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THE NEEDS AND CONCERNS OF THE SIBLINGS OF THE DEAF-BLIND

by

Lori P. Rowan

A masters project submitted in partial fulfillment
of the requirements for the degree

of

MASTER OF EDUCATION

in

Communicative Disorders

Approved:

UTAH STATE UNIVERSITY
Logan, Utah

1990

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ABSTRACT

The Needs and Concerns of Siblings of the Deaf-Blind

by

Lori P. Rowan

Utah State University, 1990

Major Professor: James C. Blair, Ph.D.
Department: Communicative Disorders

The needs and concerns of the siblings of children who are deaf-blind were studied. Subjects included 12 siblings (eight males, four females) whose families are involved in the Utah Intervener Services Program.

Information was collected by conducting one-on-one interviews with the siblings. The Siblings' Perceptions of the Intervener Interview (SPII) and Taylor's Siblings' Problems Questionnaire were administered.

The results indicated that individual sibling's perspectives were unique, varying from positive to negative. As a group, the siblings made positive comments about the intervener and their life with their deaf-blind brother or sister.

(92 pages)

PROBLEM STATEMENT

There are two basic problems to be addressed by this project:

a. The lack of information from the siblings of deaf-blind children about their needs and concerns related to their handicapped brother or sister; and

b. The lack of information on the siblings' perceptions of the services received by the family in the Utah Intervener Services program.

Concerning the first problem, very little research has focused on siblings of deaf-blind children (Banta, 1979; Klein, 1977). Most of the research that has been done on siblings of handicapped brothers and sisters has concentrated on siblings of the mentally retarded (Abramovitch, Stanhope, Pepler, and Corter, 1987; Byrne and Cunningham, 1985; Chinitz, 1981; Cleveland and Miller, 1977; Crnic, Friedrich, and Greenberg, 1983; Gath, 1972, 1973, 1974; Gath and Gumley, 1987; Graliker, Fishler, and Koch, 1962; Grossman, 1972; Kaplan and Colombatto, 1966; McHale and Gamble, 1989; Murphy, Pueschel, Duffy, and Brady, 1976; San Martino and Newman, 1974; Schreiber and Feeley, 1965; Stoneman, Brody, Davis, and Crapps, 1987, 1988; Wasserman, 1983).

As one considers the lack of information on the needs and concerns of siblings of deaf-blind children and reviews the literature, several issues emerge related to obtaining information from siblings about their handicapped brother or sister. The issues include:

1. To obtain current information by interviewing the siblings directly in their present situations.
2. To determine the siblings' perceptions of positive and negative effects of the handicapped child.
3. To obtain information on the siblings' feelings and attitudes in different situations.
4. To determine the siblings' perceptions of the pressure to achieve to compensate for the handicapped child in the family.
5. To determine the siblings's perceptions of their care-taking and household responsibilities.
6. To determine the siblings' perceptions of parental attention towards the handicapped and nonhandicapped children in the family.
7. To determine the siblings' perceptions of double standards and parental fairness towards the handicapped and nonhandicapped children in the family.
8. To obtain information on the siblings' perceptions of family finances due to the expenses of the handicapped child.
9. To determine the siblings' perceptions of parental attitudes towards the handicapped child.
10. To determine the siblings' perceptions of the communication that exists between parents and nonhandicapped children in the family.
11. To determine the siblings' perceptions of peers' reactions to the handicapped child.

12. To determine the siblings' need for behavior management and tutoring information in coping with their handicapped brother or sister.

Concerning the second problem, there is no information on the effect of the Utah Intervener Services program on siblings of deaf-blind children. The Utah Intervener Services program provides direct service to severely multihandicapped sensory impaired children in their homes through an intervener who is a non-professional under the supervision of a professionally trained parent advisor. The intervener provides services to the child for several hours each day. Because of the lack of information on the impact of this service model on deaf-blind children and their families, a three-year research grant was awarded to the SKI*HI Institute called Validation of the Intervener Program (VIP). As part of the grant to document the overall effectiveness of the Intervener program, information about the siblings is vitally needed.

REVIEW OF LITERATURE

Introduction

The focus of the literature on the handicapped has been on the parents and the handicapped child. There is little written about the nonhandicapped siblings' feelings and thoughts from their point of view.

> Because families are a system, distress in one member affects both the system and each member in it. Given that siblings play such an important and influential role in shaping each others' lives, one child's illness or disability will certainly impact siblings to some extent. (Siemon, 1984, p. 294)

It is important that professionals recognize siblings as part of the family system and use strategies to recognize and meet siblings' needs.

Studies on Siblings Through Parent and Teacher Interview

Information needs to be obtained directly from the siblings of the deaf-blind to discover their specific needs and concerns. Studies that have been done by a number of researchers (Banta, 1979; Breslau, Weitzman, and Messenger, 1981; Schwirian, 1976; and Simeonsson and McHale, 1981) on siblings of children with handicaps through direct interviews with the mother or in some cases, the mother and teacher (Gath, 1972, 1973, 1974) may be biased and may not indicate the true reactions of the siblings. Parental reports about siblings may be distorted by the parents' frustrations and needs (Wasserman, 1983) and by the mothers' perceptions and adjustment to the handicapped child (Lobato, 1983). Teachers' ratings may also reveal different results in comparison to results obtained when siblings are interviewed directly (Lobato,

1983). Siemon (1984) suggests that because siblings have not always spoken for themselves, there are conflicting conclusions. As Atkins (1987) states, related to the hearing impaired,

> If we are to understand the impact of a hearing impaired sibling on the family, we must try to get into the minds of the brothers and sisters and look at the situation through their eyes, hear what is being said through their ears, and understand the situation through their minds. (p. 38)

Studies in Retrospect

Other studies in the literature have used interviews or discussions with siblings in retrospect (Cleveland and Miller, 1977; Gath, 1972; Graliker et al., 1962; Grossman, 1972; Klein, 1977) rather than interviews conducted in the present. Information obtained in retrospect may be selectively recalled from childhood (Lobato, 1983) and may not be separated from the reality of family interactions (Brody and Stoneman, 1983). McHale, Sloan, Simeonsson (1986) note that the problematic aspects of sibling relationships may be very different today than in the past due to changes in educational services. It appears that more useful information can be obtained from siblings when information is obtained while growing up with their deaf-blind brother or sister. This way, siblings are able to guide parents and professionals so their needs can best be met in the present (Powell and Ogle, 1985).

Positive and Negative Effects on Siblings of the Handicapped

According to the research, the presence of a handicapped child in the family has both positive and negative effects on the siblings. Some studies report that a handicapped brother or sister has a positive influence on the siblings. Jacobs (1969)

found siblings of handicapped children to be sympathetic, helpful, understanding, and not adversely affected. Siblings were more responsible, mature, altruistic, and humanitarian than their peers (Grossman, 1972) and showed higher levels of nurturance (Abramovitch et al., 1987). Ferrai (1984) found that learning to live with a handicapped child facilitated the development of prosocial behaviors and social competence. Siblings report that growing up with a handicapped child enriched their lives, brought them closer to their families, and gave them insight (Grossman, 1972; Powell and Ogle, 1985). Iles (1979) found that siblings of special needs children were tolerant, compassionate, and empathetic to parents.

Other studies report that a handicapped brother or sister has a negative effect on the siblings. Lavigne and Ryan (1979) note that siblings of the handicapped have a negative self-image and high anxiety levels. Others report role and identity confusion and feelings of resentment and neglect (Grossman, 1972; San Martino and Newman, 1974). Tew and Laurence (1973) found that siblings of spina bifida children were four times as likely to be maladjusted as compared to subjects in the control group. Poznanski (1969) and Trevino (1979) found that siblings of handicapped children showed signs of pathology. Banta (1979) suggests that siblings of the deaf-blind suffer greater effects than their parents because they lack mature coping mechanisms.

Both positive and negative effects are found within the same study and by the same researcher over time. In Grossman's (1972) study, some siblings (45%) benefitted from having a handicapped sibling and were more tolerant and compassionate, others (45%) showed resentment and guilt, while others (10%) were unaffected. McHale et al. (1986) found highly variable responses. Some children

reported very positive relationships while others described very negative relationships. Gath's (1972, 1973, 1974) studies show different results over time. No differences were found in comparing siblings of the handicapped to a control group (Gath, 1972), more siblings of the handicapped were rated as deviant than children in the control group (Gath, 1973), and older female siblings were a high risk group for adjustment problems (Gath, 1974). Later, Gath and Gumley (1987) found little direct detrimental effect of a handicapped child on the siblings.

Different reasons have been given to explain the diversity among studies. McHale and Gamble (1987) emphasize the difficulties in drawing general conclusions on negative and positive effects because of the diversity in how families cope with a handicapped child including the differences among handicapped children. Different needs at different ages and at different stages of development plus changing family factors may contribute to these differences. Siblings may have a healthy, positive attitudes at one time and then show negative behaviors and feelings at another time (Powell and Ogle, 1985). Characteristics of the family in general and the characteristics of the child with the handicap may be related to the discrepancies in the research findings (Lobato, 1983; McHale, Simeonsson, and Sloan, 1984; Powell and Ogle, 1985). Schreiber and Feeley (1965) suggest that positive and negative effects depend on family structure, relationships, and parental attitudes. They also suggest that positive and negative effects depend on the nature and severity of the child's handicap and the adjustment of the siblings. Dyson and Fewell (1989) found that the effect of a handicapped brother or sister on a sibling is individualistic and suggest that other factors besides the presence of a handicapped child appears to affect the sibling.

Siblings are differentially affected by their experiences (Israelite, 1986). For example, stress may lead to emotional problems but may also foster maturity and competence in the child (McHale and Gamble, 1989).

Feelings of the Siblings of the Handicapped

According to Featherstone (1980) siblings of the handicapped endure many feelings alone without support. These feelings vary across children as reported in the literature and may be positive or negative. According to Powell and Ogle (1985) variables such as age and sex of the handicapped and nonhandicapped children, size of the family, religion practiced, functioning level of the handicapped child, parental attitudes towards the handicapped and nonhandicapped children, availability of outside resources, and temperament of children influence different feelings.

According to Powell and Ogle (1985), siblings of handicapped children experience feelings of loneliness because they feel isolated and rejected by their peers, isolated from their family members, and feel different because their family experiences are not shared by other families. A sibling's sense of isolation increases when the lines of communication are not open (Seligman, 1983).

Siblings of handicapped children experience greater degrees of anger than siblings with nonhandicapped brothers or sisters (Seligman, 1983) and direct anger towards the handicapped child, parents, society, and God (Featherstone, 1980). Anger is also directed at peers who treat the handicapped child badly (Powell and Ogle, 1985) and at parents who allow the handicapped child to behave in ways that the nonhandicapped child is not allowed to act (Cerrato and Miller, 1981). Resentment is

felt because of the siblings' curtailment of social activities, parents spending more time with the handicapped child, and different expectations held for the handicapped and nonhandicapped children in the family (Powell and Ogle, 1985).

One of the biggest complaints from siblings of handicapped children are feelings of confusion (Siemon, 1984). Siblings of the handicapped are confused about their roles as a sibling and as a surrogate parent, priorities given to the handicapped child over their own needs, and parents' changing reactions as they move through the stages of the grieving process (Crnic and Leconte, 1986; Powell and Ogle, 1985). Siblings of handicapped children experience confusing feelings of love and hate towards the handicapped child when parents demand siblings to protect the handicapped brother or sister while peers shun the handicapped child (Seligman, 1983).

A common reaction of siblings, especially a single sibling of a handicapped child, is a feeling of guilt (San Martino and Newman, 1974). Guilt feelings result from being born normal (Luterman, 1987; San Martino and Newman, 1974), experiencing negative feelings of anger, jealousy, hostility (Schreiber and Feeley, 1965; Seligman, 1983), having good health (Grossman, 1972; Powell and Ogle, 1985; Trevino, 1979), and feeling responsible for their brother or sister's handicap (Meyer, Vadasy, and Fewell, 1985). Resentment towards the handicapped child magnifies the guilt felt by the nonhandicapped sibling (Trevino, 1979) as do feelings of rivalry towards a sibling who has special needs (Crocker, 1981).

