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Perceptions of mothering, early intervention, and family-centered care

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PERCEPTIONS OF MOTHERING, EARLY INTERVENTION, AND FAMILY-CENTERED CARE

A Masters Thesis presented to the Faculty of the
Graduate Program in Occupational Therapy
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In partial fulfillment of the requirements for the degree
Master of Science

By

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School of Health Sciences and Human Performance

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CERTIFICATE OF APPROVAL

This is to certify that the Thesis of

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Submitted in partial fulfillment of the requirements for the degree of
Master of Science in the Department of Occupational Therapy, School of Health Sciences
And Human Performance at Ithaca College has been approved.

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Abstract

Family-centered care has been expected practice in early intervention for more than two decades; however, there continue to be difficulties with its implementation. One way to learn more about how early intervention practitioners can build effective partnerships with families is to listen to the mothers who care for the children receiving services. The purpose of this feminist, phenomenological study was to investigate the experiences of the mothers of young children in the early intervention system. A series of three in-depth interviews were conducted with each of the study's three participants, all of whom were mothers of children who were being served or had recently been served through this system. The participants were interviewed about their experience of mothering, early intervention, and family-centered care. The qualitative analysis of the interviews revealed four major themes—the work of mothers, the emotions of mothers, the constraints on mothers, and the supports for mothers—as well as 30 subthemes. These findings suggested that the primary work of mothers—facilitating the healthy growth and development of their children—produces strong, varied, and sometimes conflicting emotions. This occupation was constrained by many factors, including the early intervention system itself. These emotions and constraints, however, could be mitigated by therapists who provide skilled services including family-centered care. These findings were similar to those found in previous research; however, some of the findings appear novel to this study, including the ideas that (1) mothers find pride and joy in their mothering work, and (2) mothers may not feel a need to participate formally in setting goals or directly in treatment sessions. As a result, implications for practice include providing support for co-occupations that are valuable to mothers and providing flexible, responsive services to mothers as well as children.

Keywords: mothering, early intervention, family-centered care

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Dedication

For my family

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Chapter One: Introduction

Background

The concept of family-centered care (FCC) was first introduced by Carl Rogers in the 1940s in the context of psychological counseling of children (Rosenbaum, King, Law, King, & Evans, 1998). Since that time, this philosophy of care has been applied in a number of caring fields including early intervention (EI). FCC has been expected practice in all EI services, including occupational therapy (OT), since the implementation of amendments to the Education for All Handicapped Children in 1986 (Rosenbaum et al., 1998). This standard of care is taught to OT students and is expected of occupational therapists (OTs) working in the EI system and beyond.

FCC is premised on the idea that families know their children best (Fingerhut et al., 2013; King, Teplicky, King, & Rosenbaum, 2004). According to Brown (2004), it should not be thought of as a theory or service delivery model but as "a *context* that professionals and a family create and evolve together" (p. 349). It relies heavily on family systems theory (Bowen, 1966), which suggests that children develop within the context of their families. Parents in particular are considered "effective change agents" in their child's development (Myers, Stephens, & Tauber, 2010, p. 682). Indeed, researchers have demonstrated that positive child outcomes occur when parents have strong relationships with their children (Shonkoff & Phillips, 2000) and families are supportive (King et al., 2004). Therefore, efforts to intervene in the development of a child should recognize the influence of parents by employing and supporting parents in the cause. Toward this end, FCC includes practices such as collaborative decision-making (King et al., 2004, Myers et al., 2010), flexible and individualized services, emphasis on the strengths of the family (Fingerhut et al., 2013; King et al., 2004; Myers et al., 2010), effective communication

(Case-Smith, 2010; Myers et al., 2010; Rosenbaum et al., 1998), recognition and acceptance of the family's cultural and child-rearing practices (Case-Smith, 2010; Case-Smith et al., 2007; King et al., 2004; Myers, Stephens, & Tauber, 2010), and support for the family as well as child (Case-Smith et al., 2007; Fingerhut et al., 2013; Kaiser & Hancock, 2003; King et al., 2004). These last two elements—(1) recognition and acceptance of the family's cultural and childrearing practices and (2) support for the family as well as the child—may have particular significance to mothers, who are often the primary caregivers for the child receiving EI and therefore the primary partner with the child's occupational therapist.

