Siblings of children with disabilities: The Needs and adjustment of today's nondisabled siblings

Lynn Carragher

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Siblings of Children with Disabilities: The Needs and Adjustment of Today’s Nondisabled Siblings

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By
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In Partial Fulfillment of the Requirements for the Degree of Master of Science

Rochester, New York April 17, 1998

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Abstract

This study examined the adjustment of nondisabled siblings of children with a disability. Factors such as family income and characteristics of the nondisabled child as they relate to psychological, behavioral, and academic functioning, and parents' perceptions regarding the needs of nondisabled siblings were explored. Specific attention was given to determining parents' interest in sibling support groups. Study participants consisted of 65 parents who had at least one child between the ages of 5 and 21 with a disability and at least one nondisabled child between the ages of 5 and 18. The primary caregiver was asked to complete a 22 question Sibling Needs Assessment Survey as well as the rate the behavior of the nondisabled sibling on the Behavior Evaluation Scale-2 Home Version. Significant main effects were found for age and sex of the nondisabled sibling with respect to academic difficulties. More academic difficulties were reported when the nondisabled sibling was older than the child with a disability. In addition, males were rated as having significantly higher problems with school performance than females. Family income was not found to have a significant effect on the psychological, behavioral, or academic functioning of the nondisabled siblings.
Siblings of Children with Disabilities: The Needs and Adjustment of Today's Nondisabled Siblings

Over the past twenty years, the services available for children with a disability and their families have changed dramatically (Agosta & Melda, 1995). Prior to the early 1970’s, families with a child with a disability were faced with very few options in caring for their special needs child. Parents were often forced to choose between placing the child in a residential center or caring for the child at home with little to no support from outside agencies (Agosta & Melda, 1995). Since the 1970’s, however, a great amount of change has occurred in the way communities and schools interact with and service children with a disability and their families. Federal legislation has mandated necessary courses of action and provided these children and their families with a legal voice.

Legislation Impacting Individuals with Disabilities and Their Families

With the adoption of Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112), individuals with disabilities were finally given a legal vehicle to fight for their rights (Salvia & Ysseldyke, 1995). For the first time, this federal legislation mandated that individuals with disabilities must have equal access to programs and services. This document also paved the way for additional legislation speaking to the rights of individuals with a disability and their families.

The Education for All Handicapped Children Act of 1975, also known as P.L. 94-142, further provided individuals and their families with a foothold on their rights within the educational system. This legislation mandated actions that schools were required to take in servicing students with a disability.
In 1986, these rights were extended to preschoolers with disabilities and mandates were specified regarding assessment of preschoolers in the Amendment to the Education for All Handicapped Children Act also known as P.L. 99-457 (Salvia & Ysseldyke, 1995).

Another significant accomplishment for individuals with disabilities occurred in 1992 with the Individuals with Disabilities Education Act (IDEA, P.L. 101-476). This act reauthorized the Education for All Handicapped Children Act of 1975. In addition to including two new disability categories and outlining transition services, it marked a large advance in the thinking surrounding individuals with disabilities (Wilson, Blacher, & Baker, 1989). Countering the terminology of previous legislation, IDEA removed the derogatory “handicapped” term and replaced it with the term “disability.” IDEA also recognized that persons with special needs are not defined predominantly by their disabilities by referring to them as individuals with disabilities rather than disabled individuals.

Federal legislation force change to occur in the treatment of individuals with disabilities both within the community and the educational system (Bagenholm & Gillberg, 1991). Systems were required to adapt and met the needs of individuals with a disability and their families. With this pressure to change came an increased need for awareness and understanding about providing services to individuals with a disability and their families. As a result, research seeking to provide knowledge on the needs of individuals with disabilities and their families flourished.
Review of Research Exploring the Impact of Individuals with Disabilities on the Family

Much of the early research on the needs of families of a child with a disability focused on the impact the child with a disability had on either the family system as a whole, on the mother, or on the marital subsystem (Breslau & Prabucki, 1987; Correa, Silberman, & Trusty, 1986; Hannah & Midlarsky, 1985; Poznanski, 1969; Slade, 1988). Most studies concluded that the presence of a child with a disability has a profound impact on family dynamics. Specifically, research suggested that a child with a disability negatively impacts upon family finances, the marital relationship, and maternal health (Crain, Sussman, & Weil, 1966). As a part of the family system, it was assumed that siblings of children with a disability were also negatively impacted by the changed family circumstances. Empirical data specific to sibling effects, however, was initially limited (Slade, 1988). Given the function of the sibling relationship in development and socialization, researchers realized the importance of exploring the changes that may occur as a result of a significant disability in the sibling dyad (Lobato, Faust, & Spirito, 1988; McHale & Gamble, 1987: Summers, White, & Summers, 1994). As a result, researchers sought evidence documenting the impact of a child with a disability on the nondisabled sibling.

siblings of children with a Disability

Early literature on siblings of children with a disability was often based upon clinicians’ experiences with these individuals, and emphasized the struggles and difficulties encountered by the siblings. Some practitioners such as Poznanski (1969),
and San Martino and Newman (1974), for example, concluded that a child with a disability always impacted negatively upon the nondisabled sibling and that all nondisabled siblings were at increased risk for psychological and adjustment difficulties. Subsequent studies, however, have not produced suggestive conclusive evidence, and many investigators have noted methodological problems in earlier research (Breslau & Prabucki, 1987; Clayton, Glidden, & Kiphart, 1991; Summers et al., 1994). Criticisms have been raised that early studies were often anecdotal in nature, lacked a control group, were based on small samples, were retrospective in nature, and utilized institutionalization as an independent variable (Correa, et al., 1986; Gallagher & Powell, 1989; Lobato, et al., 1988). As a result, it was believed that numerous studies provided an overly negative outlook that lacked sound empirical support (Correa, et al., 1986).

Although research has not substantiated the overwhelmingly negative accounts of early clinicians, numerous studies have continued to indicate that siblings of individuals with a disability are indeed at an increased risk for behavioral, psychological, and academic difficulties. Research has frequently mentioned the increased problems with anger, anxiety, depression, aggression, interpersonal relationships, school performance, and physical complaints (Breslau, Weitzman, & Messenger, 1981; Gath, 1974; Grossman, 1972; Hannah & Midlarsky, 1985; McAndrew, 1976). In a study comparing preschool aged siblings of children with a disability and controls, Lobato, Barbour, and Miller (1987) found differences in rates of depression, aggression, and privileges. According to mothers’ ratings, over 64% of brothers and 60% of sisters of a child with a disability scored in the clinical range compared to 28% of control brothers and 25% of control sisters. A longitudinal study conducted by Breslau and Prabucki (1987)
examining the impact of a child with a disability on the nondisabled sibling found that compared to controls, siblings of a child with a disability reported more depressive symptoms and more oppositional behavior. On the Psychiatric Screening Inventory completed by mothers in this study, siblings of a child with a disability demonstrated significantly more difficulty overall and on subscales measuring aggressive, conflictual behavior.

While not discounting the negative effects a child with a disability may have on the nondisabled sibling, many researchers continue to assert that research findings have been misleadingly negative. They refer to previously mentioned methodological problems and offer research indicating positive impacts that a child with a disability has on the nondisabled sibling (Hannah & Midlarsky, 1985; Summers et al., 1994). Many studies, for example, have suggested that nondisabled siblings are likely to be more compassionate, altruistic, and caring than children without a sibling with a disability (Summers et al., 1994; Wilson, et al., 1989). A study by Burton and Parks (1994) investigating self-esteem and locus of control of college-age siblings of individuals with disabilities found no difference in levels of self-esteem between individuals with and without a sibling with a disability. Burton and Parks (1994) also found that siblings of an individual with a disability reported higher levels of internal locus of control. They concluded that although negatives may exist, siblings of individuals with a disability can also benefit from the experience. Wilson et al. (1989) interviewed 24 children ages 9 to 13 with younger siblings with a disability. They discovered that while difficulties such as sadness, anxiety, and anger were acknowledged, the situation was typically presented in a
positive light as siblings reported high levels of involvement and positive sibling interaction.

Variables Affecting Nondisabled Sibling Adjustment

Research suggesting that the presence of a child with a disability can positively affect nondisabled siblings is compelling and it is reasonable that interaction between disabled and nondisabled sibling could result in heightened qualities in the areas mentioned. It cannot be ignored, however, that research also has continues to suggest that a child with a disability can negatively impact upon the nondisabled sibling. Given that research is often inconclusive and even contradictory at times, researchers continue to explore why some nondisabled siblings of children with a disability appear to be at an increased risk of psychological and adjustment difficulties. Researchers have turned to the examination of factors that may increase or decrease the risk of maladjustment in siblings of children with disabilities. The existing research will thus be reviewed according to the following factors: family characteristics, characteristics of the child with a disability, and nondisabled sibling characteristics.

Family Characteristics

Some nondisabled siblings appear to be at higher risk for behavioral and psychological difficulties than controls while others do not. This has led researchers to examine what differences may exist from family to family that may explain the discrepancy. Numerous researchers have explored what, if any role factors such as family size, socioeconomic status, communication patterns, and marital status play in the adjustment of nondisabled siblings.
Family size. Research indicates that nondisabled siblings from smaller families appear to be at a higher risk for adjustment problems than nondisabled siblings from larger families (McKeever, 1983; Trevino, 1979). This is especially found to be a predominant factor when socioeconomic status is controlled (Trevino, 1979). Trevino suggests that in larger families the child with a disability is less conspicuous, thus allowing for more normalcy in daily activities and in siblings interactions. Another explanation is that in larger families, the siblings share the parental pressure and expectations, whereas in smaller families, the burden of performance rests only on the one sibling (McAndrew, 1976). Simeonsson and McHale (1981) also offer that in larger families, responsibilities in caring for the individual with a disability are more dispersed and thus do not greatly limit or overwhelm any sibling in particular.

