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PARENTS AND THEIR DEAF CHILDREN

THE EARLY YEARS

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With contributions from
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Preface

Any research-based book has a large cast of characters to whom the authors are indebted, and this book is no exception. Our first debt of gratitude is to the parents who contributed their experiences with intervention services during their children's early years. More than 400 parents completed a questionnaire, and more than 80 were interviewed. Their enthusiastic participation was a motivating force. We salute their dedication to their children and thank them for their time and thoughtful contributions.

The Gallaudet Research Institute provided welcome financial support, and we appreciate the encouragement of Thomas Allen and Michael Karchmer. We are grateful for the contributions of four Gallaudet graduate students: Kimberley Scott-Olson (1996–1998; 2001), Selena Steinmetz (1997–1999), Jennifer Pittaway (1999–2001), and Susan Medina (2000–2001). The school personnel who organized focus groups must remain anonymous to protect the identity of the sites and participants, but they have our gratitude.

Members of Gallaudet's Center for Assessment and Demographic Studies were helpful in the survey phase: Thomas Allen, Brenda Rawlings, and Arthur Schildroth helped to design the questionnaire; Sue Hotto and Arthur Schildroth supplied information for program sampling.

We thank the following for their contributions to the survey instrument: Carl Dunst for permission to incorporate items from the Family Support Scale; Project Dakota for the use of items from a service-satisfaction scale; the Utah SKI*HI program for items from the Language Development Scale; Rita LaPorta and Karen Saulnier for assistance in development of the communication items; Barbara Raimondo and Leslie Proctor for providing parents' perspectives.

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Several chapters incorporate interview material that appeared in a chapter by Mertens, Sass-Lehrer, and Scott-Olson, “Sensitivity in the Family-Professional Relationship: Parental Experiences in Families with Young Deaf and Hard of Hearing Children” (P. E. Spencer, C. J. Erting, & M. Marschark [Eds.], *The Deaf Child in the Family and at School: Essays in Honor of Kathryn P. Meadow-Orlans*, Mahwah, NJ: Erlbaum, 2000.) We have also included comments from attendees at national conferences where data from the project were presented.

The book is very much a team effort, with the three senior authors participating in planning and carrying out each phase of a complex effort. Meadow-Orlans coordinated the survey and took the lead for chapters 1, 3, 5, and 6. Mertens and Sass-Lehrer supervised the interviews and focus groups. Mertens took the lead in chapters 4, 7, and 8, and Sass-Lehrer, in chapters 2 and 9. Kimberley Scott-Olson contributed to many aspects of the data collection and coding and collaborated on chapter 7. Jennifer Pittaway helped to prepare the resources appendix.

Thanks to the chairs of two Gallaudet University departments for support during the years of our involvement in the National Parent Project: Barbara Bodner-Johnson (1996–1998) and Richard Lytle (1998–2002), Department of Education, and Thomas Kluwin, Department of Educational Foundations and Research.

We echo the thought of one parent participant: “I hope that it helps somebody else. I really hope it helps some other parent some day—that would make me feel really good.”

Kathryn P. Meadow-Orlans

Donna M. Mertens

Marilyn A. Sass-Lehrer

Chapter 1

Introduction to the National Parent Project and Survey Results

This book details the experiences of a representative group of American parents and their deaf or hard of hearing children from identification of hearing loss to the early elementary grades during the last decade of the twentieth century. The parents report their goals and expectations, the children's achievements and troubles, their family's satisfactions and disappointments with health and educational systems. When the children were born, in 1989 and 1990, these systems were in the throes of dramatic shifts in provisions for infants and toddlers with disabilities. Technological advances led to the expanded use of cochlear implants and earlier identification of hearing loss. The Individuals with Disabilities Education Act (IDEA), passed in 1986 and reauthorized in 1997, required that parents be included in planning educational programs for their children with disabilities and that programs be designed to meet the needs of these children and their families (Craig, 1992; Moores, 2001; Sass-Lehrer & Bodner-Johnson, 1989).

