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A STUDY OF RESOURCES AND SUPPORT NEEDED FOR FAMILIES OF STUDENTS RECEIVING SPECIAL EDUCATION SERVICES

An Education Specialist Field Project
Presented to the
Department of Educational Administration
and the
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University of Nebraska at Omaha

by
Janis Norgaard
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EDS FIELD PROJECT ACCEPTANCE

A STUDY OF RESOURCES AND SUPPORT NEEDED FOR FAMILIES OF SPECIAL EDUCATION STUDENTS

BY

JANIS NORGAARD

Acceptance for the faculty of the Graduate College, University of Nebraska, in partial fulfillment of the requirements for the Specialist in Education degree, University of Nebraska at Omaha.

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Abstract

A STUDY OF RESOURCES AND SUPPORT NEEDED FOR FAMILIES OF SPECIAL EDUCATION STUDENTS

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University of Nebraska at Omaha, 2001-

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The purpose of this study was to identify the use of resources and support needed by families of children with disabilities. The study also examined the perceptions of importance regarding resources and support by families of children with disabilities, the relationship of size of the school district and use and perceptions of importance of resources and the relationships of time since initial identification of the child's disability and the use and perceptions of importance of resources and support.

This quantitative study used Hornby's (1975) theoretical model for parental involvement for the development of a survey that was administered to parents of children with disabilities. The design of the survey instrument was organized around four areas: communication, liaison/advocacy, education and support. Parents of children with disabilities within the geographical area of Loess Hills Area Education Agency in southwest Iowa identified levels of usage and perceptions of importance. The responses to the survey were analyzed using frequency distributions, one-way analysis of variances (ANOVAs), and Pearson product-moment correlation coefficients.

The results of this study were: (1) fifteen resources and support systems have varying levels of usage by parents of children with disabilities; (2) seventeen resources and support systems have varying perceptions of importance of need by parents of children with disabilities; (3) size of the school district did not result in a statistically significant difference in use and perceptions of importance, except for categories related to communication with other parents of children with disabilities and use of school personnel for information; and (4) the time since the initial identification of the disability did not result in a statistically significant difference in parents' use and perception of importance of resources and support systems. The information gained from this study was useful to school districts and other service providers who collaborate with parents of children with disabilities in meeting their needs.

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Chapter 1

Introduction

Current issues in education have caused school districts across the nation to restructure or redesign their systems. The standards movement, assessment practices and accountability have all been set in motion as a result of a variety of change forces. Economic, social and technological forces have had an impact on many of the traditional systems. Increased attention on the rights of individuals has been a change force that has resulted in legislative and political backing. Beginning with the Civil Right movements in the 1950s, forces that increased the value of individual rights commenced. Evidence of the forces for individuals was supported with the passage of Title IX, which allowed more opportunities for females. The Vocational Rehabilitation Act in 1973 pushed schools to redesign and remodel existing structures in order to provide equal accessibility. The most notable legislative act that promoted the rights of individual students was the historical passage of P.L. 94-142 in 1975, later reauthorized as the Individual Disabilities in Education Act (IDEA) in 1997. These legislative acts put in place rights and due process for students with disabilities and their parents that were not guaranteed previously (Conley, 1993).

Parents and families of special education students began to access services and collaborate with school personnel at different levels not accepted prior to the legislative foundation. The legislative foundation guarantees parents' basic rights and allows parents to become active participants in the development and implementation of the child's Individual Education Program (IEP). The law validates the roles of members of a decision-making team that support collaboration between parents and schools. Collaborative actions and exchanges between parents and schools identify the support needed for students with disabilities. The services and resources are clearly identified in each child's IEP.

According to IDEA '97, initial identification of individuals with disabilities can occur anytime from birth through the age of 21. The responses from parents and families of children with disabilities following the initial identification can be emotionally charged and can often leave the families with an intense feeling of helplessness. The emotions and responses of parents and families continue to evolve and change as the child grows and develops. By recognizing the emotional responses of parents and families, school personnel can respond by providing the support and resources needed in order to develop and maintain a collaborative system to meet the needs of students with disabilities.

Recognizing the level of emotional turmoil and acceptance is often not a priority with school personnel as each student's IEP is developed. By failing to recognize or acknowledge the parents' level of emotional needs, barriers in communication that interfere with mutual collaboration often develop. In addition, the resources and support parents and families may need differ and change in each individual situation. Can school personnel recognize the emotional level and needs of parents and families of a child with disabilities? What support and resources can school systems and personnel provide parents and families to foster mutual collaboration and unify efforts to ensure that each child with disabilities is provided the opportunity to develop to his/her full potential?

Purpose of the Study

The purpose of this study was to identify the type of resources and support that parents and families are currently accessing or using to meet the needs of their children with disabilities. The study also identified resources and support that parents perceive as important and needed. The study examined the resources and support structures to determine if there exists a relationship between the identified resources and support and (a) the size of the school district the child attends and/or (b) the time span since initial identification.

Research Questions

The research questions guiding this study are:

- What are the resources and support that parents are currently using or have used to assist them in meeting the needs of their child with disabilities?
- What resources and support do the parents perceive as important in meeting the needs of their child with disabilities?
- What relationship is there between the resources and support that parents are currently using or have used and the size of the school district in which the child with disabilities is enrolled?
- What relationship is there between the resources and support that parents perceive as important and the size of the school district in which the child with disabilities is enrolled?

- What relationship is there between the resources and support that parents of children with disabilities currently use or have used and the time since the initial identification of the disability?
- What relationship is there between the resources and support that parents of children with disabilities perceive as important and the time since the initial identification of the disability?

Theoretical Framework

The involvement of parents in education was initially led by practice versus a specific theory. Theoretical models have evolved that provide schools with the frameworks to review policy and practices to ensure that parents' needs are met and contributions to the educational processes are being made. Hornby (1995) developed a theoretical model for parental involvement that was based on other existing models (Bastiani, 1989; Kroth, 1985; Lombana, 1983; Wolfendale, 1992). Figure 1 shows the model for parental involvement that consists of two pyramids. One of the pyramids represents the hierarchy of parents' needs. The other pyramid represents the hierarchy of parents' strengths and possible contributions. Both pyramids recognize the different levels of needs and contributions. The hierarchy represents that all parents have some needs and have contributions that can be utilized at some time. As parents' needs approach a higher level, the time and expertise of teachers and school systems required to meet the parents' needs increase. Likewise, as parents make greater contributions to teachers and school systems supporting the needs of the child, higher levels of expertise and time by the parents are involved.

Model for Parent Involvement

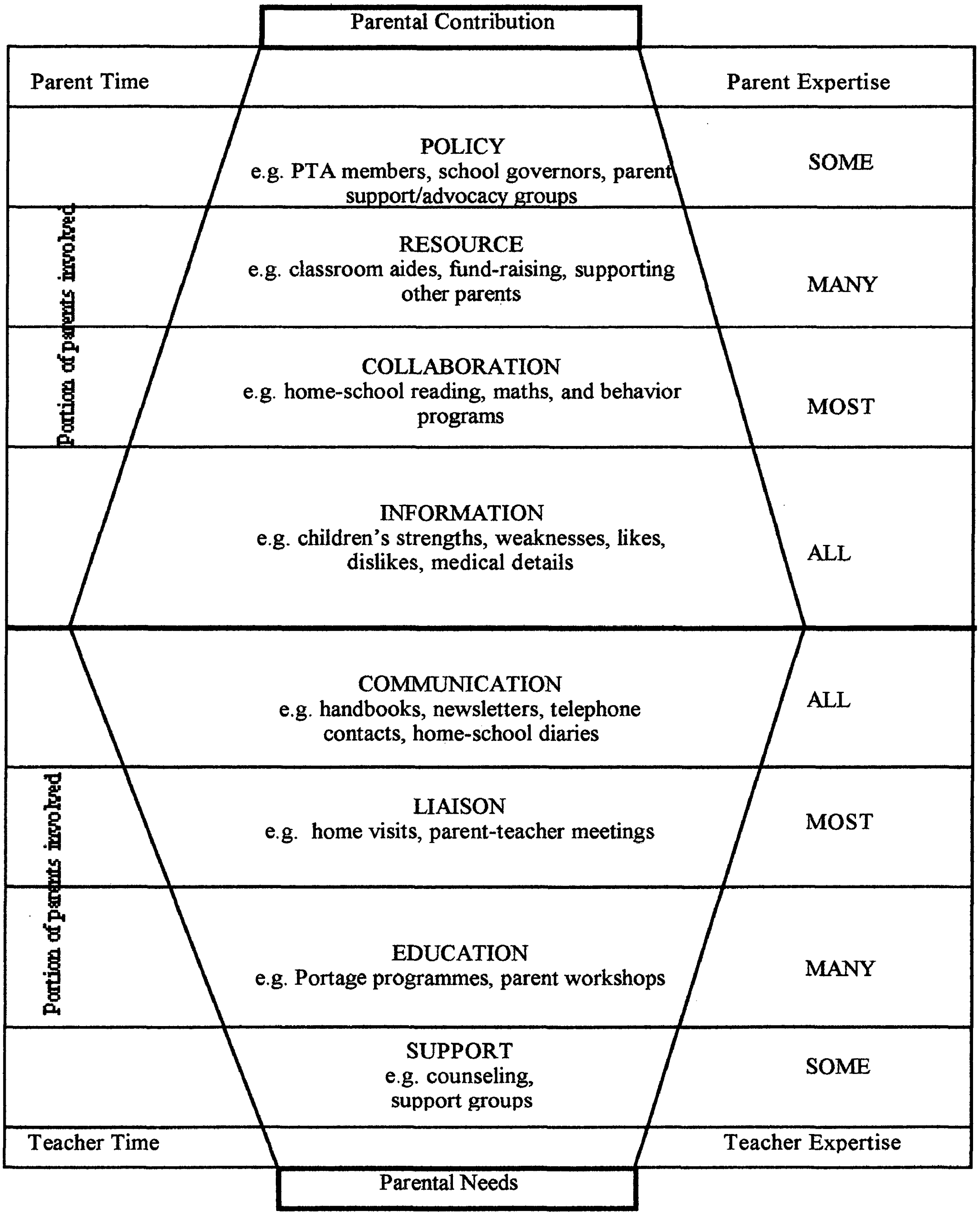

Figure 1. (Hornby, 1995, p. 24)

Definition of Terms

The following terms are used throughout the study.

- Collaboration is the mutual relationship between parents of children with disabilities, educational systems and other systems of support.
- Educational systems are the systems and support structures that are available within the public school system.
- Children with disabilities are children from birth to the age of 21 who have been identified as having a disability that qualifies for all the services and due process rights identified in IDEA '97.
- Parent needs are the services, resources and support that parents are seeking to support the needs of their child with disabilities.
- Resources and support are the specific services that are currently being accessed or needed by parents. The resources and support vary in types including information/education, communication, liaison/advocacy and support systems.

