

2006

How mothers orchestrate their engagement in an early intervention program

Patricia Eileen Brennan

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HOW MOTHERS ORCHESTRATE THEIR ENGAGEMENT
IN AN EARLY INTERVENTION PROGRAM

by

Patricia Eileen Brennan

Thesis

Submitted to the Occupational Therapy Program

School of Health Sciences

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Occupational Therapy

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June 10, 2006

Ypsilanti, Michigan

DEDICATION

To my family...mere words cannot capture the gratitude I feel for the love, support, and patience I have received from you over these last four years. I could not have done it without you. To Terry, my husband, I truly appreciate the patience and faith you have shown as I worked my way through this thesis. Your gentle critiques of my writing and making me a hot breakfast after a long night helped me stay focused and motivated. To Curran and Terranne, my children, you have always filled me with awe as your lives have unfolded. You have tolerated my distractions over the past four years and gradually accepted that I was going to school even though I did not have to.

To the mothers...the gentle ladies who gave so willingly of their time, their thoughts, their heart. You opened your doors to me and told your stories candidly and honestly. I hope I did justice to your words and gave power to your voices.

ACKNOWLEDGEMENTS

This thesis is a culmination of four years of graduate study at Eastern Michigan University. Throughout that time I encountered outstanding educators from various fields of study. However, I would like to specifically acknowledge the people who had a direct influence on my education, research, and writing reflected in this thesis.

Elizabeth Francis-Connolly, PhD, OTR, School of Health Sciences...my mentor, my taskmaster, my cheerleader. Initially, through coursework she guided me through the initial steps for developing my thesis proposal. It was an unexpected gift to have her as my thesis advisor. She has done extensive research on the topic of mothering, and I benefited greatly from her expertise. Her feedback was always timely, direct, and concise. She made an overwhelming task manageable, her guidance kept me on track, and it didn't hurt a bit.

Ruth Hansen, PhD, OT, FAOTA, Professor Emeritus...she was there with the first attempt and kept after me for a second attempt. Her enthusiasm for occupational therapy remained constant over the years that I had the privilege to learn from her. She is greatly respected by her colleagues for her knowledge base, ethical integrity, and editing capabilities. It is an honor to have her involved as I finish my degree.

Valerie Howells, PhD, OTR, Associate Professor, School of Health Sciences...her enthusiasm for qualitative research inspired me to give voice to the mothers' stories. As my professor she encouraged, and required, me to read, read, read. She helped me to question stereotypes and look beyond them to see the person. I tried to follow her mantra of keeping it, "a nice, neat little project."

Judith Olson, PhD, OTR, Associate Professor, School of Health Sciences...she expanded my vision of occupational therapy, but more importantly my vision of a mother's

role. My first course for this degree was Occupational Science, taught by Dr. Olson. Her approach and perspective made me completely re-evaluate how I functioned as a therapist. She challenged me to write, a skill I did not feel was my strong point. Her willingness to share her knowledge provided me with the confidence to pursue my interest in the mothering role as a research topic.

Valerie Polakow, PhD, Professor, Teacher Education...a professor well worth coming on campus weekly to learn from. She introduced to me the tools to be used for conducting qualitative research. Her exercises for observation, coding, and delineating “meanings” provided the direction for me to follow in my own research. Additionally, her approach to qualitative research inspired me to seek out the voices of society’s most influential but often unrecognized members, mothers.

Dorothy Scott, Program Supervisor, Early Intervention Program, ... my supervisor for many years. We have seen the program grow from 17 staff members to more than 65 members. We have seen procedural changes resulting from legislative mandates. However, the focus on families as the context for a child’s development has remained unchanged. Without her support and assistance in obtaining approval from administration, this research study would not have come to fruition.

To my co-workers...they exhibited faith and generosity in sharing their “families” with me. My co-workers are well respected for their diligence at work, ability to establish and maintain relationships with families, and professional integrity in their day-to-day work performance. Together, we have shared the joys and frustrations of working in a community-based program with families of young children experiencing developmental delays.

ABSTRACT

A family-centered approach was espoused in IDEA Part C as the context for service to families with young children experiencing developmental delays. A phenomenological inquiry was conducted to explore how mothers of young children with disabilities orchestrate their engagement in an early intervention program, and to identify factors that support their participation. In-depth interviews were conducted with five mothers of children enrolled in a community-based program located in an urban area. An over-arching theme addressing the need for service providers to be “In my reality” emerged. Sub-themes highlighted needs of the mothers to understand their child’s condition, promote their child’s development, and have valued experiences/opportunities for their child. The mothers described how positive and negative informal and formal supports either enhanced or constricted their engagement. The study emphasized how family-centered programming should be the service mode, embracing and facilitating each family’s reality, and not just a stated philosophy.

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Chapter 1: Introduction

Problem Statement and Background

The birth of a child is a welcomed event in most women's lives. It is also a life-altering event not only for the mother but also the family. New roles are assumed, routines are changed, and accommodations made (Francis-Connolly, 2000). Each step of development is greatly anticipated. Families' lives are altered further when the child is diagnosed with a disabling condition or a developmental delay. How is the family affected? What services are available to them, or their child, and are they aware of the services? How willing, able, or desirous are parents to seek assistance outside of their family?

In an effort to provide early detection of developmental delays and assist parents in obtaining the services needed to ensure their child's development, federal legislators passed Part H of the Individuals with Disabilities Education Act (IDEA) in 1986 (Dunst, 1999). In 1997, Part C (Amendments to IDEA) expanded services to children at risk for developmental delay, ensured a family-centered approach, and included services for the child *and their family* under provisions for early intervention services (National Early Intervention Longitudinal Study, 2004). Early intervention services are provided through the first three years of a child's life, and children may enter at any age within that time. According to the National Early Intervention Longitudinal Study (NEILS, 2004), there is variability in the age when children begin receiving services. The study documented that 38% of participants enter within the first 12 months of life due to a diagnosed condition or were considered at risk for developmental delay. A third of the population receiving services did not enter until after the age of two years. Ongoing monitoring by the Office of Special Education Programs (OSEP) indicated notable variability within and between states in their provision of mandated

services (NEILS, 2004). It is unclear if the factors related to variability in service provision are owned solely by the programs providing the services (program design, personnel approach, and/or administrative policy) or shared by the target population (families).

Justification and Significance

Programs providing early intervention services have the common goal of ensuring a child's healthy development and recognize the critical role the parent-child relationship plays in a child's development (Dunst, 1999; Gomby, Culross, & Behrman, 1999; Mahoney & Bella, 1998; Mayer, White, Ward, & Barnaby, 2002; Wagner & Clayton, 1999). However, parental engagement in early intervention services is not a given. McNaughton's (2000) synthesis of research studies on the outcomes and processes of home visits by public health nurses noted that the establishment of a collaborative relationship with a client was built on the nurse's ability "to secure and maintain entry into the client's situation" (p. 409). Gomby et al. reviewed six studies of national home programs and found all had difficulties enrolling and retaining families. They noted that the attrition of families during the studies might have contributed to the modest magnitude of benefits found. While early intervention services are mandated for eligible children and their families, the families are not mandated to accept the service.

Purpose of Study

The following study was carried out in an attempt to understand in greater detail the factors that contribute to a mother's engagement in an early intervention program. I chose the perspective of the mothers, as they tend to be the caretaker who is most often present for both in-home and center-based programming at the site of the study. The view that a mother is an

agent of change for her child (Mayer et al., 2002), is connected with a principle of Elder's (1998) life course theory:

... that individuals construct their own life course through the choices and actions they take within the opportunities and constraints of history and social circumstances. (p. 4).

As an agent of change, how do mothers construct or "orchestrate" their engagement in early intervention services? The idea of "orchestration" can be defined as "...complex processes that require anticipation, forethought, sifting of information, decision-making, and a coordinated response" (Larson, 2000, p. 270). The purpose of this phenomenological study is to illuminate what is anticipated, felt, thought, and done by a mother in the process of her initiating and maintaining engagement in early intervention service with her young child.

An Ecological Framework

The factors contributing to a mother's participation in early intervention services are complex, multifaceted, and dynamic. A systematic approach for organizing the factors may be gleaned from the framework proposed by Bronfenbrenner (2005) in his bioecological perspective on human development. He builds on his ecological theory of human development (Bronfenbrenner, 1979) by describing the concept of proximal processes as "the primary engines of development" that may vary in form, power, content, and direction, due to the combined factors of the person, environment, outcomes being considered, and changes occurring over time (p. 6). He also details a chronosystem model, in that "its design permits one to identify the impact of prior life events and experiences, singly or sequentially, on subsequent development" (p. 83).

The multidimensional transactions taking place within and around a mother's participation in early intervention service is difficult to present in narrative form. An attempt

is made to examine each factor of interest (person, process, context, and time) by detailing each factor's influence on the phenomena as evidenced in research. The "nested structures" of Bronfenbrenner's (1979) ecological framework for human development was used to organize the literature review. His ecological framework presents four levels of environmental influence that are "nested" within an individual's experience. First, a person's immediate environment (microsystem); second, the relationship between single settings in which the individual is involved (mesosystem); third, settings having an indirect influence on the person (exosystem); and fourth, the ideology and organization of social institutions within an individual's culture (macrosystem). The interconnectedness experienced within and between the structures is an integral component of the framework. An appreciation for the impact these environmental influences may have on a mother's ability to participate in an early intervention program will be examined in detail.

Occupation Therapy Perspective

The field of occupational therapy has focused on the construct of occupation or occupational behavior as both an outcome and a mode of intervention. The profession's domain and process is centered on the performance of daily activities through the engagement in meaningful occupations that support an individual's participation in their relevant context or contexts (AOTA, 2002). The Occupational Therapy Framework specifically states that engagement in an occupation involves subjective (emotional and psychological) and objective (physically observable) aspects of performance (p. 611). Occupational behavior as defined by Yerxa, Clark, Frank, Jackson, Parham, Pierce, Stein, and Zemke (1989) is the "active engagement in occupation which includes (1) an act of the

will, (2) an experience of engagement, and (3) a planning and organization of resources” (p.19).

The Ecology of Human Performance (EHP) framework (Dunn, Brown, & Youngstrom, 2003, Dunn, Brown, & McGuigan, 1994) for occupational therapy practice considers the relationships between people, context and task, and how their dynamic transactions impact a person's occupational performance. The framework incorporates theory from environmental psychologists' research and emphasizes context as a key variable in the evaluative and intervention process. Simply put, it states that, "...performance cannot be understood outside of context" (Dunn et al., 1994, p. 598).

The following study was done through a theoretical lens that combines Bronfenbrenner's bioecology theory of human development and occupational therapy's focus on occupational behavior. Mothering is viewed as an occupation (Francis-Connolly, 2000; Larson, 2000; Lawlor, 2004) requiring a wide range of skills, incorporating a variety of roles, and continuing over the life span. Francis-Connolly (2000) found, in her research examining two stages of mothering, that preschool mothers were "immersed in motherhood," meeting the many demands of young children and tended to "enfold activities" into their daily routines, thus addressing care-taking, nurturing, and teaching activities. How mothers of young children with disabilities orchestrate their engagement in an early intervention program into an already demanding schedule warrants further investigation.

Chapter 2: Literature Review

A mother of a young child with a disability or developmental delay is evolving and developing in her mothering role. The following literature review presents one view of what is currently known about the opportunities and constraints of the personal, social, and temporal circumstances a mother may experience within the domain of early intervention services. In the following section, “person” refers to the mother, the service provider, and the child as contributors to the phenomena to be investigated. The term “process” addresses aspects of active engagement in both the mother-child relationship and the parent-professional relationship. The quality of these relationships may be viewed as outcomes of a mother’s participation in services. A third outcome would be facilitation of her child’s development. The third factor to be examined, “context,” incorporates the legislative (exosystem), social (macrosystem), and a program’s (mesosystem) conceptualization of family-centered care, in addition to the natural setting (microsystem). The final factor considered, “time,” is examined also through Bronfenbrenner’s (1979) “nested structures” and personal perspectives.