However, if professionals are to provide individualized support services, they must first identify salient characteristics of families and children so the services will fit unique circumstances. This seems a straightforward statement, but it masks a complex imperative. Deaf and hard of hearing children comprise a heterogeneous population: They come from every region and state; from farms, inner cities, and suburbs; and from every racial, ethnic, and socioeconomic group. They may be adopted or fostered, have many siblings or none, and live in large or small extended families where parents speak English or one of many other languages. Those parents may be hearing, deaf, or hard of hearing; married or single, living with a partner, divorced, or separated. The children themselves may be deaf or hard of hearing, may or may not have additional conditions, and may or may not be developing at age level. All of these characteristics (and others as well) have an impact on the kinds of services that are most

appropriate, on parents' evaluations of services, and on parents' responses to a child's hearing loss.

To date, few efforts have been made on a national level to explore the relationship of child and parent characteristics to early intervention services. This gap was one reason for the National Parent Project (NPP), which is reported in this book. A nationwide survey was conducted that was designed to reach parents of 6- and 7-year-old deaf and hard of hearing children and to gather information about their early experiences with the professionals who provided identification and intervention services.¹ To gain an in-depth understanding of those experiences, the survey was followed by interviews with 80 of the parents.

A growing body of research documents the positive effects of early comprehensive intervention for the social and cognitive development of children born at risk for developmental delay (Greenberg & Crnic, 1988; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). For children who are deaf or hard of hearing, positive results of early intervention are shown for social and communicative competence, and support networks relate to positive mother-child interaction and better language development (Calderon & Greenberg, 1997; Meadow-Orlans & Steinberg, 1993; Yoshinaga-Itano, 2000). Children in responsive and supportive families demonstrate better socioemotional, communicative, and cognitive development compared to others (Meadow-Orlans, *in press*). A lingering question for practitioners is how best to connect with families to provide information, support, and resources to enhance parents' and caregivers' abilities to promote children's development. Professionals also face the challenge of changing demographics of children in special education programs (Holden-Pitt & Diaz, 1998; Schein, 1996). As immigration has increased the proportion of foreign-born children in public schools, nonnative children in deafness-specific programs have increased even more rapidly (Schildroth & Hotto, 1993), perhaps because economic disadvantage places them at greater risk

1. See Appendix A for a detailed description of the survey methodology. Appendix B includes the survey and interview instruments.

for repeated middle-ear infections and poor medical care (Cohen, Fischgrund, & Redding, 1990).

These demographic changes, added to legislative and technological shifts, mean that both early intervention programs and the children and families they serve are quite different from those of earlier years. Information about the composition of the population and about parents' views of their early experiences should benefit professionals and future consumers alike.

Design of the Project

The NPP was conducted in three stages: (1) a national survey of parents whose 6- and 7-year-old children were enrolled in educational programs for pupils who were deaf or hard of hearing (404 respondents); (2) telephone or TTY interviews with parents randomly selected from survey respondents who agreed to provide additional information (62 interviews); and (3) face-to-face interviews (one with an individual mother, one with a mother-father pair, and three in focus groups with a total of 17 mothers). Readers will find detailed descriptions of the research methodology in Appendix A and copies of the survey questionnaire and interview guides in Appendix B.

Parents of 6- and 7-year-old children were targeted for the following reasons: (1) All children with even a mild congenital hearing loss will probably be identified by age 6; (2) all of the children and parents would have had an opportunity to participate in (or would have failed to receive) intervention services; (3) a fairly narrow age span would increase the homogeneity of parental expectations for developmental progress; and (4) parents would be close enough in time to the infant and preschool years to provide accurate retrospective reports and also sufficiently removed to gain some perspective on those experiences.

Plan of the Book

The following pages of this introduction present the survey results, providing a broad snapshot of the characteristics of 6- and 7-year-old deaf and hard of hearing children and their parents, drawn from across the United

States. In addition, we have summarized the parents' assessments of early intervention services, their responses to their child's hearing loss, and their child's behavioral status and linguistic progress. The following chapter draws from comments from all of the parents, discussing their communication choices for their deaf and hard of hearing children. The next five chapters provide perspectives of parents from important subgroups: (1) children who are hard of hearing, (2) children with additional conditions, (3) children who have deaf parents, (4) children with cochlear implants, and (5) children from minority families. The final section includes two chapters with a general focus, again drawing on the advice from all of the parents (1) to other parents of deaf and hard of hearing children and (2) to the professionals who serve those children and their families.

