

MATERNAL LOCUS OF CONTROL AND PERCEPTION OF FAMILY STATUS AT
ENTRY AND EXIT OF BIRTH TO THREE EARLY INTERVENTION

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Birth to three early intervention is unique time in the life of a family of a child with a disability in that confidence and competence of the parents can be addressed as part of the intervention goals and objectives. Locus of control is a quality measure of a parent's perception of their ability to be their child's teacher, advocate, and champion and is associated with confidence and competence. The purpose of this dissertation was to examine the association of locus of control orientation using Rotter's Locus of Control Scale (Rotter, 1966) with perception of family status as it relates to the child with the disability at entry and exit of birth to three early intervention using the Family Outcomes Survey (Bailey, 2006) in two groups of mothers at entry and exit of services. Analysis indicated there was no difference in locus of control between the two groups. Further, locus of control was not associated with the Family Outcomes Survey. The Family Outcomes survey demonstrated differences between the two groups and additional association with the socioeconomic proxy of type of insurance, length of time the family took part in early intervention, and the reason the child qualified for early intervention.

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1.0 INTRODUCTION

1.1 MY PERSONAL VIEW

I am speaking to a class of graduate students about my son with severe disabilities and the effect he has had on my family. I want to tell my story carefully to this class and make a lasting impression. It has not been an easy fifteen years. My husband would say “nobody knows.” The years have been filled with medical crises, behavioral issues, struggles with typical family occurrences such as relationships, holidays, and travel, none of which my son handles well, and, I probably should mention, school has had some bumps too. I want to paint an honest picture of the difficulties we have faced but I also want the message to the students to be one of how we continually regain our balance and how, above all, we have found an indescribable joy in an alternate route down the path of parenthood. Not some stupid trip to Holland. I have been to Holland. This is more than that; harder than that, and better than that. How was this accomplished by my family and how is it accomplished by other families? .

There are two other parents sharing their story as well. Our stories have similarities. We have fared pretty well; we have had happy times; we are all still married. Our stories, however, also have some differences. One parent tells the student audience that the message of hope is the single most important thing they can impart to parents early in the intervention

process. I share my thoughts. I try to convey the significance of the resilience that has shaped my story, but the message from the other parent of the importance of hope mulches around in my brain for days and days. Why am I uncomfortable leaving the students with the idea that hope is the single most important quality for adapting successfully?

I slowly reconcile how hope is related to not only personal attributes such as optimism, but concrete constructs such as control beliefs. I realize that this parent is not advocating that early intervention specialists encourage hope in the sense of denial coupled with false expectations. To allow parents to hope that their child will be typically developing, or hope for a cure is not the unrealistic or damaging hope of this parent. Hope is, rather, the beginning of personal control, self-efficacy, and strategic thinking. This parent, too, regained balance and strength when he recognized his ability to parent effectively and confidently, gained skills particular to the child, and understood a bit about the future. McCubbin, McCubbin, Thompson, Han, and Allen (1997) state that there are critical factors in the “recovery” phase of adaptation to stress including family optimism (there’s that hope), control, and mastery. In some instances, as with this particular parent, having hope is synonymous with having an internal locus of control, the topic of this dissertation.

Locus of control refers to the extent to which individuals believe that they can control events that affect them. Individuals with an internal locus of control believe that events result primarily from their own behavior and actions. Those with an external locus of control believe that powerful others primarily determine events. The question posed here is how maternal locus of control is related to maternal perception of family status. Locus of control is important because it is a two-fold indicator of the coping process. When a mom has an internal locus of

control she feels confident in her ability to accomplish the task at hand and she then proceeds in accomplishing the task with competence.

Before my child with disabilities was born, I had two typically developing children to parent. Parenting my two typically developing children was a continually reinforcing process. I was immersed in a sea of other relatively like-minded parents that shared thoughts, tips, giggles, references, and advice on any parenting, childcare, or school issue that might arise. Quite naturally and with little effort, our roles fluidly drifted between being mentored and being the mentor. It was a tremendously strengthening journey. Brooks-Gunn (1995) would attribute this reinforcement to my “neighborhood.” Along came Brian, my child with disabilities. Instead of being shoulder to shoulder with other parents, I was suddenly on some Survivor-type remote location. Yes, there were other parents, but we were all deeply buried in our own lives; our issues were dissimilar and our children had unique needs. I remember feeling as though parents held onto their knowledge as if it would evaporate if they shared it. Maybe their hard-earned knowledge was like their own precious, unshareable immunity idol. Whatever the case, during this time my confidence and competence took a hard hit. There was no book to guide me and inconclusiveness continually shrouded me from doctors, therapists, family and friends. Possibly because my child has severe disabilities with no actual diagnosis, this was a relatively long time period, well past the birth-to-three warm cocoon of the family centered care we received. Regaining the balance and control of my family’s well being was paramount to my well being and now guides my dissertation. For me there is nothing more important than the study of the family and how early intervention specialists can empower each family toward regaining their balance. I believe it is in regaining control that the families find “the will and the way”, or the confidence and competence to parent their child with a disability. My hypothesis for my own

resilience is that supports and resources were put in place, time passed, we were knowledgeable enough, money helped, and I slowly gained control and focus. Though each family is unique and will adapt to having a child with a disability in their own way, research gives us strong clues regarding a general path to follow. Demonstrating how enhancing and strengthening of the whole family is more likely to result in the perception of control is the goal of this research paper.

1.2 MY PROFESSIONAL VIEW

Locus of control is a theoretical concept designed to assess an individual's perception of control over his or her own behavior (Rotter, 1975). Traditionally, although locus of control has been described as a dichotomous variable, internal versus external, it is best thought of as a continuum, rather than two polar qualities (Rotter, 1975). An individual with internal locus of control refers to an individual's perception that he or she possesses the ability to control the outcome of life events or destiny (i.e. happiness, career, health) by their own skill or effort (Rotter, 1975). An illustration of this is a student that studies long, hard hours, convinced that his or her efforts directly influence the outcome, in this case a grade in a course. Individuals with the contrasting belief, those with an external locus of control, perceive that the control of their lives is out of their hands (i.e. fate, chance). An illustration of a student with an external locus of control is one who feels it is useless to study or work hard for a grade because the teacher is not fair. Individuals having an external locus of control often demonstrate lack of persistence and low expectations of themselves. Conversely, individuals with a strong internal locus of

control possess a compelling internal feeling of guiding their own destiny and a sense of being in control (Ross & Broh, 2000).

Maternal locus of control in the context of a family of a child with a disability refers to the mother's perception of her ability to influence or control the developmental outcomes and well being of her child with a disability with parenting practices (Belsky, 1984; Smith, Oliver, Boyce, & Innocenti, 2000). Maternal locus of control is an important reflection of how a mother views her ability to control her own life and the life of her child (Affleck, Allen, McGrade, McQueeney, 1982; Fox, 1980; Maisto & German, 1981). While all parents at times act as advocates, and seekers of information for their children, parents of children with disabilities are required to be confident and competent in these roles very early on. An individual with an internal locus of control may still believe that God, or a higher power has a hand in her life (Aspinwall & Leaf, 2002). This was exemplified recently in an article about a national vocabulary contest for high school. The winning student was an honors student from a local high school and studied Latin to prepare for the contest. However, in speaking of winning the (speculated) highly "internal" student claimed that while he studied hard to win, he didn't know some of the other vocabulary words and acknowledged that chance played a part in his victory. There is room for "other than ourselves" as an influence even with individuals with a strong internal locus of control (Weiner, 1974).

Does this mean that having an internal locus of control is always preferable? The question arose in the Major Area Paper defense for this author during a discussion about whether or not it was always advantageous for a mother of a child with a disability to have an internal locus of control. The point made was that possessing an external locus of control may allow the mother to distance herself from any guilt associated with having a child with a disability, and

may actually aid in coping. This was an interesting premise about locus of control and led this author to ask questions regarding situations, if any exist, in which it may be of value for a mother of a child with a disability to have an external, rather than internal, locus of control in relation to parenting a child with a disability.

A small body of research exists on *acceptance* of a child with a disability and locus of control (Galligan, 1982; Morris, 1992). Morris (1992) compared locus of control to three patterns of acceptance: active, passive, and limited, in urban black mothers of sons with disabilities. Locus of control was found to be central to active acceptance, affecting self-esteem, attitudes toward the child, and ability to gain access to resources. Overwhelmingly, researchers concur that having an internal locus of control is preferable to having an external locus of control for more positive adjustment or adaptation in families of children with disabilities (Hall, 1995; Hassall, Rose, & McDonald, 2005; Jones & Passey, 2005; Turnbull et al., 1993).

Adjustment to having a child with a disability is addressed by Part C of the Individuals with Disabilities Act (IDEA) by recognizing the importance of the mother and family in the life and development of a young child by making the assertion that birth to three early intervention (herein referred to as EI) is designed “to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities” (Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 100 Stat. 1145 as cited in Bailey et al., 1998). This goal is known as family-centered services and has been cited by researchers as a main path to increasing parental confidence, competence and control (Dunst, 1997; Dunst, Boyd, Trivette, & Hamby, 2002).

Approximately three years ago, the Center for Disease Control (CDC) initiated a parent education campaign entitled, “Learn the Signs. Act Early.” The purpose of the campaign in part

was to increase parental confidence in knowing developmental milestones and to increase competence in assessing if their children had attained milestones and knowing when to seek professional advice. By creating this campaign, the CDC sent the message that parents play a key role in the daily care and education of their children. This campaign led this author to begin thinking about parents of children participating in EI and asking questions about the confidence of these parents.

Personal experience led to early speculation that the birth of a child with a disability may negatively influence confidence, competence, or perception of competence, and locus of control in mothers. This could be the result of their child having an atypical trajectory or timeline of development, or simply that a sense of imbalance occurs early in the discovery phase when a child has a disability. Among other variables, time is needed for the re-stabilization and adjustment of the family that would accompany regaining confidence, competence and internal locus of control. This author began to reflect on the limited time a parent often has to (re)gain this sense of confidence and recalled that researchers such as Guralnick (1998) state that confidence threats prevent an individual from gaining mastery or control, leading to increased stress and less than optimum child developmental outcomes. This reflection led to speculation that it would be of value to know if locus of control and family adaptation were associated at the exit of EI.

Guerin and Chabot (1992) iterated that when stress creates imbalance in a family, the family strives to adapt through coping mechanisms. One model to illustrate how this occurs is the Double ABC-X model of adjustment and adaptation (McCubbin & Patterson, 1983). The Double ABC-X model is a framework used to describe critical variables that interact when stress, called a stressor event by the authors, is introduced into a family. The model is used for

multivariate analysis of the stress events (A), resources that aid in dealing with the situation (B), family perceptions of the event (C), and the outcome in terms of how the family has adapted or adjusted (X) (Lavee, McCubbin, & Patterson, 1985). Understanding that the linear relationship among stressors (A), family factors (B), maternal perceptions such as locus of control (C) are associated with family adjustment and adaptation (X) will lend valuable insight to help guide the direction of services offered in the home setting. This model will be used in the literature review portion of this paper to describe the relationship of locus of control (C) to stress (A), resources (B) and adjustment and adaptation (X). This model was originally used to describe family adjustment and adaptation of mothers in the absence of spouse support (McCubbin & Patterson, 1983). In this study, the Double ABC X model will be used to provide a theoretical base to maternal perception of the family's current status with regard to their child with a disability.

Currently in Pennsylvania, the family of a child who qualifies for EI services under Part C has a dual role in the provision of services. The family is part of the education team, but can also be the recipient of services and supports up to age three as outlined in the Individualized Family Services Plan (IFSP). Generally after age three, the family's role is to be part of the education team rather than included in the service focus. As of July 1, 2008, Pennsylvania has one plan for both age groups in EI. By design, this suggests the parent, by the time the child is three years of age, needs to be relatively confident about what matters to them and their child in terms of special education focus, to be able to find and secure resources and supports, to understand their child's strengths and needs, and to know their rights and advocate for their child. The federal government requires states to gather and report family outcome data, at the exit of birth to three EI on at least these objectives. One of the commonly used instruments to measure family adaptation is the Family Outcomes Survey (Bailey & Bruder, 2005). The Family Outcomes

Survey is described by the authors as measuring a benefit experienced by families as a result of services and supports received not as the actual receipt or satisfactions with services (Bailey et al. 2006). In this study, the mother's perception of the status of her family at exit of EI is measured by using the Family Outcomes Survey and compared with responses from mothers as they enter EI.

Many families participating in birth to three EI enter the system close to their children's third birthday and do not have the luxury of time with home-based family centered services, as often is the case, for example, with children diagnosed on the Autism Spectrum. Consequently, there is little time for some families to acquire confidence and competence that may be required of them post home-based, family-centered services. If EI is doing its job, assuming that there is a relationship between confidence and competence, we might ask whether the length of time in EI or locus of control orientation is associated with benefit to the family as measured by the Family Outcomes Survey.

In a general sense, the CDC campaign and a specialist in birth to three EI have similar objectives of building confidence and competence in parents and families. Family centered services help build parental confidence, competence and control (Dempsey & Dunst, 2004). Allen and Cowdery (2005) state that EI has a broader purpose designed to "empower a family to carry out interventions in a manner in which family members acquire a sense of control over their own developmental course" (pg. 168). Specifically, locus of control is associated with parent involvement (Fox, 1980; Helm, Comfort, Bailey, & Simmeonsson, 1990), confidence (Park, 2004), and other factors that are key intervention components that can significantly impact child outcomes and family adjustment, making maternal locus of control a particularly salient variable to study.

1.3 PROBLEM STATEMENT

The Double ABC-X model of adjustment and adaptation provides the theoretical foundation for understanding the significance of locus of control. It is a fact that parents of children with disabilities report more stress (Beckman, 1991; Crnic, Friedrich, & Greenberg, 2002; Walker, 2002). Such stress may come at any time, according to the Double ABC-X model. Parents of children with disabilities have roles that encompass being an information seeker, problem solver, public educator, political activist, and spokesperson for their children who may be unable to communicate their own needs. Parental control over these roles and the direction of a child's growth and development is an important direction for research with families of children with disabilities. Locus of control research regarding family adaptation remains largely theoretical and definitional in nature.

This dissertation will commence with a discussion of the significance of locus of control using the Double ABC-X model of adjustment and adaptation as a framework. This framework will allow the reader to understand the influence locus of control exerts in the family adjustment process. The purpose of this dissertation is to examine differences in maternal perception of family status as it relates to the child with a disability between entry and exit of EI program participation in two independent groups of mothers. The impact of length of time in the program and other demographic and child variables will also be examined with regard to maternal perception of current family status, or family outcomes, and locus of control. Comparing measures of maternal locus of control and family status will have theoretical implications in the

area of confidence a mother has about her ability to affect her family's status and effectively control family outcomes and of changes in locus of control orientation that are affected through the EI process..

1.4 OUTLINE OF THE PRESENTED WORK

The remainder of this dissertation is organized as follows: the **Review of the Literature** highlights background material that is essential for a complete understanding of the issues involved in maternal locus of control in families of children with disabilities. This chapter includes a detailed historical account and review of the literature showing how previous work has left a gap in understanding and knowledge. The review will be guided by the following questions prompted by the Double ABC-X model of adjustment and adaptation: 1) What is locus of control (C)?, 2) What is the association between locus of control (C) and stress (A)?, 3) What is the relationship among locus of control (C), and supports and resources (B), and 4) how is locus of control (C) related to family adaptation (X)?

The **Methodology** is an outline of the research method that will be applied in order to collect information on maternal locus of control, family resources, and family adaptation. The **Analysis of Data** will be an explanation of the results of the research and the **Discussion** will be a synthesis of the results and future implications for practice.

2.0 REVIEW OF THE LITERATURE

For the purpose of this portion of the literature review the topic of Maternal Locus of Control was searched exhaustively and narrowly, using the full phrase of “Maternal Locus of Control”, the word ‘Maternal’, the Boolean term ‘*and*,’ and the phrase ‘Locus of Control’, and was searched with the phrases “Maternal” and “Locus of Control” and all other reasonable combinations that center on the early life of a child with a disability and his or her family. This search took place using the resources provided by the University of Pittsburgh Library system on campus, as well as digital resources, and the Internet. Search engines used included Ovid, Medline, Eric, Ebsco, and Google.

2.1 LOCUS OF CONTROL AND THE DOUBLE ABC-X THEORY

Parenting a child with a disability is not necessarily a negative experience (Summers, Behr, & Turnbull, 1989), although parents of children with disabilities consistently report more stress than do parents of children without disabilities (Beckman, 1991; Crnic et al., 2002; Walker, 2002). Research confirms a higher level of stress in families of children with disabilities by using matched control families of children without disabilities (Friedrich & Friedrich, 1981; Kazak, 1987; Sanders & Morgan, 1997). Longitudinal studies of families of children with disabilities demonstrate that the stress is chronic in nature, remaining elevated over the course of the family

lifespan (Baxter, Cummins, & Polak, 1995; Dyson, 1993; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999). Although most parents adapt well to the situation of caring for a child with a disability, some struggle. Parent perceptions are a key component in successful adaptation to the complex nature of stress. It is imperative that EI specialists understand ways to address parental adjustment and adaptation to the stress involved in having a child with a disability.

Parental adjustment and adaptation to stress can best be illustrated and understood using a framework, such as the Double ABC-X model, that illustrates the variables that come together to form an individual's reaction, or adjustment, to a stressor (Frey, Greenberg, & Fewell, 1989; Ostberg & Hagekull, 2000; Raina et al., 2004). The reaction by the parent is the way in which the parent adjusts or adapts; it represents one of the outcomes of birth to three EI. The terms family status, family outcomes, and adjustment and adaptation are used synonymously throughout this dissertation. Research on parenting stress associated with raising a child with a disability has typically been conducted more with mothers than fathers, possibly due to the greater number of mothers as primary caregivers. Research conducted with both parents has demonstrated that both parents have similarly high levels of parenting stress (Cameron, Dobson, & Day, 1991; Dyson, 1997), although mothers and fathers may experience different aspects stress.

Rueben Hill (1949), considered the father of family stress theory, published an organizing framework in which to conceptualize family stress and adaptation. He first conceptualized stress based on wartime separation and reunion adjustment data from Iowa families. Hill used this situation to develop a two-part model of stress and adjustment. In this model he held that families were in a homeostatic mode until a stressor occurred. Once the

stressor occurred, the family would work to regain the homeostatic state they held prior to the stressor.

In 1965, Hill developed his theory further to become the ABC-X equation of stress. In this later version, Hill (1965) proposed a set of interdependent variables and relationships that have remained almost unchanged to this day. In the ABC-X model, “A” represents the provoking stressor or hardship produced by the event; “B” symbolizes the resources and strengths of the family; “C” stands for the family’s definition or meaning they attach to the stressor or hardship, and “X” represents what Hill termed the crisis, or the outcome of interaction of variables. This model recognizes that different families, according to their perceptions of the event, and their supports and resources could end up with a different outcome (X) from the same stressor (A).

Criticisms of Hill’s ABC-X model were that the stressor event, or A, was conceptualized as a distinct and single event; in actuality, the event could be a culmination of smaller events where the beginning and end are blurred. McCubbin and Patterson (1983) recognized the need for a broader definition of the stressor event and proposed the Double ABC-X model to capture the phenomenon of a “pile-up” of stress and strain. The term pile-up refers either to the synergy created from many stressors or from the introduction of a new stressor as the family is trying to adjust to the initial stressor involved with caring for a child with a disability. Parents may react to a seemingly small, singular event with the weight of all the other events already on their minds. In this revised model, the single stressor A is represented by multiple child characteristics and disability related issues (A, a, a...) experienced by the family that multiply to exert negative influence. Similarly, multiple existing resources (B, b, b...) and family perceptions (C, c, c...) interact to produce the outcome, or X. The Double ABC-X model identifies the types of

families, conditions, resources, and perceptions that coincide with positive adjustment and adaptation to stress that can occur in response to non-normative events, such as the birth of a child with a disability. The message of the Double ABC-X model is that the EI specialist can potentially manipulate maternal adjustment by influencing maternal perceptions, such as maternal locus of control.

In actuality, the way in which an individual perceives and processes stressful events is the most significant intermediary in determining consequences of stress. There is a large body of research in the area of resources, including social support (Dunst, Trivette, & Cross, 2002; Manuel, Naughton, Balkrishnan, Smith, Koman, 2003; Walker, 2002) but not much research on perceptions as a way of adapting, or coping, to threatening events (Affleck & Tennen, 1993). Parental perceptions as coping strategies refer to the ways in which individual parents change their subjective perceptions of stressful situations (McCubbin et al., 1980). The study of how parental perceptions influence family adjustment, adaptation, and ultimately, family outcomes are tightly entwined with effective and confident parenting has received less attention from researchers. There has been research in the areas of parental locus of control and child health and education outcomes (Barakat, Lutz, Nicolaon, Lash, 2005; Lynch, Hurford, & Cole, 2002), but not in the area of parenting a child with a disability. Empirical research shows that a child's development is likely to benefit from a parent who is psychologically healthy and mature (Belsky, 1984). More specifically, child development is positively influenced by a parent that is outgoing, agreeable; possess a positive self-esteem, and an internal locus of control (Belsky & Barends, 2002). Therefore, the review of the parental perceptions that may influence feelings of well-being, psychological health, and adjustment and adaptation in stressful situations are important parental characteristics to study. The following review will focus on the framework of

the Double ABC-X theory with relation to locus of control. To facilitate the natural flow of discussion of locus of control, the review will begin with a thorough overview of locus of control (C) in the Double ABC-X model, the relationship between locus of control (C) and stress (A), the relationship between locus of control (C) and, supports and resources (B), and then proceed to a discussion of how locus of control (C) contributes to family adjustment and adaptation (X).

2.2 MATERNAL LOCUS OF CONTROL: C IN THE DOUBLE ABC-X MODEL

The beliefs, attitudes, perceptions, and characteristics of a mother affect the manner in which she is able to adapt to the experience of caring for a child with a disability (Jones & Passey, 2005; Petrosky & Birkimer, 1991). Maternal locus of control in the context of a family of a child with a disability refers to the mother's perception of her ability, or skill, to influence the developmental outcome and well being of her child with a disability, and her perception that developmental outcomes can be influenced with her parenting practices (Belsky, 1984). Skinner (1995) concluded, "Five decades of research have established [personal control] as a robust predictor of people's behavior, emotion, motivation, performance, and success and failure in many domains of life" (p.3). This quotation from Skinner reinforces that maternal locus of control reflects the degree of confidence and self-assurance of a mother, and her ability to accomplish positive family outcomes. For this reason, the review of locus of control will commence with comparing locus of control to confidence and competence.

2.2.1 Maternal locus of control, confidence, and competence.

Confidence is a feeling of self-assurance and competence is the perception of having ability or a particular skill set. Confidence (Judge, 1998; Park, 2004) and competence are associated with locus of control (Hagekull, Bohlin, & Hammarberg, 2001; Silsby, 2004).

In a study comparing maternal perception of parenting skill and actual ability in parents of children with disabilities, Morrin (1988) found that perception and actual ability were positively correlated. Additionally, maternal locus of control, income, and perceptions of the child were related to the child's developmental outcome. This strong correlation between perception and actual ability supports the relation between confidence and competence. Morrin (1988) demonstrated that when mothers had *confidence* in their knowledge it did, in fact, correlate to their actual *competence* with that knowledge. Although these terms cannot be used interchangeably, Morrin (1988) demonstrated they are strongly associated concepts.

Other authors have found an association between competence and locus of control (Luster & Rhodes, 1989). McKinney and Peterson (1987) found that sense of competence was the only predictor of perceived locus of control in a sample of 67 mothers and their children with developmental disabilities.

