

MOTHERS' PERCEPTIONS OF THE TRANSITION PROCESS FROM EARLY
INTERVENTION TO EARLY CHILDHOOD SPECIAL EDUCATION:
RELATED STRESSORS, SUPPORTS, AND COPING SKILLS

by

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(ABSTRACT)

This study investigated 10 mothers' perceptions on the transition process, for their children with disabilities, from early intervention to early childhood special education. The issues of related stressors, supports, and coping skills were further explored. This research was guided by the ecological or systems theory.

The issue of transition between the two service programs (early intervention to early childhood special education) is addressed specifically in the legislation (Part C, Section 619, IDEA 1997). Federal law defines several elements that must be included in the transition planning. Each state must ensure a smooth transition for toddlers receiving early intervention services to preschool and other appropriate services. Since transition is such a critical time for young children with disabilities and their families, stress will presumably occur. The parents need to learn new terminology and procedures because each program is unique in which services are provided. Families are to receive information and training during the transition period.

This study was guided by the following research questions:

(1) What are the mother's perceptions of the transition process? (2) What factors facilitate or inhibit their satisfaction and involvement with the process? (3) What types of stressors and supports do these mothers experience during this process?

Qualitative methods were used to secure data. In-depth interviews provided the most information, but document analysis was also utilized. Each participant was interviewed two times. Participants were found from a variety of resources in the local communities. The criterion for this study included mothers whose children had a diagnosed disability or developmental delay, had been in an early intervention program, and had transitioned within the last two years.

The mothers from this study had positive transitions for their children. They were involved in this process and became better advocates. They were supported by family members and friends. Much support was provided by the professionals working within the early intervention system. The individuals who work with families of children with disabilities need to be aware of the whole family system. By knowing the family system, professionals will be able to provide services based on the individual needs of the family. Specific recommendations for policy makers in rural areas include the availability, location and cost of services. The medical model versus the education model was also discussed as an issue for these families when transitioning their children from one program to another.

In memory of
Dr. Samuel Dean Morgan
for all of his spiritual and
inspirational support
December 30, 1930 - September 14, 1999

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After teaching children with special needs for 11 years in Florida, I decided that I needed a change in my life. I applied for graduate school at Virginia Tech in the field of special education administration and supervision. I was accepted and that is where I spent 3 years of my life pursuing a doctorate degree. I met many new people while I attended graduate school. I wish to thank my family, friends I have known for many years, and new friends as I pursued this career change.

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Samuel

“My name is Elizabeth and my son, Samuel has mild to moderate right hemiplegic cerebral palsy. He was born at 36 weeks, six pounds, 11 ounces, on September 11, 1994. He suffered a traumatic birth, which included a skull fracture, mild to moderate asphyxia, a low APGAR score, and two mild seizures within the first 24 hours of birth. After nine days in the Neonatal Intensive Care Unit (NICU) we brought him home. At about three months old, we noticed that he kept his right hand tightly fisted, and his thumb inverted. He was scheduled for a visit to the developmental follow-up clinic at five months of age. Of course by this time, we already knew something was wrong. The follow up clinic referred up to the early intervention system.

At about six months of age, he began receiving physical therapy twice per week. He also received services from early intervention specialists once a week. My husband and I feel that the services he received through early intervention have been better than any of the other services, including therapies, that he has received. At two years of age, Samuel transitioned into the public school system, where he attends four mornings a week, and receives physical therapy and speech therapy twice per week. After much debate, he now receives occupational therapy weekly.

Samuel began walking shortly before his second birthday. He walks well, but drags his right foot slightly. Most of his problems concern his right arm, and more specifically his right hand. He has very little strength and little control, but he tries so hard! We have been told by many that he is a very determined little boy! Oh how well we know! He also talks very well now. Above all, Samuel is a very happy, well-adjusted, bright, and lovable little boy. He has brought and continues to bring much joy into the lives of my husband and me.” (Elizabeth)

CHAPTER 1

Introduction

The birth of a child can represent a significant transition for most families and requires establishment of new family roles and routines. The birth of a child with a disability, however, creates an unanticipated crises (Parks, 1977), alters family patterns in ways that are stressful (Kazak & Marvin, 1984), and makes coping demands for dealing with a disabled child more pronounced for the family system (Trute & Hauch, 1988). How

families respond to stress will depend on the interaction of multiple factors such as the severity of the child's handicap, economic and social stability of the family and its internal support system, and the amount of external support to which the family has access (Peterson, 1987). Gabel, McDowell, and Cerroto (1983) point out that the availability of services, or lack of support, such as medical, educational, counseling, and respite services, can also contribute to the level of stress that parents report.

Families who have a child with a disability may go through a four stage grieving process similar to that described by Kubler-Ross (1969). The five stages she identified included denial and isolation, anger, bargaining, depression, and acceptance. Gabel et al., (1983) describe the stages that parents of children with disabilities experience. These include mourning, shock, denial and hope, grief, anger, guilt, and adaptation. Parental reactions to the infant with a disability will be individual, and each parent will react in his or her own way. Some parents may experience their feelings intensely, mildly, or not at all (Gabel et al., 1983). These stages may or may not occur each time the family experiences a new transition with their disabled child.

Statement of the Problem

If a family has a concern about a child, the early intervention system can be contacted. A referral can be made by the family, along with permission for an evaluation to be conducted. A multidisciplinary evaluation will be given by a team of professionals on the child. After the evaluation, the family and the team will meet and decide if the child is in need of services. If the child is eligible, the services are provided under Part C - Infants and Toddlers with Disabilities within the federal special education law of the Individuals with Disabilities Education Act (IDEA). If everyone is in agreement, an individualized

family service plan (IFSP) will be developed that concentrates on the needs of the child and the family (Commonwealth of Virginia, Part C of IDEA, 1996).

IDEA, Sec. 1472 (2)(A)(C) defines the term “early intervention services” as developmental services which are provided under public supervision, and are designed to meet the developmental needs of an infant or toddler with a disability in any one or more of the following areas: physical, cognitive, communication, social or emotional, and adaptive development. To be eligible for early intervention services in Virginia, infants and toddlers; (a) must have at least a 25% developmental delay in one or more of the developmental areas, (b) who are without a 25 % developmental delay but are developing atypically in sensory-motor responses, emotional development, or behavioral disorders, and (c) must have a diagnosed physical or mental condition with a high probability of resulting in a developmental delay even though no delay currently exists (Commonwealth of Virginia, Part C of IDEA, 1996)

“Early intervention is a term used only when speaking about services to children birth through three years and their families” (Thurman, 1997, p. 3). Thurman (1997) defines early intervention as:

an array of services that is put in place through a partnership with families for the purpose of promoting their well-being and the well-being of their infants, toddlers, and young children whose development may be at risk due to a combination of biological and environmental factors. (p. 3).

In Virginia, a child with disabilities who is determined eligible can transition into the local school system and receive early childhood special education services under Part B (ages three to 21), within the federal special education law (IDEA). Eligible children

who will be two years old by September 30th can begin to receive special education at the start of the school year. The team decides when the child transitions as part of the IFSP. Early intervention is made available to families until the transition occurs or until the child's third birthday (Commonwealth of Virginia, Part C of IDEA, 1996).

The Virginia Department of Education and the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services (1996) state:

“The transition from early intervention services into local school division services is a critical time for young children with disabilities and their families. This will be one of several transitions that children and families will make throughout their lives. Yet, it is a transition for which planning should begin as soon as the child and the family enter the early intervention system.”

Transition may be defined as the movement of children and their families from one service delivery setting to another. Transition may not always be smooth for the families and staff professionals, but if they work together to develop and implement transitions plans, there may be minimal disruption or gaps in the service delivery (Lazzari, 1991). The law helps to ensure a smooth transition for all involved, yet best practice by professionals may not always be guaranteed.

Because transition is such a critical time for families as well as children, stress will presumably occur as numerous scholars suggest (Fowler, Chandler, Johnson, & Stella, 1988; Hains, Fowler, & Chandler, 1988; Hains, Rosenkoetter, & Fowler, 1991; Johnson, Chandler, Kerns, & Fowler, 1986; and Lazzari & Kilgo 1989). The literature on transition calls for families to receive information and training throughout the transition process. In response to the recommendations, the state of Virginia requires local early intervention service systems to ensure that families are provided information regarding possible future placements, transition options, and other matters related to the child's transition. This

information should be based on the needs of the family as determined through the IFSP. The transition plan must include clarification of local early intervention service providers and local school system roles and responsibilities related to the sharing of information with the family at each step of the transition process and support of the family as needed throughout transition. Assistance is more helpful when it is provided in a way that families are supported by, but not dependent on the system (Virginia Department of Education and Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, 1996).

New parents are often unfamiliar with the school system serving their children, and they need to learn new terminology and procedures as a part of this transition. The terminology and procedures of the preschool special education program will be different from that of early intervention under the federal law. Factors under the law include; (a) differences in documents, from an Individualized Family Service Plan (IFSP) to an Individualized Education Plan (IEP), (b) service coordination, (c) diagnostic labels - developmental delay (non-categorical) to mentally handicapped (categorical), and (d) least restrictive environment (Chandler, Fowler, Hadden, & Stahurski, 1995). Other differences not created by federal law may include; (a) differences in service delivery from a family-centered approach to a child-centered focus, (b) differences in provisions for services and funding under Part C and Part B of the IDEA, (c) differences in location of services from home-based instruction to center-based instruction (Hains et al., 1991).

Parents who have children with disabilities or developmental delays will make several transitions throughout their child's life span. Discussing issues with parents and establishing perceptions at an early stage of their children's lives might assist them in

making these future transitions for their children. Mallory (1986) states that early intervention specialists should continue to keep in contact with the family during and after the transition to early childhood special education. Professionals working with this group of parents will then be aware of the issues that are or are not being addressed through this process. Such informed communication could ensure smoother transitions for everyone involved.

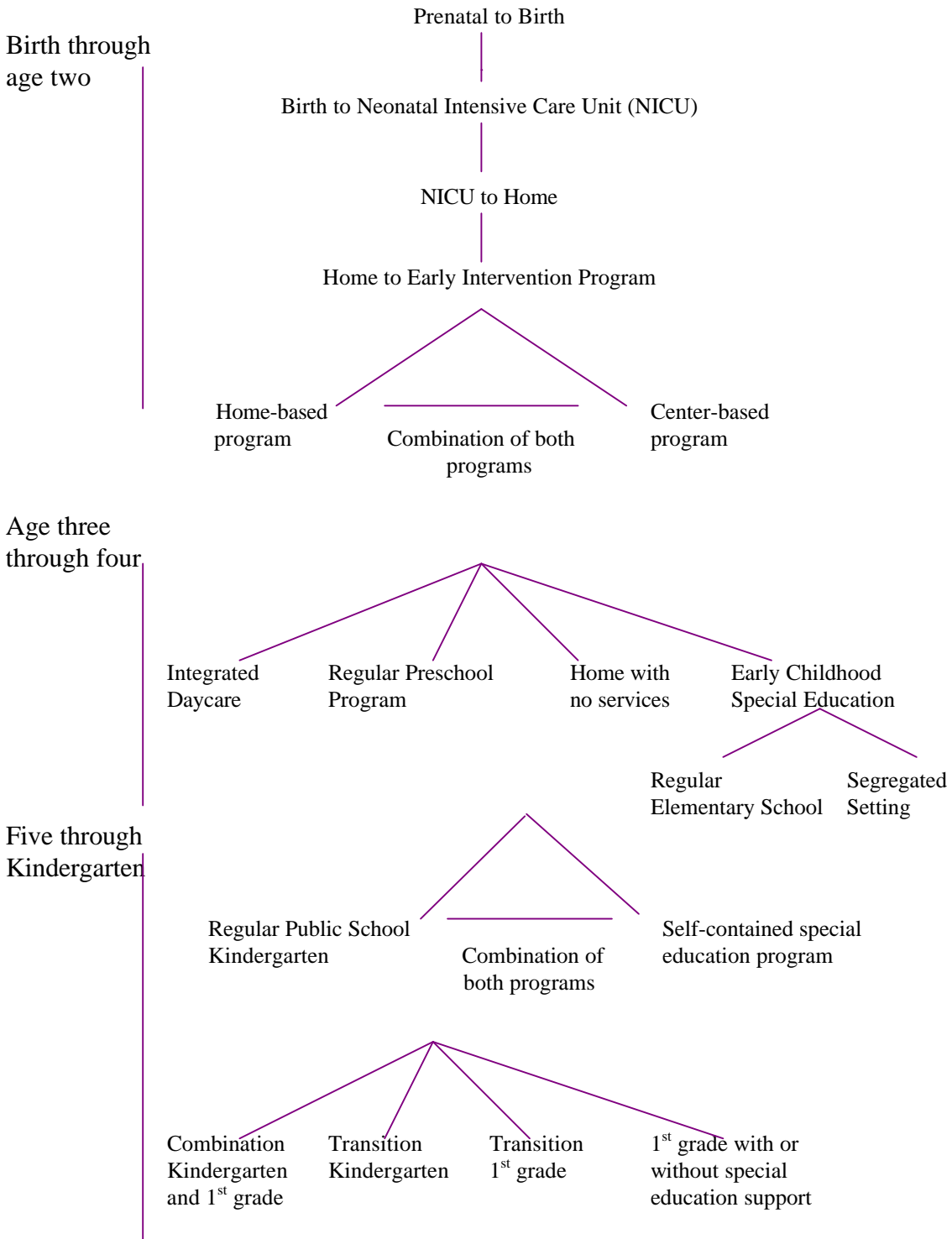
All families should receive information about anticipated transitions, the transition steps and tasks to be completed, options for the child and family for future services, and options for participation in the transition process. Families should be considered as equal partners of the transition team. Families should be given the opportunity to meet with providers from the sending and receiving programs, to observe possible programs and service options before the transition occurs, to attend all transition meetings, and to participate in programmatic decisions which affect transition (DEC Recommended Practices, 1993).

Transitions Birth through Age Five

Parents of children between birth and five years of age who are identified developmentally delayed, at-risk, or disabled will experience, along with their child, a number of transitions in developmental and educational service delivery. If the diagnosis occurs at birth, the family could experience five or more transitions as they move from one service delivery setting to another as shown in Figure 1 (Ratajczak, 1990). Infants will move from a hospital setting to home, home to early intervention programs offering home or center-based options, early intervention programs to early childhood special education

programs, and preschool programs to kindergarten. These changes often cause stress for families and the young children, and careful planning is essential (Bowe, 1995).

Figure 1. Transitions birth through age five.



Babies who are placed in a neonatal intensive care unit (NICU) are usually born with major birth defects or are considered at risk because of low birth weight. Transition from birth to the NICU may require medical treatment and may be the most stressful event that might occur in a child's life (Rice & O'Brien, 1990). Rosetti (1986) states that transition from hospital to home is another difficult period an infant can experience. After the child arrives home, and is need of support, another transition may occur within an early intervention program. Peterson (1987) addresses the advantages and disadvantages to home-based vs. center-based programs and discusses how families have to weigh the differences of each option. Once a child reaches age three, transition continues within a public school system. Areas of concern associated with a public school may include program eligibility, program philosophies, transition planning, and curriculum (Fowler et al., 1988; Hanline & Knowlton, 1988; and Wheeler, Reetz & Wheeler, 1993). Other sources of stress for families with children in the preschool years is interacting with multiple professionals at one time. In early years, a child's medical, education, therapy, and social service needs are often met by several agencies (Mallory, 1986). The child, at age five or six must transition into a kindergarten special education classroom or regular classroom. This can produce stress for the child and the family, as new relationships are formed and new rules of behavior are learned (Bowe, 1995).

Transition should fulfill four goals (Wolery, 1989); (a) to ensure continuity of services, (b) to minimize disruptions to the family system by facilitating adaptation to change, (c) to ensure that children are prepared to function in the receiving program, and (d) to fulfill the legal requirements of P.L. 99-457. It is necessary to assist families of children with disabilities in order to achieve these goals. Both the sending and the

receiving programs must support this transition process, and work collaboratively together. Many areas within local school systems have not adapted formal procedures to facilitate the transition of families and children with disabilities.

Transition reflects change in who receives services, what services are received, where services are delivered, how they are received, and who delivers them, as noted by Fowler and Ostrosky (1994). These authors suggest that “planning for change, while maintaining continuity and quality of services becomes the critical element of the transition process” (p. 143). The members of the transition planning team can help families in the following ways; (a) reduce transition-related stress and deal more effectively with stress, (b) learn about and prepare for changes that will occur during the transition period; and (c) identify child and family transition-related needs (Fowler et al., 1988).

The number of transitions may increase the degree of uncertainty, confusion, and anxiety for the family and child (Fowler & Ostrosky, 1994). Early intervention professionals should be aware of families’ concerns during the transition process and be able to support them (Fowler et al., 1988). Expressed concerns include; (a) the transfer of friendship, (b) changes in service delivery which include a shift from family-focused to child-focused services, differences in types of services that are offered, coordination of services, a shift from home-based to center-based services, and who delivers services, (c) discrepancies in eligibility, (d) variations in labeling, and (e) concerns about social ability (Hains et al., 1991).

Role of the Administrator

Early childhood special education leaders need to possess administrative skills, articulate the effectiveness of early intervention, and demonstrate a commitment to

children with disabilities and their families (Linder, 1983). Decker and Decker (1976), as cited in Linder (1983) outline administrative policies and procedures for early childhood special education programs in the following areas:

- (1) Administrative policy -- legal mandates, administrative operation;
- (2) Child-related policy -- referral, assessment, placement, services to parents;
- (3) Staff-personnel policy -- staff development, staff evaluation;
- (4) Fiscal policy – funding, budgets, system of accounts; and
- (5) Public relations policy – program facilities, media for communication to public.

Early childhood administrators, who are at the state level, are to establish the guidelines to promote a smooth transition under the law (Lerner, Lowenthal, & Egan, 1998). Administrators in agencies who provide services for children with disabilities, birth through age two, special education directors in exceptional education programs, and principals in elementary schools which house early childhood special education programs play an important role in the transition process (Ratajczak, 1990). Ratajczak (1990) adds that the responsibilities of these administrators include participation in the development, implementation, and enrichment of a transition plan for infants, young children, and their families, as well as making sure that the transition complies with the federal regulations (Lerner et al., 1998).

Administrators are important to the early intervention system. In Virginia, the special education directors in local school divisions are responsible for transition coordination along with the early intervention service coordinator. Their responsibilities include; (a) directing staff and families to information related to transition, (b) helping communication flow between agencies and with families, and (c) overseeing the transition

process on an ongoing basis. The directors and service coordinators should meet at least on a semi-annual basis for the purposes of planning, tracking, and evaluating the transition process with recommendations for changes as needed (Transition Plan for the New River Valley, 1996).

Rosenkoetter, Hains, and Fowler (1994) propose a list of challenges and responsibilities that confront transition (early childhood) now and in the future. These include; (a) developing trusting relationships and appropriate procedures to accomplish early childhood transitions in a timely and effective manner, (b) involving all transition participants – families and sending and receiving programs – information sharing and decision making, (c) placing and appropriately serving children with special needs in natural environments among typically developing peers, to the maximum extent possible; (d) preparing children and their families for transition and supporting their successes in new surroundings; (e) evaluating transition practices in efforts to improve them, and (f) training personnel in planning effective transitions locally in their communities.

Purpose of the Study

The intent of this study was to determine mothers' perceptions of the transition process from early intervention to early childhood special education. Mothers whose children were termed developmentally delayed or disabled, who had recently transitioned, and were currently in a preschool setting were the subjects comprised for the study.

Another goal was to gather information from mothers about the related stressors, coping skills, and supports they experienced throughout the transition process. In order to gather information, in-depth interviews were conducted with the mothers. Bronfenbrenner's (1979) ecological theory provided the theoretical framework to guide this study.

Research Questions

The following research questions guided this inquiry:

1. What are mothers' perceptions of the transition process?
2. What factors facilitate or inhibit their satisfaction and involvement with the process?
3. What types of stressors, supports, and coping skills do these mothers experience during this process?

Assumptions

This study was limited to parents in a region located in Southwest Virginia and examined only the mothers' perceptions of the transition issues for children with disabilities who were moving from an early intervention program to an early childhood special education program on their third birthday. Transferability of the findings was best applied to the state of Virginia and to families similar to those described in this study.

It was assumed that the participants responded truthfully to the questions during the interview, and it is acknowledged that for some mothers the interview process was used therapeutically as a support mechanism. The results of the study were assumed to be a sampling of the representative of mothers' concerns. It was also assumed that these participants experienced a positive transition.

Definition of Terms

1. At-risk infant or toddler – an individual under 3 years of age who would be at risk or experiencing a substantial developmental delay if early intervention services were not provided to the individual (Sec. 1432, IDEA 1997).

2. Coping – a collection of strategies used during confrontation with a challenge. Getting information, considering alternatives and making decisions about a course of action are included as problem-solving responses (Wills, Blechman & McNamure, 1996).
3. Developmental delay – lags in child development in any one of the five domains (cognitive, communication, physical, adaptive, social or emotional). In Virginia, there is a 25% delay.
4. Early Childhood Special Education (ECSE) – joins Part C and Section 619 of Part B of the IDEA. ECSE is a unified system of services for infants, toddlers, and preschool-age children with disabilities from birth to five inclusive.
5. Early intervention –services to infants and toddlers, and to their families, to address the special needs of very young children who have disabilities, have developmental delays, or are at-risk of development delays (Part C of IDEA).
6. Early intervention services – services for infants and toddlers that are designed to identify and treat a problem or delay as early as possible. Early intervention services are offered through a public or private agency and are provided in different settings, such as the child’s home, a clinic, a neighborhood daycare center, hospital, or the local health department (National Information Center for Children and Youth with Disabilities, NICHY, 1997).
7. Individualized Education Program (IEP) -- a written document that identifies the unique needs of the child, the special education and related services needed to meet those unique needs, annual goals and short-term objectives, how the child’s progress will be assessed, the date of initiation services, and the projected duration of those services. The IEP is used in Part B of the IDEA.

8. Individualized Family Service Plan (IFSP) -- a written document outlining services for infants and toddlers, and (if the families concur) their families as well. IFSPs note the infant's or toddler's development in five domains, services the child (and family) will receive, and similar information as well as the service coordinators name.

9. Individuals with Disabilities Education Act (IDEA) -- the IDEA is the landmark special education law in the United States. Formerly called the Education of the Handicapped Act, it includes (as Part B) P.L. 94-142, the Education of the Handicapped Children Act of 1975.