Survey Results

Characteristics of the Children

Meadow-Orlans and Sass-Lehrer (1995) proposed that the following child and parent characteristics are especially relevant to the success of early intervention: a child's hearing level; age at identification; the presence or absence of additional conditions; and the parents' hearing status, racial/ethnic group membership, and educational level. Data from the NPP survey suggest that these characteristics are indeed related to parents' evaluations of services, the support they receive, their assessment of the impact of deafness on the family, and assessments of children's social behaviors and language progress.

Hearing Level

Forty-six percent of the children the NPP survey describes were identified as deaf: "can't understand speech, even with a hearing aid"; the remainder were identified as hard of hearing: "can understand speech when in a quiet room, with a hearing aid." Lengthy discussions led to the decision to use this functional definition rather than asking parents to report decibel levels or audiological categories (e.g., "mild" to "profound") because responses might be more reliable if categories were couched in everyday language. Also, the survey was designed to capture parents' perceptions of their children's auditory functioning.

Age at Identification and Intervention

The child's average age when parents suspected a hearing loss was 17 months. On average, hearing loss was confirmed at age 22 months (an elapsed time of 5 months between initial suspicion and confirmation). However, 31% of parents reported confirmation less than 1 month after the initial suspicion, and 4% waited 2 years or more. Degree of hearing loss greatly influenced the confirmation age: Children who are deaf had a confirmed identification on average at age 14.5 months; those described as hard of hearing had a confirmed identification at 28.6 months. Thus, children who are deaf received confirmation of hearing loss earlier than those born even a decade earlier. Time between parental suspicion and confirmation of hearing loss is within the expected range, confirming the guarded optimism that Harrison and Roush (1996) express—that age of identification is slowly decreasing. Also heartening are reports that implementation of newborn hearing screening in Colorado “has increased dramatically” the number of children identified before the age of 6 months (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

Like age at identification, age at intervention varied greatly. Children who are hard of hearing began speech training 8 months after their hearing loss was identified; those who are deaf began training 11 months after identification.² Although the average time required for a child to receive a hearing aid was almost 8 months after identification, 20% of the children received a hearing aid within 1 month. One source of this variation is the children with deaf parents, who tend to delay procuring amplification. Children with deaf mothers got hearing aids at an average age of almost 19 months. Children with hearing mothers were exposed to sign language at differing ages, depending on the racial or ethnic background of their parents: White children at 9 months, Hispanic children at 15 months, and African American children at 19 months.³

2. Ages are rounded to the nearest month. Unless otherwise noted, reported group differences are statistically significant. Appendix C includes supplementary tables showing additional data. For ages at which deaf and hard of hearing children received hearing aids, speech and auditory training, sign language, and cued speech, see Appendix C, Table 1.

3. For the survey, parents checked their race or ethnicity as White, Hispanic, Black/African American, Asian Pacific, Native American, or Other.

Additional Conditions

Almost by definition, the needs of a child with a hearing loss are compounded by cognitive or physical disabilities (Meadow-Orlans, Smith-Gray, & Dyssegaard, 1995). Traditionally, approximately one third of school-age children who are deaf or hard of hearing are reported to have additional conditions (visual, cognitive, motor, or learning disabilities; health or behavioral problems) that may interfere with educational achievement (Schein, 1996). Parents participating in the NPP survey identified 32% of their children with some additional condition, although data from the annual survey of 6- and 7-year-olds conducted by the Center for Assessment and Demographic Studies (CADS) show that only 24% have additional conditions. However, CADS data (collected from program personnel rather than from parents) for children of all ages show that about one third have additional conditions (Wolff & Harkins, 1986; Schildroth & Hotto, 1993). It is possible that program personnel are reluctant to label children as young as 6 years, especially for conditions such as learning or developmental disabilities and emotional or behavioral problems. These data suggest that parents may be more likely than teachers to identify these conditions when their children are young.