Socioeconomic status. Many researchers have also examined how the family’s financial status affects the well being of nondisabled siblings. The difference appears to lie in the way the family perceives the disability. Farber (1960) suggested that families of middle and upper class status tend to view the presence of a child with a disability as a “tragic crisis” whereas families of lower socioeconomic status view it as a “organizational crisis.” In other words, families of higher SES are more likely to focus on the ramifications and limitations the disability will have on the child’s future. Families of lower SES are more likely to focus on the burden of caring for the child when resources are already taxed.

Another distinction among families of different SES deals with available resources. Higher SES families are more likely to be able to afford additional help in caring for the child with a disability, whereas in lower SES families, the responsibility

**Communication patterns.** The level of openness and communication in a family as well as parental attitude regarding the child’s disability has also been demonstrated as a factor in nondisabled siblings’ adjustment. McHale et al. (1984) suggested that nondisabled siblings are better adjusted when parents are more accepting of the condition and promote an openness in the home regarding the disability. It has also been found that siblings attribute their adjustment to the communication patterns and attitudes in the family regarding the brother or sister’s disability (Hayden, 1974; Trevino, 1979). It is suggested that in families with poor communication and in which parents cope poorly with the reality of the child’s disability, parents are likely to experience reactions such as excessive guilt, anxiety, and depression (Trevino, 1979). Not only may this result in displacement of feelings onto the nondisabled sibling, but it is likely to create an environment in which open discussion about the child’s disability is not encouraged or allowed. Therefore, the opportunity does not exist for the nondisabled sibling to gain information that may reduce anxiety, increase understanding, and lay the groundwork for positive adjustment.

**Marital status.** Although not as researched as other family characteristics, marital status is yet another factor thought to influence the adjustment of the nondisabled siblings. Single parent households are likely to experience even more financial difficulties, lack of resources, and lack of emotional support than two parent families
(Fisman & Wolf, 1991). As a result, more stress is added to the already burdened family system. The nondisabled sibling is likely to be required to play a more active role in the responsibilities of caring for the child with a disability and receive less support from the parental figure.

**Characteristics of the Child with a Disability**

In addition to family characteristics, the characteristics of the child with a disability have also been examined in an attempt to determine the role they may play in the adjustment of nondisabled siblings. Factors such as the type of disability and the severity of the disability have received the most attention.

**Type of disability.** Research regarding a differential impact on nondisabled siblings as a result of disability type has been inconsistent (McHale & Gamble, 1987). The research suggests that the type of disability does not result in significant differences in nondisabled sibling adjustment (Gallagher & Powell, 1989; Lobato, 1983). They contend that other factors such as parental attitude and family size are more important. It is argued, however, that disability type is important, and that disabilities that are more apparent and easily visible result in more stress for the family (Farber, 1960). It should be noted that most studies comparing types of disabilities have looked at disabling conditions such as autism, mental retardation, and Down's syndrome. No studies were found that looked at a wider spectrum of disabilities such as those typically defined in state education laws. It may be worthwhile not only to extend the examination of disability types to include a broader spectrum of disabling conditions, but also to use classifications typically seen within the educational system.
Severity of the disability. Whether severity of the disability plays a role as a risk factor for nondisabled siblings is also unclear (Fisman & Wolf, 1991). It is, however, suggested that severity of the disability rather than the type is of greater importance in examining nondisabled sibling adjustment. Many researchers contend that the more severe the disability, the more detrimental the effect on the nondisabled siblings (Farber, 1960; Grossman, 1972). A study by Breslau et al., (1981), however, failed to find a relationship between the severity of disability and the adjustment of nondisabled siblings. Of interest is a study by Tew and Laurence (1975) in which it was suggested that severity of disability may result in a curvilinear relationship. In other words, nondisabled siblings are more adversely affected when the severity is either minimal or extreme. This finding corresponds in part to arguments made by Grossman (1972) and Hannah and Midlarsky (1985), that sibling adjustment may be negatively affected when the brother or sister’s disability is vague or unclear.

Characteristics of the Nondisabled Sibling

Certain characteristics of the nondisabled sibling such as sex and age are also believed to impact upon sibling adjustment.

Sex. Studies examining mothers’ rating of their nondisabled children indicate that males are viewed as being more depressed and aggressive than their female counterparts and male controls; whereas females are seen as more aggressive than female controls and more likely than their male counterparts to develop physical problems (Lobato, et al., 1987). Most researchers also seem to suggest that females are more at risk for developing psychological and behavioral difficulties than males (Farber, 1960; Lobato et al., 1987). This is thought to result from females assuming a larger role than males in
caretaking activities (Simeonsson & McHale, 1981). This increased responsibility is believed to interfere in the normal activities in which the sibling would have partaken.

**Age.** The age of the nondisabled sibling compared to that of the sibling with a disability is also believed to impact upon adjustment and is often considered to interact with the sex of the nondisabled sibling. Research is often contradictory, however, in determining what effect age has upon nondisabled sibling adjustment. A study by Lavigne and Ryan (1979), for example, found that older males and younger females demonstrated the most maladjustment. Other research, however, indicates the exact opposite, that maladjustment is most likely to occur in older females and younger males (Breslau, 1982; Powell & Ogle, 1985). McHale and Gamble (1987) contend that older females experience the greatest risk of maladjustment. They found that older females reported more symptoms of depression and lower feelings of self-worth than males. In their longitudinal study, Breslau and Prabucki (1987) found that significant age effects occurred on measures of self-destructive tendencies and isolation. Maladjustment in these areas became more pronounced over a 5-year period, and overall, the psychiatric profiles of the nondisabled siblings had deteriorated and were indicative of more behavioral and emotional difficulties than control children. Still further, Breslau (1982) and Wagner, Schubert, and Schubert (1985) found that age spacing, rather than simply age alone, is an important factor in sibling adjustment. Closeness in age has been suggested to increase risk of adjustment difficulties in nondisabled siblings with respect to likelihood of depression, interpersonal struggles, and academic problems. Age spacing has also been found to impact most negatively upon older rather than younger nondisabled siblings, and on males as opposed to females.
Needs of Nondisabled Siblings

Although the research on how a sibling with a disability affects the nondisabled sibling and risk factors which may contribute to increased risk of maladjustment is at times inconclusive and even contradictory, findings do warrant investigation into the needs of nondisabled siblings. Existing research suggests that nondisabled siblings frequently lack information regarding their brother or sister's disability. Bagenholm and Gillberg (1991) interviewed siblings of children with a disability and found that 55% of siblings who had siblings with Autism, and almost 66% of siblings who had a sibling with mental retardation were unable to formulate any explanation of what was wrong with their brother or sister.

Research also indicates a need for siblings of children with a disability to talk and ask questions about their brother or sister’s disability (Seligman, 1983). Bagenholm and Gillberg (1991) found that many of the children indicated feeling as though they were unable to talk about their brother or sister’s disability in the home. Wilson, et al. (1989) found that 55% of siblings of a child with a disability expressed an interest in participating in a sibling support group, and 60% of parents expressed an interest in having their nondisabled children participate.

Meeting the Needs of Today’s Nondisabled Sibling

It is apparent that researchers have explored the risk factors and needs of siblings of children with a disability. One may wonder then why further research is needed. Two issues come to the forefront. First, as discussed earlier, much of the existing research is inconclusive and contradictory. Second, much of the research cited took place prior to the 1990’s. While it is reasonable to assume that siblings of children with a disability
have specific needs, it is also reasonable to assume that these needs may be different than previously thought. Changes have continued to occur over the years with respect to the servicing of children with a disability and their families (Bagenholm & Gillberg, 1991). The number of supports and services available to individuals and their families has increased and the inclusion movement continues to grow (Bagenholm & Gillberg, 1991).

Children with disabilities are educated more frequently within regular education settings, and more often than ever, nondisabled siblings are coming face to face with issues related to their brother or sister’s disability. As a result of these changes in attitudes and service provision over the years, current information on the needs of siblings of children with a disability is imperative.

This study surveyed primary caregivers to examine the current needs as well as behavioral, academic, and psychological functioning of siblings of children with a disability. In an effort to further understand variables that may affect the risk of maladjustment for siblings of children with a disability, characteristics of the family, the nondisabled sibling, and the child with a disability were also examined.

This study also sought to better understand the services parents have utilized as well as perceive siblings of children with disabilities as needing. The specific issue of whether parents feel their children could benefit from a sibling support group was examined as were factors influencing the willingness of families to utilize such a resource. Overall, it was hoped that with this study, updated information would be provided regarding the factors affecting the behavioral, psychological, and academic functioning of today’s siblings of children with a disability and that new light would be shed on how schools and communities may better service these individuals.
Method

Participants

The participants consisted of 65 parents who had at least one child between the ages of 5 and 21 with a disability and at least one nondisabled child between the ages of 5 and 18. All children with a disability attended Creekside School at Monroe #1 Board of Cooperative Educational Services in Fairport, New York. The Board of Cooperative Educational Services (BOCES) is an organization servicing students from various districts within Monroe County whose needs demand that they attend a specialized school setting. Creekside, one of the BOCES schools, services children with severe disabilities between the ages of 5 and 21.

Instruments

Sibling Needs Assessment Survey. The Sibling Needs Assessment Survey is a survey designed for this study to collect demographic information and assess the needs of siblings of children with disabilities (see Appendix A). It consists of 22 questions to be completed by a primary caregiver. Questions include multiple choice and/or open-ended format. Information from this survey was used to analyze how demographic characteristics such as socioeconomic status, age of child with a disability, age and sex of nondisabled sibling, and use of available resources correlate with ratings of nondisabled siblings' academic, behavioral, and psychological functioning. It will also examine parent perceptions of the needs of siblings of children with disabilities and help determine whether families are interested in having sibling support groups in school. This survey was developed based upon research suggesting that certain characteristics of the family and child with a disability have been found to impact upon the nondisabled
siblings' psychological well being and adjustment. The inquiries on interest in participation in sibling support groups and sibling needs are based on research suggesting that siblings of children with a disability demonstrate a need for open communication and accurate information regarding their brother or sister's disabling condition.

