recommendations. The findings of this study lend support to the development of decision aids that can guide parents and clinicians to clarify parental goals and preferences in the child’s potential functional outcomes, even when the decisions are complex and the outcomes are uncertain.

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