Competence, confidence, and locus of control were of interest in a study by Hassall, Rose, and McDonald (2005) in which they examined the effects of cognitions, including efficacy, satisfaction, and locus of control, on parenting stress and use of social support in mothers of children with an intellectual disability. Hassall and colleagues (2005) collected data on 46 mothers of children with a cognitive disability, with a mean age of 9 years, using measures including Vineland Adaptive Behavior Scales, Parenting Stress Index-Short Form (PSI), Family

Support Scales (FSS), Parental Locus of Control scale-Short Form Revised (PLOC), and the Parenting Sense of Competence Scale (PSOC).

Several hypotheses were confirmed in Hassel's study including: 1) associations between the children's behavioral difficulties and parenting stress, 2) an inverse association between parenting stress and self esteem as well as parenting stress and sense of competency, 3) an association between higher levels of stress and an external locus of control, and 4) an inverse association between social support and parenting stress. It is these last three findings that are of particular interest to this literature review.

To study the inverse associations of parenting stress with self esteem and parenting stress with competency, Hassall et al. (2005) looked independently at the correlation between the scores on the Parent Stress Index, the Parental Locus of Control scale, and the Parental Sense of Competence scale. They found correlations between the Parental Locus of Control scores and the Parent Stress Index scores. They also found correlations between the Parent Sense of Competence subscales, satisfaction and efficacy, and the Parent Stress Index. Lastly, there was an association with the subscale of efficacy and Parental Locus of Control but not between the satisfaction subscale and the Control measure.

Because locus of control and sense of competence represent parents' perceptions of themselves, Hassall et al. (2005) compared the correlation of the scores from the Parental Sense of Competence scale and the Parent Locus of Control scale as a way of determining conceptual overlap and to compare results with other studies. Analysis of the Parental Sense of Competence scale and the Parental Locus of Control scale revealed correlation between the two scales. Additionally, the subscales of efficacy and satisfaction of the Parental Sense of Competency scale were correlated to the Parent Locus of Control total score and the parental efficacy

subscale. However, the subscale of satisfaction of the Parental Sense of Competency scale was not correlated to locus of control.

In response to the question of whether there is conceptual overlap between Parental Locus of Control and Parental Sense of Competence in this study, the answer is both yes and no. The Efficacy subscale of the Parenting Sense of Competence scale, which reflects competence, problem-solving ability, and capability, is related to parental stress and parent locus of control orientation. Parents that feel competent perceive themselves as good problem-solvers, and are capable, generally have an internal locus of control and lower parental stress. The Satisfaction subscale, which reflects parenting frustration, anxiety, and motivation, is associated with parent stress independent of locus of control. So although there is some conceptual overlap between locus of control and sense of competence, parenting satisfaction and parenting locus of control are distinct measures.

Hassell and others (2005) third finding theorized that mothers with a more external locus of control report higher levels of stress. The fourth finding uncovered an inverse association between social supports and parenting stress. This analysis involved Hassell using the Parent Stress Index as the dependent variable in a stepwise regression with the measures of control and competence entered as independent variables. They found that the measure Parental Locus of Control accounted for 44% of the variance on the Parent Stress Index. Also, the Parent Sense of Competence-satisfaction subscale combined with Parental Locus of Control scale to account for 54% of the variance. Parental Locus of Control, Parental Sense of Competence, and the Vineland Adaptive Behavior Scales accounted for 59% of the variance. Family Social Support did not enter the regression. The authors tested the correlation between Family Social Support and the Parent Stress Index while regulating the measures of Control, Competence, and the

Vineland. Family Social Support and the Parent Stress Index were no longer correlated, which illustrates that the association of social support and parental stress is mediated by parental locus of control. The authors concluded that when a parent perceives that they have social support and are in control of this support, parent stress is reduced.

In this important study of parent perceptions of stress in mothers of children with disabilities, higher levels of maternal confidence and higher levels of internal locus of control were related to decreased levels of parenting stress. This study confirmed that in families of children with disabilities maternal locus of control and maternal competence share convergent qualities when using the Parental Locus of Control scale and the Parental Sense of Competence-subscale parental efficacy. Both of these measures are strongly associated with parental stress.

Researchers (Belsky & Barends, 2002; Guralnick, 1998) note that the influence of personal beliefs shape parents thinking that then directs the way in which they care for and influence their child's development. A mother that has an internal locus of control orientation is a more confident, competent mother. As will be discussed later in this review, locus of control orientation appears to be quite malleable. Shaping locus of control may be one way for the EI specialist to support and enhance the family, thus influencing child outcomes.

2.3 THE RELATIONSHIP BETWEEN LOCUS OF CONTROL AND THE STRESSOR EVENT: $A \times X$ IN THE DOUBLE ABC-X MODEL

Stress is a normal part of family life. A stressor event, so named by McCubbin and Patterson (1983), is an occurrence that exerts strain on a family or exposes the family to increased vulnerability and is the A variable in the Double ABC-X model of adaptation. According to the

Double ABC-X model, a family may feel stressed from a seemingly everyday occurrence. The model reveals that this is because the stressor may actually be the “straw that broke the camel’s back” referring to the pile-up of stressors that may become overwhelming. Using the model as an example, a pile-up of stressors may occur and depending on the family resources (B) and the perceptions used to interpret or manage the stressor event (C), family and child outcomes could suffer depending on the resources and perceptions brought by the mother into the equation. This section of the review will focus on discussion of stress in families of children with disabilities and the association of locus of control with stress.

There is a large body of literature that substantiates that parents of children with disabilities experience more stress than parents with typically developing children, and that this stress intensifies over the course of the lifespan (Beckman, 1991; Crnic, et al., 2002; Walker, 2002). Research into the association of parental stress and child characteristics indicates that type of disability, self-regulatory issues, and behavior problems predict parental stress (Hauser-Cram, et al., 2001). For example, Beckman (1983) studied the influence of selected child characteristics on stress. She found that responsiveness, temperament, repetitive behavior, and the presence of additional or unusual care giving demands were all related to stress levels in families of children with disabilities. Similarly, Cameron et al. (1991) compared stress levels between parents of preschoolers identified as having delayed and non-delayed development using the Parent Stress Index. Only the Child Domain of the Parent Stress Index was associated with increased parent stress. The authors speculated that specific child characteristics such as adaptability, distractibility, and demanding behavior may increase stress in mothers of children with developmental delay. In fact, adaptive behavior (Weiss, Sullivan, & Diamond, 2003) and

difficult child behavior (Baker et al., 2002; Creasey & Jarvis, 1994; Hallam-Helbich, 2001; Keller, 1999) are strongly associated with increased parent stress in a number of studies.

Increased maternal stress has the ability to negatively alter child outcomes (Assel et al., 2002; Crnic et al., 2002; Magill-Evans & Harrison, 2001; Pisula et al., 2002). These outcomes result from less positive maternal affect and sensitivity resulting in poorer mother-child interactions. Because stress is highly associated with poor child outcomes, reducing maternal stress can be considered a family centered practice that is able to positively influence child outcomes. Locus of control appears to have a twofold association with stress. First, an internal locus of control is associated with less maternal stress as discussed in the previous section (Hassall et al., 2005; Jones & Passey, 2005). Second, an internal locus of control is associated with more positive appraisal of the situation or potential stressor (Rimmerman, 1992; Wiggs & Stores, 2001). Mothers with an internal locus of control report less behavior difficulties even when evidence suggests that child behaviors have not changed or diminished (Galligan, 1981). There is also evidence that a decrease in parental stress is associated with less behavior difficulties for the child (Guralnick, 2000; Silsby, 2004). This suggests a cyclic pattern of internal locus of control leading to less stress, leading to more positive appraisal of child, or actual better child behavior, leading to less stress.

Using the Early Childhood Intervention Study data collected by Hauser-Cram and colleagues (2001), Silsby (2004) found that parent functioning was associated with the child's level of behavior problems and social skills above and beyond the significance of child characteristics. Moreover, maternal locus of control and stress were significant factors in understanding behavior outcomes of children with disabilities. This is saying that, all other

things being equal, having an internal locus of control, without any change in actual stress, can potentially positively influence child behavioral outcomes.

McKinney and Peterson (1987) studied maternal locus of control as a moderator of stress in 67 mothers of children with developmental disabilities recruited from an EI program. All mothers were receiving intervention in the form of a group or individual basis for at least 1 hour per week. Measurements included the Parent Stress Index, Profile of Mood States, Spheres of Control Battery, and Social Network Form. Subjects were administered pretests and then randomly assigned to individual or group intervention sessions. Results indicate that spouse support, perceived control, and child characteristics each accounted for significant variance in a multiple regression prediction of stress scores. Further, spouse support demonstrated an interaction with perceived control meaning that if spouse support was low even though the mother had a high internal locus of control score, stress scores were considerably higher. McKinney and Peterson (1985) were able to demonstrate the association of locus of control to stress, but found that if spouse support was lacking, even with high internal locus of control, mothers experienced more stress.

It is convenient to be able to directly associate particular child characteristics with increased stress. Associating the child's difficult or demanding behavior with increased stress allows the EI professional to have a starting point in which to base interventions. Using the Early Childhood Intervention Study data collected by Hauser-Cram and colleagues (2001), Silsby (2004) found that parent functioning was associated with the child's level of behavior problems and social skills above and beyond the significance of child characteristics. However, in many of the studies designed to tease out linkages among various child characteristics and stress, maternal perceptions (i.e., the way in which the mother views the child and the child's

situation) are discussed as an important finding (Jones & Passey, 2005; Silsby, 2004). An example of this is found in a study by DeMaso, Campis, Wypij, Bertram, Upshitz, & Freed, (1991). These researchers studied the impact of maternal perceptions in interpreting medical severity of children with congenital heart disease. They found that maternal perception accounted for 33% of the variance in maternal adjustment to the child's illness, while severity of illness accounted for only 3% of the maternal adjustment variance.

The literature is conclusive that parents with an internal locus of control report less stress than do parents with an external locus of control (Hassall et al., 2005; Jones, 2005; Longnecker, 2003; Silsby, 2004). An internal locus of control is also associated with a more positive appraisal of the child with a disability, and stressors associated with the disability (DeMaso et al. 1991; Silsby, 2004). Knowing locus of control orientation is vital for the EI specialist and reflects the "stress health" of the mother.

2.4 THE RELATIONSHIP OF MATERNAL LOC TO LIFE EVENTS AND RESOURCES: C × B IN THE DOUBLE ABC-X MODEL

The development of locus of control is associated with family style and experiences with effort leading to reward (Kampen, 1989; McClun & Merrell, 1994) and is generally thought to develop over time, often at a young age. Individuals with an internal locus of control have grown up with families that modeled typical internal beliefs. These families emphasized effort, education, responsibility and thinking. Parents delivered promised rewards. In contrast, individuals with an external locus of control have increased stress, poorer coping or adaptation skills, and, in addition, are typically associated with lower socioeconomic status (Duncan, Brooks-Gunn, &

Kebanov, 1994; Huston, McLoyd, Coll, 1997). Research has examined individual parent characteristics, such as locus of control, for insight into the elements of a family that provide positive adaptation skills in the presence of poverty and increased parental stress. This research is vital because the culture of poverty typically promotes stress-coping that is passive (i.e., individual hopes that problem will go away), emotional (i.e., individual is focused on the emotion of the situation more than on assessing and acting on the problem), and evasive (i.e., individual avoids confronting the problem) rather than active coping and adaptation (Banyard & Graham-Bermann, 1998; Greenlee & Lantz, 1993; Kutscherousky, 1997).

Investigators have attempted to prove the association between locus of control and socioeconomic status with varying results. Lachman and Weaver (1998) report that individuals with lower income also have a lower sense of control than individuals with higher income. Their study was designed in an attempt to examine the relationship between what they termed sense of control and family income. Actual locus of control measures were not used. To examine the relationship between sense of control and social and economic differences, they conducted an in-depth phone survey. The analysis examined the association between a measure of control they named *mastery*, perceived constraints, and income. Income was divided by three categories, low, medium, and high. The results indicated that there was an association between mastery and all three levels of income, as well as large within group variance. There was also an association between income and perceived constraints. The authors' results indicated that those in lower income groups had lower levels of perceived mastery and stronger beliefs in the existence of external constraints on their lives. The authors acknowledge that mastery and perceived constraints and income were associated at all income levels with a high degree of within group variance, indicating a large range of association within the group. This author

questions how they can find significantly varied results in all three income categories and then suggest that low income is related to a lesser sense of control. The important conclusion from this study is in the suggestion that future research should focus on possible antecedents of control beliefs and the elements that help shape control beliefs.

In a study that reaches a different conclusion from the Lachman-Weaver study, Landau (1995) studied the association among locus of control, socioeconomic status indicators, and coping ability in 150 Israeli widows. Data analysis suggests no support for the theory of interaction among socioeconomic indicators, locus of control and coping. Rather the authors found that locus of control and socioeconomic status were related to life satisfaction and depression independently, and locus of control reflects more than socioeconomic resources.

Recently, Lever et al. (2005) studied socioeconomic status and a number of psychological variables including locus of control in an attempt to better explain the relationship among the variables. Their 918 Mexican subjects were classified in three categories of poverty including extreme, moderate, and not poor. Other socioeconomic indicators were measured including age, marital status, employment, and education. The Folkman and Lazarus Scale of Coping Styles and La Rosa Locus of Control Scale, among other measures, were used. Results indicated that the extremely poor population had the lowest levels of direct coping and internal locus of control. This was followed by the moderately poor and finally the not poor. Interestingly, the moderately poor, and not the extremely poor, were the group that most often sought social support for coping purposes. The authors conclude that there are several routes on which poverty impacts perceptions of well-being. These include passive, evasive coping strategies, a lack of a sense of mastery, or control, the unstable living conditions of extreme poverty, and the negative impact on the individual's perception of his or her well-being.

It seems probable that maternal locus of control is correlated with socioeconomic indicators. The actual association of low socioeconomic indicators is somewhat associated to a more external locus of control although some researchers find little or no association. The important thing to consider is that in research on locus of control it is essential to examine socioeconomic indicators. Other important findings for this review are suggested by Lachman and Weaver (1995) and Lever et al. (2005). In their conclusions, Lachman and Weaver suggest that future research should focus on possible precursors of control beliefs and the elements that help shape control beliefs and the ability to shift control beliefs once formed.

Maternal supports and resources refer to crisis-meeting assets of the mother. These crisis meeting resources include supports and resources available in the community that serve to block or buffer stress for the entire family. Mash and Johnston (1990) emphasize the importance of perceptions as traits of the parent, which are related to how the parent views their child with a disability and the issues associated with having a child with a disability, as well as how they use resources and supports. In fact, some theorists have suggested that resources such as social support actually enhance family functioning by enabling parents to access perceptions that reduce feelings of stress associated with an event (Shumaker & Brownell, 1984). Yet generally these factors have been much less extensively explored as they relate to families of children with disabilities.

2.4.1 Association of social support and resources with locus of control.

Social support and resources for the family of a child with a disability are defined as help in and outside of the home that lends physical and emotional support to the primary caregiver and the family. Social support can be in the form of a spouse, friend, relative, or community agency and

must be identified when the coping effects of social support are considered. Support and resources are one type of coping mechanism that can be an effective barrier to stress among parents of children with disabilities (Bradley & Corwyn, 2002; Diviney, 2001; Dunn, et al., 2001; Kazak, 1986; Keller, 1999; Manuel et al. 2003; Reddon, McDonald & Kysela, 1992; Smith, Oliver, & Innocenti, 2001; Summers, 2002; Walker, 2002). Social support generally leads to positive outcomes in families of children with disabilities (Dunst et al., 2002; Manuel et al., 2003).

The path by which social support acts as a coping mechanism and reduces parental stress is presumed to be due to the support providing information, knowledge, or actual services that lighten the load of the full time responsibility of having a child with a disability. Some researchers have cited social support as providing parent-to-parent linkages that allow parents a safe, accepting environment to vent frustrations and worries. Parents are also mentored as their child grows and enters new arenas such as school or work. Social support can alleviate stress by allowing the parent to resume other activities of importance. In any case, social support contributes to the stress equation by creating a buffer in the “B” area of the Double ABC-X model.

The buffering effect of social support is illustrated in research conducted by Hauser-Cram et al. (2001) investigating cognitive and behavioral development of children with developmental disabilities as well as the adaptation of their parents. The parental assets of social support and problem-focused coping predicted positive changes in maternal stress and adaptation. It is unclear from this study if parents developed higher quality or quantity of social support networks by utilizing this problem-focused coping.

Authors have attempted to link locus of control orientation, social support and resources, and family adaptation. Dunn et al. (2001) suggests that locus of control is the parent quality that explains the complex effects of social support. They question whether an internal locus of control empowers a parent to feel hopeful enough, and in control enough, to seek out the best fit of support for their family or whether locus of control orientation determines satisfaction of services regardless of quantity. Lastly, they question whether an individual with an internal locus of control requires less support to feel satisfied. Some authors link utilization of social supports to a parent's style of coping, citing that a parent with particular type of mindset may seek out and utilize social support differently than another parent. This leads to theorizing about an association between utilization of social support and locus of control orientation.

Social support and coping positively predicted family adaptation in a study by Bristol (1987). The author concluded the study by reflecting on the potential influence of parental attributes such as locus of control and self-esteem. This led Hall (1995) to investigate the role of parents' attributes in predicting the success of social supports and coping strategies as factors in successful family adaptation. Fifty-eight families of children diagnosed with autism or cerebral palsy participated in this study. The children ranged from 2 to 10 years of age. Instruments included the Coping Health Inventory for Parents, Social Support Inventory, Adult Culture Free Self-Esteem Inventory, Adult Irrational Ideas Inventory, Rotter's Locus of Control Scale, and the Family Stressors Index. Data from these instruments were used to predict successful family functioning, which was measured using the Family Assessment Measure. Parental stress was not measured.

Hall (1995) began by examining whether parental attributes of locus of control, self-esteem, and irrational beliefs were correlated. Analysis revealed that a high level of external

locus of control for the mother was significantly correlated with a lower level of overall self-esteem, and a higher level of irrational beliefs. Correlation analysis revealed significant relationships among a higher internal locus of control, higher self-esteem, lower irrational beliefs, and higher family functioning. Hall (1995) then asked if locus of control, self-esteem, and irrational beliefs accounted for some of the variance in family adaptation. The author developed a model to test the predictive relationships among the independent variables of social support and coping strategies and the interceding variables of locus of control, self-esteem, and irrational beliefs, and the dependent variable of family functioning. Eighty-eight percent of the variance in family functioning was accounted for by social supports, coping strategies, and parental attributes. Since parent stress was not measured, it is unclear if higher family functioning was related to lower parental stress.

Results from Hassall et al. (2005) indicate that locus of control was the link in the strong relationship between family supports and parenting stress in a study on the relationships between parental cognitions, child characteristics, family support, and parenting stress. This was also the case in a study by Jones and Passey (2005). These authors explored the impact of perceptions of control, coping ability, and social support on stress in 48 primary caregivers of children with disabilities. They gathered information on child and parent characteristics using a variety of measurement tools including the Questionnaire on Resources and Stress, Family Stress and Support Questionnaire, Parental Locus of Control scale, Family Support Scale, and the Coping Health Inventory for Parents. Step-wise multiple regressions were used to explore associations among predictor variables with the Questionnaire on Resources and Stress as the dependent variable. Results indicated that family coping style and parental locus of control were the most significant predictors of parent stress, explaining 15% and 32% of the variance respectively.

Further step-wise regressions were conducted for each of the parental stress sub-scales. This analysis revealed that family and support coping styles, internal locus of control, and perceived helpfulness of social support predicted parental stress. Parental stress sub-scales, the dependent variable, demonstrated that the variables of locus of control, perceived helpfulness, and family coping style are measuring different aspects of the variance. However, one can't help but question how each of these variables is correlated. Do parents with a more internal locus of control seek out a different type of social support than parents with an external locus of control? Is support accessed more frequently by parents with an internal locus of control or is their perception of need of social support different? The Jones and Passey study supported other findings that suggest that active coping strategies are associated with reduced stress for parents of children with developmental disabilities (Grant & Whittell, 2000; Jarvis & Creasey, 1991; Quine & Pahl, 1991). However, this study left the author curious as to how locus of control influences both seeking and receiving social support. Experiences with social services or child protection agencies may result in hesitancy to trust or find value in external community services. When stress or uncertainty is the highest, it is reasonable to speculate that family members may resort to closing others out as a way to gain control over the situation. There is not actual evidence of this supposition in the broad literature search completed by this author. However a significant number of parents of young children with disabilities report low confidence in seeking and securing social support as evidenced by findings by Bailey and Bruder (2005) using the National Early Intervention Longitudinal Study (NEILS) data.

Research differs in opinion about the association of locus of control and utilization of social support. Rimmerman and Stanger (1992) failed to show a relationship between locus of control orientation and utilization of social support in a group of mothers of children with

disabilities. The exception was a group of older mothers who perceived their child's functioning as severe. Similarly, Dunn et al. (2001) studied the relationship of stress, social support, locus of control, and coping style in parents of children with autism. They found that external locus of control, distancing, and escape coping styles significantly correlated with maternal depression. Feelings of wanting to escape also correlated with social isolation. Next, the authors performed a stepwise regression using social support, locus of control, and the eight subscales of the coping measure as the independent variables, while depression, social isolation, and spouse relationship difficulties were the dependent variables. Only two subscales, escape-avoidance and confrontive coping, entered into the regression formula. Locus of control did not. The authors speculate that locus of control was not part of the stepwise regression because external locus of control and escape-avoidance coping styles share a variance and therefore would not appear as separate variables in a stepwise regression model. They conclude this after finding that internal locus of control and increased reappraisal was associated with decreased social isolation. They note that having a strong internal locus of control may predict the ability to positively reappraise a situation; therefore, the two variables of escape-avoidance and external locus of control would share the same variance. However, locus of control was overshadowed in the regression analysis because it shared a variance with coping styles. This prompted the authors to conclude that encouraging an internal locus of control does not enhance the positive effects of social support.

Research by McKinney and Peterson (1985) suggests that social support operates as a moderator in the relationship between stress and locus of control, meaning lack of social support boosted stress levels in mothers even in the presence of an internal locus of control. In this example, locus of control is treated as a constant. However, it is known that locus of control is malleable. Others (Hassall et al., 2005; Jones & Passey, 2005) found locus of control to mediate

the relationship between family support variables and stress, meaning that locus of control was required for family support to effectively reduce stress.

These results paint an inconclusive picture about the relationship among locus of control, social support, and stress. Clearly locus of control influences perceived levels of stress (Jones & Passey, 2005) and family adaptation (Hall, 1995), but the influence of locus of control on social support is unclear. Utilization is not increased by an internal locus of control (Rimmerman & Stanger, 1992) nor is improvement in social support (Dunn, et al. 2001). Bailey and Bruder (2005) used the Family Outcomes Survey to survey parents and consistently found low parental confidence and competence in seeking and securing social support. The question of whether maternal locus of control is associated with parent report on the Family Outcomes Survey is of particular interest to this author. In addition, how is the length of time enrolled in the EI program associated with family outcomes?

2.5 THE RELATIONSHIP OF LOCUS OF CONTROL AND FAMILY ADAPTATION: $C \times X$ IN THE DOUBLE ABC-X MODEL

Possessing an internal locus of control reflects a mother's perception of confidence and competence in her role as a guiding influence on her child. Although the importance of this cannot be overestimated, ultimately the goal of EI is to support the family in order to positively impact child development outcomes. Therefore, it is important to review the literature associated with the impact that maternal locus of control orientation has on the mother which in turn has the potential to impact child developmental outcomes. It is through this portion of the review that

this author is able to make a case for the importance of maternal locus of control as a viable predictor of family outcomes.

