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Family Supports and Resources for Parents of Children Who
are Deaf or Hard of Hearing

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FAMILY SUPPORTS AND RESOURCES FOR PARENTS OF CHILDREN WHO ARE DEAF OR HARD OF HEARING

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HE STUDY examined family supports after identification of children's hearing loss. On a questionnaire, 456 respondents rated the importance of different aspects of family support, the quality of supports they experienced, and their preferences about informational resources. They verified the importance of informational resources, social-emotional support, and educational advocacy. Families expressed a preference for discussion with other parents of children with hearing loss over discussion with parents of children without hearing loss. The quality of support was rated higher by parents of children with cochlear implants than by parents of children with hearing aids. Top-ranked sources of support included individual professionals and service providers, other parents of children with hearing loss, family support organizations, and grandparents and extended-family members. Open-ended written responses indicated that parents desired additional opportunities to connect with mentors, role models, and other parents.

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Special education, deaf education, and related disciplines have undergone a paradigm shift, as the critical roles of the family, community, and complex ecosystems are increasingly recognized in service provision (Allen & Petr, 1996; Bailey & Bruder, 2005; Bailey et al., 1998; Bodner-Johnson, 1986; Bruder, 2000; Calderon, Bargones, & Sidman, 1998; Dunst, 2002; A. P. Turnbull & H. R. Turnbull, 2001). The historical trend of centered-based, impairment-focused services has gradually shifted to acknowledge the importance of building the capacity of family members and existing support systems within the child and family ecosystem and natural envi-

ronments. This change in focus reflects not only a philosophical paradigm shift but a response to legislation. The Individuals With Disabilities Education Act mandates that early intervention be family centered and delivered in natural environments. In a recent consensus document, the Workgroup on Principles and Practices in Natural Environments (2007) concluded that "the primary role of the service provider in early intervention is to work with and support the family members and caregivers in children's lives" (p. 2). This consensus document acknowledges the importance of building the capacity of family members, stating that "all

families, with the necessary supports and resources, can enhance their children's learning and development" (p. 2).

With the implementation of family-centered services after early identification of hearing loss, programs serving children who are deaf or hard of hearing and their families have been challenged to acknowledge and respond to a diverse, evolving family system that includes a growing predominance of primary caregivers employed outside the home, blended families, and the dynamic roles of extended-family members. Given the centrality of the family's role in early detection of hearing loss and intervention, there is growing recognition of the importance of family well-being, family resources and supports, and the involvement of families in services for children who are deaf or hard of hearing. Educators of the deaf and service providers in related services strive to foster families' strengths and support the child's development within the context of the family.

Family support is recognized as an essential aspect of service provision following early identification of deafness. The term *family support* refers to varied resources to address the family's needs related to emotional well-being, health, material well-being, parenting, disability-related considerations, and family interactions (Beach Center on Disability, 2009). Family supports are intended to "strengthen the caregiving efforts of families (with special emphasis on their emotional, health, material, parenting, disability-related, and family interaction characteristics), enhance the quality of life and community integration of families whose members have disabilities, and increase their access to supports and services for themselves and their members with disabilities" (Beach Center on Disability, 2009).

Family support traditionally has been provided through various venues such as parent-to-parent support, disability-specific agencies or entities, community-based family resources, and emotional or informational support provided by professionals, friends, and extended family. In many states, formalized entities have organized to provide support tailored to families who include members who are deaf or hard of hearing. Family support organizations or programs may be offered at the local, state, or national level. At the local level, service providers arrange family support groups or meetings. Statewide family support organizations such as Beginnings are available in some states. National organizations such as the Alexander Graham Bell Association, the American Society for Deaf Children, Hands and Voices, and the National Association of the Deaf offer a variety of family supports and resources, such as connecting families, offering informational resources and workshops, providing training for educational advocacy, and assisting with access to funding and services. Programs such as Guide by Your Side, provided by Hands and Voices, offer individualized mentorship and coaching by training parents of children who are deaf or hard of hearing to provide ongoing support to other parents with similar experiences. Although organizations offer resources and supports through various venues and programs, there has been relatively little empirical research related to evidence-based design and implementation of family support.

Furthermore, with systemic changes resulting from the implementation of universal newborn hearing screening, growing availability of technological advances, and dynamic family systems, additional research is needed to reexamine preferred systems of family

resources and support. Several recent studies have focused on family outcomes and aspects of family-centered services for parents and children after identification of hearing loss (Asberg, Vogel, & Bowers, 2008; C. W. Jackson, 2009; C. W. Jackson, Traub, & A. P. Turnbull, 2008; C. W. Jackson & A. P. Turnbull, 2004; C. W. Jackson, Wegner, & A. P. Turnbull, 2010; Luckner & Velaski, 2004; Most & Zaidman-Zait, 2003; Zaidman-Zait, 2007). Recent themes in findings and areas recommended for further research were reviewed in the development of a questionnaire on family resources for the present study.

In a previous study (C. W. Jackson et al., 2010), two colleagues and I examined family members' perceptions of well-being following early identification of deafness. A family quality-of-life questionnaire was used to solicit ratings of impact and satisfaction from family members of 207 children who were deaf or hard of hearing and under 6 years of age. Parents reported that the largest impact of deafness was on their emotional well-being. Participants were generally satisfied with areas of family life but demonstrated lower satisfaction ratings in the area of emotional well-being. Family members noted areas of desired support that may be important to family well-being by initiating written comments specifically related to social supports, sources of stress relief, support of grandparents and extended-family members, informational resources, and financial assistance. The written comments were open ended and self-initiated by small numbers of families in the C. W. Jackson and colleagues (2010) study; therefore, further inquiry was warranted to expand our understanding of these indicators and to consider whether the themes were also shared by families in a larger, diverse sample. Although subsections of existing scales

assess related areas (e.g., sources of stress, social supports, informational resources), existing surveys did not encompass all specific desired aspects of family support identified by families.

In an effort to follow up on aspects of support identified by families to determine if such themes were shared by other families, survey questions on family support and resources were drafted for the present study. Additional literature review was conducted related to these specific aspects suggested by families in order to further explicate potential questions that warranted further consideration for inclusion regarding informational resources and sources of support for families after identification of hearing loss.

In one study, Luckner and Velaski (2004) identified aspects thought to be important to family support by surveying families' strengths and use of resources. The investigators conducted interviews with 19 parents of children 4–18 years old. Parents were asked about factors that they felt contributed to being a healthy family, challenges they experienced, and advice to other families. Participants reported that support from extended family, friends, professionals, and the community was essential to a healthy family with a child who was deaf or hard of hearing. Among the challenges parents reported were overcoming barriers impeding access to high-quality educational programs and appropriate services, helping people understand deafness, learning communication methods, efficiently allocating financial resources, and assisting their child in forming friendships. Parents advised other families to gather informational resources, be involved, learn multiple communication modalities, have high expectations, and provide love and encouragement to their child daily.