Person

Roggman, Boyes, Cook, and Jump (2001) found that variations in families’ responsiveness to service providers may have been related to their own feelings about parenting and/or their feelings about the service provider. McCall and Schneck (2000) reported parental satisfaction with clinical therapy services for their children, but parents were desirous of a more active role in their child’s therapy. Olson and Esdaile’s (2000) phenomenological study of two young mothers of children with disabilities identified an overarching theme of “What I got to do” described by the mothers as being “what is

required” to take care of their child and normalize their life. They viewed their home environment as isolating and felt the need to have society recognize and value their “work” as young mothers. Research has begun to document the complexities of mothering; however, the valuing of what a mother may already be doing for a child with a disability has not been thoroughly explored in the literature.

The literature suggests that a mother of a young child with a disability will take on unique roles to meet the needs of her child. Lawlor (2004) outlined the need for mothers to act as a “cultural broker” (making connections between the family and clinic or programs); work to have professionals “see” their child and understand the “developmental pathway” they have charted for their child; and advocate for the appropriate care of their child without being viewed as a bad parent. Additionally, Dunst (1999) pointed out that a cultural bias exists in which parents from low socioeconomic status are held up to models of parental involvement that are based on middle- to upper-class patterns of parental engagement. He indicated that parents with decreased resources tend to make decreased commitments to early intervention programs.

Dunst (1999) postulates there is a conceptual and empirical relationship between a child’s development and three factors: social supports available to parents; personal well-being of the mother; and the parenting style employed by the parents. Larson (2000) undertook a phenomenological study of six mothers of children with disabilities and the relationship between their sense of well-being and how their orchestration of daily activities is affected. Results indicated that the mothers’ sense of well-being was enhanced by a sense of control in life, a positive evaluation of their situation (including their child’s progress), and the optimism gained from “embracing the paradox.” Embracing the paradox was

demonstrated by “embracing the child despite the disability, ...simultaneously rejecting the disability, continuing to aspire to a more typical experience of mothering” (Larson, 2000, p. 273). The research indicates a need to further understand the emotions, experiences, and attitudes held by mothers regarding early intervention programming.

Process

Engagement in early intervention services involves, at a minimum, three people: the child, the parent or caregiver, and the service provider. Mayer et al. (2002) reported that therapists see themselves as the change agent for parents, and parents as the change agent for their child. This view aligns with the EHP framework's dynamic transactional nature (Dunn et al., 1994) by emphasizing that a parent's ability to use environmental supports and opportunities, along with their current skills, enhances their performance as change agents for their child.

Part C (Amendments to IDEA) not only acknowledged the pivotal role parents hold in their child's development (Gomby et al., 1999) but recognized the need to incorporate parents as active participants in the assessment of, planning for, and implementation of services that would address their child's needs. Mahoney and Bella (1998) found significant variability in the emphasis of family-centered components of service among 36 programs across five states. Dunst (1999) points out that recent funding changes in Part C have promoted greater professional services (reimbursable) and fewer of the services that support the parent and make a real difference in families (parent education and service coordination).

Maternal engagement. A mother's engagement in early intervention services may be viewed as an occupational behavior or, in the bioecological view, a proximal process.

Bronfenbrenner (2005) notes:

...human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects and symbols in its immediate external environment. (p. 6).

Mayer et al. (2002) described the transactional dynamic between the parent-child relationship and the child's development as noted by therapists in early intervention. Positive interactions led to increased attachment behaviors, which promoted nurturing responses by parents and development in the child, enhancing interactions between the two. Larson (2000) identified eight thought processes used by mothers in their planning of child-sensitive occupations and their own daily occupations: planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting, and meaning making. The last two processes involve both emotional and mental components that assist in the coming to terms with a child's disability; accepting the altered lifestyle being imposed on them; and finding hope, a new perspective, and love for their child. The thought processes were seen as structuring and supporting the occupations selected by the mothers. However the thought processes were "constrained and afforded by...personal and cultural values and the personal resources available within family's ecocultural context..." (p. 273). Ecocultural factors included family finances and other family members' participation in household and childcare tasks.

Collaborative partnership. Enhancement of the parent-child relationship is considered to be the desired outcome of early intervention services when it does not occur naturally within the family context, or when a child's development is compromised by a disabling condition. The establishment of a collaborative relationship with a home visitor or service provider is also a reciprocal interaction. McNaughton's (2000) study delineated a four-step process in the home visit relationship: pre-entry, entry, working, and termination. During each step of the process the nurse and parent have clearly defined roles, but is clear

that the parent has control over providing entry to and maintaining the “relationship context.” The privacy inherent to a family’s home acknowledges the need for a trusting relationship to be established if a service provider is to be effective (Roggman et.al., 2001).

Goetz, Gavin, and Lane (2000) proposed that as a cooperative partner, a parent would display similar verbal interactions as the service provider. Their research to validate an assessment tool found that only 3 of the 11 possible verbal interactions categories discriminated between family-centered (praise/encouragement and giving of information) and nonfamily-centered (silence) sessions. Lawlor and Mattingly (1998) warn that the assumption of an equal relationship between parents and therapists would not necessarily reflect the uniqueness of each person’s perspective. Family members frequently view themselves as the “voice of the child” and are sensitive to the “hierarchy of partnerships” (collaboration viewed as compliance), fragmentation of service (multiple service providers), and the infraction of social contracts by service providers. Lawlor (2004) emphasized further that demands are placed on both partners in a collaborative relationship, as cultural views of family, disability/illness, and health-care may impact each other’s perspective. Survey results reported by McCall & Schneck (2000) discussed the concept of a “bi-directional communication gap” existing between parents and therapists when one party “doesn’t tell” and the other “doesn’t ask.”

Context

Family center approach. The context of early intervention services is embedded in a family-centered approach. The NEILS (2004) defines family-centered practices as

...those in which families are involved in all aspects of the decision-making, families’ culture and values are respected, and families are provided with accurate and sufficient information to be able to make informed decisions (p. IV-34).

Implementation of this approach is evidenced in the outcome of a collaborative relationship between parent and service provider. Mahoney and Bella (1998) examined the effectiveness of this approach with no significant differences found in family or child variables. However, they questioned consistency in implementation of family-centered practices across programs and service providers (intensity of service provision, professional preparation of service providers, and evaluation of how services affect families), in addition to several design weaknesses, as possible reasons for their findings. A stated design limitation was in the accurate measurement of the family-centered service phenomena. Their recommendation was for future research to “devise better measures and procedures for assessing the impact of this agenda” (p. 92). Further research is also needed to provide in-depth parental perspectives of a family-centered service approach to programming.

The application of three assumptions from the EHP framework (Dunn et al. 2003), emphasizing the uniqueness and dynamics of a person and their context, are presented to clarify the implementation of a family-centered approach. First, it is not possible to understand a family or mother without understanding their context (physical, social, cultural, temporal). Second, the transaction between a mother and her context determines a mother's performance range, e.g. parent-child relationship, collaborative partnerships, and the engagement in early intervention services. Third, it is through the engagement of these tasks that a mother and her contexts transact and influence each other.

Natural environments. Provision of services within a child's natural environment is a Part C mandate and may include home visits or visits to day-care settings. Home service programs have received extensive study (Gomby et al., 1999; Mahoney & Bella, 1998; McNaughton, 2000; Roggman et al.; 2001) with a focus on their processes and outcomes

reflecting the program's purpose. Home visiting programs provide the unique perspective of families in their natural environments and are usually the best way to reach a family (Gomby et al., 1999). However, Gomby et al.'s research indicated that once parents were enrolled in a program, they received only 38-56% of the services they were eligible for. The decreased number of visits resulted from a combination of factors. Limits in programs' designs included staff turnover, inflexible schedules, and policies regarding hard-to-reach families. Factors relating to decreased family engagement were level of interest, chaotic family life, and other time commitments.

Time

Elder (1998), in his discussion of life course theory, outlined how changes in today's world can influence a child's world, e.g. downsizing of the job market creates family disruption and hardship, expanding levels of economic inequality, changes in the welfare system, and the "re-design of schools and learning through information-age technology." One cannot be unaware of how these continuing changes over time can impact a family and a child's development. Current legislation regarding provision of early intervention services has evolved over time in conjunction with research regarding child development, parent-child relationships, and family-centered practices (Mahoney & Bella, 1998). Professional service providers may not have received instruction on these relevant topics in their initial training (Lawlor & Mattingly, 1998), which may contribute to the variability of service provision. Some professionals have found their own approach to interventions have changed from being "directive" to "facilitative" over time and through experience (Mayer et al., 2002). Professionals need to be aware of changes in social policy, in addition to legislation, and their impact on the services they are providing.

Within the family context Dunn et. al. (2003) noted that temporal considerations include the chronological development of the child, family members' placement within the life cycle (career, parenting, life phases), and the health status of the child and family members (continuum of disability, acuteness of injuries or illness, etc.). In their discussion of the relationship between parents and therapist, Lawlor and Mattingly (1998) point out another variance in perspective, as each are working within a different time frame. The family's time frame with the child is life-long, rather than the short-term goal oriented approach of therapists.

Time is also experienced via daily routines as Yerxa (1989) described:

humans...make conscious decisions about what they will and will not do and sequence their choices in time so that, on each day, a round of activities is orchestrated. The net effect is engagement in a daily blend of occupations... (p. 18).

A study of how mothers construct daily routines for their children to promote their self-care skills (Kellegrew, 2000), found that mothers made accommodations for their child's current skill level and made choices of what to focus on based on what they anticipated their child would need in future situations (e.g.: preschool). Time constraints of the mother's schedule also impacted daily routines. Therapists were advised to be aware of these factors when planning interventions, and that it is important to assist mothers in accurately assessing their child's abilities and "envisioning" their child's potential.

Summary

A general consensus of the research states that parents should be provided with a spectrum of services to meet their needs and concerns regarding their child (NEILS, 2004; Dunst, 2000; Gomby et al.,1999; Mahoney & Bella, 1998). It is apparent that further research is needed to determine how best to facilitate parental engagement in the services

available to them. The majority of research on parental engagement is conducted from the perspective of service providers or objective researchers. Research regarding parental perspectives tends to draw on surveys, interviews regarding satisfaction with services (process and outcomes), and objective rating scales. Qualitative studies of the mothering role have provided a closer look and richer experience of what mothers are truly dealing with in their daily lives. The next step is to explore how mothers orchestrate their participation in a community-based early intervention program in an effort to meet their child's needs.

Governmental agencies will continue to monitor and assess the implementation of early intervention services between and within states. At the individual program level it is essential to address the individual experiences of each family. Through the exploration and documentation of families' stories; support can be established for the provision of relevant programming, enriched research opportunities, appropriate education of service providers, and valuable input for future legislation. This study hopes to contribute to this base of support for families by exploring in depth how mothers orchestrate their engagement in an early intervention program.

Chapter 3: Methods

Situating the Researcher

As an occupational therapist working in the arena of early intervention for a large urban school district, I have provided in-home and center-based therapy for children with special needs previous to the inception of IDEA Part H. Initially and currently, the program functions under state regulations for special education service requiring a specified level of disability for eligibility. Inherent to this approach is the focus on a child's deficit functioning. Although Part H mandated a family-centered approach, implementation of programming varied little except for the inclusion of an Individualized Family Service Plan (IFSP). Through the provision of in-home therapy, it became apparent to me the role that mothers and family members have in their child's development. Additionally, as I experienced motherhood myself, I began to truly appreciate the direct impact on personal time and energy having a child produced.

The development of parent-professional relationships tended to evolve, with frequent variations dependent on parental needs and/or concerns. As the relationships strengthened, personal stories about the joys and pitfalls of parenting were shared by each of us. However, a medical model approach, with therapist as expert, continued to hold sway over the parents and me. My initial professional education, more than twenty years ago, was embedded in the traditions of the medical model. As a therapist, my goal was to help patients become functional by addressing their area of dysfunction. Many of the parents I work with also receive services through local medical agencies and do not delineate between rehabilitation-based and educational-based therapies.

The initiation of graduate studies has provided me with the increased skill at assessing and working with children and families in context. This was gained via close examination of the common characteristics and unique variations interwoven within individual families. I also gained greater appreciation for the spirit of Part C (Amendments to IDEA) by expanding my perspective to encompass both the family and child as co-clients, and recognizing the parent as the agent of change for the child.