10. Infant or toddler with a disability -- an individual under 3 years of age who needs early intervention services because the individual is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in on or more of the areas of cognitive, physical, communication, social or emotional, and adaptive development; or has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay; and may also include, at a states discretion, at-risk infants and toddlers (Sec. 1432, IDEA 1997).

11. Parent -- anyone who is in charge of the care and well-being of a child. These can be guardians, single parents, grandparents, surrogate parents, foster parents, or other family members (NICHCY, 1997).

12. Part B -- the part of the IDEA describing how children with disabilities aged three through 21 shall receive a free appropriate public education.

13. Part C -- the state operated program created in 1986 for infants and toddlers with disabilities and their families. It is an early intervention program for children under three years of age and (with family concurrence) their families.

14. Perceptions -- an awareness of ones own environment; ability to understand (Merriam Webster Dictionary, 1994).

15. Service Coordinator -- someone who acts as a coordinator of an infant's or toddler's services, working in partnership with the family and providers of special programs (NICHCY, 1997).

16. Stressor -- a life event that impacts upon the family unit that produces, or has the potential of producing, change in the family system (McCubbin & Patterson, 1982).

17. Supports -- (a) emotional support -- the availability of a person with whom one can discuss problems, share feelings and reveal worries when necessary; (b) instrumental support -- having a person available who can provide assistance with instrumental tasks; (c) informational support -- the availability of advice, guidance, and information about community resources (Wills et al., 1996).

18. Transition -- movement from one stage or program to another (Brandt, 1987).

Amanda - A Valentine's Miracle

"It was February 14, 1995, Valentine's Day when Amanda was born. I was scared that morning. I knew that something was wrong on the way to the hospital. I had gotten to the hospital and I remember the doctor checking me and telling the nurse to get me ready for emergency surgery, that my baby and I were in trouble. By the time we got to the ER, Amanda's heart rate had dropped to 30 beats. Amanda was born dead at 6 pounds, 11 ounces and required resuscitation. I remember awaking in my hospital room. My sister was there. Two doctors came into the room and said "Amanda is not doing too well, we are sending her to another hospital." Before they left, they brought her to see me. I could not hold her, there were too many tubes. All I could think of was, "I will never see her again."

Three days later I went to see her and she was still very sick. The doctors said they were going to do everything possible. Days and days passed and still there was no change. All I wanted was for her to wake up. I remember thinking, "If she is going to die, let God take here and quit letting her suffer...." All I wanted was some relief.

Early intervention stepped into our lives in May, 1995 and they have helped me tremendously. Amanda has mild tone cerebral palsy, asthma, and seizure disorder, but she walks, talks and is doing great!" (Karen)

CHAPTER 2

Review of the Literature

Organization of the Chapter

This literature review covered five themes; (1) intent of the law with state and federal policies on transition, (2) perceptions of the transition process for young children with disabilities, (3) models used in transition, (4) perceptions of the early intervention system, and (5) stressors, supports, and coping for families of children with disabilities. These themes formed a strong theoretical rationale for the need to investigate parents during the transition period from an early intervention program to an early childhood preschool program. Bronfenbrenner's theoretical framework, and how it related to the research studies, was discussed.

Intent of the Law with State and Federal Policy on Transition

The law passed in 1986, (Public Law 99-457), The Early Childhood Education Act applied to children from birth to five years of age who were experiencing developmental delays. Part C, Infants and Toddlers with Disabilities, (formally called Part H), of the newly reauthorized Individuals with Disabilities Act (IDEA) 1997 established federal policy for early intervention programs for infants and toddlers (birth through three) who are handicapped or at-risk. Part C provides financial assistance to states to develop a comprehensive, coordinated, multidisciplinary interagency program of early intervention for infants, toddlers, and their families (Council for Exceptional Children, 1988).

The issue of transition between the two service programs (early intervention to early childhood special education) is addressed specifically in the legislation (Part C, Section 619, IDEA 1997). Federal law defines several elements that must be included in transition planning. Each state must ensure a smooth transition for toddlers receiving early intervention services to preschool or other appropriate services, including a description of how:

- the families of such toddlers will be included in the transition plans required; and
- the lead agency will notify the LEA for the area in which such a child resides that the child will shortly reach the age of eligibility for preschool services under Part B, as determined in accordance with the state law;
- in the case of a child who may be eligible for such preschool services, with the approval of the family of the child, a conference will be convened among the lead agency, the family, and the LEA at least 90 days (and at the discretion of all parties, up

to six months) before the child is eligible for the preschool services, to discuss any such services that the child may receive; and

- in the case of a child who may not be eligible for such preschool services, with the approval of the family, make reasonable efforts to convene a conference among the lead agency, the family, and providers of other appropriate services for children who are not eligible for preschool services under Part B, to discuss the appropriate services that the child may receive;
- procedures must occur to review the child's program options for the period from the child's third birthday through the remainder of the school year; and
- a transition plan must be established (Council for Exceptional Children, 1988)

In Virginia, the agency that has designated specific roles and responsibilities related to services for children with disabilities ages birth through two and their families is the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services. This agency monitors children who; (a) do not turn age two on or before September 30th and remain Part C eligible, (b) turn age two on or before September 30th, remain Part C eligible, but are not Part B eligible, and (c) turn age two years on or before September 30th, remain Part C eligible, are not Part B eligible, but whose parents do not consent for an evaluation or placement under Part B. The Virginia Department of Education, and through its local school system, mandates a free appropriate public education (FAPE) under IDEA, Part B, for children with disabilities age two (2) through twenty-one (21) years (Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, 1996).

In Virginia, eligible children with disabilities who will be two years old by September 30th of that year can begin early childhood special education at the start of the school year. As part of the Individualized Family Service Plan (IFSP), the parent along with the IEP and IFSP teams decide when the child will transition. This occurs whether the move to preschool will be in September of the year the child is eligible or later in the school year. Sec. 636 (d)(8) (IDEA, 1997) specifies the content of the IFSP and states that “the steps taken to support the transition of the toddler with a disability to preschool or other appropriate services.” Early intervention services are available until the transition occurs or until the child’s third birthday (Commonwealth of Virginia, 1996).

The steps include; (a) discussion with and training of parents regarding possible future placements and other matters related to the child’s transition, (b) preparing procedures for the child in service delivery, including steps to help the child adjust and function in the new setting, and (c) with the parent’s consent, transfer of information about the child to the local school system, to ensure continuity of services, including evaluation and assessment information and IFSPs (Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, 1996).

Perceptions of Transition

Hains et al. (1988) propose that a smooth transition between services is important to young children with special needs and their families because well-coordinated transitions promote; (a) placement decisions that meet individual needs; (b) uninterrupted services; (c) non-confrontational and effective models of advocacy that families can challenge throughout their children’s lives; (d) avoidance of duplication in assessment and goal planning; and (e) reduced stress for children, families, and service providers.

Common early transitions are from hospitals to community early intervention services, from infant/toddler services to preschool services around age 2 or 3, and from preschool to kindergarten services at ages 5 or 6 (Shotts, Rosenkoetter, Streufert, & Rosenkoetter, 1994).

Hains et al. and colleagues (Rosenkoetter & Fowler, 1991) suggest a four phase plan for supporting family involvement in transition planning. Phase 1 includes professionals' talking to families about the transition process. Kilgo & Noonan (1991) state that the age of the child and the severity of the disability will affect the parents' readiness to consider the next educational program. The case manager assigned to the family plays an important role in this phase. He/She should review the timelines of the transition activities within the early intervention program and the preschool program, and determine who will be involved in the child's transition, discuss the family needs and roles in the transition process, review the IFSP, and explain the parental consent form. Having conversations with families about future programs and discussing the IEP make up Phase 2. The case manager can assist the family in preparing IEP activities and encourage them to participate in the decision making processes. Phase 3 consists of discussions between professionals and families who are entering the new program. The families can assist the new program by providing information about the family and child. This process can prepare for the final transition. Families' satisfaction with the transition is evaluated in Phase 4. The feedback the family provides about the quality and value of transition activities helps in keeping programs responsive to the needs of the child and family. Lazarri and Kilgo (1989) have suggested that positive experiences with early transitions may help families and children with later ones.

A strategy for determining family concerns about the transition process is to interview parents following their child's transition from preschool intervention services to kindergarten. In an exploratory study of 19 parents, Johnson et al. (1986) found that 80 % of the parents reported satisfaction with their child's transition from a preschool program into the public schools, yet the idea of change proved somewhat stressful . Reported by more than half of the parents was the needed time their child had to adjust to a new program. Less than half of the parents communicated that their families needed time to adjust to their child's attending a new program.

The participants were interviewed using The Retrospective Transition Interview (RTI), which provided the parents an opportunity to discuss the issues they confronted during their child's transition. Parents rated their satisfaction on all items as moderate to very high. These parents expressed greatest satisfaction with parent-teacher conferences and the least satisfaction with the amount and type of their involvement in the public school program.

As a result of the findings by Johnson et al. (1986), another study by Fowler et al., (1988) developed two interview protocols that assisted parents in planning the transition of their child from an early intervention preschool to elementary school. Thirty families participated in this study, 18 in a suburban community and 12 in a rural county. Two transition planners (questionnaires) contained categories that helped parents identify information they needed for their child's transition. These planners contained rating scales and open-ended questions. Transition Planner 1(TP1) - Gathering Information, was the first interview conducted in the fall of the child's preschool year. The second interview was termed, Transition Planner 2(TP2) - Choosing the Best Program, and parents

completed this during the spring of their child's final preschool year. Some items rated very important by 80% of the parents were their opportunity to participate in planning and selecting the next program and receiving information about these programs. Forty percent of the parents reported that stress was experienced during the transition process, and half of the parent's children also demonstrated signs of stress.

Hanline (1988) reported the results of a survey of parents' needs and concerns as their children transitioned into a new setting. Hanlines' study is similar to Johnson et al. (1986), yet this study further identifies parent needs and concerns as their children make the transition into the public school system or already have entered the system. Thirty-eight parents of infants who were awaiting but had not yet made the transition were surveyed as well as 54 parents whose children were already in preschool and had completed the transition. Hanline developed a written questionnaire. The parents rated the helpfulness of 19 specific areas of information and the helpfulness of 9 specific transition support services. The Spearman rank-order correlation between the perceptions of the two groups of parents was .65 in both cases, which showed validity within the study. Lack of information about school district services, anxiety about working with an unfamiliar agency, and uncertainty as to whether the child would receive appropriate services were the major concerns of the parents.

Like the studies cited earlier, Hamblin-Wilson and Thurman (1990) also investigated the parents' perceptions of the transition process . The children had gone from placement in early intervention programs to placement in the public schools. More specifically, Hamblin-Wilson and Thurman's study focused on satisfaction with the transition process, the importance of service relationship, the support and explanations

they receive, and the importance of their preparation for transition. This study surveyed 91 parents who completed a questionnaire. Results indicated that 68% of the parents felt involved in the transition process, and 60.4% felt that they received more support from their child's early intervention program than from that of the public schools. Parents see themselves as being involved in the transition process, yet not necessarily empowered.

Another approach to studying parents' perceptions of the transition process is to provide the parents with an education program that assists them in making the transition smoother for their children. The transition model described in this study by Spiegel-McGill, Reed, Konig, & McGowan, (1990) focused on educating and empowering parents to become long-term, independent, informed advocates for their children. Six workshops in this parent education program were provided for eight parents who were involved in an early intervention infant program, and were making the transition to a center-based preschool program. The topics of the workshops included; (a) The Effects of Transition on Our Lives, (b) Knowing Your Child, (c) Program Options and Services, (d) Effective Communication, (e) Educational Rights, and (f) Putting the Puzzle Together. After the parents completed the parent education program, they responded to a survey that rated the usefulness of the program. The parents found the program to be useful, and they felt more prepared for their child's transition as indicated by the mean rating of 4.0 on a 5-point Likert scale (1=not at all to 5=very much). In this study, transition planning focused on the needs of the individual families.

Shotts et al. (1994) conducted a study that centers on transition issues from all of the 50 states. They surveyed state-level early childhood leaders in each of the 50 states. The survey contained 13 items related to transition issues. The state leaders were also

asked to address their progress in developing state transition policies on the movement from one setting to another. Results from the respondents indicated a strong concern across the nation about transition issues. Some examples of concerns included; (a) a limited range of options available for placement after transition, (b) the need for training service providers and policy makers about transition strategies, and (c) the need for training families on transition issues. States also varied in their progress in transition planning, and this depended on what was the lead agency. Shotts et al (1994) also found that transition continues to be an issue for families, service providers, and state program coordinators.

Another way to collect data on perceptions of the transition process is to survey and interview the professionals who are involved in the process. In Australia, Newman (1996) investigates teachers' perceptions of the transition process. 45 early childhood teachers were surveyed on their beliefs and practices in the areas of Teaching and Learning, Families and Transition Management. Six interviews were also conducted with two preschool teachers, two early intervention teachers, and two kindergarten teachers. The results indicated that there are significant differences between each teacher's transition related beliefs and their practices. Differences between teachers were related to the program in which the teachers worked. The teachers also reported a lack of communication between preschool and school programs.

A recent study conducted by Jewett, Tertell, King-Taylor, Parker, Tertell, & Orr (1998) used narrative inquiry techniques with four experienced preschool and primary school teachers in describing the process of helping young children with special needs make the transition to kindergarten. Open-ended questions were provided to guide the

teachers as they wrote in their reflective journals. The following categories of transition tasks in teachers' writing are identified as; (a) the overwhelming sense of responsibility experienced by the teachers, (b) the understanding and implementing laws and regulations which protect children with disabilities, (c) developing knowledge of the child with disabilities and the family, (d) preparing students and families for a smooth transition, and (e) serving as a liaison within the transition process. This study indicated that these teachers have concerns in dealing with transitions that are not necessarily addressed in the literature. These teachers felt that the transition tasks are demanding.

In conclusion, as these studies indicated, there seemed to be satisfaction with the transition process from preschool to kindergarten, yet there are some reservations about the school experience after the transition was completed. There was limited research in transition from early intervention to a preschool special education classroom. The studies cited date back from the years 1986 and 1988 when the law was first passed, up to the 1990s. Of the literature reviewed, there is a lack of clarification of who is responsible for implementing transition components. Family involvement is increasing in the area of special education and early intervention, especially with the family-focused model that is used with families enrolled in early intervention. These studies also indicated that there is always a need for further research in the areas of families, service providers, and preschool teachers.

Models used in Transition

Hanline and Knowlton (1988) state that the need for professional services is supported by P.L. 99-457 during the time of transition. The individualized family service plan developed by early intervention programs includes steps to be taken to support

families during the transition to programs providing services for 3- to 5- year olds (IDEA 97, Sec. 677). Models are often developed to assist families and to provide support as their children transition into a preschool program from an early intervention program (Hanline and Knowlton, 1988). One such model is Project STIP (Supported Transition to Integrated Preschools). This program is used in the San Francisco area. Its focus includes both the sending and the receiving programs in the transition process where resources and expertise are combined, therefore ensuring a smoother transition and comprehensive services for parents. Three phases are included in this model. They are; (a) preparation for the transition, (b) school district intake assessment, the educational program meeting, and placement, and (c) follow-up. After completion of the transition process, parents are asked to evaluate the program that was implemented. Parents rated their overall satisfaction with services equally high (mean rating = 1.44), with 1 = excellent to 5 = very poor on a five-point Likert scale. This model provides support prior to, during, and after the child has made the transition to the preschool program.

The transition of children and families from infant/toddler programs to preschool programs has become a concern for persons working with young children and their families. Depending on interagency collaboration at the state and local levels, as well as the preparation of children, families, and staff, a smooth transition can occur (Rous, Hemmeter, Schuster, 1994). Project STEPS (Sequenced Transition to Education in the Public Schools) is a model project that is used in Kentucky to facilitate interagency collaboration at both the state and local levels. The four primary components of Project STEPS include, (a) interagency and administrative issues, (b) staff involvement in the transition process, (c) family involvement in the transition process, and (d) child

preparation for the next environment. Project STEPS uses this model for team training that is related to each of the four components, as well as the overall transition system development.

Another model, developed by Rosenkoetter and Shotts (1997), is the Bridging Early Service Transition (BEST) Project. This project is located in Kansas and is designed to help young children with disabilities and their families prepare for and adjust to new service settings. The BEST project emphasizes advanced planning and communication between the sending (early intervention) and receiving (preschool) program and the home. Family members are also offered opportunities to become involved as active participants in their child's transition. This model includes a variety of formats to be used throughout the transition process. The model includes formats for (a) local interagency needs assessment, (b) interagency agreements, (c) communicating between families and service providers, (d) family partnership in decision making, (e) constructing interagency and intra-agency transition timelines, (f) building within the IFSP a transition timeline for each child, (g) preparing the child for changes in program and personnel, (h) systems change to incorporate more options for inclusive services, and (i) evaluation of transition procedures.

The Preschool Preparation and Transition (PPT) project (Kilgo, Richard, & Noonan, 1989) was developed at the University of Hawaii. This project was designed to assist families of infants and toddlers with special needs in coordination for transition to preschool. The Parent Needs Assessment (PNA) is a major component of the PPT model. This was developed to determine parental preferences and abilities, and provide support

during the transition to preschool. The IFSP, and this document must be responsive to the individual needs of each family as transition is planned.

The Kids in Transition (KIT) Project, located in Iowa, assists in preparing children and their families transition from early childhood special education programs to elementary regular or special education programs and from home-based early intervention programs to preschool special education. The KIT model includes two components, an educators' guide and a parents' guide. The guide for educators describes the planning process of the project and recommends meetings, prescribed timetables, and conferences that should occur with the parent/child and the receiving school's staff (Goff & Hemmesch, 1987a). The parents' guide involves four parent meetings. The first meeting reviews parents' rights in the special education process. The second meeting discusses handicapping conditions and special education program options. The focus of meeting three is on parental responsibility and sharing of information with others. Meeting four is on developing a cooperative home-school partnership (Goff & Hemmesch, 1987b).

The goal of Project TEEM (Transitioning into the Elementary Education Mainstream) is to develop a model that empowers parents and staff from early childhood special education and elementary school programs to work together in establishing and implementing a system-wide transition process for planning transition (Conn-Powers, Ross-Allen, & Holburn, 1990). The TEEM model was developed and implemented in Vermont. This model is not a single model for transition planning, but one that provides information and guidelines. The steps included in the TEEM Project include; (a) establishing a planning team, (b) developing goals and identifying problems, (c) developing

written transition planning procedures, (d) gaining system-wide support and commitment, and (e) evaluating the transition process.

Diamond, Spiegel-McGill and Hanrahan (1988) describes an approach based on Bronfenbrenner's ecological-developmental model to plan a child's transition from a preschool special education program to a public school classroom. The transition model begins in the fall prior to kindergarten entrance through the first part of the kindergarten year. There are a total of 15 steps that take place over the course of a year. These include:

1. Preliminary Transition Plans - occur in the months of September and October and include three steps; (a) The IEP, (b) Identification of preschool liaison with school district and, (c) Parent Education.

2. Contacts with the School District - are initiated in the months from November through February. These include; (d) Referral to the school district's multidisciplinary team, (e) Parent conference to discuss child's current level of functioning and parent's expectations for school placement, (f) Informal contact with the school, and (g) Assessment reports provided to school and parents.

3. Developing Placement Options - occur in the months from February through June. These include; (h) Planning a meeting with multi-disciplinary team chairperson, (i) Visits to the proposed school programs, (j) Continued parent education focusing on due process rights, and (k) Multi-disciplinary team meeting to recommend an appropriate placement and develop the Phase 1 IEP.

4. The Transition Planning Process - occurs between June and August. These include; (l) Visit by public school teacher to the preschool, (m) Visit by the child to the public school he/she will attend, (n) School records sent to the public school and parents by the

preschool program, (o) A follow up occurs in October in contact with the public school. This type of model could also be incorporated into the transition from early intervention to preschool with some minor adjustments.

“By enhancing the interrelationships between the child’s present and future educational environments through the use of information and personal and direct contacts, communication is enhanced across these environments” (Bronfenbrenner, 1979, p.210). When this model is used, the child, family, preschool, and the public school share in the transition process. This tends to facilitate the child’s transition from one educational environment to another (Diamond et al., 1988).

These models offer a variety of ideas and tools for service providers, parents, and preschool teachers. These models may be to promote a smoother transition for all those involved in the process. The individuals who are involved in the transition process need to be aware that these packaged programs exist and that they are being used in other places, and have been proven to be successful.

Perceptions of Early Intervention

Family-centered early intervention service models have an emphasis on enhancing and supporting the effectiveness of families caring for their children (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). With the use of this family-centered model, federal early intervention legislation was developed to promote three goals for parent and family involvement. These include; (a) the scope of family services to be broadened to include the full range of services needed to help parents cope and adjust with the stressors and demands that go along with raising children with disabilities, (b) parents who are to become full members in the planning of early intervention services, and (c)

parents who are to be considered as full partners in the early intervention process (Mahoney & Filer, 1996). The following research studies are meaningful to this proposed study because parents need a comprehensive understanding of the early intervention system. Satisfaction with early intervention services may assist parents progressing onto the next step of transition.

Fifteen parents of children with severe handicaps were interviewed in a study conducted by Calhoun, Calhoun, and Rose (1989). All of these parents had recently enrolled their child into an early intervention program. Three broad headings emerged as areas of concern, which included worries about early intervention programs, perceived benefits of early intervention programs, and sources of advice that influenced enrollment decisions. Parents experienced worries in making the decision to enroll their child into an early intervention program. Clear benefits were perceived once the child was enrolled. A great deal of sensitivity and an increased knowledge of the benefits of early intervention were important to the parents of babies with severe handicapping conditions.

McBride et al. (1993) investigated the meaning of family-centered intervention and the extent to which it is implemented from the perspectives of both professionals and families who participated in the development of the IFSPs. Semi-structured interviews were conducted. The fifteen families participating in this study were new referrals to the early intervention program. Of the 14 professionals, 12 of them were early childhood special educators, while one was an occupational therapist and the other a social worker. Themes that emerged from the findings included the family as focus of services, family roles and choices in decision making, and strengths of intervention in family functioning. The results indicate that professionals have an understanding of the change in focus from

child-centered to family-centered. Families were satisfied with the services that they received.

McWilliam et al. (1995) gathered descriptive data on families' perceptions of early intervention services. Of particular interest was how satisfied families were with these services. Families of 539 children participated in filling out questionnaires. For overall satisfaction, ninety-four percent of the families claimed the services that were provided were the same or better since they began receiving services. Six families were also interviewed. The interview portion of the survey indicated that individual professional behaviors were often directly linked to families' positive impressions of early intervention services. Overall, families were generally pleased with the quality of early intervention services they received. Much of the satisfaction was the result of personal support given by the individual professionals.

Nine families, four administrators, and ten service providers were the primary participants for the study conducted by Minke and Scott (1995). Data were collected on the parent-professional partnerships that occurred during the IFSP development in three early intervention programs. Videotaping the IFSP meetings and interviewing were the primary methods for data collection. The role of personal parent-staff relationships in encouraging active parent participation and staff reactions to parent participation were the two major themes that emerged. Personal relations were reported as being important between the parents and the staff. The staff was concerned about whether all parents had the skills necessary for full participation in the IFSP process.

Mahoney and Filer (1996) explored two similar studies using the Family Focused Intervention Scale. The first study included 357 mothers responding to a questionnaire.

The mothers involved in the study were to characterize the type and intensity of services the early intervention program had provided. Also included on the questionnaire were items that assessed parents' needs and priorities for services received from their early intervention program. Results indicated that early intervention provided services in response to the parents' priorities. Filer and Mahoney's (1996) second study included 73 service providers and 193 parents. The parents responded to a survey that included the Family-Focused Intervention Scale. Results indicated that professionals and parents have significantly different perceptions of the types of services that occurred in that early intervention program. There was little evidence to support the view that parents and professionals are similar to one another regarding any of the constructs included in the survey. An example showed that parents expressed some needs for personal and family-level services, their need for these types of services were secondary to their need for services related to the well-being of their children. This contrasted with the professionals' viewpoints who supported personal and family-level services as being equally important as child-level services.

Wesley, Buysse, and Tyndall (1997) conducted a series of focus groups to explore parent and professional experiences and perspectives regarding inclusion and early intervention. The participants included 13 parents of young children with disabilities and 32 professionals representing service providers and administrators from a variety of human service programs and agencies. Four major themes emerged from the data. These themes were; (a) professionals, when compared with parents, could articulate and describe the existing system of early intervention services, (b) parents had a continued need for information from the professionals including the need for clearer communication about the

complex interrelationships of programs and agencies, (c) professionals identified more barriers than did parents to inclusive early childhood settings, and (d) compared to professionals, parents offered a number of articulated ideas for an ideal system of early intervention services. One such example parents mentioned was that the competent and caring human services professionals are essential in the ideal system. The findings of this study reveal different perceptions that exist between families and professionals.

From these studies cited, it can be seen that families and professionals have different perceptions about the services that are provided in early intervention. Family-centered services are stated in IDEA and the service providers need to be aware of the issues that surround the families. There are a number of interpretations of what “family-centered” means for both the parents and the professionals. From the studies described above, parents seem to be satisfied with early intervention. The type of disability can also affect the concerns that parents have about the early intervention process. Parents and professionals, even though working together seem to have reached some different opinions on the issue of early intervention.

Stress, Supports and Coping for Families of Children with Disabilities

As one study suggests (Noh, Dumas, Wolf, & Fisman, 1989), it is not clear whether the increased stress for parents of exceptional children is due to the disability of the child, the gender differences of the child or to parenting in general. The following studies (Bennett, DeLuca, & Allen, 1996; Dyson, 1997; Kazak & Marvin, 1984; Marcenko & Myers, 1991; Noh, et al. 1989; Orr, Cameron, & Day, 1991; Trute, 1990; and Trute & Hauch, 1988) focused on related issues to families of children with disabilities and their coping skills, but dealt with a range of degree and types of disability, age, and

caregivers' roles. These studies are important to this research effort because of the stress factors, coping skills, and supports that families of children with disabilities may encounter.

The study conducted by Kazak and Marvin (1984) discussed the differences in 100 families of children with and without disabilities. The disability diagnosis was for children with spina bifida. The purposes of the study were to determine (a) if families of children with disabilities experience more individual, marital, and parenting stress than a matched comparison group, (b) and to determine if families with disabled children have smaller and denser social support networks. The instruments used to measure parental stress included The Langer Symptom Checklist, The Parenting Stress Index, and the Dyadic Adjustment Scale. Mothers of the children with spina bifida experienced more stress than fathers as well as mothers and fathers in the comparison group.

Trute and Hauch (1988) conducted a study using methods that elicited both qualitative and quantitative data. A total of 40 families of children with a variety of disabilities were represented in this study. The average age of the child was three. Data collection involved personal interviews with both parents. The Family Assessment Measure III and the Dyadic Adjustment Scale (DAS) were also used to gather data. The findings from this study indicated that having a child with a disability is an issue for the family and one that should be addressed across family systems. The parents in this study viewed themselves as members of strong families.

Noh et al. (1989) compared the levels of perceived stress on dimensions of parenting among parents of children with disabilities and among parents of normal children. The sample consisted of 159 children -- 97 of the children were considered to be

disabled, while 62 were developmentally normal. The Parenting Stress Index (PSI) instrument was used to assess stress in this study. The PSI included a Parent and Child Domain. The conclusion of the study stated that parents of children with autism and conduct disorders suffered the most stress, which made parenting more difficult. Parents of normal children and those with Down syndrome were seen as not being as stressed.

Trute (1990) conducted a similar study. He surveyed a cross-sectional, random sample of 88 families containing young developmentally disabled children (those having multiple handicaps, physical disabilities, and Down's syndrome) using in-home interviews of both mothers and fathers. The Family Assessment Measure (FAM III) and the Dyadic Adjustment Scale (DAS) were given to both parents to collect data regarding key aspects of the family system. Findings from this study suggested that family functioning (parent, child, and marital attributes) has little to do with specific characteristics of a child with a disability. Additional findings suggested that families with children who are disabled are not any more distressed or disorganized than families with children without disabilities.

In an article by Orr et al. (1991), a study was designed to examine issues of parental stress and coping skills within the context of a theoretical framework that included the Double ABCX model of McCubbin and Patterson. The variables included family stress and coping skills among 86 families raising children classified as trainable mentally retarded, ages 5-21. Quantitative data were collected and a path analysis was the statistical tool. Three instruments were used for data collection. They included; The Parenting Stress Index, The Family Inventory of Resources and Management, and The Family Crisis Oriented Personal Evaluation Scale. The results indicated that the Double ABCX model provided evidence that the most significant stressors were directly related to

the perception of the stress event, the use of resources, and the general level of parental stress. The family's use of resources appeared to be more related to the family's perceptions of the stressor event as compared to the actual severity of the child-related problems. The use of resources was more directly related to stress, while perception was less related to stress.

A study of the informal social support systems of 89 mothers of children with severe developmental disabilities was conducted by Marcenko and Myers (1991). Interviews and questionnaires were used as part of the data collection. The authors utilized a semi-structured questionnaire to gather demographic data and data on the amount of instrumental, emotional, and informational supports mothers were receiving. The mothers took on most of the day-to-day responsibilities for the care of their children. Many of the mothers did not receive help with daily tasks, and those who did indicated the supports were important. Married women tended to receive more support from their husband and his family than single mothers received.

Bennett et al. (1996) conducted a qualitative study using interviews with 12 parents of children with disabilities ranging in age from 15 months to 30 years. In this study, three networks provided data sources. They were friends and family, parent groups, and professionals who were in different stages of the family life cycle. The study focused on the understanding of family adaptation and resources across the stages of the family life cycle. The findings showed that some of the most important informal resources for parents of children with disabilities were family and friends, parent groups, and professionals.

A recent study (Dyson, 1997) compared 30 fathers with 30 mothers who had school-age children with mental retardation and other disabilities along with 32 mother

and father pairs of parents of children without disabilities. This study was designed to show that comparison groups differ in parental stress, family functioning, and social support. The study also addressed a relation between stress of fathers and mothers of school-age children with disabilities, and family functioning and social support as experienced by spouses. The instruments used to collect data were comprised of the following: (a) Questionnaire of Resources and Stress -- Short Form, (b) The Family Environment Scale -- Form R, and (c) The Family Support Scale. Results indicate that fathers and mothers are similar in their family experiences involving a child with disabilities. Families of children with disabilities did experience different stressors than the fathers and mothers of children without disabilities.

Forty-two mothers of children with varying disabilities participated in a study by Seligman, Goodwin, Paschal, Applegate, & Lehman (1997). The mothers were from an early intervention program and were asked to complete a questionnaire about the support offered by the child's grandparents. Results indicated that mothers perceived their mothers as more supportive than their spouse's mother. Maternal grandparents were more supportive and more knowledgeable about the disability than fraternal grandparents. The study also reveals that grandmothers are more supportive than grandfathers.

In conclusion, many of the studies cited above found stressors, coping skills, and support systems for the families of children with a variety of factors including disabilities and ages. A number of investigators have found that families of children with disabilities have less support available to them as compare to families with non-disabled children. Many of the studies indicated that stress was a major factor in the lives of families with a

child with a disability, while others claimed little or no stress. Family roles seemed to be divided into traditional female and traditional male roles.

Theoretical Framework

From the literature review, no consistent theoretical framework in the area of early childhood transitions was found (Rice & O'Brien, 1990). Some of the research has focused on the child, others on the family, and others on service providers. All three factors should be included to form a more comprehensive theoretical model of transition plus the broader and cultural influences that impact on each factor and on the way they interact (Rice & O'Brien, 1990).

In human ecology theory (Bubolz & Sontag, 1993), the family is seen as an energy transformation system that is interdependent with its natural physical-biological, human-built, and social-cultural milieu. Emphasis for this theory is the creation, use, and management of resources for creative adaptation, human development, and sustainability of environments (Bubolz & Sontag, 1993). Thurman (1997) suggests that early intervention is a human purpose and results from the interaction of people with their environments: "The ecology of early intervention is defined as the interaction of various environments where early intervention takes place with individuals who, through their behavior, are engaged in the practices associated with early intervention" (p. 3).

Bronfenbrenner (1979) suggests that individuals inhabit or operate as part of a number of different systems and settings that are embedded within each other and at the same time are interactive with each other. He conceptualizes these systems as a series of concentric circles, which he refers to as the "ecological environment" (p. 22). He identifies

four levels of environmental systems, differentiated on the bases of the immediacy with respect to the developing person. These include micro, meso, exo, and macro systems.

Bronfenbrenner's (1979) definition of a "microsystem" is: a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics (p. 22). A "mesosystem" comprises the interrelations among two or more settings in which the developing person actively participates (p.25). An "exosystem" is one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person (p. 25). The "macrosystem" is consistencies, in the form and content of lower-order systems that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies (p. 26).

Rice and O'Brien (1990) discuss The Ecocultural Niche model developed by Gallimore, Weisner, Kaufman, and Bernheimer (1989). These authors view the child as a member of the family that is in turn part of a broader social and cultural community.

Families are considered agents of change, capable of taking individual and collective action to modify outside influences. Listed below are several features of the Ecocultural Niche model as a conceptual framework for transition (Gallimore et al., 1989);

(a) There are multidimensional, interconnected influences on families and children where the model assumes a social constructivist perspective. Importance is placed on the family's view of circumstances; (b) there is a hierarchy of influences on families; (c) there are daily family activity settings and routines that reflect features of the ecocultural niche. These are composed of five settings: (1) who is present; (2) their values and goals; (3) what tasks are

being performed; (4) why they are being performed; and (5) what scripts govern interactions; (d) there are families that accommodate changes in features of their ecocultural niche by changing their daily routines and activities (Rice & O'Brien., 1990). The issue of transition requires recognition of the role of any one professional in the life of a child with a disability, and the appreciation of collaboration and cooperation in the provision of the best services possible for that child and family.

The ecological-developmental model proposed by Bronfenbrenner (1979) provides a framework for the transition process which views a child's development in relation to his or her environment. When an infant is born with a disability, intervention focuses on the child's family, and this may be the most immediate environment. As the child matures, the environment expands and extends beyond that of the family to include peers, community, and school. All of these environments become the focus of intervention for the child attending school (Diamond et al., 1988).

The movement of a child from one setting to another consists of three distinct steps (Bronfenbrenner, 1986). The first step occurs during the intersetting (existing in each setting about the other) relationships that exist prior to the actual transition process. These may include previous interaction between the two settings, as well as information, attitudes, or expectations existing in each setting with respect to the other. The second step occurs when the child has entered the new setting. The family system must recognize the child's transition into a new role in a new setting. The third step occurs after the transition and the results in changes in the relationship that exist between the child's various environments (Diamond et al., 1988). When using Bronfenbrenner's (1986) ecological model, the child and the family, the early intervention system, and the preschool

share in the transition process. This, in turn, facilitates the child's transition from one educational environment to the other. By using this approach, there may be less of a breakdown in the interrelationships between the child's environments.

Summary

In this chapter, a review of literature, which included parent's perceptions of early intervention, transition, and issues of raising a child with a disability was discussed. This current study will add to the research from the mothers' perception of these topics, because mothers assumed the role of the primary caregiver.

Chad

“Chad was born 12/1/95, an apparently normal, healthy, happy baby. But he had a failure to thrive episode when he was just two weeks old, which sent him to a community hospital for four days. And as he grew older, he was delayed in meeting typical developmental milestones like rolling over and sitting up.

By the time he was seven months old, he was flagged for having a three month developmental delay by his daycare providers and the early intervention program. The right side of Chad’s body was also weaker than his left and this led to him being seen by a developmental pediatrician who diagnosed him as having neurological damage. Chad underwent an MRI brain scan which showed that his brain had not formed correctly in utero. There was more damage on the left side of his brain than on the right side although both sides of his cerebral cortex were affected. Lower brain function was normal and his hearing and sight appeared to be intact.

Thanks to early intervention, Chad started receiving physical, occupational and speech therapy by the time he was ten months old. At first he received services at home and then at clinic when private insurance would not pay for home visits. Chad is still developmentally very delayed - but he continues to make slow, steady improvement as he rewires his brain and at two, he is learning to walk in a gait trainer.

Along the way, early intervention has provided emotional support and some funding which helped Chad’s family pay for some of his medical bills. Chad’s long-term prognosis remains unclear as it is not known how much of his brain Chad can rewire to circumvent existing damage. Chad’s neurologist could not predict how well he would recover, but early intervention has given him his best chance for a full and functional life.” (Christine)

CHAPTER 3

Methodology

This section includes the purpose of the study, research questions, methodological approaches, instrumentation, selection of participants, data collection, data analysis, and the summary.

Purpose of the Study

The purpose of this study was to determine the primary caregivers’ perceptions and experiences regarding the transition process of their disabled children from an early

intervention program to an early childhood special education program. Parental involvement and satisfaction with the transition process were also assessed, as well as related stressors, coping skills, and supports (Martinez Valle-Riestra, 1998). Rather than using traditional assessments or experimental methods for investigation, in-depth interviewing was used to obtain a more comprehensive representation from these individuals on this particular transition period. The major goals of the interviews were to record, as accurately as possible, the perceptions, feelings and experiences of primary caregivers during this transition process. The findings were generated from these interviews with selected primary caregivers whose children were currently in a preschool setting and were diagnosed with a developmental delay or disability. IFSP documents, which included transition statements, were collected and reviewed for further evidence. This inquiry was guided by the research questions given below.

Research Questions

1. What are the mothers' perceptions of the transition process?
2. What factors facilitate or inhibit their satisfaction and involvement with the process?
3. What types of stressors and supports do these mothers experience during this process?

Methodological Approaches

An approach to the investigation of a problem or question is called naturalistic inquiry (Lincoln & Guba, 1985). This type of inquiry has been supported by many who have examined the needs of children with disabilities and their families (Odom & Shuster, 1986). The methods used in a naturalistic inquiry are termed qualitative. Qualitative

methods are well suited for an inductive approach to data collection and analysis. Qualitative research (Bogdan & Biklen, 1992) is used as an umbrella term to refer to several research strategies that share certain characteristics. Research questions are formulated to investigate topics in all their complexity within a certain context. The researcher is concerned with understanding behavior from the subject's own frame of reference. Qualitative research can provide a holistic analysis of policy and practice in early intervention and can increase understanding of the diverse issues facing families and agencies serving them (Brotherson, 1994).

In-depth interviewing and participant observation are two examples of data collection methods used in qualitative research. The purpose of the interviews was to gather information that was not available from observation (Odom & Shuster, 1986). With the use of the interviews, descriptive data in the subject's own words were gathered so that the researcher understood how the participants viewed some piece of the world (Bogdan & Biklen, 1992). In-depth interviewing is a data-gathering technique used in qualitative research when the goal is to collect detailed, richly textured, person-centered information from one or more individuals (Kaufman, 1994). The value of this technique is that the researcher can investigate what is meaningful to the individual. In this study, the primary method used was analysis of transcripts of in-depth interviews with mothers.

Instrumentation

The initial step in the research activity consisted of identifying certain components of mothers' perceptions of the transition process. These components were found in transition related literature from early childhood and special education fields. This step assisted with the development of the interview guide, which was used to document

mothers' perceptions of the transition process. Because the interview was the major method of data collection in this study, piloting the questions to develop clarity and justification was incorporated. A description of the development of the interview guide and the pilot test follow.

Development of Interview Guide. The interview questions were derived from the research questions of the study in an attempt to collect information. The interview guide (Appendix A) was created to answer the questions that pertain to the research topic, problem, or goal (Kaufman, 1994) and assisted in asking questions of the mothers about the transition process. Many of the questions were written based upon literature related to early intervention. The questions pertained to perceptions about the transition process, and to other factors, such as stressors, coping skills, and supports. For breadth and accuracy of the content, two early intervention educators reviewed the interview guide. Their suggestions were helpful in refining it. Additional revisions were also made based on comments of the mother who participated in the pilot test.

Pilot Test. In a pilot test, selected representatives of the target audience were asked to comment on the researcher's questions as well as on other aspects of the study (Krueger, 1994). The pilot test provided suggestions for refining and clarifying the questions as well as for making adjustments in the research design. A pilot test also provided an opportunity to gain a better sense of the type of comments that might be expected in the actual study (Kreuger, 1994). In preparation for my dissertation study, I conducted a pilot test using an informal interview approach to determine if the participant understood the relevance and the use of language in the interview guide. This informal interview was conducted with a mother whose sons (twins) recently transitioned into a

preschool program. This mother was very helpful in determining the kinds of questions to ask. She understood the language and the content of the questions.

Selection of Participants

Participants in this study consisted of primary caregivers, all of whom lived in a rural region. Requirements for participation in the study were established. These participants were identified through a network of formal and informal contacts and invited to be part of this study. A description of this process follows.

Criterion. In the Commonwealth of Virginia, there are 40 Early Intervention Interagency Councils. These councils include public and private agencies that provide early intervention services to children with disabilities. They meet monthly to plan and coordinate these services. In the geographical area, (rural Southwest Virginia) in which this study was conducted, the council included a total of five counties that represented one of the 40 councils. Primary caregivers of children with disabilities, who had once been in an early intervention program and had transitioned, were the population. The selection of participants was determined by the following criteria: (a) the child must have been in the early intervention program (Part C under IDEA) in the particular area where the study took place, (b) the child must have been eligible for Part B under IDEA and diagnosed with a developmental delay, disability, or be termed at-risk, and (c) the child must have transitioned into an early childhood special education service delivery system (Local Education Agency - LEA) two years previous to the current school year (1999).

Gaining Access. Because this study looked at a transitional period, contact with the different systems (early intervention and preschool) had to be established. I had to learn how each of these systems operated before I could interview primary caregivers,

therefore I had to gain access to these systems. I had already been involved in the early intervention system as a graduate student by attending the monthly council meetings. I had also served as an intern with the early intervention council coordinator for a semester. This study grew out of an interest resulting from my participation in and observation of the system. I became aware of the problems that existed between these two systems as stated by professionals and parents.

A variety of methods were used to locate the primary caregivers. In order to obtain a sample, I first contacted the three service coordinators in the early intervention program that served the five county area. Secondly, I communicated with the five special education directors in each local school district to make them aware of my study. Each granted me permission to contact the preschool teachers or the day care centers from their specified counties that provided services to preschool children with disabilities.

There are two different service delivery options for children with disabilities that exist in the five county area. Four of the counties that teach children with disabilities offered an early childhood special education classroom in a school setting with a special education teacher and aide. I contacted the teachers in the schools and explained my study to them and asked for their assistance. I sent a packet of flyers (Appendix B) to these teachers and they were asked to distribute them to the families. In county A, children are taught in a full-inclusion model in day care centers where they are with regular education children. I called all the day care centers in the one county and narrowed the list to only those that served children with disabilities. I visited each site, left the flyers, and asked the staff to send them home to the families.

I also notified the individuals who organized the Parent Resource Centers in the area and they agreed to send the transition flyer along with their monthly newsletters. I met with a coordinator for the Head Start program in the area. I discussed my study with her and she agreed to distribute the flyers to any families in her program.

Selecting the Participants. Throughout the five month period, I received a total of 12 names from the individuals with whom I had made contact. When I called one mother, she mentioned that she was not comfortable talking to me, so I excluded her from the study. I had interviewed another mother in March, and two weeks after that I received a telephone call from the special education director saying that the child had died of complications. I also removed this mother from my study. In the end, nine mothers and one grandmother (legal guardian) participated in the research study. I will be referring to all of them as “mothers.”

Because I had attended monthly early intervention council meetings over a two-year period, I became acquainted with a few mothers. I approached each of these acquaintances and asked if they would be interested in participating in my study. They had met the criteria that were established and were willing to be participants. The early intervention council coordinator talked to another mother who was willing to participate in my study as well. One of the service coordinators provided me with another name of a mother. The transition coordinator gave two additional mothers’ names to me. The early childhood special education teachers provided the other five mothers’ names in my study. Three of the mothers were interviewed in January and February. I obtained a list of the other mothers over the course of March, April, and May and interviewed them during those months.

This study was conducted over a five-month period in the winter and spring of 1999. Many factors contributed to a delay in the research. The weather in the winter months was severe with heavy snow and ice storms. At times, I would have to reschedule an interview due to school closings or illness of the mother or child. Also, obtaining all of the participants took time due to the fact that I had to rely on the professionals to pass out the flyers and talk to the primary caregivers. It took additional time for the professionals to call me with the names and the numbers of the participants.

I explained my study to the mothers, and asked them questions to determine if they could participate in my study. All mothers who were contacted agreed to be interviewed. I began building rapport with all mothers as I spoke to them. They were willing to provide me with any information that I needed. We scheduled a time and place for the interview, one that was convenient for them.

Participants. Pseudonyms were used to protect the privacy of the mothers and children. The counties in which the mothers resided were identified by the first five letters of the alphabet (County A,B,C,D,E). The mothers ranged in age from 23-44, with the average being 34. One mother was working on her Master's degree, while three mothers held Bachelor's degrees. Four of the mothers had a high school education. One completed her GED and another finished the 11th grade. Eight of the mothers were Caucasian, one was Hispanic, and one was Black. Eight of the mothers were married, one was unmarried and living with her partner, and one was unmarried and living alone. Four of the mothers worked full-time, two worked part-time, and four did not work outside of the home. Each mother had between one and four children. The children were diagnosed with the following disabilities; cerebral palsy (5), autism (2), epilepsy (1), and multiply disabled (2).

Four of the mothers resided in County A, three in County B, and three in County C. I was unable to locate any mothers from County D and E. Table 3.1 characterizes the participants and their children in narrative form (Farnsworth, 1994).

Table 3.1 Narratives of the Participants

Karen:

Karen was a 29-year-old Caucasian woman who was married and had two daughters. Amanda, her youngest, had cerebral palsy. Karen was a high school graduate and was working full-time as a certified Nursing Assistant. She resided in County C.

Christine:

Christine was a 37-year-old Caucasian woman who was married and had two sons. Chad, her youngest, had cerebral palsy. She held a bachelor's degree in architecture and worked part time in that field. She resided in County A.

Elizabeth:

Elizabeth was a 38-year-old Caucasian woman who was married and had one son, named Sam, who had cerebral palsy. She held a bachelor's degree in business and worked full time at a university with adult learners. She resided in County A.

Susan:

Susan was a 34-year-old Caucasian woman who was married and had three children, two sons and a daughter. Her second child, Tony had autism. She was working on her master's degree in history, and taught part time at a nearby university. She resided in County A.

Judy:

Judy was a 35-year-old Caucasian woman who was married with four children, two sons and two daughters. Alexis, her third child, had epilepsy. Judy had a bachelor's degree in business and did not work outside of the home. She resided in County A.

Debbie:

Debbie was a 23-year-old Caucasian woman who was single, and resided with her boyfriend and her only daughter, Kathy, who had multiple handicaps. Debbie's mother also assisted with the care of Kathy. Debbie had an 11th grade education and did not work outside of the home. She resided in County C.

Roxanne:

Roxanne was a 28-year-old Black woman who was single and lived with her only son, Douglas, who had cerebral palsy. She was a high school graduate and had worked previously in a nearby factory. She did not work outside of the home. She resided in County B.

Carol:

Carol was a 35-year-old Hispanic woman who was married and lived with her two daughters. Carol's mother also resided in the home. Her youngest, Jamie, had autism. Carol had her GED, and worked full-time at a furniture store in the bookkeeping department. She resided in County C.

Tracy:

Tracy was a 35-year-old Caucasian woman who was married and lived with her two sons. Her youngest, Bobby, had multiple handicaps. She was a high school graduate and did not work outside of the home. She resided in County B.

Alice:

Alice was a 44-year-old Caucasian woman who was married and lived with her son. Alice was the grandmother and legal guardian of her grandson, John, born to her daughter. He had cerebral palsy. Alice was a high school graduate and worked full-time as a clerk in a drug store. She resided in County B.

Table 3.2 summarizes information regarding the mother's name, the child's name, the type of disability, the birth of the child, when the child entered into early intervention, and when the child was dismissed from early intervention to transition into the preschool setting.

Table 3.2 Information Regarding the Children

Mother's Name	Child's Name	Child's Disability	Date of Birth	Referred to Early Intervention	Dismissed from Early Intervention
Karen	Amanda	Cerebral Palsy	2-14-95	6-29-96	2-28-98
Christine	Chad	Cerebral Palsy	12-1-95	8-7-96	8-26-98
Elizabeth	Sam	Cerebral Palsy	9-11-94	2-20-95	11-22-96
Susan	Tony	Autistic	12-7-93	9-16-96	5-7-97
Judy	Alexis	Epilepsy	3-30-94	10-22-96	5-21-97
Debbie	Kathy	Multiply Disabled	7-25-95	12-7-97	12-9-98
Roxanne	Douglas	Cerebral Palsy	8-29-94	7-30-96	7-30-97
Carol	Jamie	Autistic	10-28-93	11-29-94	5-4-96
Tracy	Bobby	Multiply Disabled	9-9-95	2-15-96	8-26-98
Alice	John	Cerebral Palsy	3-1-96	5-8-96	3-12-99

Data Collection

Data were collected from two sources. Although documentation was used, interviews were the primary method of data collection in this study.

Interviews. Interviews provided the principal source of information. As the process of gathering participants for my study happened over the course of five months, each mother identified herself as willing to participate in the study. Once I made contact with the mothers, the goal and purpose of the study was discussed. At this time, we set up an agreed upon time and place for the first interview. A letter (see Appendix C) was mailed immediately to each mother, following the first telephone conversation, to reiterate what was discussed. A total of 20 interviews (two face to face with each mother) were conducted. The interviews were done in the homes of eight of the mothers. One mother met with me at her work site for the first interview, while she preferred to meet in the local public library for the second interview. Another mother met with me during her lunch breaks at her work site for both interviews.

At the initial interview, each mother was given a written consent form which addressed the description of the study and the protection of subjects (see Appendix D). The mothers were encouraged to read the form, ask questions, and sign to indicate willingness to participate in the study. Each was provided a copy of the signed form.

All interviews were audio taped, with the permission of the mothers, in order to gain an accurate account of what they had to say and to help me with my analysis of their responses. The initial interview, approximately 45-60 minutes in length, was used to gather background information about both the child and family. The interview began with "Tell me about your special child." (Farnsworth, 1994). During the first interview, I had

the opportunity to meet the children of these mothers. The two mothers who I met outside of the home brought photographs of their child.

During the second interview, a series of structured questions was used as a basis for discussion (interview guide). I let the parents know that there was an agenda of topics to be covered in the second interview and that the topics might not be covered in one session or in any particular order (Burgess, 1984). These interviews lasted between 90 and 120 minutes. Verbal prompts were used in the interview process to get responses of greater depth. I also took notes during the interview process. This consisted of key phrases, lists of major points made by the respondent and key words (Patton, 1980). Immediately following the interview, I took extensive notes and made comments on perceptions, feelings and insights while the interview was still fresh in my mind.

I mailed each mother a thank-you card and a \$10.00 gift certificate to a local grocery store after the second interview. After all the tapes had been transcribed and common themes began to emerge, a 10-20 minute follow-up telephone conversation was conducted with the mothers to provide an opportunity to clarify and expand on the generated themes. Member checks, or the practice of presenting knowledge learned to participants for verification (Guba & Lincoln, 1981; Patton, 1990) were accomplished by calling the mothers and reading over a summary of the findings and asking for their feedback (comments and suggestions). The mothers suggested no changes during the phone conversation. All were in agreement with the themes and the results in which I discussed.

Documentation. Primary sources are the materials that are gathered first hand and have a direct relationship to the people who are being studied (Burgess, 1984). Among the

documents included as primary sources in this study were the official documents and/or the child/family records which included the Individualized Family Service Plans (IFSP). The IFSP's are those documents which are used in early intervention programs. The mothers were asked to provide any documentation pertaining to the transition process. Of the participants, only three mothers had notebooks of all their children's educational records. These provided additional information about transition planning. Letters to families regarding transition meetings were read and reviewed to determine whether transition was included or discussed. If no plans or discussions existed, this was noted. In order to gain access to transition statements on the IFSP, I received verbal permission from each mother and from the Early Intervention Services Manager to look through each child's IFSP record that was written at that particular time.

Data Analysis

Bogdan and Biklen (1992) define data analysis as the process of systematically searching and arranging the interview transcripts, fieldnotes, and other materials that are accumulated to increase the understanding and allow for the presentation of what was discovered. They further add that analysis involves working with data, organizing it, breaking it into units, synthesizing it, searching for patterns, discovering what is important, and deciding what to tell others.

Transcription. The first two interviews with each mother were audio taped and transcribed verbatim immediately after the interview occurred. The benefit of hearing the tapes again and the process of analyzing helped me plan how I would structure and organize the information. The tapes were also reviewed again for verification of what was transcribed. The tapes were transcribed verbatim because the words spoken by the

mothers were indications of their true feelings. These transcripts became the basis for data analysis.

Organization. The analysis process followed procedures by Taylor and Bogdan (1984) and Bogdan and Biklen (1992). Two copies of each transcribed interview were copied and the originals were stored in an expandable file folder, along with the tapes and other personal information from the mothers. The pages were numbered in the chronological order in which the interviews occurred. Each transcribed interview was read two times. On the third reading of the transcripts, I wrote notes in the margins. I went through each transcribed interview and listed all of the notes that were written in the margins. I shared the task of reading the transcripts with one other graduate student who read, confirmed, added to, or modified the notes. Discussions were held until a consensus was reached.

A preliminary list of codes was developed. This list of codes was assigned abbreviations to the units of data. Initially, there were a total of 77 codes. The transcripts were read again, in an attempt to streamline the coding system. There was a consistent number of themes that began to emerge because the interview guide was in a sequential order from one educational setting to another. Subsequently, each section in the transcripts was marked with the appropriate coding category. The major codes were written, then subcodes were added. After narrowing the codes to a smaller number, I had five major coding families with a combined total of 21 codes (See Appendix E). The five coding categories were: (1) Talking About My Child, (2) Understanding Early Intervention, (3) Transitioning From Part C to Part B, (4) Moving Into the Preschool Setting, and (5) Concerns of Mothers.

Since the data consisted of interview transcripts, each interview was assigned a number (100, 101, 102) (Allen & Farnsworth, 1996; Bogdan & Biklen, 1992; Farnsworth, 1994). The written transcripts were then cut into units, and placed into labeled manila folders with the codes. All of these were then placed into file folders. The phrases were then glued on to poster board by the numbers along with the coding categories and sub-categories. This precise classification process helped me recognize the stories the mothers were sharing. The quotations were selected on the basis of what the mothers presented. Even though the same interview guide was incorporated throughout the interview process, the mothers had different descriptions of the events that occurred. The themes that were coded contained specific positive and negative supporting examples of the mothers' perceptions of the transition process. Results are discussed in Chapter Four.

Summary

Qualitative methodology was chosen for the study to further capture the experiences that mothers of children with disabilities encounter when they experience a particular transition period. Each transition that these mothers face in the future for their children with disabilities may be a difficult one, but by expressing themselves, they may feel more confident in the process.

Douglas

“Douglas was born on 8/29/94 at the local hospital. He weighed 5 pounds, 14 ounces, and the doctors said that he was normal when he was born. Even though this was my first child, I felt that something was wrong. He wasn’t eating right, and he wasn’t cooing like other babies do.

I was worried, so I called a program, and people came out and did an evaluation on him. Douglas then began to get services. Women would come out to the apartment and teach him different activities. I would watch and learn and try these on Douglas.

Douglas has come a long way since he started. He was not saying nothing, and now he can say a few words. I was so pleased with early intervention. They got the ball rolling for him going to the school.” (Roxanne)

CHAPTER 4

Results

This study involved in-depth interviewing with 10 mothers whose children were diagnosed with a developmental delay or disability. The participants in this study were women of various ages and races, financial levels, and educational backgrounds. Their children’s disabilities ranged from mild to moderate to severe (see narratives and table in Chapter 3). Mothers were interviewed to gather information on their perceptions of and experiences with the transition process from an early intervention program to an early childhood special education program. The differences between these two programs will mean different things to different families (Hebbler, 1997). Transitioning a child from these programs can often create uncertainty and anxiety (Wilson, 1998). Not only was this theme of transitioning identified, but the process of how these children were first diagnosed, identified, and educated seemed to have a major impact on this study as well. These mothers’ stories captured the experiences they have encountered thus far when raising a child with a disability.

The framework used in this study was that of Bronfenbrenner's (1979) ecological model where a child's environment is a nested arrangement of structures. The four levels Bronfenbrenner identified are the microsystem, mesosystem, exosystem and macrosystem. The microsystem includes the setting in which the child spends most of his or her time, and this usually includes the child's home. The mesosystem relates to the relationships among the microsystem and this oftentimes is between the parent and the teachers, therapists or physicians. Societal structures, such as public and private agencies, make up the exosystem level. The macrosystem consists of the cultural and legislative realm in which the other three levels of the child's ecological environment operate. When planning intervention strategies for families of children with disabilities, the dynamics of each level (i.e., microsystem, macrosystem, exosystem, and macrosystem) need to be considered in the child's ecological environment (Wilson, 1998). The mothers' responses along with this theory were the basis for this study. At any time these could change, therefore changing the way the family operates.

The 10 mothers who agreed to be interviewed were chosen because they met the established criteria for participation in this study. Only mothers were interviewed because they were the primary caregivers of their children. It was imperative that mother's voices be heard if agencies and schools are to communicate effectively with them about the transition process (Pianta and Kraft-Sayre, 1999). The mothers were encouraged to talk freely about their families. This provided an opportunity for the mothers and myself to establish further rapport during the interview process.

After I listened to the tapes and transcribed the interviews, a number of themes began to emerge. I was interested not only with the transition process but also how the

programs, both the sending and the receiving, had affected the child and the family. At times, the mothers gave rich details of their daily family life and what it was like to live with a child who has a disability. They shared stories of their children who they characterized as a “special” child in their lives.

After extensive listening to the audiotapes and reading the transcripts, I was able to identify the five coding families. They included the following themes: (1) Talking About my Child; (2) Understanding Early Intervention; (3) Transitioning to Part C; (4) Moving into the Preschool Setting; and (5) Mother’s Concerns - Stressors /Supports /Coping Skills. This chapter was organized around each of these five families. What follows is a characterization of the positive and negative features found in anecdotes that mothers used to describe their children’s experiences. The mothers’ stories under each section are in the order in which they were described in narrative form in Chapter 3.

Talking About My Child

I asked the mothers to go back several years and describe how they were affected by the different stages their child experienced. The mothers responded with sequential stories about their children’s lives. They also discussed some of the daily obstacles they face when raising a child with a disability. Listening to and sharing their stories gave me an opportunity to know the mothers better and to establish a relationship with them.

Pregnancy, Delivery, Infancy

When I first met with the mothers, I opened the interview by saying: “Tell me about your special child.” Many of the mothers began the discussion by talking about the problems that occurred during the pregnancy, the birth trauma as they were delivering, or the infancy stages of their child. They recalled the events:

Karen, overdue with her second child, explained the birth of her daughter:

Amanda was at 41 weeks, she was way overdue. She was born dead, and they (medical staff) had to resuscitate her. She had also swallowed bowel. She then had five seizures and was rushed to the NICU in [nearest city]. Amanda was in the hospital for four months. She wasn't eating too good either. (Karen)

Christine remembered her joy as her second child was born. Everything, at first, seemed normal:

My child had a normal birth, there were no complications, um... and his APGAR scores were good. He (Chad) had a 7, then a 9 a couple of minutes later. We did not know that there was anything wrong with him at the beginning, a normal everything. Two weeks after he was born, he had a failure to thrive. He just turned his face to the wall. He didn't eat, he just... We took him to the doctors, put him into the hospital. They (the medical staff) went searching to try to find a reason as to why he was starting to fail. Chad was in the hospital for four days. (Christine)

Elizabeth described that something was just "not right" when she went into the delivery room:

They (medical staff) delivered me quickly, which turned out to be real good, because he (Sam) was blue, and he wasn't breathing. They had to incubate and resuscitate him. He was born in [local hospital] about 4:30 in the afternoon and he was then taken to another hospital in a larger city. And about 10:00 that night they sent him to the NICU. Because within the first 24 hours, he had 2 seizures, which the doctor said was a good indication of brain damage. So, he was in the hospital until Wednesday. He was there for 9 days. He weighed 6 pounds, 11 ounces. He seemed to be a big baby since he was early, so it had nothing to do with his prematurity. His lungs were fully developed, his weight was fine. He just had to do... everything just had to do with his traumatic birth. (Elizabeth)

Susan, a mother with a toddler and pregnant with Tony, was also taking care of her mother, who had been diagnosed with cancer. Susan remembered this about her pregnancy and delivery:

When I was pregnant with Tony, I guess the worst part about it was that I was severely nauseated the first trimester. Really sick. So, but for him (Tony), I lost like 15 pounds, and then regained it. The doctor was like, he wasn't too concerned as long as I keep fluids down. And he said, "As soon as you can't do that, then we'll have to hospitalize you." But that was okay, so I started gaining weight.

When Tony was born, I mean he had, he had a nine or 10 on an APGAR score. He was considered perfectly healthy and fine. As far as they (doctors) could tell, developmentally. Um...when we brought him home actually, he cried a lot more. But we were told, "Well you know, children are all different." (Susan)

Debbie remembered the day her daughter was born:

When she (Kathy) was born, they (medical staff) said they had to rush us on into the operating room, because she had her umbilical cord wrapped around her hand and she was sucking her thumb, and was cutting off her airway, and they rushed us into surgery. (Debbie)

Roxanne noticed that Douglas was not eating when he got home, but that

everything was normal about the delivery:

Douglas weighed 5 lbs. 14 oz. He was a week early. Um... the doctors said that he was normal when he was born. But I noticed when he got home, he really did not want to eat a whole lot, and I kept going back and getting his formula changed and all that stuff. (Roxanne)

Carol remembered that she had pains with her second child. At that time she was also under a great deal of stress. She recalled the events that occurred at the time of her pregnancy and the birth of Jamie:

Well, they (doctors) don't have no idea. The way I see it, um... I had all the symptoms that something wasn't right. I gained a lot of weight, and the doctor told me to exercise and um... I used to work a lot far away from where I used to live and it was the stress, the stress and traffic. Then I have my other daughter, which she was overweight, and we used to live in a building and I used to carry her. And I think everything, the stress, and the, you know. When I told him (doctor) about the complaints in my back, and pain, and this and that. He told me not to worry. She was 7 weeks premature. And then it was too late. And when I went to the hospital, I was already dilated 8 cm. They tried to hold her for four days. But she came out. And then they (medical staff) told me that she wasn't going to make it. And I guess it was, since she was coming in a breech position. It went through a period that she went through a lack of oxygen, cause the nurse was trying to get a hold of her. Then I had a contraction, and the doctor told me not to push, and that, in that period, they (medical staff) think that's the reason why she is having these problems. (Carol)

Tracy remembered her pregnancy because she was bedridden, and related the frightening experience that occurred after the birth of her son:

Well, I had in the last month had gotten high blood pressure. And they (doctors) gave me medicine for it. Then I couldn't eat or drink water. If I smelt food or thought about it, it made me sick. I had emergency surgery. I had eclampsia toxica, and I gained about 25 pounds of fluid with him (Bobby). And he was dead when they took him. He was on life support and he was on it for a week. In the hospital, he went from 2.6 pounds to 3.5 pounds. They had to do surgery when he was a day and a half old... and then he dropped more. And then it took him a while to build up, it's real slow. He would go up, and then down, up and down. He would take one step forward and two back. (Tracy)

Alice was so excited to be a grandmother. She recalled the information that was given to her before her grandson was born to her daughter. Because of the projected complication, her daughter decided she could not deal with a disabled child:

Well, she found out that he had hydrocephalus, probably a week to two weeks before he was born through the ultrasound. They had to do a Cesarean section, because his head was so big. (Alice)

Initial Diagnosis

Not all disabilities are easily recognizable at birth, nor do they occur in the first months of life. It was difficult for most of the mothers to accept the fact their child had some very serious problems. The mothers in this study received opinions about their children from medical professionals, daycare staff and even family members. Many of the mothers themselves knew, by looking at their own child, something was not quite as it should be.

Christine admitted there was a big difference between her first son and her second son:

But, at least I had one that there were no problems at all, so I knew that there was something different about Chad, but I couldn't put my finger on it. Well, the family doctor that we went to couldn't put their finger on it either. I had put Chad in daycare at seven months of age. He was there for three weeks in the baby room, and then they (staff) flagged him as having some kind of problem. They said developmentally, he is not like the others. Women in that room, who had taken care of, you know, hundreds of babies over a number of years. (Christine)

Elizabeth discussed this situation with her son, Sam:

Sam had an appointment at a [developmental follow-up clinic] in February, and you meet with a Developmental Pediatrician and Occupational and Physical Therapists, and they (doctors) tell you all the things that's wrong, that's wrong with your child. But nothing can ever prepare you for what they are looking for. You know, I don't think that they gave him his diagnosis, you know, I can't even remember which appointment they gave him his diagnosis. It was either... It was sometime within that year, I think, um... Cerebral Palsy, and he (Sam) started receiving physical therapy when he was six months old. They referred us immediately to early intervention. (Elizabeth)

Susan had been dealing with real life issues: the death of her mother and raising three children. Tony was just about to enter preschool at the time:

My mother died in June, 1996. When we came back, Tony started school right at the end of summer. So he was in school, and actually, the preschool teachers were thinking, maybe it was his hearing. Maybe it's his hearing, maybe he isn't hearing. I mean, they were suspicious about that. And he had his hearing tested, and he was fine. We were hoping at that point that it was his hearing. I talked with some others and someone said that he might have something called Pervasive Developmental Disorder, and I kind of had done my homework by then, and I knew that PDD was just a nice way of breaking the news. And then we took him to the [Developmental Center], and they (doctors) told us (husband and myself). And my husband and I said: "Don't come back with that PDD label." So, he was officially diagnosed with moderate autism. (Susan)

Carol also had to hear the news that her daughter was diagnosed with autism as she remembered how the situation began for her and her family:

She (Jamie) was way, way behind, and then she did have a problem. She had a hole in her stomach. And everything that she used to drink, used to come out the same way. So, that's one of the reasons that I took Jamie to [Developmental Center], because I had to blend everything for her. And, um... she had a chewing problem,

and so we went there, and she was there for two weeks, and they (nursing staff) actually, I guess trained her to swallow everything.

Carol goes on to add:

They don't want to call her an autistic kid, because it's very minor. But the PDD, it goes in that area. You know, like not making eye contact. Um... before she used to bang her head, um... walking on tippy toes. Before early intervention started, the light, the wind, the sun, the grass used to bother her. Giving her a bath, the towel, clothes, the water, almost everything used to bother her. Just by brushing her skin and her body. (Carol)

Health Concerns

Not only did these children develop normal childhood illnesses, there was usually a major health issue that coincided with the type of disability with which each child was diagnosed. Mothers discussed feeding issues, number of times in the hospital, and seizure disorders. Most of the mothers faced each new challenge courageously and learned to deal with it:

Karen's daughter had asthma as one of the health concerns. Amanda had also been hospitalized several times as Karen discussed:

But she only had to take her inhaler, she takes her inhaler in the bag, but she's only had to use it, like in the summer, when the weather... She has been in the hospital six or seven times since she was born. (Karen)

Christine has a bag packed for her son, ready to take him to the hospital. She always has an established routine complete with a typed copy of all his medical information ready for any emergency room physician:

It started out gradual, they (seizures) were petit mal, and then once a month, twice a month. And then it got to be, it was basically twice a month for a long time, um... then finally he (Chad) got sick and he ran a high fever. And that kicked off a petit mal seizure, but turned into a grand mal, and it wouldn't stop. And then he had to be taken to the hospital and they had to put him into a medical coma. That happened, in um... September of 1998, right after he had entered early intervention. (Christine)

Susan knew that something was wrong with her son before the initial diagnosis.

The family tried several interventions before one finally worked:

Oh, yeah, because when we first got him on it (diet), four weeks into the diet, we got eye contact for the first time, because he used to do a lot of stim things. That was another thing, that when the language started decreasing, and was almost gone, he started to do a lot of head spinning, and running back and forth. He would spend his day running back and forth, and back and forth. That's what he would do, down the hall. And when we (family) moved out here (new house), it was like, he was going to have a longer hall (laughter). (Susan)

Judy and her husband realized their daughter was going to have seizures and they learned to accept that fact:

She (Alexis) was just having seizures. Her health is such a major issue. Well, then, she didn't really lose ability, but she never really gained ability, so she got farther and farther behind. And so, we had to come to the realization that she's just a normal girl with seizures. There is something else going on, which you know, when you have to find out about that, you have to come to accept it, but you are angry and mad and all that other stuff. (Judy)

When Debbie's daughter, Kathy, was ill, Debbie needed to be around and hold her daughter all day:

No, I mean sometimes I like to stay home, and sometimes I don't. The main problem is, when she gets sick, I can't, I mean, she wants to sit on top of your lap all the time. And, you know, you lay her down, and she cries and throws a fit, and you pick her up, and it get aggravating sometimes, but I put up with it. I get scared too, because when she gets sick, she runs a real high fever. I mean, a high fever, and it took her like from last Tuesday to maybe Saturday for her to stop running the fever. (Debbie)

Even though Carol had taken her daughter for treatment to a center specializing in working with children with disabilities, Jamie continued to have problems:

Well, she (Jamie) is still having a problem with chewing. You know, she can eat, like a piece of a chicken nugget and it can take her half an hour, just one piece. If you cut her a slice of pizza, a small slice of pizza, it can take her probably like an hour. She still have problem. So, like for school, I would send soft things, like banana pudding, and you know, something that doesn't have a hard time. Because,

you know, they don't have a lot of time for lunch. I think it's only like 20 minutes.
(Carol)

Alice had seen her grandson go through a number of operations and being hospitalized several times whenever he would catch a cold:

Um. All of the operations and that he had to go through. And this, what he is going through now. And I cry a lot because I want to get to the bottom of this
(Alice)

Living with a Disabled Child

The mothers recalled several events in their lives that occurred as a result of raising a child with a disability. Not only are the health concerns of importance, but other issues often arise. Mothers with disabled children often deal with challenges different than those probably faced by a typical family.

Karen was concerned about how other children would treat Amanda in public, because Amanda did show signs of Cerebral Palsy (mouth open with drooling, and dragging leg). Karen responded this way:

And, I'm just wondering, you know, if they're (public) gonna make fun of her (Amanda). You know, she was in Wal Mart a couple of weeks ago, and was looking at a truck or something, and you know, she couldn't say truck, and there was a little boy there who was making fun of her. And I said: "You know there's a reason that she talks like this, and I think your mom needs to teach you some better manners." (Karen)

Christine had concerns about her other son who asked a lot of questions about Chad. She tried to help him understand what was going on:

And John really suffered, until we figured out ways to cope with situations. We do stuff now, I mean it's part of our life. John comes to the hospital. We take pictures. But it's hard. (Tears followed). He does ask questions and you wish that a five or six-year old didn't have to ask: "Is my brother going to die?" (Christine)

Susan, the mother of an autistic son, described her nights:

His (Tony) room is totally aseptic. I mean, we've got locks on all the doors, and locks on all the windows. He basically has a bed and sofa in there (room), because before he used to overturn the drawers and pull things out. So, you know, I just have baby toys, or two toys in there, because he is orally fixated and lock him in at night. So, when he wakes up, I'll check in on him, and see if he soiled himself or something. You know, I can kind of half sleep that way. Before he was on (medication), he would be up at 2:00, 3:00, 4:00, pretty much the whole night. Now with this medicine, I would say out of a week, he gets maybe three or four solid full... you know, by putting him to bed at 7:00 and him getting up at 6:30. (Susan)

Roxanne knew that her son would grow up to have difficulties and that others would tease him:

The toughest part, what affects me, because, you know, other kids look at Douglas and wonder what's wrong, and say: "Why can't he talk?" And I have a lot of people make fun of him. I want my child to communicate with me. I want him to be able to express himself. That is why I guess I am self-conscious about going places with him and stuff. (Roxanne)

A Mother's Love

Mothers loved their children unconditionally as indicated by their responses during the interview process. These mothers showed a nurturing affect towards their children and made sacrifices to raise them.

Debbie is a single mom raising her daughter by herself, and the joy she gets from her is so exciting to see:

She (Kathy) always has something to smile about. She is always happy. She's usually, other than being sick, she is a going child, I mean constantly. She is just so happy. That's her main thing she loves to do, bounce. (Displayed this) and said: 'I'm a bouncing baby. (Debbie)

Roxanne was a single mother and she gave her son everything she could provide for him to the best of her ability:

A woman from Social Services once asked me if I thought about giving him (Douglas) up. I looked at her. It shocked me. I was like... wait a minute. I can't believe that she is asking me this, and I said: 'Absolutely not, I was woman enough

to have this kid. I will love him, no matter what his disability is, because he is all that I have, and I am sure all that he has.' So, I have to be the mom, the dad, the grandma, and the baby-sitter, all in one. (Roxanne)

Carol has learned a lot of patience after having her daughter and the types of behaviors Jamie exhibits:

You know, like when things, they don't go right, or she has one of her days. Where before, I used to lose control. The family that I have now is in the church. They can help me out to see things in a different way. Where before, I used to blame myself. I used to see her like... now I see her like a special child. A special gift. (Carol)

Tracy was a strong woman who loved her son so much. She was with him every step of the way during the first three years of his life, and she would never give that up:

That's something that you can't take away from. You can never take away those first excitement on watching his first steps. Bobby, he didn't know what smiling was. He couldn't smile. And then when they done the surgery, took his adenoid glands out, the he was smiling. He could laugh, but he could never close his mouth. So, that is something that I got to see. If I had been working, I wouldn't have. And think... nobody can take that away from me. (Tracy)

Understanding Early Intervention

Early intervention includes services and instruction for children with developmental delays or disabilities, during the early infancy, toddler, and beginning preschool years. Because not all disabilities are diagnosed at birth, professionals in the medical or educational fields may identify a child who needs assistance. Early intervention and related services may be made available if the child qualifies for the program. Becoming part of the early intervention program is another transition for families to encounter. These families will meet yet another group of professionals, over the course of a few years, who will become part of the family's lives.

Referral and Eligibility

In order to be eligible for early intervention, a child must qualify for services. The parents, along with a team of infant professionals participate in an assessment to look at the child's strengths and needs. Mothers included in this study had several different professionals who flagged their children for early intervention services. These are described below.

Christine recognized that her younger son was developing slightly different from her older son. The doctors kept saying that each child develops differently. She explained how she received assistance from the daycare center that her son attended:

Through [Day Care], she was the one who had helped flag him, and then she said look, we have um... I believe that early intervention had pamphlets there, but she knew the early intervention council coordinator, and she had helped others there, and since the school system had placed him into [Day Care]. (Christine)

Elizabeth felt somewhat uneasy about the process of evaluation that needed to be done in order for her son to begin to receive services. She had already been through it at the hospital setting:

At the hospital, they (medical staff) are the ones who referred us to early intervention, and then we had to go through it (evaluations) all over again, where someone from early intervention, and a physical therapist. All of these people come to the house and sit down on the floor with your child, and do all these tests, and determine what they think he needs. The negative aspect would be so many people telling you what's wrong with your child within an hour of evaluating him, when I've lived with him for six months. I guess there's no easy way for them to do that. That was probably the most difficult, just everybody all at once. And they determined that he get PT twice a week. And at one point, we decided to have a service coordinator come to the house. (Elizabeth)

Susan didn't understand what was happening to her son:

From the start, I was at a total loss, I was getting all of this diagnosis and stuff and had barely ever heard of autism, just "The Rainman" movie. I was pretty much in a haze, so it was really nice to have a bunch of people come, and not really take

control, but kind of, well in a way, at first they did kind of take over. I mean they told me where I needed to go, and what I needed to do. Um... and you know, guide me, and they were the ones who told me about the [medical center] actually. (Susan)

Debbie described how she received assistance for herself and her daughter from all professionals who were working with her in the hospital setting:

Well, um... well everybody just kept calling, wanting to do this and that, and they (service coordinator), she's the one who got it all started. And, um... she went through the physical therapist at the hospital. My daughter was also getting occupation therapy along with a vision teacher. (Debbie)

Roxanne was a single mom who noticed that Douglas was not progressing like others kids his age:

And then I noticed that he was not cooing and stuff like most kids do, and he, he was behind then. So, I went to the school, and they referred me to the early intervention people. They come and did an evaluation. They seemed to do evaluation after evaluation. But he qualified when he was two years of age. (Roxanne)

Carol noticed some differences between her daughters, and was concerned, so she took Jamie to the doctor:

When I took Jamie to the doctor, and they noticed that she was behind almost in everything. They told me, they advised me to call, you know, different numbers. And I called early intervention. From there, they came. Did an evaluation, and said that she qualified. And then from there, you know, they started seeing her. (Carol).

Due to Bobby's traumatic birth, and his long period in the hospital, Tracy knew right away that he would start needing some sort of interventions when he returned home.

A nurse was the one who began assisting her with these issues:

She (nurse) would come two or three times a week to weigh him, and check him. She was a home health nurse with the health department. She is the one who mentioned that they had a program that would help with Bobby, and she told me that it would be in his best interest and mine, to teach me. Because he still needed the therapies. We had to massage him four times a day. One, we knew that he needed constant care, 24 hours around the clock, and two, because he was getting

at a point that part of his body was growing and another part wasn't. And there was new stretches that I needed to learn. And then, we brought in a therapist because he wasn't, even though I was working with him, I wasn't trained to do everything that should have been done, and a lot I didn't know. And we took him, and they showed me what to do, and I would work with him. But we started out with a therapist and then we went into the early intervention program. So, we went from one to the other. And he was still receiving his therapies. (Tracy)

Because John was classified with hydrocephalus, the nurse had made contact right away for John to begin receiving services as Alice explained:

Well, (nurse) was involved with the Health Department right after he was born. And I guess the [hospital] contacted the Health Department cause he had hydrocephalus and everything. I think it was them, that, you know, they told me about it. And I got involved, I guess when he was two or three months old. (Alice)

Community Resources

The geographical location of the interview held with the mothers was a rural area. Resources, such as the Parent Resource Center and the University Training and Technical Assistance Center, and activities such as Mothers' Night Out and Child Play groups were made more available in one of the larger counties. But not all mothers had transportation, nor were all places within close proximity to their homes. Some of the mothers expressed important concerns about this problem. Yet, each mother utilized community resources as she saw fit for their own family.

Karen was able to receive some assistance from the community as she explained:

Um... I learned what services were available out there in the county, because I had never heard of respite care and that kind of stuff. I also took CPR again, and stuff like that, because I had adult CPR license, and I didn't have infant CPR. I also got to go to a lot of conferences on cerebral palsy, and stuff like that, but I really like them. (Karen)

Christine had access to numerous amounts of information, but she found the best resource from another mother, 'mentor mother' as she described:

I went to, I went to different places to get information. There was one mother who was very instrumental. Her children had just transitioned into the school system before I did, and she had an interesting situation, because there was some questions to the services that were going to be provided. And she was able to give me a lot of tips on how things worked. (Christine)

Elizabeth felt that early intervention professionals assisted her with a variety of resources:

They'll give me names of doctors to maybe consider, and I trust their opinion, because they have done it for so long. They have been good, early intervention part has been so good. I think that they need something in a school system. I'm not sure if that's where the breakdown in communication is or not. I kind of feel like it. (Elizabeth)

Susan was provided with a great deal of resources, partly because she knew how to utilize the professionals to get assistance, and partly because she wanted to know everything there was to know about autism:

Yeah, you see I really didn't know that much about that kind of stuff. But again, the transition team had lead me to the Parent Resource Center, and she gave me a bunch of books. Um... they (professionals) got in touch also with the university's resource center. I was also told about respite money and also moneys they told me about buying stuff like this. As a matter of fact, some of that money was used to buy that turtle (mother points out the turtle in the room). (Susan)

Roxanne lived in one of the most rural areas. She had limited transportation as well, so she didn't have the opportunity to meet others who were dealing with some of the same issues:

The resources are very limited in County C. And it's really not so much the school's fault, just the whole community. We have no places to work because they closed the biggest factory. We have no where to buy clothes. We have no day care providers, but two through social services. And they are full. And if you are a single parent like I am, and if you have a child, like I have, it is very hard to find baby-sitting. And, I was working, but I had to quit because the baby-sitter raised the money I was paying, and I couldn't afford it, and you know, keep up my other bills too. So now, I'm unemployed. (Roxanne)

Insurance Issues

Insurance was a major factor for these families where both parents were working, thus having a two-parent income. At times, they had to pay for services, while those receiving Medicaid, or who were on welfare, did not have to pay for many of the services rendered. Those on Medicaid mentioned no insurance problems at all. Insurance was an issue only for those families who had to pay for certain therapies, service coordination or special equipment for their child.

Both Karen and her husband worked full time, so they had a more difficult time in receiving as many services without having to pay for them. She discussed her problems:

Because, I mean, I'm still paying for early intervention services, but you know, it's hard when you got all these bills to pay, and I think that's... and I think when Amanda went to the school system and these were going to be offered for free, you know, I thought that I could breathe a little easier. But, I mean, like her hearing aids, they were like \$3000, you know. Here we had, well the Lions Club helped us out, paid \$1000, but we were still stuck with a big chunk of it. (Karen)

Christine's son was able to receive more services. She described a different version of insurance through the early intervention system:

But it turned out to be an insurance issue. He was evaluated by the oral motor therapist, and she sent the letter that said, "Yeah, he's got problems." And everyone who had evaluated my son, they were the persons that I wanted. I actually was assigned to the therapists. But at the time... that the insurance would not pay for him to receive O.T. (Occupational Therapy), speech or P.T. (Physical Therapy) as a home visit because he was declared medically not fragile. So he had originally started services at the house, which was good because he was little, but then we went to a clinic for O.T. and P. T. (Christine)

Elizabeth and her husband also worked full time, and their son, Sam, was in need of physical therapy due to his cerebral palsy. She explained why they decided to transition their son into the school system at the age of two:

So, we never had to pay for any special instruction with the service coordinator, we were right on the verge of having to pay for it, and I mean it was some unbelievable amount of money. And it was more than we were paying for physical therapy. You know, we said, we weren't paying for that, it's ridiculous. We chose to transition Sam at the age of two because everything, all the therapies provided by the school system, were free. So we really couldn't see any reason at that point not to, because we were paying a CO-pay for physical therapy. And then he also began receiving speech therapy when he went into the school system, and then he got occupational therapy as well. You know, therapy that many times a week is very expensive. (Elizabeth)

Susan's autistic son was receiving speech services. She explained her concerns with the payment of this service:

The only negative aspect that I saw in the early intervention system was worry about how to pay for the speech therapy. But nobody was sure if it was going to be covered, so that was the only thing really for me. (Susan)

Judy had to pay for some insurance:

We had to pay a portion. I mean...she needs more than they are offering. Well, and like right now, with this intensive speech therapy, which we really feel that she needs, but I was never sure if insurance will pay for it or not. (Judy)

Tracy was not working because of the 24 hour care that was needed for her son.

Bobby had already had several surgeries. She discussed the medical issues that arose in her home:

The surgeries are paid for, but not all the medication, depends on what they use. So, not all of it's paid. Like his glasses, they will pay for it one time, every two years. If he breaks them in between that, we have to pay for them. No matter if it's one or seven, we pay for it. Early intervention did pay for all his therapies. Because, they had, at that time, he had two Medicaid cards. One was from the state and one was from local medical. He had two different ones. If one didn't pay, the other one did. (Tracy)

Home-Based Instruction and Staff

Those families whose children qualified for early intervention services received them in the natural environment which usually included the home setting. The

professionals (therapists, service coordinators), according to the IFSP, come to the family's (caregiver's) home and conducted services, depending upon who was assigned to the family or the geographical area. Because of isolation and lack of transportation, many of the mothers who did not work enjoyed these visits with the professionals. Those who worked with the families became friends to many of these mothers.

Karen expressed her pleasure with the early intervention service coordinator and the therapists because they were more family centered:

Um... I liked early intervention, um... I like them, the fact that they, um... cared about the family as much as they did Amanda. They did help us a lot, I did learn a lot from them. (Karen)

Christine explained the difficulties she and her husband experienced when their son was first diagnosed with a problem. He was in a day care center at the time, receiving center-based instruction then he began receiving home-based instruction through early intervention services:

At nine months old, we had the MRI, we had the diagnosis, we had the therapies. At that point, I pulled him out of day care. It was more important to get his therapies, and we frankly could not pay for all the therapies and full-time at the day care. The therapies were excellent, and I don't know (sigh), I realize now, it was just the luck of the draw. But (occupational therapist) was the best trained, and she was head of pediatrics, plus (physical therapist) was the best person for the types of physical therapy that Chad had. Um... they both liked neurological patients. (Christine)

Elizabeth's son, who had cerebral palsy, was receiving physical therapy and early intervention services through the service coordinator. She expressed her belief that he learned a great deal from these individuals:

So, but, you know, the service coordinator was really good. She probably got him to do more things than the, even the therapist. She worked with him in a different way, she brought in different toys, and things that were of interest to him, that would hold his attention. She focused a lot more on his hand and his motor skills.

We always joked that he knew his colors by the time he was 18 months old (Laughter). I thought ‘why is she teaching him his colors, he’s little, he doesn’t need to know his colors.’ But boy he knows his colors now, very good. (Elizabeth)

Judy stated that she liked the professionals assisting her with her child, yet she blamed herself for not having enough time, because she was so involved with her sick daughter and also the care of raising three other children:

I feel that they (early intervention) were good, but I think I wasn’t. I think that I was so involved with taking care of Alexis that I didn’t research a lot. I didn’t know what services were out there. I don’t know if we were getting what we should have been getting. I am taking their word for it. (Judy)

Carol had a difficult time accepting the fact that her daughter had a disability. At first, she didn’t quite understand why the professionals were making her daughter do a task. She described how she came to understand and appreciate their persistence:

Well, in the beginning, in the beginning, it was very hard to accept the fact that she had a problem, you know. And then also, I thought that it was a wasting of time, just coming here, and then like, “Uh.” In the beginning, it was rough, because number 1, There is not communication there. She (Jamie) didn’t have any idea what was going on, so there was a lot of crying. And a lot of discipline, and I honestly thought that it wasn’t fair. Because especially, putting the blocks, you know, on top of one, you have to build 10 and this and that, and it was very hard for her to do, and she used to cry and cry. But they (professionals) were very persistent. In the beginning, it used to bother me, I used to go to the kitchen and stay in tears and say: “Why?, why?, why?, if she doesn’t want to do it, then fine.” But now, I am glad that they were persistent and they didn’t quit on her. It took them a lot of effort. And a lot of patience! (With enthusiasm). (Carol)

Tracy was receiving early intervention services for her son Bobby where the service coordinator and the therapists were coming out every week. She explained that because she lived in such a rural area, she did not have the opportunity to get out much:

[Service Coordinator] started coming out once a week. I seem to think it was every other day, or twice a week or something. She was coming and working with him (Bobby) because he was little, fragile. And she started him with little stuff and then [therapist], she came, I think it was every other day. I think they was coming the opposite... Oh, I loved it. I mean, one, it was company. Because I was all

alone, and nobody, nobody understands what you go through unless they either help with you, or they have been there. I looked forward to seeing them. I was tickled pink. And Bobby enjoyed it. And it was like: “Ha, ha, mom, I am not looking at you all the time, I got somebody else.” So, he was happy with that.
(Tracy)

Alice’s needs were accommodated when her grandson began receiving early intervention services. The service coordinator would visit in the mornings before Alice went to work and assist John with the skills written on his IFSP. Alice also felt that she could call this woman any time:

[Service Coordinator] brought a bunch of different things for me, she was really helpful. About seizures and cerebral palsy. She brought a lot of pamphlets and stuff for me. She came out once a week on a regular basis. I mean, she was really sweet and supportive, and if I needed anything, you know, I could call her at her house.
(Alice)

Transitioning from Part C to Part B

This section of themes dealt with the main core of the study. In order to get to this point, the sections of early intervention and preschool were important because they were events that had occurred in these families’ lives. This will be one of many transitions these mothers and children will encounter while they continue to have special needs. Before they can transition into the school system, the children need to become eligible to receive services. At this time an evaluation is conducted. This transition was important because the two systems under IDEA, Part B and Part C are different, as explained in Chapter 1 of this study.

Sending and Receiving Professionals

In order for transition to be a smooth process for all involved, the sending professionals from the early intervention system and the receiving professionals from the school system must work as a team. They need to communicate with one another. In the

literature, there are a number of ways that this can be done effectively. A timeline should also be implemented in order for this smooth transition to occur. Transition needs to be discussed with the parents as soon as a child enters the early intervention system. Most mothers encountered positive experiences with the transition process.

Karen understood that her daughter was turning three and that she would have to transition into the school system, yet she expressed different concerns about the experience she encountered with the professionals:

They (early intervention) did tell me that when Amanda turned three, that, um... she would be transitioning into the school system, and that, um... she would have, you know, a school teacher, different, basically that none of the people that worked with Amanda would be the same. I would have liked to have seen the early intervention people at the transition meeting. You know, it's hard, it's a hard transition. I mean, it's like, I was walking into a room full of people I didn't know. (Karen)

Christine knew it was time for her son to transition into the school system. She had already had him in the day care at one time while she worked, so she was familiar with the staff. She had to take him out due to illnesses. She explained why they wanted her son to go in when school started:

I had gotten the number of [transition coordinator], and she told me that based on, you know, their school year runs from September to June. And, um... in order for them to continue to keep the right number of therapists for the people coming into the school system, they very much preferred for people to be in, accepted into the school system at the beginning of the school year, instead of having to like try to add people in at the middle of the year, and they had a very good aide that they really wanted to keep. And they decided that the aide would be a good candidate to work with my son. (Christine)

Elizabeth shared concerns about the transition process. The sending and receiving individuals had done their jobs, yet there was an administrative problem. Elizabeth was a

conscientious woman, and knew she had done everything that was supposed to have been done:

Because of paper work, and instead of, I'm pretty up on these things. I'd already called everyone, and I try to keep up with those things really well, and I thought that he (Sam) was all set to go. I thought that I had done everything that I needed to do. I think everybody else thought they had done everything too. But it was an administrative. OK, it really wasn't. [Service coordinator] was great, she did everything I thought she was supposed to do. I thought that the teacher did everything that she was supposed to do, but then when it all came time for him to start school, there was something else needed to be done. (Elizabeth)

Susan had just been given a diagnosis for her son's autism, so she wasn't in early intervention for a long period of time, but she was assisted when needed:

I guess the contact was the service coordinator. It must have been her, because I certainly didn't know where to go. I met [Special Education Coordinator and the Transition Coordinator]. I mean I really don't recall any time where I was going out seeking people. It was kind of like at that moment, I was trying to read what autism was. They were great, because otherwise -- you are just so busy trying to internalize everything and on top of trying to, you know, they you have to turn around and try and find information about the school system. (Susan)

Judy explained that the professionals on both sides were willing to do whatever they could to make the transition a smooth one for her daughter:

Yeah, [service coordinator] was the one that transitioned Alexis. And she introduced me to [transition coordinator], and even after we were hooked up with the woman from the school system, she called me back and asked how things were going, if I needed any more information, or if there was anything else that she could do. (Judy)

Roxanne seemed comfortable that her son was ready to go into the school system:

Yeah, I was really pleased with early intervention, because that's what got the ball rolling for him to go to the special needs classroom. They (early intervention) got in touch with the school system, and they came out and did an evaluation. It was a quick process. I got to meet his teachers, they came to my house. They introduced themselves, and he went to school. (Roxanne)

Debbie was concerned about her daughter having to go to school, because she had been with her for all the time:

The [Service Coordinator] talked about it and she called the school and then her teachers came up and we did that and everything. I went down to the school and looked at it. (Debbie)

Carol had transitioned her daughter into the school system, but an unlikely event happened with the teacher, and she removed her daughter from that setting. Carol described how the schools assisted her in locating another site for her daughter to attend:

They (school system and early intervention) all did. They came and gave me some advice, and then from there, I said fine, I am going to take her to school. (Carol)

Because Tracy did not work, she and her son had spent so much time together, along with the early intervention professionals, she had a difficult time with the transition process. She came to realize it would be beneficial to her son:

I had so much to deal with. Well, I thought maybe at five years of age. I didn't know I was going to lose them (early intervention). Then I said: 'Well, I know it (transition) will be good for Bobby.' Then [service coordinator] sat down and talked to me about it. Then another professional talked to me forever about it. The therapist was there when we went for the meeting. (Tracy)

Parental Involvement

Many of the mothers learned to take a more proactive role during the transition process. Each mother chose her level of participation when working with professionals. The fact that some parents did not participate as much in their child's education did not mean they cared for or loved their child any less. Professionals need to respect the amount of participation parents are willing to give, and not make judgments about them.

Christine was a real advocate for her son Chad:

I had to be Chad's project manager. I came with all of his medical information, which included the original letters, and this was given to the school system. So,

what I did was make sure that I was there, that Chad was there, that I had an entire medical record for him. And then I also did a um... I did this, which was basically a synopsis of everything that was going on with him. And I gave it to each one of the group who was going to be working with Chad. (Christine)

Elizabeth was pleased Sam was doing so well, but she still had concerns and just wanted what was best for her child:

They (professionals) worked with me, they worked with us, but still as a parent, you feel kind of... you just want to do what's best for your child, and you understand there are certain things you have to do, and certain things you can't do. I don't know if it all comes together... perfect, like you want it. (Elizabeth)

Susan felt as if her and her husband were treated as parents and as partners when it came time to discussing their son's issues to professionals:

I liked the fact that they came to the house. I know part of the diagnosing procedure is... you know, getting a lot of information from the parent. Yeah, they included my husband quite a bit too, because many times, in those situations, they will talk mostly to moms. But they talked to my husband equally, which was nice. (Susan)

Judy was trying to be so involved in her daughter's education:

I feel they were very good, but I think I wasn't. I think that I was so involved with taking care of my daughter that I didn't research a lot. I didn't know what services were out there. I don't know if we were getting what we should have been getting. I am taking their word for it. You know how you always second guess yourself. I don't know what I could have done different. (Judy)

Service Delivery Options

In the five counties included in this study, four of the counties provided early childhood special education in self-contained classrooms in a school setting with a full-time Pre-K special education teacher and aides. One county provided these services in a daycare setting, where the children were fully included in a classroom with their own peers. A teacher designated by the county would travel to the daycare settings where the children were located and provide services, along with the therapists. The mothers had

different opinions on the option for services. Some of the mothers were concerned because they did not have a choice of where their child would attend preschool.

Karen lived in the county where all children attended an early childhood special education classroom within the one school setting. Karen expressed her displeasure with the fact that her daughter would be on a bus for a long period of time:

Well, we had [school]. Um... I really didn't hear of any other schools, but all the other kids from the county area go to there. So I was assuming that was the only choice I had. But, I mean the school is so far from the house, I mean it's like 25 or 30 miles. It's a long bus ride for Amanda. She gets on the bus about 3:00 and gets home at about 4:30. So, it's like an hour and a half, for her to ride the school bus, which she has some behavior problems on the school bus. (Karen)

Christine lived in the county where she had a choice of day care settings to send her son. She and her husband looked at several sites:

Actually, I looked, I looked, um... and the one that I was most intrigued about was the [university lab school], but that turned out not to be. I mean if you think that the educational model is restrictive in that you only get services for nine months. Well, the lab school is on the university calendar, so there are more days that are off. (Christine)

Susan and her husband were having a difficult time choosing where they wanted their son to receive preschool services. She vividly described the situation:

I guess they were afraid of [husband] and me at the time because they (professionals) weren't sure where we were going. I had already contacted a lawyer and all that if there was going to be a problem. And actually they offered [Catholic preschool] to become a site, and that really thrilled me. But then the thing that really upset me, was that they (teachers) took a vote, the teachers took a vote, and they said that they didn't want any children like Tony in there, which really hurt me, because I was standing up thinking that they had been so good to Tony. And here, then they are turning and saying this. (Susan)

Judy and her husband went to many of the daycare settings where their daughter Alexis could attend as their public school choice:

Well, I didn't know anything about the preschool program either. She (transition coordinator) thought it was best for Alexis. You know, because Montessori was so structured. Alexis had not really been around children before she started preschool. Her brothers, but not any peers. Then we (husband and myself) couldn't decide, we wanted to look around. So, we visited one of the day care sites, then we visited the [university lab school], and we just really liked how clean and neat the lab school was, and we liked the playground better than the other day care, and so we said that we wanted to try it there. (Judy)

Debbie knew there was only one place for Kathy to go and receive her education when she transitioned into the public schools:

I went down and looked at it. I went down to see how it was, and seen if it was okay for her. I mean, it's sort of okay and not okay. They do good with her, and you can tell a difference. (Debbie)

Separation Anxiety

When their children transitioned to a school setting, many of the mothers experienced separation anxiety. Those who did not or could not work, because of the time required to care for their children, had a more difficult time during the transition period when their children started the preschool program because they were so used to being at home and taking care of their child. They weren't used to anything else. In many cases, it was the just the mother and child.

Karen felt that Amanda seemed so young to be getting on a school bus and going to school, but yet she was relieved that things worked out:

I was a nervous wreck at first, but to be honest, I was relieved when Amanda started school, because that meant that I had two days by myself. I mean....
(Karen)

Debbie also was a stay at home mom and felt somewhat uneasy about someone else taking care of her child during the day:

Well, at first I didn't like it, you know. I got upset because she had been with me for two years. You know, it's always me and her, me and her. And I just wasn't

ready to let her go. But I knew that I could call down there every single day to see how she was, and they (teachers) told me that she was good. I was afraid that they wouldn't know how to handle her, you know, the way she is. I think of her as a normal child with disabilities. (Debbie)

Tracy had a very difficult time when Bobby was going to be transitioning into the public schools. She did not work, and basically took care of him by herself for three years:

Now, he had problems at first, the first week. This is what I was going to tell you. I had to take him every day because he, well he had always been with me and no one else. I mean his dad would keep him one or two hours out of the day. I was like, OK. I was like, I guess the main thing was that Bobby had never been away from me. It was hard for me, more than I think it was for him. After the first week, because after that he was fine. Because he wakes up in the morning, and says; "I don't want to go to school." Then when it's time for the bus, he gets all excited. I still cry because I was so used to having him here. (Tracy)

Transition Statements

On an Individualized Family Service Plan for each family, a transition statement must be included when the child will be transitioning from Part C to Part B. These statements are discussed according to the county in which the parent received services.

County A included Christine, Elizabeth, Susan and Judy. Karen, Debbie and Carol resided in County B. County C included Roxanne, Tracy and Alice. Below are the transition statements from each IFSP:

County A (Christine): "For Chad to transition from early intervention services to County A in order to receive services after his third birthday, the service coordinator will set up a meeting with the school to discuss services. The service coordinator will visit the centers if family wishes to do so. The school will invite the family and service coordinator to the eligibility meeting and the IEP meeting. The service coordinator will attend."

County A (Elizabeth): "To transition services from early intervention to County A schools in order to receive OT/PT and any other needed services, the service coordinator will contact the schools in August for IEP meeting and transition services."

County A (Susan): “The service coordinator will make a school referral when family feels it is appropriate, and assist with the transition process from Part C to Part B.”

County A (Judy): “To establish a relationship with County A in order to transition Alexis into the school system, the service coordinator will make a referral to the school and will attend the eligibility meeting and provide the needed records.”

County B (Karen): “Transition paper - child reached 36 months.”

County B (Debbie): “Before Kathy is 3, the service coordinator will make a referral to County B public schools in order to assist Debbie with Kathy’s transition to the public school. The service coordinator will assist as needed during the transition process.”

County B (Carol): To refer Jamie to County B public schools in order for Jamie to receive services, the service coordinator will call and set up the school visit and take Carol to visit the classroom, and attend the IEP meeting.”

County C (Roxanne): “To transition Douglas in County C public school in order for him to begin preschool in the fall of 1996, the service coordinator will make the referral to County C schools and will be available to support the transition process.”

County C (Tracy): “The service coordinator will refer Bobby to County C elementary school, and will provide information and assistance through the transition process.”

County C (Alice): “John will be transitioning into the school system in the spring of 1999. The service coordinator will set up the referral to County C and assist the family with the transition process.”

Moving Into the Preschool Setting

In the state of Virginia, children who are diagnosed as developmentally delayed, or who have a diagnosed disability at the age of two or three may attend the public school system, Part C of IDEA. Services for preschool may be provided through a variety of models, which may include home-based, center-based or a combination program. The length of the school day and school year may vary from that of school-aged children. County B offered a center-based program and operated on a schedule of five days per

week from 8:30 a.m. to 2:30 p.m. County C provided a center-based program from 8:30 a.m. until 12:00 p.m. Monday through Thursday with a home visit on Friday for one and a half hours in length. Home-based programs were offered twice a week depending on the child's needs. In County A, the children attended day care settings. The schedules were the same times as the operations of that particular day care. All teachers and therapists in the counties taught the children according to what was written on the IEP.

Educational Model

A few of the mothers expressed concerns that the educational model is used in the public schools while the medical model is utilized in the early intervention program. Some mothers thought that this was a major difference in services.

Karen explained that she missed the services that were offered in early intervention but not in the school system:

I mean I don't see her therapists as much. I don't get to talk to them like I get to talk to [ECSE teacher], so I really don't know what goes go in Amanda's therapy sessions. I also wish they could get it to where the IEP was similar to the IFSP. I mean, just because they're a little older, and less harder to take care of in school, doesn't mean that the family still doesn't need support. (Karen)

Christine brought up the educational and medical model throughout the interview process. She had some strong points to make on this matter when it comes to educating her child with a disability:

But there is, you know, the fact that you have to go from a medical model to an educational model. Parents need to understand that the school system is not going to be the end all and be all. They can give you some relief and they can help your kids, and provide therapists that let him see the world in a new way, but if your child is really medically involved, you've got to somehow scrape together the money and the time and the will to get them that extra help, because the school system can't do it.

She goes on to add:

Oh, the other, there's one other thing, though, that also you need to think about. There's no therapy provided, because it's the educational model, there's no therapy provided over the summer. So, there's a big question: 'What do you do over the summers?' (Christine)

Elizabeth explained the differences she saw between the two services:

I feel that the IEP, they look at everything from an educational standpoint. And sometimes what they think is educational and what I think is educational may not necessarily be the same thing. And that's why we are having so much difficulty with the occupational therapy because his fine motor skills in his left hand are good, but they are virtually non-existent in his right hand. And he does very well with his left hand, so educationally, he was okay, but I remember briefly you learned things in school like putting on your coat, tying your shoes, going to the bathroom, pulling up clothes, buttoning, zipping. Uh... so many things take two hands, climbing, swinging. (Elizabeth)

Scheduling

Elizabeth felt scheduling was a problem when Sam began attending preschool:

It's different to coordinate, I won't let him ride the bus that far, it's a long way. It's about a 25 minute ride and I don't feel that comfortable having a four year old ride a bus that far. See, I take him every morning and my husband picks him up. (Elizabeth)

Socialization for Child

Many of the mothers shared a common theme and expressed positive comments when they talked about the opportunities for socialization that their children received at their designated school sites.

Christine felt that one of the biggest benefits to being in the schools was the fact that Chad could be around other children:

The fact that Chad was going to be able to be around lots of other kids on a daily basis was a definite, definite benefit. Um... we (parents) had done, you know, just taking him (Chad) to the playground kind of thing. Um... then early intervention had times when you could bring the children and play in a play group. But, that turned out to be not very successful, and part of it, Um... was the timing, you know, not a lot of people could get there at the time it was scheduled, and the

other thing was that a lot of kids got sick. You know, that's the thing about early, you know, about special needs, is that a lot of them aren't there on a regular basis, because they are fragile. (Christine)

Elizabeth had her son in outside activities so he could learn socialization skills at other places besides the school:

He's a happy child. I have had people all the time, they have never seen him without a smile on his face. He is well adjusted, he likes to do lots of different things. I have him in a Tae Kwon Do class as well. (Elizabeth)

Susan was extremely happy when she received messages from the teachers about how her autistic son was learning from the other students in the class:

And he has been, you know, all of the teachers have said that he looks very intently at what the other kids are doing. Which is good, because I worry, maybe he's missing it. (Susan).

Even though Judy had three other children, and Alexis played with her brothers and sister, Judy noticed that her daughter began modeling other children at the school site:

It is, now with therapy, I am thinking that some things she wouldn't do, but the physical therapy, she would let the other kids try it. Well then Alexis watched them do it, and would do it, so that worked the other way. (Judy)

Since Roxanne had no other children, she was glad that her son Douglas was attending a preschool setting, so he could interact with other children his own age:

And Douglas could be around other children. And he could get used to others, because he is an only child. I think that's my biggest, that he could be around other kids. (Roxanne)

Tracy wanted her son to go to school and learn things that everyday children learn in a school setting as she discussed:

One, he was never around other kids, I wanted him to learn to share. He only knows how to share with his brother, but then he wants to dominate. So, I wanted him to learn how to share, and I wanted him to learn that not, just because I'm his mother, don't mean I can't be his friend and have fun with him. And I wanted him to learn that there is someone else who can teach you besides just mom. And it's

like, daddy's a big ball to bounce around and play with him, and momma's the one that cracks down and be hard on him. (Tracy)

It was difficult for Alice to send John into a classroom. He was medically fragile, and she wasn't sure how he would react to the new situation. But she was glad she did send him to be with other children:

They've (teachers) been really good. I was surprised, he (John) seems like he enjoys getting up, and you know, waiting for the bus. He gets impatient. They say that he really loves being around the other kids. The socialization is good for him. Because if he is having a good day, he laughs out loud up there. And he will watch the other kids and see where they are going. (Alice)

Center-Based Instruction and Staff

Those children with disabilities who transitioned in this study have different options depending on the particular county in which the family resides. County A provided services for children in a full inclusive daycare setting. The special education teacher and any therapists would work with these children according to their IEP. The other counties offered preschool services in a school building in a self-contained classroom. These children received instruction through a special education and related services according to their IEP. Many of the mothers expressed that they liked the classroom setting and the professionals involved in their children's education.

Karen felt very involved in her child's education. She would always be one of the mothers who would assist the teacher in any way she could:

Yeah, I love her teacher to death, she has been wonderful with Amanda. I mean, also, I can pop in anytime unannounced. I can go eat lunch with Amanda and do those things anytime I want to. And she (teacher) told me that I could come in and spend a day with Amanda. Also the teacher asks me for extra things, because she knows that I will help her out. I guess I am the room mother. (Karen)

Christine really felt the day care center was a positive learning environment for Chad. Even though he was a child with special needs, he could perform the activities that his peers were doing:

They (staff) have some group activities which is basically is the reading, and then they do music which is pretty organized. And sometimes, they'll do art work, and everybody does the artwork. At least at [Day Care], they do, Um... emergent curriculum, so there's a lot of choice and the child can do any of it, all of it, or none of it. And that's been true from day one. So, for some special needs kids, [Day Care] is not the place to be, but for Chad, it's fine. (Christine)

Elizabeth felt 'out of the loop' when it came to hearing about her child's education in the day care setting:

I really don't like the way this county does it. I really don't like it being in a daycare because he has had 3 new special education teachers since September and is on the second teacher from the daycare itself. So, I really like it in the school system than daycare. That's just my opinion, I'm sure some people prefer it that way. (Elizabeth)

Debbie had definitely missed the time she was with her daughter the past three years, and had some issues she needed to deal with as well. But after seeing how the teachers were with her child, she became used to the idea that Kathy would be okay with these professionals:

They (teachers) give her their most attention, and whatever she needs. They'll talk to me or they will write in her notebook, and then I'll rewrite back and send it back to her, and let her know my opinion of how I thought. (Debbie)

Roxanne really appreciated the teachers that Douglas had for his preschool years:

The teachers that Douglas have are wonderful. You couldn't ask for... you know, they gave Douglas Christmas gifts and stuff, and they came and played Santa Claus. I mean he had a big bag of stuff, of toys. This child does not lack for nothing in his classroom. (Roxanne).

Other Concerns of Mothers

Mothers in this study also responded to stressors they have experienced, formal and informal supporters in their past and present times, and coping skills, which they found to help them relieve some of the stress.

Stressors

The following data illustrates the stressors that some of the mothers experienced while their children transitioned to another program. They also shared stories of everyday stressors affecting their lives while raising children.

Money Issues

Karen was stressed over money issues that her family had experienced:

I mean, I was relieved at the fact that services were free. Physical therapy and occupational therapy were free, and as for early intervention, you had to pay for them. Because, I mean, I'm still paying, but you know it's hard, which you got all these bills to pay. I mean I work full-time, and have 2 kids. (Karen)

Lack of Support Group

Christine was very capable of getting assistance when needed, but she still enjoyed communicating with the mothers whose children were in the early intervention system:

Lack of support, because in early intervention, once you've transitioned, your not still in the support group. And in this county - they have full inclusion in the schools, they have multiple points of entry, so there is no, the only master list of who has, who are the special needs families is in (town) and you can't access it because of confidentiality. So, you can't hook up with anyone, unless you physically see them. (Christine)

Bureaucracy Issues

Elizabeth understood everything the professionals were discussing, yet she was not very happy with the way they all went about it:

The paperwork - all the communication with the professionals. Just what they said, they thought he needed, and what was best for him. And when there is something wrong with your child to begin with, it's hard, and they are telling you again and again, it's hard, it doesn't get any easier. Just kind of rehashes it over and over again. (Elizabeth)

Susan was so tired of hearing what everyone else thought of her son. But every time he had to go into a new program, he had to be evaluated to see if he qualified:

During transition, actually, that's when things didn't work as great for us. I was begin sent to a bunch of places. I was sent to schools, and he needed a psychological evaluation, and there were a bunch of evaluations that I didn't feel were necessary, and he already had the (Developmental Center), he had already had that in early intervention, and I felt very threatened. (Susan)

Carol did not want to send her child into another school because of the incident that occurred in the classroom with the teacher. She never really was given a thorough explanation of the incident:

Putting Jamie into the school system was fine. But what happened from there. The teacher let her in the bathroom for 40 minutes for punishment. I removed Jamie from that place. The professionals came back and gave me advice. We decided on Head Start. I used to go there during lunch time to feed here, then little by little, I started to trust this teacher, and I'm okay, I'm okay now, 100 percent. (Carol)

New Places

Judy had been in the area for a few years, yet she was so far away from her extended family. Her husband was supportive, but he was the bread winner, so he had to work to support the family:

Plus moving here. My husband brought our family here to start a business, so he would come home and eat dinner, then go back to work. He would work weekends. He was here, but he was busy. And I felt like that I was the only caregiver to her really. My other children are cheated, especially not have another extended family member around to help out with me. (Judy)

Support Networks

Mothers experienced several sources of supports as demonstrated by the following responses.

Formal Supports

Formal supports were those individuals who provided services to the child and the family. Many of the mothers thought the service coordinators in the early intervention program were the most supportive. They felt a strong bond with these individuals.

Amanda had been in the early intervention system for almost two years, so Karen was very familiar with these women:

The early intervention women, her service coordinator especially, and the therapists were wonderful to me and Amanda - they cared about the family.
(Karen)

Even though Chad had been in the early intervention system for two years, Christine did not receive services for her son from the service coordinator. She felt others assisted her more with her son:

Individuals I had met in early intervention and other mothers. My son's aide was a perfect match thanks to the transition coordinator who did an excellent job.
(Christine)

Elizabeth enjoyed working with the early intervention professionals. She felt that they worked a great deal with her son and their family:

The service coordinator, she did, she was probably the most helpful person.
(Elizabeth)

Susan's son was not in the early intervention system for a long period of time, but she was helped in a number of ways:

The service coordinator, I don't know what I would have done without her. The preschool staff were very supportive as well. (Susan)

Alexis had only been in the early intervention system for seven months. Judy lived in the county where there was a transition coordinator, and she assisted the family the most:

Well, Alexis wasn't in early intervention for too long. The transition coordinator for the county was supportive - she helped me and my husband decide on a preschool placement for Alexis. (Judy)

Debbie enjoyed the women who came out to her house to work with Kathy and her:

Everyone who has worked with me and Kathy has been good. (Debbie)

Roxanne also liked the women who came to her house to work with her and her son. She learned a lot of information from them:

The women who came out to my house, they were wonderful. They really helped both of us out. (Roxanne)

Carol was so pleased with the service coordinator and the early intervention staff. They helped her through the emotional turmoil she experienced with her daughter in the school system:

Professionals - they gave me a lot of help, emotional, you call it, emotional. I consider them as friends. (Carol)

Tracy was so thrilled to have these professionals coming out to her house and talking to her and her son. She enjoyed the company these individuals shared:

The service coordinator and the nurse was real strong. They have been there every step of the way. We have had a lot to go through. (Tracy)

Alice's grandson had been in the early intervention system for nearly three years, so she was very familiar with the service coordinator:

I still talk to the service coordinator sometimes, she was so good with helping me.
(Alice)

Informal Supports

Informal supports were also discussed by the mothers. These included a variety of family members and friends. Some of the mothers' spouses supported them and some did not recognize any problems with their children. Also, some of the immediate family members could not accept the fact that their grandchild, niece, or nephew had any disability.

Karen seemed to be alone when making decisions about her girls. Her husband was not as supportive as she would have liked him to be:

You know, I mean my husband loves his kids to death, but I would just wish instead of me making all the decisions to what Amanda needs, or what my other daughter needs, that he would say: "Well, they need this." (Karen)

Karen's parent had a hard time dealing with Amanda:

When Amanda was first born, mom and dad went to down to see her, and she was hooked up to all these tubes. And when she got a little older, and started climbing on furniture, they couldn't deal with it. (Karen)

Christine received support from her family and from her husband's family. But, her parents treated Chad differently than his brother, while her in-laws treated both children equally:

My husband's mother, she has been in education for years. She worked at an elementary school, and she has been a school bus driver. But she's just great. She's great with kids. I mean for any issues, whether it be for son #1 or son #2, you just call her up and go UH!!, and she goes: "All right, this is what you do." My family on the other hand, the attitude is: "Oh, he is going to get over this." Because you see, all of them do, we are all so healthy. They treat him differently, son #1 is welcome, son #2, they want us to stay with them, because they are not sure how to deal with him. (Christine)

Elizabeth felt that she received support from her family and from her in-laws, but they were older and they always weren't sure what to do:

Well, certain members, my husbands' parents, particularly. My parents are in their 70's, they just don't know. (Elizabeth)

Susan's parents were both deceased, but she could always rely on her in-laws for support. Her sister, though, could not really understand Tony and his disability:

My parents are deceased. But my husbands' parents are really sweet. His mom, especially. She actually was a preschool teacher, and she knows how to buy toys that are appropriate. She has come and takes care of the kids for weeks, while my husband and I can go and do something. So, she has been great that way. I have a sister, but she really doesn't understand him. I mean she knows that I'm hurting, but at the same time, she will say: "Well, look, you have two normal children." It's not meant to be hurtful, but she is not thinking. She thinks I'm very lucky. And I consider myself very lucky. But the things I keep trying to say to her: "Yes, I have that, but I also have this child that I am hurting for." (Susan)

Judy comes from a large family, and she receives support from her parents:

I can call my mom and my sister. My parents are so-so. I mean, my mom, she is always saying to watch out for Alexis, which you have to, but... And my dad, I think he is pretty attached. You know, he wants to cure her, and I keep telling him that we're doing what we can do. (Judy)

Debbie's biggest source of support is her mother. Kathy's biological father used to come and see his daughter, but he just could not deal with her disability:

My sisters are supportive. Mom and dad, those are the biggest. Her (Kathy) dad used to come over and play with her for a couple of hours. He pays child support, but he don't want to see her. He don't call and check to see how she is doing. He sends gifts. But she's better off where she's at. (Debbie)

Roxanne is alone most of the time, just her and Douglas. She does not have a lot of outside support from her immediate family:

My sisters, they don't want to deal with Douglas, because he is so hyper. It's not that they don't love him, it's just that they don't know how to deal with him and they are always asking me how I do it. And his dad is in jail and he doesn't have any contact. We don't go see him no more, because he got remarried and stuff. We

don't, we leave him alone. My mom will watch him, but it's not like she will call me and say: "Bring Douglas over." (Roxanne)

Carol does not receive a lot of emotional support from her husband. She does get a great deal of help from her mother, because she lives in the same house:

My husband still doesn't accept the fact that she's different. He is not supporting me like he should. He never seems to back me up. Never, never, never (shaking her head). So, we went through a lot of family problems, especially my husband and me. And we still are going through. My mom is a help. She lives with us. Her and Jamie do okay together. She knows my mom doesn't understand English. Jamie will pull my mother to whatever she wants. Even though she doesn't really understand all that is going on. (Carol)

Tracy does not receive a great deal of support from her husband or his mother.

They seem to have different views on how to raise Bobby. She receives love and support from both of her sons:

My other son has been the most support. Also, Bobby had gave me a lot of support. My husband, no, I mean I didn't get much until after he understood what was going on. My husband's mom, well she wants everything her way. She thinks that, she don't believe in correction or that Bobby should be whipped or that he should go to time out. She helps at times, but she needs to keep out of certain situations. (Tracy)

Alice did not anticipate that she would be raising her grandson. She gets a great deal of support from her husband, her other son, and her mother:

My family. Yeah, my mom. She lives right down there in the gray house (pointing out the window). If it hadn't been for my family, I don't think that I could have gotten through it. I never expected to be raising, you know. When they found out who the father was, he was going to come down her and help out. They did for a while, and then they just quit coming. I think that figured out that he's got so many disabilities, that they don't have anything to do with him. And that just breaks my heart. (Alice)

Other Sources of Support. Mothers also receive support from organizations, such as parent groups who have children with similar disabilities as their own children.

Elizabeth is always looking for ways to help her son with his disability, and she gets some extra support through the Internet and the resources that are available:

I keep in contact with some people who have children with disabilities on the Internet. And I'm on a listserv with parents of children with hemoplegia.
(Elizabeth)

Susan knows how to obtain resources in the community and through the use of the Internet:

I am very much a book person and I'm usually the one who goes out and gets the information myself. But like, if I want information at this point and time, I usually use the Internet or go to the library. And I also go to meetings and conferences. In some regards, I probably know more than some other people. (Susan)

Coping Skills

These mothers were able to cope with their situation in a number of ways. Some of them just dealt with it, others relied on their families or religion, while exercise was a good outlet.

Karen knew her daughter was in good hands at school. Now she had some free time to do things she wanted to do:

I was relieved when Amanda started school, because that meant I had a few days to myself. I get to go shopping by myself and do some things. (Karen)

Christine was an advocate for her son:

Learn as much as possible about everything, because part of me is still learning.
(Christine)

Elizabeth had a strong family unit:

We deal with issues as a family, my husband and myself. Just do the best that you can. Just when it gets to the point you think that it's going to drive you absolutely crazy, then it gets better. It just something you have to do, something to do.
(Elizabeth)

Susan always seemed to be on the go. She was raising three children, working part-time and going to school part-time, but she always found some time to herself:

I love to exercise and that is a good coping mechanism for me. I am very physically active and that has been a good outlet. (Susan)

Judy was doing everything she could possibly do, but she was never sure if it was the right thing:

Just trying to get through every day. You always second guess yourself, like: “Am I doing this right thing or maybe I should be doing something else.” You are never satisfied. Maybe you are doing things, but you aren’t satisfied. (Judy)

Debbie learned to deal with the situations that were put before her:

Just do it. I just have to, there is just no way of getting out of it. I just have to deal with it. (Debbie)

Roxanne was on her own, she just automatically knew what to do:

Just deal with it. (Roxanne)

Carol was a religious woman, and she relied on faith to get her through the tough times she experienced:

Well, right now, it’s just faith. And I cope by loving my child. (Carol)

Tracy learned to cope in a variety of ways:

I cope by praying and screaming. Every now and then, I take a screaming fit. (Tracy)

Alice’s grandson was ill most of the time:

Just take it one day at a time, that’s the only way I know how to cope with it, without losing it. (Alice)

Summary

In summary, the data presented in this chapter bring mother’s voices into the discussion of children’s transition to early childhood special education. These voices will

assist in reminding agencies and educators about families during this process and what areas are in need of improvement.

The mother's responses were organized by themes as indicated in Chapter 3 and shown in Chapter 4. In order to cross- reference a particular mother and her story, refer to Mother's Individual Responses (See Appendix F) and her story will be told by following the page numbers listed.

Bobby

“I got a lot of help with early intervention. I was really pleased with the progress he made, and the help he got with them.

They would come out and spend time with him. Working and playing with him. On the days that he wasn't able to do the work or play, they would just talk to him. They listen to him and understood. Bobby is a very active little boy. With the help that we got with the program.

I couldn't have done it without their help. They would play special games to get him motivated and to get his circulation going. They would make him listen and say what he wanted. They was hard, but very gently. My son had to be pushed to do things. If they hadn't pushed him, he wouldn't have done anything. He would still be sitting or laying down.

The games was easy but hard for him at first. He took a very long time to catch him up with some of the games which was easy. They never got discouraged with him. Although my son would give them a hard time. They would change their days around when he was so sick. They always had a kind word of encouragement, when we really needed it. I am very pleased with the progress that my son has made with them. I have told others about the program. I recommend them to everyone. May God bless them.” (Tracy)

CHAPTER 5

Discussion

The purpose of this investigation was to study the transition process from early intervention to early childhood special education as seen through the eyes of mothers with children, ages three to five, with varying disabilities. Specifically, this study looked at satisfaction and involvement with this process. This study also identified stressors experienced by the mothers and the formal/informal supports received during the transition process.

Through in-depth interviewing, the mothers provided stories about their children with disabilities and the educational programs they have experienced. Not only were transition issues important to this study, but other issues around raising a child with a

disability came into play throughout. The commonality among their voices stressed that they are loving mothers who adore their children: “He is wonderful, and you are going to have to accept him as he is.” “We just have to take our kids for who they are.” “I will love him no matter what his disability is.”

The findings originated from this investigation are related to the research issues. The following elements include: (1) the ecological theory and how it applied to the mothers’ stories; (2) the mothers perception of and satisfaction with the transition process from early intervention to early childhood special education; (3) parental involvement and advocacy issues; (4) and the stressors and supports.

Ecological Theory

Systems theory, specifically the ecological theory developed by Bronfenbrenner (1979), was used as a basis for this study. He states that individuals are part of a series of nested systems. This nested system considers what is taking place within the immediate environment of the family (microsystem), the relationships that occur between the family and other social systems (mesosystem), the organizations with which the family interacts (exosystem), and the cultural beliefs and values (macrosystem) (Shea & Bauer, 1991).

Turnbull et al. (1984) proposed that the family systems approach has suggestions for the design of intervention efforts. First, each family is unique and has different characteristics and styles. So, those working with these families need to be aware of their cultural backgrounds, religious beliefs, and socioeconomic status. These factors will have an influence on the way a family responds to a child with a disability. Second, each family system is constantly changing. Siblings may become more or less involved, and outsiders may change as well. Third, each family has a different function to be filled by individual

members. The needs of the individual consist of economic, social, recreational, and domestic care. Finally, each family will change, and therefore this will affect all family members. All of these elements need to be taken into consideration when providing services for a family.

Hanson and Lynch (1995) state that the family systems perspective involves the needs of the child with a disability, as they are examined within the contexts of the family where assessments and programs look at the family dynamics, as well as the child's needs. This perspective is recognized in Part C of IDEA, which requires the IFSP, and focuses on the child and the family along with their beliefs and values. Service coordination and IFSPs join the system and settings within the ecological system as stated by Brown and Conroy (1997). These must act individually with the systems theory so the family is more aware of the resources and the services available in a variety of settings, while being provided on an individual basis for each child and family. In using this approach, the service providers need to look at the whole family picture. Interventions can then be planned because it becomes easier to understand the different priorities that mothers experience and to respect her competing demands.

When planning intervention strategies for families of children with disabilities, the dynamics of each level [micro (family), meso (economic), exo (sociopolitical), and macro (cultural)] need to be considered in the ecological environment. By coordinating the efforts within and across the different levels of the ecological structure, a better intervention strategy is created (Wilson, 1998). Intervention strategies cannot be successful without knowing how factors are interpreted by the family (Berheimer, Gallimore, & Weisner, 1990). Because families vary in resources, priorities, concerns, and

cultures (Bailey et al., 1998), each mother's view, whether positive or negative, must be thought of as meaningful by those who coordinate services for these families.

The birth of a child with a disability will impact each family in a different way.

Below are examples of how each family may be represented as they interact with services and resources in the community according to the ecological or systems theory.

Karen, along with her husband, was working full-time and raising two daughters, one with a disability, (**micro**) and received little help from her extended family (**meso**), therefore, she was on her own most of the time. Because she did not work two days during the week, she was able to participate in a number of meetings and workshops that would assist her with raising her disabled child (**exo**). She usually had to work 12 hours a day to support her family (**macro**).

Christine was working part-time, while her husband worked full-time. They were raising two sons, one with a disability (**micro**). Christine had support from her extended family (**meso**). She was able to utilize resources in the community, and was an active member on committees in early intervention (**exo**). Insurance became an issue for her family which affected certain services her son could receive (**macro**).

Elizabeth and her husband both worked full-time and raised their disabled son (**micro**). Elizabeth had a strong family support system (**meso**), and she used community resources a great deal for information about her son's disability (**exo**). But she had to deal with insurance issues about coverage for certain therapies that her son was receiving (**macro**).

Susan and her husband were raising 3 children (**micro**). Susan had family support (**meso**). She was well versed on outside community resources for her son and was able to utilize these resources. She was also active in parent groups (**exo**). Yet because of the inclusion model used in the county in which she lived, she was not as pleased with the education setting that her son was receiving (**macro**).

Judy did not work, and lived with her husband and four children, one with a disability (**micro**). She did not have family nearby (**meso**), so phone support was used. Her daughter had a seizure disorder, so she was caring for her most of the day (**exo**), therefore she couldn't attend meetings and had to run the other children around. Her husband moved to the area because of a new job, but this move caused the loss of family support (**macro**).

Roxanne was a single parent raising her son with a disability (**micro**) with little outside assistance from her immediate family (**meso**). She had a difficult time

finding a caregiver to watch her son (**exo**), so she was unemployed because of inadequate daycare and job availability in her community (**macro**).

Debbie was a single parent raising her disabled daughter (**micro**) with a supportive extended family (**meso**) and outside community assistance (**exo**). She did not work because of the full-time care that was needed for her daughter (**macro**).

Tracy was married, taking care of her two sons, one with a disability (**micro**). She did not work outside of the home, but relied on professionals for assistance due to the rural region in which she lived. They came to her (**meso**) to assist her with her family's needs. She did not work because of inadequate caregivers (**exo**) and the rural area (**macro**).

Carol, along with her husband was raising two daughters, one with a disability (**micro**). She had a lot of support from her mother because she was living with the family (**meso**). Carol used community resources as she saw fit. She worked full-time (**exo**) to help support the family, and she dealt with issues as a family (**macro**).

Alice worked full-time and raised her grandson along with her husband (**micro**). Alice had a great deal of support by her mother (**meso**). She did not have the opportunity to attend outside activities because of the distance and because she worked (**exo**), therefore she had to rely on others to provide her with resources for her family (**macro**).

From this ecological model, it is possible to anticipate very different outcomes for two families who have children with similar disabilities. Limited resources in the form of insufficient income, lack of concrete help, and lack of emotional support may combine with the disability itself to result in adverse outcomes for a particular family. In contrast, a family having support may have a different experience. Awareness of differences will assist professionals who provide services to children with disabilities and their families to plan accordingly.

Mothers' Perceptions of Transition

Mothers of children with disabilities reported overall satisfaction with the transition process that occurred between early intervention and early childhood special education.

They stated during this process that general written and verbal information was offered, professional assistance was provided from both the sending and the receiving programs, and follow-up support was conducted (Mack, 1995). They also indicated they were comfortable working with the professionals from both the sending and receiving programs, especially from early intervention, because they felt they received more support from the early intervention program (Hamblin-Wilson, & Thurman, 1990). Because early intervention programs focus on the family, there is frequent communication between early intervention and the family (Bruder & Chandler, 1996), while preschool focuses on the child in an educational setting where there may be less parent-professional communication (Hains et al., 1991). The outcomes in this study support those of (Fowler et al., 1988, 1991) with respect to mothers and how they view the transition process. Hanline and Knowlton's (1988) study also found parents were satisfied with the amount and quality of services received. Overall satisfaction with services was seen as high.

Knowledge.

The mothers interviewed for this study seemed to be knowledgeable about the differences between the two programs, early intervention and early childhood special education. Hains et al. (1991) discussed the differences which include; provisions for services and funding, home-based to center-based, IFSP to IEP, family-centered to child-centered, a labeling component for eligibility, year round to a school calendar, and fees being charged under Part C, but not Part B of IDEA. Not all of the listed issues between the two programs were seen as difficulties for the mothers, but they did voice areas of concern.

Satisfaction with family-centered. All mothers were satisfied with the way that early intervention was so family-centered. The mothers felt as if the family were viewed as a whole unit with a variety of services that were offered to them. Services on the IFSP for families can range from providing information on resources to family counseling to parent group meetings (Huntiger, 1988). Some mothers were able to attend conferences that met their specific needs, some were assisted financially, and all were provided supports through a “Mother’s Night Out” program. Mothers had more opportunities to experience the family-centered concept because they were receiving services for the child and family. In the preschool setting, where the focus is on the child, the services were more narrowly focused. The findings from Hamblin-Wilson & Thurman (1990), Mahoney et al. (1990), and McWilliam et al. (1995), drew the same conclusions as this study in which families were satisfied with the concept of family-centered intervention (Dunst et al., 1988; Winton & Bailey, 1988).

Preferences for home-based provision. Many of the mothers perceived that home-based provisions were somewhat better than center-based for their children. Mothers felt more comfortable with the service providers (therapists, service coordinators) who came to their homes. Wheeler, Reetz, & Wheeler (1993) add that rural programs are unique in their service delivery options because of the sparse communities, less availability of programs, and possible distance from family support systems. These families became attached to the individuals who had provided the early intervention services. They had better communication with them and were considered as “friends”. These professionals provided educational and therapeutic support for the children, and also emotional support for the mothers if needed.

Preferences for services in the medical model. Another issue a few of the mothers discussed rather openly was the topic of the medical model versus the educational model. The mothers' comments indicated there were not enough services, especially therapy services, provided in the school system. These findings confirm those of Mahoney et al. (1990) regarding multiple services. The medical model was received under early intervention, where therapists (OT, PT, Speech) came to the natural environment and provided services for the child. This usually occurred all year, as often as once a week. When children with disabilities receive therapy services within the school system, (i.e. educational model), it is during the school year, generally from September to June. If school is canceled for some reason (snow, holiday, teacher workday), then therapy is canceled. Therapy sessions usually do not start as soon as school begins because of scheduling, and tend to end earlier so therapists can complete paperwork and testing. Therefore, children with disabilities may not be getting the true amount of recommended services. As Christine commented; "I mean if you think that the educational model is restrictive in that, you only get services for 9 months at the lab school at [University] because they are on the college calendar".

Concerns with cost in the medical model. Another aspect under the medical and educational models was that of cost. Most families in this study discussed financial struggles, especially with insurance companies. Because transition involved moving from one system to another, parents who were struggling or who were receiving assistance from a public funding agency often did not cite finances as a major constraint simply because they did not consider program changes to be different. The families who made a certain amount of income above poverty level generally had to pay for therapies and

service coordination in early intervention. So, these families were somewhat relieved when their children could attend the public schools because therapies and educational services would be provided free under Part B of IDEA.

Parental Involvement

The number of family members, the sources of social support, needs, strengths, and job status of the families all become factors that can affect the mother's ability and desire to become involved in her child's transition (Chandler, Fowler, & Lubeck, 1986; Turnbull, Summers, & Brotherson, 1983). All of the mothers participated in the transition of their children from an early intervention program to an early childhood special education program. Each mother was involved, to some extent, in the decisions that had occurred, yet the level of participation differed with each mother. This is consistent with previous research about parent involvement in the transition process (Fowler, Chandler, Johnson, & Stella, 1988; Fowler, Schwatz, & Atwater, 1991; and Johnson, Chandler, Kerns, & Fowler, 1986). Christine, Susan, and Judy shared their extensive notebooks consisting of notes from meetings, IFSPs, and other letters of information. All of the mothers visited the sites where their children would be attending. The teachers also conducted a home visit with each family. Those mothers in County B and County C were assigned to a preschool program located in a specific school. Since County A offered preschool in day care settings, these mothers had to "shop" around for the site that they thought would most benefit their child. All of the mothers were involved in the actual transition meetings as well, but some of the mothers would have liked more information and would have liked all of the early intervention people to attend, because some of the mothers claimed that they were; "Walking into a room full of people that I did not know."

Johnson, Chandler, Kerns, & Fowler (1986) reported that transitions can be successful if they are well-planned, include opportunities for discussion, involve parents in the decision making process, and include transition preparation. Christine received a transition booklet from the service coordinator, while other written and verbal information was provided to each of the mothers. Mothers commented that they had some questions and concerns, but they were involved in the referral, evaluation, and placement process. An area of frustration for some of the mothers was why their children had to be evaluated again to attend a preschool. They felt as if their children had already been over-evaluated, having been through the initial rigorous testing process. Elizabeth explained; “And there you are again in that position, and you have six or seven different people sitting around a table telling you what’s best for your child. And then they make these recommendations for him in an hour, after they assess him”.

If mothers are prepared for the new placement and are allowed to participate in planning their child’s transition, the effects of change can be lessened (Hains, Fowler, & Chandler, 1988). These authors also state that mothers should be able to select the type and level of involvement they feel is most appropriate, noting that this may change over time. Mothers adopted different roles during the transition process (as teachers, advocates, partners), and felt supported as the primary decision makers. The mothers also learned to assume a more proactive role than a passive one.

Stressors and Supports

Parents may experience more stress during the transition period because of the challenges and changes that occur (Fowler, Chandler, Johnson & Stella, 1988; Hanline & Knowlton, 1988; Rosenkoetter, Hains & Fowler, 1994). These authors further add that

parents who use support services may help reduce the stress associated with the transition into the public school system. All of the mothers in this study experienced different stressors based on the make-up of the family system. Not only were the mothers dealing with transition, but other daily obstacles all families encounter. The mothers were glad their children were going to receive appropriate services, no matter where or how the services were provided. Some of the mothers were upset because of the separation from their children. Those mothers who did not work and stayed home for the first three years to raise their child expressed this feeling. This confirms the findings of Hanline's (1988) study where the mothers experienced stressors because they were separated from their child.

The Speigal-McGill, Reed, Konig, and McGowan's (1990) study reported that a variety of issues caused stress for the parents participating in a parent-education program. One particular issue included sending a 3-year old child to school on a bus and having the child attend school for five days a week. These issues coincide with stress-related issues from this study. Some mothers experienced stress because of the long bus ride their children had to encounter. The children in County B and County C only had one school which offered preschool services, because of a centralized county service model, so no matter where the family lived in the county, the children had to attend that facility. This concern was also addressed by the study conducted by Hanline and Halvorsen (1989). Elizabeth chose to drive her son to school daily and her husband picked him up. They did not want their young child to be on a bus for a long period of time, so they had to make arrangements and adjust their schedules.

Parents of children with a specific disability (Downs, cerebral palsy, autism) present different functional abilities and care-taking demands (Van Riper, Ryff, & Pridham, 1992). The children in this study had a variety of disabilities from mild to severe. From my observations and interviews, the nature of their child's disability caused stressors for the mothers, but they seemed to learn to adapt to the situation. Each family unit 'played the cards they were dealt'.

The immediate family members and other mothers (peers) (Hanline & Halvorsen, 1989) were identified as the primary sources of emotional support. Mothers were able to identify both formal and informal supports. Seligman, Goodwin, Paschal, Applegate and Lehman's (1997) findings revealed mothers thought their mothers were more supportive than their spouses' mothers and maternal grandparents were more supportive than paternal grandparents. The findings of the current study showed different results. Of the ten mothers, three of them had mothers who really could not deal with the situation. The grandparents did not feel comfortable watching the child with the disability, but were willing to watch the siblings without the disability. These grandparents were not as supportive as the other mothers' parents were in the study. Two of the mothers expressed that their in-laws were very supportive and would watch all of their children at any time. Roxanne, who was a single mother, reported that she experienced a great deal of stress because she had little support. This is consistent with Beckman's (1983) study, where support is seen as a characteristic associated with stress. Each family is unique as to the support received from the extended family.

Because these mothers were the primary caregivers, they had to rely on the advice and experience of professionals. This was the first time these mothers had to deal with

special education issues, and they were not experienced in this process, therefore these individuals became their lifelines. Mothers had to be the major decision makers and were provided advice from the early intervention professionals. Mothers felt confident in their role of parenting and were able to be better prepared for future transitions. They perceived professionals as caring about the needs of the family and the child. This is consistent with the findings of McBride, Brotherson, Joanning, Whidden, and Demmitt (1993).

Suggestions for a Smoother Transition

These findings will be useful for professionals working in rural areas. Even though these mothers found transition to be satisfactory, they identified three constructive ideas which could improve the transition process. These ideas fit the mothers particular concerns, needs, and priorities. The first suggestion was that of a “mentor mother”. This would consist of a mother who could offer informational, emotional, and educational support. Mothers need peer support in order to share their experiences (Stonestreet, Johnston, Acton, 1991) and they need to know they are not alone. Mothers also may feel less threatened in talking to peers. Support/Learning groups were the second suggestion. They felt meetings should be held in their particular geographical areas because of transportation and baby sitting issues that may occur. The mothers thought of this as time consuming, but beneficial. A third suggestion was a checklist. The mothers stated that a booklet was too long to read. The checklist would state everyone’s responsibility in the program and would make it easier for a parent to follow and check off when something had been completed. These are just some suggestions the mothers mentioned for a possibly smoother transition. But again, it all depends on the way the family is structured as to how successfully these may be incorporated into the process.

A recommendation all the counties could use would be that of a transition coordinator. County A employed a transition coordinator whose main role was to assist families and the sending and receiving agencies ensure a smoother transition for all those involved in the process. County A was one of the largest counties in the five county area. There were more children and all were in a full inclusive setting where services were provided. County B and County C did not have a transition coordinator, due to the fact these were more rural areas, there were not as many children, and all went to a centralized preschool in a public setting. Even though communication occurred between the sending and the receiving programs, a transition coordinator would be beneficial to all areas to work with the professionals and the families.

There are also a number of manufactured transition models available. These were developed to assist families and provide support prior to, during, and after children transition from early intervention to a preschool program. They are also used by professionals to provide information and guidelines to families during the transition period. These might be used based on the state level interagency agreements.

Limitations

Several limitations restricted the generalizability of this present study. The total number of participants (n=10) was modest, suggesting that additional research on this subject should consider a larger pool of participants. The study was also conducted with a restricted geographical location. The results of this study focused only on the mothers' perceptions of the transition process because the mother traditionally assumes the role of the primary caregiver. If fathers were asked to offer their perceptions, they might be able to provide a richer picture of the nuclear and extended family. Another limitation is the

mothers had to recall information from up to two years ago because of the span of time since the transition had been accomplished. Therefore, they may not have not recaptured an accurate account of the events that occurred. In addition, each case was different because of the length of time from first diagnosis to early intervention to dismissal from early intervention. The length of time these children had been involved in the early intervention system ranged from seven months to 34 months. In order to obtain accurate information, mothers should be interviewed right after their children transition. This study indicated the needs of the family unit should be considered when providing intervention strategies from the service providers.

Implications for Future Research

The results of this present study have several implications for future research for early intervention providers and families who have children with disabilities. Early intervention staff can use these interviews to help them understand the family's individual strengths and needs and to design interventions accordingly. The professionals need to be aware of the different concerns mothers and fathers might share about their child with a disability. Future research would benefit from a collection of data from several members within the family system. Research in this area would profit from a more specific and proactive effort to directly encourage fathers to participate. The severity of the child's disability might have a different impact on the transition process because of the types of services each child would need. Research would also be enriched by studies that focus on the different transition needs by parents of children with extensive and expansive needs.

The families, agencies and schools should make decisions benefiting all participants. All of these individuals need to work as a team and focus on the needs of the

child and the family. The ecological theory is important at this time, because when one of the systems change, all could affect the family and the agency. Professionals working with families in these situations need to be aware of the whole family situation when providing services. Service providers from both the sending and the receiving programs could be interviewed about the transition process along with the parents to see if there are any discrepancies in communication and in perception. It would also be advantageous to interview administrators from both sides of the service spectrum to see if their perceptions are the same as those who work directly with the families who are being provided services. Administrators usually work indirectly with the families and professionals, yet they need to be aware of any problems that exist.

Implications for Policy Makers.

Factors under IDEA, Part C to Part B include; IFSP to IEP, service coordination, diagnostic labels, and least restrictive environment. Other factors considered in the differences between these two programs include; location of services (home-based to center-based), provisions for services (Part C - cost; Part B - free), medical model to educational model, year long calendar to school year, service delivery (family-centered to child-centered), and evaluation procedures. These differences that exist between these two programs need some attention, especially in the rural areas.

Conclusion

The goal of Part C of IDEA was created to provide a seamless delivery system for transition services during the preschool years. An IFSP is developed which includes a transition plan. A conference needs to be held 90 days before the child turns age three and becomes eligible for early childhood special education. The transition plan must include

steps supporting the transition of the child. These steps include discussing all aspects of transition and intervention with parents, preparing the child for the transition, and communicating with the receiving school. When developing transition plans, school districts, service providers and parents determine what works best on an individual basis (Lerner, Lowenthal, & Egan, 1998).

Because transition involves moving a child from one system to another, communication becomes an essential component between the sending and receiving agencies and schools. Mothers did not perceive the transition process to be very formal or structured as suggested in IDEA, but they considered the transitions that occurred for their children to be positive. This may be due to the fact there was communication conducted between the professionals.

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APPENDIX A

Interview Guide

Thank you for letting me visit in your home today. As stated in the letter you received, I am looking closely at the parent's perceptions of the transition process from early intervention to early childhood special education. Stressors, coping skills, and supports during this process will be examined as well. I also want to know of any benefits or problems that may have arisen during this process. Anything that you tell me will be strictly confidential from both the new program staff and the early intervention staff. The reason I want to record this conversation is to gain an accurate account of what was being said by both of us.

1. First, please tell me about your child with special needs and your family?
2. What were your perceptions of early intervention services?
3. What type of information was offered, and how was the transition process explained to you? Who explained the process to you? What information would you have liked to receive?
4. What were some of the benefits you saw for your child and the family during the transition process?
5. What were some of the barriers you saw for your child and the family during the transition process?
6. What types of preparation activities did professionals assist you with during the transition process?
7. Is there documentation written on the IFSP that states any transition activities? If so, how are they stated? If not, did you inquire about these activities?
8. In what ways did you feel that you were treated as a partner in the transition process?

9. What were some of the major stressors (if any) that you can identify that occurred for your child and your family during the transition process?
10. Who were your formal and informal supports during the transition process for your child and your family?
11. What were some of the coping skills that helped you move through the transition process for your child and the family?
12. Did you have an opportunity to visit the receiving school? If so, how were you received? What types of procedures took place?
13. Tell me about the new preschool program, and how it has affected your child and the family?
14. Is there a difference between early intervention services and the preschool program?
Please explain the differences.
15. What are some ideas that you felt would be beneficial to new mothers going through the transition process?

APPENDIX B

Transition Flyer

TRANSITION STUDY

EARLY INTERVENTION TO EARLY CHILDHOOD
SPECIAL EDUCATION

CRITERIA

- Child must have a diagnosed disability, developmental delay or be termed at-risk
- Child must have been in an early intervention program
- Child must have transitioned within the last 18 months

REQUIREMENTS

- Interviews with the primary caregiver
- 3 interviews at a time and place convenient for you

BENEFITS

- Help families in the future
- Confidence to meet future transitions
- Provide your opinions about the transition process

If you are interested in participating in this study, you can contact Paula Hoover in Blacksburg at (540-961-6162). Participation in this study is strictly voluntary and confidential. A \$10.00 gift certificate to a local grocery store will be given for participation. Thank you.

APPENDIX C

Letter to the Mother

January 27, 1999

Dear Karen,

As you know from our telephone conversation, I am a doctoral candidate in Administration and Supervision of Special Education at Virginia Tech. The topic of my dissertation is "Mothers' perceptions of the transition process from an early intervention program to an early childhood special education classroom: Related stressors, coping skills, and supports". I will be asking you questions about the transition process that you and your family went through with your child.

I will be using a descriptive research design and will need to tape record the interviews so that I can remember what we talked about. There will be a minimum of 3 interviews. The first interview will consist of you talking about your child and family. Questions pertaining to the transition process will be the topic for the second interview. The third interview will consist of a phone conversation to verify what we discussed. Everything you tell me during the interview will be kept confidential. I will not use your name or any information that will identify you personally.

The information that you provide may be helpful for service providers to use when they are working with families who have children with disabilities during the transition process between the two programs. Taking part in this study is voluntary for you and will not affect your child's present program.

I appreciate your interest in this topic and your willingness to meet with me at your convenience. Per our phone conversation, our first meeting time, date, and place is:

I look forward to seeing you. Any documentation that you can share regarding transition would be beneficial. These may include IFSPs, IEPs, and letters of scheduled meetings. Please call me at (540)-961-6162 if you have any questions. Thank you so much for being a part of my research study.

Sincerely,

Paula J. Hoover

APPENDIX D

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants
of Investigative Projects

Title of Project: Mother's Perceptions of the Transition Process from Early Intervention to Early Childhood Special Education: Related Stressors, Coping Skills, and Supports.

Principal Investigator: Paula J. Hoover

I. The Purpose of this Research

You, as a parent, are invited to participate in a study which will provide you an opportunity to express your opinions about the transition process from early intervention to early childhood special education for your child with disabilities. Issues of related stressors, coping skills, and supports will be further explored. One purpose of this study is to gain an understanding of the ways parents perceive this transition process. Another purpose for this research study is to help create a seamless system for children from birth through five. This study will involve 10 participants.

II. Procedures

The procedure to be used in this study will include in-depth interviewing. You will be asked to be available for up to three interviews. The anticipated time for the first two interviews will last from 1 to 2 hours. The last interview will consist of a follow-up phone call to clarify some of the information that will be collected to ensure accuracy.

You will be asked to share any kind of documentation on the transition process. These will include copies of the IFSP, IEP, and other letters that informed you of meetings being held about the transition process for your child.

This research will take place at a convenient time and place, one in which the participant feels comfortable.

III. Risks

You may be uncomfortable at times discussing the issue of transition for your child with disabilities. If at any time you want to discontinue the interview or withdraw from this study, please indicate that to me.

IV. Benefits of this Project

Your participation in this study will provide information to other parents and professionals, both in early intervention and the school system, about the transition

process for children with disabilities. No guarantee has been made to encourage you to participate in this study. Discussing the issues of transition from the parent's perspective may assist others in providing a smoother transition for all those involved.

If you are interested and at your request, you may contact me at a later time for a summary of the results of the study.

V. Extent of Anonymity and Confidentiality

All responses made by you as a participant in this study will be kept strictly confidential. Your child's current program will not be affected. At no time will the researcher release the results of the study to anyone other than the individuals working on the project without your written consent. The information that you provide will have a pseudonym which will identify you during the analysis and any written reports for this study.

The interviews will be audiotaped to gain an accurate account of the discussion. The tapes will be secured only by Paula J. Hoover. She will be the only person who will listen to the tapes and transcribe them. The tapes will be erased following the study.

VI. Compensation

You, as a participant will be compensated for your time. A \$10.00 gift certificate to a local grocery store will be presented to you after the interviews have been completed.

VII. Freedom to Withdraw

You are free to withdraw from this study at any time without penalty.

VIII. Approval of Research

This research project has been approved, as required by the Institutional Review Board for Research Involving Human Subjects at Virginia Polytechnic Institute and State University, by the Department of Educational Leadership and Policy Studies.

IX. Subject's Responsibilities

I voluntarily agree to participate in this study. The following responsibilities are to meet with Paula J. Hoover a minimum of two times at a convenient time and place. If I am unable to keep my appointment with Paula, I will call her.

X. Subjects Permission

I have read and understand the Informed Consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

If I participate, I may withdraw without penalty. I agree to abide by the rules of this project.

Signature Date

Should I have any questions about this research or its conduct, I may contact:

Paula J. Hoover
Investigator

540-961-6162
Phone

Diane N. Gillespie
Faculty Advisor

540-231-9713
Phone

H. T. Hurd
Chair, Institutional Review Board
Research Division

540-231-5281
Phone

APPENDIX E

Coding Categories

- 100 **Talking about my Child**
- 101 Pregnancy/Delivery/Infancy
- 102 Initial Diagnosis
- 103 Health Concerns
- 104 Living with a Disabled Child
- 105 A Mother's Love

- 200 **Understanding Early Intervention**
- 206 Referral and Eligibility
- 207 Community Resources
- 208 Insurance Issues
- 209 Home-Based Instruction and Staff

- 300 **Transitioning from Part C to Part B**
- 310 Sending and Receiving Professionals
- 311 Parental Involvement
- 312 Service Delivery Options
- 313 Separation Anxiety
- 314 IFSP Transition Statements

- 400 **Moving into the Preschool Setting**
- 415 Educational Model
- 416 Scheduling
- 417 Socialization for the Child
- 418 Center-Based Instruction and Staff

- 500 **Concerns of Mothers**
- 519 Stressors
- 520 Support Networks
- 521 Coping Skills

APPENDIX F

Mothers Individual Responses

1. Karen - pages 65, 69, 71, 76, 78, 80, 83, 87, 88, 90, 91, 94, 96, 98, 100, 103

2. Christine - pages 65, 67, 69, 71, 74, 76, 78, 80, 83, 86, 87, 89, 91, 92, 95, 96, 98, 100, 103

3. Elizabeth - pages 65, 68, 74, 77, 78, 80, 84, 86, 90, 92, 93, 95, 96, 98, 100, 102, 103

4. Susan - pages 65, 68, 70, 71, 74, 77, 79, 84, 86, 87, 90, 93, 97, 98, 101, 103

5. Judy - pages 70, 79, 81, 84, 86, 88, 90, 93, 97, 99, 101, 104

6. Debbie - pages 66, 70, 72, 75, 85, 88, 89, 90, 95, 99, 101, 104

7. Roxanne - pages 66, 71, 72, 75, 77, 84, 90, 93, 95, 99, 101, 104

8. Carol - pages 66, 68, 70, 73, 75, 81, 85, 90, 97, 99, 102, 104

9. Tracy - pages 67, 73, 75, 79, 81, 85, 89, 90, 94, 99, 102, 104

10. Alice - pages 67, 71, 76, 82, 90, 94, 99, 102, 104

APPENDIX G

Vita for Paula J. Hoover

Paula J. Hoover

Home Address

113 Crooked Pine Dr.
Sanford, Fl. 32773
(407) 302-7816

Office Address

400 East Lake Mary Blvd.
Sanford, Fl. 32773
(407) 320-7859

Educational Background

- 2001 Ed.D. in Administration and Supervision of Special Education, Virginia Polytechnic Institute and State University, Blacksburg, VA.
- 1998 Ed.S. in Administration and Supervision of Special Education, Virginia Polytechnic Institute and State University, Blacksburg, VA.
- 1995 M.S. in Pre-K Handicapped, Nova Southeastern University, Ft. Lauderdale, FL.
- 1985 B.S. in Special and Elementary Education, Slippery Rock University, Slippery Rock, PA.
- 1983 A.A. in General Studies, Butler County Community College, Butler, PA.
- 1981 Diploma, Freeport High School, Sarver, PA.

Work Experience

- 1999 - present Staffing Resource Specialist in Seminole County, FL.
- 1996 - 1999 Full-time Graduate Assistant and Doctoral Student in Administration and Supervision of Special Education at Virginia Polytechnic Institute and State University.
- 1990 - 1996 Special Education Teacher of the Educable Mentally Handicapped in Orange County, FL.
- 1985 - 1990 Special Education Teacher of the Educable Mentally Handicapped in St. Lucie County, FL.

Professional Associations

- Council For Exceptional Children - Secretary of Local Chapter (2000 - present)
- CEC/Division for Early Childhood
- American Educational Research Association
- Professional Association of Staffing Specialists (1999-present)

Creative Products

Dissertation:

Hoover, Paula J. "Mother's Perceptions of the Transition Process from Early Intervention to Early Childhood Special Education: Related Stressors, Supports and Coping Skills". Published dissertation, Virginia Polytechnic Institute and State University, Blacksburg, VA., 2001

Thesis:

Hoover, Paula J. "Increasing Parents' Awareness of Strategies for Use with Young Children with Special Needs Through a Parent Program". Unpublished master's thesis, Nova Southeastern University, Ft. Lauderdale, FL., 1995.

Papers Presented at Meetings

"Parents' Perceptions of the Transition Process from Early Intervention to Early Childhood Special Education: Related Stressors, Supports, and Coping Skills" Poster session presented at the CEC Annual Convention, Charlotte, N.C., April 14-17, 1999.

"Transition Planning from Early Intervention to Early Childhood Special Education for Parents of Children with Disabilities" Seminar presented at the Virginia Early Childhood Education Conference, Roanoke, VA., March 11-13, 1999.

"Parents' Perceptions of the Transition Process from Early Intervention to Early Childhood Special Education: Related Stressors, Supports, and Coping Skills" Paper presented at the Eastern Educational Research Association Conference, Hilton Head, S.C., February 24-27, 1999.

"Crossing Boundaries: Integrated Service Systems" Group presentation at the Inquiring Voices Graduate Research Conference, VPI & SU, Blacksburg, VA., March 27, 28, 1998.

"Research Reform in the Preparation of School Leaders" Group presentation at the Eastern Educational Research Association Conference, Tampa, FL., February 25-28, 1998.

"Increasing Parent's Awareness of Strategies for Use with Young Children with Special Needs Through a Parent Program" Paper presented at the VA. State Federation CEC, Fredricksburg, VA., February 28-March 1, 1997.

References

Dr. Diane Gillespie
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(407) 320-0206

Dr. Robert Allen
Elementary School Principal
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Orlando, FL. 32804
(407) 354-2630

* Additional References are available on request.

Epilogue

Because this study was conducted two years ago, I followed up by contacting each mother to see what had transpired since we last spoke. After several attempts, I could not contact two of the mothers. One of the mother's phone was disconnected. The mothers that were contacted provided me with some information on the lives of themselves and their children in the educational setting. Below are the responses given to me by the mothers.

1. Karen was contacted several times and messages were left on her answering machine, but there was never a response.
2. Christine was contacted, and stated that her son was still attending the day care center and would continue there for the remainder of the 2000-2001 school year.
3. Elizabeth was contacted and stated that her son had attended kindergarten (regular education classroom) in the 1999-2000 school year. He would be attending first grade for the 2000-2001 school year.
4. Susan was contacted and stated that her son attended kindergarten for the school year 1999-2000. She was moving to another state because she was not happy with the "full-inclusion" environment that was provided for her son. He had nine different aides working with him that year. He would be attending first grade in the new place for the 2000-2001 school year.
5. Judy was called and the phone was no longer in service, and a forwarding number was not provided. Her family may have moved back up north to be closer to her extended family.

6. Roxanne was contacted and was working full-time at Head Start in the community as of September, 1999. Her son was in kindergarten for the 1999-2000 school year and would be attending kindergarten again for the 2000-2001 school year.
7. Debbie was contacted several times and messages were left on her answering machine, but there was never a response.
8. Tracy was contacted and stated that her son was in the preschool program again for the 1999-2000 school year. He would be attending kindergarten for the 2000-2001 school year.
9. Carol was contacted and stated that her daughter was in kindergarten for the 1999-2000 school year and would be attending a Special/Regular Education class for the 2000-2001 school year.
10. Alice was contacted and stated that her grandson would continue in the preschool program for another two years.