Expanding on the factors suspected to be critical to family support, Asberg

and colleagues (2008) explored correlates and predictors of stress in 35 parents of children with hearing loss. Parents completed self-reported measures of parenting stress, perceived social support, received social support, and life satisfaction. Receipt of support was positively correlated with life satisfaction ($r = .42$). Higher ratings of enacted support predicted parents' life satisfaction ratings ($p = .026$). Parenting stress was negatively correlated with perceived adequacy of social support ($r = -.41$). Perceived social support was a significant predictor of parenting stress ($p \leq .01$), although receipt of a higher level of support was not a significant predictor ($p > .05$). The results suggested that perceived social support may act as a buffer against parenting stress, although the quantifiable amount of support families received was not a good predictor of parenting stress.

Several researchers have concurred on the importance of support, particularly social support, in reducing parents' stress. A relationship between perceived adequacy of social support and stress has been reported in studies by Hintermair (2000), Lederberg and Golbach (2002), Quittner, Glueckauf, and D. N. Jackson (1990), and Zaidman-Zait (2007). Hintermair found that parents who reported supportive social relationships and frequent interactions with other parents demonstrated lower stress scores on the Parenting Stress Index. Similarly, the perceived value of social-emotional support was also made evident in a qualitative study by Zaidman-Zait (2007), who examined the experiences of 15 parents of children who were deaf or hard of hearing. In this study, 92.6% of the parents' surveyed said they perceived talking with other parents who had children who were deaf or hard of hearing as an important source of support. Parents pointed out

potential advantages of meeting with other parents: not only receiving emotional support but getting help with practical needs and learning from firsthand experiences. Among the surveyed parents, 92.6% also indicated that professional support was helpful to them in coping with their child's hearing loss. Nearly three quarters of the parents (74.1%) noted that social support from a family member or friend was helpful.

Grandparents and extended-family members have also been identified as an important source of support in several studies (McNee & C. W. Jackson, 2011; Morton, 2000; Nybo, Scherman, & Freeman, 1998). In the McNee and C. W. Jackson study (2011), 50 parents and 35 grandparents were interviewed regarding the role of grandparents after identification of hearing loss. Parents generally reported a high level of grandparent involvement. Maternal and paternal grandparents were reported to provide emotional support, nurture and provide caregiving, aid in decision making, and provide monetary assistance. Obstacles to the involvement of grandparents included distance, poor health, and financial limitations. Similarly, Morton (2000) interviewed 10 parents, 80% of whom reported that their mothers were supportive in the raising of their child who was deaf or hard of hearing; 70% reported that their fathers had been supportive. Additionally, 70% of mother-in-laws and 60% of father-in-laws were reported by parents to be supportive.

Other studies have also identified religion and religious-affiliated organizations as important sources of emotional support for parents of children with special needs (Poston & A. P. Turnbull, 2004; D. G. Skinner, Correa, M. Skinner, & Bailey, 2001). These studies have sampled parents of children with a variety of disabilities but

have not focused on deafness specifically. D. G. Skinner and colleagues (2001) interviewed 250 parents of Mexican and Puerto Rican origin living in the United States. Based on themes in the interviews, it appeared that religious beliefs, religious practices, and communities mitigated stressors for some families and were a source of support to parents. For the families in the study, personal faith was perceived to be a higher-level source of support than organized religious entities. In a study by Poston and A. P. Turnbull (2004), 187 family members of children with a disability participated in focus groups or were interviewed regarding religion and spirituality. Families described spirituality and participating in religious communities as important sources of support.

Additional research is needed to identify and enhance aspects of family support that families value in an effort to build the capacity of parents, contribute to family well-being, enhance family involvement, and improve child and family outcomes. In response to the need to reexamine aspects of family support for children with hearing loss and follow up on desired areas identified previously by families, the present study was designed to identify and describe preferred informational sources, valued aspects of family support, sources of support, and family members' perceptions of the quality of family support they received.

Specifically, this inquiry sought to expand knowledge and understanding of families' perceptions of resources and supports by exploring four questions:

1. What resources and supports do families value as highly important?
2. How satisfied are families with the resources and supports they have experienced?

3. What are primary sources of support?
4. Are there differences in average ratings between groups who differ in communication method or type of sensory device used? In other words, does communication mode or type of sensory device explain a significant amount of the variability in parents' ratings of importance, preferences, and quality of family resources and supports?

Method

The study used survey methodology consisting of an eight-page questionnaire. My institution's internal review board for research involving human subjects reviewed and approved the survey study. Parents' submission of the completed survey served as confirmation of their consent to participate. Parents were informed that they could discontinue participation at any time. Information about the opportunity to participate was distributed through both the Internet and paper mailings to accommodate families' preferences to participate either online or with paper-based responses. The combination of online and postal distribution was also employed to facilitate distribution across a broad pool of potential participants located across a wide geographical area reflecting varied communication modalities, experiences, and types of sensory devices. Thirty-five percent of respondents (159) elected to participate through paper survey in the mail. All others accessed the survey online. A reliability check was conducted on 21% of the paper surveys to ensure that they had been entered into the electronic database accurately. No discrepancies in data entry surfaced during the reliability check.

Participants were recruited from across the United States. Cooperating

organizations posted an announcement and link to the survey in newsletters and/or e-mail announcements. Additionally, two organizations chose to mail paper copies of the survey to their membership rather than post an electronic link to the survey. Cooperating organizations included the Alexander Graham Bell Association, the American Society for Deaf Children, Beginnings, Hands and Voices, the National Association of the Deaf, and a parent conference in Florida. An electronic link remained available on a website for 10 months. The website provided information about the purpose of the survey and a link to the survey, which was housed on SurveyMonkey. The parameters of the electronic survey were set to allow a single access from each Internet Protocol address one time to prevent multiple responses from the same individual. Due to the voluntary and anonymous nature of the distribution and responses, individual follow-up was not completed and an exact response rate could not be calculated. Estimating a return rate would have created the risk of overstating responsiveness, as it was not possible to ascertain how many parents read the announcement on an organization's website or in an electronic newsletter and chose not to link to the survey.

Instrument

A questionnaire was developed to survey families' perceptions of resources and support. Although alternative options in published scales were available for soliciting data on certain aspects of family support (i.e., stress and coping, family well-being), the present study was designed to follow up on specific aspects of family support identified by parents in the open-ended written comments in a prior study (C. W. Jackson et al., 2010). The nature of the subsets in the question-

naire pertained to (a) the importance of specific types of family support, (b) sources of family support and preferred informational resources, (c) the quality of family support that was experienced, and (d) child and family demographic characteristics. A 10-member parent advisory committee and a 3-member professional advisory panel reviewed the survey and provided feedback that resulted in the addition of two items and changes in wording on the final version. In testing of the initial survey, items rated on average as “relatively important” or “unimportant” (i.e., 2.0 or lower) would be removed from the evaluative section in which parents were asked to rate the quality of the family support aspects they experienced. All 19 aspects of family support met the

importance inclusion criterion, and were therefore retained.