The review of research indicates larger studies sampled parents/caregivers, while the more detailed qualitative research focused on mothers. Through my current position I have interacted with fathers, extended family members, foster parents, and other caretakers, but most frequently with mothers. Having worked closely with mothers over the years I believe will provide me with access to the stories they have to tell. My experience in home-based programming has emphasized the need for respecting another's home, the importance of personal consideration and a worthwhile purpose when asking for another's time, and the necessity of confidentiality and empathy in establishing a trusting relationship. Additionally, the professional and personal respect I share with co-workers facilitated connections to potential participant mothers (for the study) whom I had not worked with.

Design

Qualitative research investigates the everyday experiences of humans, their thoughts, beliefs, attitudes, and actions. These experiences occur within the natural environments in which people exist. An experience cannot be viewed separately from the context of the person(s) involved and their environment, for each contributes to its reality. Yet the perception of this reality is a subjective experience where "knower and knowledge are interrelated and interdependent" (Depoy & Gitlin, 1998, p. 27). Creswell (1998) points out

in his discussion of ontological issues, or the nature of reality, that individuals in a research situation construct their own reality. It becomes the researcher's responsibility to present the diversity of perspectives accurately through meaning statements and reflective themes that incorporate words from informants' quotes.

Following a holistic philosophy, a phenomenological study was undertaken to explore the essence of mothers' engagement in early intervention programming. This research methodology seeks to discern the meaning (Glesne, 1999) and value individuals perceive through their lived experience of an identified phenomenon (Creswell, 1998). Essential to this approach is the researcher's ability to set aside his/her own prejudgments; participants' descriptions of their "lived experiences"; and an analytical process that evolves from meaningful statements to thematic clusters; and ultimately a thorough description of the "essence" or unifying meaning of the phenomenon (Creswell, 1998).

The following investigation explored the meaning that mothers attribute to early intervention services and how it supports, or does not support, their engagement in the program. It is believed that there are social, cultural, and psychological factors that influence their engagement, in addition to the needs of their child. Findings provide insight into the expectations that mothers of children with disabilities have for community-based services. An in-depth perspective of how mothers view "family centered services" contributes to the enhancement of program planning and the education of service providers.

Participants

Early intervention services cover a variety of options, and early intervention programming can be formatted in a variety of ways. For the purposes of this study, the program for which I work was selected due to my familiarity with the format and the

accessibility I have established. The program's mission statement incorporates the basic beliefs that each family is unique, individual differences are respected, and the promotion of trust and respect is necessary for partnerships between families and staff.

The program provides in-home visits twice a week for children under the age of two years. A child's Individualized Educational Plan (IEP) will identify the recommended service providers, in addition to goals and objectives for the child's program. The primary service provider is a certified teacher, with support service provided by an occupational, physical, or speech therapists. Occupational therapists tend to provide the second visit in the home for children under the age of two due to primary concerns in the areas of sensory-motor processing and the development of functional skills. At the age of two, a child's program is modified to include one weekly home visit and one weekly session at our center (center-base) for a parent-child playgroup. Occupational therapists are active in the planning and implementation of activities within this group setting.

The program is affiliated with a large, Midwestern, urban school district that includes mothers from varied economic, social, and cultural backgrounds. Economic and time limitations were inherent to the boundary setting of the study; thus, achieving a representative sampling of demographic factors was not ensured (See Tables 1 and 2). The five participants ranged in age from 22 to 41 years. Three of the mothers were African-American, one was Caucasian, and one had immigrated from Africa. Three of the women were married, two were single mothers, and all had two or more children. Educational levels spanned from a vocational technology program graduation or high school diploma to three years of college. Three of the mothers had stopped working to provide care for their child

with special needs, and two mothers had attempted part-time work at some point in their child's first years of life.

The establishment of good working relationships between my co-workers and me provided access to mothers with whom I had minimal to no involvement. The goal of connecting with three mothers whom respected co-workers perceived as an "engaged mothers," or having exhibited 80% or greater participation rate for at least four months previous to their selection, was achieved. For the purpose of including the perspective of a disconfirming case(s), two mothers were selected based on co-workers' perceptions as being "non-engaged mothers" who had exhibited 50% or less participation rate for the four months previous to their selection. I submitted my thesis proposal for approval by Eastern Michigan University's Human Subjects Review Committee (See Appendix A) and the school district's research review board, in addition to obtaining the program director's signed agreement to participate in the study, previous to the recruitment of participants.

I met individually with five service providers (four occupational therapists and one teacher) to explain the purpose of the study and to come to a consensus regarding the concepts of "engaged" and "non-engaged" for the identification of potential participants. A letter of introduction (See Appendix B) was presented to mothers identified as possible participants by their direct service providers. My coworkers provided me with the names of six mothers who indicated a desire to participate in the study; four were identified as engaged, and two were described as being non-engaged. I contacted each potential participant by telephone and reviewed the purpose of the study. Upon receiving an oral agreement to participate, I scheduled an appointment to meet with each one individually at a place and time at their convenience. Appointments were scheduled with all the identified

participants, except for one (engaged) who was in the process of moving. Attempts to connect with her at a later date were unsuccessful.

All initial interviews were conducted in the participants' homes, with their children in attendance. I presented an informed consent (See Appendix C), along with an oral explanation previous to the initial interview. The opportunity was provided for questions to be answered and clarifications made regarding the study. The participants were made aware of the purpose of the study; of their rights in the process, including information on how material (audio-recorded interviews, transcripts, program documents) would be handled to ensure confidentiality; and that their participation was voluntary, which allowed them to rescind their consent at any time. A description of each participant follows. To maintain confidentiality, a pseudonym was given for each participant.

Anna is a single mother of three children; two daughters, 10 and 4 years old, and a one-year old son, currently enrolled in the program. The family resides in a single-family home within an older urban neighborhood. Anna had worked full-time before experiencing the significant loss of her mother just previous to the premature birth of her second daughter. Her situation was further complicated when her job was terminated with no explanation. She made the difficult decision not to seek work so she could participate in the early intervention program with her daughter. In doing so, she went against the opinion of family and friends who felt her daughter would do fine without the outside help. Her son was born just before her daughter was promoted from the early intervention program to a preschool program, where she continues to receive special education services due to a speech delay and behavioral problems. Initially healthy, her son experienced several seizures before being released from the hospital. Anna once again delayed returning to work so as to get the help

she felt he needed while receiving negative comments from people around her. Over the past year she has done part-time seasonal work but has placed a priority on being available for the services her child is eligible to receive. The family was also receiving early childhood services from a neighborhood community mental health agency at the time of this study.

Denise is married and the mother of two girls, 8-1/2 and 2-1/2 years old, residing in a nicely kept middle-class neighborhood of modest single-family homes. Following the birth of their second daughter, Denise and her husband were informed by doctors of the multiple health concerns that compromised their daughter's functioning. They found themselves immediately submerged into a whirlpool of doctor appointments in attempts to determine the causes of her right-sided weakness and other health and developmental concerns. Denise chose to stop working in order to pursue the services and supports she needed to help her daughter work towards the goal of independence. She started receiving services from the school district's early intervention program after her daughter received outpatient therapy services through the local children's hospital. Her daughter received occupational therapy, physical therapy, and teacher services in the home previous to participating in the center-based program at 2 years of age. At the time of the study, her daughter was beginning the promotional process to a preschool placement.

Nadine is in her early twenties and a single mother of two boys, 3 years and 8 months. Her oldest son is enrolled in the early intervention program due to developmental and speech delays. She was seventeen at the time of his premature birth, and during her pregnancy had mixed feelings about being becoming a mother. Nadine has been conscientious about her son's health due to his prematurity, making frequent trips to the local children's hospital early in his life. He was referred to the program via the hospital's

developmental assessment clinic. She felt her concerns (small stature, enlarged head) were not adequately addressed by the medical community, and began to feel negatively toward their continued recommendations of further testing. She has lived with family (mother, step-father, siblings) since before and after her sons' births in a large single-family home located in an older neighborhood of homes in varied states of upkeep. Family demands (her son's and extended family's) and limited transportation prohibited her consistent participation in the center-based component of the program, but she did receive home services of a teacher and speech therapist. Her son is beginning the evaluation process for transitioning from the Early Intervention Program to a preschool setting. Nadine is currently attempting to procure an apartment of her own, in addition to employment and child-care. She feels that in establishing her independence by getting a job and moving out, she is also limiting her options for child-care to be provided by her mother and sister. Nadine believes the move is necessary to maintain her parental authority in her sons' eyes.

Elise is married and the mother of two daughters, 7 years and 21 months. She describes herself as getting married later in life. The family resides in a modest single-family home in a nicely kept middle-class neighborhood near the city's border. She experienced serious complications during her second pregnancy resulting in her daughter's diagnoses of significant health and physical impairments. She chose to stop working to be her daughter's caregiver, and describes the first year of her daughter's life spent just keeping her alive. She has been proactive in seeking out information, resources, and support services on her own via the Internet or people she meets through medical and community agencies. She connected with the Early Intervention Program through an Internet search. Elise has stated her biggest frustration is in finding appropriate respite services due to her daughter's level of care. The

early intervention program has provided occupational therapy, physical therapy, and teacher services in the home on a weekly basis. At the time of the study, a transition to center-based programming was soon to take place for part of her daughter's service, and she was mounting a campaign to also maintain her current in-home services.

Renee is married and the mother of two daughters, 4 years and 2 years, and a one-year old son. The family resides in a two-story single-family home in an older, multiethnic neighborhood. Two of the children are enrolled in the early intervention program due to a hereditary condition that limits their mobility and hand function. The condition requires continuous monitoring by Renee to minimize the impact of environmental factors that might further compromise their functional abilities and health. In addition, the performance of daily care activities require an extended amount of time to address the physical needs caused by their condition, resulting in increased physical and emotional stress on Renee. She did not hear about the early intervention program until her a second child was diagnosed with the condition, and she eagerly welcomed the service into her home. At the time of the study she had participated in both the home and center-based components of the program with her children. Renee had been considering home-schooling her children due to their physical needs; however, she is now considering starting her oldest daughter in a church-based preschool that previously enrolled a child with the same diagnosis.

Data Collection

Phenomenological research assumes an iterative and simultaneous process of data collection and data analysis, with each informing the other as the study progresses to the point of saturation or redundancy in the data collection and analysis. Interviews were the main mode of data collection. Individual interviews were scheduled at the convenience (time and location) of the mothers identified as "engaged" and "non-engaged," and who were

willing to participate in the study. The interview was recorded via a digital recorder and followed a protocol of semi-structured, open-ended questions (See Appendix D). Probes were used as needed for facilitation of deep reflections and rich descriptions.

Immediately following interviews, field notes were recorded to provide descriptions of the environment, any of the informants' reactions or emotions, and observed nonverbal communication. Additionally, field notes were used to record my feelings, assumptions, and biases in an attempt to control their influence on interpretation of the data.

Data Analysis

Transcriptions were made of the recorded interviews, and reviews conducted to ensure accuracy of the content. Significant statements were identified, color-coded by participant, and the meaning of each delineated and classified accordingly as meanings evolved. Drew (2001) noted how statements that "stand out" in a participant's description tend to be "the individual's accounts of interpersonal events, reflective or introspective statements, as well as expressions of emotions" (p. 5).

An iterative review of the statements was conducted to determine the patterns or themes among the mothers' statements. It is accepted in phenomenological research that multiple realities exist, and it became the challenge of this researcher to interpret the meanings and form a framework of themes from the data. Themes were checked by the review of interview transcripts to ensure accuracy and relevancy. A log of theoretical memos and diagrams were kept to record my reflective thoughts throughout the data analysis. As the simultaneous processes of data collection and analysis occurred, special attention was given to keep the theoretical memos separate from the field notes. The final step of analysis resulted in the "construction of an overall description of the meaning and essence of the

experience” (Creswell, 1998, p. 150). Participant feedback regarding the accuracy and relevancy of the experience descriptions was obtained through telephone interviews with each mother.

There were periodic debriefing sessions with my thesis advisor throughout the data collection and data analysis phases to ensure the appropriateness and accuracy of my activity. A thorough review of the data analysis and findings was conducted by the thesis committee members, each an experienced researcher. It is believed that through this collaboration the findings reflect a rigorous and systematic approach and should be considered relevant.