According to Powell and Ogle (1985), siblings feel fearful and anxious about how they should interact with the handicapped child. McHale and Gamble (1989)

found that children who perform more care-taking responsibilities experience more anxiety.

Female siblings of handicapped children report more depression while male siblings report lower levels of perceived competence (McHale and Gamble, 1989). Israelite (1986) found that siblings of hearing impaired children share similar perceptions of self-esteem as siblings of nonhandicapped children, but define themselves as siblings of hearing impaired children. She suggests this contributes to feelings of inadequacy in social situations.

According to Cerreto and Miller (1981) siblings have concerns about their future and worry about the responsibility of caring for their handicapped brother or sister after their parents are gone. Seligman (1983) also notes that siblings are overly concerned about the future for their handicapped brother or sister, their parents, and themselves.

Siblings also feel pressure to care for the handicapped child (Grossman, 1972), feel frustrated in their efforts to establish a relationship with the handicapped brother or sister (Featherstone, 1980), feel jealous of the attention the handicapped child receives (Powell and Ogle, 1985), and feel they are not loved as much as their handicapped brother or sister (Schreiber and Feeley, 1965). According to Powell and Ogle (1985) most siblings at some time feel embarrassed about their handicapped brother or sister. Embarrassment may be caused by others' reactions to the handicapped child or by questions asked about the handicapped child (Klein, 1972).

Although many negative feelings have been cited in the literature, some positive feelings have also been noted. Powell and Ogle (1985) suggest that a sibling

feels pleasure from the handicapped brother or sister's accomplishments and experiences feelings of warmth and compassion. Siblings of the handicapped feel empathy (Cleveland and Miller, 1977; Grossman, 1972) and appreciate their own strengths and are grateful for them (Grossman, 1972).

Wasserman (1983) questions that the siblings of the handicapped experience more problems with feelings than siblings of normal children. McHale et al. (1986) also emphasize that it is difficult to conclude that nonhandicapped children's feelings of jealousy and rivalry toward the handicapped child are different from feelings experienced between nonhandicapped siblings. According to Siemon (1984) siblings' feelings do not fit into neat categories.

Pressure to Achieve

Atkins' research consistently found that siblings of the hearing impaired try to compensate for the handicapped child in the family. Featherstone (1980) also supports the idea that siblings of handicapped children feel parental pressure to achieve. "Siblings, therefore, may believe they must be extremely well-behaved, academically able, athletic, attractive, socially adept, and above all else, 'normal'" (Hannah and Midlarsky, 1985, p. 513). Seligman (1982) also notes that siblings try to compensate for their parents' disappointments and frustrations because of the handicapped child. Banta (1979) notes that siblings of the deaf-blind may feel compelled to overachieve to compensate for the deaf-blind child's limitations, causing added stress to the sibling relationship. To compensate for the deficits of the handicapped child, siblings tend to be more educationally orientated and competitive (Cleveland and Miller, 1977) and are

compelled to achieve at high levels in school, athletics, and work (Schild, 1964). It is important to note that in some cases, nonhandicapped siblings feel the need to compensate because of their own perceptions while in other cases, parental expectations create pressure on siblings to excel. Gath and Gumley (1987) found that parents had higher expectations of their nonhandicapped children as compared to their handicapped children. Trevino (1979) also found that nonhandicapped children siblings may be targets for unrealistically high parental expectations causing the siblings to be pushed beyond their limits to compensate for the handicapped child who is regarded as a failure. Taylor (1974) suggests that in two-child families, parents may rest all their hopes and expectations on the nonhandicapped child.

Care-taking and Household Responsibilities

Siblings spend significantly more time taking care of their handicapped brother or sister (McHale and Gamble, 1989; Cleveland and Miller, 1977) and are responsible for more household duties (McHale and Gamble, 1989; Klein, 1977). According to Stoneman et al. (1988) a less competent child who has fewer self-help skills places more demands on sibling care-taking. McHale et al. (1986) suggest that siblings of a handicapped brother or sister may be relieved of care-taking responsibilities because of the increase in programs for handicapped children.

Negative effects of care-taking and household responsibilities on siblings have been noted. Skrtic, Summers, Brotherson, and Turnbull (1984) cite the balance of home responsibilities with school and other demands as a potential mental health risk. Excessive responsibility for a handicapped child may lead to feelings of anxiety,

depression, anger, and possible psychological disturbance (Breslau et al., 1981; San Martino and Newman, 1974). McHale and Gamble (1989) found that sibling's greater involvement in household chores and care-taking may result in more arguments and negative experiences with mothers. Seligman (1982) notes that because a handicapped child absorbs a great deal of time, energy, money, and emotional resources, the nonhandicapped children in the family may be pressed into parental roles before they are ready, moving them through the developmental states too rapidly and depriving them of important relationships and experiences. The role of care-taker seriously curtails children's development of peer relationships (Wasserman, 1983). McHale and Gamble (1989) found that because of extra family responsibilities, siblings miss out on experiences outside the home which facilitate cognitive, social, and affective development. Responsibilities of care-taking are also projected into the future (Featherstone, 1980) where siblings fear care-taking responsibilities of the handicapped child when parents can no longer provide the care (Correa, Silberman, and Trusty, 1986). Studies done by Gath (1974), Grossman (1972), and Crnic and Leconte (1986) found that siblings from low socioeconomic status families are more burdened with the care of a handicapped brother or sister. However, Stoneman et al. (1988) found no significance between lower family income and increased child care demands on siblings.

Positive effects of care-taking and household responsibilities have also been found. Furman and Buhrmester (1985) suggest that sibling care-taking may be a significant socialization opportunity for learning parental roles. Hannah and Midlarsky (1985) give evidence that voluntary helping may provide productive and successful

coping strategies in living with the stress of having a handicapped brother or sister and may have positive outcomes. According to McHale and Gamble (1989) care-taking may foster maturity, a sense of responsibility, and enhance competence and self-esteem.

It is widely noted that sisters of a handicapped child are often given more care-taking responsibilities (Breslau et al., 1981; Cleveland and Miller, 1977; Grossman, 1972; Schwirian, 1976). Older sisters appear to be most vulnerable because of the extra child-care and household responsibilities assumed (Byrne and Cunningham, 1985) and are adversely affected by the handicap because of the high expectations of parents in carrying out this role (Gath, 1973, 1974). Cleveland and Miller (1977) note that parent-surrogate duties are heaviest on the oldest sister and may effect her adult life commitments. Stoneman et al. (1988) found a relationship between multiple care-taking responsibilities of older sisters and sibling conflict, decreased opportunities with peers, and activities outside the home. Stoneman and Brody (1984) found that older sisters of handicapped girls were almost four times as likely to assume teacher/helper roles as compared to sisters of nonhandicapped girls but found no relationship to adjustment. Different expectations by parents regarding the responsibilities of male and female siblings may be a significant source of distress (Crocker, 1981). Lobato, Barbour, Hall, and Miller (1987) suggest that parents appear to respond to the presence of a handicapped child by increasing expectations and demands on daughters and relax those on sons. However, Stoneman et al. (1988) found that male siblings are more involved than their peers and babysit as often as older female siblings. McHale and Gamble (1989) found that although female siblings spend almost twice as

much time than male siblings in care-taking activities, male siblings of handicapped children perform more care-taking duties than male siblings of nonhandicapped children. Through home observations, Abramovitch et al. (1987) found no evidence that females are put into more active roles with their handicapped brother or sister.

Other studies show no significant differences between siblings of the handicapped and nonhandicapped as related to care-taking and household responsibilities. No convincing evidence was found that siblings of Down's Syndrome children bear domestic burden (Gath and Gumley, 1987) or that siblings of hearing impaired have greater levels of family responsibilities than siblings of the nonhandicapped (Israelite, 1986). As a group, siblings of the handicapped do not differ from others their age in frequency of contact with friends or participation in activities outside the home (Stoneman et al., 1988).

Lack of Attention

There are many factors responsible for the problems that siblings of the handicapped encounter including excessive parental attention to the handicapped child and neglect of his or her siblings (San Martino and Newman, 1974). Berggreen (1971) found that siblings of the multihandicapped are frequently subject to gross neglect. According to Klein (1977) the approach that parents take in dealing with their deaf-blind children affects family interactions. She explains that if the handicapped child is the priority in all of the family activities, the siblings suffer from lack of attention and disregard for their needs. Hannah and Midlarsky (1985) also state this idea under parent neglect, "Daily schedules, activities, and even vacations as well as

allocation of time and monetary resources take the handicapped child's needs into account before those of normal siblings" (p. 513). Often, the care that parents must give a handicapped child cut into the time and attention that they would otherwise devote to other children in the family (Crocker, 1981; Grossman, 1972). As a result, parents are emotionally and physically unavailable to their nonhandicapped children (Trevino, 1979). Correa et al. (1986) found that younger siblings develop behavior problems to gain attention. Contrary to these studies, Stoneman et al. (1987) found that maternal attention was not given to the handicapped child at the expense of the older nonhandicapped siblings.

Double Standard and Parental Fairness

McHale and Gamble (1987) found that parental fairness affects a child's well being. According to Nemon (1974) siblings feel that parents favor the handicapped child by not imposing consequences for inappropriate behavior. Two completely different sets of rules may exist within the same family, intensifying sibling rivalry (Trevino, 1979) and causing siblings to experience conflict (Crocker, 1981). Very often, it is believed that the nonhandicapped child should behave better because he or she is normal (Trevino, 1979). Contrary to these studies, Gath and Gumley (1987) found no evidence to support the conclusion that parents have separate standards for handicapped and nonhandicapped children.

Finances

Undue stress is placed on the family when expenses mount from medical expenses, prosthetic devises, and physical adaptations within the home because of the

deaf-blind child's dual sensory handicap (Klein, 1977). "Older children may rage secretly about the sometimes colossal sums of money spent on diagnosis and therapy resources that might otherwise finance family comforts and college tuition" (Featherstone, 1980, p. 147). Families with greater financial resources can afford to have their nonhandicapped children join clubs and participate in activities outside of school which buffer the demands placed on the nonhandicapped siblings (Stoneman et al., 1988) while the family with limited finances has little choice but to ask the nonhandicapped children to share the load in helping to supervise the handicapped child (Trevino, 1979). McKeever (1983) notes that parents of handicapped children must make important decisions concerning the distribution of resources which have short and long-term consequences for all family members, especially for the nonhandicapped siblings. Coddington (1972) notes that for families of a child with health problems, relocating to a new center which has a treatment facility involves financial costs that affect healthy siblings. This is sometimes the case for families of the handicapped that move in order to receive appropriate educational services for their handicapped child. Cairns, Clark, Smith, and Larsky (1979) note that due to financial stress in having a child with special needs, parents and siblings are deprived of fulfillment of basic needs as well as the luxuries of live. Vacation plans and the family's leisure activities may be altered to accommodate a child's special needs (McKeever, 1983).

Parental Attitudes

According to Graliker et al. (1962) the adjustment of normal siblings to the presence of a handicapped child is related to the parental reactions and the coping mechanisms within the family. For example, Schreiber and Feeley (1965) found that when parents handle a situation constructively and supportively, the siblings develop maturity, patience, and responsibility. The coping strategies used depend on the family's beliefs and perceptions about the handicap (Crnic et al., 1986).

Siblings' perceptions of parental attitudes have a powerful influence on the sibling (Luterman, 1987). How a nonhandicapped child deals with the presence of a handicapped brother or sister is determined by the family's expressions of attitudes which are spoken and unspoken (San Martino and Newman, 1974). Nonhandicapped children's attitudes and feelings reflect those of the parents (Caldwell and Guze, 1960; Correa et al., 1986). Grossman (1972) found that siblings accept the handicapped child when parents are open and have a positive attitude. When parents are more accepting of the handicapped child, siblings are better adjusted (McHale et al., 1984) and respond in a similar manner as parents toward the handicapped child (Seligman, 1982; Luterman, 1987). McHale et al. (1986) report that when children perceive their parents and peers reacting positively toward the handicapped child and have a good understanding of the handicap, the sibling relationship is more positive. Parents who cannot accept their child's handicap may find that their nonhandicapped children reflect their negative feelings (Glimps, 1985) and experience difficulties in coping (Correa et al., 1986). The profile of a family in which siblings have the worst prospects is the family in which parents are unable to accept the handicap (Trevino,

1979). Dyson and Edgar's (1986) study found a relationship between parental attitudes and siblings' self concept. When the parental stress is intense and the parents' perceptions of the handicapped child is negative, the nonhandicapped children perceive themselves as less happy and satisfied.