**Behavior Evaluation Scale-2 (Home Version).** The Behavior Evaluation Scale-2 is a tool developed by Stephen B. McCarney and published by Hawthorne Educational Services to aid in early identification of students with behavioral and/or emotional difficulties (see Appendix B). The 73 item rating scale is based upon the federal definition of the emotionally disturbed classification found in the Individuals with Disabilities Education Act (McCarney, 1994). Questions explore the frequency of behaviors that were identified by parents as being the most representative of serious behavioral difficulties in the home. The primary caregiver rates how often the child performs the behavior by selecting from the following 7 quantifiers: "not in my presence"; "one time"; "several times"; "more than one time a month-up to one time a week"; "more than one time a week-up to once a day"; "more than once a day-up to once an hour"; "more than once an hour" The scale provides an overall quotient of functioning as well as a measure of behavior with respect to the following five domains in accordance the IDEA's criteria for emotionally disturbed: learning problems, interpersonal difficulties, inappropriate behavior, unhappiness/depression, and physical symptoms/fears. Primary caregivers were asked to rate the behavior of the nondisabled sibling closest in age to the child with a disability. Information from this instrument was used in determining if the behavioral ratings of siblings of children with disabilities differ from the normative statistics based upon typical children.
Overall, the technical characteristics of the BES-2 are adequate. According to the detailed manual, the scale was normed on 1,769 students ages 4.5 to 21 years who were rated by 1,845 primary caregivers. The fact that one child can be rated by more than one primary caregiver accounts for the difference in number between ratee and rater. The normative sample consisted of individuals from 18 states and 59 school systems. Males and females were equally represented. A breakdown of the student sample according to age level demonstrates lower sample sizes at the floor (4.5-5 years, n = 86) and the higher age limits (15 years, n = 83; 16 years, n = 79; and 17 to 20 years, n = 51). The normative sample was also slightly overrepresentative of Caucasian students with the sample percentage at 97% compared to the national percentage of 84%, and underrepresentative of African American students with a sample percentage of 3% compared to the national percentage of 12%.

The test retest reliability of the BES-2 (HV) was tested on 201 student ratings. Results for each subscale range from a low of .88 to a high of .93, with a total score reliability coefficient of .90. Inter-rater reliability coefficients range from a high of .91 to a low of .85 for all age levels. This suggests consistency of the instrument in construct measurement as well as consistency among raters. Internal consistency reliability coefficients range from a low of .74 to a high of .93. Low subscale correlation coefficients of between .50 to .78 suggest adequate convergent validity in that each subscale measures a different construct with inappropriate behavior and interpersonal difficulties experiencing the most overlap.

Content validity of the scale also appear adequate to good as the manual details efforts such as literature review, input from educators, diagnosticians and parents, and
statistical item analysis in scale construction. Construct validity also appears to be adequate as statistical analysis indicates that each subscale measures the anticipated construct of behavioral difficulties.

Independent reviews of the BES-2 also found the scale to have satisfactory reliability, validity, and standardization, and support its use for the stated purpose of identifying children with emotional and behavioral difficulties (Goldman; 1994; Olmi, 1994).

**Procedure**

Through the cooperation of Monroe #1 Board of Cooperative Educational Services, permission was obtained to survey parents of the children attending Lois E. Byrd Elementary, Morgan Middle School, and Creekside School. Each school services children with disabilities from various Rochester area school districts.

A pilot survey project occurred in August during summer programming at Lois E. Byrd and Morgan Middle School. Packets containing a Sibling Needs Assessment Survey, a Behavior Evaluation Scale-2 -Home Version, a Parent Letter (see Appendix C) to explain the study and request participation, and return envelopes for completed material were prepared. Teachers were instructed to distribute the material to the students and collect any returned material from the students. A box was placed in the office of each school for returned material. A total of 220 packets were distributed; 75 at Lois E. Byrd and 145 at Morgan Middle School. Returns were collected after one week as summer program came to an end. Survey response was low, with an 18.75% parent response rate. Of the 42 responses, 15 indicated that they did not fit the profile and 5 did not wish to participate. Of the 22 completed surveys and rating forms, 20 surveys were
Based on this pilot survey response, the survey procedure and survey material were modified with the hope of increasing response ratios during later distribution at Creekside School. Several changes were made in both the material as well as the survey procedure prior to conducting the primary research project at Creekside School.

The Parent Letter was rewritten (see Appendix D), was copied on green paper to stand out, and included a return date of one week from the date of distribution. A letter from the principal of Creekside School encouraging parents to complete the material was also added (see Appendix E). A cover sheet was added to the Behavior Evaluation Scale-2 requesting the minimal information needed such as date of completion, birthdate and grade of nondisabled sibling (see Appendix F). One change was made to the Sibling Needs Assessment Survey to clarify to parents which questions should be based upon the child with a disability (see Appendix G). A Teacher Letter was created to inform teachers of the study and request their assistance in material distribution and collection (see Appendix H). Finally, a follow up letter was created to be sent home immediately following the initial due date thanking those who responded and requesting that the remaining surveys be returned within one week (see Appendix I).

The primary research project was conducted at Creekside School in October of the 1997 school year. Two hundred and twenty-seven packets containing the Sibling Needs Assessment Survey, the Behavior Evaluation Scale-2 Home Version, the Parent Letter, the Principal's letter, and a return envelope were addressed to the parents and distributed to teachers along with the Teacher Letter describing the project. A box was placed in the Creekside office for returned material. After the initial return date of one
week, the follow up letter was distributed to teachers to again be sent home with the students.

A request was made in the Teacher Letter that surveys not be sent home if it was known that a particular student did not have a nondisabled sibling. As a result, 21 surveys were returned prior to being sent out to parents thus reducing the number of surveys distributed to 206. Of the 206 surveys distributed, 48 responses were received prior to the initial return date. An additional 59 responses were received subsequent to the distribution of the follow up letter. In all, 107 responses were received resulting in a response rate of 51.94%. Of the 107 responses, 40 indicated that they did not fit the profile, 3 did not wish to participate, and 4 surveys without the behavior rating form were completed. Of the 60 completed surveys and behavior rating forms, 54 were useable in their entirety.

For analysis purposes, responses from the Sibling Needs Assessment Survey were coded according to response category except in the case of the child's handicapping condition. When more than one classification was indicated, a decision was made by this examiner regarding the primary handicapping condition. Three or more responses were interpreted as "Multiply Handicapped". When "Learning Disabled" was indicated with "Emotionally Disturbed", the classification was considered to be "Emotionally Disturbed" given the likelihood of a special school setting occurring as a result of emotional and behavioral needs rather than solely learning needs. If "Learning Disabled" was indicated with "Speech Impaired", "Learning Disabled" was chosen as the primary handicapping condition.
Results

This section details the demographic information relating to the study's participants, the children with disabilities, and the nondisabled siblings. In addition, caregivers' perceptions of needs of nondisabled siblings, family support services, and observed characteristics of the nondisabled siblings are reported. Finally, statistical analyses examining socioeconomic status, sex of the nondisabled sibling, and age of the nondisabled sibling as they relate to academic, behavioral, and psychological difficulty as measured by the BES-2 are presented.

Respondent Characteristics

Demographics of the respondents are presented in Figures 1 through 6. Eighty-nine percent of respondents were biological parents of a child with a disability (See Figure 1). Seventy-three percent were Caucasian (See Figure 2), and 64.6% were married (See Figure 3). Over 66% reported household incomes less than $60,000 (See Figure 4), and over 53% were between 40 and 50 years of age (See Figure 5). The majority, 61.5%, resided in suburban neighborhoods (See Figure 6).

Reported Characteristics of Children with a Disability

The demographic characteristics of the children with a disability are reported in Table 1. The majority of respondents, 63.1%, reported caring for a male with a disability. Approximately 83% of the children with a disability were being serviced in a self-contained BOCES setting. The classification of "Multiply Handicapped" occurred most frequently with 53.8% falling into this category. Sixty-nine percent of disabling conditions were reported as being moderate to moderate/severe.
Figure 1. Respondent relationship to child with a disability.
Figure 2. Ethnicity of primary caregivers.
Figure 3. Marital status of respondents.
Figure 4. Respondent income level in dollars.
Figure 5. Age of survey respondents.
Figure 6. Survey respondents' area of residence.
Table 1

Reported Characteristics of Children with a Disability

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>41</td>
<td>63.1</td>
</tr>
<tr>
<td>Female</td>
<td>24</td>
<td>36.9</td>
</tr>
<tr>
<td><strong>Educational Placement</strong></td>
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<td></td>
</tr>
<tr>
<td>Home district with mainstreaming</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td>Home district, self-contained</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Special school setting (e.g. BOCES)</td>
<td>54</td>
<td>83.1</td>
</tr>
<tr>
<td>Other setting</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Special Education Classification</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autistic</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>Deaf-Blind</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Emotionally Disturbed</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Learning Disabled</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>Mentally Retarded</td>
<td>9</td>
<td>13.8</td>
</tr>
<tr>
<td>Multiply Disabled</td>
<td>35</td>
<td>53.8</td>
</tr>
<tr>
<td>Other Health Impaired</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>2</td>
<td>3.1</td>
</tr>
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</table>

**Severity of Disability**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
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<tr>
<td>Mild</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Mild to Moderate</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Moderate</td>
<td>25</td>
<td>38.5</td>
</tr>
<tr>
<td>Moderate to Severe</td>
<td>20</td>
<td>30.8</td>
</tr>
<tr>
<td>Severe</td>
<td>11</td>
<td>16.9</td>
</tr>
</tbody>
</table>

**Note.** Cumulative percentages may not total to 100 due to omissions.
Characteristics of Nondisabled Siblings

The demographic characteristics of the nondisabled siblings of children with a disability are reported in Table 2. The majority, 61.8%, of nondisabled siblings was female, and 49.1% were younger than their brother or sister with a disability.