2.5.1 Maternal locus of control and the association with child involvement and developmental gains.

Researchers have questioned whether maternal locus of control orientation is associated with the amount of involvement a mother has with her child with a disability and if that involvement results in higher developmental gains for the child. Maisto and German (1981) studied the association between maternal locus of control and developmental gain in a cohort of 24 high-risk infants followed longitudinally for four years. Rotter's uni-dimensional Internal-External Scale was used to assess locus of control orientation. Rotter (1975) described the dichotomous nature of his Internal-External Locus of Control Scale as most effectively used to predict behavior in situations that are ambiguous or novel for the individual. During the first year of the Maisto and German study, the infants, whose mean age was 10 months, and their mothers participated in a center based, Parent-Infant Training program that was conducted for 1½ hours every 3 weeks. This program consisted of the mother-child dyad being referred to a multi-disciplinary team of professionals whose responsibility was to provide services ranging from physician care, audiology advice and services, special education collaboration, communication disorder specialist therapies, and nutrition advice. The premise of the program was based on a family-centered model that provided a broad range of developmental services for the infant and immediate family as "primary educational agents" of the child (p.215).

The Maisto and German study assessed the child's developmental progress on 5 occasions during the first year and assessed maternal locus of control once, during the last of the

5 infant assessments. Maternal education and socioeconomic status were partialled out of the relationship between maternal locus of control and developmental gains to see if a relationship existed between these two variables, other than what could be attributed to socioeconomic factors. Results indicated that maternal locus of control predicted child developmental change; a high internal locus of control was associated with increased cognitive and language gains for the infant. These gains remained higher when the child was assessed at 4 years of age.

Maisto and German (1981) conducted one of the first studies that found a relationship between maternal locus of control and infant developmental gains. In retrospect, it is difficult to attribute these developmental gains specifically to increased maternal involvement since actual involvement in the parent training program and implementation of initiatives presented in the parent-training program were not measured. Just prior to the Maisto and German study, Fox (1980) conducted a study on the correlation between maternal locus of control and maternal involvement in the day treatment program of 42 children with emotional disturbances. All mothers had low socioeconomic status and were assessed as being highly stressed, but otherwise the sample was heterogeneous. Fox (1980) found that mothers with an internal locus of control were highly likely to be involved in their child's day program and conversely, mothers with an external locus of control were not likely to be involved. Child gains in emotional health were not assessed, so it was not possible to attribute locus of control orientation to the progress made during the day treatment program.

Helm et al. (1990) also demonstrated that locus of control was a significant predictor of maternal involvement in both adolescent and adult mothers of children with disabilities. The authors assessed 174 mother-child dyads and compared adolescent pairs with adult pairs in a number of areas including locus of control orientation. To assess locus of control orientation, the

authors used the Nowicki-Strickland Internal-External Scale. This 40-item scale was designed for non-college adults. The format is true/false and is considered to be less difficult to complete than Rotter's Internal-External Scale. Using regression analysis and controlling for socioeconomic status, Helm et al. (1990) found that, consistent with the literature, the adolescent mothers of children with disabilities were significantly less contingent and verbal and provided a less positive affective climate than adult mothers. Additionally, they found that locus of control orientation predicted maternal involvement for both adolescent and adult mothers. Developmental gains were not measured.

In all three of these studies locus of control orientation played a significant role in either greater involvement in treatment or in better developmental outcomes. The gap in information in the Maisto study, however, is that, although children of mothers with an internal locus of control experienced higher developmental gains, it is really not known if locus of control influenced involvement with the training program or involvement with the child. The Fox and Helm studies confirm that an internal locus of control orientation is actually associated with increased involvement in a treatment program, but we do not know if more involvement made a difference in the outcomes of the child, as developmental progress was not a measured.

In a study by Smith et al. (2000), the intent was to replicate the association between locus of control and child developmental gains that Maisto and German found, and also to measure maternal involvement. Their study was comprised of 131 mother-child dyads participating in an EI preschool program. The children were diagnosed with developmental disabilities and were about 4 years of age at the first assessment. Smith et al. (2002) used the Child Improvement Locus of Control Scales (DeVellis et al., 1985) to assess maternal locus of control. This scale consists of 5 scale dimensions that focus on measuring parents' beliefs about

their children's improvement. The 5 scales assess parental beliefs that improvement in their children is attributed to chance, divine influence, parent, professional, and child. The authors also tracked the mothers' compliance with treatment by noting attendance at sessions and using teachers' ratings of mothers' support and knowledge.

Results from this study indicate that mothers endorsed the Child and Parent subscales more than the Professional and Divine Influence subscales, while they endorsed the Chance subscales the least. This indicates that mothers generally demonstrated stronger internal locus of control than feelings that either the staff or God was influencing their child's outcome. None of the five subscales of the locus of control instrument were related to child developmental gains. The authors conjectured that they did not find a relationship between locus of control and developmental gains because of one of three possible reasons: the children they studied were older, therefore developing and changing less rapidly, the study was 1 year long in comparison with Maisto and German's 4 year study, or that the multi-dimensional scale produced different results. The authors also found that three of the subscales, professional, chance, and child, were all significant predictors of the mother's involvement in treatment. High scores in the professional subscale were associated with enhanced maternal involvement in treatment, whereas large differences in the mother's scores between the two subscales of chance and child were associated with lower treatment compliance. Smith et al. (2000) felt the important finding in this study was that maternal locus of control orientation predicted maternal involvement in an EI treatment program.

The previous studies reach different conclusions about maternal locus of control and its relationship to child developmental gains. None of the four studies measured parental stress. Although Maisto and German concluded that the child developmental gains were the result of

more maternal involvement, these results are questionable because attendance/involvement data were not collected. If maternal stress had been measured pre and post intervention and if stress decreased post intervention, then arguably a more internal locus of control orientation was associated with decreased stress, resulting in better child outcomes. This was not the case. The other three studies found a significant association between internal locus of control and maternal involvement. The implied theory used to explain locus of control and maternal involvement is that locus of control changes as a function of perceived circumstance. None of the studies are able to clarify the causal path implied by the locus of control-involvement theory, nor can they clarify that the perception of circumstance can be altered by confidence building measures administered by the professionals involved with the family.

2.5.2 Locus of control and parent training programs.

In this section of the review the question of how locus of control is associated with parent education or training programs is reviewed. It is important to know if locus of control is a malleable variable particularly since locus of control is shaped over time, often early in life, and may be associated with socioeconomic status of the mother. Finally, it is important to study the best and most efficient way to make a shift in locus of control with mothers of children with disabilities so that this information can be shared with practitioners.

Roberts, Joe, and Rowe-Halbert (1992) hypothesized that parents with an external locus of control would be more likely to drop out of therapy or only partially complete their treatment than parents with an internal locus of control. They tested the reliability of the Parenting Locus of Control scale using 31 parents of children between the ages of 2 and 12. Each parent was tested twice with an average ratio of test-retest of $r = .829$. The conclusion was that the

Parenting Locus of Control Scale was an adequate instrument for testing the above hypothesis with samples of preadolescent children. This led the researchers to phase two of the study.

Phase two included 72 families referred for treatment of oppositional child behavior. Children's ages ranged from 2 to 10 years. Family and child characteristics were gathered and mothers completed the Parenting Locus of Control scale. Subsets of the sample participated in a variety of pretreatment measurements designed to assess the level and form of coercive child behaviors as well as parenting skills. Two independent observers coded parent-child behavior during the pretreatment measures. There was a 96% agreement ratio and an inter-rater reliability (r) of 0. The means of the Parenting Locus of Control scale and each criterion from the pretreatment measures of parent-child behavior were compared. It was determined that parents with an external locus of control orientation had children that were more oppositional and coercive in their behavior than those with an internal locus of control. The authors theorized that the external orientation may also precede or exacerbate oppositional child behavior because the parent believes that the child cannot be influenced in anyway.

The third and final stage of the Roberts et al. (1992) study involved following the families through the course of treatment and comparing locus of control orientation with parent training dropout rates. Training consisted of a parenting program for child noncompliance plus specific parenting strategies to reduce sibling aggression, tantrums, negative verbalizations, bedtime, and community issues. The program length was approximately two months, occurred in the clinic setting and consisted of handouts, modeling, role-playing, guided practice with the child, homework, participant observation, and phone support. Parents were explicitly and implicitly told that a change in their behavior could improve their children's behavior. Results indicated that parents who successfully treated their oppositional children via a standardized

parenting program tended to report a more internal locus of control regarding child rearing following treatment. This result lends support to the theory that locus of control is impressionable through parent education.

As a final example of how locus of control can be shaped through parent education, Koger (1999) and Michigan State University Extension, studied 100 mothers with children birth to age 5. Fifty mothers were enrolled in the experimental group and fifty volunteered to participate in the comparison group. All women were participants of the Woman Infants and Children Program (WIC) which signifies an income of less than or equal to 150% of the current poverty index. Data were collected pre and post assessment using The Adult Norwicki-Strickland Internal-External Control Scale, The Parenting Behavior Assessment, and the Family Record Form. An intervention was developed that involved curriculum designed to emphasize the importance of parenting in a child's early development. The materials did not assume literacy, marriage, spouse support, or an intact family. The intervention was delivered in small groups or one-on-one.

Findings from this study indicate that participation in this program was related to significant increases in internal locus of control orientation. Mothers in the comparison group experienced no changes in locus of control orientation. Given what is known about internal locus of control orientation and the relationship to decreased stress and positive parenting behaviors, it is a significant finding that locus of control orientation is malleable within the context of a parent education program provided in the home.

The impressionability of locus of control through parent education is exciting for the field of birth to three EI. The knowledge that a parent-professional partnership could result in a mother exiting EI with increased feelings of control, confidence, and competence over the care

and management of the issues regarding her child with a disability is significant and provides cause for further study and investigation into specific parent-professional partnership qualities that build control. Currently, the specific nature of the interactions that culminate in increased desired parent outcome is not well established by empirical research. In the mid-1980's Dunst (1985) proposed that parent empowerment was achieved through parent-professional partnerships that emphasized strengths rather than weaknesses, family control over access to resources and supports, and collaboration as the focus of intervention.

To back this hypothesis, Trivette, Dunst, and Hamby (1996) describe two studies designed to examine perceived control among parents of children with disabilities who participated in a family-centered EI support program. Participants were 128 and 81 parents (98% mothers) in Studies 1 and 2, respectively. Both samples were purposely homogeneous because participants were involved in a family-centered EI or family support program serving children with disabilities or at risk for disabilities, but were diverse in terms of socioeconomic characteristics, and child disability type and degree. The Helpgiving Practices Scale and the Personal Control Appraisal were completed in both studies. Study 2 participants also completed the Early Intervention Control Scale.

Regression analysis with the Personal Control Appraisal scale as the outcome variable was used in both studies. In Study 2, the Early Intervention Control Scale was also an outcome variable. Results for Study 1 indicated that *none* of the parent, family, or child characteristics, including parent age and education, family socioeconomic indicators, child diagnosis or developmental quotient, were related to the outcome of personal control. Rather, professional background of the staff, in this case social workers, accounted for a significant amount of variance in perceived control. Results suggested that parents who worked with social workers

indicated a greater degree of control over the provision of resources compared to parents who worked with staff who had nursing backgrounds. Partial correlation also indicated that participants who played active roles in help-giving and help-receiving exchanges indicated a greater degree of control over the provision of resources.

The results in Study 2 indicated that only Helpgiving Practices were significantly related to the variance in both control measures. Parents working mainly with social workers and, to a lesser extent, nurses, compared to staff from other disciplines, reported greater levels of perceived control. In addition, parents who experienced more participatory help-giving practices reported higher levels of perceived control.

Results from these two studies indicate that both groups of parents involved in family-centered EI family support programs, the significant predictors of perceived control were not parents' or children's personal characteristics or family determinants but staff disciplines and help giving style (Trivette et al., 1996). The authors theorized that parents experiencing help-giving practices that allowed participation and active involvement in decision-making indicated greater perceived control compared to parents experiencing less participatory help-giving practices. The results suggest that, while building a good relationship with help seekers is an important prerequisite for developing a sense of control, it is not enough. Providing opportunities for active involvement and participation of an individual increases competence, which, in turn, when acknowledged by the parent, increases a sense of control.

Most recently, Dunst and Dempsey (2007) examined parent-professional partnerships in an effort to explain elements of the relationship that leads to parent empowerment, competence, confidence, and enjoyment. This is an area in which Dunst et al. (2000) conclude that there is little agreement. The participants were 150 parents and caregivers of infants, toddlers, and

preschoolers with disabilities involved in an early childhood intervention program. Participants completed the Enabling Practices Scale, two investigator-developed control appraisals, and the Everyday Parenting Scale. Parent empowerment was measured by using indicators of parent control and self-efficacy. Control was assessed in terms of participant's judgments of their perceived ability to procure supports and resources.

The results of this study indicated that higher partnership scores were related to elevated feeling of empowerment even after background variables were partialled from the relationship between the predictor and outcome measures. Personal control and self-efficacy were not related to confidence, competence, and enjoyment. Recall that the personal control measures were all centered on assessing parent access and ability to obtain supports and resources. This is a re-confirmation of earlier research indicating that parents do not feel confidence in this area (Bailey & Bruder, 2005). Further, data on time spent in the program were not gathered in this study. Dunst and Dempsey (2007) conclude by stating that although there is evidence demonstrating participatory parent-professional partnerships are associated to perceptions of personal control, the relationship between parents, professionals and parenting capabilities is yet to be substantiated (Dunst & Dempsey, 2007). This author questions whether the time spent in an EI program is an essential element in the explanation of parents becoming empowered.

2.6 SUMMARY OF THE LITERATURE

The EI specialist is constantly searching for the best practices to build confidence, competence, and facilitate adaptation in mothers and families of children with disabilities. Locus of control is a unique, measurable attribute (Campis et al., 1986; Rotter, 1975). An internal locus of control is

associated with less stress (Hassall et al., 2005; Jones & Passey, 2005), more confidence (Judge, 1998; Park, 2004) and competence (Luster & Rhodes, 1989; McKinney & Peterson, 1987), better adaptation (Hassall et al., 2005; Longenecker, 2003; Turnbull et al., 1993) greater situation and child acceptance (DeMaso et al., 1991; Silsby 2004; Wiggs & Stores, 2001), and more positive child-parent interaction (Helm et al., 1990; Houck, Booth, & Barnard, 1991) and greater involvement with the child (Fox,1980; Smith et al., 2000). An internal locus of control has been speculated to be related to utilization of supports and resources (Dunn et al., 2001), although this is generally not the case (Dunn et al., 2001; Rimmerman & Stanger, 1992). Dunn et al. (2001) speculated this was because mothers with an internal locus of control reappraised their situation in a more positive light and actually needed less social support than mothers with an external locus of control. This author questions this speculation due to the findings of Bailey and Bruder (2005) that families report lack of confidence and competence in the area of seeking and securing social support at the exit of birth to three EI. Perhaps most importantly, locus of control is a malleable perception. This ability to shift locus of control has been demonstrated with populations similar to those served in birth to three EI (Koger, 1999; Roberts et al., 1992).

2.7 STATEMENT OF THE PROBLEM

There is speculation that an internal locus of control can be fostered through family-centered parent-professional partnerships (Dunst & Dempsey, 2007). Research is getting close to answering the question about the nature of the relationship that best supports and drives an internal locus of control in the parent (Dunst & Dempsey, 2007). In conjunction with research being conducted elsewhere to determine the elements of the parent-professional relationship that

best support and increase an internal locus of control, locus of control should be evaluated at the entrance to and exit from home-based, birth to three EI in order to determine if maternal locus of control changes during the course of EI. Locus of control orientation measures should then be compared to one of the commonly used exit assessment tools used to measure family adaptation. Such measures of family adaptation provide mothers the opportunity to assess the status of their family at a given point in time, most commonly after exiting EI, thus the term family outcomes. Data comparing a mother's locus of control orientation and her responses about family outcomes will lend insight into the following areas:

1. Are there differences in maternal locus of control at entry and exit of EI?
2. Is there an association of maternal locus of control and perception of family status at entry and exit of birth to three EI?
3. Is length of time in a program associated with locus of control or family outcomes?
4. Can a model that includes locus of control be developed to predict responses about family adaptation?

3.0 METHODOLOGY

3.1.1 Design of the Study

This is a non-experimental study using descriptive statistics to examine relationships between measures of locus of control and family status with regard to the child with a disability (i.e. family outcomes), gathered from independent groups of mothers at entry and exit of EI. Descriptive statistics provide a picture of the basic features of the variables in the study (Schuyler, Huck & Cormier, 1996). Information for these comparisons was gathered by survey method in an attempt to find relationships between the mothers' locus of control orientation and their opinions about how their family is faring in regard to their child with a disability.

3.1.1.1 Institutional review board

As per the requirement of the University of Pittsburgh's Institutional Review Board (IRB) for Human Research, the author completed the on-line certificate modules required for human research by the University of Pittsburgh. The IRB proposal for the study was written and approval was solicited before commencement of the study. Under advisement of the IRB staff, the author devised a questionnaire to be given to the participants to supplant the need to examine client records so that the study could be reviewed under expedited status. This advice was heeded and this study was approved.

3.1.2 Participants

The participants were mothers currently over the age of 18 years whose children qualified for EI services either by having a minimum 25% delay in one developmental area or by clinical opinion. Participation in EI was defined as having an Individual Family Service Plan (IFSP) written for the child. The entry group consisted of 47 mothers with children ranging from one to thirty months of age, the average age of entry into EI was 14.96 months ($SD = 8.85$). Data were collected within 3 months of the IFSP being written. The exit group consisted of 37 mothers whose children exited EI between nine to thirty six months of age; the average age of EI exit was 31.14 months ($SD = 6.26$). Data were collected within 3 months of the IFSP being closed.

One exit participant was a mother of twins, both of whom qualified for EI. Because this is a study about the opinions of the mother, only one twin's demographic information was recorded and was chosen at random from the two surveys. Two foster mothers participated in the study. Both functioned as the primary caregiver for the entire period in which the child was enrolled in EI.

3.1.3 Procedure

Once the IRB approval was received, a meeting between the investigator and service coordinators from the Alliance for Infants and Toddlers (AFIT) was arranged in late November 2008. AFIT is a coordinating agency for birth to three EI in Allegheny County and can act only as a conduit for research. At that time, the investigator presented the study and asked for participation from the 65 service coordinators. The service coordinators were asked to distribute the entry (Appendix A) and exit (Appendix B) survey packets to mothers using the provided

script (Appendix C) that gave a brief explanation of the study. Participation from both service coordinator and the families was encouraged through an incentive program.

As the survey packets were returned in the mail to the author, the envelopes were opened, the surveys were numbered, data were coded, and the codes were entered into SPSS. A personalized thank you along with service coordinator and family incentives were sent to the service coordinator.

3.1.3.1 Sampling

The purpose of the sampling was to achieve two independent groups that were similar on collected demographic and child data so that survey data could be compared. The average number of discharges per month at Alliance for Infants and Toddlers is 155. The average number of new cases per month at the Alliance for Infants and Toddlers is 187. Since a moderate correlation of .4 is an expected reasonable outcome, then a sample of 44 participants from those entering and another 44 from those exiting would be considered sufficient to demonstrate a power of .8 (80%). Consequently, the target number of participants per group seemed reasonable and attainable.

Data were collected by using a convenience sample. All mothers over the age of 18 were asked by the service coordinator if they wanted more information about the study and those that were interested were read the prepared script. The service coordinator then left the survey packet with the mother. The service coordinators did not help the mother fill out the surveys but were instructed to have the mother contact the investigator if more information with regard to question clarification or data use was needed. Two mothers contacted the investigator, both inquiring if the study was still in progress.

It was theorized that a major sampling bias could be introduced due to “selection” of participants by the service coordinators that may occur if they selected only those mothers that they perceived as having a positive EI experience or being able to accomplish completing and returning the surveys. In order to avoid a sampling bias bi-weekly emails were sent to the service coordinators. The emails consisted of short take-home messages and were meant to remind the service coordinators of the significance and importance of including all eligible mothers without regard to their perceived level of stress, literacy, or even ability to follow through with completing and returning the survey.

The final sample consisted of those mothers who returned the surveys; two surveys were received after the close of the study but were not included. A total of 170 entry and 110 exit surveys were distributed with a return rate of 34.89% for the entry group and 20.72% for the exit group. A convenience sample of 47 participants, slightly more than the target number, was obtained from those entering EI and 37, somewhat less than the target number, from those exiting.

The service coordinators were asked to write their name or initials on the survey packet as they distributed them. As part of an expedited study, the primary investigator is not allowed information that would identify the participant. For this reason, initially only the service coordinators were given a monetary incentive of a ten dollar Giant Eagle gift card for each returned survey packet along with a personalized thank-you and entered into a cash drawing for distributing the survey. In addition to monetary incentives, recruitment was encouraged via bi-weekly emails. These emails were sent by the investigator to the one AFIT contact person and then distributed by this individual to the service coordinators. This was the only sanctioned mode of contact between the primary investigator and service coordinators.

After about 5 weeks of data collection it was determined that survey return was slowing. The incentive was increased to a forty dollar Visa gift card to the family and a twenty-five dollar check to the service coordinator. To accomplish adding a family incentive that would allow the family to remain anonymous, the service coordinators were asked to place an identification marker on the survey so that they alone could identify the family. When the primary investigator received a completed packet in the mail, a personalized thank you, the incentives, and a stamped, blank envelope was sent to the service coordinator, who then mailed the family incentive to the family.

The monetary increase in the incentive worked well and the entry data collection target was reached in about 5 months. At about 4 months into recruitment, it became apparent that exit surveys were being returned at a much slower rate. Consultation with the AFIT revealed that while the numbers of families entering and exiting EI in Allegheny County per month are relatively similar, the families enter EI in only one way—through an evaluation and if qualified, a plan. This allowed entry data to be collected through one pool of participants. However, exiting EI can occur for a number of reasons and at anytime post IFSP. Exit data pools are influenced by the family changing their mind about participation, moving without a forwarding number, or other reasons that may influence a family to discontinue participation.

Although the numbers of families entering and exiting EI was similar as a whole, the exit pool for potential participants was actually smaller. This revelation prompted the primary investigator to continue collecting exit survey for about 3 weeks after the entry survey collection was completed. Emails to the service coordinators focused on exit surveys only and reiterated thanks and incentives. Survey collection was stopped at 5 ½ months because the service coordinators were embarking on a new, complex data entry system.

3.1.4 Instrumentation

The instrumentation used in this study included: 1. The Family Outcomes Survey (Bailey 2005), 2. Rotter's Internal-External Locus of Control Scale, (herein referred to as Rotter's Scale), 3. Parent Scale, and 4. Family Information Questionnaire. The entry group received the entry packet (Appendix A) which included a cover letter providing a description of the study, the Family Information Questionnaire, the Rotter's Locus of Control Scale, the Family Outcomes Survey, plus the script (Appendix C) for the service coordinators, and an addressed, stamped envelope. The exit group received the exit packet (Appendix B) containing the same materials as the entry group plus the Parental Locus of Control scale, which we call the "Parent Scale" in this study. The Family Information Questionnaire and the Family Outcomes Survey were slightly different for each group.

3.1.4.1 The Family Information Questionnaire

The Family Information Questionnaire was developed in order to collect the demographic and child information from the sample. Demographic information collected included date, type of insurance, and the age of the mother at the time of birth of child. Child information included the birth weight, current age of child and age at entry into EI, and type and frequency of services. An open-ended question was also added that asked the mother the specific reason the child qualified for EI. At exit the mother was asked the type of preschool her child would attend.