Problem

Despite more than two decades of efforts and expectations, there continue to be challenges in the implementation of FCC. In a recent study, interviews with parents of children with physical disabilities receiving physical therapy (PT) and OT revealed that parents knew little about what happened during therapy and were not well informed about the goals of intervention (Egilson, 2011). In another study of rural, low-income families with children receiving EI services, the researchers found a significant disconnect between the stated goals of parents and the goals on the children's individualized family service plans (IFSPs) (Ridgley & Hallam, 2006). Another study investigator also found that parents felt pressured to participate in activities they did not view as relevant (Brown, 2007). In their examination of the complexities within FCC in OT, Lawlor and Mattingly (1998) suggested effective partnerships are especially difficult if there is a "substantial cultural or socioeconomic gulf between practitioners and families" (p. 262). This idea is supported by the findings of a recent survey that indicated that differences in language, socioeconomic status, and culture between occupational therapists and families impeded FCC in home-based, school-based, and clinic-based settings (Fingerhut et al., 2013).

Rationale/Significance

Listening to the lived experiences of the mothers within the EI system may provide insights into the specific elements of practice and social and cultural conflict that produce the challenges mentioned above as well as ways they may be overcome through effective models of FCC. According to Lawlor and Mattingly (1998), FCC models “require a more fine-grained analysis of day-to-day perspectives, values, assumptions, and practical dilemmas facing practitioners and families as they struggle to create effective partnerships” (p. 261) and suggest that listening to mothers’ perceptions of their own lived experiences has the potential to strengthen FCC by improving these partnerships. Mothers are best positioned to describe their unique experience of mothering a child who is receiving EI. By listening to their stories, OTs can better understand how this experience is shaped by the mother’s cultural and childrearing values, the child’s developmental delay(s) and/or disabilit(ies), and the inclusion of home-based OT into the family’s routine. By asking them about their experiences with FCC and their perceptions of how it is helped or harmed, OTs can gain insight into a) whether or not FCC is being experienced by families, b) what work mothers are or are not doing in order to create partnerships with OTs, c) what might facilitate or impede this work, and d) what efforts from the OT are most effective for implementing this philosophy of care. These insights may have implications for how FCC is taught to OT students and how it is practiced by OTs working with these mothers .

Basic Definitions of Terms

Mother: Arendell (2000) defines mother as “[t]he person who does the relational and logistical work of childrearing” (p. 1192). In this study, this definition was adopted. The fact that this work may be performed by men was not dismissed but rather the author acknowledged that in most cultures, this work is traditionally performed by women, and that this social norm creates a gendered experience of motherhood that is unique to women.

Mothering: Dunbar and Roberts (2006) define mothering as "the nurturing work that women engage in" which includes "protection of the child, as well as the fostering of growth and development" (p. 52). This definition is derived from earlier work by Chodorow (1978) and Ruddick (1989).

Family-centered care: Rosenbaum et al. (1998) define family-centered care—or, to use their term, family-centered service—as "a constellation of new philosophies, attitudes, and approaches to care for children with special health service needs" which has at its heart "the recognition that the family is the constant in a child's life" and "is built on partnerships between parents and professionals" (p. 5).

Purpose of the Study

The purpose of this study was to investigate the experience of mothering a young child receiving EI.

The specific goals were to:

- Describe in words and pictures their experiences.
- Explore the ways in which EI services impact their occupation of mothering.
- Describe their perception of their experiences of FCC and non-FCC.
- Identify their perceptions of the supports for and impediments to effective collaboration with EI practitioners.