Perceived Needs of Siblings of Children with a Disability

Caregiver responses regarding the needs of families with a child with a disability and specifically with respect to the nondisabled siblings are reported in Table 3. The majority of respondents, 58.5%, indicated that siblings need information about their brother or sister's disability, 44.6% indicated they need to talk with similar children, and 38.5% said more time with parents is needed. Decreased time with parents (44.6%), followed by increased responsibilities (40%), and conflict with parents (26.2%) were most often reported as the concerns caregivers have regarding siblings of children with a disability.

Family Support Services

Caregiver responses regarding family support services are reported in Tables 4 and 5. Services utilized most in the last year include case management services (52.3%), respite care (36.9%), and counseling (24.6%). Eighteen percent of caregivers reported that their children had participated in a sibling support group in the past. Reported helpfulness of the sibling support group varied.

Those who did not report having utilized a sibling support group reported not knowing of a group available (38%), not feeling as though their children needed the service (23.1%), and time constraints (20%). Thirty-six percent of caregivers believed that a sibling support group would have been helpful for their nondisabled children, 7.7% did not believe it would have been helpful, and 50.8% were unsure.
Table 2

Reported Characteristics of Nondisabled Siblings

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>21</td>
<td>38.2</td>
</tr>
<tr>
<td>Female</td>
<td>34</td>
<td>61.8</td>
</tr>
<tr>
<td><em>Age in Relation to Sibling</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older</td>
<td>22</td>
<td>40.0</td>
</tr>
<tr>
<td>Younger</td>
<td>27</td>
<td>49.1</td>
</tr>
<tr>
<td>Same age</td>
<td>6</td>
<td>10.9</td>
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Table 3

Caregivers’ Perceptions of Needs of Siblings of Children with a Disability

<table>
<thead>
<tr>
<th>Needs</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on disability</td>
<td>38</td>
<td>58.5</td>
</tr>
<tr>
<td>Talk to others in similar situation</td>
<td>29</td>
<td>44.6</td>
</tr>
<tr>
<td>Talk to a counselor</td>
<td>12</td>
<td>18.5</td>
</tr>
<tr>
<td>Teacher awareness</td>
<td>21</td>
<td>32.3</td>
</tr>
<tr>
<td>Talk to a school psychologist</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td>More time with parents</td>
<td>25</td>
<td>38.5</td>
</tr>
<tr>
<td>Visit sibling’s class</td>
<td>23</td>
<td>35.4</td>
</tr>
<tr>
<td>Additional support</td>
<td>15</td>
<td>23.1</td>
</tr>
<tr>
<td>No special needs</td>
<td>8</td>
<td>12.3</td>
</tr>
<tr>
<td>Other needs</td>
<td>4</td>
<td>6.2</td>
</tr>
</tbody>
</table>

Concerns for Nondisabled Siblings

<table>
<thead>
<tr>
<th>Concerns</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggression</td>
<td>11</td>
<td>16.9</td>
</tr>
<tr>
<td>Conflict with parents</td>
<td>17</td>
<td>26.2</td>
</tr>
<tr>
<td>Decreased time with parents</td>
<td>29</td>
<td>44.6</td>
</tr>
<tr>
<td>Delinquency</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Depression</td>
<td>11</td>
<td>16.9</td>
</tr>
<tr>
<td>Increased responsibilities</td>
<td>26</td>
<td>40.0</td>
</tr>
<tr>
<td>Social isolation</td>
<td>15</td>
<td>23.1</td>
</tr>
<tr>
<td>Other concerns</td>
<td>9</td>
<td>13.8</td>
</tr>
</tbody>
</table>
Table 4

**Reported Family Support Services Utilized in Past Year**

<table>
<thead>
<tr>
<th>Services used in past year</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling</td>
<td>16</td>
<td>24.6</td>
</tr>
<tr>
<td>Respite care</td>
<td>24</td>
<td>36.9</td>
</tr>
<tr>
<td>Parent Support Groups</td>
<td>9</td>
<td>13.8</td>
</tr>
<tr>
<td>Case management services</td>
<td>34</td>
<td>52.3</td>
</tr>
</tbody>
</table>
Table 5

Reported Involvement In and Perceptions of Sibling Support Groups

<table>
<thead>
<tr>
<th>Sibling Support Group Involvement</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children have participated</td>
<td>12</td>
<td>18.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Helpfulness of Sibling Groups Utilized</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all to somewhat helpful</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>8</td>
<td>12.3</td>
</tr>
<tr>
<td>Somewhat to very helpful</td>
<td>2</td>
<td>3.1</td>
</tr>
<tr>
<td>Very helpful</td>
<td>2</td>
<td>3.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived Helpfulness of Sibling Groups</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Believe would be helpful</td>
<td>24</td>
<td>36.9</td>
</tr>
<tr>
<td>Do not believe would be helpful</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>Unsure</td>
<td>33</td>
<td>50.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasons for Not Participating</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not know of a group available</td>
<td>25</td>
<td>38.5</td>
</tr>
<tr>
<td>Transportation difficulties</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Did not feel group was needed</td>
<td>15</td>
<td>23.1</td>
</tr>
<tr>
<td>Children did not want to participate</td>
<td>10</td>
<td>15.4</td>
</tr>
<tr>
<td>Time constraints</td>
<td>13</td>
<td>20.0</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>10.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factors Affecting Participation</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Convenience of location</td>
<td>44</td>
<td>67.7</td>
</tr>
<tr>
<td>Availability of transportation</td>
<td>10</td>
<td>15.4</td>
</tr>
<tr>
<td>Time involvement required</td>
<td>35</td>
<td>53.8</td>
</tr>
<tr>
<td>Disruption to family schedule</td>
<td>13</td>
<td>20.0</td>
</tr>
<tr>
<td>Childcare needs</td>
<td>8</td>
<td>12.3</td>
</tr>
<tr>
<td>Other factors</td>
<td>13</td>
<td>20.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Preferred Location for Sibling Groups</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>At school, during school day</td>
<td>14</td>
<td>21.5</td>
</tr>
<tr>
<td>At school, after school day</td>
<td>18</td>
<td>27.7</td>
</tr>
<tr>
<td>Mental health agency</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Support services agency</td>
<td>15</td>
<td>23.1</td>
</tr>
<tr>
<td>Local hospital</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>Other setting</td>
<td>8</td>
<td>12.3</td>
</tr>
</tbody>
</table>
Factors affecting willingness of participation in a sibling support group most often included group location (67.7%), time commitment involved (53.8%), and amount of disruption that would occur to the family schedule (20%).

A school setting was the preferred location for sibling support groups with 21.5% of respondents preferring groups to be offered at school, during the school day, and 27.7% wanting groups offered at school but after school hours.

**Observed Characteristics of Siblings of Children with a Disability**

Respondent ratings regarding their nondisabled children are reported in Table 6. Approximately 40% of caregivers indicated their children are often able to explain their brother or sister's disability, 35.4% said they frequently discuss their feelings, and 60% said they often bring friends to the house. Roughly 13% said the nondisabled siblings frequently express anger about extra attention received by the child with a disability, 40% said they frequently help with caring for their brother or sister, and 7.7% said they frequently help with their brother or sister's education or therapy.

**Results of the Behavior Evaluation Scale –2**

Responses on the Behavior Evaluation Scale –2, Home Version were scored, and subscale scores as well as an overall quotient were obtained and used in analysis. Subscale and quotient scores obtained from the caregiver ratings of the nondisabled siblings were analyzed with respect to the frequency with which they fell more than one standard deviation below the mean of the normative sample. Findings are reported in Table 7. Approximately 25% of scores on the Learning Problems scale, 12.7% of Interpersonal Difficulties scores, 9.1% of Inappropriate Behavior scores, 18.2% of Unhappiness/Depression scores, 10.9% of Physical Symptoms/Fears scores, and 13% of Total Scale scores were one or more standard deviations less than the mean.
Table 6

Percentages of Primary Caregiver Responses Regarding Skills and Behaviors of Their Nondisabled Children

<table>
<thead>
<tr>
<th></th>
<th>Often</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can explain about disability</td>
<td>40.0</td>
<td>41.5</td>
<td>7.7</td>
</tr>
<tr>
<td>Discuss feelings about disability</td>
<td>35.4</td>
<td>38.5</td>
<td>16.9</td>
</tr>
<tr>
<td>Bring friends to the house</td>
<td>60.0</td>
<td>29.2</td>
<td>4.6</td>
</tr>
<tr>
<td>Express anger about attention</td>
<td>13.8</td>
<td>44.6</td>
<td>32.3</td>
</tr>
<tr>
<td>Help with care of sibling</td>
<td>40.0</td>
<td>44.6</td>
<td>7.7</td>
</tr>
<tr>
<td>Help with education or therapy</td>
<td>7.7</td>
<td>50.8</td>
<td>30.8</td>
</tr>
</tbody>
</table>
Table 7

**Frequency of Behavior Evaluation Scale-2 Quotients and Subscale Scores More Than One Standard Deviation Below the Mean**

<table>
<thead>
<tr>
<th>Scales</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Problems</td>
<td>14</td>
<td>25.9</td>
</tr>
<tr>
<td>Interpersonal Difficulties</td>
<td>7</td>
<td>12.7</td>
</tr>
<tr>
<td>Inappropriate Behavior</td>
<td>5</td>
<td>9.1</td>
</tr>
<tr>
<td>Unhappiness/Depression</td>
<td>10</td>
<td>18.2</td>
</tr>
<tr>
<td>Physical Symptoms/Fears</td>
<td>6</td>
<td>10.9</td>
</tr>
<tr>
<td>Total Scale Quotient</td>
<td>7</td>
<td>13.0</td>
</tr>
</tbody>
</table>

*Note. BES-2 subscale \( \bar{x}=10, SD=3 \); BES-2 quotient \( \bar{x}=100, SD=15 \).*
Statistical Analyses

A Shapiro-Wilk statistic was generated to test for normality on BES-2 data. As the sample was shown to depart from approximation of a normal curve, a determination was made regarding the use of nonparametric versus parametric tests. Based upon findings that the analysis of variance procedure has been shown to be largely unaffected by small departures from normality (Hurlburt, 1994) this parametric statistic was used. An Alpha Level of .05 was used for all statistical tests.