A factor analysis was conducted on items within each section to examine the covariance, communalities, eigenvalues, and total variation explained. All participants were asked to rate the quality of 19 aspects of family support. Correlations between rating of all pairs of family support aspects ranged from .49 to .82, and are shown in Table 1. Suitability of the data for factor analysis was assessed with a Kaiser-Meyer-Olkin measure of sampling adequacy, which yielded a value of .96, indicating that the data were appropriate for factor analysis. A principal components method was used to extract factors, and orthogonal rotation of factors was performed by means of the VARIMAX method. Based on analysis of the scree

plot, two components accounted for 70% of the combined variance of ratings of the 19 aspects of family support. Based on the loadings, factor 1 was interpreted as representing general family support and factor 2 was interpreted as representing aspects of family support that may be associated with aspects of Deaf culture (e.g., connecting with adults who are deaf). Communality values indicated that the two factors accounted well for variance in ratings of family support, with the first factor accounting for the majority of the variance (64%), with an eigenvalue of 12.15. The second factor accounted for a small portion of the cumulative variance (6%), with an eigenvalue of 1.06, and therefore was borderline in being considered a separate factor.

Table 1
Covariance of Ratings of Quality of Supports Experienced by Families

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1	—																			
2	.79	—																		
3	.61	.68	—																	
4	.59	.63	.74	—																
5	.64	.72	.54	.66	—															
6	.66	.75	.59	.60	.80	—														
7	.50	.55	.56	.65	.59	.59	—													
8	.61	.66	.57	.66	.81	.77	.72	—												
9	.61	.65	.59	.72	.72	.70	.64	.75	—											
10	.49	.52	.54	.66	.55	.53	.58	.59	.69	—										
11	.63	.66	.64	.65	.66	.66	.57	.68	.71	.65	—									
12	.57	.61	.70	.73	.60	.59	.58	.61	.68	.62	.69	—								
13	.53	.54	.64	.68	.50	.49	.57	.50	.61	.59	.59	.82	—							
14	.63	.65	.59	.58	.63	.66	.55	.65	.64	.60	.69	.64	.56	—						
15	.59	.60	.59	.60	.61	.59	.58	.65	.65	.60	.61	.65	.59	.74	—					
16	.57	.60	.56	.57	.59	.60	.50	.60	.59	.64	.66	.62	.50	.66	.67	—				
17	.51	.52	.58	.61	.54	.54	.54	.56	.60	.68	.62	.67	.68	.60	.62	.65	—			
18	.55	.60	.49	.57	.61	.61	.55	.62	.69	.56	.62	.56	.50	.58	.58	.62	.57	—		
19	.62	.68	.60	.68	.69	.66	.63	.68	.74	.67	.69	.69	.60	.64	.68	.66	.64	.68	—	
20	.70	.73	.63	.64	.71	.72	.58	.69	.72	.55	.72	.64	.55	.70	.68	.62	.54	.66	.70	—

Notes. 1 = Helping all family members understand deafness. 2 = Understanding our family members' experiences. 3 = Connecting our family with parents of children who are deaf or hard of hearing. 4 = Connecting with trained parents to provide support. 5 = Unbiased emotional support. 6 = Communicating clearly. 7 = Accessible website. 8 = Unbiased emotional support. 9 = Educational advocacy. 10 = Connecting with researchers. 11 = Accessing community resources. 12 = Connecting with mentors and role models. 13 = Connecting with adults who are deaf or hard of hearing. 14 = Accessing skilled professionals. 15 = Informing on technical advances. 16 = Access to funding. 17 = Access to interpreters. 18 = Assisting with individualized education program/individualized family service plan (IEP/IFSP) development. 19 = Representing at the local, state, and national levels. 20 = Overall quality of support experienced.

To further test the authenticity of the items, simultaneous regression analysis was conducted to examine how well parents' ratings on the 19 individual items predicted their overall rating of the quality of family support they experienced. The ratings on the 19 items together accounted for 81% of the variance in parents' ratings of overall quality of family support experienced, reflecting good internal consistency. The specific items in each subset are further described below, and the family member survey is provided in its entirety in the Appendix, "Survey of Family Support and Resources."

Importance of Specific Types of Family Support

Family members were asked to indicate the importance of specific aspects of family support provided by organizations using a descending 5-point scale: "very important," "moderately important," "somewhat important," "relatively unimportant," and "unimportant." The inclusion of an importance rating prior to a satisfaction rating was designed to allow for additional confirmatory factor analysis, in that if an indicator was rated on average by families as relatively unimportant, that rating would support a decision to remove the indicator from the subsequent consideration of quality and satisfaction ratings. The 19 indicators of family support were grouped by areas of support, including eight informational resources, seven relating to social-emotional supports; and four on educational advocacy. Each section led with a question that began, "How important is it that organizations or programs . . ." The informational resources section asked about the importance of unbiased informational resources, assistance in finding resources in the community, connecting with skilled professionals, providing

information about technical advances, information about funding, communicating clearly and effectively, offering an accessible website, and connecting with researchers and current findings. The social-emotional section asked about helping family members understand hearing loss, connecting with families of children with hearing loss, understanding families' experiences, connecting with parents who are trained to provide support, providing access to mentors and role models, providing unbiased emotional support, and providing access to adults who are deaf or hard of hearing for mentoring. Finally, the educational advocacy section consisted of questions pertaining to training and support for educational advocacy, navigating the development process for individualized family service plans (IFSPs) or individualized education programs (IEPs), appropriate use of interpreters, and representing families' issues and priorities at the local and national levels.

Sources of Support

The section on sources of support consisted of questions related to (a) preferences for accessing information and (b) rank-ordering of sources of support. Parents were asked to rate their preferences for accessing informational resources by indicating the general helpfulness of specific sources of information. The directions included the question "When you want information how do you prefer to get it?" Given 10 items, parents, were asked to consider how they preferred to receive information using a descending 5-point scale: "highly preferred," "preferred" "somewhat preferred," "nonpreferred," and "don't like." The items were parent-friendly books, detailed professional books, brochures and pamphlets, explanations by professionals, videotapes and DVDs, Internet sources, discussion

with parents of children with hearing loss, discussion with parent of children without hearing loss, adults who are deaf or hard of hearing, and educational workshops.

Additionally, respondents were asked to rank-order sources of support during the period from birth to age 3 years and during the school-age years. Sources of support identified previously in recent literature were provided as options for ranking. The items, presented in alphabetical order, were family support organizations or programs; grandparents or other extended-family members; individual professionals, specialists, or service providers; neighbors or friends; other parents of children who are deaf or hard of hearing; other parents of children with disabilities (not deaf or hard of hearing); physicians; professional/educational institutions (e.g., agencies or schools); religious-affiliated groups or organizations; and teachers or general educators.