Chapter Two: Review of Literature

The occupation of mothering encompasses many activities, such as protecting and caring for the child, fostering the child's growth and development, meeting the child's basic needs, and teaching the child (Chodorow, 1978; Dunbar & Roberts, 2006; Francis-Connolly, 2000; Ruddick, 1989). Across cultures, however, mothering is a highly individualized experience that is socially and culturally informed (Arendell, 2000). Francis-Connolly (2000) described motherhood as "constructed within layers of micro and macro variables such as intrafamily dynamics, economic and social resources, ethnicity, and culture" which "provide diversity to the role of motherhood" (p. 282). This maternal standpoint is a subset of feminist standpoint theory, which, according to Oleson (2011, p. 130), "replaces the concept of essentialized, universalized woman with the idea of a situated woman with experiences and knowledge specific to her place in the material division of labor and the racial stratification systems. In one illustration of the diversity of motherhood, Collins (1994) found that women of color described survival, power, and identity as the "bedrock" of "motherwork" (as cited in Arendell, 2000, p. 1194). Mothering a child with a developmental delay or disability is yet another variable that may add diversity and complexity to the experience of mothering (Lawlor, 2004). All of these societal and cultural influences on mothering affect the mother's shared occupations, family relationships, routines, and rituals (Dunbar & Roberts, 2006). These factors also affect the meaning that mothers attach to these activities and influence their performance. Dunbar and Roberts (2006) state that "the way a mother will prepare a meal, or facilitate dressing, will indicate the meaningfulness of these activities to her and her children" (p. 63).

While for many women, mothering is a valued occupation, in the first years of a child's life it can be "exhausting, overwhelming, and constant" (Francis-Connolly, 2000, p. 284). Francis-

Connolly (2000) refers to these feelings, brought on by "the endless demands of young children" and "the intensity of mothering" as *motherhood immersion* and states, "[These mothers] are completely surrounded by the demands of their mother work and engrossed by it" (p. 284). This intensity may result from the enfolding of multiple tasks so that mothers may attend to more than one task at a time (Bateson, 1996). In a phenomenology of his experience as a single father, Krieger (1996) describes the intensity of mothering: "[T]here is never much breathing room, there is always more to do…" (p. 244). For the mothers of children with disabilities, this view is at least as true, if not more so. These mothers describe their work as a 24/7 job with responsibilities that are intensive and continuous (Case-Smith et al., 2007). They struggle to do their work well and are often under a great deal of stress (Hastings, 2002). Furthermore, mothers of children with a developmental delay or disability may have additional mothering and caregiving work "well beyond the demands of routine care for a child with special-health care needs" (Lawlor, 2004, p. 311), such as caring for aging parents. Therapy can add to this stress by placing even greater demands on the family's time (Edwards, Millard, Praskac, & Wisniewski, 2003). Mothers may have to make significant changes to their schedules and priorities in order to accommodate therapy (Llewellyn, 1994). Additionally, because the mother's time, resources, and energy are already limited, she may not have the additional resources needed to perform activities recommended by her child's therapists (Bailey, 1987).

For the mother of a child with a developmental delay or disability, this work includes specific and complex tasks. These tasks include responding to changing needs (Ruddick, 1994), such as during routine caregiving tasks (Kellegrew, 2000), "envisioning possible futures for their children, creat[ing] experiences that will propel the desired developmental trajectory, and manag[ing] the contingencies that threaten to alter or derail a desired developmental pathway"

(Lawlor, 2004, p. 315). Managing these contingencies may include promoting a positive image of the child to the therapist, presenting a “good parent” persona to the therapist, and advocating for the child in a way that does not diminish this “good parent” persona and thereby diminish the level of care the therapist provides to the child (Lawlor & Mattingly, 1998). This behavior is complex work that may cause a mother to question her expertise or “anguish over regrets that [she] did not challenge professionals or care decisions sooner or harder” (Lawlor, 2004, p. 319).

The intensity of mothering work and the pressure to maintain a “good parent” persona may be compounded by social pressures to conform to an idealized mother role. Larson suggests that in Western culture, there is a current overarching view of mothers as “naturally devoted, self-sacrificing, loving maternal figures” (2000, p. 250). Francis-Connolly (2000) believes this idealized mother has an impact on mothering. She quotes Ruddick (1989) who says “mothering must be done within acceptable parameters of the social group because mothers are held accountable for raising their children” and suggests that, when the “acceptable parameters” are this narrowly defined, mothers have “conflicting demands” which they must “solve and negotiate” (as cited in Francis-Connolly, 2000, p. 282). When further complicated by feelings of inadequacy, unhelpful spouses, and role conflicts, the role of mother becomes even less manageable (Dunbar & Roberts, 2006). As a result, the experience of mothering can be dichotomous (Dunbar & Roberts, 2006) and produce ambivalence (Arendell, 2000).