Chapter 4: Findings

The mothers' stories expressed an over-arching theme that was strongly woven throughout each of their narratives: the need to be understood and have their realities valued. Elise articulated this theme when talking about the impact of other people's perceptions, noting, "...some people really are not in reality to me about certain situations." Each mother had selected her own home, with her child or children present, for the interview setting. The invitation into their home allowed me a brief glimpse of their reality. Each mother described her experiences, feelings, concerns, and goals surrounding her engagement in the early intervention program, a service originating outside of their reality. Thus I have labeled this theme, "In my reality."

Subthemes found within the over-arching theme of "...in my reality" were seen in the 1) timing and mode of how they came to understand and deal with their child's disability, 2) approaches the mothers employed to promote their child's progress, 3) their mode of participation in the early intervention program, and 4) opportunities they valued through their experiences with the program. Some mothers spoke easily of how views of themselves changed over time, being directly affected by their perceptions of how they impacted or were impacted by their child's condition. Others had notable difficulty reflecting on perceptions of their strengths and contributions to the child's development.

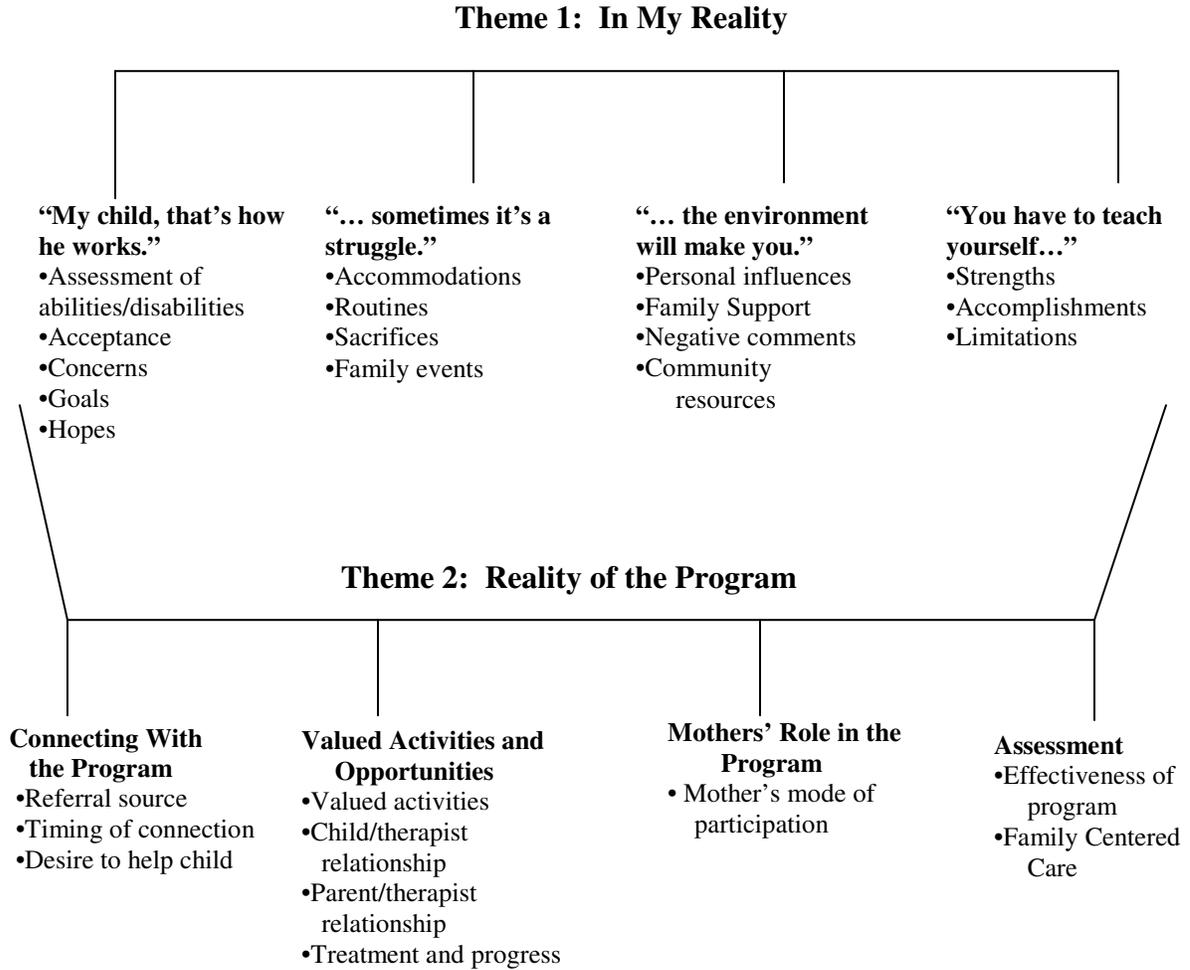
The orchestration of a symphony incorporates movements, or the flow of notes moving faster or slower as a composition is performed. Variations in movements could be seen in each mother's orchestration of engagement in early intervention services. Each mother made the decision to engage in the program at some point in the first three years of her child's life. The timing and flow of each one's participation, from being directly involved

in goal-directed activity to being a passive spectator, was influenced by her level of understanding regarding her child's condition, the ability to formulate and follow through on goals regarding her child's development, the quantity and quality of support present in her reality, and the amount of control she perceived regarding her situation.

The overarching theme of "In my reality" is presented in two parts (See Diagram 1: Orchestration of Engagement). The first expands on the participant descriptions and introduces additional subthemes that contribute to an understanding of each mother's reality. The sub-themes illuminate the factors in each mother's reality that supported their decision to engage in early intervention services. Personal (self-assessment, hopes), contextual (child's condition, positive and negative supports, environmental limitations) and process oriented (accommodations, impact on family) factors are integrated into the sub-themes of 1) "...my child, that's how he works," 2) "...sometimes it's a struggle," 3) "...the environment will make you," and 4) "You have to teach yourself..." Time is viewed as a dynamic factor seen in different dimensions within the subthemes; including how the mothers adapted over time (life course), the impact of time shortages, dealing with their child's development occurring at a slower rate, and what they hoped for in the future.

Once the decision was made to engage in the services, the same factors influenced how well the program "fit." In the second part, an understanding of the mothers' realities (person, context, process and time) is incorporated into the descriptions of their experiences with the program from 1) how they connected with the program, 2) the activities and relationships they valued, 3) to what they saw as their role, and 4) their perceived effectiveness of the program.

Diagram 1: Orchestration of Engagement



In My Reality

My child, that’s how he works.

The mothers learned about their child’s conditions or delays in a variety of ways. The children with significant physical conditions were diagnosed early, and the medical staff explained the possible implications on development. Several of the children had conditions resulting from prematurity but were not referred for therapy services immediately due to a focus on the health conditions by the medical agencies. All mothers learned more about the impacting conditions through daily interactions and observations of their child’s

development. The ability to communicate their concerns facilitated understanding and establishment of goals for their child's development.

Following her daughter's birth, Denise described herself as too exhausted to think, and she began to feel panic when the doctors first began explaining her daughter's condition. She remembers her immediate concern was, "...how do I start dealing with this in terms of how do I help her?" She learned through medical tests that in addition to the cardiac and orthopedic concerns, her daughter had experienced a stroke in utero, resulting in weakness of her right hand and leg. Although the doctors were unable to explain to her and her husband the cause of her daughter's condition, she did not view it as a curse that her daughter was born that way. Denise viewed it as, "...tests from God. He'll put you through something to strengthen you, because I would never have known I could do all that I did." She notes that she willingly takes her daughter's progress a little at a time, inch by inch. She pursued therapy through the hospital and the early intervention program, to achieve the main goal she set for her daughter, that she "...be to the point where she has her independence."

Elise's daughter was immediately diagnosed with multiple neurological and health conditions, resulting in numerous doctor appointments. Elise reported that her daughter has medical needs that must be addressed in daily care but are not severe enough to warrant nursing care. "Its sort of a Catch-22; it's not really considered a medical need, but if you don't take care of it right, it becomes a serious medical need." She is focused on improving her daughter's feeding skills, an activity that previously took up a good portion of the day. Elise's observations have taught her that strange environments irritate her daughter, and after a year of intense care-taking demands her daughter is now able to be comfortable with herself for periods of time, allowing Elise to attend to other family-oriented tasks. She has

been seeking a source for respite care that would meet the level of care her daughter requires. Elise has accepted her daughter's condition but is aware of the continuing struggle to not be overwhelmed by the situation. She acknowledged,

...it's still not all the way something that's okay, this is what it is, and you know, it's not. I don't know that it's going to get better, but I'm hoping...you always hope that what you think is not so, that you'll see great improvement over time.

Renee finds herself dealing with two mentally active and verbal children experiencing significant physical limitations, explaining, "They're smart, there's nothing wrong with their thinking. It's just that, the physical, and it's really nothing I can help them with..." She experiences frustration daily due to the desire to have her children perform a simple task in a reasonable amount of time (e.g.: take two steps in a minute), trying to exhibit patience, fighting against doing it for them, and at times not pushing them because, "...they hurt, you know, you don't want to see your babies hurt." Renee enrolled her children in the Early Intervention Program for help with their physical and social development, "...getting her to walk more often...but also the social too." She recognizes the need for her children to be around other children and to get used to other people being in charge and not to expect others to do for them. Although she has accepted her children's condition, she remains sensitive to the reaction of others, stating, "...I know it's different. I know people can see a difference, but to sit there and stare at somebody's kid..." A particular concern is that her older child is now becoming aware of other people's stares.

Nadine was surprised by how little her premature son turned out to be, but this was not her only concern. She recalled, "I was kind of scared, and then when I saw how little he was...when I saw him in bed I just knew something was wrong." He appeared to have an enlarged head, had difficulty digesting milk-based formula, and was exhibiting motor delays.

Nadine knew normal development from having been around babies. She had concerns about his growth rate and his height that still persisted. Her friends had babies that were younger but doing more, contributing to her concerns. Once he started moving she relaxed, and later was able to recognize both his strengths (sociability) and weaknesses (limited speech) noting, "...you have to love your child for what he do...you can't let nobody, put you, bring you down with him." Comments made by others made her realize though that she would have to do something for him, "...being my child, cause you don't let nobody talk bad about your child."

Anna was initially concerned about her daughter not walking; she hadn't realized that her speech was behind. The doctors helped by informing her that possible speech and perceptual motor delays may be helped through early intervention programming. Once her daughter was enrolled in the program, Anna observed other children more closely and saw that they were doing a lot more work. She realized her daughter did have a problem, adding, "Most parents don't want to accept the fact that their children may be delayed." Concerns also developed around her daughter's acting out behaviors or temper tantrums when she is frustrated. Anna found herself frustrated because, "...she just never showed her behavior whenever they (service providers) was around." Her third pregnancy was unexpected, and she hoped that her son would not exhibit any of the same problems as her daughter. However, when he had a seizure before being discharged she knew what to do. She pursued the referral to the program for her son and believes he was enrolled due to concerns regarding his muscle tone. She described his body as being real tense all the time. Anna's hope that her children be a success in whatever they want to do is one of the reasons she sought help for her daughter, and son, before it was too late.

Sometimes it was a struggle.

The determination of their child's eligibility into the program was not necessarily the answer to all the mothers' concerns, nor did it ease an already demanding and compromising family situation. Demands on time had the biggest impact, including the adaptation of routines to meet child-care needs, accommodating appointments at the medical and educational agencies, and time being taken from other family members. Denise pointed out how a child with special needs "... takes times five more of you to help the child, because they are totally helpless." This increased demand for attention takes time away from the rest of the family, and Elise noted that there is no way around it.

Four of the five mothers purposely stopped working outside of the home to meet these demands, while the fifth was initially unemployed. Service provision in the home was frequently viewed as convenient, while transporting the child to the school for the center-based component of the program at times proved to be complicated due to weather and the accessibility and dependability of transportation. Free school bus service was provided if needed. In general the mothers had the specific goal of getting the help their child needed as the motivation for sustaining their engagement in the program.