Characteristics of Families

Hearing Status of Parents and Siblings

Among responding parents, 10% of mothers and 11% of fathers are deaf or hard of hearing. Ten hearing mothers are married to deaf (DF) or hard of hearing (HH) husbands; nine hearing fathers are married to DF or HH wives; 7.5% of the children have two DF or HH parents; 5.5% have one DF or HH parent. Eighteen percent of the children have no siblings; 3% have one deaf sibling only; and 79% have one or more hearing siblings.

Educational and Occupational Status

Parents' educational levels are moderately high: Some training beyond high school was reported by 39% of mothers and 31% of fathers; 27% of mothers and 33% of fathers have 4 years of college or more. More than half of the mothers (58%) work outside the home: 55% in professional or managerial positions, 32% in clerical or sales work, and 14% in blue-collar

jobs. Fathers' occupations are described as professional or managerial (40%), clerical or sales (20%), or blue collar (40%).

Racial/Ethnic Background

The proportion of Whites in the survey data (67%) is somewhat higher than that reported for this age group (58%) in the CADS annual survey for 1996–1997 (Holden-Pitt & Diaz, 1998). However, the NPP distribution of Hispanic and African American respondents is somewhat different from that for the CADS annual survey. This might be partially attributed to schools' differing classifications of children from mixed-race families. CADS and NPP survey distributions are as follows: Hispanic (17% and 11%, respectively); African American (17% and 9%); Native American (1% and 1%); Asian/Pacific (3% and 3%); and mixed or other (2% and 9%). Mixed-race families were most likely to be African American-plus-White or Hispanic-plus-White.

Services Received

Special Services for Children

Parents identified, described, and evaluated the early intervention program that their child attended the "longest." Children who are deaf entered that program on average at age 29.5 months; those who are hard of hearing entered the program on average at age 34.5 months. Elapsed time after identification was 16 months for the deaf group and 11 months for the hard of hearing group.

About 60% of parents reported that they had more than one program to choose from. (Note that fully 40% of parents reported that they did *not* have a choice of programs for their child.) Of those who had a choice, 29% selected a program because sign language was offered as a communication approach; 12% chose the program because an oral approach was available. A few mentioned location, individual attention, availability of special services, and opportunity to be with other deaf children or to be included in programs with hearing children as decisive attributes. Of those who reported that they had no program choices, 80% either said that they preferred the program or gave no response to the question about preference. Four percent would have preferred a signing program; another 4%

would have preferred an oral program. Almost half (48%) reported that program staff included one or more deaf adults.⁴

In about one quarter of the programs, speech alone was the communication approach used; sign language plus speech was used in two thirds; sign language alone in 5%; cued speech in 3%; and sign language plus cues in 3%.

Services for Parents

Apparently, programs are doing a good job of providing relevant information to parents. Three quarters received information about deafness; 68% had information on legal rights for their children; 64% had information on child behavior and/or development; and 59% had information on choices for future school placement. Sign language instruction was available to 71% (and to 89% of parents whose children were enrolled in programs that used signs). About half of the fathers and three fourths of the mothers attended classes. Parent group meetings were available to 69% of the parents. Of those, 44% of fathers and 85% of mothers attended meetings. Individual counseling was available to 43% of families; 25% of fathers and 70% of mothers made use of those services. Parents identified the single service that was most helpful to them. About one third of mothers selected information about deafness, legal rights of children, child behavior or development, or school placement. Another third selected sign language instruction. Other responses were divided among several different categories. For 27% of the fathers, information was the most helpful; sign language instruction was the most helpful for 41% of the fathers.

Parents' Evaluations of Early Services

Most parents had positive evaluations of their services.⁵ When we assigned scores from 1 to 4 to responses and summed these scores, the average score was 14 of a possible 16 points. Hearing mothers evaluated services significantly more positively than did mothers who are deaf or hard of hearing,

4. See Table 2 in Appendix C for tabular data on communication approach used in "first" and "current" educational programs and "at home" for all of the children and by hearing status.

5. Appendix C, Table 3.

and White mothers were more positive about services than mothers from non-White or mixed-race families.⁶

Neither the mothers' education (no college versus some college) nor the child's hearing status nor the presence of an additional condition affected service evaluation scores. However, the child's age at the time of identification was a significant factor in the evaluation of services by parents of non-White and mixed-race children, and older ages were associated with less positive evaluations.