Because of the consistencies found across the literature, it appears that parents are important in shaping their children's attitudes, feelings, and behaviors towards the handicapped child.

Family Communication

It appears that communication between nonhandicapped children and their parents is very important. Open communication about the handicapped child facilitates sibling functioning (Hannah and Midlarsky, 1985; Seligman, 1983) and siblings' acceptance of the handicapped child (Grossman, 1972). Schreiber and Feeley (1965) suggest that good communication depends on the type of relationship that exists between the parents and children. If there is a good relationship, children feel comfortable to approach their parents when they feel the need. Trevino (1979) found that family secrets or rules forbidding the discussion of the handicap put nonhandicapped siblings into conflict.

Lobato et al. (1987) found that siblings could not accurately describe their handicapped brother's or sister's condition as compared to a control group that had less experience. According to Hannah and Midlarsky (1985) siblings lack this information because of the inhibited communication that exists in families of the handicapped. Murphy, Pueschel, Duffy, and Brady (1976) suggest that parents lack

confidence and emotional strength to inform siblings about the diagnosis of the handicap. "This blocks the flow of information and leaves the siblings' questions unvoiced and unanswered" (Powell and Ogle, 1985, p. 59). Because children lack information and have limited experiences, they do not have the ability to put the handicap into perspective. In some cases, children may blame themselves for their handicapped brother's or sister's condition (McHale and Gamble, 1987), believe that they will develop the same handicap (Featherstone, 1980), and endow the handicapped brother or sister with mysterious and non-human qualities (Chinitz, 1981). According to other studies, siblings avoid asking questions and voicing their concerns because they feel the pain in parents and are afraid of hurting them (Powell and Ogle, 1985; Stewart, 1978). Burton (1975) suggests that children rarely ask questions because they believe this will cause parents to reject them.

It also appears that siblings need information about the future. McCullough (1981) found that parents and nonhandicapped children do not discuss future care-taking responsibilities. McHale et al. (1986) found that worries about the handicapped child's future are associated with more negative sibling relationships. According to studies done by Grossman (1972) and Schreiber and Feeley (1965) adolescents indicate they would adjust to their situation better if they understood what the future held. This shows the importance of including all family members in family discussions and decision-making.

McKeever (1983) notes that nonhandicapped siblings often must assume a role of family informer. She stresses that siblings be informed so they are able to give explanations about the handicapped child to peers and others. According to Schreiber

and Feeley (1965) nonhandicapped adolescents need and want accurate, up-to-date information on the handicap so they know what to do to help their families and the handcapped child. To obtain this information, the lines of communication must be open.

Peer Reactions

Schreiber and Feeley (1965) found that a common problem among adolescent siblings is how to tell their friends, especially friends of the opposite sex, about their handcapped brother or sister. Parfit (1975) found that an acute problem among siblings is their reluctance to bring their friends home where there is a handicapped child. Trevino (1979) suggests that young peers may feel uncomfortable or fearful of the handicapped child and may be reluctant to visit the sibling's home. He explains that siblings may be teased, taunted, and gossiped about by others and must frequently explain things to their friends that they do not understand. He also notes the additional strain put on the nonhandicapped children when they are forced to include the handicapped child in peer group activities when they are reluctant to do so. Stoneman et al. (1988) and Graliker et al. (1962) also found that siblings do not hesitate to have others meet their handicapped brother or sister and are willing to explain the situation if asked. McHale et al. (1986) made an interesting point concerning peer reactions. They noted that siblings may cope more often with the reactions of peers towards their handicapped brother or sister because of the increased contact due to mainstreaming.

Behavior Management and Tutoring Roles

It appears that siblings of the handicapped may benefit from receiving information that would enable them to cope with various aspects of their relationship with their handicapped brother or sister. Training siblings of mentally retarded children in behavior management techniques is effective (Miller and Cantwell, 1976) and helps siblings to be better informed and better able to cope with problems (Weinrott, 1974). Lavigueur (1976) notes the benefits to siblings who serve as behavior modifiers and found the siblings improve in the specific behaviors that they treated in their handicapped brothers or sisters. Bargh and Shul (1980) and Cicirelli (1976) suggest that siblings who assume teaching roles may benefit in intellectual development. Crnic and Leconte (1986) caution that teaching siblings to take responsibility in these areas may add to care-taking burdens.

Summary

There is conflicting research on the effects on siblings who have handicapped brothers and sisters, some positive and some negative. It appears that differences exist because of the diversity among families. Every family is unique and within a family there are many factors which influence how a family reacts to, copes with, and faces challenges.

The literature reveals that siblings experience a wide range of feelings that are both positive and negative. Differences have been reported in the literature across siblings of the handicapped and the nonhandicapped as related to care-taking and household responsibilities. Both positive and negative effects of care-taking and

household responsibilities have also been found. The literature reports varying ways that siblings are affected by peer reactions. It also appears that siblings of the handicapped may benefit from behavior management and tutoring roles but may be burdened by this role.

Other areas in the literature show consistencies across studies. A significant relationship appears to exist between parental attitudes and siblings' attitudes, feelings, and behaviors. It also appears that family communication is very important and effects sibling functioning in regards to information on the handicapping condition and the future. Although less information is available on siblings and the pressure to achieve, most studies show that siblings over achieve to compensate for the handicapped child. The majority of the studies also support that siblings lack parental attention and follow separate standards as compared to the handicapped child although the latter topic is not widely discussed across the literature. There is some evidence, although limited, that finances effect the nonhandicapped siblings.

In order to identify the needs and concerns of the siblings of the deaf-blind, it is evident from the literature that information must be obtained currently and directly from the siblings. It is also apparent that there is little information about siblings of deaf-blind children and that there is a need for more information regarding the needs and concerns of this population.

PURPOSE

The purpose of this project is to identify the needs and concerns of the siblings of the deaf-blind by obtaining information directly from the siblings.

The review of literature revealed the following issues as important:

1. To identify the positive and negative effects (pleasures and hardships) in growing up with a deaf-blind brother or sister.
2. To identify feelings and attitudes towards the deaf-blind brother or sister in different situations.
3. To identify siblings' perceptions of the pressure to achieve.
4. To identify care-taking responsibilities and engagement of other activities which include the deaf-blind brother or sister.
5. To identify siblings' perceptions of their household responsibilities.
6. To identify siblings' perceptions of lack of attention from parents.
7. To identify siblings' perceptions of double standards related to conduct rules.
8. To determine if siblings perceive that they and family members do without because of finances and the deaf-blind child.
9. To identify the ease or difficulty of communicating in the family including discussion of the handicap.
10. To identify siblings' needs for information on the handicap.
11. To identify how the sibling explains the deaf-blind handicap to others and the ease of difficulty in doing so.
12. To identify future concerns of siblings.

13. To identify how the sibling is affected by peer reactions towards the handicapped child.

14. To identify siblings' leisure time and time with peers.

15. To identify siblings' needs in behavior management and tutoring roles.

Another purpose of the project is to determine the siblings' perceptions of the services of the intervener of the Validation of the Intervener Project (VIP) and how the intervention affects the sibling on some of the issues previously listed (i.e., care-taking responsibilities, attention from parents, information on deaf-blindness, etc.). Services to deaf-blind children can be improved by obtaining information on needs and concerns from siblings (i.e., ways for parents to foster positive attitudes in siblings) so family needs are better met. This information can contribute to the VIP, showing how this service helps families so this type of service can be refined and replicated.

PROCEDURES

Subjects

The respondents of this study consisted of 12 siblings of deaf-blind children from five families involved in the Utah Intervener Services Program. The sample consisted of eight males and four females whose ages ranged from 7 years to 16 years. The mean age was 9.9 years and the median age was 9.5 years. All of the siblings interviewed were older than their deaf-blind brothers and sisters.

The deaf-blind children consisted of two males and three females. The ages of the deaf-blind children at the time of the interviews ranged from 1 year 10 months to 3 years 5 months. The mean age was 2 years 5 months and the median age was 2 years 10 months. The deaf-blind children varied in their handicapping conditions, including: failure to thrive, cortical visual impairment, and profound hearing loss; cortical visual impairment and mild hearing loss; cortical visual impairment and cortical hearing impairment; severely handicapped, cortical visual impairment, and cortical hearing impairment; and profound hearing loss, retinopathy of prematurity and exotropia of the right eye. In addition to being deaf-blind, the majority of these children had other complications requiring oxygen and tube feeding, and many of the children had seizures.

The families contacted to participate in the study were those that had siblings of 7 years of age and older. Of the 7 families contacted, 2 families chose not to participate. In one case, the siblings did not want to be interviewed and in the other,

the parents explained that the siblings were not yet aware that the deaf-blind child had problems. One family consented to have 2 of the 5 siblings interviewed.

Instrumentation

Two instruments were used to obtain information from the siblings of the deaf-blind in this study. One instrument, the Siblings' Perceptions of the Intervener Interview (SPII) was developed by the researcher (see Appendix A). The second was the Taylor's Siblings' Problems Questionnaire (see Appendix B).

Siblings' Perceptions of the Intervener Interview (SPII)

The Siblings' Perceptions of the Intervener Interview (SPII) was designed by the researcher to identify the siblings' perceptions of the services of the intervener and how this intervention effects the sibling on issues such as attention and time spent with parents, care-taking and household responsibilities, family cooperation, information on deaf-blindness, communication, self-stimulation behaviors of the deaf-blind child, interference of the intervener in the home, family activities, and activities with the deaf-blind child. The SPII consists of 17 items which focus on how the sibling perceives the intervener. The first five questions are open-ended questions while the other 12 items consist of statements about the intervener with yes or no responses. These items are shown in Appendix A.

The original SPII interview form was developed by the researcher after reviewing information contained in the Validation of the Intervener Project (VIP) grant document and through discussion with professionals involved in the VIP project (see

Appendix C). The interview form was reviewed by four professionals whose expertise is deaf-blindness. Five changes were made in the interview form following the comments given by these professionals. These were adding four negative statements about the intervener to help the child know that negative feelings are permissible and adding one item on activities that the intervener may have taught the sibling. Changes were also made in the wording of some items to make them more comprehensible to young children (both the original and revised questionnaires are in the Appendix).

Taylor's Siblings' Problems Questionnaire

The Siblings' Problems Questionnaire was developed by L. S. Taylor at the University of North Carolina (see Appendix D). Permission to use the Scale is shown in Appendix E. It was designed to identify siblings' needs and concerns related to their life with a handicapped brother or sister.

In order to meet the needs of this study, the Siblings' Problems Questionnaire was modified by the researcher and the interview was then reviewed by four professionals whose expertise is in the field of deaf-blindness. Further modifications were made in the interview form for siblings of the deaf-blind population following the comments and changes recommended by these professionals. These were as follows: Move the Future Concerns category to the end of the interview because young siblings may not be dealing with these issues yet; add an item on activities that the sibling could not do because of the deaf-blind child; omit question number 4 in the Hyper-responsibility category because of the assumption made that all deaf-blind children are not smart. It was also necessary to modify Taylor's interview by

changing the wording of some items to make the items comprehensible to younger children (both the original and revised questionnaires are in the Appendix).

The result of these modifications was a 38-item interview. The items were classified into the same categories of problems previously devised: Feelings of rejection toward the sibling, perceived favoritism toward the handicapped child, positive reactions by parents and peers, feelings of burden, self-doubt, and hyper-responsibility, ability to cope with the siblings' handicapping condition, and future concerns. In addition to these categories, household and care-taking responsibilities, finances, double standards, and need for information on the handicapping condition were added to obtain necessary information (see Appendix B).