Quality of Family Resources and Support

Participants were asked to rate the quality of family support they experienced based on a descending 5-point scale: "excellent," "good," "adequate," "poor," and "very poor." Respondents rated their experiences with the 19 aspects of family support described previously in the importance rating section of the survey. Parents were also asked to provide an overall general rating of the family support received as a whole. Finally, the survey included additional open-ended questions asking parents to indicate how family supports could be improved and to describe resources or supports that were helpful to them.

Participants

The study included responses from 456 parents or other adult family

members responsible for children who were deaf or hard of hearing. Among those who identified their location were residents of 39 different states, with the highest number residing in North Carolina (50), Florida (48), and Colorado (46). (The geographic distribution of respondents by U.S. Census region and division is provided in Table 2.) Data were collected not only on region of origin but on family and child characteristics, race, income, family role, educational level, marital status, and community size, among other demographic characteristics (see Table 3). Children of the respondents are also described by the type of sensory device used, communication method, age of identification, age at time of survey, and degree of hearing loss (see Table 4).

Demographic Characteristics of the Families

Demographic characteristics of the survey respondents are provided in Table 3. The majority of respondents were mothers who reported being the primary caregiver. Most respondents (85%) were Caucasian. About two

Table 2
Geographic Distribution of Respondents

<i>U.S. Census region (and division)</i>	<i>n</i>
West	
Pacific	13 (3%)
Mountain	72 (18%)
Midwest	
West North Central	46 (11%)
East North Central	95 (23%)
South	
West South Central	14 (3%)
East South Central	5 (1%)
South Atlantic	149 (36%)
East	
Middle Atlantic	11 (3%)
New England	5 (1%)

Notes. N = 410. Percentages do not total 100 because of rounding.

Table 3
Demographic Characteristics of Family Respondents

<i>Characteristic</i>	<i>n</i>
Family role (N = 419)	
Mother	386 (92%)
Father	28 (7%)
Grandmother	2 (> 1%)
Other	3 (1%)
Marital status (N = 392)	
Married	355 (91%)
Never married	28 (7%)
Divorced	2 (1%)
Separated	5 (1%)
Widowed	2 (1%)
Number of family members who are deaf (N = 402)	
Child only	326 (81%)
2	52 (13%)
3	16 (4%)
4	8 (2%)
Education (N = 416)	
No high school diploma	7 (2%)
High school diploma or GED	32 (8%)
Some college but no degree	66 (16%)
Associate's degree	41 (10%)
Bachelor's degree	157 (38%)
Graduate degree	113 (27%)
Community size (N = 412)	
Large city (population > 200,000)	159 (39%)
Urbanized area	103 (25%)
Town or small city	109 (26%)
Rural area	41 (10%)
Racial distribution (N = 411)	
Caucasian	348 (85%)
Hispanic	18 (4%)
Asian	13 (3%)
African American	19 (5%)
American Indian	3 (1%)
Other	10 (2%)
Annual household income (N = 398)	
≤ \$34,999	63 (16%)
\$35,000–\$74,999	132 (33%)
\$75,000–\$124,999	130 (33%)
≥ \$125,000	73 (18%)
Number of adults supported by household income (N = 411)	
1	45 (11%)
2	345 (84%)
3	11 (3%)
4 or more	10 (2%)
Number of children supported by household income (N = 409)	
1	98 (24%)
2	194 (47%)
3	82 (20%)
4	23 (6%)
5 or more	12 (3%)

Notes. Because of rounding, percentages in some categories do not total 100. N varies because not all respondents answered every survey item.

Table 4
Demographic Characteristics of the Respondents' Children

Characteristic	n
Communication mode or system used (N = 405)	
Auditory-verbal approach	132 (33%)
Oral speech without sign language	129 (32%)
Simultaneous or Total Communication	76 (19%)
American Sign Language	51 (13%)
Cued Speech	6 (1%)
Other	11 (3%)
Sensory device used (N = 390)	
Hearing aids	204 (52%)
Cochlear implant	107 (27%)
Bilateral cochlear implants	60 (15%)
Other	19 (5%)
Degree of hearing loss in worse ear (N = 412)	
Mild	9 (2%)
Mild-moderate	44 (11%)
Moderate	33 (8%)
Moderate-severe	76 (18%)
Severe	39 (9%)
Profound	211 (51%)
Age of identification (N = 417)	
Birth to 6 months	203 (49%)
7–18 months	112 (27%)
19–48 months	77 (18%)
> 48 months	25 (6%)
<i>Notes.</i> Because of rounding, percentages in some categories do not total 100. N varies because not all respondents answered every survey item.	

thirds of respondents who reported household income fell in the middle range, that is, between \$35,000 and \$124,999. The majority of participants (84%) reported that their household income supported two adults. A large plurality (47%) reported supporting two children on their household income. A large majority (91%) reported having some postsecondary education.

The participants reported receiving family support during their child's first 3 years from various organizations or programs, including the Alexander Graham Bell Association (37%), Hands and Voices (28%), Beginnings (19%), the National Association of the Deaf (8%), and the American Society for Deaf Children (7%). About a quarter of the family

support programs that families accessed (23%) were organized or sponsored by a service provider, and some of the local or statewide programs consisted of parents of children with disabilities, though not exclusively hearing loss (15%). The organizations or programs from which families reported receiving support were fairly consistent across the school years, with the exception of an increased percentage reporting support from Hands and Voices (41%) during the school-age years.

Characteristics of the Children Related to Hearing Status

Characteristics of the children related to their hearing status are provided in Table 4. All the children whose hearing status was provided were identi-

fied as being deaf or hard of hearing. The majority, 60%, were reported to have either severe or profound worst-ear hearing loss. Approximately half of the participants (49%) had been identified with hearing loss prior to age 6 months old; more than three quarters (76%) had been so identified no later than age 18 months. Among the variety of sensory devices the children were reported to use, hearing aids were the most common, with their use reported in 52% of responses. In regard to primary communication method, the auditory-verbal approach, oral speech, and sign language (American Sign Language or sign as a component of a Total Communication approach) were all about equally popular, each used by about a third of the children for whom responses were provided. The children ranged in age at the time the parents completed the survey. In regard to those children for whom a birth date was reported, those 6 years old or younger made up 51% of the sample, with the remaining 49% being school-age children or adolescents. The mean age was 57 months, with a standard deviation of 16 months.

Results
Importance of Different Aspects of Family Support

Participants rated the importance of family support elements including aspects of informational resources, social-emotional support, and educational advocacy. All 19 aspects of family support on the survey were rated as moderately important or very important by 75% or more of participants, with little variation in the distribution of ratings. All of the average rating scores for aspects of informational resources, social-emotional support, and educational advocacy were high, with average numeric ratings ranging from 4.12 to 4.85 on a 5-point scale. A complete listing of the

distribution of importance ratings is provided in Table 5.

Preferred Informational Resources

Based on descriptive analysis, the informational resource with the highest average rating of preference was discussion with parents of children who are deaf or hard of hearing, at 4.47 on the 5-point scale. The lowest rated, discussion with parents who are not deaf or hard of hearing, with a mean rating of 2.74, was far behind the next lowest: detailed professional

books, at 3.17. For a complete listing of the informational resources and distribution of preference ratings, see Table 6.

To determine if there were statistically significant differences between mean preference ratings of items, paired *t* tests were used on items of interest. A paired-sample *t* test revealed that the mean preference for discussion with other parents of children who were deaf or hard of hearing ($M = 3.48, SD = 0.78$) was significantly higher than the mean rating of discussion with parents of children who

were not deaf or hard of hearing ($M = 1.64, SD = 0.78$), $t(434) = 27.14, p < .0001$. The effect size as measured by *d* using the standard deviation of the mean difference between all pairs was 1.41, a value that is considered large. Additionally, the paired-sample *t* test revealed that the mean preference rating for explanations by professionals ($M = 3.24, SD = 0.80$) was significantly higher than the mean preference rating for instructional videos and DVDs ($M = 2.71, SD = 1.0$), $t(436) = 13.42, p < .0001$, with a medium effect size, $d = .46$.

Table 5
Distribution of Ratings of Importance for 19 Aspects of Family Support

<i>How important is it that organizations or programs . . .</i>	<i>Very important</i>	<i>Moderately important</i>	<i>Somewhat important</i>	<i>Relatively important</i>	<i>Unimportant</i>	<i>Rating average (1–5 scale)</i>
Informational resources						
Provide unbiased informational resources	84.2%	10.8%	3.8%	1.1%	0.0%	4.78
Help you find resources in your community	87.4%	11.2%	0.7%	0.7%	0.0%	4.85
Connect you with skilled professionals	81.8%	11.9%	4.5%	1.6%	0.2%	4.73
Provide information about technical advances	66.9%	23.0%	8.7%	1.1%	0.2%	4.55
Provide information about funding	63.0%	19.6%	13.5%	2.9%	0.9%	4.41
Communicate clearly and effectively	85.0%	11.6%	2.7%	0.7%	0.0%	4.81
Offer an accessible website	57.8%	26.3%	12.1%	2.9%	0.9%	4.37
Connect you with research and funding	53.0%	29.3%	12.9%	4.5%	0.2%	4.30
Social-emotional support						
Help all family members understand hearing loss	70.7%	19.4%	9.0%	0.7%	0.2%	4.60
Understand your family's experiences	62.2%	28.6%	7.4%	1.6%	0.2%	4.51
Connect you with families of children who are deaf or hard of hearing	67.6%	23.4%	7.4%	1.6%	0.0%	4.57
Connect you with parents who are trained to provide support	46.0%	32.3%	17.7%	3.6%	0.4%	4.20
Provide access to mentors and role models	56.2%	27.1%	13.0%	3.6%	0.2%	4.35
Provide unbiased emotional support	63.8%	24.5%	9.9%	1.1%	0.7%	4.50
Provide access to adults who are deaf or hard of hearing	47.9%	27.9%	14.6%	7.6%	2.0%	4.12
Educational advocacy						
Provide training and support for educational advocacy	79.8%	16.6%	2.7%	0.7%	0.2%	4.75
Help navigate the IFSP or IEP development process	80.2%	15.5%	3.0%	1.1%	0.2%	4.74
Provide information about appropriate use of interpreters	50.6%	25.6%	15.0%	4.6%	4.2%	4.14
Represent families' issues and priorities at the local and national levels	72.6%	21.1%	4.7%	1.3%	0.2%	4.64
<i>Notes.</i> Because of rounding, percentages for some items do not total 100.0. IEP, individualized education program. IFSP, individualized family service plan.						

Table 6
Preferred Informational Resources

Type of resource	Rating					Mean rating (1–5 scale)
	Highly preferred (5)	Preferred (4)	Somewhat preferred (3)	Nonpreferred (2)	Don't like (1)	
Parent-friendly books	34.3%	31.8%	26.6%	6.4%	0.9%	3.92
Detailed professional books	13.0%	22.0%	39.8%	19.8%	5.5%	3.17
Brochures and pamphlets	18.0%	34.8%	34.1%	11.8%	1.4%	3.56
Explanations provided by a professional	45.8%	35.9%	15.8%	2.5%	0.0%	4.25
Videotapes and DVDs	26.1%	32.9%	30.2%	9.5%	1.4%	3.73
Internet sources	55.0%	30.2%	11.9%	2.5%	0.5%	4.37
Discussion with parents of children who are deaf or hard of hearing	63.6%	21.9%	12.0%	2.5%	0.0%	4.47
Discussion with parents of children who are not deaf or hard of hearing	11.5%	9.9%	29.0%	40.0%	9.7%	2.74
Adults who are themselves deaf or hard of hearing	33.7%	31.2%	26.4%	8.0%	0.7%	3.89

Notes. Because of rounding, percentages for some items do not total 100.0.

The effect of communication method, type of sensory device, and age of identification on preference rating for discussion with other parents of children who were deaf or hard of hearing was examined by means of a two-way analysis of variance (ANOVA). The ANOVA revealed that there was a significant main effect of sensory device, $F(1, 386) = 8.67$, $p = .003$, $\eta^2 = .025$, but not for communication mode ($p = .713$) or age of identification ($p = .649$). There were no significant interactions. Thus, parents of children with cochlear implants expressed a slightly stronger preference (with a mean difference of 0.31) than parents of children using hearing aids; although participants as a whole indicated a strong preference regardless of type of sensory device used. Parents of children who used manual communication did not show a significantly different mean preference for connecting with other parents of children who were deaf or hard of hearing when compared to parents of children who used oral approaches. There were no statistically significant differences in average preference rat-

ing between groups of parents whose children were identified early (prior to age 36 months) and those whose children were later identified; however, the majority of children in the present sample were identified early.

Sources of Support

When asked to rank-order sources of support, families identified professionals, parents of children with hearing loss, family support organizations, and grandparents or extended-family members as the top four (see Table 7). These top four sources of support were consistently ranked among the top sources for both birth to age 3 years and the school-age years. The two lowest-ranked sources of support for both age groups (birth to 3 years and school-age) were parents of children who were not deaf or hard of hearing and religious-affiliated groups.

Satisfaction With Family Resources and Support

Table 8 presents the mean quality ratings of family support experienced. Based on descriptive analysis of participants' responses, there were five

aspects of family support that 60% or more of participants rated good or excellent: (a) communicating clearly and effectively (71%), (b) understanding their family's experiences (69%), (c) helping all family members understand hearing loss (68.5%), (d) providing unbiased informational resources (65%), and (e) providing unbiased emotional support (61%). These five aspects yielded the highest average ratings of quality of support experienced. In contrast, low ratings of quality (indicated by a rating of poor or very poor by approximately a third or more of participants) were given for (a) connecting with researchers (41%), (b) informing about appropriate use of interpreters (36%), (c) providing access to adults who are deaf or hard of hearing for mentoring (35%), (d) providing information about funding and insurance coverage (33%), and (e) connecting with parents trained to provide support (33%).

A multivariate analysis of variance (MANOVA) was conducted to examine potential differences between groups that accounted for a significant portion of the variability in ratings of qual-

Table 7
Mean Ranking of Sources of Support

<i>Source of support</i>	<i>Mean ranking</i>	<i>N</i>
<i>Birth to 3 years</i>		
Individual professionals, specialists, or service providers	2.70	363
Grandparents or other extended-family members	3.68	354
Other parents of children who are deaf or hard of hearing	4.17	331
Family support organizations or programs	4.18	329
Professional/educational institutions (e.g., agencies or schools)	4.71	329
Neighbors or friends	5.22	324
Physicians	5.29	326
Teachers or general educators	5.49	321
Other parents of children with disabilities (not deaf or hard of hearing)	6.95	286
Religious-affiliated groups or organizations	7.24	289
<i>School-age years</i>		
Individual professionals, specialists, or service providers	3.17	363
Other parents of children who are deaf or hard of hearing	3.91	331
Teachers/general educators	4.11	287
Family support organizations or programs	4.17	329
Professional/educational institutions (e.g., agencies or schools)	4.20	329
Grandparents and extended-family members	4.40	280
Neighbors or friends	5.58	324
Physicians	5.74	326
Other parents of children with disabilities (not deaf or hard of hearing)	6.58	286
Religious-affiliated groups or organizations	7.31	289

Note. The lower the number, the higher the rank-ordering (i.e., 1 is the highest ranking, indicating the top source of support).

Table 8
Ratings of Quality of Family Support Experienced by Families Using Different Sensory Devices

<i>Type of support</i>	<i>Mean rating of quality (1–5 scale)</i>		
	<i>HA</i>	<i>CI</i>	<i>p</i>
Help all family members understand hearing loss	3.75	4.00	.050
Understand your family's experiences	3.74	4.10	.002
Connect you with families of children who are deaf or hard of hearing	3.39	4.00	< .001
Connect you with parents who are trained to provide support	2.99	3.28	.032
Provide unbiased emotional support	3.64	3.77	.302
Communicate clearly and effectively	3.89	4.08	.068
Offer an accessible website	3.34	3.60	.027
Provide unbiased informational resources	3.67	3.85	.134
Provide training and support for educational advocacy	3.34	3.67	.011
Connect you with researchers	2.70	3.06	.006
Help you find resources in your community	3.24	3.53	.025
Provide access to mentors and role models	2.94	3.33	.002
Provide access to adults who are deaf or hard of hearing for mentoring	2.82	3.25	.001
Connect you with skilled professionals	3.60	3.91	.007
Provide information about technical advances	3.16	3.59	.001
Provide information about funding and insurance coverage	2.92	3.25	.009
Inform about appropriate use of interpreters	2.74	3.08	.008
Help navigate the IFSP or IEP development process	3.29	3.67	.004
Represent families' issues and priorities	3.11	3.46	.006
Overall rating of quality of supports experienced	3.6	3.9	0.009

Notes. 5 = excellent, 4 = good, 3 = adequate, 2 = poor, 1 = very poor. HA = hearing aid users. CI = cochlear implant users. IEP, individualized education program. IFSP, individualized family service plan.

ity of experiences on 19 items and one rating of overall quality. The MANOVA revealed that there was a significant main effect of sensory device, $F(1, 262) = 2.10, p = .005, \eta^2 = .14$, but no significant effects for communication mode ($p = .112$) or age of identification ($p = .99$). There were no significant interactions. Parents of children with cochlear implants reported higher quality of supports than parents of children using hearing aids. The mean difference was statistically significant for 17 of the 19 aspects of family support ($p < .05$). For the other two aspects of family support (unbiased emotional support and unbiased informational resources), the mean quality rating appeared slightly higher for parents of children with cochlear implants, but the difference was not statistically significant, $p = .506$ and $p = .057$, respectively.

Desired Supports

The investigators conducted a descriptive analysis of key words present in participants' responses to an open-ended question regarding other desired family supports. Frequently occurring themes included (a) connecting with others, (b) informational resources, and (c) educational programs. Table 9 provides a numerical distribution of themes and related categories.

Connecting With Others

Written comments associated with the cluster "connecting with others" generally contained one or more words relating to social support, including *social* ($n = 10$), *meet with* (13), *contact* (14), *talk to* (10), *call* (10), *mentor* (7), *interact with* (4), *connect* (15), and *support* (86). This cluster involved several subcategories of different entities with which families desired to connect. Families identified a desire to connect with parents

Table 9
Frequency of Key Word Clusters Noted in Open-Ended Comments About Desired Supports

Theme	Number of occurrences
<i>Connecting with others</i>	
Connect with other parents of children who are deaf or hard of hearing	47
Meet with parents who use a specific communication modality	2
Find or get involved with a family support organization	56
Get together with other children who are deaf or hard of hearing	10
<i>Informational resources</i>	
Access general resources and information on deafness	44
Acquire resources related to a specific communication modality	2
Find web-based informational resources	7
Access cutting-edge research findings	3
Attend workshops	6
Get more information about available technology	4
Locate unbiased informational resources and support	47
<i>Educational programs</i>	
Educational programs specializing in deafness	13
More early intervention	12
School-age programs	10
Professionals with specialized training	12
Supports focused on enhancing child's social skills	5
Services provided in natural environments	1
Access to educational supports in rural communities	8
Service coordination	4
Improved follow-up	5
Supports for children who are deaf or hard of hearing and have another disability	5
Support for transitions	2
Help with accessing funding for services and supports	14
Access to educational advocates	13
Better service coordination	13
More frequent communication	9
Information on assistive listening devices	3
<i>Note.</i> Values represent the number of written comments containing the related key words, out of 357 total written responses to an open-ended question about additional desired family support.	

of children with hearing loss ($n = 47$), family support organizations (56), other children who were deaf or hard of hearing (10), and adults who were themselves deaf or hard of hearing (25). A comment that exemplifies the responses in this category was "I remember not finding any family support as soon as my daughter was born and I just needed someone to talk to and reassure me that everything was going to be all right." Similarly, a participant identified a "need to know

more families with the same situation." Other participants identified a specific need for mentors, such as one parent who expressed a desire for "simply having an adult deaf person to talk to, or a person who had a child older than mine to show me the ropes." Parents wrote about the importance of connecting with others. As one stated, "Nothing has helped more than talking to other parents who have navigated these difficult waters."

Informational Resources

The desire for informational resources was expressed in a large proportion of the written comments. Key words and terms included *resources* (22), *information* (36), *find out* (3), *update* (3), *web/Internet* (10), *research* (6), *unbiased/biased* (23), and *technology* (5). Parents primarily highlighted the need for additional resources and information generally ($n = 44$). Other specific types of desired resources identified by participants included unbiased information, Internet resources, workshops, current or new technology, research findings, and streamlined access to informational resources.

Unbiased informational support was the largest subcategory of written comments on informational resources (34 occurrences), with the specific key words *biased* and *unbiased* occurring 23 times. Additional comments expressed a desire for resources that were neutral with regard to communication modality or information about “all options.” Some participants explicitly stated the importance of unbiased information. For example, one parent recommended, “Make sure information is unbiased with regard to mode of communication so that families are fully aware of all choices.” Additional examples of comments that highlighted this notion included “Provide us with all of our options and let us decide what is best for our child” and “Inform parents of all options and help them navigate the system.”

Educational Programming

Other written comments clustered across a variety of subcategories with key words associated with educational programs. These comments mentioned a desire for specialized programs, early intervention, school-age programs, highly trained professionals, programs addressing social skills, services in natural environments, ac-

cess to specialized support for families in rural communities, service coordination, supports for children with additional disabilities, better transitions, access to funding, educational advocates, community-based supports, and access to assistive listening devices. A complete listing of the frequency of occurrence is provided in Table 9.

Discussion

The present study was designed to examine the family resources and support experienced by family members of children who are deaf or hard of hearing in order to expand on the available literature to inform educators and programs serving these children and their families. The findings confirm and broaden understanding of resources and supports that families regard as highly important, identify preferred sources of support, and provide feedback on the perceived quality of supports experienced by parents after identification of their child’s hearing loss.

The finding that parents rated all of the 19 aspects of family support as important is consistent with findings of previous studies (Hintermair, 2000; Lederberg & Golbach, 2002; Luckner & Velaski, 2004; Morton, 2000; Zaidman-Zait, 2007). The lack of variability in parents’ ratings of importance may be interpreted as providing additional validation of the importance and relevance of the 19 investigated aspects of family support. Although informational resources, social supports, and educational advocacy appear to be important domains of family support, this does not imply that the survey consisted of an exhaustive list including all aspects of family resources and support. It is possible that other aspects of family support, not included on the survey, were equally or more important to families.

Although there was general consensus on the importance of the 19 aspects of family support that were studied, families differed in their ratings of the quality of support experienced. Parents of children who used cochlear implants reported experiencing significantly better quality of support than parents of children who used hearing aids. Further research is warranted to explore the discrepancy in experiences and examine parents’ reflective evaluation of supports and possible underlying reasons why they assigned low or high ratings of quality. It cannot be determined from the present findings if poor ratings were primarily attributable to the absence of support, insufficient quantity, difficulties in accessing support, poorly constructed support, or poor delivery of support. Follow-up studies may benefit from additional survey options allowing parents to provide further explanation or a rationale for their ratings. In addition, follow-up studies are needed to examine aspects of family support to which parents gave poorer quality ratings, as these findings had not all been well substantiated in the previous literature. These aspects of family support include connecting them with families of children who are deaf or hard of hearing, offering an accessible website, providing training and support for educational advocacy, helping families find resources in their community, providing access to mentors and role models, connecting with skilled professionals, providing information about technical advances, helping to navigate the IFSP or IEP development process, and representing families’ issues and priorities at the local and national levels. Additional research would be beneficial to identify ways to enhance family supports in those areas that received lower quality ratings on average.

Connecting with other parents of

children who were hard of hearing or deaf was the most highly preferred informational resource for families who participated in the present study, particularly for parents of children with cochlear implants. One possible explanation for the higher ratings of social support is that parents may value personal interaction with someone who has had similar experiences. The finding that participants rated discussion with parents of children who were not deaf or hard of hearing as their least preferred type of informational resource was somewhat surprising, since this kind of support still involves personal interactions with other parents. Parents do not appear to value general disability experiences to the same extent; rather, having experiences in common that are related to hearing loss may be the critical component of preferred support. This may reflect the perceived advantages of firsthand experience with the unique aspects of raising a child who is deaf or hard of hearing. The importance of connecting with families of children who are deaf or hard of hearing was also reflected in the ranking of supports, and also in parents' responses to the open-ended questions. As one parent wrote, "Professionals and providers need to realize that parent support from someone who has been there is invaluable."

The high ranking of parents of children with hearing loss, professionals, and extended-family members as sources of support is consistent with findings of recent studies (Asberg et al., 2008; C. W. Jackson, 2009; C. W. Jackson et al., 2010; Most & Zaidman-Zait, 2003; Zaidman-Zait, 2007). The identified sources of support were substantiated by Most and Zaidman-Zait (2003) in their study, in which mothers expressed a preference for support from professionals, family members, and other parents of chil-

dren with similar experiences. The fact that respondents ranked grandparents and extended-family members among the top four sources of support is consistent with the findings of other studies identifying the important role of grandparents and extended-family members (Luckner & Velaski, 2004; Luterman, 1987; McNee & C. W. Jackson, 2011; Morton, 2000; Nybo et al., 1998). This finding substantiates the notion that parents of a child with hearing loss turn to their own parents for emotional support, highlighting the potential need for family support organizations to make informational resources and supports available to extended-family members such as grandparents.

Findings of low mean rankings for particular sources of support were also of interest and may warrant further investigation to identify potential barriers and solutions. Further research is warranted to explore factors that influence families' perceptions of support and further explain why families assigned high or low rankings or utilized specific sources of support. Although the lowest-ranked sources (parents of children who are not deaf or hard of hearing and religious-affiliated groups) commonly offer family support and resources, the current data suggest that they may be underutilized or perceived as not being as helpful as other sources of support. The low ranking of religious-affiliated support in the present study contradicts reported findings in the existing literature. Previous studies on early intervention experiences have suggested that religious groups provide a great deal of support for families of children with other disabilities (Poston & A. P. Turnbull, 2004; D. G. Skinner et al., 2001). Reporting a finding that contrasts with those of the present study, D. G. Skinner and colleagues (2001) found

that Latino families of young children with developmental disabilities regarded faith or religion as a significant source of support. Speculation on the cause of the lower ratings found in the present study is beyond the scope of the study. Reasons for parents' perceptions cannot be determined from the findings, but this discrepancy may warrant follow-up in future studies.

Also noteworthy as a new finding not widely reported in the previous literature was the strong preference for Internet sources, which received the second-highest rating of preference as an informational resource. This finding is not surprising, given the increasing access to the Internet and the growing bank of online resources. This finding should be interpreted cautiously, however, since the majority of the survey respondents participated by means of a web-based survey, and therefore may have been more favorably disposed to digital technology than the larger population of parents of children who are deaf or hard of hearing. The extent to which this preference for Internet-based resources applies to the larger population of parents of children with hearing loss warrants further investigation in future studies.

Limitations

The findings of the present study should be interpreted cautiously, given several potential limitations. Due to the nature of survey research, findings are descriptive of the sample population, and there is no assurance that the respondents' views and opinions reflect those of the larger population of parents of children who are deaf or hard of hearing. The proportion of parents in the study who reported using an oral or an auditory-verbal approach to communication appeared to be higher than among the general population as reported in previous studies. Addition-

ally, perceptions of different family members within the same family were not solicited on this questionnaire, so it cannot be assumed that other family members would have perceptions like those of the study sample, which was primarily composed of mothers. Furthermore, the ethnic and socioeconomic distribution of the sample did not reflect the national distribution based on U.S. Census data, although the demographics of the respondents were consistent with the demographics of families who typically participate in mail and Internet survey research (Dillman, Smyth, & Christian, 2009).

Additionally, the questionnaire used in the present study was not formally field-tested in a large-scale national study. Additional items not included on the survey may be equally as important as items that were included. The questionnaire was formulated on the basis of open-ended comments initiated by parents in a previous study, piloted with a panel of parent advisers and reviewed by leaders in family support organizations. However, the set of items is not necessarily exhaustive in regard to important aspects of family supports and resources.

Implications and Recommendations

Trends in responses on the questionnaire offer insights and recommendations for educators and other personnel who serve children who are deaf or hard of hearing and their families. The results add to the literature identifying supports that are perceived to be important and valued by families after identification of hearing loss. The findings highlight preferred informational resources, including other parents of children with hearing loss and Internet sources, ratings of quality, and valued sources of support. Open-ended comments reiter-

ated that parents desire unbiased supports and social connections, specifically with other parents of children who are deaf or hard of hearing.

Further research is needed to explore innovative statewide or networked systems for connecting families to provide additional access to social supports and family support organizations. Additional research is also needed to identify ways to build the capacity of grandparents, other extended-family members, and professionals to enhance family support, since these three groups are common sources of support drawn upon by parents. The results of the present study underscore the need for additional research to explore innovative programs to prepare mentors or parents with specialized training who have experience with deafness. Model demonstration programs are needed to identify and examine innovative solutions to surmount the barriers of distance and geography in the effort to connect families. Additional research is warranted to explore evidence-based methods for delivering desired family support and resources to a diverse population of children and families.

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Appendix

Survey of Family Support and Resources

Survey of Family Support & Resources

Family Support

We are interested in learning about your experiences in an effort to improve services for children and families. The following questions ask about the resources and supports your family has received. Thanks for your time in sharing your experiences with us. Your responses will be kept confidential.

1. Informational Resources: How important is it that organizations or programs...

	Very Important	Moderately Important	Somewhat Important	Relatively Unimportant	Unimportant
Provide unbiased informational resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help you find resources in your community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connect you with skilled professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide information about technical advances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide information about funding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicate clearly and effectively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Offer an accessible web site	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connect you with researchers and current findings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments

2. Social-Emotional Support: We are interested in identifying types of social-emotional support that are essential and valuable to families. How important is it that programs...

	Very Important	Moderately Important	Somewhat Important	Relatively Unimportant	Unimportant
Help all family members understand hearing loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understand your family's experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connect you with families of children who are deaf or hard of hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connect you with parents who are trained to provide support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide access to mentors & role models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide unbiased emotional support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide access to adults who are deaf or hard of hearing for mentoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments

Survey of Family Support & Resources

3. Educational advocacy: How important is it that organizations and programs...

	Very Important	Moderately Important	Somewhat Important	Relatively Unimportant	Unimportant
Provide training & support for educational advocacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help navigate the IFSP or IEP development process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide information about appropriate use of interpreters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Represent families' issues and priorities at the local and national level.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments

4. Please rate your preferences for accessing informational resources by indicating the general helpfulness of the following sources of information.

i.e. When you want information how do you prefer to get it?

	Highly Preferred	Preferred	Somewhat Preferred	Nonpreferred	Don't like
Parent-friendly books	<input type="radio"/>				
Detailed professional books	<input type="radio"/>				
Brochures and pamphlets	<input type="radio"/>				
Explanations provided by a professional	<input type="radio"/>				
Video tapes and DVDs	<input type="radio"/>				
Internet sources	<input type="radio"/>				
Discussion with parents of children who deaf or hard of hearing	<input type="radio"/>				
Discussion with parents of children who are not deaf	<input type="radio"/>				
Adults who are themselves deaf or hard of hearing	<input type="radio"/>				
Educational workshops	<input type="radio"/>				

Survey of Family Support & Resources

5. Please rate the following aspects of family support you experienced.

How well did family support organizations or programs...

	Excellent	Good	Adequate	Poor	Very Poor
Help all family members understand hearing loss.	<input type="radio"/>				
Understand your family's experiences	<input type="radio"/>				
Connect you with families of children who are deaf or hard of hearing	<input type="radio"/>				
Connect you with parents who are trained to provide support	<input type="radio"/>				
Provide unbiased emotional support	<input type="radio"/>				
Communicate clearly and effectively	<input type="radio"/>				
Offer an accessible web site	<input type="radio"/>				
Provide unbiased informational resources	<input type="radio"/>				
Provide training & support for educational advocacy	<input type="radio"/>				
Connect you with researchers	<input type="radio"/>				
Help you find resources in your community	<input type="radio"/>				
Provide access to mentors & role models	<input type="radio"/>				
Provide access to adults who are deaf or hard of hearing for mentoring	<input type="radio"/>				
Connect you with skilled professionals	<input type="radio"/>				
Provide information about technical advances	<input type="radio"/>				
Provide information about funding and insurance coverage	<input type="radio"/>				
Inform about appropriate use of interpreters	<input type="radio"/>				
Help navigate the IFSP or IEP development process	<input type="radio"/>				
Represent families' issues and priorities at the local and national level.	<input type="radio"/>				

Comments

6. Overall, how do you rate the quality of family supports you have received?

Excellent
 Good
 Adequate
 Poor
 Very Poor

7. How could we improve family supports provided to you? Please enter your suggestions in the box below.

Survey of Family Support & Resources

8. Please identify or describe resources & supports that have been most helpful to you.

9. Please select and rank order sources of family support during the first 3 years of age. (1 being your strongest source of support)

Family support organizations or programs	<input type="text"/>
Grandparents or other extended family members	<input type="text"/>
Individual professionals, specialists, or service providers	<input type="text"/>
Neighbors or friends	<input type="text"/>
Other parents of children who are deaf or hard of hearing	<input type="text"/>
Other parents of children with disabilities(not deaf or hard of hearing)	<input type="text"/>
Physicians	<input type="text"/>
Professional/educational institutions (e.g. agencies or schools)	<input type="text"/>
Religious affiliated groups or organizations	<input type="text"/>
Teachers or general educators	<input type="text"/>

10. Please select and rank order sources of family support during school-age years. (1 being strongest source of support)

Family support organizations or programs	<input type="text"/>
Grandparents or other extended family members	<input type="text"/>
Individual professionals, specialists, or service providers	<input type="text"/>
Neighbors or friends	<input type="text"/>
Other parents of children who are deaf or hard of hearing	<input type="text"/>
Other parents of children with disabilities(not deaf or hard of hearing)	<input type="text"/>
Physicians	<input type="text"/>
Professional/educational institutions (e.g. agencies or schools)	<input type="text"/>
Religious affiliated groups or organizations	<input type="text"/>
Teachers or general educators	<input type="text"/>