Sources of Help for Parents

Thirteen potential sources of help for parents were listed, and parents indicated the helpfulness of each source.⁷ Teachers received the highest score of any support source. Two thirds of parents characterized their child's teacher(s) as "extremely helpful"; an additional one quarter characterized a teacher as "very helpful." This compares with 47% and 20% for spouses and only 19% and 20% for medical doctors. Parents of children with additional conditions reported *less* support than parents of children whose deafness was not complicated by some disability. Non-White respondents and those with no college training reported less support than did other groups.⁸

Children's Behaviors and Language Ratings

Children's Behaviors

We asked parents to characterize their child's behavior by reacting to 10 behavioral descriptions, for example, "My child forms warm, close attachments to or friendships with peers."⁹ A behavior score summarizing these items shows that (1) for children with no additional conditions, those who are deaf have more positive behaviors than those who are hard of hearing and that those with early diagnoses have more positive behaviors than those with late diagnoses; however, (2) for children with one or more

6. Appendix C, Table 4.

7. Appendix C, Table 5.

8. Appendix C, Table 6.

9. Appendix C, Table 7.

additional conditions, those who are hard of hearing have more positive behaviors than those who are deaf, and those with late diagnoses have more positive behaviors than those with early diagnoses.¹⁰ Perhaps for children with other conditions, those whose hearing losses were diagnosed late had services related to another condition that supported their behavioral development. It appears that hard of hearing children with late diagnoses and no additional conditions may need special help during the pre-school years.

Children from non-White or mixed-race families whose mothers have no college training are also at additional risk for behavior problems. Their behavior scores are significantly below those of other children.¹¹ This suggests that additional counseling resources would benefit parents and children in programs with high concentrations of less-educated minority families.

Language Ratings

As expected, hard of hearing children received significantly higher language scores than children who are deaf.¹² Age at identification and additional conditions also influence language performance. Children with one or more cognitive or physical conditions have lower scores than their peers without disabilities. For hard of hearing children without additional conditions, early identification is associated with higher language scores. For children with additional conditions, those with later diagnoses have significantly higher language scores regardless of whether they are deaf or hard of hearing. This result, which is counterintuitive but similar to that for behavioral problems, is puzzling and warrants further investigation.¹³ The mother's education and racial/ethnic group are also related to language scores: White and non-White children with more highly educated mothers score higher than same-race peers whose mothers have less education.¹⁴ Within educational levels, White children have higher language scores than non-White and mixed-race peers.

10. Appendix C, Table 8.

11. Appendix C, Table 9.

12. Table 10 in Appendix C shows these items in abbreviated form together with the proportions of children with the highest ratings.

13. Appendix C, Table 11.

14. Appendix C, Table 12.

Parents' Feelings about Deafness

Parents responded to nine statements designed to measure the impact of deafness on them and/or their families and registered agreement or disagreement on a five-point scale.¹⁵ Parents of children with conditions in addition to deafness reported a significantly more negative impact compared to parents of children without additional conditions. Mothers' hearing status had a lesser but still significant influence on impact scores. A child's deafness had a less significant impact on deaf mothers than on hearing mothers. Parents' racial/ethnic background also influenced the impact scores: Hispanic mothers reported a more negative impact than White mothers.

Conclusion

Early intervention specialists may want to give special attention both to late-diagnosed children who are hard of hearing and to minority-group parents with less education. A report of interviews with Hispanic parents includes provocative insights into their attitudes, perceptions, and beliefs about deafness and contains important information for educators. Religious and cultural values influence families, some of whom attribute deafness to divine will and experience the stigmatization of a deaf child by the extended family (Steinberg, Davila, Collazo, Loew, & Fischgrund, 1997). Demographers predict that the current population trend toward smaller proportions of non-Hispanic and larger proportions of Hispanics and African Americans in the U.S. population will continue at least until 2050 (Hernandez, 1997). This forecast adds urgency to the challenge of meeting the needs of children and families from minority backgrounds.