3.1.4.2 Rotter's Locus of Control Scale

Rotter's Locus of Control Scale (Rotter, 1975) is comprised of 29 forced choice statements of which 23 were designed to be used in analysis. The authors included six additional statements in

the scale as a way prevent bias (Rimmerman, 1992). Questions are scored as a zero or a one and the results are summed for the 23 questions; a higher score indicates an external locus of control.

Rotter's Locus of Control Scale has been consistently demonstrated to be a reliable and valid instrument (Lange & Tiggeman, 1981; Wallston, Wallston, & DeVellis, 1978; Zerega et al. 1976) in measuring the multidimensional internal-external personality trait of locus of control (Lange et al. 1981). This instrument was chosen for this study for its ease of access and use and because it is a valid and reliable predictor of locus of control orientation. It is also an appropriate instrument for the parents of very young children that are potentially experiencing heightened stress due to their child's developmental or other issues.

3.1.4.3 Family Outcomes Survey

In 2003, the Office of Special Education Programs, U.S. Department of Education convened a focus group with twenty-two stakeholders to discuss and identify potential family outcomes and a methodology for collecting information about family outcomes from families whose children received birth to three EI. This measure was to be used by states and the federal government to evaluate family indicators for Part C programs. Constructs of the survey were developed using information from the National Early Intervention Longitudinal Study (NEILS) survey as a starting point. The resulting instrument was called the Family Outcomes Survey.

According to the authors of the Family Outcomes Survey, a family outcome is a benefit experienced by families as a result of services and supports received. The outcome is what happens as a result of services provided to families (personal communication, M. Raspa, July 2008). The authors of the Family Outcomes Survey recognized that, unlike child outcomes, family outcomes may not develop linearly, but be more cyclic in nature reflecting the changing needs of a family at a particular time point in their life. The authors state that due to the cyclic

nature of family needs in relation to supports and services, and the range of what is considered normal due to family culture or ethnicity, developing normative data, or standards against which to measure family outcomes is not possible (Bailey et al., 2005). Rather, the authors sought to develop an instrument that captured the perceptual nature of family outcomes. The authors actually describe the intent of the question as measuring perceived ability or competence, not confidence in ability (D. Bailey, personal communication, April 7, 2007). The authors also make a case for the primary caregiver, typically the mother, to be the voice for reporting her perception of family status as opposed to a professional reporting on the outcomes of the family. The authors argue that a professional working with the family may perceive the family as competent in a given area, but if the mother perceives herself to be less competent, that should be the measure of adjustment (Bailey, Hebbeler, Olmstead, Raspa, & Bruder, 2008).

This survey has undergone multiple revisions and has had strong input from actual participants. Additions were made according to the stakeholder suggestions. The entire instrument was field tested in Texas and Illinois by groups of parents currently enrolled in EI or recent “graduates”. As a result of the field test, editorial changes were made to the instrument. This process occurred several more times, resulting in the current survey. At present the Family Outcomes Survey is being used by over eleven states to measure Part C family indicators to determine the extent to which parents know their rights, effectively communicate their children’s needs, and help their children develop and learn (Indicator #4 in the PA State Performance Plan, 2005-2010).

Permission to use the Family Outcomes Survey was given by the authors (ECO Center, personal communication, February, 2008). Currently it is found on-line and states and local agencies are invited to use it with crediting the authors (Bailey et al., 2006).

The Family Outcomes Survey (latest version 02/22/07) contains 18 questions that measure family outcomes and perceived services of EI in six areas. The survey contains the three areas of impact of services on families required by Office of Special Education Programs (OSEP) (noted by bold print).

- 1. Understand their child's strengths, abilities, and special needs**
- 2. Know their rights and advocate effectively for their children**
- 3. Help their children develop and learn**
4. Have support systems
5. Access desired services, programs, activities in their community
6. Recognize Early Intervention as helpful

Each of the six areas has three questions that are worded descriptively, rather than evaluatively or critically. Each survey item is rated on a scale from 1-7. Based on research, respondents use the full range of options on the 7 point scale to indicate their perceptions. Descriptive statements are included for anchor ratings of 1, 3, 5, and 7. Blank spaces indicate "in between" ratings of 2, 4, and 6. The author's report that the scale was developed so lower scores indicate less of a perception by the parent of perceived ability regarding the question and higher scores, more of a perception of perceived ability (Bailey & Bruder, 2005). Completion of the instrument takes approximately 10 minutes.

The authors of the Family Outcomes Survey describe what they are measuring as the "benefits" of EI to the family (Bailey et al., 2008). Consequently, the Family Outcomes Survey was used in entirety for the exit participants. If a shift of maternal locus of control is found between entry and exit groups, it would also be important to demonstrate that there was a concomitant shift in outcomes, i.e., how mothers perceived their family's status and abilities as it

related to their children with disabilities. Giving the Family Outcomes Survey at entry was a logical way to address this. However, given that one cannot measure one's satisfactions with EI services at entry to EI, questions 3, 9, 16, 17, and 18 were eliminated from the Family Outcomes Survey for the entry participants as these questions asked opinions about the progress or satisfaction with EI services. The remaining questions addressed family perceptions of their status in dealing with issues related to the child with the disability that were also related to the goals of EI. Because one cannot have an "outcome" or a "benefit" at entry, the term "family status as it relates to the child with a disability" or simply "family status" is used often interchangeably with "outcomes" throughout the study. Scoring was done by determining the total for each of the 6 areas using the same questions for entry and exit so that the score could be equally compared with statistical analysis.

The 5 questions mentioned above that were eliminated for the entry group included two questions on the survey ask opinions about the progress the child was making in EI. Two questions asked opinions about the progress the child was making in EI. The other 3 questions asked about understanding rights within the IFSP process, communicating needs of the child to others, and helping the child develop and learn. These questions were analyzed separately for the exit group.

3.1.4.4 Parent Locus of Control Scale (short form revised) renamed the Parent Scale

A shortened form of the Parental Locus of Control Scale (PLOC) was developed by Hassall et al. (2005) and used for this study with exit participants only. The Parent Scale attempts to measure perceptions about the parent- child relationship. It was reasoned by the investigator that this instrument would have a detrimental effect on the entry group because either the child would be

too young for the parents to have perspective on the questions or the parent would be disturbed by the questions that probed the nature of the child's difficulties.

Originally, the PLOC was developed by Campis et al. (1986) as a criterion specific locus of control measure, developed to measure influence specific to the parent-child relationship. Previously, other instruments such as Rotter's Internal-External Locus of Control Scale (1975) were used to assess generalized expectancies and could only predict behavior in situations that were novel or ambiguous to the participant. Out of recognition of the necessity for accurate measure of specific, criterion-based expectancies for control, Campis et al. (2005) developed a specific instrument to assess parental locus of control that was comprised of six subsections and 47 questions.

To reduce the burden on participants in this study a shortened version of the PLOC was used. This shortened version was created by Hassall et al. (2005) by removing one of the original subscales (Fate/Chance) which was found to lack discriminate validity in the study by Campis et al. (1986), who recommended that it should be omitted by future researchers. One item from the original Parental Efficacy subscale (My child usually ends up getting his/her way, so why try) was also omitted per recommendation from Campis et al. (1986). Campis felt the item was ambiguous and reduced the subscale alpha. Hassall et al. (2005) created the shortened version by selecting the six items with the highest factor loadings on each subscale in the Campis et al. (1986) study. The instrument now consists of 24 items in 4 areas with half of the items reverse coded.

With this survey the total score can range from 24 to 120 with a higher score indicating a more internal locus of control. Similar to Rotter's, this data is meant to be used as a continuum measure of internality or externality rather than a dichotomous measure. This will

allow the researcher to estimate to what extent the mother has feelings of internal or external control.

3.1.5 Treatment of Data

SPSS Statistical program was used for analysis. Survey data were entered into SPSS by using the corresponding number written on the survey for cross referencing ease and were grouped according to entry or exit. In this study variables are maternal age, birth weight of child, current child age, child age at entry into EI, length of time in study, type of insurance, reason for EI entry, number of services, preschool choice (exit), and scores on the Rotter's Locus of Control and Family Outcomes survey at entry and exit and the Parent survey at exit, all described in detail previously.

Missing data for all variables were entered as -1. SPSS was programmed to read -1 as a missing value and perform analysis by not including missing values. For the Rotter's Locus of Control survey, Family Outcomes Survey, and Parent Scale (exit) SPSS was programmed to calculate the mean of the survey questions the mother responded to and replace the missing value with the mean score. Any survey with greater than 3 missing values was not used in the final comparisons. This qualification eliminated 1 entry Rotter's Locus of Control survey from comparison.

The Family Information Questionnaire is composed of 9 questions. The information was coded and entered into SPSS as follows: age of mother in years, type of insurance (public insurance = 1, private insurance = 2, both public and private = 3, and no insurance = 0). As noted earlier, insurance information was used as a socioeconomic proxy. Therefore insurance was recoded by using public = 1, private or public and private = 2, and no insurance = 0. Birth

weight was converted to grams and entered. The current age of the child, age at program entry, and age at program exit (exit) were entered. A length of time in program was calculated by subtracting the current age from the age at entry and entered.

The frequency of services used by the family was determined by multiplying the number of services provided by the frequency to result in a numerical score. For example if speech was offered weekly and developmental was offered twice monthly, a numerical score of 6 was entered into SPSS. The reason the child qualified for EI was coded by using responses from an open-ended question that prompted the mothers to describe why their child qualified for EI. Initially the responses were numerically coded into the categories of expressive language delay, expressive and receptive language delay, prematurity or low birth weight or neonatal intensive care unit (NICU) stay, prematurity or low birth weight or NICU stay plus some type of medical issue(s), diagnosed syndrome or disability, diagnosed syndrome or disability plus medical issue(s), motor issues, feeding issues, child identified on the autism spectrum, two or more areas of concern identified by the mother - for example speech and motor issues, sensory issues, and medical issues.

To check accuracy of this method of the way in which the child was categorized for the reason of eligibility, cross comparisons were made between the exact statement from the open ended question and the assigned reason category. After cross checking for accuracy, categories were collapsed to add analytical power. This was accomplished by comparing the number of services score to the reason for eligibility using a histogram graph. It was determined that reasons for eligibility could be combined and retain the integrity of the original comparison, as follows: 1 = expressive, expressive and receptive, motor; 2 = premature or LBW or NICU plus medical issues; 3 = feeding, 2 or more areas identified, premature or LBW or NICU; 4 =

medical, sensory, diagnosed syndrome or disability plus medical; 5 = diagnosed syndrome or disability, autism spectrum.

Rotter's Locus of Control Scale uses 23 of the 29 questions in analysis. Each question was scored as a 0 or 1. Scores can range from 23 to 0 with a high score denoting an external locus of control and a low score denoting an internal locus of control. Missing data were treated as detailed above. Total score was used in analysis.

The Family Outcomes Survey is composed of the 6 areas described above with a total of 13 questions used at entry and 18 questions used at exit. Each question is answered on a scale from 1 to 7. Several questions on the Family Outcomes Survey have an area that allows the parent to have one or two additional responses that signify the question was not currently applicable to the parent. In that case the additional options are coded 8 and 9 for individual question analysis between groups and -1, the missing data code, for Family Outcomes Survey total score analysis. The responses to the questions were entered into SPSS and a total score and score for each area (6 scores) was calculated.

The Parent Scale is composed of 24 questions. Mothers were asked to circle responses based on a Likert Scale. Eleven questions are reverse coded. Responses were scored and entered into SPSS and a total score was calculated. Scores can range from 24 to 120 with a mid score of 96. A higher score indicates internality. Missing data were treated as described above.

4.0 ANALYSIS OF DATA

The purpose of this study is to examine relationships between measures of locus of control and family outcomes gathered from independent groups of mothers at entry and exit of EI. Specifically, the study is designed to answer the following research questions:

1. Are there differences in maternal locus of control gathered at entry and exit of EI?
2. Is there an association of maternal locus of control and perception of family status at entry and exit of EI?
3. Is length of time in program associated with a more internal locus of control or more positive family outcomes?
4. Can a model that includes locus of control be developed to predict responses about maternal perception of family status?

This chapter, guided by the research questions above, will present the results of the analysis of data collected.

4.1.1 Establishing Sample Equivalency

Two independent samples of mothers were used for comparison on measures in this study. These samples will be referred to as the *entry* group consisting of mothers entering EI and the

exit group consisting of mothers exiting EI. In order to be able to compare the samples, it is necessary to establish that the two groups do not differ significantly on demographic and child data. The sample size for the entry group was 47 and for the exit group 37.

Demographic data collected included maternal age, age of child as he/she entered EI, and his/her birth weight, type of insurance as a socioeconomic proxy, the reason the child entered EI as reported qualitatively by the mother, and the number of services received by the family. The variables of maternal age, age of the child at entry into EI, birth weight in grams and (pounds), and the number of services received are reported in Table 1.

Table 1. Demographic and child data on the Entry and Exit Groups

| Variable | Entry Group | | Exit Group | | <i>p</i> |
|--------------------------------|---------------|-----------|---------------|-----------|----------|
| | Mean | Std. Dev. | Mean | Std. Dev. | |
| Maternal Age in years | 29.09 | 6.92 | 32.05 | 6.96 | .06 |
| Child age at entry in months | 14.96 | 8.85 | 16.97 | 10.22 | .34 |
| Birth weight in grams (pounds) | 2915.07(6.08) | 752.43 | 3009.77(6.10) | 817.71 | .58 |
| Number of services | 4.86 | 2.66 | 6.97 | 5.65 | * |

* determined to be non-comparable

To establish that the demographics of the independent groups are comparable, an independent samples *t*-test was performed on maternal age, birth weight, and the age at which the child started EI. It was expected that the number of services could change over time, therefore this variable was not compared. The *t*-test for independent groups showed no significant difference for maternal age $t(81) = -1.94, p = .06$, child age entering EI $t(82) = -.97, p = .34$, or birth weight $t(81) = -.55, p = .58$.

The groups were also compared on the type of insurance, the economic status proxy, and reason the child entered into EI. Over half had private insurance at both entry (54.3%) and

at exit (56.8%). This was compared using Pearson Chi Square analysis and demonstrated no significant differences at $p = .826$. The coding of each mother's response regarding the reasons for her child to enter EI was analyzed qualitatively as described in chapter 3. In a Pearson Chi Square analysis, no significant differences at the $p = .603$ were demonstrated between the two groups of mothers on overall reasons. Responses are presented in Table 2.

Table 2. Reason for EI referral by Entry and Exit Groups

| Reason | <u>Entry Group</u> | | <u>Exit Group</u> | |
|---|--------------------|------|-------------------|------|
| | # | % | # | % |
| expressive / expressive & receptive / motor | 24 | 51.1 | 22 | 59.5 |
| premature or LBW or NICU + medical | 2 | 4.3 | 1 | 2.7 |
| feeding / 2 areas identified / premature or LBW or NICU | 15 | 31.9 | 6 | 16.2 |
| medical / syndrome or disability + medical /sensory | 3 | 6.4 | 2 | 5.4 |
| syndrome or disability / ASD | 2 | 4.3 | 3 | 8.1 |

p = .603 between groups

The strength and direction of the relationships among the variables of maternal age, birth weight, the child's age at the start of EI, and number of services received were examined with correlation analysis in order to discover associations that may lend additional information about the composition of the two groups. Establishing positive or negative relationships allows the investigator to draw conclusions about the data and the sample. Some associations are expected. For example, it is assumed that an infant of very low birth weight would enter EI earlier and so a significant correlation would be found between the variables of birth weight and age at entry. One might also expect to find a correlation between the variables of a child entering EI earlier and number of services, as research has demonstrated that children entering EI

at a younger age often have a more serious diagnosed medical condition or disability (Gueorguieva, Carter, Ariet, Roth, Mahan, Resnick, 2001; Summers, 2002). In fact one of the expected correlations present was the child's age at entry of EI was moderately associated with birth weight $r(81) = .38, p = .000$, indicating that as the birth weight of the child decreased the child entered EI earlier.

There were also correlations that were less expected. Maternal age had a moderate, inverse correlation with age at entry into EI, $r(81) = -.28, p = .01$, and was positively associated with the number of services the child received $r(77) = .32, p = .005$. In this sample, as maternal age increased, the child entered EI earlier and required more services. The literature supports that as maternal age increases the incidence of low birth weight increases (Chan & Loa, 2008), as well as certain diagnosed syndromes or disabilities (March of Dimes) and autism (Bilder, Pinborough-Zimmerman, Miller & McMahon, 2009). It would stand to reason that there could be an association between maternal age and the number of services received by the child if in fact the maternal age was associated with the reason categories that may reflect more severe disabilities. To corroborate, the entire sample was divided into two groups using the average age of 30.41 years ($SD = 7.06$) as the filter. Mothers with an average age of 30 and under and over 30 were compared to the reasons given that the child entered EI. Results of this comparison are presented in Table 3.

Table 3. Reason for EI referral by maternal age

| Reason | M-age \leq 30 | | M-age $>$ 30 | |
|---|-----------------|------|--------------|------|
| | N | % | N | % |
| expressive / expressive & receptive / motor | 28 | 68.3 | 18 | 42.9 |
| (premature or LBW or NICU) + medical | N/A | | 3 | 7.1 |
| feeding / 2 areas identified / premature or LBW or NICU | 10 | 24.4 | 10 | 23.8 |
| medical/ (syndrome or disability) + medical/ sensory | 1 | 2.4 | 4 | 9.5 |
| syndrome or disability / ASD | N/A | | 5 | 11.9 |

None of the mothers under the age of 30 reported the category of *premature or LBW or NICU + medical*, and *diagnosed syndrome or disability / ASD*. Mothers 30 years or younger had a small percentage (2.4) in the category of *medical / syndrome or disability + medical / sensory* compared to mothers over the age of 30 years (9.5).

It was theorized that the two blank referral categories for mothers aged 30 years and under may explain the correlation between maternal age and number of services. To confirm this it was important to look at the average number of services for each category of reason and to then look at the average number of services by age. Results are in Table 4 and demonstrate that the correlation can be mostly explained by the mothers 30 years of age and under not having children enter EI in the categories of *premature or LBW or NICU + medical*, and *syndrome or disability / ASD*.

Table 4. Mean number of services by reason for EI referral and maternal age

| Reason | <i>M</i> Services | <i>M</i> Services for M-age ≤ 30 | <i>M</i> Services for M-age > 30 |
|---|-------------------|----------------------------------|----------------------------------|
| expressive / expressive & receptive / motor | 4.8 | 4.2 | 4.8 |
| premature, LBW, NICU & medical | 10.5 | N/A | 10.5 |
| feeding / 2 areas identified / premature, LBW, NICU | 7.0 | 5.6 | 7.0 |
| medical / syndrome or disability + medical /sensory | 2.5 | * | 2.5 |
| syndrome or disability / ASD | 14.0 | N/A | 14.0 |

* *Mother indicated reason for entry but did not indicate number of services*

Finally, the associations of type of insurance, the socioeconomic proxy, was examined with maternal age, birth weight, child's age on entry into EI, reason of entry, and number of services as a way to further describe the two samples. Type of insurance was associated with birth weight $r(80) = -.23, p = .03$ but no other significant correlations were found for type of insurance.

4.1.2 Analysis of Locus of Control in the Two Samples

Once it was determined that the two groups of mothers were comparable on the demographic and child information collected, the first question for analysis was whether there were differences in maternal locus of control measured in the entry and exit groups. The scored total of Rotter's Scale was used in analysis and as explained in detail earlier, is measured on a continuum of control with scores between 0 and 23 with 11.5 being the average, a higher score being on a

continuum of increasing externality and a lower score being on a continuum of increasing internality. The average score of the 47 entry group participants was very slightly skewed toward internal at an average of 10.06 ($SD = 3.50$) with a range in scores from 1 to 16. The only demographic or child variable associated with the Rotter's Scale was the maternal age $r(44) = -.30, p = .05$, meaning as the mothers age increased the scores were more internal. The average score of the 36 exit group participants was also slightly internal at 9.69 ($SD = 3.64$) with a range in scores from 4 to 20. Recall that one exit survey for the Rotter's data was not included due to too much missing data. No demographic or child was associated with the Rotter's Scale on the exit group of mothers. An independent samples t -test, $t(81) = .37, p = .64$, demonstrated no significant difference between the two groups. Further analysis was conducted to see if a small sample size was the cause of not significant findings by calculating the effect size of the difference between groups. Effect size is a name given to an indicator that measures the magnitude of a treatment effect. Unlike significance tests, these indices are independent of sample size (Lipsey & Wilson, 1993). The effect size for the difference between the two groups on the measure of Rotter's Scale was Cohen's $d = .10, r = .05$ indicating a very small effect. This tiny effect indicates that the difference has little practical significance.

This not significant finding led the author to then explore whether the second measure of locus of control, the Parent Scale measured with the exit group only, was correlated with Rotter's Scale. As previously discussed, the Parent Scale is a 24 item questionnaire that is scored on a 5 point Likert-type scale resulting in a possible range of scores from 24 to 120. Like Rotter's, this scale is generally thought of as a continuum, but scored in the opposite direction with a score higher than the average score of 48 indicating a more internal locus of control. The 37 exit mothers had an average score of 85.63 ($SD = 10.81$) and a range of scores from 61 to 106

placing the mean score of the participants in the high internal range. Only insurance demonstrated a small association with the Parent Scale $r(35) = -.30, p = .07$, meaning private insurance was associated with a more internal locus of control using this instrument.

Correlation analysis was conducted to observe the association between Rotter's Locus of Control survey and the Parent Scale. Correlation between the two surveys demonstrated a trend towards significance, $r(35) = -.29, p = .08$. The negative correlation was due to the instrument scaling measuring in opposite directions with Rotter's demonstrating internality with lower scores and the Parent Scale demonstrating internality with higher scores.

4.1.3 Family Status in the Two Samples

The second part of the second question for analysis, which will be discussed first, was whether there were differences in maternal perceptions of family outcomes at entry and exit of EI. As discussed earlier the Family Outcomes Survey of the entry and the exit groups were compared on 13 questions from the survey that could be answered by both groups, however, two questions were analyzed individually and were not included in the total score because the respondents could indicate the question was not applicable to them. This left eleven questions to be included in a total score for comparison in the two samples.

Instrument discrimination was conducted by examining the association between the survey total and each question score to provide confidence that higher individual question scores are associated with a higher total score. Results indicated good overall item discrimination. Three questions asked only at exit, 16, 17, and 18, regarding program satisfaction were not associated with the total score. This seems to indicate that, as will be discussed later, although program satisfaction was high as indicated by responses on questions

16, 17, and 18, program satisfaction was not associated with maternal perception of family status. Two questions, 15 at entry and 14 at exit, demonstrated no significant association with the total score possibly due to the low sample size available for analysis on these questions as the mother had an option to indicate these questions were not applicable. Results are presented in Table 5.