Relationship between family income and nondisabled sibling functioning as determined by the BES-2 was analyzed using a one way multivariate analysis of variance (MANOVA), between-groups design. This analysis failed to reveal a significant multivariate effect for family income, Wilks' lambda = .48, $F(24, 124) = 1.39; p = .118$. Sample means are displayed in Table 8.

Results of a two-way analysis of variance (ANOVA), with two between-groups factors was utilized to explore the existence of main effects and an interaction effect between sex of nondisabled sibling and birth order of nondisabled sibling on adjustment as measured by the BES-2 are reported in Table 9. This analysis revealed a significant main effect for sex of nondisabled sibling, $F(1, 44) = 9.70; p < .003$, and a significant main effect for birth order of nondisabled sibling, $F(1, 44) = 4.62; p < .037$ on occurrence of learning problems. Males were more likely to be reported as having learning problems than females, as were older versus younger nondisabled siblings. This analysis failed to reveal a significant interaction effect on learning problems, $F(1, 44) = .01; p = .91$.

The analysis failed to reveal a main effect for sex on the Interpersonal Difficulties scale, $F(1, 45) = .32; p = .58$; on inappropriate behavior $F(1, 45) = .29; p = .59$; on
Table 8

Means and Standard Deviations of Scores on BES-2 Scales by Income Level in Dollars

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>7.85</td>
<td>10.45</td>
<td>8.00</td>
<td>9.50</td>
<td>11.33</td>
</tr>
<tr>
<td>SD</td>
<td>4.56</td>
<td>2.46</td>
<td>4.66</td>
<td>4.24</td>
<td>1.41</td>
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<tr>
<td>Interpersonal Difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.77</td>
<td>11.00</td>
<td>10.20</td>
<td>11.12</td>
<td>10.78</td>
</tr>
<tr>
<td>SD</td>
<td>4.42</td>
<td>3.92</td>
<td>2.35</td>
<td>4.12</td>
<td>2.22</td>
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<tr>
<td>Inappropriate Behavior</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.00</td>
<td>10.72</td>
<td>10.10</td>
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<td>7.96</td>
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Note. Level 1 = 0-20,000; Level 2 = 21-40,000; Level 3 = 41-60,000; Level 4 = 61-80,000; Level 5 = 81,000+
Table 9

**Mean Scores on BES-2 Scales by Age and Sex of Nondisabled Siblings**

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*Note.* * indicates significance, $p=.003$, and $p=.037$ respectively
unhappiness/depression, $F(1, 45) = .00; p = .99$; on physical symptoms/fears, $F(1, 45) = 2.12; p = .15$, and on total adjustment $F(1, 44) = .79; p = .38$. The analysis also failed to reveal a significant main effect for birth order of nondisabled sibling on Interpersonal Difficulties scale, $F(1, 45) = .28; p = .60$, on inappropriate behavior, $F(1, 45) = 2.43; p = .13$; on unhappiness/depression, $F(1, 45) = .11; p = .74$; on physical symptoms/fears $F(1,45) = .39; p = .53$; and on total adjustment $F(1, 44) = .83; p = .37$.

Further, the analysis failed to reveal a significant interaction effect on interpersonal difficulties, $F(1, 45) = .14; p = .71$; on inappropriate behavior $F(1,45) = .65; p = .43$; on unhappiness/depression, $F(1, 45) = .27; p = .60$; on physical symptoms/fears, $F(1, 45) = .75; p = .39$; and on total adjustment, $F(1, 44) = .20; p = .66$.

Discussion

This study examined adjustment of nondisabled siblings of children with a disability. Factors such as family income and characteristics of the nondisabled child as they relate to psychological, behavioral, and academic functioning, and parents' perceptions regarding the needs of nondisabled siblings were explored. With respect to perceived needs and services utilized, specific attention was given to parents' interest in sibling support groups. This section will discuss the study's findings, limitations, and implications for future research.

Effect of Family Income, Sex, and Age of Nondisabled Sibling

This study found that significant differences do not exist between socioeconomic status and adjustment of nondisabled siblings. Income level was not found to have a significant effect on academic performance, interpersonal skills, degree of inappropriate behavior, unhappiness or depression, or somatic complaints and fears of the nondisabled
siblings. This finding does not support earlier research by Gath (1974) and Farber (1960) that nondisabled siblings in lower SES families are at increased risk for difficulties.

The difference in findings between earlier research and this study may be related to the availability of services today versus in the 1960's through 1980's. Gath (1974) and Farber (1960) believed that nondisabled siblings of children with a disability were at increased risk in lower SES families due to an inability to access support services as a result of their financial situation. As institutionalization was more common at that time and support services were less extensive than they are now, lower SES families who chose to care for their child at home very well may not have been able to enlist as much assistance as a higher SES family would. As a result, as offered by Seligman (1983) and Simeonsson and McHale (1981), nondisabled siblings may have been expected to take on greater responsibility in caring for their brother or sister with a disability. Today, however, many support services and organizations are more easily accessible to lower SES families. Free services, sliding scales, and provision of childcare and transportation are more common. Although higher SES income families still may be able to access a higher degree of support services, family income may not be as significant of a barrier to services as it once was.

The nonsignificant finding across income levels may also be a result of sample size. Although not significant, Table 8 demonstrates that the lowest scores on all areas of functioning were obtained by those in the lowest income category, and a trend exists on overall functioning with better functioning reported as family income increases. As Figure 4 demonstrates, over 66% of the reported household incomes were less than 60,000 dollars per year. Small sample size and number of respondents across categories
may have impacted this study's findings.

With respect to sex of the nondisabled sibling, males were reported to experience a significantly higher degree of learning problems and poor academic performance than females. Caregivers were not significantly more likely to report a difference between males and females on measures of interpersonal relationships, inappropriate behavior, unhappiness/depression, somatic complaints, fears, or overall functioning. This finding does not support the belief that males are more likely to be reported as aggressive and depressed whereas females are more likely to develop physical symptoms and fears (Farber, 1960; Lobato et al., 1987). The findings do support research by Wagner et al. (1985) with respect to increased academic difficulties of male siblings of an individual with a disability. Although this study's finding with respect to poorer male academic performance may be a specific comment on male siblings of children with a disability, it may simply be reflective of the higher incidence of learning problems typically experienced by the male population as a whole. The standardization sample of the BES-2, for example found that males were reported as having more academic difficulties not accounted for by a learning disability than females.

Older siblings of children with a disability as opposed to younger were also reported as experiencing higher degrees of academic difficulties and learning problems. No differences were found in other areas of behavioral and psychological functioning. The sex of the nondisabled child when combined with age, was not found to result in a significant difference. In other words, whether the older or younger sibling was male or female made no difference in the finding that older siblings experienced more academic difficulty. This finding does not support either position offered by the contradictory
earlier research suggesting that older males and younger females (Lavigne & Ryan, 1979) or that older females and younger males (Breslau, 1982; McHale and Gamble, 1987; Powell & Ogle, 1985) are the populations at greatest risk for difficulty. It does, however, support findings by Wagner et al. (1985) that older nondisabled siblings experience more difficulty academically than younger nondisabled siblings. One common explanation for this finding postulates that increased pressure to perform in school may be placed upon the older sibling as that as the sibling moves toward higher education (McHale & Gamble, 1987; Wagner et al., 1985). As a result, parental expectations and judgements on what the child should be achieving academically increase.

Caregivers' Perceptions of the Nondisabled Siblings

Most of the reported needs and concerns regarding the nondisabled siblings were related to family functioning. Contradicting much of the earlier research, individual characteristics such as aggression, depression, delinquency, and social isolation were not highly endorsed by the primary caregivers as being of concern. Instead, the impact that the child with a disability has on family communication and family roles was of greater concern. Caregivers pinpointed decreased time with parents and the increased responsibilities of the nondisabled child as areas of potential difficulty.

The needs caregivers perceive the nondisabled children as having further illustrate the concern and level of importance given to communication and awareness. Responses most often endorsed relate to the need for the nondisabled sibling to have knowledge about their brother or sister's disability, to visit the classroom, and to be able to communicate with others (e.g. teachers, children in similar circumstances). Although the caregivers in this study believe that their nondisabled siblings possess the skills in
explaining about their brother or sister's disability, they also recognize the importance of continued support and knowledge in this area.

**Caregiver Perception of Sibling Support Groups**

Based upon the findings of this study, sibling support groups do not appear to be a widely utilized or recognized service. Few respondents report having had children participate in a sibling support group, and many report knowing very little about such services. Considering the caregivers' emphasis on communication and the importance placed upon the nondisabled siblings' need to talk to others familiar with their situation, the low participation in sibling support groups is surprising. Sibling support groups, with emphasis placed upon bringing together individuals in similar circumstances to support, share, and impart knowledge, is a seemingly advantageous vehicle in meeting the needs of nondisabled siblings as expressed by the primary caregivers. In fact, of the respondents whose children participated in a sibling support group, the majority rated the experience as being helpful. Why then are few families utilizing the service? The problem appears to lie in the availability and knowledge of sibling support groups. Few groups exist, and many families in the community lack information on existing groups.