Complicated routines and obstacles for meeting a child's health and physical needs impacted more than one mother. Elise described the first year of her daughter's life of being focused on soothing her, keeping her comfortable and alive. Her decision to be her daughter's primary caregiver and to stop working outside her home resulted in seeing her household income cut in half. Having no prior knowledge or experience with developmental disabilities, she spent time and energy learning about her daughter's dietary concerns, seizure disorder and diagnosis of cerebral palsy, and their potential impact. She talked of household

tasks not getting done due to care routines, time spent reading or searching the Internet for information to assist, and calling agencies for the help she sought. She emphasized her frustration:

...in every aspect of dealing with issues regarding my daughter, whether it be medical, educational, social, everything, there seems to be an obstacle that you gotta cross to get to it...It's frustrating as heck, but you know, you just find out that if you don't do it, then it just doesn't get done."

Elise's prioritizing resulted in self-neglect. She admitted being aware of the need to take care of herself, but she always felt there were other things that needed to be taken care of.

Renee described a daily routine governed by her children's level of physical comfort, clarifying, "...whenever they're happy we get stuff done. Whenever they're settled (pause) ...a lot of stuff don't get done, does it?" It is the children's physical need for attention that limits daily activities. The treatment for their condition is multi-step and painful. Renee stated with feeling, "...it's a painful disease, I know that but I hate to see them go through having to do that everyday, so some days I'll just let it go and I won't do nothing, and then it gets worse." She and the children will usually hang out at home or spend the day at her parents while Dad works. There has been no difficulty in opening the door to early intervention services. The twice a week visits are looked forward to by the children and Mom.

Denise elaborated on the impact in regards to herself, "I had to swept (sic) my feelings out, I mean, I had to throw that out. There was no time for me, it was time to start..." The schedule of doctor and therapy appointments, her older daughter's school and homework, and keeping her family and home going kept her very busy and exhausted. She did not have time to feel sorry for herself. She believes that by keeping her focus on her daughter, things started falling into place. Denise learned quickly how to organize her

schedule and easily accommodated the home services from the school's early intervention program. She loved the idea of them coming to her home while other family members were at school or work.

Anna explained her decision to not look for work due to all of her daughter's appointments being during the day once she was enrolled in the early intervention program,

I just had to see if it could help. And I figured that it would be better to try it to see if it would help, than to miss the opportunity, and she end up getting older and it's too late to get any help.

She stated that she did not have anybody available to stay with her daughter at home for when the teacher came out, or to take her to the center. She attempted part-time seasonal work with her son's enrollment in the program; however, last minute changes in her work schedule resulted in the cancellation of the home visits. She concluded, "...sometimes it was a struggle... it's hard, you have to make sacrifices. Well, I personally have had to make sacrifices to have them in the program."

Nadine was uncertain initially about becoming a mother; however, once her son was born prematurely, her decision was made and she made it clear that "...he was the main person." She went on to describe changes made in her sleeping pattern, and how careful monitoring of his health resulted in trips to the hospital. She had to deal with broken down cars and having a friend drive her or come with her when taking her baby on a city bus. Once he was enrolled in the program she had difficulty coming to the center due to obligations at home. Her sister's children had been placed with her mother via a family-foster placement, and she was called on to assist with child-care. Her son's assumption that he did not have to go to school because his cousin didn't go did not help. Additionally, she found herself pregnant for the second time and described herself as, "being real lazy not taking him up to

the school.” The birth of her second child has increased the demands on her as a single mother, but she continues to make plans for a better future for her and her sons, noting “... so much stuff comes up upon (you) while you’re trying to aim for one goal, and you have to learn how to just dive, you have to make big decisions.”

The environment will make you.

Positive influences were felt not only within the immediate family environment, but also across geographical distance and reaching out from childhood experiences. Personal faith was seen to provide strength, childhood memories gave direction, and the connection with others contributed to personal value. A circle of family and friends were generally supportive for the mothers who were married. The two single mothers, Nadine and Anna, dealt with confusion and frustration due to comments received and fluctuating support from family and friends. Nadine summed up her situation with, “...the environment that I’m in, it’ll make you, it’ll make you have some problems.”

Denise and Elise talked of how faith and family influenced their perspectives in life. Denise expressed a strong belief in miracles based on what she had seen in life. She credits strong family support for what she has achieved with her daughter. She also drew strength from the examples set by her own mother and grandmothers, of their going to work when ill, putting the children first, of working hard in rural conditions and not making excuses. Denise respectfully noted, “If they can do that, then I ask myself, ‘What’s my excuse?’”

Elise, having been raised by her paternal grandmother, grew up in an “extremely religious type of, miracles type of religion.” She does not ascribe to such strong beliefs. Elise views herself as a realist, but not Godless. While she feels support from the family, she does not feel they truly understand her situation, “...they have so much faith that they don’t

see getting from here to there is just, you know..." Elise remains close with her grandmother, who is eighty, but does not see her as being able to provide more than emotional support. Her mother lives a great distance away, but she is felt to be extremely supportive, noting she always recognizes the extra work Elise has to do to meet her daughter's needs. She has also assisted with financial support in procuring special equipment for her granddaughter. Elise has connected with a friend from her past who has an older daughter with severe physical and health concerns. She stated, "...now I know someone that definitely knows where I am coming from..."

Renee told how strongly her husband reacted to her children's diagnoses, as he has the same condition, "...cause when they were first born, he cried and cried and cried." He has shown continued difficulty helping with their care, as he knows how painful it is, thus leaving the bulk of the care up to Renee. She is grateful for the help given by her parents and sister; besides her husband, they are the only people she trusts leaving the children with so she can do errands, grocery shop, or just relax.

Anna described how she tries to include her older daughter in school activities following the path her mother had set for her growing up, but did not identify any specific positive supports currently in her immediate environment. The children's father is not physically in the home, and is inconsistent in his presence. She stated, "...I mean they know him and he's around, but then he goes through a period where he's not around..." She acknowledged that he might not even realize that the children are in an early intervention program. Additionally, she feels that his family does not value education and this is not the attitude she wants her children to have. Anna has received a good amount of negative feedback regarding her stopping work and accepting services from outside of her home, and

is told she's wasting her time. Comments regarding her children not needing help, that they are still young and will "come around," confused Anna initially until she realized that the help was needed. She now says, "...not that they're helping me pay my bills, but, you know they don't understand...I guess because they didn't know, and they didn't have to deal with it on a daily basis."

Nadine has experienced a change of support in her home environment. The initial concerns she had about her son had been calmed by family members. Her mother pointed out that she too was small like her son. When the doctor indicated that further tests were needed due to the size and growth rate of her son's head, she was assured again by her mother who told her, "...not to let them have no surgery cause nothing wrong with his head, when you see his daddy's head." Living in her mother's home she was surrounded by family and felt the responsibility to help out as she was being helped. However, there were comments expressed regarding her ability to be a mother, to which she responds, "...now everybody know that I'm not a bad parent...they think that I wasn't never going to be for my kid because of the environment I'm around." She is attempting to move out on her own to establish her independence on several levels: gain control over herself and her children, provide opportunity for the children's father to be present in their lives, and become eligible for community resources. She concluded, "...it's like they try to take away from what you got when they know you trying to do something."

Beyond their immediate environments, the impact of community resources also lent varying support. Financial resources had restrictive eligibility. Elise found her household income to be over the qualifying level, but not enough to meet the special needs of her daughter. She was eligible for the provision of her daughter's special formula. Eligibility

requirements were motivating Nadine to seek an independent living situation. Having one's own source of transportation allowed increased participation in agency programs, including the early intervention parent/child group. Anna noted that she did not have "real good" transportation and wouldn't be able to "go places" all the time. Accessing the limited community transportation was seen as difficult with small children, and school buses, though available through early intervention, were not always dependable. Additionally, the structure of the parent/child group at the program's center did not allow for other siblings or young family members to attend, once again limiting Nadine's attendance.

Community agencies at times were viewed as a paradox, helpful in providing answers or achieving a goal, but on their terms, not always taking into account the difficulties parents were facing. Denise noted that the local children's hospital was very professional and stringent about being on time for therapy appointments, even though the weather might hinder driving. She recognized that the therapists did accomplish what they intended to do. While she did not actively participate in, nor after a time observe, the sessions, they did provide her with more than enough material for home programming. Elise was having one of her main concerns, her daughter's difficulty with feeding, addressed through out-patient therapy but after several weeks the therapy was discontinued due to the therapist's family moving and the unavailability of another therapist to be assigned. Nadine came to view the doctor's setting as a negative environment due to the confusing talk about the need for tests and always about finding something wrong with her child. She was also frustrated by not having her concerns addressed.

You have to teach yourself.

All the mothers talked about the journey they are on, from finding out about their child's condition, learning how to help them, and seeing differences in themselves. Elise and Nadine spoke specifically of making their love known for their child; however, the actions of all the mothers demonstrated this emotion in their determination to help their children. All the mothers recognized that their children have made them grow. Several mothers talked about discovering strengths and skills within themselves, and a few explained how a perceived weakness is being worked on. Participation in the program provided some direction for Anna and Renee in assisting with their children's development. Others viewed the program as an additional tool they are using as part of their plan to promote their child's development.

Denise spoke of feeling empty, of thinking, "Whoa!" when her daughter's condition was first talked about and referrals were made. She realized that her energy should not go toward self-pitying but rather in a positive direction, bringing out another side of herself. She learned to slow down and not push so hard. She modeled the type of behavior she wanted from service providers: consistency in follow-through, being on time and ready for home sessions, and maintaining good records of everything she was involved in. Denise noted, "...this is critical to do when you have so many things going, because you can't depend on your memory anymore." She is proud that she has accomplished with her daughter what she intended to. She continues to feel the fatigue but says her body has adjusted to it and wants to keep going, "because if she sits down..."

Elise credits her younger friend, whose daughter has a severe delay, with the ability to deal with issues she would not have been able to at the same age. Due to her life and work

experience she perceives herself as now being stronger and displaying the persistence and skills necessary to get her and her daughter's needs met. She does not take for granted her ability to read and comprehend medical information accessed through the reports from her daughter's evaluation and her Internet searches. She knows a lack of literacy is a serious obstacle in the community. Although she continues to feel frustration in not knowing everything regarding her daughter's condition, she sees her knowledge base expanding.

Having a child at seventeen made Nadine take a good look at her life. Initially she did not like the idea of having a baby, did not feel any joy while she was pregnant, but once her son came home the realization also came that she wanted to be his mother. She felt the impact of other people's comments and remembered the stress that made her stronger, saying

...and when standing by the edge I'll always focus in my head in that I gotta kid. I can't act quickly, I can't act silly, I can't act nothing. I have to act like an adult.

Nadine has learned not to allow other people's comments to bring her down, nor to dwell on the idea of "what if..." by focusing on the positive things her son is and will do.

Anna and Renee both had difficulty elaborating on what they valued about themselves, what their strengths were, and what they contributed to their children's development. Anna believed that she would be much more frustrated with her daughter's behavior and son's development if she had not engaged in the program. Her participation provided her with the direction of what to do to help her children. However, she was unable to provide any self-reflections regarding her own strengths, explaining, "I never thought about it." Renee also had difficulty identifying her strengths, and tended to focus on what she perceived as a fault, saying, "What I do wrong is I'm very protective of them. I don't let

them do a lot of things on their own.” It is her desire to protect them from being hurt that leads to this protectiveness, but she notes that she needs to be more open.

Reality of the Program

Connecting with the program.

The point of connection with the early intervention program for each mother tells a story about the differences in community resources, personality factors, and the children's level of disability. The more significant the disability, the more actively the mothers sought outside assistance. Medical or public health personnel referred four of the five mothers to the educational-based program, while one mother had to seek out alternative services outside of the medical setting on her own. The children averaged about a year of age at the time of program initiation, except for the two who were the second child in the family to be enrolled; their program initiation was earlier, by six months of age.