The interview data presented in the following chapters provide important views of parents and are intended to flesh out the less personal information available from a statistical analysis of data derived from a survey questionnaire.¹⁶

15. Table 13 in Appendix C lists these statements with the mean score for each item.

16. Many of the data reported in this chapter appeared previously in *American Annals of the Deaf* (1997, 142, 278–293).

Chapter 2

Communication Conundrum: Family Solutions

Within the first day after we found out, I knew I had to start signing with her because . . . nobody could tell me whether she'd ever be able to hear enough to learn how to talk, and I didn't want a frustrated child or—or me. So it was a real easy decision. I didn't even think twice about it. (Survey 293)

[He] was already learning speech . . . and [we wanted him to] keep going with it—being oral. He has some hearing; he has some residual hearing; he's already speaking. He wants to speak. "Do it!" It wasn't even a decision. It was made for me rather than me making one. I never even thought of sign language, to be honest with you. Unless he was going to go totally deaf and then, you know, obviously I was going to have to go sign language. (Survey 76)¹

Communication is the central concern for families with children who are deaf and hard of hearing. Parents struggle to establish effective communication in their families and ensure that their children receive the necessary support from schools and professionals. Early language acquisition and child and family functioning, regardless of the mode of communication, are critical to the overall development of the child with a hearing loss. However, parents and professionals may lose sight of this as they grapple with a decision. Recognizing the vital importance of effective com-

1. Survey forms were numbered consecutively from 1 to 404 when they were received at Gallaudet. Numbers were also used to identify the interviewees. They are retained here merely to reflect the large number of different respondents included as sources. Excerpts from focus groups are also identified by a sequential numbering system.

munication between families and children, researchers have studied the relationship between various methods of communication, child language outcomes, academic achievement, and social development (Calderon & Greenberg, 1997; Carney & Moeller, 1998; Desselle, 1994; Geers & Moog, 1992; Greenberg, Calderon, & Kusché, 1984; Lynas, 1999; Meadow-Orlans, 1987; Vacarri & Marschark, 1997; Yoshinaga-Itano, 2000).² Communication mode and parent-child interactions have also been the subject of numerous investigations (Calderon & Greenberg, 1997), and research has more recently focused on the quality of communication and overall family functioning (Rosenbaum, 2000). Despite efforts to determine the best mode of communication for children with hearing loss, definitive answers remain elusive (Carney & Moeller, 1998).

Early attempts to determine the most appropriate communication approach were based on a system that weighted factors such as degree of hearing loss and presence of additional conditions (Downs, 1974; Geers & Moog, 1987). Stredler-Brown (1998) suggests that professionals can make recommendations based on a data-driven approach utilizing assessment protocols that focus on the child's development and parent-child interactions, along with consideration of parent preference. Attempts to reduce the decision to an objective, quantifiable measure that minimizes the importance of subjective variables that influence parental choices may have limited success. In a recent study of factors contributing to parents' selection of a communication mode, Eleweke and Rodda (2000) find that decisions are heavily influenced by the information parents receive, perceptions of the effectiveness of assistive technology, attitudes of service professionals, and the quality and availability of support services. Steinberg and Bain (2001) conclude from interviews with 30 families that communication decisions are based as

2. See the following websites and books for a description of the different modes of communication that people who are deaf or hard of hearing commonly use: <http://www.beginningssvcs.com>; <http://clerccenter.gallaudet.edu/SupportServices/series/4010.html>; *Choices in Deafness: A Parent's Guide to Communication Options* (2nd edition), Sue Schwartz (Ed.); *The Silent Garden: Raising Your Deaf Child* (2nd edition), by Paul W. Ogden.

much on child and parent characteristics as they are on the information and guidance that professionals provide and the availability and quality of services. Parental knowledge, experiences, and personalities influenced the communication decisions of one family who participated in Spencer's in-depth study (2000a). Kluwin and Gaustad (1991) suggest that attitudes about hearing loss, acceptance of a child with a disability, and parental expectations for the child's role in the family influence the family's communication decision. Decisions are often complicated by perceived time pressures, that is, the need to develop early language, the ability to understand complicated information, and the parents' emotional state (Steinberg & Bain, 2001). Steinberg and Bain interviewed families whose children's hearing losses were identified by 6 months of age. These families discussed the impact of accuracy, completeness, and timeliness of information, as well as support they received.