It also cannot be ignored that families with a child with a disability are likely to be pressed for time and resources (Herman & Thompson, 1995). As a result, consideration needs to be given to offering services in a manner that is least disruptive to the family. This study found that the convenience of group location as well as time involvement were the most frequently cited concerns with respect to participation. Given the concern that exists regarding increased demands that participation in a sibling support group may have on the family, it is not surprising that school was indicated most often in this study as the
preferred location for sibling support groups.

Limitations of the Study

The primary limitation of this study is the fact that information on the needs and functioning of nondisabled siblings of children with a disability was obtained from reports of primary caregivers rather than directly from the siblings. As a result, subjectivity as well as informer bias are factors which need to be considered in the conclusions being drawn regarding the behavioral, psychological, and academic functioning of the nondisabled siblings. This study is based upon the caregivers' perception of the nondisabled child, which may or may not be an accurate reflection especially as it relates to more internalized behaviors such as levels of unhappiness or depression.

Lack of control group is an additional limitation in that the nondisabled siblings' ratings on the BES-2 were unable to be compared with those of siblings without a brother or sister with a disability. Rating scale scores could be examined with respect to the variance accounted for by different variables as well as the frequency with which ratings fell below one standard deviation below the mean thus indicating a significant difficulty. It was not possible, however, to determine whether siblings of children with a disability are at increased risk compared to siblings of nondisabled children for psychological, behavioral, or academic difficulties, or the variance accounted for by different variables on their BES-2 scores.

Sample size and its impact upon the generalizability of results also limits this study's findings. The sample size was small and not representative with respect to handicapping condition and educational setting of the child with a disability. Although
Gallagher and Powell (1989), and Lobato (1983) contend that no significant difference can be found between type of disability and adjustment of the nondisabled sibling, research continues to be vague. As a result, it cannot be assumed that the results of the study generalize to other classifications as they are defined by IDEA. Additionally, because the sample was obtained through a BOCES setting, this study focused on nondisabled siblings of a brother or sister serviced in a self-contained BOCES setting. These findings cannot be assumed to generalize to nondisabled siblings of a brother or sister serviced in more inclusive settings.

Implications for Future Research

The findings of this study suggest that while nondisabled siblings of children with a disability do not appear to be at as great a risk for experiencing behavioral and psychological difficulties as once believed, they are a population with specific needs. A great amount of attention has been placed upon how variables such as family income, marital status, type of disability, age, and sex affect sibling adjustment. Some variables, such as the sex and age of the nondisabled sibling in this study, have been suggested to play a role in functioning. In consideration of this, an argument can be made regarding the importance of further examination of the factors affecting the adjustment of nondisabled siblings. Additional research, utilizing control groups, can be beneficial in further understanding whether siblings of children with a disability are a population at risk and what factors increase this risk. The argument can also be made, however, that it is time for a shift in focus.

Siblings of children with a disability do appear to have needs specific to growing up with a brother or sister with a disability. Needs for communication, support, and
knowledge about the brother or sister's disability, to name a few. Given this, it may be beneficial for research to focus on developing and implementing programs to meet these needs rather than to continue a search for a combination of variables that may provide little applicable information. In other words, it would be beneficial for research to examine what support should be provided to siblings of children with a disability, and effective manners in providing it, rather than analyzing why the support is needed. Researchers should seek to obtain information directly from siblings, and develop materials useful in helping schools and agencies engage in more effective communication and appropriate service provision to siblings of children with a disability.
References


Olmi, D. J. (1994). Review of the behavior evaluation scale-2. In J.C. Conoley & J.C. Impara (Eds.), The supplement to the eleventh mental measurements yearbook (pp. 29-30). Lincoln, Nebrasksa: University of Nebraska Press.


Appendix A. Sibling Needs Assessment Survey
# Sibling Needs Assessment Survey

To be completed by the primary caregiver.

The individual completing this survey has the following relationship to a child with a disability:

- Biological parent
- Foster parent
- Adoptive parent
- Step-parent
- Other

2. Please indicate your current marital status:

- Single
- Married
- Separated
- Divorced
- Remarried
- Widowed

3. Family Income:

- $0-20,000
- $21,000-40,000
- $41,000-60,000
- $61,000-80,000
- $81,000-100,000
- $100,000+

4. Your Ethnic Background:

- African American
- Asian American
- Caucasian
- Hispanic
- Native American
- Other. Please specify

5. Your Age:

- Under 20
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70

6. Area of residence:

- Rural
- Urban
- Suburban

7. Age of child with a disability:

8. Sex of child with a disability:

- Male
- Female

9. Educational placement of child with a disability:

- Included in regular classroom in home district
- Mainstreamed in some regular education classes in home district
- In a self-contained special education classroom in home district
- In special school setting (e.g. BOCES)
- In residential setting
- Other.

10. Classification of child's disability:

- Autistic
- Deaf
- Deaf-Blind
- Emotionally Disturbed
- Hearing Impaired
- Learning Disabled
- Mentally Retarded
- Multiply Disabled
- Orthopedically Impaired
- Other Health Impaired
- Preschool child with a disability
- Speech Impaired
- Traumatic brain injury
- Visually Impaired
11. Please rate the severity of your child’s disability: Please circle one number.
   1  2  3  4  5
   Mild  Moderate  Severe

12. Please indicate the age and sex of the siblings of child with a disability:
   1.____________________
   2.____________________
   3.____________________
   4.____________________
   5.____________________
   6.____________________

13. Siblings of children with disabilities have the following needs........please check all that you feel apply to your child(ren).

   ___ Information about brother/sister's condition
   ___ To talk with other children who have a sibling with a disability
   ___ To talk to a counselor on a regular basis
   ___ To have a teacher who is aware of the sibling’s condition
   ___ To talk to a school psychologist on a regular basis
   ___ More time with parent(s)
   ___ To visit sibling’s classroom
   ___ Additional support
   ___ No needs that differ from those of children without a sibling with a disability
   ___ Others. Please feel free to elaborate: ___________________________

14. Which of the following services related to your child’s disability has your family utilized in the past year?
   ___ Counseling
   ___ Respite care
   ___ Parent support groups
   ___ Case management service

15. My children have been involved in a sibling support group:
   ___ YES  ___ NO

16. If “YES”, how helpful was this involvement? Please circle one number.
   1  2  3  4  5
   Not at all  Somewhat  Very
   Please feel free to elaborate:

   ___________________________
   ___________________________
   ___________________________

17. If “NO”, please indicate reasons for no involvement in sibling support groups: Check all that apply.
   ___ Do not/did not know of any group available
   ___ Transportation difficulties
   ___ Did not feel it was needed
   ___ Child(ren) did not want to participate
   ___ Time constraints
   ___ Other. Please feel free to elaborate: ___________________________
   ___________________________
   ___________________________
   ___________________________
18. I believe that a sibling support group would be/would have been helpful to my child(ren).

___ YES  ___ NO  ___ NOT SURE
Please feel free to elaborate.

19. What factors would influence your willingness or ability to have your child(ren) participate in a sibling support group? Check all that apply.

___ Convenience of group location
___ Availability of transportation
___ Time involvement
___ Disruption to family schedule
___ Childcare
___ Others. Please feel free to elaborate.

20. Sibling support groups can be offered in a number of settings. Please indicate your location of choice.

___ At school, during the school day
___ At school, after school hours
___ Mental health agency
___ Support services agency
___ Local hospital
___ Other.
Please feel free to elaborate.

21. Please indicate which of the following concerns you have regarding the nondisabled children in your family. Check all that apply.

___ Aggression
___ Conflict with parents
___ Decreased time with parents
___ Delinquency
___ Depression
___ Increased responsibilities
___ Social isolation
___ Others.

22. Please indicate whether or not the following statements are "O"—often, "S"—sometimes, or "N"—never true with respect to the nondisabled sibling(s).

___ My child(ren) is/are able to explain to others about their brother/sister’s disability
___ We discuss my child(ren)’s feelings about his/her brother/sister’s disability
___ My child(ren) bring their friends to our house
___ My child(ren) express anger about the extra attention their brother/sister receives because of the disability
___ My child(ren) helps with the care of his/her/their/sibling with the disability
___ My child(ren) helps with the education or therapy of his/her/their sibling with a disability
Appendix B. Behavior Evaluation Scale-2, Home Version
Behavior Evaluation Scale - 2
Stephen B. McCarney, Ed.D.

HOME VERSION RATING FORM

Name of Child: ____________________________
School: ____________________________ Sex: __________
Class: ____________________________ Grade: __________
City: ____________________________ State: __________
Date of Rating: ____________________________ (year) __________
(month) __________ (day) __________
Date of Birth: ____________________________ (year) __________
(month) __________ (day) __________
Age at Rating: ____________________________ (year) __________
(month) __________ (day) __________
Rated by: ____________________________________________________________________________
Relationship to child: __________________________________________________________________

SUMMARY OF SCORES

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Sum of Subscale SS (Appendix B) __________ %ile (Appendix B) __________

TOTAL SCALE __________

HOME VERSION PROFILE

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Toll-Free number 1-800-542-1673

Page 4
TO THE PARENT OR GUARDIAN: Rate your child on every item using the quantifiers (1-7) provided. Use the number that best describes the behavior of your child in or around your home. All items MUST be rated. Leave no items blank.

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<th>MORE THAN ONE TIME A WEEK</th>
<th>MORE THAN ONE A DAY</th>
<th>MORE THAN ONCE AN HOUR</th>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

**SUBSCALE 1**

1. Has difficulty with short-term or long-term memory (e.g., does not remember directions, does not recall information previously learned, etc.)

2. Has difficulty understanding abstract concepts (e.g., time, distance, speed, units of measurement, etc.)

3. Has difficulty understanding what he/she sees, hears, reads, etc.

4. Requires repeated experiences to learn what others learn easily

5. Has a short attention span (e.g., does not sit still while a story is being read, does not keep his/her attention on homework assignments, is easily distracted, etc.)