Delimitations and Limitations of the Study

The study was delimited to surveying parents of children with disabilities in a limited geographical area. Parents of children with disabilities who reside and receive services within the boundaries of Loess Hills Area Education Agency (AEA 13) in southwest Iowa were surveyed. The limited area decreased the generalizability to other regions. The survey was administered to a limited number of parents of children with disabilities with variance in household design, age of child, types of disabilities and size of school district in which child is or was enrolled. Knowledge and accessibility of resources and support available differ from various areas within the State of Iowa and across the nation. A limitation to the study was the interpretation by the participants in the study to the degree of current use and the perception of need.

Significance of the Study

The intent of this study was to provide information useful in improving the resources and support that school systems can provide parents and families of children with disabilities. This study is significant for several reasons. Although federal legislation has mandated that schools and parents work collaboratively in a decision-making model to determine the needs and services for students with disabilities, the specific resources and support that parents need in order to be active members in their child's world are often not identified. This study identified the specific resources and support that parents are currently accessing and the resources and support that parents perceive as important. The size of the attending school district was a factor in comparing the various resources and support. The study also addressed the relationship between the type of resource and support and the time since the initial identification of the disability.

This study was designed to provide school systems and personnel with the information to guide the on-going development of resources and support currently in place in school systems and those that need to be developed or enhanced to assist parents of children with disabilities. In addition, school systems and personnel may be able to prioritize and channel the financial resources needed in the support structures as a result of the study.

Chapter 2

Review of Literature

The collaborative efforts between parents and school systems have been in place since the beginning stages of the formalized school structures. The type and degree of mutual collaboration changes if the child who is the focus has an identified disability. The literature review of the study will first address the phases of concern and acceptance that parents of children with disabilities evolve through following the initial identification of a disability. Then, the needs of parents in a collaborative relationship between home and school will be identified in this review, including the rationale for collaboration and different types of collaborative efforts. Legislation that supports the rights of children and students with disabilities will be discussed. The theoretical framework and a summary of the desired support of parents from the school system will be presented. This summary will provide the rationale for a survey instrument designed to address the services and support school systems have available and those that need to be enhanced in order to meet the needs of parents and children with disabilities.

Phases of Acceptance

Reactions

The preparation of becoming parents begins before a child is born. During the in vitro phase, mothers and fathers enter the preparation for parenthood by developing images of the type of parents they wish to become. Future parents continue the processes of envisioning the responsibility of raising a child. These images often include the fear of giving birth to a child who may be disabled.

Initial identification of a disability of a child can occur prior to birth, at the time of birth or at later points in the child's life. The reaction of parents to the initial identification is similar to the stages associated with mourning and grief (Cohen, 1982; Hornby, 1995; Shea & Bauer, 1985; Simpson, 1982). Kübler-Ross (1969) identified the stages in relation to death and dying.

First Stage: Denial and Isolation
Second Stage: Anger
Third Stage: Bargaining
Fourth Stage: Depression
Fifth Stage: Acceptance

Hornby (1995) developed a model that displays the continuum of stages of reactions parents may go through until a mature emotional adjustment to the situation associated with having a child with a disability is achieved. The movement from the feelings of isolation and denial to those of a willingness to become active participants represents the various phases or reactions to a child's disability similar to the model by Kübler-Ross (1969).

- Shock: Upon the initial identification of having a child that is disabled, parents report a reaction of shock with accompanying feelings of helplessness and confusion. The length of this phase can last from a few hours to several days.
- Denial: The disbelief that the situation is real or that a mistake has been made can have parents seeking second opinions. When professionals disagree about identification or progress, the stage of denial by the parents becomes only more

prolonged or intense. There is a need by parents at this stage to have information that is accurate, objective and honest.

- Anger: Feelings of guilt about being responsible for a child with disabilities can lead parents to seek a cause of the disability or to search for someone to blame. These reactions can often result in behavior by the parents that could be identified as hostile or aggressive.
- Sadness: Loss of opportunities and goals for a child or family may result in a reaction of sadness, depression and despair that can pervade occasionally through the continuum of acceptance and other milestones in the child's development.
- Detachment: The reactions of hopelessness by parents, feeling empty, and that life has lost meaning may be a turning point in the parents' acceptance of reality. McDowell in Parents and Teachers of Exceptional Students: A Handbook for Involvement by Shea and Bauer (1985) identified this point as a stage when parents frequently respond by seeking professional help and assistance.
- Reorganization: Parents begin to be realistic in the situation and the future. The focus begins to change from opportunities missed to possibilities for the future.
- Acceptance: Parents are fully aware of the special needs of the child and set goals to provide for the child. The engagement of the child as a regular member of the family to maximum extent possible occurs.

Having a child with disabilities also has an effect on the members of the family. Hornby (1995) stated that mothers tend to move through the emotional and adaptation processes quicker than fathers due to a greater accessibility of resources for support.

Fathers often demonstrate reactions associated with denial to avoid feelings about the situation that could lead to depression and personality difficulties. Marital relations may be in a state of conflict due to the different levels of parents' acceptance of the child's condition.

Crisis Periods

Although there is no significant difference in the reactions of parents based on certain categories of disabilities (Marion, 1981), parents of children whose disability was obvious at birth were better able to cope with the various feelings and emotions. Various emotions may resurface as the child passes through developmental stages. Hammer (1972) identified six critical periods of stress in the lives of families with children with disabilities and associated the parental needs at these critical periods.

1. At birth or upon suspicion of the disability - the need for emotional understanding and support.
2. At time of diagnosis and treatment of the disability - the need for information and facts.
3. As the child nears age of school placement - the need to be an active participant in planning.
4. As the child near puberty - self-needs for present and future issues, including sexual needs, peer relationships and behavior responses.
5. As the child nears the age of vocational planning - the need for a thorough and dynamic understanding of roles.

6. As parents age and the child may outlive them - the need for present and future expectations.

Simpson (1982) stated that the stages of critical stress that correspond to the developmental age of the child with disabilities (Hammer, 1972) determine the various services and support that parents and families need. Simpson (1982) identified the four stages:

- Preschool - information on developmental expectations, home and community-based resources and programs, emotional support;
- Elementary - information on academic and social progress, strategies to develop partnerships with school personnel, mechanisms for influencing policies;
- Adolescents - information and channels on responding to issues such as sex, drugs, alcohol and rebellious behavior; and
- Young adults - information for facilitating independence and adjustment to post-secondary options in regard to community, living and vocational issues.

In summary, the reactions of parents and families to having a child with a disability are an emotional continuum from the initial reactions of confusion and helplessness to the acceptance of becoming fully aware of the child's special needs and striving to meet the needs. The various emotional reactions can resurface at transitional points in a child's development, which has an impact on the support and information that parents and families need.

Needs of Parents and Families

As parents and families continue to identify and respond to their own reactions, there are critical issues that need to be addressed (Marion, 1981). The critical needs of parents and families of children with disabilities are:

1. Emotional understanding and support
2. Information and facts
3. Active participation in planning and habilitation
4. Identification of themselves as parents, as participating members of the community, and as competent individuals within themselves
5. Thorough understanding of their role in the habilitation process
6. Knowledge of present and future expectations of the child with disabilities.

The ecological model of family functioning (Hornby, 1995) identified four different levels of influences and interactions with the family and other social systems. This model recognizes the factors and variables that affect the parents and families caring for a child with disabilities.

The microsystem level is at the core of family functioning. Variables that impact at this level are the severity of the disability, age of initial diagnosis, birth order in the family, parents' ages, personalities, socioeconomic status, and quality of the parents' marriage. The level of functioning at the microsystem level is dependent on how the variables influence the nuclear family.

The next level of functioning is the mesosystem level. This level includes the interactions and reactions with extended family members, neighbors, and community members. The relationships with individuals and agencies outside the immediate family can influence the degree of needs and acceptance that parents and families of children with disabilities require.

The exosystem level of functioning consists of social systems that can affect the families, including health, education and social services. The availability and quality of services have a critical influence on the functioning of the family unit.

The level that identifies and associates itself with the beliefs, attitudes and values that support the family of a child with disabilities is the macrosystem level. This level of influence has been instrumental in the development of legislation for children with disabilities that identifies and establishes the needed support and resources.

Legislation

The involvement of parents of children with disabilities has been the driving force in many of the major legislative actions (Cohen, 1982). The Plowden Report in 1967 (Hornby, 1995) recognized and acknowledged the benefits of involving parents in determining the needs and resources for children. In 1971 the Pennsylvania Association for Retarded Children promoted legislation that guaranteed a free and appropriate education for all children, including children with disabilities (Berger, 2000). The Vocational Rehabilitation Act - Section 504 of 1973 stated that there would be no exclusion of individuals due to disabling conditions.

P.L. 94-142 or Education for All Disabled Children Act in 1975 provided the foundation for the expectations of the educational systems in meeting the needs of children with disabilities from the ages of 5 to 17. P.L. 94-142 was reauthorized in 1997 as P.L. 105-17 or the Individuals with Disabilities Education Act Amendments, known as IDEA (IDEA'97 Amendments, Final Regulations, 1999). IDEA '97 strengthens the academic expectations and continues to bridge the differences between what children with disabilities learn and the requirements of children in the mainstream of regular education. IDEA '97 identifies parents as full-participating members in the decision-making processes of the child's educational program. Parents have the right to participate and to obtain and access information. Parents must be notified prior to any evaluation and placement in programs.

The extension of including parents and families with children with disabilities from birth to three was supported in the legislative actions known as P.L. 98-199 in 1983 and P.L. 99-457 in 1986. These amendments to the original legislation in 1975 supported early intervention services for infants, toddlers and families with children with disabilities (Berger, 2000).

The rights of children with disabilities and their families have only been in place for approximately the last 25 years. The legislative foundation validates that parents are active members of the child's program and supports the need for collaboration between parents and educational personnel.

Rationale for Collaboration

The research indicates that parents and families of children with disabilities have specific needs to assist them in their continuum of understanding and acceptance. Legislative actions have responded to the needs by setting in place structures that guarantee rights to the families and children with disabilities. From birth to the time when post-secondary options are available, the educational system is the primary vehicle to assure the rights of children with disabilities are being met.

Parents and families historically have not been perceived as a resource in the development of the plan for the child with disabilities, even though the parents and families represent the most economical and available resource (Simpson, 1982). The perception of avoiding or lessening the importance of the parents' input is based on the traditional belief systems by educators that view "parents as problems, adversaries, vulnerable, less able, needing treatment, causal, and needing to be kept at a 'professional' distance" (Hornby, 1995, p. 4).

In the study by Pruitt, Wandry and Hollums (1998), 73 families with children with disabilities identified that school systems need to be more sensitive and demonstrate a level of respect regarding the needs of families. Seventy percent of the responses of families indicated that educators should realize that parents know and understand the identified child and that their contributions are valuable. Educators are encouraged to see the family's point of view and get to know the family more in depth. Sensitivity and the development of respect between parents and educators are promoted with the focus on effective communication. Communication is the key to beginning, developing and maintaining an effective partnership. Keys to effective communication include actively listening to each other, demonstrating trust and respect, and collaborating with honest and open appreciation (Shea & Bauer, 1985).

A conclusion of a study of nine cases for family involvement (Center for Effective Collaboration and Practice, 1998b) identified three categories of strategies for implementing collaborative processes. The categories include: (1) structural elements; (2) relationship-building strategies; and (3) engaging families and communities in collaborative processes. The study states that "the emergence of families as full partners in systems of care is the key to true and lasting collaboration" (p. 4). The process of involving the family evolves from viewing the family as a client, to a guest, to a participant, to the actualization that the parent is a full partner in the collaborative efforts.

The development of a comprehensive system that supports and provides appropriate child-centered and family-centered services was concluded in a study of systems of partnerships with families and service systems (Center for Effective Collaboration and Practice, 1998a). The service systems include school systems, as well as social, medical and mental health providers. By strengthening the role and empowering the family members in the development of the plan of services, a unified collaborative effort is established. The need for collaboration between parents and schools at the various levels of child development, including young children and adolescents, is supported in additional studies (Coleman, 1991; Indiana State Department of Education, 1996; Primer & Brown, 1995; Robertson, 1997).

Collaboration between parents and schools is a necessary component when addressing the needs and services for children with disabilities. Efforts for collaboration are not only best practices in special education today but are also mandated through recent federal legislation, IDEA ' 97.

Expectations of Collaboration

Hornby (1995) conducted a study of educators and parents of children with disabilities. The study identified that there are some key elements of support that parents are seeking from educators and school systems. The fundamental elements are:

- Consulting with the parents and families, including listening to their point of view.
- Allowing the parents to be part of the decision-making processed in the planning and implementation of educational programs.
- Being more conscious and empathetic toward the family unit when making suggestions for implementation and remediation.
- Being more open and honest when the schools or educators do not know the exact answer or resource needed.
- Focusing less on academic growth and skills and more on skills needed in the self-help and community areas.
- Promoting regular interaction between parents and schools.

Hornby (1995) continued the study by identifying the elements that teachers are wanting from parents to support collaborative relationships. The elements that are desired by teachers are:

- Reinforcement of programs at home.
- Involvement by parents by being visible in the school setting.
- Promotion of the child's independence to the highest degree possible.
- Maintenance of realistic expectations of the child's ability.
- Open communication with the school about performances at home that may affect performance at school.

When the parents and educators exchanged the elements with each other, the participants were surprised about the expectations that were identified. The study indicates that there is a need to communicate the expectations of parents and schools. Effective collaboration between parents and schools is possible if everyone recognizes and respects that there are expectations by both parties.

Needs and Contributions

Hornby's (1995) model for the study recognizes that there are different levels and types of needs and contributions involving parents.

Parent Contributions

- Information: Parents can contribute a vast amount of knowledge and information about their child because they have been involved at a personal level for a longer time period than any other service provider.
- Collaboration: Although parents are usually willing to support the efforts and recognize the need to follow through with programs at home, service providers need to acknowledge and support parental choices that may result at times in programs not being implemented at the home level.

- Resource: Parents can often contribute resources by utilizing time, special skills, and knowledge with other parents of students with handicaps and service providers.
- Policy: Membership and leadership regarding the advocacy positions for the rights of children with disabilities are a contribution that parents have and will continue to assume.

Parent Needs

- Communication: Channels of communication to collaborate with school personnel and others about their child are needed. Communications include formal channels such as knowledge of rights and responsibilities and written communications. Informal channels of communication would include the skills and abilities to relate to school personnel and others in a face-to-face situation.
- Liaison: Parents have the need to know how their child is progressing in a variety of environments and situations. A variety of options for liaisons helps guarantee that the parental needs are addressed.
- Education: Opportunities and resources that provide information on issues associated with students with disabilities are needed by parents. These resources could include information on specific disabilities, parent training and other sources on specific programs and opportunities as a child develops.

- Support: There is a need to collaborate and support parents and families in an informal or formal setting. Examples of support resources would include parent support groups and counseling.

Summary

The review identified the many reactions of parents who have a child who has a disability. These reactions continue to vary as the child grows and meets each developmental milestone and transitional period. Associated with the reactions, the review recognized that there are support mechanisms that can assist parents in coping and responding to having a child with a disability. IDEA '97 has mandated that parents will become active participants in the development of their children's Individual Education Programs in a school system. The review has supported the need to clearly identify and associate the types of support that are needed in the collaborative exchange between parents and schools. The purpose of the study was to identify the resources and support that parents are seeking and needing as they respond to their reactions and needs of having a child with a disability.

Chapter 3

Methodology

The purpose of this study was to identify the resources and support systems used by parents of children with disabilities. The study identified the perceptions of parents of children with disabilities regarding the importance and need of resources and support systems. The study also addressed the relationships between the resources and support systems regarding the size of the school system in which the child is enrolled and the time since the initial identification of the disability occurred. The methods used to conduct the study are described in this chapter, including the research design, the sample, data collection procedures, instrumentation, research questions, and data analysis.

Research Design

A focus of the study was the identification of resources and support used and perceptions of importance and need by parents of children with disabilities. A survey was administered to parents of children with disabilities to secure the data needed for the study. The method for collecting the necessary data was appropriate for the study because the survey provided the information for subsequent data analysis that allowed inferences to be made from the sample to the population of parents of children with disabilities. The survey was cross-sectional with the information collected during a short period of time from a variety of parents of children with disabilities from school districts of varying enrollments. Authorization to conduct research was secured from the Institutional Review Board (see Appendix A).

Sample

Surveys were distributed to 200 parents of children with disabilities within the geographical area of Loess Hills Area Education Agency. Surveys were distributed to each of the three different school population groups or enrollment classes – rural (up to 999 students), suburban (1000 – 1999 students), and urban (2000 students or more). A self-addressed stamped envelope was provided to return the survey and to assure confidentiality. A rate of 48% or 96 surveys returned was obtained during the initial mailing. In order to secure a minimum of 30 surveys in each of the three different school population surveys, 40 surveys were distributed to additional parents residing in suburban (1000 – 1999 students) and urban (2000 students or more) school districts. A final return rate of 51% or 122 surveys was used in the study.

Demographic Data

One hundred twenty-two completed surveys were used in the study. Demographic information was provided by parent(s) who completed the survey. Gender of parent completing the surveys (n = 122) showed that 99 surveys (81%) were completed by the female of the household, 3 surveys (2%) were completed by the male member with the remaining 20 surveys (16%) completed by both parents in the household. Gender of the child with disabilities was 63.1% male (n = 77) and 36.9% female (n = 45).

Household design of the individuals who completed the survey indicates that 82% have both parents living in the household (n = 100), 15% are single parent households (n = 18) with the remaining 3% of the surveys having a grandparent as head of household or other arrangements (n = 4).

The range of the ages when the child was initially identified with a disability ranged from birth to the age of 15 (see Table 2). The most frequent age of identification of disability was birth to age 1 (20.5% or n = 25). Other frequent ages were age 3 (11.5 % or n = 14), age 8 (10.7% or n = 13), age 6 (9.8% or n = 12), and age 7 (9.0% or n = 11).

The current age of the children with disabilities who were the focus of the study ranged from less than 1 year to 23 years of age. The most frequent age of the children with disabilities in the study was 11 (14.8% or n = 18).

Disability type of the children involved in the study varied. Table 3 shows the frequency distributions of the varying disabilities.

Data Collection Procedures

Participants completed and returned the survey as instructed in the cover letter (see Appendix B). Demographic data was also collected from the participants (see Appendix C). The survey was distributed to parents by personal delivery or by mailing to parents in the study with a self-addressed stamped envelope for the return of the survey instrument. The distribution of the surveys to parents of children with disabilities was by personal delivery by Parent-Educator teams in local school districts or by special education teachers in local schools, usually at staffings, conferences and Parent-Educator activities in school districts. Distribution was also made by direct mailing to parents.

Table 2

Age Range of Initial Identification of Disability

Age (in years)	Frequency	Percent
At Birth to 1.0	25	20.5
1.0	5	4.1
1.5	5	4.1
2.0	4	3.3
2.5	2	1.6
3.0	14	11.5
4.0	9	7.4
5.0	8	6.6
6.0	12	9.8
7.0	11	9.0
8.0	13	10.7
9.0	8	6.6
10.0	4	3.3
11.0	2	1.6
12.0	1	.8
13.0	1	.8
15.0	1	.8
TOTAL	**122**	**100%**

Table 3

Distribution by Disability

Disability	**Frequency**	**Percent**
Learning Disability	54	44.3
Behavior Disability	5	4.1
Mental Disability	10	8.2
Autistic or Autistic-like	9	7.4
ADD/ADHD/ODD	18	14.8
Down Syndrome	6	4.9
Head Injury	3	2.5
Hearing or Visual Disability	6	4.9
Other	11	9.0
TOTAL	**122**	**100%**

Special education personnel of Loess Hills Area Education Agency delivered the additional surveys needed to secure adequate sampling from the various enrollment districts to parents during face-to-face meetings and staffings. Parents were asked to respond to the survey instrument and return the survey in the self-addressed stamped envelope that was provided. The methods (direct mailing, distribution by local special education teachers and Parent-Educator teams, and direct distribution by Loess Hills Area Education special education staff) provided a sample with a wide diversity of backgrounds, school districts and ages of children with disabilities.

Participation in the study by parents was voluntary. Participants' answers are anonymous.

Instrumentation

Parents of children with disabilities identified the resources and support that they are currently using or have used in the support of their child. Parents also identified the resources and support that they perceive as important in meeting the needs of their child. The parents responded using a researcher-designed instrument.

Parents responded to the list of resources and support identifying past and current use using a 5-point Likert response scale (see Appendix D).

1 – Have never used

2 – Use seldom

3 – Use occasionally

4 – Use frequently

5 – Usually use or always

Parents of children with disabilities responded to perceptions of importance of resources and support systems by using a 5-point Likert scale (see Appendix E).

1 – Not important with no need

2 – Minimal importance with little need

3 – Important with need on an occasional basis

4 – Important with need on a frequent basis

5 – Extremely important with an ongoing need

In addition, the parents participating in the survey provided other demographic data. Demographic data gathered included: gender of parent completing survey, household design, age of child when disability was diagnosed, current age of child, gender of child, school group child is attending, and primary area of disability. An optional section for narrative comments by parents on resources and supports needed as a parent of a child with disabilities was included.

Validity

To provide evidence of content validity, the survey was reviewed by 10 professionals who have experience with special education programs and services prior to distribution to parents. Based on the comments of the professional review, revisions, deletions and additions to the survey were made.

Reliability

Following the analysis and revision of the survey, the survey was administered to 20 parents of children with disabilities for the purpose of piloting the survey instrument. The reliability of the survey instrument using Cronbach's alpha indicated that coefficient alpha for "Use of Resources and Support Systems" was .8043. The reliability of the survey instrument using Cronbach's alpha indicated that coefficient alpha for "Perception of Importance of Resources and Support Systems" was .9114.

Research Questions

The research questions guiding the study are:

1. What are the resources and support that parents are currently using or have used to assist in meeting the needs of their child with disabilities?
2. What resources and supports do the parents perceive as important in meeting the needs of their child with disabilities?
3. What relationship is there between the resources and support that parents are currently using or have used and the size of the school district in which the child with disabilities is enrolled?
4. What relationship is there between the resources and support that parents perceive as important and the size of the school district in which the child with disabilities is enrolled?
5. What relationship is there between the resources and support that parents of children with disabilities currently use or have used and the time since the initial identification of the disability?
6. What relationship is there between the resources and support that parents of children with disabilities perceive as important and the time since the initial identification of the disability?

Data Analysis

Data analysis included the following steps:

- Data regarding the use of resources and support for parents of children with disabilities were analyzed using frequency distributions (research question #1).
- Data regarding the perceptions of importance and need of resources and support for parents of children with disabilities were analyzed using frequency distribution (research question #2).
- Data regarding the relationship between the use of resources and support for parents of children with disabilities and the size of the school district were analyzed using a one-way ANOVA (research question #3).
- Data regarding the relationship between the perceptions of importance and need of resources and support for parents of children with disabilities and the size of the school district were analyzed using a one-way ANOVA (research question #4).
- Data regarding the relationship between the use of resources and support for parents of children with disabilities and the time since the initial identification of the disability were analyzed using the Pearson product-moment correlation coefficient (research question #5).
- Data regarding the relationship between the perceptions of importance and need of resources and support for parents of children with disabilities and the time since the initial identification of the disability were analyzed using the Pearson product-moment correlation coefficient (research question #6).

- Because multiple statistical tests were conducted, a .01 level of significance was used in all of the analyses to control for Type I errors.

Summary of Methodology

A survey of parents of children with disabilities residing in Loess Hills Area Education Agency was conducted. Sampling of the survey was secured through personal delivery or mailing of the survey. The results of the survey identified the resources and support that are currently being used or have been used and the perceptions of importance and needs of resources and support. Parents' use and perceptions of resources and support were the dependent variables in the study. The independent variables in the study were the size of the school district and the time since the child's disability was identified. Data analyses included frequency distributions, ANOVAs and correlation coefficients.

Chapter 4

Results and Interpretation

The purposes of this study were to determine (a) the resources and support systems that are currently being used or have been used by families with children with disabilities, and (b) the resources and support systems families with children with disabilities perceive as important for supporting their needs. Relationships with the resources and support used and perceived by parents of children with disabilities, the size of the school district in which the child is enrolled, and the time since the initial identification of the disability were also examined.

Research Questions

The specific research questions for this study were:

1. What are the resources and support that parents are currently using or have used to assist them in meeting the needs of their child with disabilities?
2. What resources and supports do the parents perceive as important in meeting the needs of their child with disabilities?
3. What relationship is there between the resources and support that parents are currently using or have used and the size of the school district in which the child with disabilities is enrolled?
4. What relationship is there between the resources and support that parents perceive as important and the size of the school district in which the child with disabilities is enrolled?

5. What relationship is there between the resources and support that parents of children with disabilities currently use or have used and the time since the initial identification of the disability?
6. What relationship is there between the resources and support that parents of children with disabilities perceive as important and the time since the initial identification of the disability?

Findings of the Study

In order to clarify the results of the responses to the survey, the data were analyzed and displayed with respect to the six research questions. Research questions 1 and 2 were analyzed using frequency distributions. Research questions 3 and 4 were analyzed using one-way analysis of variance (ANOVAs) with follow-up Tukey pairwise comparison tests. Research questions 5 and 6 were analyzed using Pearson product-moment correlation coefficients. Because multiple statistical tests were conducted, a .01 level of significance was used in all of the analyses to control for Type I errors.

Research Question 1

What are the resources and support that parents are currently using or have used to assist in meeting the needs of their child with disabilities?

To determine the resources and support that parents currently use or have used, the survey responses were analyzed using frequency distributions of the 5-point Likert scale included on the survey instrument. The 5-point scale that parents used included:

1 – Have never used

2 – Use seldom

3 – Use occasionally

4 – Use frequently

5 – Usually use or always

Responses indicate that the resource and support system that parents currently use or have used the most is *"I attend parent-school meetings, including I.E.P. meetings"* (n = 122, M = 4.48, SD = 1.10). The resources and support systems that parents have used or currently use the least is *"I have contacted Protection and Advocacy personnel services to get assistance in a better understanding of my rights and those of my child"* (n = 120, M = 1.46, SD = 1.01) and *"I attend a support group with other parents of children with special needs"* (n = 120, M = 1.46, SD = 1.01). The responses of the parents regarding use of resources and support systems are included in Table 4.

Research Question 2

What resources and supports do the parents perceive as important in meeting the needs of their child with disabilities?

To determine the resources and support that parents perceive as important, the survey responses were analyzed using frequency distributions of the 5-point Likert scale included on the survey instrument. The 5-point scale that parents used included:

1 – Not important with no need

2 – Minimal importance with little need

3 – Important with need on an occasional basis

4 – Important with need on a frequent basis

5 – Extremely important with an ongoing need

Table 4

Use of Resources and Support Systems

What resources and support systems have you used or do you currently use to support your child with special needs?

COMMUNICATION	n	M	SD
I have talked to other parents with children with special needs about various concerns and topics.	122	2.89	1.29
I receive or communicate information regarding my child using personal written communication forms such as personal letters or email.	121	2.49	1.33
I read newsletters or journals that help me understand and learn about my child.	121	3.05	1.10
I gain information through discussions and meetings with professionals, such as school, medical and community personnel.	120	3.78	1.08
LIAISON/ADVOCACY			
I attend parent-school meetings, including I.E.P meetings.	122	4.48	1.10
I have accessed the mediation processes to assist in communicating to school or other service providers.	118	2.39	1.55
I have contacted Protection and Advocacy personnel services to get assistance in a better understanding of my rights and those of my child.	120	1.46	1.00
EDUCATION			
I have attended workshops and group meetings on various topics related to being a parent of a child with special needs.	122	2.23	1.34
I have accessed materials (books, articles, videos) to gain information and knowledge on topics that support and inform me on issues related to my child.	121	3.06	1.34
I have used internet to search and locate information on various topics related to my child.	121	2.30	1.48
I have used professional personnel in the school system to help me gain information on the needs and services of a child with special needs.	121	3.16	1.37
I have used professional personnel in the medical field or in community services to help me gain information on the needs and services of a child with special needs.	122	3.15	1.49

(table continues)

Table 4 (continued)

Use of Resources and Support Systems

What resources and support systems have you used or do you currently use to support your child with special needs?

SUPPORT SERVICES	n	M	SD
I receive support and understanding as a parent of a child with special needs from my immediate family and close friends.	122	3.43	1.29
I attend a support group with other parents of children with special needs.	120	1.46	1.01
I communicate with another parent of a child with special needs when I need to ask questions or gain information and support.	122	2.23	1.20

Responses indicate that the resource and support system that parents perceive as most important for supporting the needs of their child is *"Information on my child's disability"* (n = 122, M = 4.41, SD = .89). The resource and support system that parents perceive as least important for supporting the needs of their child is *"Contact with other parents of children with special needs using letters or email"* (n = 122, M = 2.35, SD = 1.23). The responses of the parents regarding perceptions of importance of resources and support systems are included in Table 5.

Research Question 3

What relationship is there between the resources and support that parents are currently using or have used and the size of the school district in which the child with disabilities is enrolled?

When examining the relationship between the resources and support systems that parents are currently using or have used and the size of the school district, a one-way ANOVA was used to examine the 15 statements of use and the school enrollment in which the child was enrolled. The school groups were divided into three categories:

Group 1 – Enrollments up to 999 students
Group 2 – Enrollments 1000 to 1999 students
Group 3 – Enrollments over 2000 students

On the survey item *"I have talked to other parents with children with special needs about various concerns and topics"*, there was a statistically significant difference between school districts with enrollments up to 999 students (M = 2.50, SD = 1.15) and

Table 5

Perceptions of Importance of Resources and Support Systems

What resources and support systems do you perceive as important for supporting the needs of your child with special needs?

COMMUNICATION	**n**	**M**	**SD**
Personal contact (face-to-face) with other parents of children with special needs	122	3.02	1.31
Contact with other parents of children with special needs using letters or email	122	2.35	1.23
Newsletters and journal articles on information about my child's disability	122	3.41	1.30
Regular meetings with service providers for my child (school, medical, community)	121	4.01	1.01
LIASON/ADVOCACY			
Information on parent involvement, procedures and rights associated with my child's Individual Education Plan (I.E.P.)	122	3.86	1.14
Information on mediation services to improve communication between parents and service providers	121	3.39	1.18
Information about rights and legal support available through protection and advocacy services	121	3.36	1.29
EDUCATION			
Information on my child's disability	122	4.41	.89
Information on services available from medical and community resources for my child	121	4.13	1.23
Accessing needed information through books and videos	122	3.63	1.23
Accessing needed information through known internet sites	121	3.11	1.52
Workshops and opportunities for parent training	121	3.37	1.26
Information on opportunities for my child after graduation	122	4.00	1.29
SUPPORT SERVICES			
Support services and information on parenting, sibling issues and respite care	121	3.18	1.34
Support groups with other parents of children with special needs	121	3.06	1.34
Contact with another parent of a child with special needs from local school to assist in accessing information and discussing issues related to being a parent of a child with special needs	121	2.97	1.28
Information on resources and services available for my child in the community	121	3.91	1.17

school districts with enrollments over 2000 students (M = 3.50, SD = 1.34) (F(2,119)=6.38, p=.002).

In addition, on the survey item *"I have used professional personnel in the school system to help me gain information on the needs and services of a child with special needs"*, there was a statistically significant difference between school districts with enrollments up to 999 students (M = 3.66, SD = 1.12) and school districts with enrollments more than 2000 students (M = 2.69, SD = 1.53) (F(2,118)=6.47, p =.002). There were not any other significant relationships for the remainder of the survey items and the size of school district (see Table 6).

Research Question 4

What relationship is there between the resources and support that parents perceive as important and the size of the school district in which the child with disabilities is enrolled?

When examining the relationship between the resources and support systems that parents perceive as important and the size of the school district, a one-way ANOVA was used to examine the 17 statements of perceptions of importance and the school enrollment that the child was enrolled. The school groups were divided into three categories:

Group 1 – Enrollments up to 999 students
Group 2 – Enrollments1000 to 1999 students
Group 3 – Enrollments over 2000 students

Table 6

Analysis of Variance for Use of Resources and Size of School

COMMUNICATION		**df**	**F**	**p**
I have talked to other parents with children with special needs about various concerns and topics.	Between Groups	2	6.376	.002*
	Within Groups	119		
	Total	121		
I receive or communicate information regarding my child using personal written communication forms such as personal letters or email.	Between Groups	2	1.656	.195
	Within Groups	118		
	Total	120		
I read newsletters or journals that help me understand and learn about my child.	Between Groups	2	.411	.664
	Within Groups	118		
	Total	120		
I gain information through discussions and meetings with professionals, such as school, medical and community personnel.	Between Groups	2	.468	.627
	Within Groups	117		
	Total	119		
LIAISON/ADVOCACY				
I attend parent-school meetings, including I.E.P meetings.	Between Groups	2	1.519	.223
	Within Groups	119		
	Total	121		
I have accessed the medication processes to assist in communicating to school or other service providers.	Between Groups	2	.985	.376
	Within Groups	115		
	Total	117		
I have contacted Protection and Advocacy personnel services to get assistance in a better understanding of my rights and those of my child.	Between Groups	2	1.894	.155
	Within Groups	117		
	Total	119		
EDUCATION				
I have attended workshops and group meetings on various topics related to being a parent of a child with special needs.	Between Groups	2	.296	.744
	Within Groups	119		
	Total	121		
I have accessed materials (books, articles, videos) to gain information and knowledge on topics that support and inform me on issues related to my child.	Between Groups	2	3.050	.051
	Within Groups	118		
	Total	120		
I have used internet to search and locate information on various topics related to my child.	Between Groups	2	.294	.746
	Within Groups	118		
	Total	120		
I have used professional personnel in the school system to help me gain information on the needs and services of a child with special needs.	Between Groups	2	6.469	.002*
	Within Groups	118		
	Total	120		
I have used professional personnel in the medical field or in community services to help me gain information on the needs and services of a child with special needs.	Between Groups	2	4.547	.013
	Within Groups	119		
	Total	121		

(table continues)

Table 6 (continued)

Analysis of Variance for Use of Resources and Size of School

SUPPORT SERVICES		**df**	**F**	**p**
I receive support and understanding as a parent of a child with special needs from my immediate family and close friends.	Between Groups Within Groups Total	2 119 121	.123	.884
I attend a support group with other parents of children with special needs.	Between Groups Within Groups Total	2 117 119	3.426	.036
I communicate with another parent of a child with special needs when I need to ask questions or gain information and support.	Between Groups Within Groups Total	2 119 121	1.995	.141

On the survey item *"Personal contact (face-to-face) with other parents of children with special needs"*, there was a statistically significant difference between school districts with enrollments up to 999 students (M = 2.54, SD = 1.15) and school districts with enrollments over 2000 students (M = 3.78, SD = 1.29) (F(2,119) = 10.06, p<.0005). There were not any significant relationships between any of remaining survey items regarding perceptions of importance and size of the school district in which the child with disabilities was enrolled (see Table 7).

Research Question 5

What relationship is there between the resources and support that parents of children with disabilities currently use or have used and the time since the initial identification of the disability?

When examining the relationship between the resources and support systems that parents are currently using or have used and time since the disabiling condition was identified, Pearson product-moment correlation coefficients were used to examine the 15 statements of use and the time since the disability was identified.

There was not a significant relationship between any of the 15 statements of use of resources and support systems and the time since the disability was identified (see Table 8).

Research Question 6

What relationship is there between the resources and support that parents of children with disabilities perceive as important and the time since the initial identification of the disability?

Table 7

Analysis of Variance and Perceptions of Importance and Size of School District

		df	F	p
COMMUNICATION				
Personal contact (face-to-face) with other parents of children with special needs	Between Groups Within Groups Total	2 119 121	10.061	.000*
Contact with other parents of children with special needs using letters or email	Between Groups Within Groups Total	2 119 121	.159	.853
Newsletters and journal articles on information about my child's disability	Between Groups Within Groups Total	2 119 121	.161	.852
Regular meetings with service providers for my child (school, medical, community)	Between Groups Within Groups Total	2 118 120	1.451	.239
LIAISON/ADVOCACY				
Information on parent involvement, procedures and rights associated with my child's Individual Education Plan (I.E.P.)	Between Groups Within Groups Total	2 119 121	.560	.573
Information on mediation services to improve communication between parents and service providers	Between Groups Within Groups Total	2 118 120	.175	.840
Information about rights and legal support available through protection and advocacy services	Between Groups Within Groups Total	2 118 120	.645	.526

(table continues)

Table 7 (continued)

Analysis of Variance and Perceptions of Importance and Size of School District

EDUCATION		**df**	**F**	**p**
Information on my child's disability	Between Groups	2	.975	.380
	Within Groups	119		
	Total	121		
Information on services available from medical and community resources for my child	Between Groups	2	1.251	.290
	Within Groups	118		
	Total	120		
Accessing needed information through books and videos	Between Groups	2	1.307	.274
	Within Groups	119		
	Total	121		
Accessing needed information through known internet sites	Between Groups	2	.641	.528
	Within Groups	118		
	Total	120		
Workshops and opportunities for parent training	Between Groups	2	1.322	.271
	Within Groups	118		
	Total	120		
Information on opportunities for my child after graduation	Between Groups	2	2.665	.074
	Within Groups	119		
	Total	121		
SUPPORT SERVICES				
Support services and information on parenting, sibling issues and respite care	Between Groups	2	.289	.750
	Within Groups	118		
	Total	120		
Support groups with other parents of children with special needs	Between Groups	2	2.679	.073
	Within Groups	118		
	Total	120		
Contact with another parent of a child with special needs from local school to assist in accessing information and discussing issues related to being a parent of a child with special needs	Between Groups	2	.125	.882
	Within Groups	118		
	Total	120		
Information on resources and services available for my child in the community	Between Groups	2	.379	.686
	Within Groups	118		
	Total	120		

Table 8

Correlations for Use of Resources and Time Since Identification of Disability

COMMUNICATION	n	Pearson Correlation	p
I have talked to other parents with children with special needs about various concerns and topics.	122	.032	.723
I receive or communicate information regarding my child using personal written communication forms such as personal letters or email.	121	-.051	.575
I read newsletters or journals that help me understand and learn about my child.	121	-.078	.396
I gain information through discussions and meetings with professionals, such as school, medical and community personnel.	120	.112	.223
LIAISON/ADVOCACY			
I attend parent-school meetings, including I.E.P meetings.	122	.038	.678
I have accessed the medication processes to assist in communicating to school or other service providers.	118	-.047	.611
I have contacted Protection and Advocacy personnel services to get assistance in a better understanding of my rights and those of my child.	120	-.026	.777
EDUCATION			
I have attended workshops and group meetings on various topics related to being a parent of a child with special needs.	122	.020	.831
I have accessed materials (books, articles, videos) to gain information and knowledge on topics that support and inform me on issues related to my child.	121	-.062	.497
I have used internet to search and locate information on various topics related to my child.	121	-.097	.289
I have used professional personnel in the school system to help me gain information on the needs and services of a child with special needs.	121	-.130	.159
I have used professional personnel in the medical field or in community services to help me gain information on the needs and services of a child with special needs.	122	-.013	.890
SUPPORT SERVICES			
I receive support and understanding as a parent of a child with special needs from my immediate family and close friends.	122	.152	.094
I attend a support group with other parents of children with special needs.	120	.071	.444
I communicate with another parent of a child with special needs when I need to ask questions or gain information and support.	122	.066	.472

When examining the relationship between the resources and support systems that parents perceive as important and time since the disability was identified, Pearson product-moment correlation coefficients were used to examine the 17 statements of perceptions of importance and the time since the disability was identified.

There was a statistically significant negative relationship between the survey item *"Accessing needed information through books and videos"* and the time since the disability was identified. This inverse relationship between the two variables means that as one variable increases, the other variable decreases. However, the correlation is low, since the variables share only 5% of the same information (Pearson $r = -.239$, $p=.008$, $n=122$).

There was not a significant relationship between any of the remaining 16 statements of perceptions of importance of resources and support systems and the time since the disability was identified (see Table 9).

Summary

The responses of the participants regarding usage of resources and support systems ranged from seldom to high frequency for the 15 survey items identified on the survey instrument (research question 1). The perceptions of importance of resources and support systems for the 17 survey items according to the responses of the participants ranged from minimal importance with little need to important with frequent and ongoing need (research question 2).

The results of the survey indicate significant difference in usage of two resources in relationship to the size of the school district (research question 3). These resources and

Table 9

Correlations for Perceptions of Importance and Time Since Identification of Disability

COMMUNICATION	**n**	**Pearson Correlation**	**p**
Personal contact (face-to-face) with other parents of children with special needs	122	.058	.523
Contact with other parents of children with special needs using letters or email	122	-.056	.538
Newsletters and journal articles on information about my child's disability	122	-.153	.092
Regular meetings with service providers for my child (school, medical, community)	121	-.109	.236
LIASON/ADVOCACY			
Information on parent involvement, procedures and rights associated with my child's Individual Education Plan (I.E.P.)	122	-.061	.506
Information on medication services to improve communication between parents and service providers	121	-.119	.194
Information about rights and legal support available through protection and advocacy services	121	-.149	.103
EDUCATION			
Information on my child's disability	122	-.150	.099
Information on services available from medical and community resources for my child	121	-.070	.445
Accessing needed information through books and videos	122	-.239	.008*
Accessing needed information through known internet sites	121	-.210	.021
Workshops and opportunities for parent training	121	-.159	.081
Information on opportunities for my child after graduation	122	.066	.473
SUPPORT SERVICES			
Support services and information on parenting, sibling issues and respite care	121	.056	.544
Support groups with other parents of children with special needs	121	-.063	.492
Contact with another parent of a child with special needs from local school to assist in accessing information and discussing issues related to being a parent of a child with special needs	121	.005	.957
Information on resources and services available for my child in the community	121	-.038	.678

support systems are (a) communication with other parents of children with disabilities and (b) usage of professional personnel in a school system to gain information. There was a statistically significant relationship between the size of the school district and the perception of personal interaction with parents of children with disabilities (research question 4).

The study did not show any statistically significant relationship between the use and perceptions of importance of resources and the time since the identification of the child's disability (research questions 5 and 6).

Discussions of the resources and support systems and the analysis of the relationships will be included in Chapter Five.

Chapter 5

Summary

This study examined the resources and support that parents of children with disabilities are using or have used. The study also examined parents' perceptions of importance of various resources and support. This examination is important for the individuals providing resources and support to parents and families with children with disabilities so that the needs of parents are met in a joint and collaborative system.

Purpose

The purposes of this study were to identify (a) the resources and support that parents of children with disabilities currently use or have used; (b) parents' perceptions of importance of resources and support for their child; (c) relationships between the usage and perceptions of resources and supports to the size of school district that a child with disabilities is enrolled; and (d) relationships between usage and perceptions of resources and supports and the time since the initial identification of the disability.

This chapter analyzes the findings from the data collection, which were presented in Chapter Four. The analysis will be used for discussions of results for each of the research questions of the study. Organizational structures for the discussion of research questions 1 and 2 will be arranged with respect to the areas of communication, liaison/advocacy, education and support services, which were headings for the survey items. These areas also are aligned with several of the organizational structures identified in the theoretical framework presented in Chapter Two (Hornby, 1995). Questions 3 and 4 will discuss the usage and perceptions of resources and support systems in relation to the size of school district. Discussion of questions 5 and 6 will focus on the relationship between the usage and perceptions of resources and support systems and the time since the initial identification of the disability. Summary of results of the survey questions will be presented. Relationships to research will refer to theories and models that were presented in the review of literature included in Chapter Two. Discussions of the study will be used to make recommendations for practice and further research.

Discussion of Results

Research Question One

What are the resources and support that parents are currently using or have used to assist them in meeting the needs of their child with disabilities?

In review, the 5-point Likert scale that parents used included:

1 – Have never used

2 – Use seldom

3 – Use occasionally

4 – Use frequently

5 – Usually use or always

Communication. The survey included four items that identify usage of various communication channels, including communication with other parents, print formats and meetings. The survey item, *"I gain information through discussions and meetings with professionals, such as school, medical and community"* (M = 3.78, SD = 1.08) had the highest mean. A possible reason for the high usage is the different types of support and resources. Each of the supports (school, medical and community) provides information to parents at various times in a child's growth and development. When individuals or organizations are working with parents of children with disabilities, it would be important to realize that use of services may increase when a specific need or mutual collaborative exchange is involved.

Communication with professionals had a higher mean or use than communication channels with other parents, personal letters or published newsletters. A possible reason for the high use of professionals could be contributed to parents' need to have information in a personal exchange with "experts".

Liaison/Advocacy. The three survey items identified resources and support systems that included parent-school meetings, mediation processes and protection and advocacy services. Based on the data from the survey participants in regard to the resources and support systems that have been used or are currently being used, the study found the survey item *"I attend parent-school meetings, including I.E.P. meetings"* (M = 4.48, SD = 1.10) listed as the most frequently used resource. Due to federal regulations of IDEA ' 97, parents are invited in a personal notice to participate. In other words, the parents do not have to seek out resources and support, but rather the resources and support are extended to them.

The survey item *"I have contacted Protection and Advocacy personnel service to get assistance in a better understanding of my rights and those of my child"* (M = 1.46, SD = 1.00) had the lowest mean for usage indicating minimal usage by the participants. Typically, the services of Protection and Advocacy are used by parents as an avenue of support when the parents are discontented or dissatisfied with services or procedures.

The low usage could be indicative of the low numbers who have used the Protection and Advocacy as a resource due to relative satisfaction with the services and procedures currently provided. Another reason for the low usage might be the number of parents who are not aware that the services are available to them as parents of children with disabilities. Service providers need to insure that parents are aware of the resource and the methods to access protection and advocacy services if the need should arise.

Education. The five survey items in the education category related to information channels through workshops, various materials, and utilization of the expertise of professional participants. Participants indicate the occasional use of professional personnel in the school (M = 3.16, SD = 1.37), medical field and community services (M = 3.15, SD = 1.49) to gain information. This level of use supports that parents access professional personnel as needs and issues arise in meeting the needs of their child with disabilities.

Participants of the survey indicate seldom or occasional usage of the survey item *"I have attended workshops and group meetings on various topics related to being a parent of a child with special needs"* (M = 2.23, SD = 1.34). Possible reasons for this level of usage could be the lack of available workshops that address a needed area, the time commitment needed for parents of children of disabilities to participate, or insecurity of parents to openly discuss issues of concern with others.

The participants of the survey indicated use of the internet to gain information was seldom (M = 2.30, SD = 1.48). The possible reason for this minimal usage could be contributed to lack of accessibility or skills to use the internet as a resource.

Support Services. Three survey items asked about support that parents of children with disabilities use. The supports of immediate family and other parents who also are experiencing similar needs and issues due to having child with disabilities were listed as survey items.

Participants indicate frequent and occasional usage by parents of children with disabilities in receiving support and understanding from immediate family and close friends (M = 3.43, SD = 1.29). This level of usage would support that individuals and families in crisis often seek comfort and understanding from their immediate support systems. Families and close friends are frequently the avenue for support and understanding in crisis situations.

In contrast, the responses of the survey participants to the item *"I attend a support group with other parents of children with special needs"* (M = 1.46, SD = 1.01) indicated no use or use that was seldom. This level of usage could be contributed to several reasons. First, availability of support groups or lack of support groups could be sparse. When support groups are available, the focus or framework for the support group may not meet the needs of the parents at a given time. Another reason may be parents' reluctance or anxiety to share personal information with other parents, even if the parents have similar concerns and needs.

Research Question 2

What resources and supports do the parents perceive as important in meeting the needs of their child with disabilities?

In review, the 5-point Likert scale that parents used included:

1 – Not important with no need

2 – Minimal importance with little need

3 – Important with need on an occasional basis

4 – Important with need on a frequent basis

5 – Extremely important with an ongoing need

Communication. Communication channels identified on the survey included four items with a range from personal contact with other parents, print formats, and meetings with service providers. Parents of children with disabilities recognized the resource and support system *"Regular meetings with service providers for my child (school, medical, community"* (M = 4.01, SD = 1.01) as important with frequent need. Parents recognized that communication in face-to-face meetings with service providers offers a direct service that has positive implications. Meetings allow everyone involved to collaborate and communicate on a more unified manner for a specific child. Another survey item with importance on an occasional or frequent basis is *"Newsletters and journal articles on information about my child's disability"* (M = 3.41, SD = 1.30). Both of these survey items are directed toward the needs and services of the specific child with disabilities. The two survey items indicate that if the need or service directly supports the individual child or family system, the perception of importance is high.

Communication in face-to-face meetings or information on specific issues for individual children is perceived as more important than *"Personal contact (face-to-face) with other parents of children with special needs"* (M = 3.02, SD = 1.31) or *"Contact with other parents of children with special needs using letters or email"* (M = 2.35, SD =

1.23). Both of these survey items indicate communication beyond the immediate child and family is not perceived as important. However, it should be noted that the face-to-face contact with other parents of children with disabilities is perceived at a higher level of need than the less-personal contact through letters and email. The difference in perception would indicate a preference to the personal, possibly informal, communication over the formal contact of letters and email.

Liaison/Advocacy. Three items related to liaison and advocacy were included in the survey and received fairly similar ratings by parents. The types of resources and support systems in the category included involvement in the child's Individual Education Program ($\underline{M} = 3.86$, $\underline{SD} = 1.14$), mediation services ($\underline{M} = 3.39$, $\underline{SD} = 1.18$), and protection and advocacy services ($\underline{M} = 3.36$, $\underline{SD} = 1.29$). The survey item *"Information on parent involvement, procedures and rights associated with my child's Individual Education Program (I.E.P.)"* ($\underline{M} = 3.86$, $\underline{SD} = 1.14$) had the highest mean for this category with a need on a frequent basis. Parents need to understand their rights as parents in the processes related to the development and implementation of their own child's Individual Education Program. Avenues for parents to access services of mediation and protection and advocacy in cases of conflict or disagreement are necessary but are needed only as occasions develop and not necessarily as an ongoing basis or need.

Education. Six items for perception of importance in the education category were included, varying from information on specific disabilities to services and opportunities. The survey items that participants responded to regarding perception of importance with frequent need involved resources and support systems for individual children and disabilities. The survey items *"Information on my child's disability"* (M = 4.41, SD = .89), *"Information on services available from medical and community resources for my child"* (M = 4.13, SD = 1.23), and *"Information on opportunities for my child after graduation"* (M = 4.00, SD = 1.29) have a common phrase: "my child." The phrase "my child" may suggest the reason that perception of importance on the survey was high: the items directly related to individual children. These responses would support the need for service providers to be supportive and directive in meeting individual needs for children with disabilities and their families and not assume that there is a generic approach or support that is needed by all.

The other resources and support systems for education in the survey instrument are related to accessing information through various materials and opportunities for information through workshops. These items are perceived as important with occasional need. There appears to be an importance to providing parents opportunities and services that offer information.

Support Services. There were four survey items for support services related to parenting, support groups with other parents and services in the community. The support service that the participants in the survey indicated had highest importance was the survey item *"Information on resources and services available for my child in the community"* (M = 3.91, SD = 1.17). The responses reveal that parents continue to seek out resources and services that can directly impact their individual child. Service providers also need to continually seek out additional supports to assist in meeting the needs of families of children with disabilities and to persist in the communication about resources and services.

The survey item *"Contact with another parent of a child with special needs from local school to assist in accessing information and discussing issues related to being a parent of a child with special needs"* (M = 2.97, SD = 1.28) had the lowest mean for perception of importance in the support services category. The reason for this perception of minimal importance compared to the other support services could be contributed to a perception that communicating with other parents of children with disabilities does not provide support at a level to meet immediate needs. Parents of children with disabilities seek support from the immediate family and close friends rather than individuals outside their support structure. Parents have a perception that there are other avenues to gain information and support to meet their needs and the needs of their children besides communicating and collaborating with other parents in similar situations.

Research Question 3

What relationship is there between the resources and support that parents are currently using or have used and the size of the school district in which the child with disabilities is enrolled?

The study showed that there was a significant relationship between the participants' responses on the survey item *"I have talked to other parents with children with special needs about various concerns and topics"* (M = 2.89, SD = 1.29) and the size of the school district. Parents of children with disabilities from school districts over 2000 students (M = 3.50, SD = 1.34) more frequently use communication with other parents than do parents of children with disabilities from school districts with enrollments up to 999 students (M = 2.50, SD = 1.15). The significant difference may be due to accessibility to other parents. A larger enrollment or population base would lend itself to the probability that there would be a larger number or percentage of other parents of children with disabilities.

The dynamics and culture of a rural area often reflect a community where there is an awareness of other members in the community. This awareness of community members can be a support mechanism in certain situations. However, the knowledge of having a child with a disability and desiring to discuss issues about the child with other members in the rural community may not be an avenue for communication that parents of children with disabilities desire or use. The culture of rural communities may be a possible reason for the significant lower usage of communication with other parents of children with disabilities than in urban communities.

Another survey item that was significant in regard to usage and enrollment was the survey item *"I have used professional personnel in the school system to help me gain information on the needs and services of a child with special needs"* (M = 3.16, SD = 1.37). Participants from school districts with enrollments less than 999 students (M = 3.66, SD = 1.12) have used or currently use the resource at a significantly higher rate than participants from school districts with enrollments more than 2000 students (M = 2.69, SD = 1.53). A reason for this significant difference maybe the availability of a variety of resources in larger school systems. It could be assumed that rural areas have less accessibility to a variety of resources so those parents of children with disabilities utilize the school personnel at a higher level of use. Likewise, parents of children with disabilities who live in more urban type of environments may have accessibility to a wider variety of resources and may, thus, use the school personnel to a lesser degree as the primary resource provider or channel.

The responses for the remainder of the 13 survey items on use of resources and support systems did not indicate any significant relationships between usage and the size of the school district. The reasons for this lack of relationship may be due to the fact that parents use the resources and support systems at the same levels, regardless of whether the family base is in a rural or urban area.

Research Question 4

What relationship is there between the resources and support that parents perceive as important and the size of the school district in which the child with disabilities is enrolled?

The study showed that the response to the survey item *"Personal contact (face-to-face) with other parents of children with special needs"* (M = 3.02, SD = 1.31) was significant in relationship to the size of the school district. Participants from school districts with enrollments over 2000 students (M = 3.78, SD = 1.29) perceived the communication channel of face-to-face contact with other parents of children with disabilities as significantly more important than participants from school districts with enrollments up to 999 students (M = 2.54, SD = 1.15). The reason for the significant difference may be related to accessibility. An assumption could be made that parents of children with disabilities in larger school districts would have more opportunity to communicate with other parents with similar needs due to a larger enrollment base. School districts with larger enrollments may have more situations and events that provide opportunities for parents of children with similar needs than do districts in rural areas.

Another reason for the differences in the perception of importance of the personal contact (face-to-face) with other parents of children with disabilities could be the culture of the community. Members of rural communities are aware of situations and needs of other members due to the closeness and way of life. Parents in rural communities may not perceive that other parents within their community would be a personal source for communication due to a potential lack of confidentiality.

The remainder of the survey items related to perception of importance did not indicate any significant relationship between the participants' responses and the size of the school district in which the child is enrolled. The lack of significance would support that resources and support systems are similarly perceived as important from parents by children with disabilities in rural, suburban and urban school districts.

Research Question 5

What relationship is there between the resources and support that parents of children with disabilities currently use or have used and the time since the initial identification of the disability?

There were not any significant relationships between the resources and support systems used by parents of children with disabilities and the time since the initial identification of the disability. This lack of relationship was not anticipated in the study. The phases of reactions by parents of children with disabilities (Hornby, 1995) would suggest that parents have varying needs for resources and support as parents evolve to acceptance of their child's disability. It would be assumed that the longer the time since the initial identification of the disability would result in more opportunities to access and use a variety of resources and support systems.

A possible reason for the lack of relationship may be the design of the survey, which may have focused on resources and support systems that are accessed at the initial stages of diagnosis. An assumption could also be made that the lack of relationship between use and the time since the identification of the disability may be due to the variety of resources that are needed both in early stages of adjustment and as the child matures and develops.

Research Question 6

What relationship is there between the resources and support that parents of children with disabilities perceive as important and the time since the initial identification of the disability?

The results of the survey indicated that there was not any meaningful relationship between the perceptions of importance of resources and support and the time since the initial identification of the disability. A possible reason for this lack of relationship may be that, regardless of the current age or time since the initial identification, parents of children with disabilities recognize the importance of resources and support equally. Parents of children with disabilities of all ages perceive the need to have available to them a variety of resources and support that they can use or access them as needs and situations develop.

Summary of Results

The analysis and discussion of the results have focused on two general issues. What are the resources and support systems that parents of children with disabilities use? What are the parents' perceptions of importance of resources and support systems needed to assist them in meeting the needs of their child with disabilities?

A review of the means of survey responses in all the categories (communication, liaison/advocacy, education, and support) showed that the order of the items was similar in both usage and perception of importance. In the communication category, discussion and meetings with service providers (school, medical and community) had the highest mean in both usage and perception of importance. Written communication (newsletters and journals), face-to-face contact with other parents and written communication followed in the same order for both usage and perception of importance.

Liaison and advocacy survey items also had means that were in the same order for both usage and perception of importance. The process and participation in the child's Individual Education Program (I.E.P.) was high for use and perception. Mediation activities and Protection and Advocacy services were in the same order for usage and perception of importance. However, the range of the means between the three items was closer in perception of importance (range from 3.36 to 3.86) than in usage (range from 1.46 to 4.48). The narrowing of the range would indicate that while the usage of the services of Individual Education Programs is high and mediation and Protection and Advocacy services have minimal use, the perception of mediation and Protection and Advocacy services is that they are important with high need.

The education category identified service providers as the most used and highest perceived resource. The other resources of materials, internet and workshops were generally in the same order for use and perception of importance.

Support services is the category identifying the structures that parents and families seek for emotional and information support. The high use of immediate family and close friends is supported with the high perception of importance on topics such as parenting, sibling issues and respite care. The lowest mean in the support services category for both use and perception of importance was the support from contact with other parents and support groups. The similar responses in use and perception support the idea that parents chose to seek assistance from their immediate family first. Support from others outside of the family nucleus was seldom used and was perceived a minimal need.

Collaboration and communication with school personnel is seen as extremely important both in usage and in perceived importance. Parents are active participants in the Individual Education Program (I.E.P.) meetings for their child. Additional collaboration with and information from other service providers in the medical and community fields is valued in actual usage and perceived importance.

Parents desire information about their child's disability. According to the perception survey, the preferred avenues for accessing information are through face-to-face meetings with school, medical and community personnel. Additional information is also secured through books, articles and videos. Utilization of internet for either information or communication is not perceived as important or used at the same level as face-to-face opportunities or print formats.

Services to assist in conflict or disagreement are perceived as important. However, use of mediation processes and protection and advocacy services is not on a frequent basis. Minimal usage could be contributed to either lack of knowledge on how to access the service or general satisfaction with services and support being provided to the parents and their child.

Support groups and contact with other parents of children with disabilities receive minimal to moderate use. Although the perception of importance for parent-to-parent exchange is moderately important, the utilization is at a lower degree. Reasons for this difference could be related to lack of accessibility, lack on knowledge on how to access other parents, or the amount of time needed to share and exchange with other parents. Support, however, is highly valued and used within the immediate family structure.

The analysis of the study did not support that there were any major significant differences between use and perception of importance of resources and support systems and the size of school district the child attends. The lack of relationship indicates that resources and support systems are seen similarly among rural, suburban and urban communities. The lack of relationship for perception of importance also supports that parents of children with disabilities have similar needs.

The study did not indicate that there were any significant relationships between the usage and perception of resources and support systems and the time since the initial identification of the disability. The lack of relationship could be interpreted in different ways. Similar usage and perception could indicate that the areas of communication, liaison/advocacy, education and support services are accessed and perceived at a constant level from initial identification throughout the child's development. Usage and perception of importance of resources and support sustains itself as parents adjust to their child's disability.

Relationship to Research

Participants in the study included parents of children with disabilities at current ages of 2 months to 23 years. The range would be indicative of parents at various phases of reactions to a child's disability (Hornby, 1995): shock, denial, anger, sadness, detachment, reorganization and acceptance. This range would also represent the "stages of dying" model by Kübler-Ross (1969). Some of the phases identified by Hornby (1995) are inferred in the survey items related to the use of resources and support systems and perceptions of importance.

Although the items on the survey were directed toward the possibility of a relationship between use and perception of importance of resources and support systems for parents of children with disabilities, the analysis of the results of this study did not clearly indicate that there was a relationship between use and perception and the time since the child was identified.

The microsystem and mesosystem levels of Hornby's (1995) ecological model of family functioning recognized the importance of immediate and extended family influences and interactions in the needs and acceptance of having a child with disabilities. The survey item *"I receive support and understanding as a parent of a child with special* *needs from my immediate family and close friends"* (M = 3.43, SD = 1.29) supports occasional and frequent usage of support within the family of a child with disabilities.

The exosystem level recognizes the health, education and social systems as being critical services for a family with a child of disabilities. The high levels of usage and perceptions of importance of resources in many of the survey items related to education, community and medical services support the exosystem level of family functioning.

Hammer (1972) identified critical periods of stress (at birth or upon suspicion of disability, at time of diagnosis and treatment of the disability, as child nears age of school placement, as child nears puberty, as child nears age of vocational planning, and as parents age and child may outlive them) in families with children with disabilities and associated the periods with needs. These critical periods of stress correspond with services and support identified by Simpson (1982): preschool, elementary, adolescents, and young adults. The study did not find any relationship between the use and perception of importance of resources and support and the time since the identification of the disability. The results support that use and perception remains constant through the wide range of current ages of the participants' children with disabilities in the study.

The theoretical framework of this study was based on the model for parent involvement developed by Hornby and identified in Figure 1, page 5 of this study. The model identified the need categories of communication, liaison, education and support. Hornby's model related the need areas to the number of parents involved. Hornby's pyramid of parent needs and involvement identified communication as the need most parents were involved with, followed by liaison/advocacy and education. Support, according to Hornby, is the need with the least number of parents involved. The survey design of this study supported the model of parent involvement with items being aligned with the same categories. By averaging the means of the four categories of the survey items, the usage reported by parents in the survey confirmed Hornby's model of parent needs and involvement.

COMMUNICATION (4 items) M = 3.05 (Highest usage or involvement)

LIASON/ADVOCACY (3 items) M = 2.78

EDUCATION (5 items) M = 2.78

SUPPORT SERVICES (3 items) M = 2.37 (Least usage or involvement)

Resources and support systems in the communication category had the highest usage with most parents utilizing. Channels include meetings, personal written communications, newsletters, journals, and discussions with other parents of children with disabilities. Resources and support systems in the support category had the lowest usage with the least number of parents. Although the support of immediate family and friends had high level of usage, the addition of support from support groups and communication with other parents resulted in an average of the means that reflected low parental involvement and usage.

In summary, the relationship to the study and research has been discussed. Discussions have identified that there are survey items and responses that can be aligned to phases of acceptance identified by Hornby (1995). The importance of the support of immediate family in providing resources was discussed. Comparison has been about the possible connections of parents' use and perceptions of importance for resources in relation to critical periods in the child's life and age of the child. Finally, relationships with Hornby's (1995) model for parent involvement and the survey results were presented.

Recommendations for Practice

This study has shown that the resources and support systems used by parents and families of children with disabilities continue to be a need. The study has also shown the many areas of resources and support systems that parents and families perceive as important. The results should help guide service providers as they continue to develop, refine and reinforce resources and support systems to assist in meeting the needs of parents and families of children with disabilities.

The study supports that parents utilize and perceive at a higher level resources and support systems that meet their immediate needs in a personal exchange. Opportunities for face-to-face exchanges with service providers for their individual child are valued and accessed. Service providers need to be aware of the need by parents to have the personalization aspect enhanced by channeling resources and support systems to this level. Educators should recognize the need for personalization by directing information and support to individual parents and not assume that all parents have the same need. Practices such as personal conferences and communication support a collaborative and mutual relationship between parents and educators. Medical and community personnel can also practice communication strategies that are directed toward individual parents and children with disabilities.

Parents perceive as important the need for information on their child's disability, services and resources available to them in their community. They also need transition information on opportunities for their child after graduation. Educators can support the need for information by providing parents with a variety of resources that can be used and accessed. The modes for channeling the information can vary with preference given to newsletters, books and videos. Electronic communication for information is used and perceived as a moderate level for communication. This low rating could be contributed to the lack of accessibility by some parents. Educators and other service providers should identify the preferred method for accessing information by individual parents.

School systems, medical personnel and community resources are often limited in the financial foundation to support all of the needs of parents of children with disabilities. Support personnel need to prioritize the limited funds to impact the most parents and families to deliver the highest quality of services possible. The study supports that priorities for practice should be directed to resources and support systems that meet individual parent and family needs in a variety of channels to provide needed information.

Recommendations for Research

The study identified the usage and perceptions of importance for a variety of resources and support systems to meet the needs of parents of children with disabilities. The results of the study provided some general conclusions on types of resources and methods of accessing necessary resources. Future research could assist service providers in the identification of the specific information. Supporting research could target parents' satisfaction about the resource in meeting their individual needs. An example for future research would be focusing on the resources and support systems that parents are using and needing as their child graduates. Information on resources for financial, medical, residential and vocational services could also be the focus for future study.

Additional research could focus on parent satisfaction as resources and support systems are accessed. A qualitative study would assist in defining the level of satisfaction in meeting individual parents' needs. Questions regarding the relationships between specific needs, identified resources and level of satisfaction could be explored. The study could be applied to a variety of service providers in education, medical and community fields.

Summary

The discovery that your child has a disability often results in an emotional response with a variety of issues and needs. Resources and support systems are a necessary support that parents use and need as they evolve through the various stages toward acceptance, and as the child experiences new situations and challenges. Service providers need to be aware that each circumstance with individual parents of a child with a disability has unique needs. This study shows that the use and perception of importance of resources and support systems remains equally important, regardless of whether the family lives in a rural community or large urban center. The study shows that resources and support systems are needed throughout the child's developmental stages. Providers should respond with support and personalized services to meet the needs of parents of children with disabilities.

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Appendix A

University
of Nebraska
Medical Center
Nebraska's Health Science Center
A Partner with Nebraska Health System

Institutional Review Board (IRB)
Office of Regulatory Affairs (ORA)
University of Nebraska Medical Center
Service Building 3000
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April 3, 2001

Janis Norgaard
449 Elmwood Rd
Shelby IA 51570

IRB#: 078-01-EX

TITLE OF PROTOCOL: A Survey of Resources and Support Needed by Families of Special Education Students

Dear Ms. Norgaard:

The IRB has reviewed your Exemption Form for the above-titled research project. According to the information provided, this project is exempt under 45 CFR 46:101b, category 2. You are therefore authorized to begin the research.

It is understood this project will be conducted in full accordance with all applicable sections of the IRB Guidelines. It is also understood that the IRB will be immediately notified of any proposed changes that may affect the exempt status of your research project.

Please be advised that the IRB has a maximum protocol approval period of three years from the original date of approval and release. If this study continues beyond the five year approval period, the project must be resubmitted in order to maintain an active approval status.

Sincerely,

Ernest D. Prentice

Ernest D. Prentice, Ph.D.
Co-Chair, IRB

lw

University of Nebraska—Lincoln University of Nebraska Medical Center University of Nebraska at Omaha University of Nebraska at Kearney

Appendix B

Dear Parents:

You are invited to provide input for a research project that I am conducting. One of the purposes of this project is to identify the resources and support systems that you, as parent(s) of a child with a disability, are currently using or have used in support of your child. The other purpose is to identify your perceptions of importance for various resources and support systems that have been or will be needed as you continue to meet the needs of your child.

Information gained from research project, A Survey of Resources and Support Needed by Families of Special Education Students (IRB#: 078-01-EX) will have multiple uses. The first use will be the completion of the necessary course work needed for my Specialist in Education degree at the University of Nebraska at Omaha. The second use will have a possible impact on the resources and support systems that are currently available through your local school district and Loess Hills Area Education Agency. As Parent-Educator Coordinator for AEA 13, I will use the information gained from this project as a needs assessment as the Parent-Educator Connection program reviews its purposes, goals and future actions. There are no risks to you or your child due to your participation in this research project.

The research project is a survey that is included with this cover letter. All responses and answers to this survey will remain **anonymous** with complete confidentiality. Your participation in this project is voluntary. The first page asks for demographic information. The next section asks for you to respond to the the level of use (current and past) of various resources and support systems that you have utilized in meeting the needs of your child. The last section asks for you to give your perceptions of importance for various resources and support systems. You will be asked to circle the number that most accurately describes your use and perceptions of importance. The survey will take approximately 15 minutes to complete.

INSTRUCTIONS: Please mark your answers directly on the booklet and follow the instructions given in the survey instrument. **PLEASE RESPOND TO EVERY QUESTION.**

You may contact Dr. Martha Bruckner at University of Nebraska at Omaha at 402-554-2721 if you have any questions. Please use the attached self-addressed stamped envelope to return the survey by **APRIL 30, 2001**. Thank you for your participation.

Jan Norgaard
Phone 712-544-2077

Appendix C

DEMOGRAPHIC INFORMATION: Please respond to the following items.

1. Gender of Parent(s) completing survey:
   Male Female Both parents

2. Household Design
   Both Parents Single Parent ____________________
   (Other)

3. Age of child when handicapping condition was diagnosed ____________

4. Current age of handicapped child ______________________

5. Gender of child: Male Female

6. Enrollment of school district that child attends or received services
   (see back for information)
   - ☐ Group 1 - up to 999 students
   - ☐ Group 2 - 1000 to 1999 students
   - ☐ Group 3 - 2000 students or more

7. The State of Iowa identified children with special needs as ‘eligible individuals’. In your opinion, check the area that would be your child’s primary area of disability.
   - ☐ Learning Disabilities
   - ☐ Behavior or Emotional Disability
   - ☐ Mental Disability
   - ☐ Autistic or Autistic-like
   - ☐ ADD / ADHD / ODD
   - ☐ Down Syndrome
   - ☐ Head Injury
   - ☐ Other ______________________________________

   (Please specify)

8. (Optional) Comments about resources and supports needed as a parent of a special needs child

____

____

____

Appendix D

Use of Resources and Support Systems

What resources and support systems have you used or currently use to support your child with special needs?

1 - Have never used
2 - Use seldom
3 - Use occasionally
4 - Use frequently
5 - Usually use or always

COMMUNICATION					
I have talked to other parents with children with special needs about various concerns and topics.	1	2	3	4	5
I receive or communicate information regarding my child using personal written communication forms such as personal letters or email.	1	2	3	4	5
I read newsletters or journals that help me understand and learn about my child.	1	2	3	4	5
I gain information through discussions and meetings with professionals, such as school, medical and community personnel.	1	2	3	4	5
LIAISON/ADVOCACY					
I attend parent-school meetings, including I.E.P. meetings.	1	2	3	4	5
I have accessed the mediation processes to assist in communicating to school or other service providers.	1	2	3	4	5
I have contacted Protection and Advocacy personnel services to get assistance in a better understanding of my rights and those of my child.	1	2	3	4	5
EDUCATION					
I have attended workshops and group meetings on various topics related to being a parent of a child with special needs.	1	2	3	4	5
I have accessed materials (books, articles or videos) to gain information and knowledge on topics that support and inform me on issues related to my child.	1	2	3	4	5
I have used internet to search and locate information on various topics related to my child.	1	2	3	4	5
I have used professional personnel in the school system to help me gain information on the needs and services of a child with special needs.	1	2	3	4	5
I have used professional personnel in the medical field or in community services to help me gain information on the needs and services of a child with special needs.	1	2	3	4	5
SUPPORT SERVICES					
I receive support and understanding as a parent of a child with special needs from my immediate family and close friends.	1	2	3	4	5
I attend a support group with other parents of children with special needs.	1	2	3	4	5
I communicate with another parent of a child with special needs when I need to ask questions or gain information and support.	1	2	3	4	5

Appendix E

Perception of Importance of Resources and Support Systems

What resources and support systems do you perceive as important for supporting the needs of your child with special needs?

1 - Not important with no need
2 - Minimal importance with little need
3 - Important with need on an occasional basis
4 - Important with need on a frequent basis
5 - Extremely important with an ongoing need

COMMUNICATION					
Personal contact (face-to-face) with other parents of children with special needs	1	2	3	4	5
Contact with other parents of children with special needs using letters or email	1	2	3	4	5
Newsletters and journal articles on information about my child's disability	1	2	3	4	5
Regular meetings with service providers for my child (school, medical, community)	1	2	3	4	5
LIAISON/ADVOCACY					
Information on parent involvement, procedures and rights associated with my child's Individual Education Plan (I.E.P.)	1	2	3	4	5
Information on mediation services to improve communication between parents and service providers	1	2	3	4	5
Information about rights and legal support available through protection and advocacy services	1	2	3	4	5
EDUCATION					
Information on my child's disability	1	2	3	4	5
Information on services available from medical and community resources for my child.	1	2	3	4	5
Accessing needed information through books and videos	1	2	3	4	5
Accessing needed information through known internet sites	1	2	3	4	5
Workshops and opportunities for parent training	1	2	3	4	5
Information on opportunities for my child after graduation	1	2	3	4	5
SUPPORT SERVICES					
Support services and information on parenting, sibling issues and respite care	1	2	3	4	5
Support groups with other parents of children with special needs	1	2	3	4	5
Contact with another parent of a child with special needs from local school to assist in accessing information and discussing issues related to being a parent of a child with special needs	1	2	3	4	5
Information on resources and services available for my child in the community	1	2	3	4	5