Elise and Denise, whose children evidenced notable physical and health concerns at birth, were caught up in medical appointments immediately, but eagerly sought additional supports and sources of information that would help them. Denise was referred by her child's neurologist to Early On, which she pursued while having her daughter receive outpatient therapy at the local pediatric hospital. She knew they started the program kind of late with a notable gap between the initial referral and completion of the paperwork, and that her daughter had received therapy for about a year at the hospital before service began in her home. Her experience with the medical agency helped with understanding her daughter's condition and providing specific exercises to be performed. The home service started when she felt capable of encouraging her child's activity within the family environment. Elise sought out additional therapeutic services through the Internet when she realized that her

daughter was not comfortable with the therapy environment at the hospital. She observed, "...it's called different things in different places, but the bottom line is there's some sort of service to help therapeutically for zero to three years old." Her daughter had just turned a year of age when home service began through the early intervention program.

Renee was never told about the Early On services or home programming available to her and her first child, by her daughter's physician. She had received no therapy service through any medical agency. Once her second child was diagnosed with the same condition, she was informed of the program through a Public Health worker. She was excited to hear about the early intervention services, but scared about her oldest child's reaction to having a stranger come into their home. Her daughter was sensitive to people looking at her, and did not open up easily to non-family members. How was she going to respond to a lady telling her what to do? Renee was surprised though, "...when she (the teacher) came, it was like my daughter sat down, like she's ready for school."

Anna related how everything happened at once when her second child was born prematurely, her mother passed, and she was fired from her job. She felt she was doing okay financially then, and that her daughter was doing okay. Her daughter was eventually diagnosed with lead poisoning and referred to the early intervention program by her pediatrician. Anna also reported that it took the program "a minute to get in contact with me, so she didn't just start right off." Anna admits though that although she had behavioral concerns, she was unaware of any developmental concerns regarding her daughter until she connected with the program. When her son (third child) experienced a seizure shortly after birth, she sought the advice of the program's social worker as to the appropriateness of the

program for him. The social worker proceeded to refer him to the program with his mother's consent.

Nadine talked about a lady coming out to her home once a month, after she brought her son home from the hospital, to make sure there wasn't a problem. As the child grew, the public health worker noted that he was "gripping his toes, like he's trying to hold his balance." Although Nadine explained that she had also walked like that, the worker referred him to the early intervention program for evaluation. However, Nadine did not immediately follow up. Only after personnel at the local pediatric hospital also referred her son to the school program did she make up her mind to follow through on the attempts by the program to reach her at home, noting, "...cause I used to always not be here. And they used to always try to catch up with me and everything." Her son was just over a year when early intervention services in her home began.

Valued activities and opportunities.

Appreciation of their child by the service provider was viewed as paramount to accepting the services into the mother's home. The observations used for weighing this factor were the quality of interactions between the child and therapist or teacher, how well the presented activities addressed the mothers' goals, and the respect shown by the service providers for the child and mother. The child's progress contributed to a mother's engagement and was facilitated by the relationship between the mother and service provider. A facet of this relationship involved the reciprocal dynamic of information-seeking and feedback. Added to the composition were noted experiences of valued activities, memorable moments, and the flexibility to adapt (mother and/or service provider) when needed. Participation in the parent-child group at the program's center provided the opportunity for

the child to engage in activities not available to them in their home environment, e.g.: socializing with other children, modeling other children, and responding to another authoritative figure. Limiting factors included disruptions to service by the program due to staff medical leaves or transportation problems, weather, locus of control, and/or family situations (as described previously).

Elise emphasized the difference in her daughter's responsiveness between the hospital setting and at home, noting she is more comfortable in the home, and more receptive to therapy. Her daughter's brief experience with feeding therapy had been abruptly discontinued at the hospital, and she wanted to continue to focus on this skill through home programming from the school. Her school therapist focused on developing the foundational skills of head and trunk control. Elise was frustrated that "...the school system has not been able to, at least they tell me, to address feeding per se..." She was eager to learn what could be done on a "continuous basis" to help her daughter, and she appreciated the improvements in head control and responsiveness. She noted, though, "...but from zero to two now, if it continues to go at this pace, we got a long way to go." Elise is looking forward to starting the center-based component of the program with her daughter and meeting other mothers of children with severe impairments with whom she can form friendships. She hopes "...that maybe we can help each other more than what we have probably found thus far."

Denise was ready for the in-home service, feeling she had a good understanding of her daughter's condition through her experience with outpatient therapy at the hospital. She observed a difference in her daughter's responsiveness to the home service providers by her tending to be more "don't touch me," which Denise felt hindered her progress initially. She valued the one-on-one relationship established in the home setting but also recognized the

difference in space available to work. The teacher and occupational therapist were seen as respecting her daughter's space, integrating their observations into their treatment approaches, and modifying their presentation of tasks to address her goals. She felt the physical therapist was limited due to her daughter's resistance to the hands-on approach inherent to stretching exercises. Denise acknowledged that the sessions were just once a week, leaving a whole lot of other time to be utilized. She appreciated that the service providers paid attention to her requests, concentrating on her concerns, providing her with information and home activities to be used between sessions, and valuing her feedback. She believes this formula of cooperation "...allowed us to go further." Overall though, progress was seen as step-by-step with the major goal of having her daughter walk. She described part of the experience:

...just before she could walk we were trying to work on her trying to pull up...they told what kinds of things to use, pillows, use this, do this, do that, and I loved that because I tried that every single day. And by the time they came back there was a little progress, and a little progress. And finally the day she decided she was going to pull up, I mean we were all just clapping. It was the most exciting thing.

Participation in the center-based component allowed her daughter to observe her peers and attempt to imitate their activity. Denise had concerns about the routine of pulling her daughter out of the center program's activities for individual physical therapy, feeling once she was engaged she didn't want to leave the activities, and thus did not fully benefit from therapy. Denise felt comfortable expressing her concerns to the providers about their mode of service within her home, but in outside settings (hospital and school) she did not feel she had the right to interfere. She describes her daughter now as a totally different soul, able to go wherever she wants to go. Now, as she prepares to have her daughter transition into a preschool setting, she summed up her experience by saying, "...when someone comes with

such knowledge and shares it with you, I think it's important to just grab it and run with it, and do the best you can."

Renee talked about combined interests, her children's and her own. Her children liked reading books with the teacher who came to their home and playing with the toys the therapist brought in. Renee liked how the service providers encouraged her children to walk, to do more things on their own, while she had a tendency to do things for them. Additionally, she was able to observe her children doing activities she was unaware they could do, e.g. stacking blocks. However, it was the easy interactions between her children and their teacher and therapist that made it easy for Renee to welcome the service into her home. Valuing the fun that her children had with the service providers, Renee related a magical memory:

...one time my daughter wasn't really walking that day, and her teacher started singing a song with her. And she just got up and started dancing and stuff, and it's like I've never seen her dance like that before... She was just so excited, both of them! I think we were running around the house.

Renee looks forward to her second child attending the center-based program, and having the same experiences her older daughter had. She believes that observing the other children's activity encouraged her daughter to do more physical activity, besides helping with her social skills. Renee noticed that after starting "center base" her daughter started opening up to people at their church. She also liked having a teacher, and Renee sees the benefit of having another adult being "in charge."

Nadine and her son experienced disruption of service on several occasions due to both family and program factors. She recalled how her son related easily to his teacher, describing the teacher's ability to mirror her son's mood and "blend into the situation." Nadine found the activities the teacher presented were appropriate and kept her son's interest.

An additional benefit was her son's acclimation to school routine, "...cause it's teaching him to get up at a certain time, it's teaching him to want to talk, when you want something you ask for it instead of screaming." She recognized her son's ability to learn, and honestly admitted he did not get to the center-based program much, but feels he had school training at home. Due to her son's speech delay, he was also receiving home service from a speech therapist. She took offense with the behavior of this service provider, describing how she brought her own chair in to avoid sitting on the furniture in Nadine's home. Additionally, she did not like how the therapist interacted with her son, e.g. verbally demanding his attention and then paying more attention to Nadine's phone conversation than her son. However, Nadine feels his speech is, "...coming out clearer and clearer every day," and hopes it will be here when he is four or five years old.

Anna felt the frustration of having her daughter's service limited due to bus service for the center base program, and later having her teacher go out on a medical leave. Once the bus came regularly, she noted that her daughter started opening up more at the center. She felt the activity level at the center matched her daughter's, and the variety of activities also engaged her. She valued the opportunity for her daughter to be around other children her age. Anna observed that her daughter kept so busy at the center, "...she didn't have time to throw a tantrum or anything like that." She continued with the summer enrichment program at the center, believing it helped her daughter make the transition to preschool. So far, her son has received only home service. Anna has found the home service providers to be quite helpful, responding to her questions or assisting her with a problem, describing them as, "...real resourceful and always come back and bring me information that I can read, or they point to the right direction." Her assessment of his progress recognized the influence of natural

development, along with the influence of early intervention services, noting that his muscles were loosening, and he was doing more on his own.

Mothers' role in the program.

The mothers' statements regarding their engagement in the program or in relationships with service providers reflected a perception of themselves as a natural part of the process, an integral and dynamic component in the process of helping their child's development. Their role incorporated facilitating, monitoring, supporting, researching, being an information officer, and, primarily, being the agent of change. Some mothers indicated that the services enhanced what they were doing already. Others felt observing and monitoring the activity between child and service provider gave them the insight of what to do. Active involvement during the session, follow-through of recommendations, and provision of feedback were seen as an essential part of being an agent of change. A few felt they needed more support, from their family and/or the school, to fully participate in and benefit from the program.

Denise spoke very emphatically about her role as her daughter's agent of change, how she made sure to follow up any recommendation, stating:

I was totally engaged from A to B, and you know we interrupted, asked questions, gave them the progress of, from the last session to this session, what I'd seen that she picked up, or in terms of what goals were set, what I feel that we still need to work on, and what I feel we have accomplished.

When the physical therapist's approach did not work with her daughter, Denise suggested they show her what to do and she would do it during their absence. She worked to balance her eagerness for her daughter's progress with patience and support, and believes, "...she feeds out of that."

Elise spent a good amount of time researching, learning and advocating for her daughter's needs. She believes you need to go through a learning stage. You need to learn what the real necessities are for your child. She spent the first year of her daughter's life learning what to do and how to sustain her. The next step in her learning process came when she connected with early intervention services, and she began to observe and learn from the therapists what she could do on a continuous basis to help her daughter, e.g. how to exercise her body.

In addition to making sure their children were available for home sessions, Renee and Anna also took the observe-and-learn approach. Renee appreciated the in-home sessions as a pleasurable time, an opportunity to see her children have fun. She knew that their everyday world was narrow and also involved moments of pain, so happy times were valued. During center base sessions she functioned as a supporter and monitor of her daughter's activities. Anna was at ease with her role as observer during the home sessions, noting that later on she would do some of the things she observed with her daughter or son. It was the enhancement of simple activities she found useful stating, "...I never knew a daily activity, playing games...would really help, like pointing to pictures..." She had not attempted activities that her children found difficult previous to receiving the service, but does so now and recognizes she would not have learned how to encourage them on her own. She has become more purposeful in finding ways to help her daughter's speech development, e.g. going places, playing games, and so on.

Nadine looked toward the service providers to provide the direction for working with her son. However, through her many experiences with young children she was able to assess the appropriateness of the activities presented. She did not indicate if and how she followed

up on what she observed or was told. Nadine did acknowledge that she became “lazy” about taking her son to the center base program when he turned two. She was thankful for the continuation of home service, and felt if given extra help for “going to that school,” her son would have progressed more than he did.

Assessment.

Overall the mothers agreed that the services from the early intervention program were a good “fit” as one resource or tool in their continuing efforts to help their children. The perceived quality of the service focused on the relationship between their child and service provider, and how well their concerns were addressed. Elise expressed her feelings, saying, “I wouldn’t cancel Early Intervention under any circumstances. Now, if it was the individual therapist or something, but that goes back to the service, and you just cancel them, and get somebody else.” The convenience of services coming to their home was truly valued. The initial process for determining eligibility may have taken longer than they would have liked, but there was appreciation that insurance companies did not have to be “fought with” to get service. Positive points were weighed against negative points. The introduction of the center component to their child’s program brought the demand to leave their home. Denise found this change to be tempered by the program’s willingness to “work with you” while the adjustment was being made or if a few sessions were missed due to weather or illness. While the center program provided more room to explore and the benefits of socializing with peers for the child, the presence of other children was also viewed as distracting when a specific goal was being focused on.