Method

The parent advisors who had been trained by the SKI*HI Institute were contacted by the Validation of the Intervener Program (VIP) Coordinator to obtain written permission from the parents in the Utah program in order to participate in the evaluation of the intervener services (see Appendix F).

Family consents to participate in the research project were obtained by the parent advisors (see Appendix G). When the VIP Coordinator received the consent forms, the researcher contacted the parent advisor by telephone to describe the study on siblings of the deaf-blind and to obtain information on the number and ages of the siblings in the family. The parent advisors were asked to briefly discuss the study on the siblings of the deaf-blind with the families and to inform the families that they would be contacted by the researcher. Parent advisors were chosen to discuss the

sibling study initially because of the trust they have established with the family. After this discussion, the researcher contacted the parent advisors to obtain information on the family's feeling about the sibling interview. The researcher then contacted the family by telephone, gave more details about the study, and sent the interview form to the parents. Another telephone call was made after the parents reviewed the interview form for consent and scheduling purposes. Because of the concerns of some families, a number of telephone calls and a brief visit were made to discuss aspects of the interview.

As mentioned previously, the interview form was sent to the parents prior to the interview. Parents requested to review the items on the Siblings' Perceptions of the Intervener Interview (SPII) and Taylor's Siblings' Problems Questionnaire before giving consent. It was stressed that parents not share any items on the interview form with the children. The parents reviewed the items, omitted questions that they did not want their children to answer, and gave their reasons. Reasons for omitting items were: Questions or statements that were not related to their situation; questions or statements that may cause unnecessary worry when the child has not yet thought about these subjects; and questions or statements that focus on sensitive areas. One family requested that the following items be omitted for two siblings: (Intervener's name) has helped me so I know what to do when _____ hits/slaps his/her head, pokes eyes, etc.; I don't let people make fun of _____ around me; I have to be perfect for my parents; Sometimes, I feel that the rest of our family goes without things because the way money is spent on _____. The same family requested that the following questions be omitted for one child in addition to those above because of the child's sensitivity:

At times I don't like the way _____ interferes with my plans; I try to do well in school to make up to my parents for _____ being deaf-blind.

The parents were informed that the information obtained from the children would not be shared with them so the children would not be influenced in their answers. The researcher explained that the children's conversations would be tape recorded and the children would be interviewed separately and privately. The families were also informed that neither family names nor child names would be used in the reporting of the results.

Child Interview

Prior to the interviews with the siblings of the deaf-blind, field testing was conducted to refine the interviewing process. Field testing helped to familiarize the interviewer with the administration of the items and helped to improve the use of prompts (i.e., additional questions) without leading the child towards a particular answer. Nine children including 5 males and 4 females were interviewed. The ages ranged from 7 to 14 years with a mean age of 10.8 years and a median age of 12 years. To provide the children with some information about deaf-blindness, a video-tape of a deaf-blind child was shown. The children were then asked to imagine that they had a deaf-blind sister or brother and an intervener who came into the home to help the deaf-blind child every day.

Interviews were then conducted with siblings of the deaf-blind brothers and sisters. The information was obtained from the siblings during one visit to the children's homes. The interview was approximately 30 minutes in duration. At the

beginning of the interview, the siblings were given a brief rationale of the study. They were told that the questions and statements read to them would concern their perceptions of the intervener and their life with their handicapped brother or sister. The children were informed that the information they gave would not be shared with their parents or other siblings in the family. They were also informed that their names would remain anonymous when reported in the results. It was also explained that the interview would be taped and if there were any questions that they were uncomfortable in answering, they were to inform the researcher and these questions would be omitted. No children in the study informed the researcher that a certain question made them feel uncomfortable.

The children were asked to answer the statements with a "yes" or "no" and expand on the reasons for their responses. When the child did not spontaneously expand on an answer, the child was prompted with additional questions. This happened frequently when interviewing the younger children. It was also explained that there were no right or wrong answers to the questions and statements. Answers were omitted in the study when the child contradicted himself/herself, gave reasons why a question or a statement did not relate to his/her situation, and if the child could not give an answer after prompting. Seven responses given for the SPII were omitted, while ten responses given for Taylor's Siblings' Problems Questionnaire were omitted.

The Siblings' Perceptions of the Intervener Interview (SPII) was administered first to allow the children to become comfortable. Taylor's Siblings' Problems Questionnaire followed which included more direct and personal questions.

RESULTS

The descriptive analysis of the Siblings' Perceptions of the Intervener Interview (SPII) was done by collecting all of the siblings' responses together for each question and statement. The descriptive analysis of Taylor's Siblings' Problems Questionnaire was also done by collecting all of the siblings' responses together for each question and statement under the categories given in the questionnaire.

Descriptive Analysis of the SPII

The SPII was administered to 11 of the 12 siblings. One family did not yet have intervener services, making it impossible to interview one sibling.

The length of time of the intervener services varied among the four families whose children were interviewed. The time ranged from one month to nine months with a mean length of intervener service of 5.2 months.

The first question asked was, "What do you usually do when the intervener is in your home?" Five of the 11 siblings reported that they are usually in school or are just arriving home from school when the intervener is in the home. During the holidays from school, the siblings reported that they watch television, play video games, and stay out of the intervener's way. Six of the 11 siblings reported that they play outside, play downstairs in their home, play video games, watch television, go out to eat with their family, run errands, go to a piano lesson, talk to the intervener, and sit and listen to the intervener when the intervener is in the home.

When asked what they liked best about the intervener coming into the home, the two youngest siblings in the study gave answers unrelated to the intervener service.

They like to walk the intervener home and enjoy it when she brings treats. Seven of the 10 siblings who answered the question, like aspects related to intervener services: The family is free to go different places and participate in activities; the deaf-blind child is given something to do; the service helps the deaf-blind child; the deaf-blind child is taught how to speak and to smile; the intervener is helpful; and the siblings learn about the deaf-blind child. One of the 10 siblings likes the intervener's personal qualities and stated: "She's nice and she really likes (deaf-blind child)."

To the question, "Would you like the intervener to spend more or less time in the home?", 6 of the 11 siblings reported that they like the amount of time that the intervener gives in the present situation. One sibling from the group likes being in school when the intervener comes because he/she does not like other people in the home. He/she stated: "It is uncomfortable with others. I like it when it is just our family." Five of the 11 siblings said they would like the intervener to spend more time in the home. Their reasons were: "She always comes when I'm at school"; "She's nice and she takes care of (deaf-blind child) which we sort of get sick of"; "I want (deaf-blind child) to be a normal boy/girl so I can play with him/her"; "She helps out a lot."

When asked, "Would you like the intervener to spend more time with you?", nine of the 10 siblings who answered the question said "no." One of the youngest children in the study said "yes" and wants the intervener to play with him/her.

To the question, "What would you like the intervener to do differently from what she is doing now?", 7 of the 11 siblings said "nothing"; "I like the way it is now"; "I think she does everything right." One of the 11 siblings reported that he/she

would like the intervener to come when he/she is at home. He/she suggested, "I'd like her to come once a week on a day when I'm at home." Other siblings suggested that the intervener assist the deaf/blind child in becoming more active and come earlier so the children can watch television without interference. One of the youngest siblings said that he/she would like the intervener to ride bikes with him/her.

Eight of the 11 siblings reported that the intervener helps them to understand the deaf-blind child's problems better. Areas of better understanding include: Playing with the deaf-blind child, changing the child's diaper, working with the deaf-blind child's muscles and hand grasp, recognizing the need for special people to help, understanding the deaf-blind child's health and eating problems, and becoming aware of the improvements made by the child. Three of the 11 siblings reported that the intervener does not help them. One sibling from this group commented, "We don't ever talk. She'll talk to my parents but not the kids." Another child from this group explained that his/her parents have helped him/her to understand the deaf-blind child's problems better than the intervener.

Five of the 11 siblings reported that the intervener helps them to communicate with the deaf-blind child. One child commented, "She sets an example for me to follow." Six of the 11 siblings reported that the intervener does not help them to communicate better with the deaf-blind child. Three siblings from this group said that their parents had taught them to communicate with the deaf-blind child.

As reported by the siblings, two of the three deaf-blind children do not have self-stimulatory behaviors. Of the nine siblings asked this question, one child said that

the intervener helps him/her to know what to do when the deaf-blind child engages in self-stimulatory behaviors.

All of the 11 siblings reported that they do not feel that the intervener is in the way. One sibling responded, "I think she's a needed part of the system."

Eight of the 11 siblings reported that they do not feel that they must stay out of the way when the intervener comes into the home. Three of the 11 siblings feel that they must stay out of the way. One sibling commented, "Whenever there is anyone special that comes, I feel that I shouldn't even be in the room. I resent it because it is our house." Another sibling reported that it was necessary for him/her to leave the room because he/she is a distraction for the deaf-blind child during certain activities.

Eight of the 10 siblings reported that they can go everywhere in their home when the intervener is present. One sibling from this group reported that although he/she can do this, there are certain rules to follow including playing quietly and keeping the volume of the television down. Two of the 10 siblings reported that they go to another room when the intervener is present.

Seven of the 11 siblings reported that their parents have more time to do other activities they want to do because of the intervener's help. The children commented that their mothers are able to do household chores, go outside of the home, and are able to spend time with the nonhandicapped siblings. Four of the 11 siblings reported that they do not notice any difference. Their parents appear to be as busy as before.

Eight of the 11 siblings reported that their parents are more relaxed and happier now after receiving intervener services. They gave the following reasons for this change: "They are happier to know that they can go different places but they still get

kind of nervous when they're not with him/her in case something bad happens"; "Before, my parents were trying to do everything and were really stressed but now with her (intervener) here they don't have to worry as much"; "My Mom can have a sleep"; "They (parents) like it. My Mom doesn't have to hurry up and go everywhere as much. Its easier for my Mom." "My Mom can read to (nonhandicapped siblings) instead of having to do things by herself"; "(Intervener) and my Mom are friends and she (mother) doesn't know the other lady that comes here very good so she's more relaxed." Three of the 11 siblings reported that their parents are the same, very busy.

Nine of the 11 siblings reported that their home is not more busy since the intervener started helping. They reported that their home has remained the same. Two of the 11 siblings reported that their home is more busy. One child whose brother/sister is medically involved commented, "Its like a hospital."

Two of the 11 siblings reported that their families get along better after receiving intervener services because their mother does not always need to play with the deaf-blind child and because the family wants to make a good impression for the intervener. Nine of the 11 siblings reported that their family gets along the same as they did before intervener services.

Eight of the 11 siblings reported that their parents are able to spend more time with them because of the intervener's help. Some of the activities that parents and siblings engage in include: playing games, going out to eat, seeing a movie, going for a car ride, going grocery shopping and to the mall, learning a song on the piano, getting a haircut, doing papers, playing baseball, and helping the sibling with his/her room. One child stated, "We can go to places that we can't usually because (deaf-

blind child) might catch something. Before half of the family went and the other half stayed at home. Now, we can do it together." Three of the 11 siblings reported that their parents do not spend more time with them. Their parents clean, help the intervener, and are very involved with the deaf-blind child when the intervener is helping.

Seven of the 10 siblings reported that they have more time to do other activities since the intervener started helping the family. Activities that the siblings engage in more are: playing baseball, basketball, and video games, playing with friends and Barbie dolls, playing outside more, completing homework assignments, and reading library books. Three of 10 siblings reported that they do not have more time to do other activities and the amount of time spent in these activities remains the same.

Two of the 11 siblings reported that they take care of the deaf-blind brother or sister less since the intervener service began. One child responded, "Usually I have to watch (deaf-blind child) when my Dad is working in the yard. With the intervener here, she can watch (deaf-blind child)." Two of the 11 siblings reported that they spend more time with their deaf-blind brother or sister. They explained: "As (deaf-blind child) gets older, he/she can play with me so that makes it more"; "The intervener tells us to spend more time with (deaf-blind child)." Seven of the 11 siblings reported that they spend the same amount of time taking care of their deaf-blind brother or sister as they did before intervener services began. One of the youngest siblings commented, "I hardly ever take care of (deaf-blind child)." Other comments included: "I usually wouldn't babysit (deaf-blind child) in the day and

that's when the intervener comes, but I do babysit him/her at night still"; "Usually the nurses do it."

One of the 11 siblings reported that he/she does less household jobs like vacuuming and taking out the garbage because his/her parents are able to do these as a result of the intervener service. Ten of the 11 siblings reported that they do not have less household jobs. Responses given were "no way" and "definitely not." Nine siblings from this group reported that they do the same amount of household jobs while one sibling explained that his/her parents want to make a good impression for the intervener so the children are expected to do better on the jobs.

Four of the 10 siblings reported that they enjoy the deaf-blind child better because of the intervener. Comments were: "Because every day (deaf-blind child) gets happier"; "He/she understands you more. Sometimes when you talk to (deaf-blind child), he/she talks back"; "(Deaf-blind child) can do stuff better because she (intervener) is helping here." One of the 10 siblings reported that he/she sees improvements in the child and enjoys him/her better but does not believe this is related to the intervener. Five of the 10 siblings reported that they enjoy their deaf-blind brother or sister the same as they did before they had the intervener.

Four of the 10 siblings reported that they like to do the special activities they learn from the intervener. These included matching puzzles, teaching songs from books that the intervener brings, teaching the child to listen and reaching for toys. Six of the 10 siblings reported that the intervener makes little difference in learning about special activities with their deaf-blind brother or sister. One sibling from this group reported that he/she learns more about special activities through the physiotherapist.

The intervener did however teach some sign language and showed how the deaf-blind child could be made to reach for toys.

Four of the 10 siblings reported that they like to help more. Comments given were: "I like to help more because I feel she's (intervener) helping so I think I should help a little more"; "To help (deaf-blind child) progress"; "I make money. I just made a little before (intervener service)." Six of the 10 siblings reported that they like to help the same now as they did before the intervener came to their home.

The analysis of the data presented in Figure 1 illustrates that siblings in this study were generally positive toward the interveners. There were two areas that were not seen positively. These were communicating better with the deaf-blind child and knowing what to do when the deaf-blind child engaged in self-stimulatory behaviors.

Descriptive Analysis of Taylor's Siblings' Problem Questionnaire

The ages of the deaf-blind children as mentioned before ranged from 1 year 10 months to 3 years 5 months with a mean age of 2 years and 10 months. The questions and staements analyzed below pertain to the siblings' lives with their deaf-blind brother or sister during this length of time.

Feelings of Rejection Toward Sibling

Eight of the 12 siblings reported that it does not bother them that other people know about their deaf-blind brother or sister. Comments made were: "I don't care because I love him/her so much"; "Most of my friends and people don't say anything about (deaf-blind child) and sometimes they think its too bad"; "I get a lot of attention"; "Its kind of fun." Three of the 12 siblings reported that they would rather

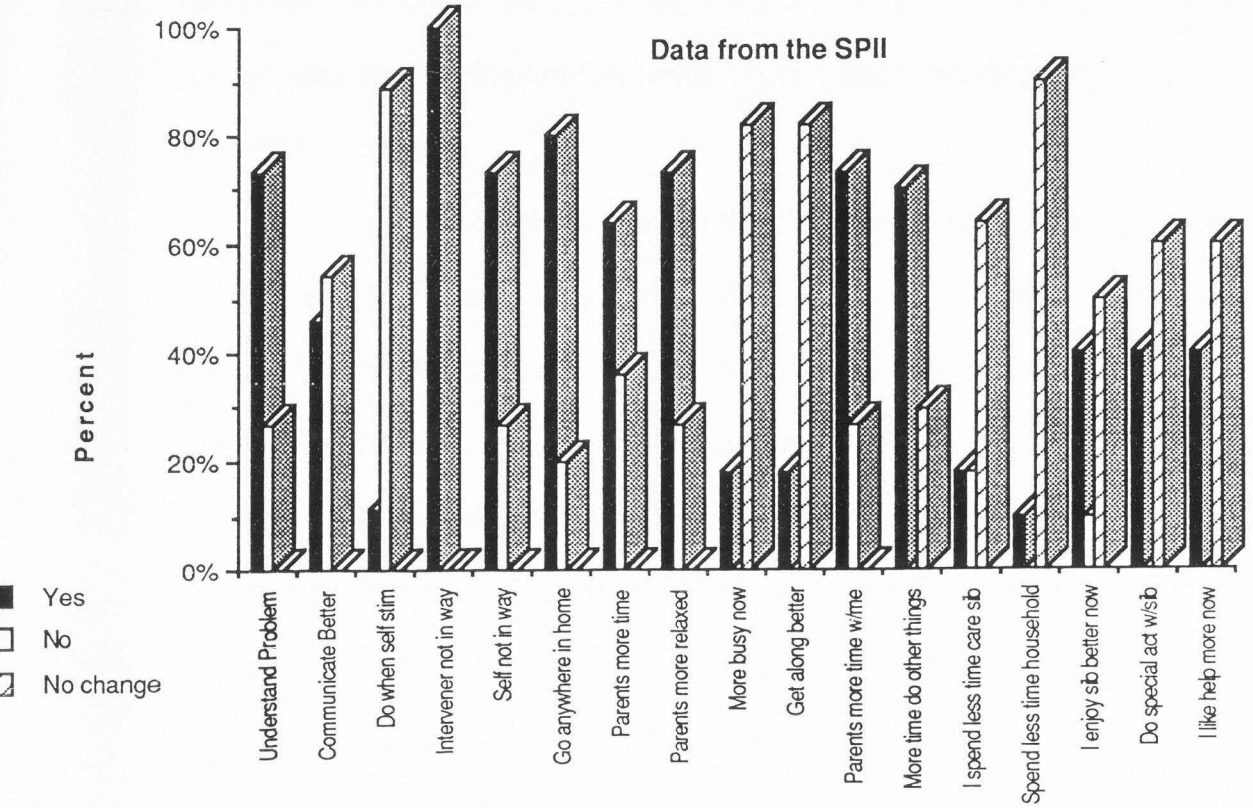

Figure 1. Analysis of the results from the Siblings Perceptions of the Intervener Interview (SPII).

that people don't know they have a deaf-blind brother or sister. Their comments included: "When people know they might tease me"; "They say rude things -- that I'm stupid because I'm in the same family as him/her." One sibling stated, "I really don't care but I kind of care." He explained this further: "When I get to know a person better then I bring him/her home. I don't want him/her to feel uncomfortable."

Seven of the 12 siblings reported that they don't wish their deaf-blind brother or sister would go away. They reported that they like their brother or sister a great deal and like him/her at home. One child in this group commented, "I wish the people (professionals and paraprofessionals) around (deaf-blind child) would just leave. I don't mind (deaf-blind child), but I do mind the other people." Three of the 12 siblings said they would like the deaf-blind child to go away. Reasons for this included: the child's behavior at times, babysitting the other siblings, and the family not being able to take part in activities. Two of the 12 siblings reported that sometimes they would like the deaf-blind child to go away.

All of the 12 siblings reported that they like having their deaf-blind brother or sister in their family. One child stated, "He/she is special to me." The siblings like playing with the child, watching him/her grow up, seeing improvements in the child, being able to do more with the child as he/she grows older, pushing him/her in the wheelchair or electric cart, taking care of him/her at church, receiving rewards when caring for the child, going to lunches and banquets for families of handicapped children, learning sign language, and receiving attention from people outside of the home. They also like the child's "neat" personality, curly hair, cute smile, laugh, and

the funny noises he/she makes because the noises make everyone laugh. Main disadvantages included: people staring at the deaf-blind child, less room in the house because of the special equipment, more noisy because of the special equipment, long car rides to the hospital, and not being able to take part in family activities.

All of the 10 siblings reported that they would not let people make fun of their deaf-blind brother or sister. Comments included: "I'd bop them"; "I'd punch them out"; "I'd knock their block off"; "I'd say they were unfair and they should feel sorry for him/her and I'd walk away"; "I'd tell my Mom." Siblings said this would cause them to feel sad, hurt, and angry. One sibling commented, "I know that people will tease (deaf-blind child). I wish I was there for him/her."

Perceived Favoritism Toward the Handicapped Child

Seven of the 12 siblings reported that their parents spend the same amount of time with them as they do with their handicapped brother or sister while four of the 12 siblings reported that their parents spend more time with the deaf-blind child. The siblings explained that the deaf-blind child needs more attention because the child is very sick, has eating problems, and needs to be played and worked with more by the parents. One sibling commented that his/her father gives equal time between the handicapped child and the siblings, but his/her mother gives more time to the handicapped child.

Nine of the 12 siblings do not think that their deaf-blind brother or sister is lucky because he/she receives special treatment. One sibling commented, "He/she may get special treatment, but its because of his/her handicap." Other siblings

explained that the child is not lucky because he/she is sick, cannot talk or walk, has difficulty breathing, and must use special equipment. Three of the 12 siblings reported that the deaf-blind child is lucky. They stated: "(Deaf-blind child) gets tons of attention. I wouldn't trade but I guess you have to have one of those things (handicap) to get attention"; "(Deaf-blind child) gets fed when he/she wants to get fed. (Deaf-blind child) gets everything." One child explained that both the deaf-blind child and he/she received special treatment.

Nine of the 12 siblings reported that their parents love them and the deaf-blind child equally. Three of the 12 siblings believe their parents love the deaf-blind child more. They commented: "Because (deaf-blind child) is handicapped and they have to take care of him/her"; "Because they're (parents) more around (deaf-blind child)." One sibling commented that he/she believes every child in a family goes through times when they feel that a parent loves another child more than another.

Positive Reactions by Peers

Four of the 11 siblings reported that their friends are comfortable about their brother or sister being deaf-blind. They said that their friends don't care, other friends know what it is like, others want the deaf-blind child to be well, and think the deaf-blind child is cute and laugh with him/her not at him/her. Seven of the 11 siblings reported that their friends feel uncomfortable about their brother or sister being deaf-blind. Some of the comments were: "Its understandable"; "They don't like being around him/her. They ask, 'Can I touch him/her?' 'Can I go close to him/her?'"; "They're uncomfortable when someone talks to them about it"; "Some of them don't

come into the (same) room"; "When they first see (deaf-blind child) the first time, they were scared, but they're not so scared of him/her now"; "They stare."

Three of the 12 siblings reported that they don't mind talking about their brother/sister being deaf-blind. They commented: "I don't mind it but I don't strike it up in a conversation"; "You don't bring it up unless someone else does. If someone speaks about deaf-blindness then you can talk as an authority on the matter. I really like that"; "I tell them what I do, I sign. I show them how to sign." Nine of the 12 siblings reported that there are times when they do not like to talk about this subject. The children commented: "It makes me feel uncomfortable"; "Because it makes me feel sad"; "I don't like to talk about (deaf-blind child) being handicapped. I don't like to talk about the bad things. I like to think about the good things--that (deaf-blind child) is fun"; "I don't like to talk about it in front of my friends."

Feelings of Burden

Three of the 12 siblings reported that they do not mind when the deaf-blind child interferes with the family's plans. Nine of the 12 siblings reported that they do not like the way their deaf-blind brother or sister interferes. One sibling commented, "We haven't really had any family plans since (deaf-blind child) was born." Three of these siblings focused on the problem of a parent staying home with the deaf-blind child rather than joining the other family members in activities. Other examples given were changing or cancelling plans to go to a movie, the park, a relative's home, the circus, and a camp-out.

Six of the 10 siblings reported that the deaf-blind child does not interfere with their plans. Four of the 10 siblings reported that they don't like the way their deaf-blind brother or sister interferes with their plans. These included: not being able to go to a friend's house, or have friends come to their house, having to be involved with the deaf-blind child, and cancelling activities because of babysitting other siblings.

Eight of the 12 siblings like to take their deaf-blind brother or sister places with them. They enjoy taking him/her on short walks and car rides, to the Santa Claus castle at Christmas time, to church, and the hospital where there are ramps, to the park, and to their grandparents' home. Four of the 12 siblings reported that they prefer to take the child to certain places and not to others. Their reasons were: "You don't take him/her to my school. Some students have no feelings. The majority wouldn't say anything and then there's others that come right out and say it"; "I don't want to take him/her to school because people would make fun of him/her."

Feelings of Self-Doubt

All of the 11 siblings stated that life in their family is different from life in other families. The siblings gave the following comments: "Most of the people I know don't spend as much time with their baby brothers or sisters"; "We can't go places"; "We're stuck at home"; "Its different because (deaf-blind child) can't walk"; "I think they're (other families) happy and we're sad"; "Its quieter in some of my friends' houses"; "There's lots of wires (special equipment) all over"; "Some (homes) are really noisy and ours is quiet"; "(Deaf-blind child) has a special feeding thing"; "We have a nurse here and doctors that come almost every day." One sibling

explained that because of different helpers who come into the home he/she cannot be himself/herself. He/she must dress nice, have his/her hair combed, and always act nice. He/she cannot go in certain rooms or do certain activities when these people are in the home.

Six of the 10 siblings reported that they do not have to be perfect for their parents. Two of the 10 siblings reported that they must be perfect in following correct procedures in caring for the deaf-blind child. Two of the 10 siblings reported that they have to be perfect sometimes in helping around the house and being quiet.

Ten of the 12 siblings reported that their parents do not think they must be extra smart. One child commented, "They expect us to know what to do in an emergency but that's all." Two of the 12 siblings believe that their parents think they must be extra smart. One sibling feels pressure to obtain good grades at school while another child feels he must know how to help the deaf-blind child.

Five of the 12 siblings reported that they don't wonder how smart they are. Siblings commented that they feel they are smart because they know how to do things with their deaf-blind brother or sister that others do not know. One such child responded, "I'm pretty smart. If you ask anybody if they can suction somebody, they don't know how. I do." Seven of the 12 siblings reported that they wonder how smart they are. Their reasons were: "You wonder if you're as good at something as other people"; "I don't get as high a grade as I think"; "Because I don't know how smart I am."

Hyper-Responsibility

One of the 12 siblings said his/her parents do not think he/she has to be more helpful. Eight of the 12 siblings reported that their parents think they have to be more helpful because of the deaf-blind child in the family, while two of the 12 siblings reported that their parents think they have to be more helpful sometimes. The siblings reported that they babysit the deaf-blind child and other siblings in the family, help young siblings with their chores, bathe the deaf-blind child, feed him/her, change his/her diaper, dress him/her, do tracheostomy care, watch and play with the deaf-blind child, assist the child when he/she wakes up at night, cook, and do household and outside jobs. One of the 12 siblings reported that his/her father expects him/her to be more helpful but his/her mother does not mention this.

Eight of the 11 siblings reported that they try to do well in school but not because of the deaf-blind child. Three of the 11 siblings reported that they feel they obtain good grades to make up to their parents for their deaf-blind brother or sister. Their reasons were: "(Deaf-blind child) is kind of a money drain here so I feel that I have to get good grades to be a rich (person) and pay my parents back"; "To make my Mom happy."

Six of the 12 siblings reported that their friends come to their home to play with the deaf-blind child. Their friends play pat-a-cake, throw a ball, hold the child's hand, and talk to him/her. Six of the 12 siblings reported that their friends do not come to their home to play with the deaf-blind child. The siblings responded: "No, they (friends) play with me"; "Most don't want to go by him/her. They think they

might get sick"; "When I have friends over they can't come in the house because they might get (deaf-blind child) sick because they might carry a disease."

Five of the 12 siblings reported that they do not have trouble explaining to their friends about their deaf-blind brother or sister. One sibling from this group commented, "Every one of my friends have asked questions about (deaf-blind child)." The siblings explain the handicap in the following ways: a seeing, hearing, and lung problem; he/she needs oxygen because his/her lungs were too small and he/she couldn't breath; he/she was born with something wrong with him/her and he/she has hydrocephalus; prematurity; overdose of medicine; he/she is blind; a shot caused brain damage; the handicap was caused by toxic chemicals in the kitty litter. Five of the 12 siblings reported that they have difficulty explaining the handicap to their friends. One sibling from this group explained, "I don't really know everything about (deaf-blind child)." Siblings gave examples of questions that are usually asked of them: Why isn't your brother or sister walking?; What happened to your brother or sister?; How can your brother or sister talk?; What's wrong with your brother or sister?; What's that? in regards to the special equipment. Two of the 12 siblings reported that they sometimes have trouble explaining the handicap to their friends.

Positive Reactions by Parents

Nine of the 11 siblings reported that their parents enjoy taking care of the deaf-blind child. They said they can sense this from the way the parents talk to the child, the time their parents spend in playing with the child, and because their parents look happy and smile at the deaf-blind child. Two of the 11 siblings said that their parents

enjoy it and sometimes they do not. One of these siblings explained, "They like it when (deaf-blind child) is nice but they hate it when they have to get up in the middle of the night."

Two of the 10 siblings reported that their parents do not feel badly because they can't do more to help the deaf-blind child. One of these siblings stated, "We can do lots with (deaf-blind child)." Eight of the 10 siblings reported that their parents feel badly. Their comments included: "They (parents) want (deaf-blind child) to hear"; "They (parents) wish (deaf-blind child) would get better some day so they could do more with the family"; "My Mom gets sad and she starts crying"; "Sometimes, my Mom thinks a lot about (deaf-blind child) and she starts to cry."

Four of the 11 siblings reported that their parents are not bothered when the deaf-blind child cannot do things that other children can. Their comments included: "They never say it bothers them"; "They don't pay attention to it (other children's skills)." Six of the 11 siblings reported that their parents are bothered. One sibling from this group explained that his/her parents are bothered when they observe a younger sibling mastering a skill that the deaf-blind child has not yet attained. Another sibling from this group stated, "They never say a whole lot, but I think it bothers them." One of the 11 siblings commented, "Not yet, but it probably will."

Eleven of the 12 siblings reported that their mother does not think that the deaf-blind child's problems are all her fault. The siblings explained that their mothers think it is the doctor's or nurses' fault. One sibling reported his mother feels that it is her fault.

Ability to Cope with the Sibling's Handicapping Condition

Nine of the 12 siblings reported that they go to their parents for help. Their parents help them in the following areas: To understand that the deaf-blind child needs special attention and treatment because he/she is fragile; how to use special equipment; how to communicate with the deaf-blind child; what to do when the child cries; and how to feed the child. Two of the 12 siblings reported that they go to their friends for help. One of the 12 siblings commented, "You don't ask your parents. You don't come out and say it. You go in an around about way and ask (professionals)."

Nine of the 12 siblings reported that they approach the people available to them to discuss their worries and problems. The siblings approach mothers most often, then fathers, followed by friends. One child approaches his/her mother and the intervener while another sibling approaches his/her mother, father, grandmother, and grandfather. The worries and concerns expressed included: "If (deaf-blind child) will learn to walk"; "I worry that (deaf-blind child) might die, but I don't think he/she will"; "I worry about when (deaf-blind child) grows up and what he/she will do to get a job"; "Sometimes I worry that (deaf-blind child) might never hear and never go to school." One of the 12 siblings said that sometimes he/she wishes he/she could talk to someone about his/her problems, but does talk to his/her friends. He/she stated, "It really gets bottled up sometimes and you want to tell the whole world. Everyone things they're special and you're discouraged from saying anything at all." One of the 12 siblings expressed the need to talk to someone. He/she stated, "I worry, but I

don't talk to anyone about it." One of the 12 siblings commented, "I never do have problems."

Six of the 12 siblings reported that they know how to help the deaf-blind child. The siblings know the following: how to feed and play with the deaf-blind child; how to hold and be careful with the child; how to give medicine; do tracheostomy care; put in aerosols; how to clean the tubes and keep them on the child; how to make the child laugh; and what to do when the child is crying. Four of the 12 siblings reported that they do not know enough about helping the deaf-blind child. One sibling responded, "I want to know what its like to be deaf so I can tell what he/she's going through." Other siblings expressed the need to know more about the use of special equipment and ways to help the child see objects. Two of the 12 siblings reported that they know a "little bit." One such sibling explained, "I know how to talk to (deaf-blind child) to see if he/she will talk back."

Six of the 11 siblings reported that people feel comfortable to talk about the deaf-blind child to them. Most of the siblings commented that people ask many questions. Four of the 11 siblings reported that people feel too uncomfortable to talk about the deaf-blind child to them. They responded" "Most of them stand and watch what he/she is doing"; "Its a sensitive subject and no one really wants to talk about it all. My family talks about it because it's our kid but when we start to talk about (deaf-blind child), people quiet down and scoot away," One of the 11 siblings explained that this depends on the person. Some are uncomfortable while others are not.

Household and Care-taking Responsibilities

Eight of the 12 siblings reported that they do not have extra household jobs compared to friends their age. Two of the 12 siblings reported that they have extra household jobs but these are not related to the deaf-blind child. They explained: "I've always had extra household jobs compared to friends my age. I started to do (household jobs) when I was four"; "I have a lot of chores because we have a lot of people in our family." Two of the 12 siblings reported that they have extra household jobs compared to friends their age because of the deaf-blind child. One of these siblings commented, "I really do a lot to help my parents because they have to spend a lot of their time with (deaf-blind child)."

Two of the 11 siblings reported that they take care of the deaf-blind child the same amount as their friends take care of their brothers and sisters. Three of the 11 siblings reported that the adults take care of the deaf-blind child. Six of the 11 siblings reported that they take care of the deaf-blind child more than their friends take care of their brothers and sisters. Comments given were: "They don't teach their brother or sister how to crawl every day. I can teach him/her a lot"; "All the kids do"; "I play with him/her and give him/her a lot of attention."

Eight of the 12 siblings reported that they are able to do activities they like to do rather than take care of their deaf-blind brother or sister. The siblings take part in swimming and baseball, play, and go outside of the home. Four of the 12 siblings reported that they are not able to play, go to a friend's house, or go to the mall because they must take care of the deaf-blind child. Their comments were:

"Sometimes, I want to go out and ride my bike, but I can't because I have to watch (deaf-blind child). I understand though"; "Yes, but I don't care."

Finances

Three of the 10 siblings reported that their family does not go without things because of the way money is spent on the deaf-blind child. Their comments were: "(Deaf-blind child) has lots of money"; "I have lots of stuff that I want and (deaf-blind child) has what he/she needs." Seven of the 10 siblings reported that their families go without things. The siblings reported that money goes towards special equipment, surgery, diapers, syringes, the electric bill in running the equipment, and long distance phone calls. The siblings in this group said they go without trips, going to "fun places", clothes, toys, sports equipment, and Christmas presents.

Double Standards

Ten of the 12 siblings reported that they feel their parents are fair when rules are involved. Comments given included: "(Deaf-blind child) can't do much so he/she doesn't have to follow any rules but I do because I can do lots of stuff"; "He/she gets away with almost anything but he/she is a baby and he/she doesn't understand"; "What two-year old ever did follow a rule?"; "(Deaf-blind child) is young"; "When (deaf-blind child) gets older like me, he/she will do the same things"; "(Deaf-blind child) has lots of rules, not hold his/her breath or pop off the equipment. That's way more than I have to do." Two of the 12 siblings reported that their parents are not fair. One commented, "Sometimes (deaf-blind child) makes a mess and I have to clean it up."

Need for Information on the Handicapping Condition

Three older siblings reported that they understand the deaf-blind child's problems fairly well and do not need more information. Nine of the 12 siblings reported that they would like to know more about the deaf-blind child's problems because it would help them understand. These included: terminology and meanings; what caused the handicap; how early the deaf-blind child was born; how the child functions; how to suction the child; how to take care of the child; what the child likes and wants; and what will happen to the child as he/she grows older.

Future Concerns

Eight of the 11 siblings reported that their deaf-blind brother or sister will not be more trouble when he/she grows older. They explained that the child will know sign language and be able to understand more as he/she grows older, will be able to do more because he/she will progress, will be able to sit in a wheelchair, and will cry less. Two of the 11 siblings from this group commented that the deaf-blind child's health has improved and they expect this to continue. Three of the 11 siblings reported that they believe their deaf-blind brother or sister will be more trouble as he/she grows older because the child may not be toilet trained and will be difficult to lift and dress.

Four of the 12 siblings thought that their deaf-blind brother or sister will not always live at home. Comments given included: "Sometimes, (deaf-blind child) will live at the hospital because he/she will probably still be that way"; "He/she will go to college, get married, and have kids"; "He/she will live on campus at a school or

here." Two siblings from this group believed that the deaf-blind child will be able to leave home because his/her health will improve. Six of the 12 siblings reported that the deaf-blind child will always live at home. The siblings explained: "He/she can't do very much that other people can"; "He/she could get murdered and he couldn't hear if someone was breaking in"; "He/she wouldn't understand the world enough to go out"; "He/she can't live on his/her own"; "Because my Mom takes care of him/her." One of the 12 siblings thought that the deaf-blind child will stay at home to be cared for or enter a rest home. Another sibling believed that if the deaf-blind child is much older, he/she will go to "another place" but if the child is younger (i.e., 20 years old), he/she will go to a school and come home.

Eight of the 12 siblings believed that their deaf-blind brother or sister will not always be deaf-blind. The siblings responded: "Sometimes, I think he/she will overcome his/her handicap. He/she will start to hear"; "I think (deaf-blind child) will get better"; "The people who work with him/her will help him/her hear and see"; "I think he/she is deaf or blind but its never been proven"; "I don't think he/she is blind": "(Deaf-blind child) isn't blind and he/she's a little bit deaf. I think he/she will get better"; "I know he/she's not deaf because when you talk to him/her, he/she talks back and he/she can see black and white so I don't think he/she will be blind all his/her life." Three of the 12 siblings believed that their deaf-blind brother or sister will always be deaf-blind. One sibling stated, "I hope not."

Ten of the 12 siblings reported that their deaf-blind brother or sister will have a job when he/she is older. Three siblings from this group reported that the child will not be able to obtain a job until he/she is much older. Jobs the siblings think their

brother or sister will have are playing football or basketball, typing, helping children, working as a banker, school teacher, and nurse. Two of the 12 siblings believed that their deaf-blind brother or sister will not be able to obtain a job.

As can be seen in Figure 2, in all but 12 of the 38 items in the Taylor's Siblings' Questionnaire, the siblings felt positive toward their deaf-blind brother or sister. The only item that appeared to be difficult for most siblings included: Life in their family is different from others, parents are bothered because they can't do more to help the deaf-blind child, talking about the handicap to others, and the deaf-blind child's interference in family plans.

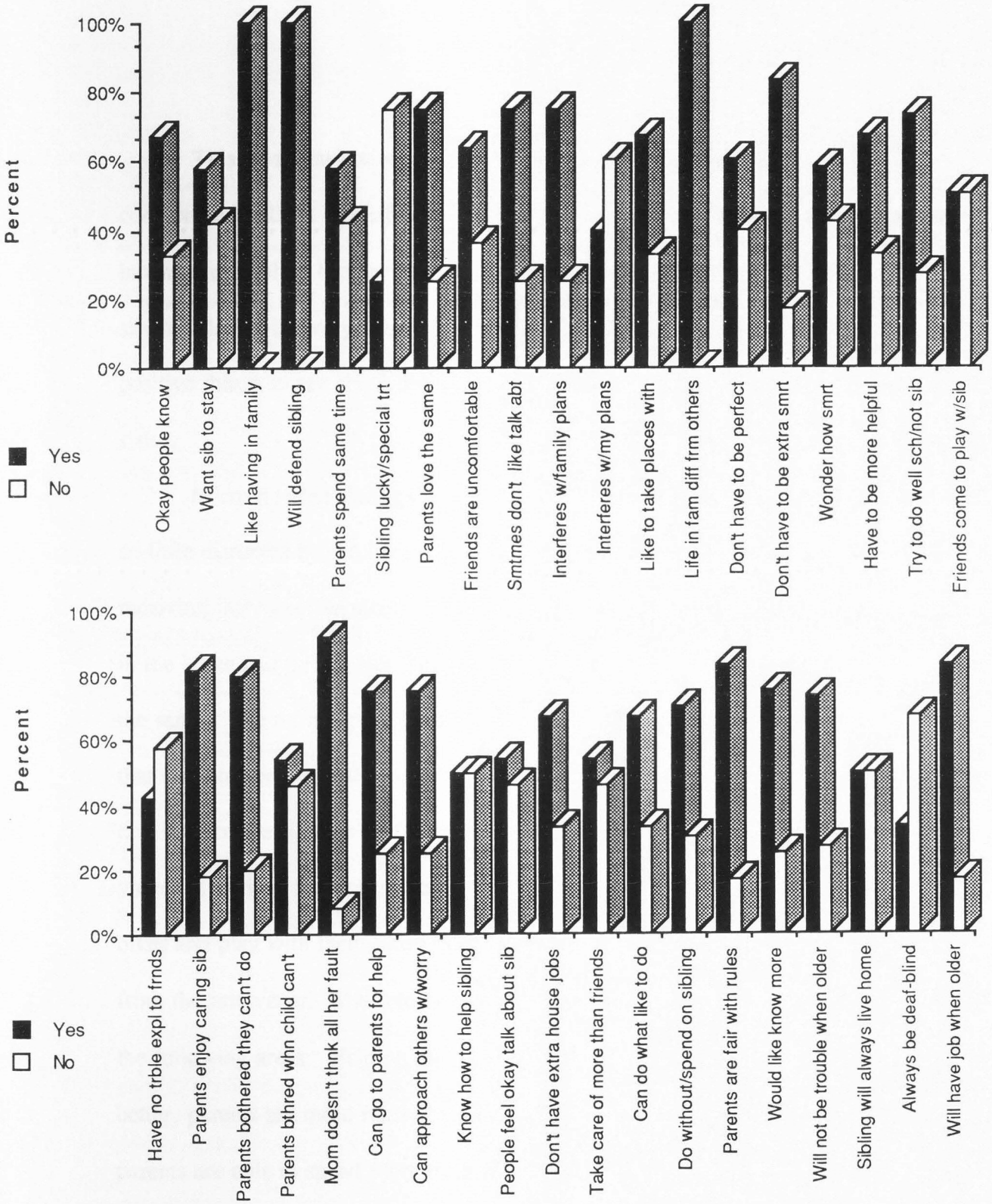

Figure 2. Analysis of the results from the Taylor's Siblings' Problem Questionnaire.

DISCUSSION

This study has attempted to address the issues surrounding the needs and concerns of siblings of deaf-blind children. Although it appears that the effects of having a deaf-blind brother or sister vary from individual to individual, with some siblings describing very negative or very positive aspects, the siblings as a whole have positive things to say about the intervener and their life with their deaf-blind brother or sister.

In considering siblings' descriptions of intervener service, family life appears to be little disrupted by the intervener. These factors have remained the same as before receiving intervener service: The home is not more busy, siblings can go everywhere in the home and do not feel they must stay out of the way, and the family gets along the same. The most significant factor related to intervener service is all siblings find that the intervener and the deaf-blind child are not in the way. It is interesting to note that 90% of the siblings prefer the intervener not spend time with them but the youngest siblings in the study continue to say they would like the intervener to ride bikes and play with them, they like to walk the intervener home, and receive treats from the intervener. The role of the intervener appears to be an important feature in the following areas: Helping the siblings to understand the deaf-blind child's problems better, parents are more relaxed and happier after receiving intervener services, and parents are able to spend more time with the nonhandicapped siblings. The role of the intervener does not appear to be effective in relieving siblings of their household duties (because parents are able to do these jobs) and care-taking responsibilities of the deaf-

blind child. The majority of the siblings spend the same amount of time in these activities.

The analysis of siblings' descriptions of their life with their deaf-blind brother or sister using the categories of the interview form provide information on positive and negative aspects that siblings experience. On the positive side, siblings perceive their parents as fair and do not perceive a double standard. Siblings do not have feelings of rejection towards the deaf-blind child, nor do they perceive favoritism towards the deaf-blind child. It is important to note that all siblings like having the deaf-blind child in the family and do not allow people to tease him/her. It is interesting that the siblings are positive about the future for the deaf-blind child. This information might be misleading because of the young child's ability to project into the future. It is also interesting to note that most siblings question that the deaf-blind child is deaf, blind or has both handicapping conditions. This may be due to the cortical visual and hearing impairments or the varying degrees of the handicap (i.e., partially sighted, mild to profound hearing loss). The term deaf-blind may also be misleading for children, implying that the child is completely deaf and completely blind.

On the negative side, the siblings have a need for more information about the handicapping condition. The importance of understanding the handicapped child's condition has been noted previously (see Review of Literature, p. 21). Siblings also perceive negative reactions by peers and feel that financially their family goes without things because of the deaf-blind child. The latter is supported by prior findings (see Review of Literature, p. 18).

Implications of Research

One implication of the results is to modify the Taylor's Siblings' Problems Questionnaire so it can be used more conveniently by professionals who work with families of the handicapped. By using a shorter format, professionals can determine siblings' needs and concerns more quickly and easily. Intervention for siblings can then be based on the needs and concerns expressed by the siblings. Related to this implication is determining the best way to meet siblings' needs and concerns. These may range from individualized intervention in the home to workshops for sibling groups. It is important that the intervention be done in such a way so it does not become burdensome to the siblings.

Another implication of this research is determining the best ways that the intervener can be used. It appears that the intervener could assist siblings in communicating with the deaf-blind child and show siblings what to do when the deaf-blind child engages in self-stimulatory behaviors. The intervener could also assist by caring for the deaf-blind child, enabling the family to take part in family activities.

Limitations

The limitations of this study were as follows:

1. This study relied on voluntary participation in obtaining parent consent and sibling participation. It is possible that individuals who had more positive attitudes consented and participated in the study.
2. The sample was small and from only one state restricting generalizations to other siblings of deaf-blind children.

3. The Siblings' Perceptions of the Intervener Interview (SPII) and Taylor's Siblings' Problems Questionnaire were designed to elicit and explore information but lack reliability and validity information.
4. It is possible that conducting only one interview gave more socially acceptable responses rather than honest responses. The siblings may have responded positively to please the interviewer.
5. The siblings' understanding of the questions and statements and the author's interpretation of the siblings' responses effect the results.

Recommendations for Future Research

Future studies on the effects that deaf-blind children have on their brothers and sisters are needed. The following is a list of some possibilities:

1. A study which utilizes larger numbers of siblings and a comparison group matched for age would provide even more information about the needs and concerns of the siblings of deaf-blind children.
2. Examining the changing needs and concerns at another time in the sibling's life would be valuable because of the changes that occur in families as the deaf-blind child and siblings mature.
3. A number of interviews conducted within a short time frame with the same sibling may be necessary to obtain more honest responses.
4. A study which addresses the effect of the deaf-blind child versus the effect of the deaf-blind multiply handicapped child on brothers and sisters.

5. Research is needed to address the best ways to involve siblings in the intervention process without causing excessive burden. Professionals and parents can benefit from gathering information on siblings' needs and concerns. This information can be used to support siblings and prevent difficulties that siblings may experience.

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APPENDICES

Appendix A

Siblings' Perceptions of the Intervener Interview (SPII)

SIBLINGS PERCEPTIONS OF THE INTERVENER INTERVIEW (SPII)

I have some questions about the intervener who comes into your home. I will read the question and then I would like you to answer it the best you can. There are no right answers--I just want to know what you think about the intervener.

Questions

1. What do you usually do when (intervener's name) is in your home?
2. What do you like best about (intervener's name) coming into your home?
3. Would you like (intervener's name) to spend more or less time in your home?
4. Would you like (intervener's name) to spend more time with you? If yes, what would you like to do with (intervener's name)?
5. What would you like (intervener's name) to do differently from what she is doing now?

I have some statements about the intervener who comes into your home. I will read the statement and then I would like you to tell me "yes" or "no". There are no right answers--I just want to know what you think about the statements.

Statements

1. (Intervener's name) has helped me to understand _____'s problems better. (Expand for more information.)
2. (Intervener's name) has helped me to communicate better with _____. (Expand for more information.)
3. (Intervener's name) has helped me so I know what to do when _____ hits/slaps his/her head, pokes eyes, etc. (Expand for more information.)

4. I feel like the (intervener's name) and _____ are in the way when she comes to help us. (Expand for more information.)

5. I feel like I have to stay out of the way when (intervener's name) comes to help us. (Expand for more information.)

6. I can't go everywhere in my home when (intervener's name) comes to help us. (Expand for more information.)

7. My parents have more time to do activities they want to do now that we have (intervener's name) helping us. (Expand for more information.)

8. My parents seem more relaxed and happier now that we have (intervener's name) helping us. (Expand for more information.)

9. It seems like our home is more busy since the intervener started helping us. (Expand for more information.)

10. My family gets along better now that we have (intervener's name) helping us. (Expand for more information.)

11. My parents are able to spend more time with me when the intervener is helping us. (Expand for more information.)

12. I have more time to do other activities now that we have (intervener's name) helping us. (Expand for more information.)

13. I spend less time taking care of _____ now that we have (intervener's name) helping us. (Expand for more information.)

14. I spend less time doing household jobs because my parents are able to do these now that (intervener's name) is helping us. (Expand for more information.)

15. I enjoy _____ better now that we have (intervener's name) helping us. (Expand for more information.)

16. I like to do the special activities I've learned from (intervener's name) with _____. (Expand for more information.)

17. I like to help more now that we have (intervener's name) helping us. (Expand for more information.)

Appendix B

Taylor's Siblings Problems Questionnaire (Revised)

ITEMS FROM TAYLOR SIBLINGS PROBLEMS QUESTIONNAIRE

I have some statements about your life with (name of deaf-blind child). I will read the statement and then I would like you to tell me "yes" or "no". There are no right answers--I just want to know what you think about the statements.

Feelings of Rejection Toward Sibling

1. I'd rather people didn't know I have a deaf-blind brother/sister. (Expand for more information.)
2. At times I wish _____ would go away. (Expand for more information.)
3. I like having _____ in our family. (Expand for more information.)
4. I don't let people make fun of _____ around me. (Expand for more information.)

Perceived Favoritism Toward Handicapped Child

1. My parents have as much time for me as they do for _____. (Expand for more information.)
2. Sometimes I think of _____ is lucky because s/he gets special treatment. (Expand for more information.)
3. Sometimes I think my parents love _____ more than me. (Expand for more information.)

Positive Reactions by Peers

1. My friends feel funny or uncomfortable about _____ being deaf-blind. (Expand for more information.)
2. There are times when I don't like to talk about _____'s being deaf-blind. (Expand for more information.)

Feelings of Burden

1. Sometimes I don't like the way _____ interferes with our family's plans. (Expand for more information.)

2. At times I don't like the way _____ interferes with my plans. (Expand for more information.)

3. I like to take _____ places with me. (Expand for more information.)

Feelings of Self-Doubt

1. Life in my family is quite a bit different from life in other families because of _____. (Expand for more information.)

2. I have to be perfect for my parents. (Expand for more information.)

3. My parents think I have to be extra smart because of _____. (Expand for more information.)

4. This sounds silly, but sometimes I wonder how smart I am myself. (Expand for more information.)

Hyper Responsibility

1. My parents think I have to be more helpful because _____ is in our family. (Expand for more information.)

2. I try to do well in school to make up to my parents for _____ being deaf-blind. (Expand for more information.)

3. My friends like to come to my house sometimes to play with _____. (Expand for more information.)

4. I have trouble explaining to my friends about _____. (Expand for more information.)

Positive Reactions by Parents

1. My mother and father usually enjoy taking care of _____. (Expand for more information.)

2. My parents feel badly because they can't do more to help _____. (Expand for more information.)

3. It bothers my parents when _____ can't do things that other children can. (Expand for more information.)
4. Sometimes I think my mother might feel that _____'s problems are all her fault. (Expand for more information.)

Ability to Cope with the Sibling's Handicapping Condition

1. I don't usually have many problems with _____ but if I do, my parents can usually help me. (Expand for more information.)

2. I wish I could talk to someone about my problems and worries about _____. (Expand for more information.)

3. I know a lot about how to help _____. (Expand for more information.)

4. People feel too uncomfortable to talk about it to me. (Expand for more information.)

Household and Caretaking Responsibilities

1. Because of _____ I have extra household jobs compared to friends my age. (Expand for more information.)

2. I take care of _____ more than my friends take care of their brothers and sisters. (Expand for more information.)

3. I'm not able to do some activities that I like to do because I take care of _____ a lot of the time. (Expand for more information.)

Finances

1. Sometimes I feel that the rest of our family goes without things because the way money is spent on _____. (Expand for more information.)

Double Standards

1. Sometimes I don't think my parents are fair because I have to follow certain rules and _____ doesn't. (Expand for more information.)

Need for Information on the Handicapping Condition

1. I wish I knew more about _____'s problems because it would help me to understand. (Expand for more information.)

Future Concerns

1. I think _____ will be more trouble when s/he gets older. (Expand for more information.)

2. I think _____ will always live at home. (Expand for more information.)

3. I think _____ will always be deaf-blind. (Expand for more information.)

4. I think _____ will be able to have a job when s/he gets older. (Expand for more information.)

Appendix C

Siblings' Perceptions of the Intervener Interview (SPII)
(Original)

Siblings' Perceptions of the Intervener Interview (SPII)

QUESTIONS

1. What do you usually do when the intervener (name) is in your home?

2. What do you like best about intervener (name) coming into your home?

3. Would you like intervener (name) to spend more/less/the same amount of time in your home?

4. Would you like intervener (name) to spend more time with you? If yes, what would you like to do with intervener (name)?

5. What would you like intervener (name) to do differently from what she is doing now?

STATEMENTS

1. The intervener (name) has helped me to understand _____'s problems better. (Expand for more information.)

2. The intervener (name) has helped me to communicate better with _____. (Expand for more information.)

3. The intervener (name) has helped me so I know what to do when _____ hits/slaps his/her head, pokes eyes, etc. (Expand for more information.)

4. My parents have more time to do activities they want to do now that we have an intervener (name). (Expand for more information.)

5. My parents seem more relaxed and happier now that we have an intervener (name). (Expand for more information.)

6. My family gets along better now that we have an intervener (name). (Expand for more information.)

7. My parents are able to spend more time with me when the intervener (name) is in our home. (Expand for more information.)

8. I have more time to do other activities and spend less time taking care of _____ now that we have the intervener (name) coming to our home. (Expand for more information.)

9. I spend less time doing household jobs because my parents are able to do these now that the intervener (name) visits our home. (Expand for more information.)

10. I enjoy _____ better now that we have an intervener (name). (Expand for more information.)

11. I like to help _____ now that we have an intervener. (Expand for more information.)

Appendix D

Taylor's Siblings' Problems Questionnaire (Original)

Taylor's Siblings' Problems Questionnaire

Future Concerns

1. I wonder if _____ will be more trouble when s/he gets older.
2. I don't think _____ will ever live in an institution.
3. I wonder if _____ will always be retarded/autistic.
4. I wonder if _____ will be able to have a job when s/he gets older.

Feelings of Rejection Toward Sibling

1. I'd rather people didn't know I have a retarded/autistic brother/sister.
2. At times I wish _____ would go away.
3. I like having _____ in our family.
4. I don't let people make fun of _____ around me.

Perceived Favoritism Toward Handicapped Child

1. My parents have as much time for me as they do for _____.
2. Sometimes I think of _____ as lucky because s/he gets special treatment.
3. Sometimes I think my parents love _____ more than me.
4. My parents know when _____ can take care of him/herself.

Positive Reactions by Peers

1. My friends don't feel funny or uncomfortable about _____ being retarded/autistic.
2. There are times when I don't like to talk about _____'s being retarded/autistic.
3. My friends like to come to my house sometimes to play with _____.
4. I have trouble explaining to my friends about _____.

Positive Reactions by Parents

1. My mother and father usually enjoy taking care of _____.
2. My parents feel badly because they can't do more to help _____.
3. My parents don't mind when _____ can't do things that other children can.
4. Sometimes I think my mother might feel that _____'s problems are all her fault.

Ability to Cope With the Sibling's Handicapping Condition

1. I don't have may problems with _____, but if I do, my parents can usually help me.
2. I wish I could talk to someone about my problems and worries about _____.
3. I know a lot about how to help _____.
4. People feel too uncomfortable to talk about _____ to me.

Feelings of Burden

1. Sometimes I don't like the way _____ interferes with our family's plans.
2. My family is about the same as other families.
3. At times I don't like the way _____ interferes with my plans.
4. I like to take _____ places with me.

Feelings of Self-Doubt

1. Life in my family is quite a bit different from life in other families because of _____.
2. My parents don't mind if their children aren't perfect.
3. My parents don't think I have to be extra smart.
4. This sounds silly, but sometimes I wonder how smart I am myself.

Hyper Responsibility

1. My parents don't think I have to be more helpful (because _____ is in our family).
2. I try to do well in school to make up to my parents for _____'s being retarded/autistic.
3. I would like my parents to be real proud of me--not just because _____ is retarded/autistic.
4. I wish I could be extra smart for my parents' sake because _____ is not.

Appendix E

Permission to Use Taylor's Siblings' Problems Questionnaire

ENNSTATE

(814) 865-1751

Department of Human Development
and Family Studies
College of Health and Human Development

Individual and Family Consultation Center
Beecher-Dock House
The Pennsylvania State University
University Park, PA 16802

January 16, 1990

Ms. Lori Rowan
#1-306 South 200 East
Smithfield, UT 84335

Dear Ms. Rowan:

I am writing in regard to your questions about the Sibling Problems Questionnaire. Provided you cite Taylor who developed the scale originally, there is no problem about using the scale, though of course, you will want to modify for application to your deaf-/blind population.

Although the sibling problems questionnaire originally was developed with a true/false format, I would advise changing this to a 4 or 5-point scale (e.g., really true, sort of true, etc.) to maximize variability across your respondents and because most subjects seem to prefer not to have to give "all or nothing" kinds of responses.

Good luck on your project.

Sincerely,

Susan M. McHale, Ph.D.
Associate Professor of
Human Development

SMM/ljr

An Equal Opportunity University

Appendix F

Validation of the Intervener Program Letter to Parent Advisors

SKI*HI INSTITUTE

Sensory Impaired Home Intervention

Department of Communicative Disorders
Utah State University
Logan, Utah 84322-9605 Phone (801) 752-4601

Project SKI*HI, INSITE, REAP, VIP, Tactile Signing, NDN Developer Demonstrator, Early Intervention Inservice

January 31, 1990

Dear

As you know V.I.P. (Validation of the Intervener Program) is a federally funded grant that is evaluating Utah Intervener Services. We need to get written permission from the parents in the Utah program for them to participate in this evaluation of Intervener Services. Their participation would include such things as completing surveys and participating in interviews and video taping. Actually our getting permission from parents for their involvement in this evaluation is a formality since federal funding agencies require that evaluation be part of the services given to the families. Could you please tell the parents you are serving that we need their official permission to include them in the evaluation of the Intervener Program and have them sign the enclosed permission form? Please get the form directly from them and mail it back immediately to Sue Watkins (not just ask them to return it to her). Thank you so very much.

Sincerely,

Sue Watkins
VIP Coordinator
SKI*HI Institute
UMC 9605
Utah State University
Logan, UT 84322-9605

SW:lp
Enclosures

cc: Sue Watkins, Dorothy Jensen, Susan Williams, Lori Rowan

Appendix G

Consent for Participation in Evaluation of
Utah Intervener Services

Permission Form to Participate In Evaluation of Intervener Services

I/We as parent(s) of a deaf-blind child hearby agree to participate in the evaluation of Utah Intervener Services by completing questionnaires and surveys, participating in interviews and video taping, and allowing my/our child to be given periodic developmental assessments by the parent advisor.

_____

(parents sign here)

_____

(date)