Table 5. Item to total correlation on the Family Outcomes Survey

| Question | Entry | | Exit | |
|--|-------|------|-------|------|
| | r^2 | p | r^2 | p |
| Q 1: How much does your family understand about your child's development? | .488 | .000 | .511 | .001 |
| Q 2: How familiar is your family with your child's special needs? | .356 | .014 | .352 | .046 |
| Q 3: How often is your family able to tell if your child is making progress? | N/A | | .046 | .786 |
| Q 4: How much does your family know about the programs and services that are available? | .568 | .000 | .677 | .000 |
| Q 5: How comfortable is your family participating in these meetings? | .690 | .000 | .481 | .003 |
| Q 6: How familiar is your family with your rights? | .718 | .000 | .704 | .000 |
| Q 7: How much does your family know about how to help your child develop and learn? | .715 | .000 | .624 | .000 |
| Q 8: How much does your family know about how to help your child learn to behave the way your family would like? | .546 | .000 | .512 | .001 |
| Q 9: How often does your family help your child learn and practice new skills? | N/A | | .470 | .003 |
| Q 10: How often does your family have someone your family trusts to listen and talk with when they need it? | .640 | .000 | .713 | .000 |
| Q 11: How often does your family have someone you can rely on for help when your family needs it? | .490 | .000 | .444 | .006 |
| Q 12: How often is your family able to do the things your family enjoys? | .550 | .000 | .636 | .000 |
| Q 13: How well does your family's medical care meet your child's special needs? | .598 | .000 | .501 | .002 |
| Q 14: How well does your family's childcare meet your child's needs? | .679 | .001 | .419 | .175 |
| Q 15: How often does your child participate in these activities right now? | .268 | .091 | .450 | .007 |
| Q 16: To what extent has early intervention helped your family know and understand your rights? | N/A | | .289 | .083 |
| Q 17: To what extent has early intervention helped your family effectively communicate your child's needs? | N/A | | .174 | .302 |
| Q 18: To what extent has early intervention helped your family be able to help your child develop and learn? | N/A | | .117 | .490 |

Raspa, Hebbeler, and Bailey (2009) suggest several methods as ways to compare data on the family outcomes survey including comparing mean scores on questions and subsections, and looking at frequency distributions for each item while having a cutoff score, or a score that connotes a standard of acceptability, in mind. This study used the authors' suggested cutoff score of 5 as an acceptable outcome score. The data collected in this study was collected for two groups, entry and exit, representing two time points in the EI process as a way to generate additional discussion about possible associations to demographic data and as a way to highlight significant and not significant changes.

The average total score for the entry group was 54.08 ($SD = 9.91$) and for the exit group was 61.40 ($SD = 8.82$). An independent samples t -test was performed comparing the two averages and was found to be statistically significant, $t(82) = -3.53, p = .001$ indicating that the exit group scored significantly higher on the Family Outcomes Survey.

The data were then compared on the thirteen questions using an independent samples t -test. Individual questions were noted for demonstrating either the largest or no difference between groups, having exit scores under the cutoff score of 5, and having a large percent of scores at exit under the score of 3. The question asking competence about knowledge of programs and services (Question 4) demonstrated the largest statistically significant change of all the questions and yet also had almost 19% of all respondents indicating low competence in this area. The question asking families if they are able to do things they enjoy as a family (Question 12) also demonstrated an almost 19% rate of low response although the difference between the entry group and exit group was statistically significant.

Two questions referring to informal social supports in the subsection of Having Support Systems asked mothers if they perceived having a trusted person to listen and talk to (Question 10) and someone to rely on for informal help with their child (Question 11). Neither question demonstrated a statistical difference between entry nor exit and both had large percentages of mothers indicating low competence. Results are reported in Table 6.

Table 6. Differences on individual questions on the Family Outcomes Survey

| Question | Entry Score | Exit Score | <i>t</i> | <i>p</i> |
|--|-------------|------------|----------|----------|
| Q 1: How much does your family understand about your child's development? | 5.02 | 5.68 | -2.51 | .014 |
| Q 2: How familiar is your family with your child's special needs? | 4.55 | 5.71 | -3.76 | .000 |
| Q 4: How much does your family know about the programs and services that are available? | 3.51 | 5.19 | -4.83£ | .000 |
| Q 5: How comfortable is your family participating in these meetings? | 5.74 | 6.08 | -1.05 | .299∞ |
| Q 6: How familiar is your family with your rights? | 4.72 | 5.41 | -1.81 | .075∞ |
| Q 7: How much does your family know about how to help your child develop and learn? | 5.06 | 5.86 | -2.95 | .004 |
| Q 8: How much does your family know about how to help your child learn to behave the way your family would like? | 4.81 | 5.46 | -2.73 | .008 |
| Q 10: How often does your family have someone your family trusts to listen and talk with when they need it? | 5.64 | 5.11 | 1.43 | .157∞ |
| Q 11: How often does your family have someone you can rely on for help when your family needs it? | 4.68 | 4.84* | -.36 | .721∞ |
| Q 12: How often is your family able to do the things your family enjoys? | 4.53 | 5.38 | -2.55 | .012 |
| Q 13: How well does your family's medical care meet your child's special needs? | 5.89 | 6.57 | -2.30 | .024 |
| Q 14: How well does your family's childcare meet your child's needs? | 5.53 | 5.83 | -.58 | -.58∞ |
| Q 15: How often does your child participate in these activities right now? | 3.83 | 4.83* | -2.30 | .025 |

* Exit score less than 5.

∞ No statistically significant difference between entry and exit

£ Largest difference between entry and exit

As stated previously, two questions posed to the mothers concerned the availability of regular childcare and participation in religious, community, or social activities. These two questions had an additional options to allow the mother to indicate that the question was not currently applicable to them. The first of the two questions, question 14, regarded the availability of regular childcare. The entry group average of 5.53 ($SD = 1.54$) was not statistically different than the exit group average of 5.83 ($SD = 1.27$), $t(29) = -.58, p = .57$. Of note were the number of mothers indicating that child care was not something they needed, 51% at entry and 53% at exit, or was not available to them, 7% at entry and 14% at exit.

The second of the two questions, question 15, with an additional response options was a question regarding the availability of religious, community, or social activities for their child. The entry group had an average score of 3.83 ($SD = 1.97$) and the exit group had an average score of 4.83 ($SD = 1.79$) and demonstrated a significant difference, $t(74) = -2.30, p = .02$. Thirteen percent of the mothers in the entry group and 5% of the mothers in the exit group indicated the question did not apply to their family.

Raspa et al. (2009) suggests that another way to inspect individual questions on the FOS is to note the questions with a high percentage of low scores. To accomplish this each exit survey question was examined in a frequency distribution of questions in which about 20% or more of the mothers responded with 3 or less. Results are presented in Table 7.

Table 7. Differences on individual questions on the Family Outcomes Survey

| Question | % < score of 3 |
|---|----------------|
| Q 4: How much does your family know about the programs and services that are available? | 18.9 |
| Q 10: How often does your family have someone your family trusts to listen and talk with when they need it? | 21.6 |
| Q 11: How often does your family have someone you can rely on for help when your family needs it? | 32.4 |
| Q 12: How often is your family able to do the things your family enjoys? | 18.9 |
| Q 15: Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now? | 28.6 |

As a post-hoc analysis to aid the practitioner, the investigator asked if there were particular questions that were asked as part of the Family Outcomes Survey that served as a predictor of the total score on the Family Outcomes Survey. This question was analyzed as part of a regression model using stepwise regression. Results are presented in Table 8.

Table 8. Regression of Questions on the Family Outcomes Survey to the Survey Total

| Question | R^2 | β | p |
|---|-------|---------|------|
| Q 10: Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it? | .76 | .87 | .000 |
| Q 1: Your child is growing and learning. How much does your family understand about your child's development? | .93 | .43 | .001 |

Of note are questions number 10 predicting 76% of the response on the survey and number 1 predicting an additional 17%. These results were corroborated using crosstab analysis to compare the total score on the Family Outcomes Survey with scores on questions 10 and 1. No

other questions from the Family Outcomes Survey were included in the model as significant outcome predictors.

There are five subsections of the Family Outcomes Survey as indicated below. Independent samples *t*-tests were performed comparing mean scores for each of the subsections on the entry group and the exit group. Results are reported in Table 9.

Table 9. Family Outcomes Survey with the Entry and Exit Groups

| Family Outcomes Survey Subsections | <u>Entry</u> | | <u>Exit</u> | | <i>t</i> | <i>P</i> |
|--|--------------|------------------|-------------|------------------|----------|----------|
| | <i>Mean</i> | <i>Std. Dev.</i> | <i>Mean</i> | <i>Std. Dev.</i> | | |
| Understanding your child’s strengths, abilities, and special needs | 4.79 | 1.22 | 5.69 | .89 | -3.77 | .000 |
| Knowing your rights and advocating for your child | 4.63 | 1.40 | 5.56 | 1.31 | -3.11 | .003 |
| Helping your child develop and learn | 4.92 | 1.05 | 5.66 | .83 | -3.49 | .001 |
| Accessing your community | 5.85 | 1.55 | 6.57 | 1.01 | -2.44 | .017 |
| Having support systems | 4.93 | 1.26 | 5.1 | 1.44 | -.58 | .60 |

All subsections demonstrated significant differences between the independent groups except for the subsection of Having Support Systems.

There were five questions that were analyzed solely on the exit survey and are described below. The three questions in bold type relate to family outcomes and are required by the Office of Special Education Programs. Means and standard deviations are presented in Table 10.

Table 10. Questions asked only with the Exit Group

| Question | Mean | Std.Dev. |
|---|------|----------|
| Q 3: How often is your family able to tell if your child is making progress? | 6.51 | .77 |
| Q 9: How often does your family help your child learn and practice new skills? | 6.32 | 1.22 |
| Q 16: To what extent has EI helped your family know and understand your rights? | 5.84 | 1.24 |
| Q 17: To what extent has EI helped your family effectively communicate your child's needs? | 6.35 | 1.00 |
| Q 18: To what extent has EI helped your family be able to help your child develop and learn? | 6.57 | .76 |

The State of Pennsylvania accomplishes the Office of Special Education Programs mandate by using the National Center for Special Education Accountability Monitoring (NCSEAM) survey to collect data on the three highlighted questions. The NCSEAM survey Family-Centered Services subscale demonstrates a moderate correlation with the Family Outcomes Survey $r = .42$ (personal communication, M. Raspa, July 28, 2009). Pennsylvania reported that fiscal year 2007 data reveals that 71% of the families report knowing their rights, 67% report effectively communicating their children's needs, and 81% report being able to help their children develop and learn. To compare data from the current survey with NCSEAM results, the seven point Likert-type scale was collapsed into three categories from the exit survey data with the responses of five, six, and seven being added to determine comparable percentages. Data revealed 83.7% of the mothers report knowing their rights, 97.3% report being able to effectively communicate their children's needs, and 100% report being able to help their children develop and learn.

4.1.3.1 Correlation of the family outcomes survey to demographic and child data

Research confirms that family outcomes are influenced by economic resources (Lever et al., 2005), maternal age (Summers, 2002), and health and well-being of family members (Belsky, 1984). In this study, family outcomes were significantly different between the entry and exit groups. To assess what these differences can be attributed to in terms of demographic or child data, correlational analysis was performed using the Family Outcomes Survey total score and the demographic and child variables including maternal age, birth weight, child age at entry into EI, type of insurance, and number of services offered. Variables were first entered into bivariate correlational analysis. Analysis indicated that only type of insurance $r(81) = -.38, p = .000$ demonstrated an association indicating that private insurance was associated with higher scores on the Family Outcomes Survey.

To illustrate further the influence of type of insurance on the maternal report of family outcomes, an independent samples *t*-test was performed on the entry group and exit group by type of insurance. The results are in Table 11.

Table 11. Family Outcomes Survey total score by type of insurance in Two Groups

| Independent Group | Public Insurance | | Private Insurance or Both | | <i>t</i> | <i>p</i> |
|-------------------|------------------|----------|---------------------------|------------------|----------|----------|
| | <i>M</i> | Std. Dev | <i>M</i> | <i>Std. Dev.</i> | | |
| Entry | 50.81 | 10.38 | 56.88 | 8.99 | 2.13 | .04 |
| Exit | 56.19 | 7.42 | 65.38 | 7.77 | 3.63 | .001 |

Next, the categorical variable of the reason the child entered EI was entered into one way ANOVA with Family Outcomes to determine association. This association was significant at the $p = .005$ level. Post hoc tests were performed to determine the reason categories associated with

lower family outcomes. The reasons of category one (1) and two (2) scored significantly higher than those entering with reason five (5). Table 12 illustrates this analysis.

Table 12. Group means for the Family Outcomes Survey by reason of entry into EI

| Reason Category and Description | N | Mean | Std. Dev. |
|---|----|-------|-----------|
| 1: expressive/ expressive or receptive/ motor | 46 | 59.11 | 8.61 |
| 2: premature or LBW or NICU + medical | 3 | 69.33 | 10.02 |
| 3: feeding/ 2 or more areas/ premature or LBW or NICU | 21 | 55.00 | 8.83 |
| 4: medical/ sensory/ syndrome or disability + medical | 5 | 61.60 | 12.36 |
| 5: syndrome or disability/ ASD | 5 | 47.40 | 4.56 |
| Total | 80 | 57.84 | 9.44 |

4.1.3.2 Correlation of the family outcomes survey to locus of control measures

The final portion of the analysis of family outcomes compared measures of locus of control to the Family Outcomes Survey total and subscale scores. Rotter's Survey was compared to the Family Outcomes Survey with the entry group and both Rotter's and the Parent Scale were compared to the Family Outcomes Survey with the exit group.

Analysis of Rotter's Locus of Control survey and the Family Outcomes Survey total showed no significant association with the entry group, $r(45) = -.04, p = .77$, or with the exit group $r(34) = .12, p = .47$. The exit group showed no significant association, $r(35) = .17, p = .32$, for the Parent Scale and Family Outcomes survey total. Analysis of the Parent Scale, Rotter's Locus of Control Survey, and the entire Family Outcomes Survey was conducted. The Rotter's Locus of Control Survey did not demonstrate association with any subscale on the Family Outcomes Survey. The Parent Scale demonstrated association with the subscales of Accessing Your

Community and Understanding Your Child’s Strengths and Special Needs. These results are presented in Table 13.

Table 13. Significant correlations of the Parent Scale with FOS subsections

| Family Outcomes Survey Subsections | Parent Scale | | |
|--|--------------|----------|----------|
| | <i>N</i> | <i>r</i> | <i>p</i> |
| Accessing Your Community | 37 | .35 | .03 |
| Understanding Your Child’s Strengths and Special Needs | 37 | .46 | .004 |

4.1.4 Length of Time in Program, Family Outcomes and Locus of Control

The final question posed for analysis focused on determining whether the length of time spent in EI impacts family outcomes or locus of control. The length of time the child was in EI calculated on the exit group data only and was an average of 14.14 months (*SD* = 9.19). A correlational analysis was completed using the length of time spent in the program, the Family Outcomes Survey total score and subsection averages and the total score on both locus of control measures. Length of time in the program was not significantly associated with either measure of locus of control but was significantly associated with the total score of the Family Outcomes Survey and three of the subsections. The results are presented in Table 14.

Table 14. Correlation of length of time in program and Family Outcomes Survey

| Family Outcomes Survey | <i>df</i> | <i>R</i> | <i>p</i> |
|--|-----------|----------|----------|
| Understanding your child's strengths, abilities, and special needs | 81 | .36 | .001 |
| Helping your child develop and learn | 81 | .23 | .05 |
| Knowing your rights and advocating for your child | 81 | .25 | .025 |
| FOS total | 81 | .24 | .033 |

4.1.5 Developing a Model to Aid the Practitioner

Predicting the variables involved in the Family Outcomes Survey could potentially aid the practitioner early in the MDE/IFSP process. Knowing key questions to pose to a family that may indicate or predict more success or additional family needs in EI, or knowing the demographic or child variables that are possible predictors of or associated with greater success or satisfaction by the mother deserve attention. It was speculated that a model could be developed using the demographic data, child information, and locus of control totals to predict family outcomes. However, locus of control did not demonstrate significant difference between the two groups or association with the Family Outcomes Survey. This was verified using regression analysis with the FOS total score as the dependent variable and the length of time in program, type of insurance, reason for entry into program, and the Parent Scale in a regression analysis. The Parent Scale remained not significant in the prediction of the FOS total score. The variables that did demonstrate an association with more positive responses on the Family Outcomes Survey were question 10 and 1 from the Family Outcomes Survey, having private insurance, having expressive, expressive and receptive, or motor delay, (i.e. communication delay) and more time

spent in EI. These variables were entered as a group into regression analysis which demonstrated that 67% of the variation in the Family Outcomes Survey total score was explained by the model with the probability this could occur by chance alone being less than 1 in a thousand.

The variables were then entered into stepwise regression to determine the unique significance of each of these variables. Results of this analysis are presented in Table 15.

Table 15. Regression of variables with FOS total score

| Variable | R^2 | β | P |
|---|-------|---------|------|
| Q 10: Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it? | .323 | .568 | .000 |
| Q1: Your child is growing and learning. How much does your family understand about your child's development? | .533 | .458 | .000 |
| Length of time in program | .596 | .272 | .001 |
| Private insurance | .631 | .193 | .012 |
| expressive / expressive & receptive / motor | .665 | .188 | .009 |

It was of interest to see if the questions 10 and 1 would continue to be relevant to the model if they were not part of the dependent variable. To accomplish this, questions 10 and 1 scores were removed from the FOS total score and then regression was repeated. The summary indicated that 55% of the variance was explained by the model with the probability this could occur by chance alone being less than 1 in a thousand. Results are in Table 16.

Table 16. Regression of variables with FOS total score minus questions 1 and 10

| Variable | R^2 | β | P |
|--|-------|---------|------|
| Q 10: Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it? | .192 | .438 | .000 |
| Length of time in program | .363 | .421 | .000 |
| Q1: Your child is growing and learning. How much does your family understand about your child's development? | .446 | .306 | .002 |
| Private insurance | .493 | .228 | .012 |
| expressive / expressive & receptive / motor | .538 | .216 | .011 |

Using the ABC-X model of adjustment and adaptation as the template and the results from this study presented above, a model was developed to predict more desirable family outcomes and is in Figure 1.

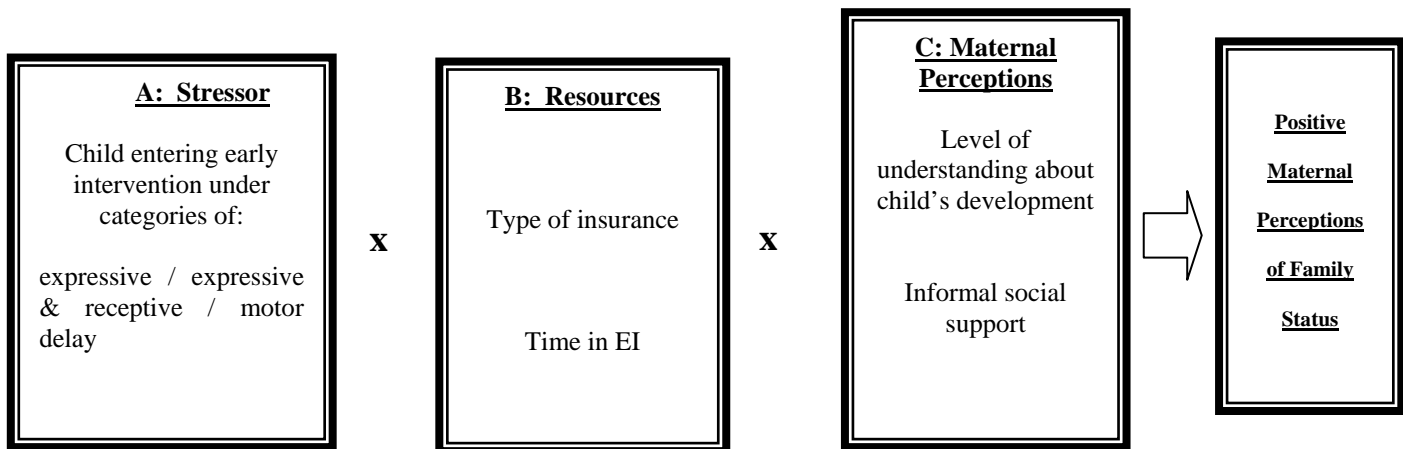


Figure 1. Prediction of Family Outcomes

5.0 DISCUSSION

The very essence of family-centered services offered to a young child and his/her family lies in the appreciation and maximization of the relationship of the family and the child. When the mother feels confident and competent about her role as a parent, there is an associated perception of control over the situation (Hagekull et al., 2001). In the past four chapters of this dissertation, the background and rationale for this research was described, a review of the literature in the field was detailed, methods and procedures used in conducting this study were identified, and results were presented. In this concluding chapter, these results are discussed with specific attention to the initial research questions as well as implications for practical applications and future research.

1. Are there differences in maternal locus of control at entry and exit of EI?
2. Is there an association of maternal locus of control and perception of family status at entry and exit of EI?
3. Is length of time in the EI program associated with a more internal locus of control or more positive family outcomes?
4. Can a model that includes locus of control be developed to predict responses about maternal perception of family status?

5.1.1 Synthesis of Results

This study examined maternal perceptions of family status using the Family Outcomes Survey and the association of these perceptions with locus of control. In addition, the length of time spent in EI was investigated for association with family outcomes and locus of control. Finally, a model including all the variables associated with positive maternal perception of family status was developed as a way to provide information for the practitioner to use in the identification of families variables and characteristics that support positive perceptions of their family's adjustment and adaptation.

A convenience sampling procedure was used to identify 47 mothers whose children were entering EI and 37 mothers whose children were exiting EI. The sampling procedure resulted in 2 independent groups of mothers with young children ages birth to three years whose children qualified for EI. Sampling took place between the November 2008 and April 2009 and resulted in a response rate of 34.89% at entry and 20.72% exit.

It was important to first determine if the independent samples were similar on collected demographic and child data and also to describe the sample. The demographic and child variables were very similar between groups as demonstrated by the lack of statistical significance of the independent samples *t*-test for maternal age, birth weight, and age the child entered EI. Insurance information was also similar in the two groups with an average of 45% having public insurance and no significant difference on the Pearson Chi Square test. This corroborated data from the National Early Intervention Longitudinal Study that showed 42% of children entering EI were in families who were receiving some form of assistance (Hebbeler et al., 2001).

Upon initial analysis there appeared to be an association between the number of services the child received and maternal age. Such an association could be plausible and explainable by the slightly subjective manner in which services are determined during the IFSP meeting. In Allegheny County, if the child qualifies during the MDE in any area of the standardized assessment or with clinical opinion, the evaluation team is at liberty to recommend any type of service that is available for the child. After the type of service is recommended, the team and the family determine the frequency at which the service will occur. An association between a greater number of services and maternal age is plausible if there was a trend of offering fewer services to younger moms with the rationale that too many providers, services, or frequency of services may overwhelm a younger mother.

In fact it became apparent that services were not based on maternal age but rather disability reason category that coincided with maternal age. Mothers above the mean age of 30 years had children entering EI for reasons that typically got more services, at least initially, such as premature and low birth weight babies with accompanying medical issues and young children diagnosed with a disability, syndrome, or on the autism spectrum (ASD). These findings mirrored literature demonstrating that maternal age is consistently associated with higher rates of intellectual disability in children (Chapman, Scott, Mason, 2002; Heikura et al., 2008), although there is no way to confirm in this sample if more services were indicative of an association between maternal age and severity of disability. Regardless of this, the two samples were similar on the demographic and child data collected and allowed for comparisons on collected variables.

5.1.2 Locus of Control in the Two Samples

Overwhelmingly, researchers concur that having an internal locus of control is preferable to having an external locus of control for positive adaptation in families of children with disabilities (Hall, 1995; Hassall, Rose, & McDonald, 2005; Jones & Passey, 2005; Turnbull et al., 1993). Children with disabilities can influence locus of control in mothers due to the atypical trajectory or timeline of development, or simply due to a sense of imbalance that occurs early in the diagnostic phase of a child's disability (Guaralnick, 1998). The premise for the first analysis was that locus of control would increase in the direction of internality between the entry and exit groups suggesting that participation in birth to three EI was associated with the development of a more internal locus of control. This premise is supported by research that suggests that locus of control is malleable with parent training programs (Roberts et al., 1992).

In this sample no difference of statistical significance was found between the entry and exit groups on the Rotter's Locus of Control scale. A very small effect size confirmed that this was not due to a small sample size. The Parent Scale was used as a measure of locus of control at exit only and was found to be very internal, but because this scale was not administered at entry it is impossible to determine if there would have been a difference between the two groups.

So why did this study demonstrate no statistical significance between the two groups of mothers on the one measure of locus of control measured at both time points? Quite possibly the answer is simply that there was no difference in locus of control orientation between the two groups even though other researchers demonstrated statistically significant differences in similar populations with Rotter's LOC (Houck et al., 1991; Konstantareas and Lampropoulou 1995;

Maisto and German, 1981; Rimmerman, 1991). However, perhaps a different result would have been achieved if the Parent Scale had been used for the entry group in addition to the exit group. Initially, the Parent Scale was argued to be inappropriate for the entry group as most of the questions required the parent to reflect on her relationship with her child with a disability. It was speculated that it would not yet be possible for mothers to have had time to reflect on her feelings and influence on child outcomes so shortly after discovering her child qualified for EI. It was thought that having to answer a questionnaire such as this might actually have caused the parent distress. In hindsight, this argument is not as strong because the average age of entry into EI was about 16 months with two-thirds of the children entering sometime between seven and twenty five months of age. This was an older age than expected by the investigator as speculation about the age of the child at entry was based on NEILS data which indicates that 41.4% enter EI prior to 12 months of age (Bailey et al., 2004). This older age of entry into EI could be attributed to a tracking program in Allegheny County. Infants born with LBW, prematurity, or with a NICU stay are tracked by the AFIT rather than immediately evaluated for services. This may attribute to infants actually entering EI at an older age than in the NEILS study. In hindsight, it would have been prudent to collect data using both locus of control instruments on the entry as well as the exit group or just to have used the Parent Scale.

5.1.3 Family Status

The literature supports that confidence in ability mirrors actual ability (Morris, 1988). Perception of competence was the theoretical concept that Bailey and Bruder (2005) used when developing the Family Outcomes Survey. In this study, mothers were assessed on a number of family and child characteristics, family status using the Family Outcomes Survey, and locus of

control. The supposition for this portion of the discussion was that maternal perception of family status would demonstrate differences between the entry and exit group and that the differences would be associated with locus of control.

The Family Outcomes Survey demonstrated differences between the perceptions of the entry and exit groups of mothers, with the exit mothers having significantly more positive outcomes than the entry mothers. Similar to the total score, the exit group of mothers demonstrated significantly higher responses than the entry group of mothers on four out of the five subsections of the Family Outcomes Survey (Table 8). Interestingly, the subsection of *Having Support Systems*, which asks the family if they have someone they trust to talk to, rely on for help, and if they are able to do things they enjoy as a family, demonstrated low scores at entry and a score (5.1) barely above the acceptable score of 5 and no difference between groups.

However, crosstab and regression analysis revealed that a higher score specifically on this question was the main overall predictor of a higher score on the family outcomes survey. This subsection is a reflection of the informal social supports of the family (M. Raspa, personal communication, July 23, 2009) and reflects current research which demonstrates that a significant number of parents of young children with disabilities report low confidence in seeking and securing social support (and resources) as evidenced by findings by Bailey and Bruder (2005) using the National Early Intervention Longitudinal Study (NEILS) data. In this study, the perception was that formal supports, as indicated by a high exit score on the *Accessing Your Community* subsection was perceived to be adequate; it was the informal supports that were deemed to be absent at entry and at exit. It was also the informal supports question on the FOS total score that was the main predictor of the FOS total score. This is of particular concern because such social support generally leads to positive outcomes in families of children with

disabilities (Bailey et al., 2007; Dunst et al., 2002; Manuel et al., 2003), and in this study seem to be both associated with positive maternal perceptions of family status, yet lacking according to the mothers.

Some authors have conjectured that families who are demonstrating positive adaptation actually report needing less social support (Shumaker & Brownell, 1984). However, in this study, mothers that demonstrated high levels of adaptation in other areas of the Family Outcomes Survey scored low in the area of *having social support* indicating that needs were not met for informal supports rather than there was less need. If mothers were satisfied with their level of informal social supports, then one must question why the two groups of mothers entered and exited EI with virtually the same low scores that are also echoed in the literature (Bailey & Bruder, 2005).

The cause for the unmet need may have been that the family had a difficult time verbalizing a requirement for something as personal as a trusted confidant, a person that they could rely on to help them with their child, or that as a family they are able to do things they enjoy. Conversely, the service coordinator or therapists involved with the family may have difficulty providing or helping the family secure such informal support services, or in fact, owning this as part of their role as a practitioner in EI. Personal experience has revealed that some professionals report feeling confident about providing empathic, reflective listening accompanied by objective, knowledgeable guidance and others report finding it difficult to be competent in so many areas, and to practice the art of reflective listening while maintaining professional boundaries.

By law, the very essence of family-centered services is the priorities, concerns, and needs of the family. The low scores in the area of social support for this study may be attributed to

what Bailey (2001) suggests is a *philosophical perspective* that influences the way in which *practices* are used to fulfill *program* requirements. Trivette et al. (1996) referred to this philosophical perspective in a study which found that differences in parent assessment of his or her ability to obtain support and resources was accounted for by variations in how the program was constituted and how personnel carried out the practices of EI within a family centered model. This was above and beyond any demographic characteristics, including socioeconomic status.

A specific question for this study may be the impact of how therapy is provided to the study sample. In Allegheny County, therapy is provided by several agencies, most of whom contract with independent therapists to provide services. While all independent therapists are required to have basic knowledge of practices that would fulfill a confidential, family-centered model of care, it is questionable as to what philosophical perspective the therapists share and the therapists' skill and comfort level of providing the reflective listening the parent may desire. Future research should focus on assessing the informal support systems of the mother or primary caregiver and the skill set of the therapists with regard to reflective listening.

5.1.3.1 Family status, demographic and child data

Bailey, Hebbeler, Spiker, Scarborough, Malik, and Nelson, (2005) analyzed NEILS data and suggested that less favorable family outcomes could be predicted from families of children whose health was only good, fair, or poor, were black or of other ethnic minority, and were single adults in the household. Like Bailey et al. (2005), this study used family and child information to describe characteristics that were associated with less favorable outcomes. Although the collected demographic and child variables were slightly different than those

collected in the NEILS study, the socioeconomic proxy of type of insurance and the reason the child entered EI were the variables that were able to predict maternal perception of family status.

In particular, ad hoc analysis revealed that mothers of children entering EI in the categories of communication delay and premature or low birth weight babies with NICU stay had significantly higher scores on the Family Outcomes Survey than those mothers with young children entering in the categories of a diagnosed syndrome or disability, including children diagnosed on the autism spectrum. This makes sense as having a child involved with EI due to communication delay, prematurity, low birth weight, or NICU stay may indicate less impairment or a better prognosis for the child. On the other hand, a child diagnosed on the autism spectrum often may not be identified or diagnosed until close to the second birthday, making his or her length of time in EI shorter, possibly not allowing for maternal perception of family status to improve.

Arguably young children diagnosed at a young age with a specific syndrome or disabilities often have more needs than those diagnosed later with a delay in a particular developmental area. In this study, having more services does not seem to be related to the mother's perception of outcome. This is indicated by examining service provision in the categories that include communication delay, low birth weight, prematurity, or NICU stay plus medical issues, and a diagnosed syndrome or disability including ASD. The average number of services for the communication delay category was 4.8 and the average number of services for the diagnosed syndrome or disability category was 14. Mothers with children entering EI due to low birth weight, NICU stay, or prematurity plus medical issues also had much higher scores on the Family Outcomes survey than mothers with children diagnosed with a syndrome or disability or on the autism spectrum, but had the second highest frequency of services. This high

frequency of services coupled with high scores could be explained by arguing that children entering EI with the reason category of NICU, LBW and prematurity initially receive many services but that these categories are not disabilities as such but rather risk conditions and the prognosis is better for these children at least in the early childhood years.

There are other variables that account for why mothers with children entering EI in these two categories scored higher on the family outcomes measure. Research supports that families with low socioeconomic status have less desirable family adaptation (Duncan et al., 1994; Jones, 2003; Lever et al., 2005) so it was of little surprise that having public insurance, the proxy for low socioeconomic status, was associated with less desirable family outcomes in this study. The surprising analysis was that while the entry group and exit group of mothers with public insurance demonstrated statistically significant differences in responses on the Family Outcomes Survey at exit, they had statistically significant lower scores on the Family Outcomes Survey at both time points. It can be hypothesized from this finding that while EI is positively associated with maternal perception of family status in mothers with public insurance, overall perception continues to lag behind those mothers with private insurance (aka higher SES). Further, families having public insurance (aka poverty) potentially may need *more* or different types of services, or different delivery options if the gap associated with poverty is to close. The *more* they need might be more EI meaning more therapies, more support in terms of social work support, or EI for a longer period of time if the mothers with public insurance are to be empowered to the same extent as the mothers with private or both types of insurance. One helpful piece of knowledge from this sample would have been if the mothers in either group, but particularly the group with public insurance, participated in any other formal early childhood

program such as Early Head Start, Healthy Start, or First Steps and if being involved in an additional program contributed to positive family adaptation.

5.1.3.2 Family status and locus of control

Maternal locus of control in the context of a family of a child with a disability refers to the mother's perception of her ability, or skill, to influence the developmental outcome and well being of her child with a disability, and her perception that developmental outcomes can be influenced with her parenting practices (Belsky, 1984). Parent perceptions, such as locus of control, are a key component to positive family adjustment and adaptation (Jones et al., 2005; Hall, 1995; Hassall et al., 2005). It was the hypothesis of this study that mother's in the exit group would demonstrate better perceptions of her family status as well as a more internal locus of control as compared to the entry group, suggesting that EI may play a role in "re-stabilization" of a mother's confidence and competence.

In fact, Rotter's Locus of Control survey and the Family Outcomes Survey were not associated for either group of mothers on the total score or any of the subscale scores of the Family Outcomes Survey. Additionally, the Parent Scale was not associated with the Family Outcomes Survey at exit on the total score but was associated on two subscales, *Accessing Your Community* and *Understanding Your Child's Strengths, Abilities, and Special Needs*. The questions that comprise the subsection *Accessing Your Community* include asking the family about their level of satisfaction with medical care, child care accessibility, and community activity accessibility.

The Parent Scale is a survey instrument that Hassall et al. (2005) demonstrated is associated with competence, problem-solving ability, and capability. Hassall et al. (2005) found an association with this particular instrument and stress, confirming research that suggests

an internal locus of control is related to less parenting stress (Hassall, et al., 2005; Jones et al., 2005). The Parent Scale asks many questions about the parent's feelings of control and competence with regard to child behavior, so it seems relevant that this scale would be correlated with the parent's ability to access medical care, child care and community activities as the parent would feel competent in their ability to control their child in social situations, or that there would be a level of predictability. Although parent stress was not measured in this study, two indicators, the parents perception of competence at accessing formal social supports, a strong indicator of reduced stress in the literature (Dunn, et al., 2001; Gomez, 2004), and the key questions about child behavior control and competence on the Parent Scale, suggests that parent stress may be lower in this group.

The Parent Scale was also associated with another subsection that reflected competence in the parent. The subsection *Understanding Your Child's Strengths, Abilities, and Special Needs* included questions regarding family competence in understanding about their child's development, their child's special needs, and if their child is making progress. This finding is similar to a great deal of research that suggests locus of control and competence demonstrate a conceptual overlap (Hagekull et al., 2001; Luster et al., 1989; Silsby, 2004). In the same study as cited above, Hassall et al. (2005) found that the efficacy subscale, reflective of the parent being a good problem solver, and having capability and competence and locus of control were related (Hassall et al., 2005).

5.1.3.3 Length of Time in Program and the Association with Family Status

The literature suggests that parent training programs for parents of children with disabilities similar to birth to three EI have the ability to reduce stress (Bailey et al., 1986), shift the parent's locus of control orientation towards internality (Koger, 1999), and shape positive family

adaptation (Fox, 1980; Helm, 1990; Roberts et al., 1992). Trivette and colleagues (1996) theorized that family outcomes were more positive depending on the type or qualifications of the professional that worked with the family. This study questioned if in fact the length of time a family spends in EI is an important variable associated with more positive family outcomes.

The length of time spent in the EI program was associated with increased perception of competence of the mother knowing about the strengths, abilities, and special needs of her child, how to be an advocate for her child, and how to facilitate development and learning in her child. The length of time in the program was also associated with overall positive family adaptation as indicated by the association with the Family Outcomes survey total score.

This is particularly relevant as the Office of Special Education Programs (OSEP) collect data on three areas (only) of family outcomes and are precisely the areas that being in the program longer are associated with namely *understanding their child's strengths, abilities, and special needs, knowing their rights – advocating effectively for their children, and helping their children develop and learn*. Knowing the association between these key family outcomes and the length of time spent in EI one question that arises is about special populations of children in EI with particular regard to children diagnosed on the autism spectrum. Do families of children diagnosed on the autism spectrum have enough time in EI to accomplish positive outcomes in the three areas measured by OSEP? Future research is needed in this area.

5.2 SUMMARY: AIDING THE PRACTITIONER

It was theorized that the information gathered from this study would lend itself to a predictive model, similar to that of the Double ABC-X model of adaptation that would provide information

to the practitioner about the variables that are associated with positive family outcomes. The supposition was that this study would support the literature and find that mothers with an internal locus of control, higher socioeconomic status, more social support and resources, and more time spent in EI would demonstrate positive family outcomes. In this study, locus of control was associated with feeling competent in the areas of accessing the community, i.e., formal social supports, and understanding the child's unique strengths and needs, but was not the maternal perception that was associated with overall more positive family outcomes. Even though locus of control did not demonstrate an association with overall positive outcomes, this investigator would suggest that the Double ABC- X model of adjustment and adaptation continues to be an appropriate and visual way of describing the important elements in this study that is associated with positive family outcomes.

5.2.1 A: stressor event

In the Double ABC-X model of adaptation, the child with a disability and all the accompanying issues and concerns that impact the family are considered to be the stressor event. Research has demonstrated that having a child with a disability can cause stress and lead to less than optimum family adaptation (Beckman, 1991; Crnic et al., 2002; Walker, 2002). It appears from research that it is not necessarily severity of disability that predicts stress but rather particular disability related characteristics such as behavioral or self-regulation issues and self-care issues (Hauser-Cram et al., 2001). This study was able to corroborate that children entering EI in the reason categories of communication or motor delay was associated with better family outcomes.

5.2.2 B: resources

What constitutes a resource for a family? Research indicates that resources that lead to better family adaptation include financial resources (Bornstein et al, 2003) allowing the family to purchase goods and services that will alleviate stress or support them in some way. The family adaptation literature also touts social support as important in the life of a family of a child with a disability as a way to alleviate stress and promote positive adaptation. Social support typically refers to the informal supports of a spouse or significant other, extended family, and the nearby community the family resides within that offers what might be described as consistent, reliable, yet casual support to the family. This type of support is typically not arranged through an agency, and is available more at the whim of the family. Resource support typically refers to support that can be purchased such as child care, respite, and possibly additional therapies.

In this study, formal supports, or resources, were perceived to be adequate by the mother and she felt competent to access them, but informal social support demonstrated no statistical significance between the entry and exit groups. In addition, large percentages of mothers exited EI with a score on the Family Outcomes Survey indicating not having the informal supports of help with their child. Information such as this is helpful to identify areas where families need extra help. Studying how informal linkages are supported by EI staff is an area for future research.

Voluminous research finds an association between higher socioeconomic status and better family adaptation (Bradley & Corwyn, 2002; Brooks-Gunn et al., 2002). In this study, type of insurance was used as a proxy for socioeconomic status with private insurance being a proxy for higher socioeconomic status. The data from this study corroborated that individuals with private insurance, aka higher socioeconomic status, had more positive family outcomes.

In addition to socioeconomic status, this study demonstrated that the length of time the family participated in birth to three EI was associated with more positive family outcomes. This is especially significant for the practitioner as length of time spent in EI rather than the age the child entering EI is the significant variable associated with family outcomes. This finding has implications for practice for birth to three EI and suggests that children entering EI at a later age, such as those entering close to or after 2 years of age and diagnosed as on the autism spectrum, can potentially still achieve the full effect of the growth in family adaptation that EI supports, but possibly requires more time in a family focused intervention environment. Further research comparing is needed in this area.

5.2.3 C: maternal perceptions

Locus of control was not the maternal perception in this study associated with positive family outcomes. In this study, a mother's perception of competence in understanding about her child's development was the perception that was associated with more positive family outcomes. The largest difference in perceptions in this study was in the mother's confidence in her knowledge of programs and services available to the family.

Research supports that parent perceptions affect child development above and beyond the significance of the child characteristics that may seem to dictate otherwise (Hauser-Cram, 2001; Silsby, 2004), and that the practitioners help-giving style can build feeling of control (Trivette et al., 1996). This has important implications for the practitioner as it is often the service coordinator and therapist working closely with the families that are able to impart insight into their particular child's developmental trajectory or to guide the family when further assessments or diagnostic tests are needed. Yet surprisingly Dunst and Dempsey (2008) state that

because there are such wide variations in the implementation of help-giving practices programs, the concept of family-centered services are compromised.

5.3 MY PERSONAL VIEW

I want to end this discussion the way I began, writing about my family's journey and how we regained our balance. Sometime post study completion I had the pleasure of hearing a champion of families, Dr. Gil Foley, speak about families of children with disabilities. He spoke about how a family must have the appropriate support to create their "personal mythology" and reframe the representation of their family when they have a child with a disability. I have vivid memories of reframing my own and my family's personal mythology. We continue to need affirmations that our version of a family is not only good enough but has been a joyful alternative, particularly to our two typically developing children.

Dr. Foley's message is a rich one of incorporating principles of infant mental health with EI. At the risk of oversimplification, one of the messages is that the EI practitioner represents more to families than their designated roles (Hochman & Foley); there is no "optimal distance" but rather the distance between the practitioner and the families varies with each family's needs. Dr. Foley states that at the heart of family-centered EI is the relationship among the family members and that the role of the EI practitioner is to support the relationship, helping the family to regain their balance, or as Dr. Foley describes, creating their new personal mythology, and thus encouraging child developmental progress.

5.4 LIMITATIONS OF THE STUDY

The results of this study and subsequent discussion and interpretation of the data should be considered with some limitations in mind. It is difficult to determine if the sample collected is representative of families participating in EI in Pennsylvania, and this is also true for Allegheny County. Collecting a convenience sample carries the risk of bias. This sample was collected not only by convenience sample, but also by a third party, the service coordinator. Although effort was taken to collect data from the spectrum of families that participate in EI, it is questionable if this was the case. Although this study was similar in terms of type of insurance to the NEILS data, Hebbeler, Spiker, Malik, Scarborough, and Simeonsson (2004) state that the families participating in birth to three EI are disproportionately poor. They question whether, in general, poor families are underrepresented for a number of reasons. This was also questioned by the investigator of this study when the exit data were so difficult to gather. Who are the families that exit EI so quickly?

The sample size was small for analysis in the area of the reasons the family entered EI. Using the same sample would have revealed change between the two groups rather than merely differences. Although maternal locus of control is measured at the entry and exit of EI, the same sample is not used for both.

Raspa et al. (2009) state that the “intensity” of services may be an important component of EI success. In this study it was difficult to determine intensity of services as services are often different when a family enters and exits EI. Devising a mechanism in which to accurately determine service intensity and its attributes would be an important element in future research.

5.4.1.1 Mulligan: if research was like the game of golf

If research was like the game of golf, there would be a few Mulligan's allowed. Mulligan's are do-over's in the game of golf and it's important for any investigator to reflect on what she would do differently given the opportunity. Of course if a do-over was possible the same group at two time periods would have been used. Some additional demographic information would have been collected including asking the mother if she had adult support in the form of a spouse, partner, significant other, or family member in the home that was consistently a source of informal support. This would have allowed the investigator to see if there was an association between this response and report of informal social support on the Family Outcomes Survey. This analysis would allow additional insight into what it is that the low scores in the area of informal supports is reflecting.

Another redo would be some additional supporting questions in the entry and exit survey packet. It would have been extremely prudent to have a question that would have allowed the mother to report her level of stress. This could have been one additional question with a Likert scale and maybe a follow up open-ended question about the cause of the stress. Knowing the stress level would have allowed for comparison between the level of stress, locus of control and maternal report of family status using the Family Outcomes Survey.

If there was such a thing as a do-over, more open-ended questions or better yet, a post-survey focus group would have leant important and rich follow up information about areas such as informal social support.

5.5 FUTURE RESEARCH

The very essence of family-centered services offered to a young child is the importance of the relationship of the family and the child. It is this relationship that supports favorable child development outcomes and is dependent on family members feel confident, confident and in control of their families outcomes. Research supports that experiences of an individual serve to either promote or diminish a sense of control, or empowerment over life (Cunningham, Henggeler, Brondino, & Pickrel, 1999). Future research concentrating on the elements of the family-practitioner relationship that serve to enhance the parents' feeling of confidence, competence and control, are valuable.

McCubbin et al. (1997) speaks of "recovery" phase with parents of children with disabilities that ultimately allows the parent to regain a sense of optimism which then leads feelings of control and mastery. Focusing only on increasing parental capabilities during birth to three EI when more effort should be placed on helping the family redefining the relationship. Regaining the balance. Restoring the optimism that is generally goes hand in hand with having a baby.

APPENDIX A

ENTRY SURVEY PACKETS

Service Coordinator Script to Prospective Study Participants

“This is a study being conducted by a University of Pittsburgh Doctoral Student about how mothers feel about early intervention. Participation is strictly voluntary and completely anonymous. If you think you might like to participate, I will leave this packet with you. It contains some questions to fill out and a stamped envelope to mail back to the primary investigator. If you have any concerns or questions there is a phone number on the first page.”

Hello,

My name is Ann Coffaro and I am a doctoral student in the field of early intervention at the University of Pittsburgh. I am writing to ask you to participate in my doctoral research designed to investigate how **mothers** feel when their children receive birth to three early intervention services. I am asking you to complete two brief surveys and answer some questions that I estimate will take about 20-25 minutes. You must be over the age of 18 years to participate. There are no foreseeable risks associated with this project, nor are there any direct benefits to you. However, you will be helping me greatly with my studies in the field of early intervention.

Please return everything (the information page and the surveys) in the stamped, addressed envelope included. This is an entirely anonymous questionnaire, and so your responses will not be identifiable in any way. Your participation is voluntary, and you may withdraw from this project at any time.

Feel free to call me, Ann Coffaro, at 412-498-4059 with any questions or concerns you may have.

Thank you very much for your time,

Ann Coffaro

Doctoral Student, University of Pittsburgh

ENTRY

Family Information Questionnaire: to be filled out by the mother.

1. Today's date: *month* _____ *day* _____ *year* _____
2. How old were you when your child was born?: _____ *years*
3. How much did your baby weigh at birth? _____ *pounds* _____ *ounces*
4. How old is your child now?: *years* _____ *months* _____
5. Circle the type of insurance your child has:
 - a. private (for example Blue Cross)
 - b. public (for example, Medical Assistance like UPMC for You, or S-CHIP)
 - c. both (both private and public)
 - d. none
6. How old was your child the first time he/she was evaluated for early intervention services?:
years _____ *months* _____
7. Was there a specific reason your child qualified for early intervention? _____

8. Circle the type of early intervention services your child receives (for example, speech, OT, PT, developmental, vision) and list how often (1 time a week, 2 times a month, etc.) your child receives the service.

| | |
|--|--|
| speech _____ week or month (circle one) | social work _____ week or month |
| OT _____ week or month | nutrition _____ week or month |
| PT _____ week or month | developmental _____ week or month |
| vision _____ week or month | other (list) _____ week or month |
9. Is there anything you would like to tell me about your child or about early intervention?

Rotter's Scale: to be filled out by the mother.

The purpose of this survey is to understand your way of thinking about the way life events happen.

Circle an answer (either a or b) for each question. Answer every question.

1. a. Children get into trouble because their parents punish them too much.
b. The trouble with most children nowadays is that their parents are too easy with them.

2. a. Many of the unhappy things in people's lives are partly due to bad luck.
b. People's misfortunes result from the mistakes they make.

3. a. One of the major reasons we have wars is because people don't take enough interest in politics.
b. There will always be wars, no matter how hard people try to prevent them.

4. a. In the long run people get the respect they deserve in this world.
b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

5. a. The idea that teachers are unfair to students is nonsense.
b. Most students don't realize the extent to which their grades are influenced by accidental happenings.

6. a. Without the right breaks one cannot be an effective leader.
b. Capable people who fail to become leaders have not taken advantage of their opportunities.

7. a. No matter how hard you try, some people just don't like you.
- b. People who can't get others to like them don't understand how to get along with others.
8. a. Heredity plays the major role in determining one's personality
- b. It is one's experiences in life which determine what they're like.
9. a. I have often found that what is going to happen will happen.
- b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.
10. a. In the case of the well prepared student there is rarely, if ever, such a thing as an unfair test.
- b. Many times exam questions tend to be so unrelated to course work that studying is often useless.
11. a. Becoming a success is a matter of hard work; luck has little or nothing to do with it.
- b. Getting a good job depends mainly on being in the right place at the right time.
12. a. The average citizen can have an influence in government decisions.
- b. This world is run by the few people in power, and there is not much the little guy can do about it.

13. a. When I make plans, I am almost certain that I can make them work.
- b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.
14. a. There are certain people who are just no good.
- b. There is some good in everybody.
15. a. In my case, getting what I want has little or nothing to do with luck.
- b. Many times we might just as well decide what to do by flipping a coin.
16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
- b. Getting people to do the right thing depends upon ability; luck has little or nothing to do with it.
17. a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
- b. By taking an active part in political and social affairs the people can control world events.
18. a. Most people don't realize the extent to which their lives are controlled by accidental happenings.
- b. There really is no such thing as "luck."

19. a. One should always be willing to admit mistakes.
b. It is usually best to cover up one's mistakes.
20. a. It is hard to know whether or not a person really likes you.
b. How many friends you have depends upon how nice a person you are.
21. a. In the long run the bad things that happen to us are balanced by the good ones.
b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.
22. a. With enough effort we can wipe out political corruption.
b. It is difficult for people to have much control over the things politicians do in office.
23. a. Sometimes I can't understand how teachers arrive at the grades they give.
b. There is a direct connection between how hard I study and the grades I get.
24. a. A good leader expects people to decide for themselves what they should do.
b. A good leader makes it clear to everybody what their jobs are.
25. a. Many times I feel that I have little influence over the things that happen to me.
b. It is impossible for me to believe that chance or luck plays an important role in my life.
26. a. People are lonely because they don't try to be friendly.
b. There's not much use in trying too hard to please people, if they like you, they like you.

27. a. There is too much emphasis on athletics in high school.

b. Team sports are an excellent way to build character.

28. a. What happens to me is my own doing.

b. Sometimes I feel that I don't have enough control over the direction my life is taking.

29. a. Most of the time I can't understand why politicians behave the way they do.

b. In the long run the people are responsible for bad government on a national as well as on a local level.

Family Survey: to be filled out by the mother.

Instructions:

- All of the responses include the word “we” or “our.” This refers to your family. Usually this means parents and others who support and care for your child. But every family is different, so think of what “family” means to you when answering.
- On every page, you will be asked to answer questions like the example below:

How much does your family know about dinosaurs?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|-------------------------------------|---|---------------------------------------|---|--------------------------------------|
| We know a little about dinosaurs | | We know some about dinosaurs | | We know a good amount about dinosaurs | | We know a great deal about dinosaurs |

Read each question and circle the number that best describes your family right now.

- If a statement almost describes your family, but not quite, circle the number just to the left or the right. For example if you feel that the statement 5 “We know a **good amount** about dinosaurs” almost describes your family, but not quite—circle the 4.
- If you do not know how to answer a question, or if you are not comfortable answering the question, skip it and go to the next question.

UNDERSTANDING YOUR CHILD'S STRENGTHS, ABILITIES, AND SPECIAL NEEDS

1. Your child is growing and learning. How much does your family understand about your child’s development?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to understand our child's development | | We understand some about our child's development | | We understand a good amount about our child's development | | We understand a great deal about our child's development |

2. Some children have special health needs, a disability, or are delayed in their development. These are often referred to as “special needs.” How familiar is your family with your child's special needs?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to understand our child's special needs | | We understand some about our child's special needs | | We understand a good amount about our child's special needs | | We understand a great deal about our child's special needs |

KNOWING YOUR RIGHTS AND ADVOCATING FOR YOUR CHILD

3. A variety of programs and services may be available to help your child and family. How much does your family know about the programs and services that are available?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|--|---|---|
| We are just beginning to learn about the programs and services that are available. | | We know some about the programs and services that are available. | | We know a good amount about the programs and services that are available. | | We know a great deal about the programs and services that are available. |

4. Families often meet with early intervention professionals to plan services or activities. How comfortable is your family participating in these meetings?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|---|---|--|
| We are just beginning to feel comfortable participating in meetings. | | We are somewhat comfortable participating in meetings | | We are generally comfortable participating in meetings | | We are very comfortable participating in meetings |

5. Families of children with special needs have rights, including what to do if you are not satisfied. How familiar is your family with your rights?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to understand our rights. | | We understand some about our rights. | | We understand a good amount about our rights. | | We understand a great deal about our rights. |

HELPING YOUR CHILD DEVELOP AND LEARN

6. Families help their children develop and learn. How much does your family know about how to help your child develop and learn?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|---|---|--|
| We are just beginning to know how to help our child develop and learn. | | We know some about how to help our child develop and learn. | | We know a good amount about how to help our child develop and learn. | | We know a great deal about how to help our child develop and learn. |

7. Families try to help their children learn to behave the way they would like. How much does your family know about how to help your child learn to behave the way your family would like?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to know how to help our child behave the way we want. | | We know some about how to help our child behave the way we want. | | We know a good deal about how to help our child behave the way we want. | | We know a great deal how to help our child behave the way we want. |

HAVING SUPPORT SYSTEMS

8. Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| We seldom have someone to talk with about things when we need it. | | We sometimes have someone to talk with about things when we need it. | | We usually have someone to talk with about things when we need it. | | We almost always have someone to talk with about things when we need it. |

9. Families sometimes must rely on other people for help when they need it, for example to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone you can rely on for help when your family needs it?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| We seldom have someone we can rely on for help when we need it. | | We sometimes have someone we can rely on for help when we need it. | | We usually have someone we can rely on for help when we need it. | | We almost always have someone we can rely on for help when we need it. |

10. Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| We seldom are able to do the things we enjoy. | | We sometimes are able to do the things we enjoy. | | We usually are able to do the things we enjoy. | | We almost always are able to do the things we enjoy. |

ACCESSING YOUR COMMUNITY

11. All children need medical care. How well does your family's medical care meet your child's special needs?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|--|---|--|
| Our medical care meets few of our child's needs. | | Our medical care meets some of our child's needs. | | Our medical care meets many of our child's needs. | | Our medical care meets almost all of our child's needs. |

12. Many families have a need for quality childcare. By this, we do not mean occasional babysitting, but regular childcare, either part-day or full-day. How well does your family's childcare meet your child's needs?
- CHECK HERE IF YOUR FAMILY HAS NOT WANTED CHILD CARE, AND GO TO QUESTION 13.
 - CHECK HERE IF YOUR FAMILY HAS WANTED CHILD CARE BUT IT IS NOT CURRENTLY AVAILABLE, AND GO TO QUESTION 13.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| Our childcare meets few of our child's needs. | | Our childcare meets some of our child's needs. | | Our childcare meets many of our child's needs. | | Our childcare meets almost all of our child's needs. |

13. Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?

- CHECK HERE IF YOUR FAMILY HAS NOT WANTED YOUR CHILD TO PARTICIPATE IN SUCH ACTIVITIES.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|--|---|--|
| Our child seldom participates in the activities we want. | | Our child sometimes participates in the activities we want. | | Our child usually participates in the activities we want. | | Our child almost always participates in the activities we want. |

THANK YOU FOR COMPLETING THESE QUESTIONS

RETURN EVERYTHING IN THE ENCLOSED ENVELOPE

APPENDIX B

EXIT SURVEY PACKET

Service Coordinator Script to Prospective Study Participants

“This is a study being conducted by a University of Pittsburgh Doctoral Student about how mothers feel about early intervention. Participation is strictly voluntary and completely anonymous. If you think you might like to participate, I will leave this packet with you. It contains some questions to fill out and a stamped envelope to mail back to the primary investigator. If you have any concerns or questions there is a phone number on the first page.”

Hello,

My name is Ann Coffaro and I am a doctoral student in the field of early intervention at the University of Pittsburgh. I am writing to ask you to participate in my doctoral research designed to investigate how **mothers** feel when their children receive birth to three early intervention services. I am asking you to complete two brief surveys and answer some questions that I estimate will take about 20-25 minutes. You must be over the age of 18 years to participate. There are no foreseeable risks associated with this project, nor are there any direct benefits to you. However, you will be helping me greatly with my studies in the field of early intervention.

Please return everything (the information page and the surveys) in the stamped, addressed envelope included. This is an entirely anonymous questionnaire, and so your responses will not be identifiable in any way. Your participation is voluntary.

Feel free to call me, Ann Coffaro, at 412-498-4059 with any questions or concerns you may have.

Thank you very much for your time,

Ann Coffaro

Doctoral Student, University of Pittsburgh

EXIT

Family Information Questionnaire: to be filled out by mother.

1. Today's date: *month* _____ *day* _____ *year* _____
2. How old were you when your child was born?: _____ *years*
3. How much did your baby weigh at birth? _____ *pounds* _____ *ounces*
4. How old is your child now?: *years* _____ *months* _____
5. Circle the type of insurance your child has:
 - a. private (for example Blue Cross)
 - b. public (for example UPMC for You or Medical Assistance, or S-CHIP)
 - c. both (both private and public)
 - d. none
6. How old was your child the first time he/she was evaluated for early intervention services?:
years _____ *months* _____
7. Was there a specific reason your child qualified for early intervention?

8. Circle the type of early intervention services your child receives (for example, speech, OT, PT, developmental, vision) and list how often (1 time a week, 2 times a month, etc.) your child receives the service.
speech _____ week or month (circle one) **social work** _____ week or month
OT _____ week or month **nutrition** _____ week or month
PT _____ week or month **developmental** _____ week or month
vision _____ week or month **other (list)** _____ week or month
9. Is there anything you would like to tell me about your child or about early intervention?

10. What type of preschool will your child attend?:
no preschool *DART preschool* *Pittsburgh Public preschool* *Head Start* *preschool with some services*

Rotter's Scale: to be filled out by mother.

The purpose of this survey is to understand your way of thinking about the way life events happen.

Circle an answer (either a or b) for each question. Answer every question.

1. a. Children get into trouble because their parents punish them too much.
b. The trouble with most children nowadays is that their parents are too easy with them.

2. a. Many of the unhappy things in people's lives are partly due to bad luck.
b. People's misfortunes result from the mistakes they make.

3. a. One of the major reason we have wars is because people don't take enough interest in politics.
b. There will always be wars, no matter how hard people try to prevent them.

4. a. In the long run people get the respect they deserve in this world
b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries

5. a. The idea that teachers are unfair to students is nonsense.
b. Most students don't realize the extent to which their grades are influenced by accidental happenings.

6. a. Without the right breaks one cannot be an effective leader.
b. Capable people who fail to become leaders have not taken advantage of their opportunities.

7. a. No matter how hard you try, some people just don't like you.
- b. People who can't get others to like them don't understand how to get along with others.
8. a. Heredity plays the major role in determining one's personality
- b. It is one's experiences in life which determine what they're like.
9. a. I have often found that what is going to happen will happen.
- b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.
10. a. In the case of the well prepared student there is rarely, if ever, such a thing as an unfair test.
- b. Many times exam questions tend to be so unrelated to course work that studying is often useless.
11. a. Becoming a success is a matter of hard work; luck has little or nothing to do with it.
- b. Getting a good job depends mainly on being in the right place at the right time.
12. a. The average citizen can have an influence in government decisions.
- b. This world is run by the few people in power, and there is not much the little guy can do about it.

13. a. When I make plans, I am almost certain that I can make them work.
- b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.
14. a. There are certain people who are just no good.
- b. There is some good in everybody.
15. a. In my case, getting what I want has little or nothing to do with luck.
- b. Many times we might just as well decide what to do by flipping a coin.
16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
- b. Getting people to do the right thing depends upon ability; luck has little or nothing to do with it.
17. a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
- b. By taking an active part in political and social affairs the people can control world events.
18. a. Most people don't realize the extent to which their lives are controlled by accidental happenings.
- b. There really is no such thing as "luck."

19. a. One should always be willing to admit mistakes.
b. It is usually best to cover up one's mistakes.
20. a. It is hard to know whether or not a person really likes you.
b. How many friends you have depends upon how nice a person you are.
21. a. In the long run the bad things that happen to us are balanced by the good ones.
b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.
22. a. With enough effort we can wipe out political corruption.
b. It is difficult for people to have much control over the things politicians do in office.
23. a. Sometimes I can't understand how teachers arrive at the grades they give.
b. There is a direct connection between how hard I study and the grades I get.
24. a. A good leader expects people to decide for themselves what they should do.
b. A good leader makes it clear to everybody what their jobs are.
25. a. Many times I feel that I have little influence over the things that happen to me.
b. It is impossible for me to believe that chance or luck plays an important role in my life.
26. a. People are lonely because they don't try to be friendly.
b. There's not much use in trying too hard to please people, if they like you, they like you.

27. a. There is too much emphasis on athletics in high school.

b. Team sports are an excellent way to build character.

28. a. What happens to me is my own doing.

b. Sometimes I feel that I don't have enough control over the direction my life is taking.

29. a. Most of the time I can't understand why politicians behave the way they do.

b. In the long run the people are responsible for bad government on a national as well as on a local level.

Parent Scale: to be filled out by the mother.

Circle the answer that best fits your opinion for each question.

1. What I do has little effect on my child's behavior

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

2. When something goes wrong between me and my child, there is little I can do to correct it.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

3. Parents should address problems with their children because ignoring them won't make them go away.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

4. If your child tantrums no matter what you try, you might as well give up.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

5. No matter how hard a parent tries, some children will never learn to mind.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

6. I am often able to predict my child's behavior in situations.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

7. There is no such thing as good or bad children—just good or bad parents.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

8. When my child is well-behaved, it is because he/she is responding to my efforts.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

9. Parents who can't get their children to listen to them don't understand how to get along with their children.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

10. My child's behavior problems are no one's fault but my own.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

11. Capable people who fail to become good parents have not followed through on their opportunities.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

12. Children's behavior problems are often due to mistakes their parents made.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

13. My life is chiefly controlled by my child.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

14. My child does not control my life.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

15. My child influences the number of friends I have.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

16. I feel like what happens in my life is mostly determined by my child.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

17. It is easy for me to avoid and function independently of my child's attempt to have control over me.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

18. When I make a mistake with my child I am usually able to correct it.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

19. I always feel in control when it comes to my child.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

20. My child's behavior is sometimes more than I can handle.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

21. Sometimes I feel that my child's behavior is hopeless.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

22. It is often easier to let my child have his/her way than to put up with a tantrum.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

23. I find that sometimes my child can get me to do things I really did not want to do.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

24. My child often behaves in a manner very different from the way I would want him/her to behave.

strongly agree somewhat agree neither agree or disagree somewhat disagree strongly disagree

Family Survey: to be filled out by the mother.

Instructions:

- All of the responses include the word “we” or “our.” This refers to your family. Usually this means parents and others who support and care for your child. But every family is different, so think of what “family” means to you when answering.
- On every page, you will be asked to answer questions like the example below:

How much does your family know about dinosaurs?

| | | | | | | |
|---|---|-------------------------------------|---|---------------------------------------|---|--------------------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| We know a little about dinosaurs | | We know some about dinosaurs | | We know a good amount about dinosaurs | | We know a great deal about dinosaurs |

Read each question and circle the number that best describes your family right now.

- If a statement almost describes your family, but not quite, circle the number just to the left or the right. For example if you feel that the statement 5 “We know **a good amount** about dinosaurs” almost describes your family, but not quite—circle the 4.
- If you do not know how to answer a question, or if you are not comfortable answering the question, skip it and go to the next question.

UNDERSTANDING YOUR CHILD'S STRENGTHS, ABILITIES, AND SPECIAL NEEDS

1. Your child is growing and learning. How much does your family understand about your child’s development?

| | | | | | | |
|--|---|---|---|--|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| We are just beginning to understand our child's development | | We understand some about our child's development | | We understand a good amount about our child's development | | We understand a great deal about our child's development |

2. Some children have special health needs, a disability, or are delayed in their development. These are often referred to as “special needs.” How familiar is your family with your child's special needs?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to understand our child's special needs | | We understand some about our child's special needs | | We understand a good amount about our child's special needs | | We understand a great deal about our child's special needs |

3. Professionals who work with you and your child want to know if the things they do are working. How often is your family able to tell if your child is making progress?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|--|---|--|
| We seldom can tell if our child is making progress | | We sometimes can tell if our child is making progress | | We usually can tell if our child is making progress | | We almost always can tell if our child is making progress |

KNOWING YOUR RIGHTS AND ADVOCATING FOR YOUR CHILD

4. A variety of programs and services may be available to help your child and family. How much does your family know about the programs and services that are available?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|--|---|---|
| We are just beginning to learn about the programs and services that are available. | | We know some about the programs and services that are available. | | We know a good amount about the programs and services that are available. | | We know a great deal about the programs and services that are available. |

5. Families often meet with early intervention professionals to plan services or activities. How comfortable is your family participating in these meetings?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|---|---|--|
| We are just beginning to feel comfortable participating in meetings. | | We are somewhat comfortable participating in meetings | | We are generally comfortable participating in meetings | | We are very comfortable participating in meetings |

6. Families of children with special needs have rights, including what to do if you are not satisfied. How familiar is your family with your rights?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to understand our rights. | | We understand some about our rights. | | We understand a good amount about our rights. | | We understand a great deal about our rights. |

HELPING YOUR CHILD DEVELOP AND LEARN

7. Families help their children develop and learn. How much does your family know about how to help your child develop and learn?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|---|---|--|
| We are just beginning to know how to help our child develop and learn. | | We know some about how to help our child develop and learn. | | We know a good amount about how to help our child develop and learn. | | We know a great deal about how to help our child develop and learn. |

8. Families try to help their children learn to behave the way they would like. How much does your family know about how to help your child learn to behave the way your family would like?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|--|---|---|
| We are just beginning to know how to help our child behave the way we want. | | We know some about how to help our child behave the way we want. | | We know a good deal about how to help our child behave the way we want. | | We know a great deal how to help our child behave the way we want. |

9. Families work with professionals to help their children learn and practice new skills at home or in their communities. How often does your family help your child learn and practice new skills?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| We are just beginning to help our child learn and practice new skills. | | We sometimes help our child learn and practice new skills. | | We usually help our child learn and practice new skills. | | We routinely help our child learn and practice new skills. |

HAVING SUPPORT SYSTEMS

10. Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| We seldom have someone to talk with about things when we need it. | | We sometimes have someone to talk with about things when we need it. | | We usually have someone to talk with about things when we need it. | | We almost always have someone to talk with about things when we need it. |

11. Families sometimes must rely on other people for help when they need it, for example to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone you can rely on for help when your family needs it?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| We seldom have someone we can rely on for help when we need it. | | We sometimes have someone we can rely on for help when we need it. | | We usually have someone we can rely on for help when we need it. | | We almost always have someone we can rely on for help when we need it. |

12. Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| We seldom are able to do the things we enjoy. | | We sometimes are able to do the things we enjoy. | | We usually are able to do the things we enjoy. | | We almost always are able to do the things we enjoy. |

ACCESSING YOUR COMMUNITY

13. All children need medical care. How well does your family's medical care meet your child's special needs?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|--|---|--|
| Our medical care meets few of our child's needs. | | Our medical care meets some of our child's needs. | | Our medical care meets many of our child's needs. | | Our medical care meets almost all of our child's needs. |

14. Many families have a need for quality childcare. By this, we do not mean occasional babysitting, but regular childcare, either part-day or full-day. How well does your family's childcare meet your child's needs?

- CHECK HERE IF YOUR FAMILY HAS NOT WANTED CHILD CARE, AND GO TO QUESTION 13.
- CHECK HERE IF YOUR FAMILY HAS WANTED CHILD CARE BUT IT IS NOT CURRENTLY AVAILABLE, AND GO TO QUESTION 13.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|---|---|---|---|---|---|
| Our childcare meets few of our child's needs. | | Our childcare meets some of our child's needs. | | Our childcare meets many of our child's needs. | | Our childcare meets almost all of our child's needs. |

15. Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?

- CHECK HERE IF YOUR FAMILY HAS NOT WANTED YOUR CHILD TO PARTICIPATE IN SUCH ACTIVITIES.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|--|---|--|
| Our child seldom participates in the activities we want. | | Our child sometimes participates in the activities we want. | | Our child usually participates in the activities we want. | | Our child almost always participates in the activities we want. |

16. *To what extent has early intervention helped your family know and understand your rights?*

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Earl y intervention has done a poor job of helping us know our rights. | | Earl y intervention has done a fair job of helping us know our rights. | | Earl y intervention has done a good job of helping us know our rights. | | Earl y intervention has done an excellent job of helping us know our rights. |

17. *To what extent has early intervention helped your family effectively communicate your child's needs?*

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Early intervention hs done a poor job of helping us communicate our child's needs. | | Early intervention hs done a fair job of helping us communicate our child's needs. | | Early intervention hs done a good job of helping us communicate our child's needs. | | Early intervention hs done an excellent job of helping us communicate our child's needs. |

18. *To what extent has early intervention helped your family be able to help your child develop and learn?*

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|--|---|--|---|--|
| Early intervention has done a poor job of helping us help our child develop and learn. | | Early intervention hs done a fair job of helping us help our child develop and learn. | | Early intervention hs done a good job of helping us help our child develop and learn. | | Early intervention hs done an excellent job of helping us help our child develop and learn. |

THANK YOU FOR COMPLETING THESE QUESTION.RETURN EVERYTHING IN THE ENCLOSED ENVELOPE.

APPENDIX C

SERVICE COORDINATOR SCRIPT

Service Coordinator Script to Prospective Study Participants

“This is a study being conducted by a University of Pittsburgh Doctoral Student about how mothers feel about early intervention. Participation is strictly voluntary and completely anonymous. If you think you might like to participate, I will leave this packet with you. It contains some questions to fill out and a stamped envelope to mail back to the primary investigator. If you have any concerns or questions there is a phone number on the first page.”

BIBLIOGRAPHY

- Affleck, G., Allen, D. A., McGrade, B. J., & McQueeney, M. (1982). Home environments of developmentally disabled infants as a function of parent and infant characteristics. *American Journal of Mental Deficiency, 86*(5), 445-452.
- Affleck, G., & Tennen, H. (1993). Cognitive adaptation to adversity: Insights from parents of medically fragile infants. In *Turnbull, Ann P (Ed); Patterson, Joan M (Ed); et al (1993) Cognitive coping, families, and disability (pp 135-150) xii, 321pp.*
- Allen, D. A., Affleck, G., McGrade, B. J., & McQueeney, M. (1984). Effects of single-parent status on mothers and their high-risk infants. *Infant Behavior & Development, 7*(3), 347-357.
- Allen, K. E., & Cowdery, G. E. (2005). *The exceptional child: Inclusion in early childhood education* 5th Albany, NY: Delmar.
- Aspinwall, L.G., & Leaf, S.L. (2002). In search of the unique aspects of hope: Pinning our hopes on positive emotions, future-oriented thinking, hard times, and other people. *Psychological Inquiry, 13*(4), 276-321.
- Assel, M. A., Landry, S. H., Swank, P. R., Steelman, L., Miller-Loncar, C., & Bailey, D. B., Jr. (2000). The federal role in early intervention: Prospects for the future. *Topics in Early Childhood Special Education, 20*(2), 71-78.
- Bailey, D. B. (2001). Evaluating parent involvement and family support in early intervention and reschool programs. *Journal of Early Intervention, 24*(1), 1-14.
- Bailey, D. B., & Bruder, M. B. (2005). *Family outcomes of early intervention and early childhood special education: Issues and considerations*. Retrieved January, 2006, from http://www.fpg.unc.edu/%7Eeco/pdfs/Family_Outcomes_Issues_01-17-05.pdf
- Bailey, D., Bruder, M. B., & Hebbeler, K. (2006). Guidance for states in documenting family outcomes for early intervention & early childhood special education. Early Childhood Outcomes Center.

- Bailey, D. B., Hebbeler, K., Spiker, D., Scarborough, A., Malik, S., Nelson, L. (2005). Thirty-six moth outcomes for families of children who have disabilities and participated in early intervention. *Pediatrics*, 116, 1346-1352.
- Bailey, D. B., Hebbeler, K., Olmstead, M. G., Raspa, M., Bruder, M. B. (2008). Measuring Family Outcomes: Considerations for Large-Scale Data Collection in Early Intervention. *Infants and Young Children*, 21(3), 194-206.
- Bailey, D. B., Jr., McWilliam, R. A., Darkes, L. A., Hebbeler, K., Simeonsson, R. J., Spiker, D., et al. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children*, 64(3), 313-328.
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal of Mental Retardation*, 107(6), 433-444.
- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 37(2), 122-147.
- Bandura, A. (1989). *Social cognitive theory* (Vol. 6). Greenwich, CT: JAI Press.
- Banyard, V. L., & Graham-Bermann, S. A. (1998). Surviving poverty: Stress and coping in the lives of housed and homeless mothers. *American Journal of Orthopsychiatry*, 68(3), 479-489.
- Barakat, L.P., Lutz, M.J., Nicolaou, D.C., & Lash, L.A. (2005). Parental Locus of Control and Family Functioning in the Quality of Life of Children with Sickle Cell Disease. *Journal of Clinical Psychology in Medical Settings*, 12(4), 323-331.
- Baxter, C., Cummins, R. A., & Polak, S. (1995). A longitudinal study of parental stress and support: From diagnosis of disability to leaving school. *International Journal of Disability, Development & Education*, 42(2), 125-136.
- Beckman, P. J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. *American Journal of Mental Deficiency*, 88(2), 150-156.
- Beckman, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95(5), 585-595.
- Belsky, J. (1984). The determinants of parenting: A process model. *Child Development*, 55(1), 83-96.
- Belsky, J., & Barends, N. (2002). Personality and parenting. [References]. In M. H. Bornstein (Ed.), *Handbook of parenting: Vol 3: Being and becoming a parent (2nd ed)* (pp. 415-438). Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.

- Bilder, D., Pinborough-Zimmerman, J., Miller, J., and McMahon, W. (2009). Prenatal, Perinatal, and Neonatal Factors Associated With Autism Spectrum Disorders. *Pediatrics*, *123*, 1293-1300.
- Bradley, R. H., & Corwyn, R. F. (2002). Socioeconomic status and child development. *Annual Review of Psychology*, *53*(1), 371-399.
- Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the Double ABCX model. *Journal of Autism & Developmental Disorders*, *17*(4), 469-486.
- Brooks-Gunn, J. (1995). Children in families in communities: Risk and intervention in the Bronfenbrenner tradition. In Moen, Phyllis (Ed); Elder, Glen H Jr (Ed); et al (1995) *Examining lives in context: Perspectives on the ecology of human development* (pp. 467-519). Washington, DC: American Psychological Association.
- Brooks-Gunn, J., Berlin, L. J., & Fuligni, A. S. (2000). Early childhood intervention programs: What about the family? [References]. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention (2nd ed)* (pp. 549-588). New York, NY: Cambridge University Press.
- Cameron, S., Dobson, L., & Day, D. (1991). Stress in parents of developmentally delayed and non-delayed preschool children. *Canada's Mental Health*, *39*(1), 13-17.
- Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The Parental Locus of Control Scale: Development and validation. *Journal of Clinical Child Psychology*, *15*(3), 260-267.
- Chan, B. C.-P., & Lao, T. T.-H. (2008). Effect of parity and advanced maternal age on obstetric outcome. *International Journal of Gynecology and Obstetrics*, *102*, 237–241.
- Chapman, D. A., Scott, K. G., & Mason, C. A. (2002). Early risk factors for mental retardation: The role of maternal age and maternal education. *American Journal on Mental Retardation*, *107*, 46-59.
- Creasey, G. L., & Jarvis, P. A. (1994). Relationships between parenting stress and developmental functioning among 2-year-olds. *Infant Behavior & Development*, *17*(4), 423-429.
- Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (2002). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. [References]. In J. Blacher & B. L. Baker (Eds.), *The best of AAMR: Families and mental retardation: A collection of notable AAMR journal articles across the 20th century* (pp. 105-117). Washington, DC: American Association on Mental Retardation.

- Dempsey, I., & Dunst, C. J. (2004). Helpgiving styles and parent empowerment in families with a young child with a disability. *Journal of Intellectual & Developmental Disability*, 29(1), 40-51.
- DeMaso, D. R., Campis, L. K., Wypij, D., Bertram, S., Upshitz, M., & Freed, M. (1991). The impact of maternal perceptions and medical severity on the adjustment of children with congenital heart disease. *Journal of Pediatric Psychology*, 16, 137-149.
- DeVellis, R. F., & et al. (1985). Development and validation of the Child Improvement Locus of Control (CILC) scales. *Journal of Social & Clinical Psychology*, 3(3), 307-324.
- Diviney, E. A. (2001). *Well-being of mothers while rearing a child with developmental disabilities*. New York U., US, 1.
- Duncan, G. J., Brooks-Gunn, J., & Klebanov, P. K. (1994). Economic deprivation and early childhood development. *Child Development*, 65(2), 296-318.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.
- Dunst, C. J. (1985). Rethinking early intervention. *Analysis & Intervention in Developmental Disabilities*, 5(1-2), 165-201.
- Dunst, C. J. (1997). Conceptual and empirical foundations of family-centered practice. [References]. In *Illback, Robert J (Ed); Cobb, Carolyn T (Ed); et al (1997) Integrated services for children and families: Opportunities for psychological practice* (pp. 75-91). Washington, DC: American Psychological Association.
- Dunst, C. J. (1999). Placing parent education in conceptual and empirical context. *Topics in Early Childhood Special Education*, 19(3), 141-147.
- Dunst, C. J. (2002). Family-centered practices: Birth through high school. *Journal of Special Education*, 36(3), 139-147.
- Dunst, C. J., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-Oriented Program Models and Professional Helpgiving Practices. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 51(3), 221-229.
- Dunst, C.J., & Dempsey, I. (2007). Family-professionanl Parternships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development, and Education*, 54(3), 305-318.
- Dunst, C.J. & Dempsey, I. (2008). Family-professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education*, 54(3), 305-318.

- Dunst, C. J., Trivette, C. M., & Cross, A. H. (2002). Mediating influences of social support: Personal, family, and child outcomes. [References]. In J. Blacher & B. L. Baker (Eds.), *The best of AAMR: Families and mental retardation: A collection of notable AAMR journal articles across the 20th century* (pp. 119-133). Washington, DC: American Association on Mental Retardation.
- Dyson, L. (1993). Response to the presence of a child with disabilities: parental stress and family functioning over time. *Am J Ment Retard*, 98, 207 - 218.
- Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal of Mental Retardation*, 102(3), 267-279.
- Fox, M. (1980). *The relationship between maternal locus of control and maternal involvement in the day treatment of emotionally disturbed children*. Adelphi U, School of Social Work.
- Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among parents of handicapped children: a multidimensional approach. *American Journal of Mental Retardation*, 94(3), 240-249.
- Friedrich, W. N., & Friedrich, W. L. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. *American Journal of Mental Deficiency*, 85(5), 551-553.
- Galligan, A. C. (1982). *The relationship between maternal locus of control, child behavior patterns, and maternal acceptance*. Columbia U Teachers Coll.
- George D. & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference*. Fourth edition.
- Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disabilities*, 13(4), 256-275.
- Greenlee, R., & Lantz, J. (1993). Family coping strategies and the rural Appalachian working poor. *Contemporary Family Therapy: An International Journal*, 15(2), 121-137.
- Gueorguieva, R. V., Carter, R. L., Ariet, M., Roth, J., Mahan, C. S., & Resnick, M. B. (2001). Effect of teenage pregnancy on educational disabilities in kindergarten. *American Journal of Epidemiology*, 154(3), 212-220.
- Guerin, P. J., & Chabot, D. R. (1992). Development of Family Systems Theory. In D. K. Freedheim (Ed.). *History of psychotherapy: A century of change* (pp. 225-260). Washington: D.C. American Psychological Association.
- Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation*, 102(4), 319-345.

- Guralnick, M. J. (1999). Family and child influences on the peer-related social competence of young children with developmental delays. *Mental Retardation & Developmental Disabilities Research Reviews*, 5(1), 21-29.
- Guralnick, M. J. (2000). Early childhood intervention: Evolution of a system. *Focus on Autism & Other Developmental Disabilities*, 15(2), 68-79.
- Hagekull, B., Bohlin, G., & Hammarberg, A. (2001). The role of parental perceived control in child development: A longitudinal study. *International Journal of Behavioral Development*, 25(5), 429-437.
- Hall, L. E. (1995). *Parental internal attributes as factors in family adaptation to a child with a disability*. U Alberta, Canada.
- Hallam-Helbich, H. A. (2001). Primary caregivers' perceptions of child behavior: The influence of parenting stress, level of depression, and developmental knowledge. *Dissertation Abstracts International*, 61(10-A), 3890, US: University Microfilms International.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49(6), 405-418.
- Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., Krauss, M. W., Sayer, A., & Upshur, C. C. (2001). Children with disabilities: a longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, 66(3), 1-114.
- Hebbeler, K., Spiker, D., Malik, S., Scarborough, A., & Simeonsson, R. (2004). Demographic characteristics of children and families entering early intervention. *NEILS Data Report*, 3, 1-6.
- Heikura, U., et al. (2008). Variations in prenatal sociodemographic factors associated with intellectual disability: a study of the 20-year interval between two birth cohorts in northern Finland. *American Journal of Epidemiology*, 162(2), 169-177.
- Helm, J. M., Comfort, M., Bailey, D. B., Jr., & Simeonsson, R. J. (1990). Adolescent and adult mothers of handicapped children: Maternal involvement in play. *Family Relations: Journal of Applied Family & Child Studies*, 39(4), 432-437.
- Hill, R. (1949). *Families under stress*. New York: Harper Row.
- Hill, R. (1965). Generic features of families under stress. Pp35-52 In H.J. Parad (ed.), *Crisis Intervention: Selected Readings*. Family Service Association of America.

- Hochman, J.D. & Foley, G.M. New directions toward an integration of early intervention and infant mental health. Retrieved August 12, 2009 at <http://www.ct-aimh.org/Gil%20Foley%20presentation.ppt>.
- Houck, G. M., Booth, C. L., & Barnard, K. E. (1991). Maternal depression and locus of control orientation as predictors of dyadic play behavior. *Infant Mental Health Journal*, 12(4), 347-360.
- Huck, S.W. & Cormier, W.H. (1996). *Reading Statistics and Research*. HarperCollins Inc.
- Huston, A., McLoyd, V. C., & Coll, C. G. (1997). Poverty and behavior: The case for multiple methods and levels of analysis. *Developmental Review*, 17(3), 376-393.
- Jarvis, P. A., & Creasey, G. L. (1991). Parental stress, coping, and attachment in families with an 18-month-old infant. *Infant Behavior & Development*, 14(4), 383-395.
- Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, 18(2), 167-175.
- Jones, S. M. (2003). *Poverty, parenting, and trajectories of children's social and emotional adjustment from ages one to three*. Yale U., US.
- Jones, J., & Passey, J. (2005). Family Adaptation, Coping and Resources: Parents Of Children With Developmental Disabilities and Behaviour Problems. *Journal on Developmental Disabilities*, 11(1), 31-46.
- Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations: Journal of Applied Family & Child Studies*, 47(3), 263-268.
- Kazak, A. E. (1986). Families with physically handicapped children: Social ecology and family systems. *Family Process*, 25(2), 265-281.
- Kazak, A. E. (1987). Families with disabled children: Stress and social networks in three samples. *Journal of Abnormal Child Psychology*, 15(1), 137-146.
- Keller, D. W. (1999). Dimensions of parenting stress of mothers and fathers of a school age child with a disability. *Dissertation Abstracts International*, 60(4-A), 1347, US: University Microfilms International.
- Klebanov, P. K., Brooks-Gunn, J., & Duncan, G. J. (1994). Does neighborhood and family poverty affect mothers' parenting, mental health, and social support? *Journal of Marriage & the Family*, 56(2), 441-455.
- Koger, D. C. (1999). The influence of the Building Strong Families program on loc control and parenting behaviors of limited resource mothers. *MSU Extension*

Family Life Bulletins — KOGER001 04/05/00. Retrieved from the Michigan State University Extension web site:
<http://web.1muse.muse.edu/imp/modfl/koger001.html>

- Konstantareas, M., & Lampropoulou, V. (1995). Stress in Greek mothers with deaf children: Effects of child characteristics, family resources and cognitive set. *American Annals of the Deaf*, 140(3), 264-270.
- Kutscherousky, Y.C. (1997). *Relative contributions of maternal coping strategies, self-efficacy, and sense of competence to home environment for premature infants*. U Texas at Austin, US.
- Lachman, M. E., & Weaver, S. L. (1998). The sense of control as a moderator of social class differences in health and well-being. *Journal of Personality & Social Psychology*, 74(3), 763-773.
- Lange, R.V. & Tiggeman, M. (1981). Dimensionality and reliability of Rotters I-E locus of control scale. *J. Pers. Assess.* 45(4), 398-406.
- Landau, R. (1995). Locus of control and socioeconomic status: Does internal locus of control reflect real resources and opportunities or personal coping abilities? *Social Science and Medicine*, 41(11), 1499-1505.
- Lavee, Y., McCubbin, H. I., & Olson, D. H. (1987). The effect of stressful life events and transitions on family functioning and well-being. *Journal of Marriage & the Family*, 49(4), 857-873.
- Lever, J., Pinol, N., & Uralde, J. (2005). Poverty, psychological resources and subjective well-being. *Social Indicators Research*, 73(3), 375-408.
- Linver, M. R., Brooks-Gunn, J., & Kohen, D. E. (2002). Family processes as pathways from income to young children's development. *Developmental Psychology*, 38(5), 719-734.
- Lipsey, M. W., & Wilson, D. B. (1993). The efficacy of psychological, educational, and behavioral treatment: Confirmation from meta-analysis. *American Psychologist*, 48, 1181-1209.
- Longenecker, H. Q. (2003). *Parent stress related to having a child with autism: Impact of educational programming*. Fielding Graduate Inst., US.
- Lovejoy, M., Verda, M. R., & Hays, C. E. (1997). Convergent and discriminant validity of measures of parenting efficacy and control. *Journal of Clinical Child Psychology*, 26(4), 366-376.
- Luster, T., & Rhoades, K. (1989). The relation between child-rearing beliefs and the home environment in a sample of adolescent mothers. *Family Relations*, 38(3), 317-322.

- Lynch, S., Hurford, D. P., & Cole, A. (2002). Parental enabling attitudes and locus of control of at-risk and honors students. *Adolescence*, 37(147), 527-550
- Magill-Evans, J., & Harrison, M. J. (2001). Parent-child interactions, parenting stress, and developmental outcomes at 4 years. *Children's Health Care*, 30(2), 135-150.
- Mahoney, G., & Wheeden, C. (1997). Parent-child interaction--The foundation for family-centered early intervention practice: A response to Baird and Peterson. *Topics in Early Childhood Special Education*, 17(2), 165-184.
- Maisto, A. A., & German, M. L. (1981). Maternal locus of control and developmental gain demonstrated by high risk infants: A longitudinal analysis. *Journal of Psychology*, 109(2), 213-221.
- Manuel, J., Naughton, M. J., Balkrishnan, R., Smith, B. P., & Koman, L. (2003). Stress and adaptation in mothers of children with cerebral palsy. *Journal of Pediatric Psychology*, 28(3), 197-201.
- March of Dimes (n.d.). Retrieved July 30th, 2009. from March of Dimes website: <http://www.marchofdimes.com>.
- Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology*, 19(4), 313-328.
- McClun, L.A., & Merrell, K.A. (1999). Relationship of perceived parenting styles, locus of control orientation, and self-concept among junior high age students. *Psychology in the Schools*, 35(4), 381-390.
- McCubbin, H. I., & et al. (1980). Family stress and coping: A decade review. *Journal of Marriage & the Family*, 42(4), 855-871.
- McCubbin, H., McCubbin, M., Thompson, A., Han, S., & Allen, C. (1997). Families under stress: What makes them resilient. Retrieved September, 2007, <http://www.cyfernet.org/research/resilient.html>
- McCubbin, H. I., & Patterson, J. M. (1983). The Family Stress Process: The Double ABCX Model of adjustment and adaptation. *Marriage & Family Review*, 6(1-2), 7-37.
- McKinney, B., & Peterson, R. (1987). Predictors of stress in parents of developmentally disabled children. *J Pediatr Psychol*, 12, 133 - 150.
- Morris, J. K. (1992). Personal power in black mothers of handicapped sons. *Affilia*, 7(3), 72-92.

- Morrin, L. K. (1988). *The relationships among maternal variables and the intellectual and social/emotional status of prematurely born children*. U Florida, US.
- Newborg, J. (2005). *Battelle Developmental Inventory, second edition*. Riverside Publishing Company, Rolling Meadows, IL.
- Ostberg, M., & Hagekull, B. (2000). A structural modeling approach to the understanding of parenting stress. *Journal of Clinical Child Psychology*, 29(4), 615-625.
- Park, J., Turnbull, A. P., & Turnbull Iii, H. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children*, 68(2), 151-170.
- Park, J.-K. (2004). A conceptual model of coaching confidence: Development of a reliable and valid Coaching Confidence Scale. *International Journal of Sport Psychology*, 35(1), 37-59.
- Petrosky, M. J., & Birkimer, J. C. (1991). The relationship among locus of control, coping styles, and psychological symptom reporting. *Journal of Clinical Psychology*, 47(3), 336-345.
- Pisula, E., Degroat, J. S., Inanami, M., Ogura, T., Rodgers, C., Nishi, N., et al. (2002). [Parents of children with autism: recent research findings]Relationship between child temperament, parental knowledge of child development, and parental stress. *Psychiatria Polska.*, 36(1), 95-108.
- Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transactional model of coping. *Journal of Community & Applied Social Psychology*, 1(1), 57-70.
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., et al. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 4(1), 1.
- Raspa, M. (2008). *The ECO Family Outcomes Survey Recent Updates and Preliminary State Data* [powerpoint slides]. Retrieved from <http://www.ideadata.org/docs/ECO%20Family%20Outcomes%20Survey-Raspa-3.pdf>.
- Raspa, M., Hebbeler, K., & Bailey, D. (2009). *A guide to analyzing data from the Family Outcomes Survey*. Menlo Park, CA: Early Childhood Outcomes Center.
- Reddon, J. E., McDonald, L., & Kysela, G. M. (1992). Parental coping and family stress: I. Resources for and functioning of families with a preschool child having a developmental disability. *Early Child Development & Care*, 83, 1-26.
- Rimmerman, A., & Stanger, V. (1992). Locus of control and utilization of social support among mothers of young children with physical disabilities. *Int J Rehabil Res*, 15(1), 39-47.

- Roberts, M. W., Joe, V. C., & Rowe-Hallbert, A. (1992). Oppositional child behavior and parental locus of control. *Journal of Clinical Child Psychology*, 21(2), 170-177.
- Ross, C.E. & Broh, B.A. (2000). The roles of self-esteem and the sense of personal control in the academic achievement process. *Sociology of Education*, 73(October), 270-284.
- Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs*, 80.
- Rotter, J. B. (1975). Some problems and misconceptions related to the construct of internal versus external control of reinforcement. *Journal of Consulting & Clinical Psychology*, 43(1), 55-66.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down Syndrome: Implications for intervention. *Child & Family Behavior Therapy*, 19(4), 15-32.
- Shumaker, S. A., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. *Journal of Social Issues*, 40(4), 11-36.
- Silsby, J. C. (2004). *Parental predictors of behavioral outcomes for children with developmental disabilities*. Boston Coll., US.
- Skinner, E. (1995). *Perceived control, motivation, and coping*. Thousand Oaks, CA: Sage.
- Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71(2), 257-261.
- Smith, T. B., Oliver, M. N., Boyce, B.G., & Innocenti, M. S. (2002). Effects of mothers' locus of control for child improvement in a developmentally delayed sample. *Journal of genetic psychology*, 161, (3), 307-313 .
- Summers, M. E. (2002). *The impact of early intervention programs on parent functioning and parent-child interaction*. Virginia Consortium For Professional Psychology (Old Dominion U.), VA, US, 1.
- Summers, J. A., Behr, S. K., & Turnbull, A. P. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. S. Singer & L. K. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27-40). Baltimore, MD, England: Paul H.
- Trivette, C. M., & Dunst, C. J. (2004). Evaluating family based practices: Parenting experiences scale. *Young Exceptional Children*.

- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (1996). Factors associated with perceived control appraisals in a family-centered early intervention program. *Journal of Early Intervention, 20*(2), 165-178.
- Trivette, C. M., Dunst, C. J., Boyd, K., & Hamby, D. W. (1996). Family-oriented program models, helping practices, and parental control appraisals. *Exceptional Children, 62*(3), 237-248.
- Turnbull, H., III, Bateman, D. F., & Turnbull, A. P. (1993). Family empowerment. In P. Wehman (Ed.), *The ADA mandate for social change* (pp. 157-173). Baltimore, MD, England: Paul H.
- University, C. (2005). *Child Poverty in the 21st Century America*. Retrieved 10/05, 2005, from http://www.nccp.org/pub_cpt.html
- Walker, A. P. (2002). Parenting stress: A comparison of mothers and fathers of disabled and non-disabled children. *Dissertation Abstracts International: Section B: the Sciences & Engineering, 62*(7-B), 3393, US: Univ Microfilms International.
- Walston, K.A., Wallston, B.S., & DeVellis, R. (1978). Development of the multidimensional health locus of control (MHLC) scales. *Health Ed. Mono. 6*(2), 160-170.
- Warfield, M. E., Krauss, M. W., Hauser-Cram, P., Upshur, C. C., & Shonkoff, J. P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Journal of Developmental & Behavioral Pediatrics, 20*(1), 9-16.
- Weiner, B. (1974). *Achievement motivation and attribution theory*. Morristown, N.J.: General Learning Press.
- Weiss, J. A., Sullivan, A., & Diamond, T. (2003). Parent stress and adaptive functioning of individuals with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 129-135.
- Wiggs, L., & Stores, G. (2001). Behavioural treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: Effect on mothers and fathers. *British Journal of Health Psychology, 6*(3), 257-269.
- Zerega, W. et al. (1976). Stability and concurrent validity of the Rotter internal-external locus of control scale. *Ed. and Psychol. Measures, 36*(2), 473-475.