Denise and Anna talked about the effectiveness of the program in terms of how it helped them. Denise saw the services as part of a continuum of help for her daughter,

explaining that her momentum started with the hospital therapy, and the in-home service from the school was more “perfecting.” She was grateful for the modern technology and agencies/people available to assist her, and noted, “I took it and ran with it. And that’s why I have no regrets of anything I did.” Anna felt that the assistance her daughter and son received helped decrease her own frustration. Her daughter continues to exhibit a speech delay but shows an improvement in her vocabulary and her willingness to try harder. Anna’s concerns about her daughter’s behavior still exist, but she would still recommend the program to others because she believes it helps. Elise spoke of advocating for continuing home services, even as she and her daughter begin to participate in the center based program. She wants to ensure the same level of service and to keep moving forward

Mothers saw the center base component of programming as playing a big step in preparing their children and themselves for the transition to a preschool setting. Renee talked of how it allowed her daughter to experience what went on at a school. She is now working with her understanding that Mom will be leaving her at the preschool, but will come back to pick her up. Denise is following up the center program with a child-care setting, before her daughter starts preschool in the fall. She eagerly anticipates going back to work, “...back to what I love doing.” Anna noted that her daughter adapted to the preschool setting faster than she expected and credits her experience with the summer enrichment program.

It was evident that several of the families still had unmet needs. Elise would like more assistance in coordinating respite care and connecting with support groups in the community, describing her wishes for “...better service coordination, like something to add on to the family.” The Early Intervention Program employs the family-centered approach to the services it provides; however there may be a discrepancy between the staff’s implementation

and the parents' understanding. When asked what the term "family-centered" meant, Anna and Denise focused on the idea of parents and children doing activities together. Anna did expand on the concept saying, "...cause it's about your family-oriented concerns, the family, well the mother, or the father has to speak." Other mothers had difficulty articulating any understanding of the concept, family-centered. All of the mothers anticipated ongoing concerns with their children as they grew older and moved through the program. Elise wonders about "...everything, acceptance, time, her condition, everything that evolves around her condition, has changed everything. So will it kind of settle out?"

Summary

Initial concepts of "engaged" and "non-engaged" were dispelled as the mothers' stories unfolded. The narratives provided individual orchestrations of engagement; however, each composition contained the essential notes of 1) the decision to seek help, 2) the formulation of goals based on an understanding of the child's condition, 3) the presence of informal and formal supports, and 4) attaining a sense of control over the situation. A sense of control was derived from the program's goals being aligned with the mother's goals, valued activities that met the child's needs, and the professional behavior of the service provider.

Chapter 5: Discussion

The concept of early intervention services has undergone modifications since its initial inception. A current definition (cited in Dunst, 2000) states:

Early intervention is the provision of support and resources to families of young children from members of informal and formal social support networks that both directly and indirectly influence child, parent, and family functioning. (p. 99)

From the formal social support network perspective, Brown (2004) notes that diversity should be recognized and celebrated, services should be flexible and responsive to family's needs, and decision-making is done in partnership with parents, reflecting their needs. If the goal is to promote a child's development and a family's functioning, then all factors influencing the achievement and maintenance of that goal need to be looked at for their contribution to the process. This study contributes to that process by focusing on the co-recipients (mothers of young children with a disability) of the formal services provided from a community-based early intervention program through the local school district, and these recipients' perceptions of their engagement in the program. Their input identified a range of factors (personal, contextual, process-oriented, and time-based) that facilitated or inhibited their participation in the program. More important, though, was their voicing of the need to have their situations, their realities, understood by the service providers. Their hopes, concerns, difficulties, opinions, and feelings were expressed throughout their narratives. Once a mother's reality is understood, will the concept of engagement be altered in the professional's perspective?

Brofenbrenner (2005) stated in his proposition of human development requiring increasing complex reciprocal interactions that "...to be effective, the interactions must occur on a fairly regular basis over extended periods of time" (p. 6). State regulations mandate

twice-a-week service, with documented regular attendance for the receipt of State aid. This study initially identified engaged and non-engaged mothers as participants based on objective (attendance $\geq 80\%$ or $\leq 50\%$) and subjective (responsiveness, carry over) measures. Upon completion of the interviews it was apparent to this researcher that the protocol was reflective of a middle-class orientation and legislative standard. It is the legislative framework that influences a professional's obligations (Brown, 2004) and establishes a program's format. Dunst (1999) referred to his research of a social systems model that noted inadequacies in resources (money, child care, etc.) unrelated to formal early intervention services, usually resulted in lowered interest and commitment in a program. Nadine and Anna indicated an inadequacy of resources (child care, family supports, transportation) but generally talked positively of their participation, though limited, in the program. The valued factors that engaged their interest were the learning opportunities provided for their child, including socialization with peers, and the increased awareness of their child's abilities and activities they could use to help their development.

Understanding a family's reality is inherent to the construct of family-centered practices. Dunst (2000) discussed how research on family-centered principles and practices has resulted in a new paradigm through the integration of theory and empirical evidence. The new paradigm embraces empowerment and strengthening of family functioning, recognizing the greater positive influence of *informal* social supports on child, parent, and family functioning. Hobbs described informal social supports as "normal socializing agents, including, but not limited to, the family, neighborhood, church, and so forth, as the primary way of supporting and strengthening family functioning" (cited in Dunst, 2000, p. 96). The role of professionals is seen as agents of the families, being responsive to their concerns and

desires. Support given by early intervention professionals “was judged as most helpful and beneficial when the practitioners were identified as members of a family’s informal social support network,” (p. 96). It was noted that an opposite effect occurred when the practitioners were viewed as part of the formal social support network. Nadine spoke of the difference she observed between her two service providers. The first “blended into the environment” and “adapted her mood to match my child.” The second offended Nadine by bringing in her own chair and tending not to focus on her son. Similarly, Thompson (1998) found that when therapists were perceived as friendly, family participation increased. The opposite occurred when the therapists were perceived as unfriendly; the mothers limited their involvement in their children’s programs. One mother simply stated, “You have got to be friends before you can have them as therapists,” (p. 217).

In general the mothers in this study did not specifically articulate their understanding of family-centered practices; however, through their narratives they spoke of responsive interactions with service providers, child-oriented activities that addressed their goals, and the provision of information and resources that assisted with their concerns. Bailey identified two areas for potential conflicts as the formation of goals for intervention and the methods by which the goals are to be achieved (cited in Brown, 2004). Elise provided an example of a conflict when she described her frustration with the method selected by the therapist to reach a mutual goal of increasing her daughter’s feeding skills. She felt focusing on head control first was not adequately addressing the goal, though the therapist may not have fully explained her intentions to Elise with the treatment approach she had selected.

Thompson (1998) found in her study of the impact services have on the quality of families’ lives that mothers felt the personal support provided by therapists was as important

as the hands-on therapy for their child. The therapists' attitudes and values were the most likely determinant of continued family involvement. This does not imply that treatment directed at the child takes a back seat but that its effectiveness is severely limited without the participation of family members. Denise highlighted how the responsiveness of her service providers to what she requested, and to her child's personality, facilitated her working on activities in their absence. Anna valued the fact that her service providers always guided her in the right direction when she expressed a concern. However, she also felt a loss when her child's teacher was out on a medical leave. A more thorough look at how practitioners initiate and maintain contact with families calls for further investigation. The need for early intervention practitioners to harmonize with each family's reality has become evident for achieving true family-centered service.

A mother's well-being is significantly impacted by the supports she experiences within her immediate environment. The transactions between a mother and her context will determine her performance range (Dunn et al., 2003). Nadine was quite open about the negative comments and limited support she was experiencing in her home, noting that her environment was making it difficult for her to fulfill her mothering role. Nadine and Anna, both single mothers and both experiencing a notable level of negative supports, willingly participated in this study to have validated the efforts they have put forth to help their children's development. A single mother's adaptive behaviors and efforts for helping their child with a disability were found not to be significantly different than a married couple in the same situation (Ellis & Hirsch, 2000). It was suggested that the single mother has "a more substantial emotional investment in the well-being of their child and in the protection of the family unit" (p. 326). This does not preclude, though, the need for additional support

within their immediate environment. Brofenbrenner (2005) addressed the need for the mother and child dyad to have further support in his application of research to future concerns:

...the capacity of a dyad to serve as an effective context for human development is crucially dependent on the presence and participation of third parties, such as spouses, relatives, friends, and neighbors. If such third parties are absent, or if they play a disruptive rather than a supportive role, the developmental process, considered as a system, breaks down...(p. 52).

The consistent support of a third party aligns with the research (Dunst 2000) finding of a positive relationship between informal supports and different aspects of children, parent, and family functioning. Occupational therapists and other early intervention service providers should explore further the informal social support networks that a family may or may not have present in their lives. Practice approaches that assist parents in seeking out and establishing informal supports, when needed, should be developed and implemented on a consistent basis.

The well-being of the mother impacts and is impacted by the child's development (Brofenbrenner, 2005; Donovan, J. M., VanLeit, B. J., Crowe, T. K., & Keefe, E. B., 2005; Dunst, 2000; Dunst, 1998; Larson, 2000). Brofenbrenner (2005) proposed that "the psychological development of parents is powerfully influenced by the behavior and development of their child" (p. 12). Renee experiences, on a daily basis, the emotional stress of causing pain to her children with their basic self-care, but finds enjoyment in seeing them be playful with the service providers. Helping mothers to develop an appreciation for the co-occupations (Olson, 2004) they engage in with their child during difficult daily care routines would assist in developing an informal, supportive relationship between the parent and therapist. An occupational therapist's focus on and support of engagement in meaningful

occupations is a natural fit for working with mothers of young children with disabilities. For example, exploring with mothers ways to incorporate more efficient physical handling techniques, while promoting more satisfying playful, social interactions during a routine self-care task (feeding, bathing, dressing) with their child addresses concerns across several domains, including the child's functional skills, time constraints, and the mother's sense of well-being. Primeau's (1998) study of how families orchestrate work and play within their daily routines highlights the use of inclusion strategies, embedding play activities within adult work that can assist therapists to provide more meaningful recommendations when talking with parents.

Donovan et al. (2005) reported on the negative impact of occupational imbalance on mothers' sense of well-being and life satisfaction, and found efforts were made to interweave activities at home as part of the family routine to allow time for continued participation in work or community-related occupations. The mothers in this study shared the same frustration of not having enough time. Renee described how attending to her children's needs resulted in "a lot of stuff don't get done." Denise felt "it takes times five more of you..." to help a child who is totally helpless. Thompson (1998) reported the same and noted that mothers employed a strict set of routine and procedures to get things done. Denise and Elise described a similar approach within their narrative, and both expressed an appreciation for consistency on the part of service providers in keeping their appointments. Occupational therapists and other service providers need to be conscientious about their "professional behavior." Additionally, therapists can implement Kellegrew's (2000) recommendations of assisting a mother in assessing her child's abilities and envisioning the child's potential, and matching within the family's routines opportunities for skill development.

Time limitations also resulted in the loss of personal time for the mothers, frequently impacting occupations that are quieter and more reflective (Donovan et al., 2005). Anna's inability to expand on her responses to interview questions involving self-reflection regarding her strengths and how she perceived her role may be evidence of time demands on her well-being. Donovan et al.'s research additionally noted that a correlation exists between time costs, the degree of a child's disability, and/or the presence of behavioral problems. Anna had expressed ongoing concerns about both her daughter's speech delay and her behavioral problems. Occupational therapists and other service providers need to listen closely to mothers and other family members, be sensitive to the time constraints already placed on families, and search out approaches that truly support family members in their efforts to help their child.