The National Parent Project (NPP) asked parents to describe the communication approaches they used with their children at home and in school and their involvement in the communication choices they made. Parents shared their perspectives on how communication decisions were managed in the early years and their satisfaction with the process. Parents identified the method of communication used at home, in an early intervention program before age 5 years, and in their child's current program (Table 2 in Appendix C).

The parents' hearing status greatly influences their choice of methodology. Parents who are deaf are more likely to sign at home with their children than hearing parents regardless of whether their children are deaf or hard of hearing. However, differences are also based on the extent of the child's hearing loss. For example, 57% of hearing parents and 40% of non-hearing parents with hard of hearing children use speech only at home with their child. On the other hand, only 9% of hearing parents and no parents who are deaf or hard of hearing use speech only if their child is deaf. In early intervention programs, speech plus sign language was the approach used most frequently with all of the children. As children moved from early intervention to elementary school, some parents reported that their children's method of communication changed from sign language

plus speech to either sign language without speech, speech without signs, or Cued Speech. Overall, very few children in this study used Cued Speech or an auditory verbal approach.³

One mother described the change of communication mode over time with her hard of hearing daughter:

They suggested having her learn some basic signing skills when she was a baby because we didn't know exactly how she would develop behaviorally with a hearing loss. We did start that, and we talked about other means of communication like Cued Speech. We kind of went through all of that and then it became apparent that she was developing orally. We subsequently stopped doing any kind of signing with Helen whatsoever because she . . . is doing well verbally. She's on target at the average 2½ years old for speech. (Survey 297)

Another parent had this to say about a child's early communication needs:

The child needs to be in a signing environment, especially at a young age. That is their communication, that is their vocabulary . . . that is the foundation. . . . How they're gonna learn when they get older? . . . [You] can make the choices as to how that child's progressing. . . . You can make your choices later on, but . . . when they're young they need to be in a signing environment, and I suggest a deaf school. (Survey 288)

3. The auditory verbal approach emphasizes the development of listening skills through one-on-one therapy that focuses attention on the use of the remaining hearing (with the aid of amplification). Because this method strives to make the most of a child's listening abilities, no manual communication is used and the child is discouraged from relying on visual cues, including speechreading. The main goal of this unisensory approach is to develop speech, primarily through the use of aided hearing alone, and the communication skills necessary for integration into the hearing community (http://www.beginningssvcs.com/communication_options/auditory_verbal.htm).

The Communication Decision

Parents utilize many different strategies to determine the communication method to use with their children. Some families have strong opinions and make decisions early with little or no input from professionals. Others struggle as they attempt to reconcile the information they receive from professionals that conflicts with their own beliefs or with the opinions of others. Many parents emphasize a desire for their children to be able to communicate with both hearing and nonhearing people. Still, some parents describe a sense of relief when they believe that their child's speech has improved to the point where they do not need sign language to communicate. Some families receive little information or support and are on their own in making a decision.

Parents consider communication options an important factor in the selection of an early intervention program. Parents who could choose an early intervention program reported that they chose a particular one mainly because of the communication approach it offered. Nearly half of the parents had no program choice, and some would have preferred another program because of the limited communication options available. Twenty-five percent reported that the early intervention program did not offer a choice in the communication approach it used.

For some parents, the communication decision is second nature. All of the deaf parents whom we interviewed used at least some sign language with their children and described their decisions as fairly straightforward. Many used American Sign Language (ASL), whereas others used a combination of speech and signs incorporating English word order or signs from English-based sign systems.⁴ For example, one deaf mother with a deaf son explained why she chose to use sign language:

4. American Sign Language is a complete signed language with distinct grammatical rules, word order, and idioms. It is the primary language of many Deaf people in the United States. Signed English systems are manually coded systems that use signs from ASL and invented signs for spoken English words, prefixes, and endings. Signed English systems are not languages but are used to support spoken English. Examples of Signed English systems are Seeing Essential English (SEE I), Signing Exact English (SEE II), and Signed English.