6. Does not do homework (If your child does not yet receive homework assignments, rate the item 1.)

7. Does not study or prepare for tests or quizzes (If your child is not yet expected to take tests or quizzes, rate this item 1.)

8. Is careless, irresponsible, disorganized (e.g., loses things, forgets things, does not come home on time, is late for school, does not return things, etc.)

**Raw Score**

**Subscale Standard Score**

---

**SUBSCALE 2**

9. Fights with brothers, sisters, or friends

10. Makes inappropriate comments to brothers, sisters, or friends (e.g., argues, threatens, curses, calls names, teases, etc.)

11. Threatens adults (e.g., verbally or physically)

12. Becomes physically aggressive with adults (e.g., pushes, pulls away, grabs, hits, etc.)

13. Makes inappropriate comments to adults (e.g., argues, calls names, curses, makes rude comments, uses obscenities, talks back, etc.)

14. Responds inappropriately to friendly teasing (e.g., jokes, sarcastic remarks, name calling, etc.)

15. Does not share possessions or materials

---

**SUBSCALE 3**

23. Does not change behavior from one situation to another (e.g., gets excited and does not calm down, does not stop one activity and begin another, etc.)

24. Leaves the house without permission

25. Blames others for his/her mistakes or to avoid responsibility

26. Behaves more appropriately when alone or with one peer than with a group of peers

27. Is impulsive (e.g., reacts immediately to situations without thinking, is impatient, fails to wait, etc.)

28. Does not follow directions from parents or other home authority figures (e.g., refuses to do what he/she is told, goes on doing what he/she was doing, does the opposite of what he/she is told, etc.)

29. Ignores consequences of his/her behavior (e.g., knows that his/her behavior will get him/her in trouble but engages in the behavior anyway)

30. Lies, denies, exaggerates, distorts the truth

31. Gets angry when told he/she is wrong, told to do something a different way, etc.
32. Behaves inappropriately in the home (e.g., runs in the house, does not sit appropriately on the furniture, yells, etc.)

33. Does not behave appropriately in the community (e.g., runs in the shopping mall, pushes and makes noises in the line at the movies, yells in stores, etc.)

34. Behaves inappropriately in the presence of a baby-sitter, guest, or visitor (e.g., becomes overly excited, cannot be managed by these persons, etc.)

35. Does not care for personal appearance (e.g., grooming, clothing, etc.)

36. Does not eat at mealtime (e.g., is not ready to eat, is not hungry, does not like what is served, etc.)

37. Engages in inappropriate behaviors during mealtime (e.g., making noises, playing with food, playing with utensils, etc.)

38. Refuses to accept decisions made by parents (e.g., does not take "no" for an answer)

39. Is easily frustrated (e.g., gives up easily, does not put forth his/her best effort, etc.)

40. Behaves inappropriately when riding in the car (e.g., refuses to wear a seat belt, throws things out of the window, fights with others, etc.)

41. Does not go to bed on time, does not go to sleep, etc.

42. Does not get up on time

43. Steals or forcibly takes things from others

44. Engages in sexually-related behaviors (e.g., makes sexual comments, sexual gestures; touches self or others, exposes self, etc.)

45. Uses drugs or alcohol

46. Destroys other persons’ possessions or property in the community (e.g., deliberately destroys or vandalizes property)

47. Destroys things in the home (e.g., other persons’ possessions, furnishings, walls, etc.)

48. Demonstrates inappropriate behavior while walking or riding to and from school (e.g., fighting, throwing things out of bus windows, etc.)

49. Cheats in games or other competitive activities

50. Plays hooky, skips school, etc.

51. Plays with things that are potentially harmful (e.g., matches, cigarette lighters, knives, medicines, etc.)

52. Has extreme mood changes (e.g., from calm to angry, happy to sad, etc.)

53. Is unpredictable in behavior (e.g., does not respond consistently to situations in or around the home)

54. Does not accept change in established routine (e.g., change in time he/she will eat, guests in the home, etc.)

55. Fails to accept failure, losing, or being unsuccessful

56. Does not independently perform chores or responsibilities (e.g., has to be reminded, does not begin or complete responsibilities without assistance, etc.)

57. Is not motivated by rewards (e.g., cannot find a reward he/she enjoys)

---

**Raw Score**

**Subscale Standard Score**

**SUBSCALE 4**

58. Threatens to hurt self or commit suicide

59. Indicates that no one likes him/her, no one cares about him/her, etc.

60. Does not smile, laugh, or demonstrate happiness

61. Frowns, scowls, looks unhappy

62. Is pessimistic (i.e., thinks nothing will turn out right)

63. Is overly critical of self and abilities (e.g., says he/she is dumb, stupid, ugly, not good at sports, etc.)

64. Throws temper tantrums

---

**Raw Score**

**Subscale Standard Score**

**SUBSCALE 5**

65. Moves about unnecessarily (e.g., walks around, rocks, shakes head, etc.)

66. Makes statements that are disconnected, unrelated, or bizarre and unintelligible

67. Reacts physically in response to excitement, disappointment, surprise, happiness, fear, etc. (e.g., flaps hands, shudders, stutters, stammers, trembles, etc.)

68. Speaks in an unnatural voice (e.g., high voice, low voice, etc.)

69. Deliberately hurts self or damages own property or clothing

70. Demonstrates phobic-type reactions (e.g., fear of school, meeting people, trying new experiences, etc.)

71. Is uncomfortable with new situations (e.g., first day of school, swimming lessons, dancing, etc.)

72. Complains of not feeling good to keep from going to school or doing things he/she does not want to do

73. Is tired, listless, apathetic, unmotivated (e.g., has little or no interest in home-related activities, does not care about school, grades, graduating, consequences of behavior, etc.)

---

**Raw Score**

**Subscale Standard Score**

**Sum of Subscale Standard Scores**

**Percentile Score**
GUIDELINES FOR RATING THE CHILD OR YOUTH

- The child or youth should be rated by parents, guardians, houseparents, etc., with primary observational opportunities. These persons would usually be persons who live with the child or youth in his/her home or living quarters.

- Any number of persons may rate the child or youth if they are considered familiar with his/her behavior in the home or other residential environment.

- It is not necessary to complete the rating for a child or youth in one sitting. Several days may elapse before the observer is able to complete the scale.

- The observer should rely on observations of the child or youth's behavior on the scale as the behaviors occur naturally in the home or residential environment.

- Demographic information should be completed on page four of the rating form.

- Should a parent, guardian, etc., rating a child or youth have no knowledge of him/her having engaged in a particular behavior on the scale, it is a must that the item be rated a 1: NOT IN MY PRESENCE. Do not leave any items blank.
Appendix C. Parent Letter for Pilot Study
Dear Parent(s),

In cooperation with Monroe #1 BOCES, I am conducting a Master's thesis study on the needs of siblings of children with disabilities. I would like to determine what parents perceive to be the needs of the nondisabled siblings in the family so that schools may be more informed in working with families and, in particular, siblings of children with disabilities. As parents, you know your children best, and your input is critical.

Enclosed is a brief survey and behavior rating form that should take about 15-20 minutes to complete. The survey questions inquiring about the child with a disability should be completed based upon the child with whom this survey was sent home. The survey questions on the nondisabled siblings in your family are based upon your perceptions of the needs of a nondisabled child in your family. Please complete the behavior rating form based upon the behavior of your nondisabled child who is in grades K-12 and is closest in age to the child with whom this survey was sent home. Completed materials can be sealed in the enclosed envelope and returned to school.

If there are no nondisabled children in your family, or no nondisabled children in grades K-12, the survey and behavior rating form will not apply. Checking off the appropriate line below and return of the uncompleted material would be greatly appreciated.

I believe that this study will help us better understand the needs of siblings of children with disabilities and I hope that you will participate. No identifying information is desired so please do not sign your name to any of the forms. You have the right to refrain from answering any of the questions on the survey or behavior rating form.

Please feel free to contact me at 385-0506 with any questions, or if you would like to receive the general findings of the study. Thank you and I look forward to your input.

Please check one of the following:

____ Survey & rating form completed
____ Survey & rating form not completed because...
    ____ No nondisabled siblings or none in grades K-12
    ____ Do not wish to participate

Sincerely,

Lynn Carragher
School Psychology Master's Candidate
Rochester Institute of Technology
Appendix D. Parent Letter for Primary Study
Dear Parent(s),

In cooperation with Monroe #1 BOCES, I am conducting a Master’s thesis study on the needs of siblings of children with disabilities. I would like to determine what parents perceive to be the needs of the nondisabled siblings in the family so that schools may be more informed in working with families and, in particular, siblings of children with disabilities. As parents, you know your children best, and your input is critical.

Enclosed is a brief survey and behavior rating form that should take about 15-20 minutes to complete. Again, I am exploring the needs of siblings of children with disabilities. If there are no nondisabled children in grades K-12 in your family, the survey and behavior rating form will not apply. Please check the appropriate line below, seal the completed or uncompleted material in the enclosed envelope, and return it to school with your child by Wednesday, October 22nd.

I believe that this study will help us better understand the needs of siblings of children with disabilities and I sincerely hope that you take a few minutes to participate. No identifying information is desired so please do not sign your name to any of the forms. You have the right to refrain from answering any of the questions on the survey or behavior rating form.

Please feel free to contact me at 385-0506 with any questions, or if you would like to receive the general findings of the study. Thank you and I look forward to your input.

Please check one of the following:

_____ Survey & rating form completed
_____ Survey & rating form not completed because...
    ___ No nondisabled siblings in grades K-12
    ___ Do not wish to participate

Sincerely,

Lynn Carragher
School Psychology Program
Rochester Institute of Technology
Appendix E. Letter from Principal of Creekside School
October 9, 1997

Dear Parents and Guardians,

Attached please find a Sibling Needs Assessment Survey to be completed by the primary caregiver. This survey is very important because it presents a way to acknowledge and identify the needs that the nondisabled siblings have, which may include but not limited to, developing a level of understanding of expectations for them, and the level of support and guidance required to follow through with those expectations. The results of this survey will also confirm the need to proceed to the process of planning, developing and implementing strategies to meet those needs.

This is a very exciting project and we are very pleased that Ms. Lynn Carragher has invited our families to have the opportunity to provide input for this special study.

Thank you for your efforts in this matter. Please don’t hesitate to contact me at 383-2239 if there are further questions or comments regarding this survey.

Sincerely,

Rena H. Gaspard, Principal, Creekside School

cc: Mr. John Campolieto, Assistant Superintendent, BOCES #1 Monroe
    Ms. Bernie Maurer, Director of Student Admissions, BOCES #1, Monroe
Appendix F. Cover Sheet for Behavior Evaluation Scale-2
Primary Caregivers,

This form may appear lengthy, but it will only take about 10 minutes to complete. Your answers can help us determine whether siblings of children with disabilities have needs that differ from children who do not have a sibling with a disability.

Beginning on page 2, you will find questions asking you to rate the frequency of behaviors your child may or may not exhibit. The purpose of this rating form is to examine the behaviors of siblings of children with disabilities. Therefore, please rate the behavior of your nondisabled child who is closest in age to your child with a disability. No information pertaining to your child with a disability is needed on this rating form.

Please also provide the following information:

1. The birthdate of the nondisabled child whose behavior you are rating.
   
   Month__________  Day__________  Year___________

1A. Child’s sex______________

2. The date you are completing this form____________________

3. Your relationship to the child you are rating:____________________

Again, thank you for your willingness to assist me in exploring the needs of siblings of children with disabilities. Your time and input are greatly appreciated.
Appendix G. Revised Sibling Needs Assessment Survey
**Sibling Needs Assessment Survey**

To be completed by the primary caregiver

1. The individual completing this survey has the following relationship to a child with a disability:
   - [ ] Biological parent
   - [ ] Foster parent
   - [ ] Adoptive parent
   - [ ] Step-parent
   - [ ] Other

2. Please indicate your current marital status:
   - [ ] Single
   - [ ] Married
   - [ ] Separated
   - [ ] Divorced
   - [ ] Remarried
   - [ ] Widowed

3. Family Income:
   - [ ] 0-20,000
   - [ ] 21,000-40,000
   - [ ] 41,000-60,000
   - [ ] 61,000-80,000
   - [ ] 81,000-100,000
   - [ ] 100,000+

4. Your Ethnic Background:
   - [ ] African American
   - [ ] Asian American
   - [ ] Caucasian
   - [ ] Hispanic
   - [ ] Native American
   - [ ] Other. Please Specify

5. Your Age:
   - [ ] Under 20
   - [ ] 21-30
   - [ ] 31-40
   - [ ] 41-50
   - [ ] 51-60
   - [ ] 61-70

6. Area of residence:
   - [ ] Rural
   - [ ] Urban
   - [ ] Suburban

7. Age of child with a disability:______

8. Sex of child with a disability:
   - [ ] Male
   - [ ] Female

9. Educational placement of child with a disability:
   - [ ] Included in regular classroom
     - [ ] in home district
   - [ ] Mainstreamed in some regular education classes in home district
   - [ ] In a self-contained special education classroom in home district
   - [ ] In special school setting, (e.g. BOCES)
   - [ ] In residential setting
   - [ ] Other. ______________

10. Classification of child's disability:
    - [ ] Autistic
    - [ ] Deaf
    - [ ] Deaf-Blind
    - [ ] Emotionally Disturbed
    - [ ] Hearing Impaired
    - [ ] Learning Disabled
    - [ ] Mentally Retarded
    - [ ] Multiply Disabled
    - [ ] Orthopedically Impaired
    - [ ] Other Health Impaired
    - [ ] Preschool child with a disability
    - [ ] Speech Impaired
    - [ ] Traumatic brain injury
    - [ ] Visually Impaired

*Questions 7-10 should be based upon the child with whom the survey came home.*
11. Please rate the severity of your child's disability: Please circle one number.
   1  2  3  4  5
   Mild  Moderate  Severe

12. Please indicate the age and sex of the siblings of child with a disability:
   1.________________________
   2.________________________
   3.________________________
   4.________________________
   5.________________________
   6.________________________

13. Siblings of children with disabilities have the following needs.......please check all that you feel apply to your child(ren).
   ___ Information about brother/sister's condition
   ___ To talk with other children who have a sibling with a disability
   ___ To talk to a counselor on a regular basis
   ___ To have a teacher who is aware of the sibling's condition
   ___ To talk to a school psychologist on a regular basis
   ___ More time with parent(s)
   ___ To visit sibling's classroom
   ___ Additional support
   ___ No needs that differ from those of children without a sibling with a disability
   ___ Others. Please feel free to elaborate: ______________________

14. Which of the following services related to your child's disability has your family utilized in the past year?
   ___ Counseling
   ___ Respite care
   ___ Parent support groups
   ___ Case management service

15. My children have been involved in a sibling support group:
   ___ YES  ___ NO

16. If "YES", how helpful was this involvement? Please circle one number.
   1  2  3  4  5
   Not at all  Somewhat  Very
   Please feel free to elaborate:
   __________________________________________
   __________________________________________
   __________________________________________

17. If "NO", please indicate reasons for no involvement in sibling support groups: Check all that apply.
   ___ Do not/did not know of any group available
   ___ Transportation difficulties
   ___ Did not feel it was needed
   ___ Child(ren) did not want to participate
   ___ Time constraints
   ___ Other. Please feel free to elaborate: ______________________
   __________________________________________
   __________________________________________
   __________________________________________
18. I believe that a sibling support group would be/would have been helpful to my child(ren).

_____ YES  _____ NO  _____ NOT SURE
Please feel free to elaborate.
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

19. What factors would influence your willingness or ability to have your child(ren) participate in a sibling support group? Check all that apply.

_____ Convenience of group location
_____ Availability of transportation
_____ Time involvement
_____ Disruption to family schedule
_____ Childcare
_____ Others. Please feel free to elaborate. ____________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

20. Sibling support groups can be offered in a number of settings. Please indicate your location of choice.

_____ At school, during the school day
_____ At school, after school hours
_____ Mental health agency
_____ Support services agency
_____ Local hospital
_____ Other.
Please feel free to elaborate.
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

21. Please indicate which of the following concerns you have regarding the nondisabled children in your family.
Check all that apply.

_____ Aggression
_____ Conflict with parents
_____ Decreased time with parents
_____ Delinquency
_____ Depression
_____ Increased responsibilities
_____ Social isolation
_____ Others.
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

22. Please indicate whether or not the following statements are "O"—often, "S"—sometimes, or "N"—never true with respect to the nondisabled sibling(s).

_____ My child(ren) is/are able to explain to others about their brother/sister's disability
_____ We discuss my child(ren)'s feelings about his/her brother/sister's disability
_____ My child(ren) bring their friends to our house
_____ My child(ren) express anger about the extra attention their brother/sister receives because of the disability
_____ My child(ren) helps with the care of his/her/their sibling with the disability
_____ My child(ren) helps with the education or therapy of his/her/their sibling with a disability
Appendix H. Teacher Letter
October 15, 1997

Monroe #1 BOCES
41 O'Connor Rd.
Fairport, NY 14450

Dear Teachers:

I am conducting a master’s thesis study on the needs of siblings of children with disabilities. I would like to determine what parents perceive to be the needs of the nondisabled siblings in the family so that schools may be more informed in working with families and, in particular, siblings of children with disabilities. Through the cooperation of BOCES #1 Administrative Coordinator, Bernie Maurer, and Assistant Superintendent, John Campolieto, I have been granted permission to survey the parents of children who attend Creekside, Lois E. Bird, and Morgan Schools. As I hope to accomplish this study by having parents complete material sent home with the children, I am requesting your participation.

I have prepared packets containing a letter and survey material to be sent home today with the children. I am asking that parents send the completed material back to school with their child within one week. A box will be placed in the main office for returned material. There is nothing for you as the teachers to complete. I only ask that you assist me in the distribution and collection of the material to and from the children.

Should you receive any inquiries from parents, I have attached a copy of the parent letter. If you are interested in viewing the survey material being sent, a copy has been given to Rena Gaspard. Rena and I sincerely believe that this study will be beneficial in better assessing the needs of siblings of children with disabilities and would appreciate your help in seeing that we get a high response rate. Also, if you know that a student in your class does not have a nondisabled sibling, please do not send the packet home, but rather return it to the office and indicate that on the envelope.

If you have any questions or would like to receive the general results of the study, please feel free to contact me at 385-0506. Thank you for your help.

Sincerely,

Lynn Carragher
School Psychology Program
Rochester Institute of Technology
Appendix I. Follow Up Letter
Dear Parent(s),

One week ago, I sent a packet home with your child and requested your participation in a project to examine the needs of siblings of children with disabilities. I would like to thank those of you who have taken the time to complete the material. Your input is truly appreciated! I would also like to thank those of you who sent the material back and indicated that it was not applicable to your situation. I can more accurately determine my response ratios if I know whether surveys are not completed because the material is not applicable or because an individual does not want to participate.

If you have not yet completed the material, I would greatly appreciate your doing so. The higher the response, the more information we will gain in serving the needs of families of children with a disability. I would very much like to hear what you, as parents, think about this topic. So please take this opportunity to share your opinion and observations by completing the survey and rating form and returning it to school with your child by Wednesday, October 29th. If you have any questions, concerns, ideas, etc., please do not hesitate to contact me at 385-0506. Thank you!

Sincerely,

Lynn Carragher