The mothers consistently made accommodations within their families to meet the needs of their child. Frequently the accommodations resulted in financial loss due to work reduction, transportation, and child-care. It was apparent that the mothers were in a continuous "cyclical process of seeking, waiting, participating in, adjusting to, and analyzing the early intervention services their child received" (Thompson 1998, p. 213). Review of this study's findings highlights how the mothers made a conscious decision to seek help outside of their home; several had to wait for the intake/evaluation process to be completed and found themselves varying their level of participation based on 1) location of service delivery, in their home or at the center, 2) their level of comfort with the service provider, and 3) supports provided or not by the program (transportation, sibling participation). Evaluation or analysis of the service focused on convenience, time commitment, relationship of the service provider with their child, alignment of activities and recommendations with their goals for

their child, and perceived progress toward those goals. There were, at times, imbalances of accommodations, with the mothers expected to fit with the program's framework. The mothers would have preferred efforts to allow sibling participation, flexibility in the service provider's schedule, and prevention of service disruption due to a service provider's leave. Consistent with this, Thompson reported that mothers felt sibling participation contributed to a family-centered approach and potentially could bring the family closer together and strengthen family relationships.

Early intervention programs need to review their approach to service provision. Dunst (2000) points out that saying a family-centered approach is used acknowledges a philosophical belief but does not mean the actual principles and practices are utilized on a regular basis. A family-centered approach, viewed as the context of service, allows the professional and parent to create and evolve together and has implications for everyday practice (Brown, 2004). The emerging evidence-based model Dunst espouses integrates early intervention and family support. At the center is the outcome of learning and development. The "how" of implementation is the family-centered practices. Child and parent-child features are incorporated, along with family/community supports and resources as the "what." The interplay of the child learning opportunities with parental supports promotes parenting styles and instructional practices. Parent supports provided through family/community resources facilitate participatory opportunities for the parent. The integration of family/community resources and supports with opportunities for the child to learn are evidenced in family/community activity settings. Community-based early intervention programs need to continually reassess their function and format of

implementation to be a viable support for families, and ultimately their children, as family-center practice evolves under a new paradigm.

Occupational therapists can take an active role in assisting programs to recognize the vital role parents have in promoting their child's development and the need to provide opportunities for active participation in the services provided. This goes beyond the parent's input of words on a document and making the child available for therapy. It requires meeting a parent at the point they are at, listening to the parent, approaching service or the "what" with an understanding of the parent's reality, allowing flexibility, and embracing the family as full participants. Additionally, occupational therapists need to be aware of and contribute to the research regarding the most effective approaches for promoting child development through the strengthening of family functioning. By taking an active role, therapists have a voice on the legislative level, program level, and family level in how their services contribute to the goals of early intervention and how they can best be utilized.

Limitations of the Study

The use of a convenience sample of mothers, due to time constraints, does not provide a true representative sample of all mothers engaging in early intervention programs. It is felt that the participants did reflect a typical service provider's caseload for an urban area but may not have represented typical mothers within a suburban or rural setting. Additionally, the inclusion of mothers from other cultures (Hispanic, Arabic, etc.) and those who work outside of the home may have provided other factors relevant to engagement in community-based programming. However, within the context of a phenomenological design, each informant's (mother's) perspective is considered valid.

The focus of this study was on mothers, as they tend to be the primary caregiver of children in general. It is recognized that other family members are involved in the care-

giving for children, and each has his or her own unique perspective and valued experiences. The contributions of fathers, grandparents, other extended family members, and foster parents should be explored for their distinctive viewpoint of supporting the engagement in early intervention services.

Bronfenbrenner (2005) discussed the concept of “proximal processes as the primary engines of development” that can be applied to both the mother and child engaging in the early intervention program. He emphasizes how factors of the person, environment, outcomes, and changes over time impact the form, power, content, and direction of the proximal processes. Each mother described her process of engagement based on the context of her child’s age and length of time in the program. It should be considered that the same mothers may have provided a different perspective if interviewed at an earlier or later date, based on the varying impact of factors related to person, environment, outcomes, and changes in themselves and their child.

Future Directions

The mothers’ stories explored within this study provide fertile ground for further research that would strengthen family-centered practices at the levels of family, program, and social policy. One thread that was interwoven throughout the narratives was the impact of informal supports. It is imperative to go beyond just identifying the specific supports and to seek out ways to promote the supports that are lacking for individual families. Occupational therapists can contribute to this important task by assessing families they work with, working collaboratively with neighborhood programs/agencies that can provide needed supports, and advocating social policy that recognizes the basic needs of the families with young children experiencing developmental delays.

Families' awareness of formal supports and services that would address their concerns, and the ease with which they are able to access them, needs to be addressed. Specifically, public awareness of available services (e.g. respite care) is inconsistent throughout communities across a county, a state, and this country. Additionally, services frequently have complex application procedures and eligibility criteria that frustrate and limit participation by those families that would benefit. State mandates and program policies are an area in which planning should be based on research to achieve a balance of accessibility with accountability. Individual programs need to review their policies and the valued services they provide to develop the flexibility in programming that promotes greater participation by families. Furthermore, it is imperative that the service providers of early intervention programs behave professionally, while facilitating supportive relationships with families.

The educational institutions that provide the professional foundation of therapists and teachers need to address family-centered practices as a core part of any curriculum focusing on early childhood education/development. This would mean going beyond the concept of a family-centered approach as a philosophy and speak to a service provider's ability to recognize each family's unique needs and concerns, understand their reality, and facilitate a relationship that is supportive and sustaining. Respect for the time constraints of family members demands that therapists use evidence-based approaches to ensure effective and efficient techniques. Occupational therapy's attention to the co-occupations of the caregiver and the child can facilitate the well-being of the individual family members by easing time constraints and addressing concerns across the developmental domains. Thus, assisting families in achieving an occupational balance, therapists can promote a family context conducive to a child's development.

Table 1.

Demographic Information for Participants-Personal Factors.

Mother	Age	Marital Status	Education	Employment Status
Anna	35 yrs.	Single	High School 2 yrs. College	Part-time Employment
Denise	37 yrs.	Married	High School 3.5 yrs. College	Home full-time Previously employed until birth of second child, due to her special needs.
Nadine	22 yrs.	Single	Vocational Technology Program/H.S.	Part-time employment
Elise	41 yrs.	Married	High School Business School Certificate	Home full-time Previously employed until birth of second child, due to her special needs.
Renee	30 yrs.	Married	High School 2 yrs. College	Home full-time Previously employed until birth of first child.

Table 2.

Demographic Information for Participants – Child Factors

Mother	Number Of Children	Number Of Children Enrolled	Age of Child with Special Needs	Level of Child's Disability
Anna	2 girls 1 boy	1 girl 1 boy	G: 4.5 yrs. B: 1.0 yr.	G: Speech Delay B: Developmental Delay
Denise	2 girls	1 girl	2.10 yrs.	Physical Impairment
Nadine	2 boys	1 boy	3.0 yrs	Developmental Delay
Elise	2 girls	1 girl	1.9 yrs.	Severe Multiple Impairments
Renee	2 girls 1 boy	2 girls	4.0 yrs & 2.6 yrs	Both: Physical Impairment

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APPENDICES

Appendix A: Approval from Human Subjects Review Committee



EASTERN MICHIGAN UNIVERSITY

February 15, 2005

Patricia Brennan
c/o Elizabeth Francis
Campus

Dear Ms. Brennan,

The CHHS Human Subject Review Committee finds that your request entitled "How Mothers Orchestrate their engagement in an early intervention program" submitted on 2/15/2005, meets the Minimal Risk Standards and is approved for initiation .

The Committee may request further approval if secondary analysis of the data is conducted.

Sincerely,

A handwritten signature in cursive script, appearing to read "Stephen A. Sonstein".

Stephen A. Sonstein, PhD
Chair, CHHS Human Subjects Review Committee

Appendix B: Letter of Introduction

Project Title: How Mothers Orchestrate Their Engagement in an Early Intervention Program**Project Supervisor: Elizabeth Francis-Connolly, PhD., OTR****Primary Investigator: Patricia Brennan, OTR**

Dear Mother,

As a mother of a young child with a disabling condition or developmental delay you may have been faced with many questions about the services available to you and your child. Additionally you may have had to make decisions regarding the demands on your time. Research recognizes that the factors supporting, or not supporting, a mother's involvement in early intervention services are many and complex. I would like to take a closer look at how and why mothers make the decisions they do about engaging in these services.

I, Patricia Brennan, have been an occupational therapist with Detroit Public Schools' Early Intervention Program for over twenty years. I am currently working on a master's degree through Eastern Michigan University, and would like to carry out a study of mothers' thoughts and feelings about their involvement with the Early Intervention Program. As a mother of two children, I am aware of the demands made on a mother's time and energy. The purpose of the study is to gain greater understanding of the meaning mothers find in the services provided, what services they value, and how they would define "family-centered care". Through my research findings I hope to help the program meet the unique needs of the families it serves, and to document mothers' stories that may contribute to service providers' education and/or future legislation.

If you chose to take part in this study I will contact you by phone to schedule an interview at your convenience. I will do this first interview in person, and it may last for an hour or more. Additional interviews may be in person or by phone, and take less time. The interviews will be audio recorded. Efforts will be made to ensure confidentiality of your and your child's identity. You will be informed of your rights, have the opportunity for any questions you may have answered, and you will be asked to sign a written formal consent before the initial interview. At the end of my research and analysis I will share my findings with you, and may ask for your feedback. There is no risk to you or your child if you decide to, or not to, become involved in this study.

I greatly appreciate any consideration you give for participating in this study. If you are interested, please let your therapist know. You may contact me if you have any questions at (313) 494-0961, ext. 205.

Respectfully yours,

Patricia E. Brennan, OTR

Appendix C: Informed Consent

Project Title: How Mothers Orchestrate Their Engagement in an Early Intervention Program**Project Supervisor: Elizabeth Francis-Connolly, PhD., OTR****Primary Investigator: Patricia Brennan, OTR****Consent to Interview**

I agree to take part in one or more interviews with Patricia Brennan, who is an OTR completing her master's thesis at Eastern Michigan University. I understand that as a mother of a young child experiencing development delays, I will be asked about my thoughts and feelings regarding my experiences with early intervention services. It is hoped that through an interview my point of view will help provide a greater understanding of the meaning mothers find in the services, and increase the awareness of how mothers define family-centered care.

I understand my taking part in the interview(s) is completely voluntary. If I agree to participate, Patricia Brennan will contact me by phone (or person) to set up an initial interview at a location and time convenient to me. The interview will be audio recorded, Patricia may take notes during the interview, and a transcript will be made of the interview(s). I may choose **not** to answer certain questions, and may withdraw or discontinue my participation at **any** time without consequence to me, or my child. Further, if I withdraw my participation at any time **during** or **after** the interview(s), I have the right to have my tapes and transcripts destroyed, and have no material from my interview(s) used in any way.

I understand that there are no known risks to me if I participate, and procedures will be followed to protect my confidentiality and the confidentiality of my child. My name will only appear on this consent form, which will be kept separate from the audiotapes and transcripts, in Dr. Francis-Connolly's office. A numerical code will be used for tape and transcript identification, a fictitious name will be assigned for field notes and for use in the thesis' narrative. All identifying characteristics will be eliminated. The tapes and transcripts will be kept in a locked drawer in Patricia Brennan's office at home until the completed thesis is submitted. Then the audio recordings will be destroyed. In addition to Patricia, her thesis advisor, Dr. Francis-Connolly, may review the recordings and transcripts.

I understand that the information I provide by interview(s) will be written up for the completion of a thesis to be submitted to Eastern Michigan University's Graduate School. It may also be submitted for publication in a professional journal or presentation.

Please feel free to contact us if you have any questions. Thank you for your participation.

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Consent to Participate in Research Study

I have read, or had read to me, all of the information regarding this study. I have received an explanation and understand the meaning and content of the information. All of my questions have been answered. I hereby consent to be interviewed as part of this study. I have received a copy of this consent.

Name of Interview Respondent	Signature	Date
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Name of Interviewer	Signature	Date
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Appendix D: Interview Protocol

Mother's Code #: _____ Date(s) Contacted: _____

Date of Scheduled Interview(s): _____

Marital Status: M S D

Child's (in program): Age _____ Sex: M F

IEP Eligibility: _____

Developmental concern:

Other Children: Age _____ Sex: M F Age _____ Sex: M F

Age _____ Sex: M F Age _____ Sex: M F

How did you first connect with the early intervention program?

Can you describe for me a typical service you received, or a session you took part in with your child?

How do you know when a service or program works for you?

What are you looking for in services for you and your child?

What do you see as your greatest strength in meeting your child's needs?

How do you decide what to spend your time/effort on?