Well, it [sign language] is just our natural language. Sometimes I use some English, I would say pidgin language. (Survey 316)

Some of the hearing parents we interviewed were also quite sure from the beginning about the communication mode they would use. A few parents had very strong feelings about their child's need to get along in the "hearing world." One parent said:

The majority of the world is a hearing world, a speech world, and . . . if she's signing to people . . . you know, most of them are not gonna understand what she's trying to say. . . . Once we realized she was gonna hear . . . you know, we were really pushing that, you know, that she'd be oral. I mean, had she not been as successful as she has been, you know, I guess we would've . . . you know, fallen back on the sign. (Survey 101)

One father who chose a combined approach (i.e., signing and speech) considered the need to get along in the hearing world but was also influenced by his experiences with Deaf adults in his church:

Well, I think at least for me it's a pretty simple decision. I feel that . . . I want her to learn to read lips, I want her to speak. . . . But I see how well adjusted these adults are that can read lips, that can sign, and that have some vocal ability. And in the hearing world in the job market, when you're an adult . . . as a parent, for Sabrina's future, I don't . . . see any other way other than Total Communication. . . . I don't believe in burying her in the Deaf culture and not teaching her to get along in a hearing world and have her just be with deaf people and just her own kind. I don't think the world's like that. . . . We need to learn with our abilities or disabilities. . . . So that's my view on Total Communication. I'm pretty adamant on that and I don't feel there's any other, any other way. (Survey 310)

Fear of “losing your child to the Deaf culture” is another concern of some parents:

If you just stuck with sign, my thinking was, he's locked in this Deaf World . . . and I decided he would have to fit into both worlds. And I told him when he was real little, once he had a hearing aid on . . . and when he heard me when I would get real close and be talking to him I'd say “We're gonna cross over and you're gonna fit into our world because I'm not gonna let go. . . . God gave you to me. . . . I'm hanging on tight. You're stuck; you're not getting away.” (Survey 16)

Some parents based their decisions on how much hearing their child had. An ear, nose, and throat specialist told one father that his daughter was able to hear at a normal conversational level, although background noise was a significant problem. Because she was “able to hear almost everything,” these parents decided to use speech only (Survey 85). Another parent said:

He has no hearing at all. . . . I can't use just speech with him . . . because I have to communicate with him. . . . I have to communicate with my son. And my whole household, my husband, and my 3-year-old daughter . . . we all sign with him. But we also use voice, and he . . . tries to make sounds, but it doesn't sound like anything. (Survey 17)

Several parents indicated that they wanted to ensure that their children had every opportunity to use whatever mode of communication would work for them. Spencer (2000a) describes one family who explored all of the communication options for their daughter. By their daughter's first birthday they were using an English-based sign system and Cued Speech, each for half of the day, to promote bilingualism. At 2 years of age they agreed to drop Cued Speech and focus on signing. By the time their daughter was 3 years old, they had decided on a cochlear implant, resting

their hopes on improved auditory and speech skills. They continued to use signs after the implant and were hopeful that these avenues would be sufficient for her to develop literacy (see chapter 6). Several parents in the NPP expressed a similar desire for their child to have everything. One Spanish-speaking mother with a deaf son shared these thoughts with a focus group:

What I was thinking is, there's lipreading, speechreading, and sign—the whole 9 yards. So they can have an option, you know, if they grow up and they said, "Oh, I don't want to sign," or "I just want to speak," that's their choice. But I want to give them some options; it's what you can do, you know. So they gave us some speech therapies at home, and they integrate much more speech in their classroom. And we got him [an] auditory FM system. (Focus Group 2)

Other mothers had similar responses:

Because we want him to have opportunity and every advantage . . . so [you] know, we don't care; we just want him to learn. We want him to be able to talk; we want him to be able to communicate; and we want to be able to communicate with him. And if that means signing, that's what we're [going to] do. (Survey 334)

Well, I wanted Derick to learn. I wanted him to use all means of communication. Whatever it was to be able to communicate. So I couldn't make that choice—one over the other. It was, like, cues, voice, and oral, and visual. . . . Communication means so much to me. My background is social work, and that's what you say. People have to talk, you have to communicate—use any means necessary. (Focus Group 3)

Some families expressed anguish about their decisions and wondered whether they had made the right ones. A discussion from one of the focus groups illustrates this struggle: