

# Impact of Deafness on Family Life:

## A Review of the Literature

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**T**he presence of deafness in a family has the potential to affect all areas of family life. An understanding of the impact on family life is critical to addressing all components of the family system in early intervention. This review synthesizes the literature on deafness as it relates to four domains of family quality of life, including family interaction, family resources, parenting, and support for the child who is deaf. Implications for future research are discussed.

This is my first time to deal with deafness . . . to get close to deafness. I never heard or read anything. I didn't know anything about that. I wanted information, but I was afraid of what I might find, what the future would be. Deafness has completely changed one of the major focuses of our family. . . . It shapes where we live. It takes up vast amounts of time. It adds additional responsibilities that we would not normally have." (Mother of a 3-year-old who is deaf)

Here you bring home what you think is going to be a perfectly normal baby, and then you find out—wow, this child can't hear my voice. . . . The whole family has to kind of give. We really had to gear toward that. We thought we were going to do this at all cost. We were going to do everything that we could to give her the same opportunities that we would any other child. (Mother of a 2-year-old whose hearing loss was identified at birth)

The birth of a child who is deaf into a hearing family may have a drastic impact on family life. The family's well-being is vital because the importance of the family's influence in the lives and development of young children is widely recognized (Allen & Petr, 1996; Bailey et al., 1998; Bodner-Johnson, 1986; Bradshaw, 1988; Bruder, 2000; Calderon, Bargones, & Sidman, 1998; Dunst, 2002; Guralnick, 1997; Karpowitz, 1991; Turnbull & Turnbull, 2001). Despite increasing access to earlier interven-

tion due to newborn hearing screening, families are at risk for being left out of support services (Boone, McBride, Swann, Moore, & Drew, 1998). Individualized Family Service Plans (IFSPs) have traditionally stressed child outcomes to the exclusion of family outcomes and broad family support (McWilliam, Ferguson, & Harbin, 1998). Despite widespread acceptance of the underlying importance of families, there continues to be a gap between philosophy and implementation because early intervention services continue to be primarily child-centered.

The purpose of this article is to review the literature on factors related to quality of life as experienced by families of children who are deaf. The literature on the impact of deafness will be reviewed as it relates specifically to family interactions, family resources, parenting, and support for the child who is deaf.

### FAMILY SYSTEM

#### *Holistic View*

Turnbull and Turnbull (2001) suggested a need for service providers to adopt a holistic view of family life by embracing a family systems perspective. A family systems perspective acknowledges the mutual impact of each member's strengths and needs and recognizes the importance of addressing issues related to family life. It is suggested that the family systems perspective should be applied to achieve a greater understanding of the impact of deafness on young children. As Henderson and Hendershott (1991) stated, "Because the deaf child is a component of the family system, the deafness belongs not just to the

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child but to the entire family. Accepting this perspective makes it necessary for the family to seek ways to recognize itself so that all the components in the family system can participate, contribute, and draw on the family's resources equally" (p. 325).

### **Concept of Family Quality of Life**

The concept of family quality of life attempts to capture the overall degree to which the family members' needs are met, the extent to which they enjoy their time together, and the extent to which they are able to do things that are important to them (Poston, Park, Turnbull, Mannan, & Marquis, 2003). A core concept of the definition of family quality of life is the notion that overall family quality of life is influenced by the interaction of domains, or areas of life (Brown, Davey, Shearer, & Kyrkou, in press; Poston et al., 2003). The domains and indicators from the Beach Center Family Quality of Life Survey (Park et al., 2003) are used in this article as a framework for reviewing the literature on the impact of deafness on family quality of life. The family quality-of-life domains include family interaction, parenting, resources, and support for the child who is deaf.

The Beach Center Family Quality of Life Survey was validated through a national survey of 1,037 family members of individuals with disabilities who identified areas important to family quality of life (Park et al., 2003). Identification of domains began with an extensive qualitative inquiry that identified 10 areas that families identified as important to family quality of life (Poston et al., 2003). Based on the results of the Park et al. (2003) study, these 10 indicators were combined and reduced to 5 primary domains, with 41 indicators across the domains.

Subsequently, a second field test was conducted to test the 40 items that emerged from the first field test. In this test, data were collected from 209 primary caregivers, mostly mothers, on both importance and satisfaction ratings. Factor analyses were conducted on the original 40 items; however, some items were subsequently dropped due to low loading, ambiguous wording, or redundancy. Preliminary analyses indicated that the domains of health/safety and resources could be combined into a single perceived resources factor. Therefore, a four-domain structure was used to examine the item loadings. Alphas ranged from .86 to .91 on importance and .82 to .87 on satisfaction.

A third field test, including data from 280 families of children in early childhood services in Kansas, was conducted. The factor loadings are similar to those from the second field test; however, a thorough analysis of the factor structure is still underway. For the purposes of this literature review, the most recent four-domain structure (family interaction, parenting, resources, and support for the member with a disability) will be used.

### **Impact on Quality of Life**

Little of the research on family quality of life has been applied specifically to families of children who are deaf. A literature search was conducted on each domain of family quality of life as it relates to deafness. The literature search used the following descriptors to capture the population of interest: children and deafness, early intervention, infants and toddlers, and families and deafness. The search included the following key words: family life and deafness, family quality of life, family interaction and deafness, social skills and deafness, parenting and deafness, deaf mentors, and deaf culture. Key words and descriptors were entered into a digital library network that searched over 25 databases, including Article First, Exceptional Child Education Resources, Med-line, PsycINFO, Wilson Select Plus, and WorldCat (OCLC).

Articles selected for the literature review included those that were published after 1985 and those that addressed topics pertaining to young children who are deaf and their family life, such as family interactions, parent-child relationships, communication, decision making, and social support. Articles focusing on the experiences of hearing children of deaf adults were not included in this review. Articles that focused on experiences of adolescents who are deaf were also excluded, as were books and articles that were not published in peer-reviewed journals.

A synthesis of 17 articles is provided in Table 1. The literature reviewed in the table reflects the recurrence of several family themes: parenting, stress, family interactions, and emotional well-being. In reviewing the literature in relation to the domains of family quality of life, it becomes apparent that each domain has the potential to be uniquely impacted by the presence of deafness in a family (see Figure 1). Each area of potential impact is discussed in greater detail within the text.

### **IMPACT ON FAMILY INTERACTION**

The family quality-of-life domain of family interaction includes indicators such as the family's ability to solve problems together, to communicate openly with each other, to enjoy their time together, and to have good relationships with extended family members (Park et al., 2003).

#### **Solving Problems Together**

Families of children who are deaf report additional stresses and challenges associated with making difficult decisions and choices (Calderon & Greenberg, 1999). Families with deaf members confront difficult problems, such as choosing between different cultural identities—deaf and/or hearing (Bat-Chava, 2000) and two languages, as well as a list of communication systems, approaches, and modes (Eleweke & Rodda, 2000). Family members may dem-

TABLE 1. The Effect of Deafness on the Family system: Synthesis of Literature

| Author  | Participants   | Measure   | Key findings   |
|---|--|---|--|
| Bodner-Johnson, B. (1986)                         | <ul style="list-style-type: none"> <li>• 120 families of 125 children who are deaf were interviewed</li> <li>• Two groups of children; high and low achievement in reading and math based on SAT-II scores</li> <li>• Children had severe-profound degrees of hearing loss; identified by 18 months old</li> <li>• Children were between 10 and 12 years old</li> <li>• Families were from 7 states in northeastern United States</li> <li>• 22% belonged to minority ethnic groups</li> </ul> | <ul style="list-style-type: none"> <li>• 70 interview questions related to family environment, family interactions, family activities, and family adaptation</li> </ul>   | <ul style="list-style-type: none"> <li>• Factor analysis yielded eight family factors that accounted for a significant percentage of variance in reading and math scores</li> <li>• Four main factors related to achievement included family involvement/interaction, guidance/knowledge, press for achievement, and adaptation to deafness</li> <li>• Children who did well in reading were more likely to come from families who reported interacting their child into family interactions and having high expectations</li> </ul>   |
| Bodner-Johnson, B. (1991)                         | <ul style="list-style-type: none"> <li>• 10 Caucasian families participated</li> <li>• Each family included a child who was deaf with 70 dB or greater degree of hearing loss</li> <li>• 4 used sign and speech simultaneously</li> <li>• 6 used oral speech only</li> </ul>   | <ul style="list-style-type: none"> <li>• A video camera was set up to record interactions in their homes during the evening meal</li> <li>• Interactions were transcribed and 100 conversational turns were coded</li> </ul>  | <ul style="list-style-type: none"> <li>• Family members' conversations with the child who was deaf were balanced, including personal contributions, stating ideas, and asking questions</li> <li>• Family conversational style affected the child's degree of participation</li> <li>• Yes/No questions facilitated entry to the conversation</li> <li>• Children tended to be more spontaneous when members asked fewer wh- questions</li> <li>• Children who were deaf were generally responsive in conversation with hearing family members but were least likely to maintain conversation</li> </ul> |
| Calderon, R., & Bargones, J., & Sidman, S. (1998) | <ul style="list-style-type: none"> <li>• 28 hearing families of children who are deaf or hard of hearing</li> <li>• Average age of children was 21 months old</li> <li>• Children had 40 to &gt;90 dB hearing loss</li> <li>• Children used total communication</li> <li>• One fourth participants were ethnic minorities</li> <li>• Middle socioeconomic status (SES)</li> </ul>  | <ul style="list-style-type: none"> <li>• Rated parent involvement and stress</li> <li>• Questionnaire given to parents and teachers</li> <li>• Interviews with parents</li> <li>• Videotapes of parent-child interactions</li> <li>• Review of records</li> <li>• Standardized child assessment tools</li> </ul>  | <ul style="list-style-type: none"> <li>• When asked how parents spend time with their child, 64% of mothers and 70% of fathers ranked dealing with hearing loss as the main emphasis</li> <li>• 28% reported changing residences to be closer to adequate services</li> </ul>  |
| Calderon, R., & Low, S. (1998)                    | <ul style="list-style-type: none"> <li>• 22 children with severe to profound deafness</li> <li>• 3 years old</li> <li>• Participated in early childhood home instruction (ECHI) early intervention program, Seattle</li> <li>• All participants had hearing parents</li> <li>• 17 had fathers present in family; 5 did not include fathers in the family</li> <li>• No significant differences in SES between comparison groups</li> </ul>   | <ul style="list-style-type: none"> <li>• Parent and teacher questionnaires</li> <li>• Videotaped mother-child interactions</li> <li>• <i>SKI HI Language Development Scale</i> (Watkins &amp; Tonelson, 1979)</li> <li>• Parent involvement questionnaire (5-point scale; Calderon &amp; Low, 1998)</li> <li>• Family stress (number of life events)</li> <li>• Follow-up measures of child outcomes</li> <li>• <i>Preschool Language Scale-3</i> (Zimmerman, Steiner, &amp; Pond, 1992)</li> </ul> | <ul style="list-style-type: none"> <li>• Significant differences were reported in language and academic outcomes between children whose fathers were absent or present</li> <li>• No significant differences found in social-emotional outcomes or nonverbal IQ scores between children whose fathers were absent or present</li> <li>• Paternal presence or absence did not demonstrate any differences in mothers' behavior or perceptions regarding their children</li> <li>• Suggests that father-child interactions are beneficial to the child's language and academic achievement</li> </ul>      |

(table continues)

TABLE 1 continued)

| Author                               | Participants   | Measure   | Key findings   |
|--------------------------------------|--|---|--|
| Calderon, R., & Greenberg, M. (1999) | <ul style="list-style-type: none"> <li>• 36 hearing mothers of children who are deaf</li> <li>• 85% were White, 6% African American, 6% Native American, and 3% Asian American</li> <li>• Families used a total communication approach</li> <li>• Children ranged in age from 8 years to 15 years old</li> </ul> | <ul style="list-style-type: none"> <li>- <i>Test of Early Reading Ability-Deaf or Hard of Hearing</i> (Reid, Hresko, Hammill, &amp; Wiltshire, 1991)</li> <li>- <i>Wechsler Preschool and Primary Scale of Intelligence-Revised</i> (Wechsler, 1989)</li> <li>- <i>Language Proficiency Profile</i> (Bebko &amp; McKinnon, 1993)</li> <li>- <i>Social-Emotional Assessment Inventory-Preschool Version</i> (SEAI; Meadow, 1983)</li> <li>- <i>Child Behavior Checklist and Child Behavior Profile</i> (CBCL; Achenbach, 1979)</li> </ul>  | <ul style="list-style-type: none"> <li>• Social support accounted for 43% of the variance in mother's reported negative life stress.</li> <li>• Mothers who have children with greater degrees of hearing loss, more life stress and less support have poorer overall personal adjustment.</li> <li>• Mothers who reported high social support were rated as better adjusted despite degree of hearing loss or life stress.</li> </ul> |
| Esp, J. (2001)                       | <ul style="list-style-type: none"> <li>• Social workers from 73 schools for the deaf</li> </ul>  | <ul style="list-style-type: none"> <li>• <i>Parent Problem Solving Assessment Task</i> (PPSAT; Calderon &amp; Greenberg, 1999)</li> <li>• <i>Inventory of Parent Experiences</i> (Crnic, Greenberg, Ragozin, Robinson, &amp; Basham, 1983)</li> <li>• <i>Structured Home Interview</i></li> <li>• <i>Social-Emotional Assessment Inventory</i> (Meadow, 1983)</li> <li>• <i>Health Resource Inventory</i> (Weissberg, Gesten, &amp; Ginsberg, 1981)</li> <li>• <i>Walker Problem Behavior Identification Checklist</i> (Walker, 1983)</li> <li>• <i>Family Environment Scale-Short Form</i> (Moos, 1974)</li> <li>• <i>Parenting Daily Hassles</i> (Crnic &amp; Greenberg, 1984)</li> </ul> | <ul style="list-style-type: none"> <li>• The most common issues reported by social workers included child abuse, behavior challenges, and emotional and physical issues.</li> </ul>  |
| Evans, J. (1995)                     | <ul style="list-style-type: none"> <li>• A 7-year-old girl (Kristin) with profound deafness, her parents, and 7 siblings (2-14 yrs old)</li> <li>• Kristin used signed English and speech</li> <li>• Kristin attended a state school for the deaf</li> </ul>   | <ul style="list-style-type: none"> <li>• Qualitative inquiry was conducted over a 6-month period</li> <li>• Observer visited 2 to 3 times a week using observation, interviews, and videotaping of family activities</li> </ul>   | <ul style="list-style-type: none"> <li>• Family members who sign well served as partners and interpreters</li> <li>• Kristin had access to the communication 66% of the time; less often in larger family gatherings</li> </ul>  |

(table continues)

(TABLE 1 continued)

| Author   | Participants   | Measure   | Key findings   |
|--|--|---|--|
| Fisiloglu, A. G., & Fisiloglu, H. (1996)                                   | <ul style="list-style-type: none"> <li>Family members varied in their communication modes from speech only, to use of sign simultaneously</li> <li>120 Turkish parents of children who are deaf</li> <li>Average age of parent was 33 years old</li> <li>Children attended special school</li> <li>Children had profound hearing loss</li> </ul> | <ul style="list-style-type: none"> <li><i>Family Assessment Device</i> (Epstein, Baldwin, &amp; Bishop, 1983), which measures problem solving, communication, roles, affective responses, involvement, behavior control, general function</li> </ul>  | <ul style="list-style-type: none"> <li>Parents acknowledge that involving child who is deaf requires extra time and effort</li> <li>Kristin's sisters think she sometimes gets special treatment</li> <li>No significant differences in functionality of families of children who are deaf and families of children who are hearing</li> </ul>   |
| Freeman, B., Dieterich, C., & Rak, C. (2002)                               | <ul style="list-style-type: none"> <li>9 parents, 2 grandparents, and 6 staff</li> <li>Children attended a university early intervention program or an inner-city preschool for children who are deaf</li> <li>Participants were from an urban environment</li> </ul>  | <ul style="list-style-type: none"> <li>Qualitative methodology was utilized</li> <li>Observations of children were conducted</li> <li>Long semistructured open-ended interviews were conducted</li> </ul>   | <ul style="list-style-type: none"> <li>Themes included: parents' struggles with diagnosis, resolving grief, communication with their child, and dealing with system barriers</li> </ul>  |
| Hintermair, M. (2000)  | <ul style="list-style-type: none"> <li>317 German parents of children who are deaf</li> <li>Children were 1 to 12 years old</li> <li>Average age of children was 6 years 6 months</li> <li>Children had 40 to &gt; 90 dB hearing loss</li> <li>Children used a variety of communication modes</li> </ul>   | <ul style="list-style-type: none"> <li><i>Parenting Stress Index</i> (Abidin, 1990)</li> </ul>  | <ul style="list-style-type: none"> <li>Only 9.5% of parents reported frequent contact with deaf adults</li> <li>Social networks with other parents of children who are deaf were associated with less isolation, acceptance of their child, and improved interactional responsibility</li> <li>Parents who had contact with deaf adults reported less depression, less isolation, and increased interactional responsibility to their child</li> <li>Greater degrees of hearing loss were associated with more difficulties in parent-child relationships</li> </ul> |
| Kashyap, L. (1986)   | <ul style="list-style-type: none"> <li>Parents of 100 children were surveyed</li> <li>All children attended special schools in Bombay, India</li> <li>Children were between 5 and 14 years old</li> </ul>  | <ul style="list-style-type: none"> <li>Questionnaire not specifically described</li> </ul>  | <ul style="list-style-type: none"> <li>39 mothers and 59 fathers reported less positive expectations from their child who was deaf</li> <li>In 2.6% of families, both parents perceived an overall negative impact on the family</li> <li>In 79.5% of families, both parents perceived a overall neutral impact on the family</li> <li>In 17% of families, parents differed in perceived overall impact of deafness</li> </ul>   |
| Meadow-Orlans, K., Mertens, D., Sass-Lehrer, M., & Scott-Olson, K. (1997). | <ul style="list-style-type: none"> <li>404 parents of children who are deaf or hard of hearing were surveyed</li> <li>137 different programs in 39 different states</li> <li>54% of children were hard of hearing</li> <li>46% of children were deaf</li> <li>66% used speech and sign to communicate</li> </ul>                                 | <ul style="list-style-type: none"> <li>Questionnaire containing 7 subsets: background, services, level of satisfaction with services, child's skill levels in behavior, communication, parents' response to diagnosis, and family background characteristics</li> <li>Reviewed articles in <i>American</i></li> </ul> | <ul style="list-style-type: none"> <li>71% of families in total communication programs reported access to sign classes</li> <li>Information about deafness received by three quarters of parents</li> <li>Parent-group meetings were available to 69% of families</li> </ul>   |

(table continues)

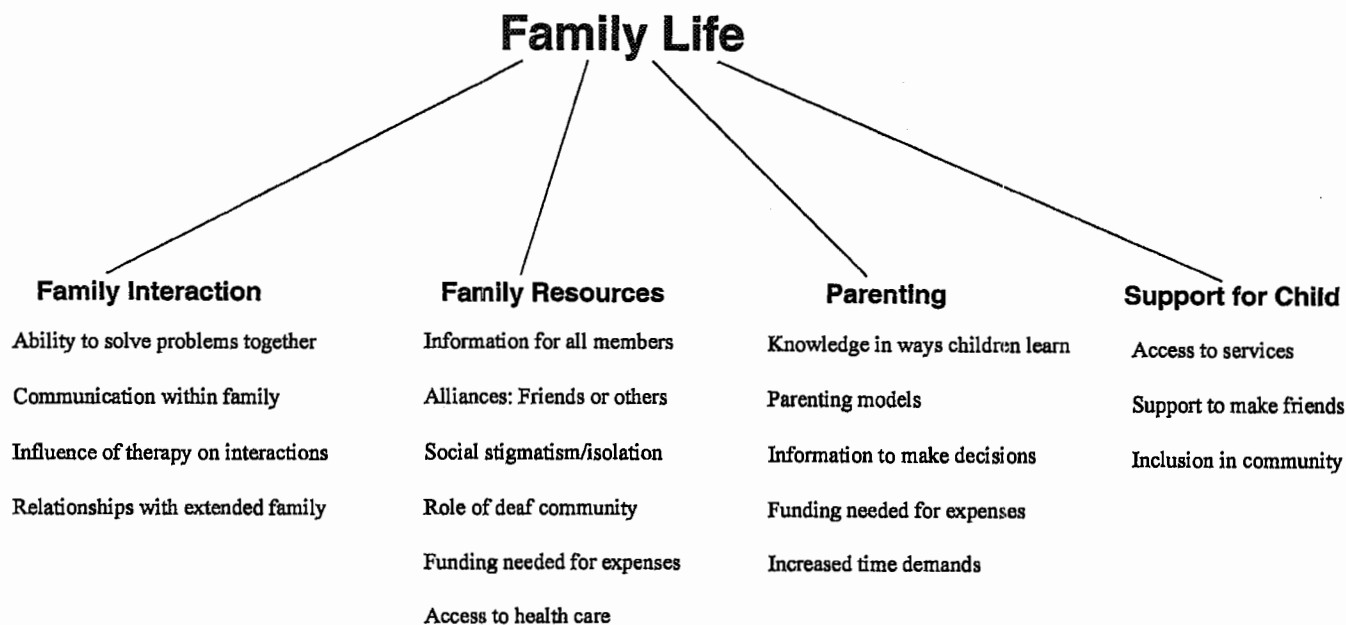
(TABLE 1 continued)

| Author   | Participants  | Measure  | Key findings   |
|--|---|--|--|
| Moore, D.,<br>Jatho, J.,<br>& Dunn, C.<br>(2001)             | <ul style="list-style-type: none"> <li>• 24% used speech alone; 5% sign alone</li> <li>• 34% had one or more parent who was deaf</li> <li>• One third were from ethnic minorities</li> </ul>  | <i>Annals of the Deaf</i> between 1996 and 2000  | <ul style="list-style-type: none"> <li>• 64% of parents had information on child development</li> <li>• 59% of parents had information on choices for future school placement</li> <li>• Parents rated teachers as the highest source of support</li> <li>• 19% to 20% of respondents reported that medical doctors were a source of help</li> <li>• Non-White families reported significantly less support and rated services less favorably</li> <li>• Hispanic mothers expressed more negative feelings toward deafness than White mothers</li> <li>• Hearing parents expressed more negative feelings about the impact of deafness than did mothers who were deaf</li> <li>• Reported that 15% of articles published on deafness pertained to four family issues: interaction and involvement, support services, stress and coping, and decision making</li> </ul> |
| Morton, D. (2000)  | <ul style="list-style-type: none"> <li>• 10 hearing parents of children who are deaf</li> <li>• 8 mothers; 2 fathers</li> <li>• Children were between 13 months and 4 years old</li> </ul>  | <ul style="list-style-type: none"> <li>• Informal qualitative survey asking 3 questions about support of grandparents at time of diagnosis; support at time of survey; and about changes in relationships following the birth/diagnosis of their child</li> <li>• 90-minute interviews, based on 9-page survey</li> <li>• Interpreter services were used for interviews</li> </ul> | <ul style="list-style-type: none"> <li>• Majority reported supportive grandparents at the time of diagnosis and at time of survey</li> <li>• 6 of 10 felt their relationship had not changed; 3 of 10 felt it had improved; 1 of 10 felt relationships worsened</li> <li>• Signed communication was an important feature of relationships</li> <li>• Grandparents initially experienced feelings of helplessness and confusion following diagnosis</li> <li>• Grandparents reported limited opportunities to learn and practice sign language</li> <li>• All families reported the experiences eventually brought them closer together</li> </ul>  |
| Nybo, W.,<br>Scherman, A., &<br>Freeman, P.<br>(1998)        | <ul style="list-style-type: none"> <li>• 21 volunteer participants consisted of children who are deaf, their most involved parent, and their most significantly involved grandparent</li> <li>• All children attended the North Dakota School for the Deaf</li> <li>• Age of children ranged from 15 months to 20 years old</li> <li>• Five families were White; one was Native American</li> <li>• Grandparents lived from 70 to 240 miles away</li> </ul> | <ul style="list-style-type: none"> <li>• Over a 3-year period, parents were interviewed during a weeklong summer program</li> <li>• Utilized a survey to obtain information</li> </ul>   | <ul style="list-style-type: none"> <li>• Average age of identification was 14.58, showing an improvement from previous report of 20.2 a few years prior</li> <li>• Delay between diagnosis and onset of services was 0 to 24 months</li> </ul>   |
| Prendergast, S.,<br>Lartz, M., &<br>Fiedler,<br>B. C. (2002) | <ul style="list-style-type: none"> <li>• Parents of 77 children with severe to profound hearing loss</li> <li>• Children attended a state residential school for the Deaf</li> <li>• Children were 8 to 71 months old; 38 girls and 39 boys</li> </ul>  |  |  |

(table continues)

(TABLE 1 continued)

| Author   | Participants  | Measure  | Key findings   |
|--|---|--|--|
| Watkins, S.,<br>Pitman, P., &<br>Walden, B. (1998) | <ul style="list-style-type: none"> <li>• 74% Caucasian, 13% Black, 11% Hispanic, and 3% Asian</li> <li>• 70 used Total Communication and 4 used an oral communication method</li> <li>• 32 children who were deaf and their families</li> <li>• Divided into 2 groups (18 in each)</li> <li>• One group lived in Tennessee and received weekly sessions with parent advisors</li> <li>• One group lived in Utah and received weekly visits with parent advisors and Deaf mentors</li> <li>• Matched for age of identification, severity of hearing loss, and language skills</li> <li>• Participants in Utah used American Sign Language (ASL) and Signed English</li> <li>• 9 participants in Tennessee used Signed English; 9 used only spoken English</li> </ul> | <ul style="list-style-type: none"> <li>• Language and communication measures including: <i>Grammatical Analysis of Elicited Language-Pre-Sentence Level (GAEL-P)</i>, <i>Patterned Elicitation Syntax Test (PEST)</i>, <i>SKLHI Language Development Scale</i>, and <i>Communication Data Sheet</i></li> <li>• A survey to assess parent attitudes toward deafness, Deaf culture, and their child's deafness. <i>The Deafness Perception Survey</i> (Watkins et al., 1998)</li> <li>• Videotapes of parent-child interactions were collected every 3 months with participants in the Utah program</li> </ul> | <ul style="list-style-type: none"> <li>• Half of respondents began services when their child was 1 year old or younger</li> <li>• Nearly half (31) received center-based services, 26 received home-based services; and 7 received a combination of both</li> <li>• 39 had been presented with information on several communication method options</li> <li>• Children in the Utah Deaf Mentor Program showed greater expressive and receptive language gains on all measures compared to the group that did not receive mentor support</li> <li>• Parents in the Deaf Mentor Program reported less frustration with communication and used six times as many signs</li> <li>• 100% of parents in the Deaf Mentor Program participated in Deaf community activities, while 12% of Tennessee parents participated</li> <li>• Perceptions of parents in the Deaf Mentor Program were more consistent with the values of the Deaf culture and the Deaf community</li> </ul> |



**FIGURE 1.** The widespread impact of deafness on family life is depicted by influencing factors in each domain of family life.

onstrate strong emotional ties to particular choices related to using technology (e.g., cochlear implants vs. hearing aids) or methodology (e.g., oralism vs. American Sign Language [ASL]; Peters, 2000).

Family interactions may be affected by the stress of decisions related to such choices (Freeman, Dieterich, & Rak, 2002). Kashyap (1986) reported both positive and negative effects on marital interactions, based on a survey in Bombay of parents of 100 children who were deaf. Of the parents surveyed, seven mothers and four fathers reported that they had grown closer to their spouse due to their common concern. An equal number of parents reported that their relationships had deteriorated since their child's diagnosis of deafness (Kashyap, 1986).

Fisiloglu and Fisiloglu (1996) used an assessment of family functioning to compare the responses of 40 Turkish families of children who were deaf with the responses of 20 Turkish families of hearing children. The comparison indicated similar functioning of the two groups of families, with the exception of the area of problem solving; in the area, families of children who were deaf scored significantly higher than families of hearing children. The authors suggested that parents of children who were deaf demonstrated strengths in the area of problem solving because they had developed skills in adjusting to stress.

### Communication

Parents often report that interactions with their child who is deaf are different from interactions with other

children in the family (Bodner-Johnson, 1991; Freeman et al., 2002; Hintermair, 2000). Bodner-Johnson analyzed videotaped conversations of 10 children who were deaf and their parents and siblings during evening meals at their homes. Differences in communication styles were described. Bodner-Johnson reported that children who were deaf were generally responsive in conversation with family members but were least likely to maintain conversations to develop an idea or topic introduced by another family member.

Some parents report frustration with communication differences and perceive a negative impact of deafness on interactions. One mother shared an example of such frustration, as reported in a qualitative inquiry (Freeman et al., 2000):

She wants me to know something and she's signing away and I really don't know what she's saying. And I have to keep asking her, "What? What? What?" She kind of gets upset because she can't get her point across to me, and I'm trying to get a point across to her, and—we're struggling. (p. 40)

Evans (1995) noted that children who were deaf often required additional support for involvement in family interactions. In a case study, Evans found that the child's access to interactions was directly related to the signing ability of family members. The researchers also observed that "Kristin's inclusion in family communication could fall along a continuum that ranged from full inclusion to total exclusion. The level of her inclusion de-



pendent on the presence or absence of an interpreter or one-to-one communication partner" (p. 237).

Difficulties in interactions may be partly due to the fact that hearing family members often do not share the same communication mode as the child who is deaf, making access to family social interactions difficult (Henderson & Hendershott, 1991). For example, if the child's primary mode of communication is sign language, the family's interactions may be influenced by how comfortable and knowledgeable each family member is with sign language and visual communication (Calderon et al., 1998; Evans, 1995; Freeman et al., 2002). Calderon et al. surveyed 28 families, and only half or fewer families reported a match between adult communication style and the child's communication style. Similarly, in a case study described by Evans, the child who was deaf had access to a communication partner 66% of the time (95 of 144 interactive episodes) and was often unaware of communicative exchanges in the larger family groupings.

Differences in the impact of deafness on communicative interactions may be partially influenced by minority status, severity of hearing loss, and social supports. Meadow-Orlans, Mertens, Sass-Lehrer, and Scott-Olson (1997) surveyed 404 parents of children who were deaf and reported that parents from minority groups and those with no college training reported more of a negative impact of deafness on their families and reported more difficulties with behavior problems and communication. Additionally, Hintermair (2000) surveyed 317 parents and reported that parents of children with greater degrees of hearing loss face more problems in establishing a mutual relationship with their child when compared to children with lesser degrees of hearing loss.

Findings also suggest that communicative interactions are generally improved when a child has at least one parent who is also deaf or when parents have frequent contacts with deaf adults (Hintermair, 2000; Watkins, Pittman, & Walden, 1998). Hintermair found that parents who had frequent contact with deaf adults demonstrated increased interactional responsiveness to their child compared to parents who had no contact with deaf adults. When other deaf adults are present, sign language may be shared by adults who facilitate interactions, making interactions more natural and comfortable. Watkins et al. reported communication benefits for parents who participated in the Utah Deaf Mentor Program, in which deaf adults mentored family members and taught them ASL. Participants in the program used six times more signs and reported less frustration when communicating with their child.

### ***Influence of Therapy***

Calderon et al. (1998) reported that issues related to deafness strongly influenced how family members spent their

time together. When the hearing parents of 28 children who were deaf were asked to rank how they spent their time with their child, 70% of fathers and 64% of mothers ranked dealing with hearing loss as their main emphasis (e.g., maintaining hearing aids and doing therapy-related activities). Both mothers and fathers rated working on speech skills as their second emphasis during interactions.

Interactions between parents and other children in the family may potentially be affected by the emphasis on therapy (Kashyap, 1986). In a survey of parents of 100 children who are deaf, 30 mothers expressed concern that there was a decrease in their interactions with their other children (Kashyap, 1986). Additionally, in this survey, 56 of the mothers reported that they experienced increased sibling rivalry between their other children and their child who was deaf.

### ***Relationships with Extended Family Members***

Relationships with extended family members may also be affected by issues related to deafness. The ease of interactions with extended family members may be influenced by the mutual proficiency in the child's preferred communication mode. Members of the family who are hearing may find themselves serving as liaison between two communication modes when among extended family members (Evans, 1995; Rienzi, 1990). Nybo, Scherman, and Freeman (1998) reported that strong relationships between grandparents and children who were deaf relied on physical proximity, signed communication between grandparent and child, and the quality of the grandparent relationship that existed before the birth of the child. Morton (2000) described relationships with grandparents with 10 hearing parents of children who were deaf. The majority of parents reported that their parents were supportive at the time of diagnosis and had continued to be supportive. Six of 10 parents felt that their relationship had not changed; in addition, 3 felt it had improved, and 1 felt the relationship with grandparents had worsened following the child's diagnosis of deafness. Nybo et al. reported that grandparents experience an adjustment process that includes feelings of helplessness and confusion; however, all families who participated agreed that these experiences eventually brought them closer together as a family.

## **IMPACT ON PARENTING**

The effect of parenting skills on family quality of life involves aspects such as having knowledge about ways to help children learn, having information needed to make decisions, and having time to meet the needs of every family member (Park et al., 2003). Families with children

who are deaf may experience uncertainties about parenting skills, difficulty finding information needed to assist with decisions, and the stress of time demands related to intervention (Calderon et al., 1998).

### **Knowledge About Ways Children Learn**

As parents assume their new role as mother or father of a deaf child, parents may feel uncertain about their knowledge of how children who are deaf learn best (Bodner-Johnson, 2001). Although deafness offers a culture and language of its own, 90% of children who are deaf are born to hearing parents who are neither natural signers nor natural members of the Deaf community (Center for Demographic Studies, 1984). With a child who is deaf, parents may feel uncertainty about their competencies in parenting (Freeman et al., 2002). As Bodner-Johnson (2001) wrote, "Being a mother or father of a deaf child means assuming a new role and a new set of responsibilities—a role they had not anticipated and for which they probably have had little preparation" (p. 264). It is suggested in the literature that everyday parenting activities, which are critical for conveying social norms, values, and accepted behavior, may be challenging when all family members do not have full access to a shared language (Evans, 1995; Freeman et al., 2002; Henderson & Hendershott, 1991). In a qualitative inquiry (Freeman et al.), parents shared concerns that their children were missing information due to lack of mutually accessible communication. As previously discussed, parents may not initially feel comfortable with their skills at adapting communication or do not feel that they have the signed vocabulary needed to take advantage of incidental language learning opportunities (e.g., describing things outside while driving or labeling and commenting while looking at picture books).

In considering how young children learn, some scholars have suggested that joint visual attention is essential to early learning and communicative development, particularly in young children who are deaf (Harris, Clibbens, Chasin, & Tibbitts, 1989; Spencer, Bodner-Johnson, & Gutfreund, 1992; Swisher, 1992). Even though joint attention is critical, accommodating the visual needs of children who are deaf may not come naturally to hearing parents of children who are deaf (Harris, 2000). Harris discussed differences in interactions between deaf and hearing children and their parents. Hearing children demonstrated more frequent, spontaneous looking at their mothers, particularly looking at their mothers in response to a sound, while children who were deaf turned to look at their mothers in response to a movement. Harris and Mohay (1997) found that deaf mothers were more successful than hearing mothers in eliciting switches in attention because they were more insistent on getting their child to turn to look at them

and used more physical elicitors such as tapping or waving.

### **Parenting Models**

With hearing children, parents may rely on learned parenting skills from their own experiences, their parents, or their peers. Without support, hearing parents often do not have access to models of parenting deaf children. Studies have reported that less than 10% of hearing parents of children who are deaf have frequent contacts with deaf adults (Hintermair, 2000). Despite the low incidence of alliances with deaf adults, Hintermair reported positive impacts of contacts with deaf adults in reducing parents' depression and isolation and increasing acceptance and interactional responsiveness. Watkins et al. (1998) found that families with deaf mentors reported more progress in their child's skills than did families without deaf mentors. These studies suggest that parent-to-parent support encourages parents and provides parents with role models as they discover their lives as parents and families with a deaf child.

### **Information to Make Decisions**

Early intervention for children who are deaf is surrounded by strong controversies about teaching methods and communication options (e.g., spoken language and sign language). Such controversies related to deaf education may cause parents to experience increased uncertainty and stress in parenting decisions. Calderon et al. (1998) wrote, "It may be difficult or impossible for parents . . . to become full participating partners in the process of teaching their child communication skills given their uncertainty and the surrounding controversy" (p. 357).

Families of deaf children often report that they did not have adequate resources for decision making (Eleweke & Rodda, 2000; Jackson, Becker, & Schmitendorf, 2002; Prendergast, Lartz, & Fiedler, 2002). Prendergast et al. surveyed parents of 77 children in Illinois who were deaf. Approximately half (39) of the families reported that they had received information on several communication options. In a survey of 60 Kansas families (Jackson et al., 2002), many parents reported that they did not feel that they were provided adequate information and resources about communication choices to assist their decisions. Families were asked to rate their satisfaction with the information they received on eight communication options as either adequate or inadequate. Of the 60 participants, the majority reported adequate information and resources on only two choices, ASL and Total Communication. More than 50% of the parents reported inadequate resources on other options, such as Cued Speech and the auditory-verbal approach.

### ***Increased Time Demands***

Many family members reported that they spend extra time on therapy-related activities that confound the demands on their time to fulfill household tasks and meet the needs of other family members (Calderon et al., 1998; Evans, 1995). Time demands may be increased by the need to accommodate therapy and related appointments, such as hearing evaluations, fitting earmolds or programming cochlear implants, and maintaining hearing aids (Evans, 1995). Families also reported feeling stressed by the extra time and efforts required for learning new skills, such as becoming proficient in a different communication mode (Evans, 1995; Freeman et al., 2002; Henderson & Hendershott, 1991; Kashyap, 1986). As discussed previously, these demands become increasingly overwhelming when parents try to balance time spent with all their children (Kashyap, 1986).

## **IMPACT ON FAMILY RESOURCES**

### ***Information for All Family Members***

The domain of family resources includes indicators such as the family's access to information, social networks, and health care. Meadow-Orlans et al. (1997) found that of 404 parents surveyed, 71% reported that they had access to sign language instruction, 43% had access to individual counseling, and 69% had access to parent group meetings. With typically developing children, it may be taken for granted that all family members share a common language and communication mode. For a child who is deaf, however, all family members, including extended family members, may not have access to resources to assist them in interacting and learning how to communicate effectively with the member who is deaf (Nybo et al., 1998). The grandparents surveyed in Nybo et al. reported that they had limited opportunities to learn and practice sign language. Luteran (1987) reported that grandparents had less direct access to informed professionals than did parents. Morton (2000) stated that members of the extended family "are an important but often underutilized resource for the successful development of the deaf child" (p. 1).

### ***Alliances: Friends or Others Who Provide Support***

This indicator reflects the extent to which family members feel accepted and supported by social networks. The literature on families of children who are deaf emphasizes the themes of social isolation or stigmatization and social networks.

**Social Stigmatization/Isolation.** The extent to which caregivers feel supported by others may also be affected

by issues related to deafness. Several scholars have suggested that families often feel isolated by stigmatization and social exclusion and by rejection from family and friends (Gregory, Bishop, & Shelton, 1995; Seligman & Darling, 1997). Gregory et al. surveyed 116 hearing parents of deaf children and found that one third reported negative changes in their relationships with others when their child was identified with deafness.

**Social Networks.** Studies have reported the benefits of social networks and relationships with other families (Calderon & Greenberg, 1999). Calderon and Greenberg reported results of 36 hearing mothers of children who are deaf on a variety of life stress and adjustment tests. The findings indicated that social support accounted for 43% of the variance in coping and adjustment scores. Based on this study, mothers who reported satisfaction with their social support were more likely to be better adjusted despite the degree of life stress or severity of the child's hearing loss (Calderon & Greenberg, 1999). This finding is consistent with the results of studies involving children with other disabilities. For example, Dunst, Trivette, and Cross (1986) also reported that the type or amount of services had less of an effect on the child's progress in development than did the number and quality of social supports for parents.

Hintermair (2000) studied the effects of families' friendships with deaf adults. This study involved interviews with 317 families with children who were deaf. Parents were asked about their contacts with other parents and with adults who were deaf. The results indicated that parents who had many contacts with other parents of children who were deaf and with deaf adults reported less isolation and showed greater emotional bonds with their child, better acceptance of their child, and improved responsiveness during interactions. The results of the Hintermair study indicated an interaction between severity of the hearing loss and the degree of benefit parents reported from interaction with other families with deaf members and interaction with deaf adults. Families whose children had more severe hearing loss reported greater gains from social interactions than did parents of children with mild or moderate degrees of hearing loss.

**Role of Deaf Community.** It should be noted that there may be vast differences in the perception of social support by caregivers who are deaf and those who are hearing. Deaf parents of deaf children may not perceive social isolation by the hearing community as problematic when they feel satisfied with the support and acceptance of the deaf culture and community (Henderson & Hendershott, 1991). This experience may be quite different from the experiences and feelings of hearing parents who may not find desirable support in the resources of the

Deaf community. An example may be found in Peters (2000), in which a hearing father of a child who was deaf shared hesitations about involvement in Deaf cultural events. The father reported, "We are nervous each time we go to such things, and we still feel like outsiders who are riding our toddler's coattails into acceptance by people whom, despite my elementary knowledge of sign, we would not have sought out otherwise" (p. 263). Additionally, Bodner-Johnson (2001) cautioned that as parents learn more about Deaf culture, they may develop some ambivalence about becoming part of the world of deafness in having to give up a part of who they are.

### **Access to Health Care**

For families with a child who is deaf, family needs may arise in locating and accessing audiologists and physicians who are skilled at addressing their child's special needs. In a survey of 404 parents of children who were deaf, results indicated that only 19% to 20% of parents rated medical doctors as "very helpful" as a source of support for parents (Meadow-Orlans et al., 1997). Families who have caregivers who are deaf may need assistance in arranging interpreter services for regular medical checkups.

## **SUPPORT FOR THE CHILD WHO IS DEAF**

The last domain of support for the family member with special needs focuses on diverse indicators of individual quality of life, which can, in turn, impact family quality of life. Such indicators include access to service providers with expertise in issues related to deafness, availability of needed services to make progress, as well as support for the child to make friends and be included in the community (Park et al., 2003).

### **Access to Services**

Carney and Moeller (1998) have suggested that children who are deaf benefit from access to a variety of professionals and services (e.g., a teacher of the deaf, speech-language services, aural rehabilitation). Despite this recommendation, families may have difficulty finding service providers who specialize in serving children with hearing loss (Arehart & Yoshinaga-Itano, 1999). These researchers indicated a lack of educators of the deaf in early intervention services. Arehart, Yoshinaga-Itano, Thomson, Gabbard, and Stredler Brown (1998) surveyed early intervention programs in 16 states and reported that only 30% of early intervention sites included a teacher of the deaf as a service provider. Freeman et al. (2002) inter-

viewed 9 parents, 2 grandparents, and 6 staff members who reported frustration with systematic barriers, including problems in staff resources, inexperienced clinicians, high rates of turnover, and difficulties in program delivery. Service providers available to children may not have adequate training in the child's communication mode or may not be familiar with teaching methodology and modifications specifically related to the learning styles of children who are deaf. The need for such specialized services may pull families in different geographic directions. Calderon et al. (1998) surveyed 28 families whose children had graduated from early intervention services to follow up on their support services. Of the families surveyed, 28% reported that they had changed residences to be closer to appropriate services for their child.

### **Support to Make Friends**

Children who are deaf may feel a sense of isolation or stigmatization in the hearing community (Henderson & Hendershott, 1991; Steinberg, Davila, Collazo, Loew, & Fischgrund, 1997). Steinberg et al. reported a stigmatization associated with deafness in Hispanic communities. In this naturalistic inquiry, 14 family members of Hispanic origin were interviewed about their young family member's experience with deafness. In this inquiry, parents reported that their child's social identity had become subsidiary to deafness. Parents expressed frustration that their children who were deaf were not included in play with children in their neighborhoods.

Much of the child's participation in social opportunities with others may rely on the adequacy of their communication means (Henderson & Hendershott, 1991). Peers may not be knowledgeable about utilizing interpreters to include the child in conversations and interactions. As one parent in a qualitative inquiry (Freeman et al., 2002) expressed, "These other kids don't sign, so it really doesn't make sense that they're in the class. But on the other hand [the preschool is] good for [my son] because this is the real world for him to see" (p. 41).

The longstanding divisions between Deaf and hearing cultures may make it difficult for children to feel accepted by both hearing and Deaf communities. Kanapell (1980) stated, "ASL has a unifying function, since deaf people are unified by their common language. But the use of ASL simultaneously separates deaf people from the hearing world" (p. 112). As Henderson and Hendershott (1991) pointed out, while some individuals who are deaf may feel that hearing loss isolates them socially, others feel bonded by a unique language and culture. Bat-Chava (2000) described four *deaf identities*: a hearing identity, immersion (seeking immersion in deaf culture), bicultural, and marginal (not certain about their identity).

### ***Inclusion in Community***

Issues for families with children who are deaf may include overcoming barriers to full inclusion in the hearing and/or Deaf community (Freeman et al., 2002; Steinberg et al., 1997). Families and service providers may evaluate and problem solve barriers to the community (e.g., a means to order at fast food restaurants, attend a movie, attend childcare, go to church or the library story time). Although few studies address participation in the community for young children who are deaf, family outcomes may include arranging interpreter services, obtaining closed captioning, and securing funding for interpreting services at community events and activities.

## **FUTURE RESEARCH IMPLICATIONS**

In reviewing the literature with respect to the domains of family quality of life, it becomes apparent that the impact of deafness encompasses multiple areas of family life (see Figure 1). The literature on the effect of deafness on family life discusses effects of deafness across family interactions, parenting, family resources, and support for the child who is deaf. Three characteristics of the available research will be further discussed: influencing factors, methods of assessing family life, and the impact of support on family quality of life. Future research implications are included for each characteristic.

### ***Influencing Factors***

The literature has suggested that several factors may influence the degree and type of impact of deafness on family life, including the severity of hearing loss, a family's ethnicity, the hearing status of parents, the education of parents, the mode of communication used, the proficiency of partners in child's communication mode, and family's access to social supports and parenting models. Further studies are needed to better understand the relationships among these influencing factors and the impact on particular domains of family life.

Analyzing influencing factors is difficult due to the homogenous nature of the majority of the participants in the available studies. Because of small sample sizes and similarities among participants, the trends may not adequately represent the experiences of a variety of families. The majority of participants were middle class Caucasian families, with the exception of Meadow-Orlans et al. (1997), Steinberg et al. (1997), and a few studies that concentrated on specific populations from Turkey, Germany, and India. Most of the participants were hearing parents of children who had severe to profound hearing loss, wore hearing aids, and used sign language, a combined approach, or an oral approach. The experiences of

families who include a child with a cochlear implant may differ from those with a member with a hearing aid. Additional studies are needed to consider the influence of various communication methods (e.g., Cued Speech, Signing Exact English, an auditory-verbal approach) on areas of family life. Moreover, available studies have primarily focused on children with severe to profound degrees of hearing loss. The experiences of families with children with moderate degrees of hearing loss likely differ from those reported in the literature on deafness. Additional research is needed on how diverse child and family characteristics influence the impact on deafness on family life.

### ***Methods of Assessing Family Life***

A variety of methods were utilized in the literature to assess individual aspects of family life (see Table 1), including interviews, observation, checklists, surveys and questionnaires, and scales and indexes (e.g., *Parent Problem Solving Assessment Task*, *Inventory of Parent Experiences*, *Social-Emotional Assessment Inventory*, *Family Environment Scale*, *Parenting Daily Hassles*). Little information about validation of the measurement tools was provided. Additional research on assessing and measuring family quality of life is warranted to identify tools that are sensitive to the unique experiences of families who include members that are deaf. Measurement tools are needed to examine the effects of deafness on the overall family well-being.

### ***Impact of Support***

Further research is needed to examine the effects of different supports and service delivery models on indicators and domains of family quality of life. A number of studies in the literature have suggested the benefits of particular supports, including social support, parenting models, and access to information and training. In the available literature, no sufficient data exists to indicate supports that are most beneficial in reducing the perceived stress of decision making and problem solving, reducing time demands, enhancing mutually accessible communication, and facilitating access to services and the community. More research is needed to determine the best match between different supports and methods of delivery (such as direct instruction, coaching; individual counseling, parent-group meetings) and different child and family characteristics. Additional research is also needed to consider the impact of different service delivery models as it relates to deafness and family life (primary provider model, activity-based instruction, and home-based vs. center-based services). Finally, future research is needed to identify support systems that have the greatest positive impact on family quality of life. ♦

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