The diversity of influence, values, and meanings within motherhood has implications for therapists working in the EI system. FCC dictates that therapists with differing understandings of motherhood due to different social and cultural norms, should recognize and respect these differences and provide individualized, flexible services as a result. One specific way in which these values and meanings affect the work of motherhood is daily routines. According to Larson

(2000), “Dismantling or revising of daily routines for the insertion of intervention requires a deep understanding of family routines and their meaning to family members” (p. 251). Practitioners of FCC avoid disrupting valued daily routines as much as possible and, when they are necessary, work closely with families to create new routines that mesh with their cultural and childrearing values. Indeed, researchers have found that mothers are reluctant to perform activities that they do not see as relevant (Bailey, 1987) and are more likely to perform elements of home treatment programs that can be embedded within their current routines (Hinojosa & Anderson, 1991).

In order to practice FCC and work effectively with families, OTs must carefully consider how their recommended interventions mesh with the cultural and childrearing values of the mother. But the work of respecting and responding to differences in values is not restricted to the therapist. Lawlor and Mattingly (1998) suggest that mothers are active in bridging the distances between the family and the therapist created by cultural differences, often taking on the role of “culture broker,” interpreting meanings for and accommodating both the therapist and the other family members (p. 264). Lawlor (2004) suggests that partnerships between therapists and mothers require “skilled relational work” involving “intersubjectivity, communication, engagement, and understanding” on the part of both parties, and that this work can result in “moments of meeting” (p. 308) where success can be achieved.

The need for support in the role of mother also has important implications for OT. As childrearing is one of the areas of occupation that falls under the purview of OT (AOTA, 2008), OTs working with children receiving EI are uniquely poised to provide direct support to the mothers of these children. According to Brown (2004), FCC is enhanced when therapists provide support for the extended caregiving responsibilities that therapy imposes. This support may be as simple as recognition of the additional burden placed on mothers by home therapy programs (Crowe, Van Leit, & Berghmans, 2000). Other direct supports for childrearing to mothers in the EI system has been found to have positive outcomes for mothers, including a) improved use of time, b) improved performance and satisfaction with occupations, c) altered self-image, and d) increase in coping strategies (Brown, Humphry, & Taylor, 1997; Helitzer, Cunningham-Sabo, Vanleit, & Crowe, 2002). Mothers have expressed appreciation for the support they receive from therapists (Edwards, Millard, Praskac, & Wisniewski, 2003). However, providing these supports may pose social, cultural, and emotional challenges for mothers. If Ruddick (1991) is right that all forms of caring are based on mothering, then all EI therapists, including OTs, are essentially "other mothers." For the overwhelmed mother whose social and cultural values mesh easily with her child's therapists' values, "other mothers" with whom to collaborate and share the responsibility of care may be a welcome social support. Some mothers may find this intrusive or unsettling. If the mother indeed feels social pressure to live up to an idealized version of motherhood, accepting support from "other mothers" may feel tantamount to admitting she is unable to meet this social expectation. Krieger (1996) suggests that for mothers, "advice [about childrearing] mostly induces guilt…" (p. 244). When social and cultural differences are present, direct supports to the mother grow more complicated as cultural differences can affect how the therapist is perceived by the family. According to Myers et al. (2010), "based on individual cultural backgrounds, the family may view the therapist as either a helper or one who interferes" (p. 683).

Chapter Three: Methods and Procedures

This research project was a feminist, phenomenological study of mothers of young children who were receiving home-based occupational therapy at the time of or just before the conduct of this study. According to Creswell (1998), the purpose of a phenomenological study is to describe “the meaning of the lived experiences for several individuals about a concept or the phenomenon” in an effort to discover “the central underlying meaning of the experience” (p. 51-52). In other words, by closely studying a few people who have experienced a phenomenon, it is possible to understand the essence of the experience. This approach has been used in the health sciences in general, notably in Cheryl Mattingly’s study of African American families of children with severe chronic illness (2010), and in occupational science in particular. In recent years, occupational science researchers have used the approach to examine the lived experiences of people recovering from mental illness (Sutton, Hocking, & Smythe, 2012), Mexican American elders with diabetes (Haltiwanger, 2012), and the mothers of children with feeding concerns (Winston, Dunbar, Reed, & Francis-Connolly, 2010). This research design is of particular relevance to a study of FCC, as the purpose of this practice is to meet the individual needs of a given family. Therefore, listening to the mother’s experience is an important means by which to gain insight into how FCC and non-FCC affects families.

Participants

A purposeful sample of three mothers was recruited for participation in this study. The sample size was set at three in order to provide for varied responses but also to allow time for in-depth interviewing of each participant. Qualified participants were women who assumed primary caregiving responsibilities for a child who was receiving EI services at the time of the study or who had received EI services within the last year. No restrictions were placed on the mother’s professional work status or the family make-up. Racial and socioeconomic diversity in the sample was desirable, but feasibility required that the earliest three of four volunteers be included in the sample. All of the participants were recruited from a small county in central New York. Letters describing the study for families were prepared and delivered to therapists working in the EI system for dissemination to eligible mothers. One mother was recruited this way; the other two were recruited through faculty members in the researcher's academic program who were acquaintances of the participants. Informed consent was obtained from all qualifiers who agreed to participate.

Data Collection

In keeping with the phenomenological approach, data collection began with a personal reflection by the researcher of her preconceived notions regarding FCC and mothering young children. In addition to her experience as a student, the researcher, a 38 y/o woman who is married and identifies as Caucasian, is both a former Early Head Start program coordinator and the mother of two young children, one of whom has been through a comprehensive evaluation including evaluation by an occupational therapist. Through these experiences, she has been both a provider and recipient of FCC, experiences which, along with her research, have shaped her standpoint. This self-examination provides the researcher with an opportunity to reveal for herself and her audience this standpoint, which colored her interpretation of the data. It also allowed her to "bracket" or put aside her preformed ideas so that she was open to the experiences as told by the participants in the study (Creswell, 1998). Additionally, the researcher has professional relationships with two therapists who feature in this study: Hannah, for whom she worked as a graduate assistant, and Emily, who was her clinical instructor during her Level 1 pediatric fieldwork. Because of these experiences, the researcher had preconceived notions regarding the skills and abilities of these two therapists, which she attempted to mitigate by reflecting on them so they too could be bracketed. The researcher hoped that by exploring and revealing these preconceived notions, her findings would be considered trustworthy to her audience.

The rest of the data was supplied by the participants. Data collection occurred at times and locations selected by the participants and included the following:

- *Basic demographic data*, including mother's age, mother's employment status, family make-up, race, ethnicity, and socioeconomic status.
- *Images of mothering*. Participants were asked to bring to the interview five images that told the story of their experience as a mother to a young child that is receiving or has received EI services. At the beginning of each interview, participants orally interpreted this "story" for the researcher. Participants were asked to provide either family photographs or symbolic images. Written consent to use any personal or public domain images in the study and in any presentations, posters, or publications resulting from the study was obtained.
- *An in-depth interview.* In keeping with a feminist, phenomenological approach, these interviews were conversational and discursive, lasting at least 45 minutes and up to 75 minutes with each participant. Rather than attempt to standardize interviews with each participant, the researcher allowed the conversation to move organically while staying within the parameters of the objectives of the study. According to Creswell (1998), the interview questions in a phenomenological study should "explore the meaning of [the] experience for individuals and [ask] individuals to describe their everyday lived experiences" (p. 54). Toward this end, participants were asked to describe meaningful

experiences with mothering their child(ren), participating in EI treatment sessions in their homes and other natural environments, and working with their child's therapists. Within these contexts, they were asked about their experiences with the tenets of FCC, such as sharing information, collaborating on goals, and receiving care that is individually and culturally appropriate, and they were invited to offer thoughts as to what helps or hurts the implementation of FCC. This discursive nature is in keeping with feminist methodology, which is relevant to a study of mothering, FCC, and OT, a field where many of the practitioners are women. In her definition of feminist methodology, Oakley (1991) recommends that "the mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias—it is the condition under which people come to know each other and to admit others in their lives" (p. 58, as cited in Mischler, 1986, p. 31). In essence, the researcher hopes to practice in her interviews the power-sharing, mutually respectful, collaborative relationships toward which practitioners of family-centered care strive.

Mothers' oral interpretations of visual images and subsequent interviews were audio-taped and transcribed verbatim by the researcher, who conducted the interviews. The researcher also took field notes regarding the context of interviews.

Data Analysis

The images of mothering were analyzed using two forms of content analysis that are appropriate for visual data analysis: semiotic analysis and contextual analysis (Banks, 2007). Semiotic analysis was used to interpret the connotations of the images, while contextual analysis was used to interpret how the rhetorical situation (i.e. being interviewed about mothering by a student researcher) might have shaped the mothers' selection of chosen images. Mothers' interpretation of the images recorded in the interviews informed but did not determine the researcher's analysis.

Data collected through interviews was analyzed by a process similar to one described by Miller in *Qualitative Research Design* (Maxwell, 2013). The *first phase* of analysis involved the creation of narrative summaries, which are "analytic abridgements of the narratives heard" that "preserve the context and story" (p. 114). Riessman (2008) suggests that this task is an important first step in narrative analysis, stating, "Rather than locating distinct themes *across* interviews, narrative researchers listen first to the voices *within* each narrative" (as cited in Chase, 2011, p. 424). Toward this end, transcription of the interviews by the researcher constituted a first-pass analysis, after which the researcher conducted additional reviews of the transcripts, identified notable "stories" within the raw data, and created "titles" for these "stories" that served as narrative summaries. The *second phase* of analysis was inductive coding and clustering of the data. Codes were informed by literature on mothering, EI, and FCC, but were driven by insights gained by the data. To accomplish this task, the researcher returned to the original transcripts for additional review and reduced the "stories" to their significant elements. From this information, codes were created, checked for reliability with the researcher's two thesis advisors, and applied to the raw data. When the researcher completed the analyses, the results were reviewed by one of the thesis advisors. Both advisors are pediatric OTs and researchers who are familiar with qualitative methodology. The researcher then returned to the literature to see if the emergent themes were substantiated by other research. From the coded data and accompanying literature, the researcher has attempted to create a “viable interpretation” of the phenomenon “grounded in the assembled texts” (Polkinghorne, 2007, p. 484).

Chapter Four: Results

Participants

From the four mothers who were recruited, three mothers were selected and provided informed consent to participate in this study. To protect their confidentiality, all of the participants, their family members, and their therapists have been given pseudonyms and identifying details (e.g., place of work) have been omitted, and photographs provided by the mothers have been obscured.

Rachel is a 39-year-old woman who identifies as Caucasian. She works part-time as an adjunct professor at a comprehensive college in the Northeast and full-time as the primary caregiver for her three children. She is an elected official in her town government and is active in her local MOMS club. Her husband is a tenure-track professor in the same department where she teaches. They have three children: Michael, who is in the first grade, and Sarah and Jason who are three year old fraternal twins. Jason began receiving EI services for developmental delays and sensory processing dysfunction as a toddler. He is currently receiving home-based PT from Linda and OT from Emily through his local Committee for Preschool Special Education (CPSE) program. In addition, he receives clinic-based OT from Hannah. All three interviews with Rachel were conducted in the kitchen or dining room of her ranch-style home, once during the day while her son received OT in another part of the home and twice in the evening after her children had gone to bed.

Emma is a 40-year-old woman who identifies as Caucasian. She works full-time as an assistant professor at a comprehensive college in the Northeast. She lives with her husband, who works in social services administration, and their two children: Chris, who is 5, and Gregory, who is 3. Greg began receiving EI services for torticollis as a young toddler. He received PT and feeding therapy from a speech and language pathologist (SLP). These sessions were conducted at his home and at his child care center. He also received clinic-based OT. All three interviews with Emma were conducted in her office at the college where she works.

Shandra declined to share her age or racial/ethnic identification. She works full-time as a dining hall manager at an Ivy League college in the Northeast, where she has worked for the past 18 years. She lives with her mother, her 12 y/o daughter, Ariel, and her 2 y/o son, Lucas. Lucas began receiving EI services for developmental delays and sensory processing dysfunction at 18 mos. He is currently receiving home-based OT from Emily, who is also Jason's OT, special education for infants and toddlers (SEIT) from Alex, and speech from Susan. All three interviews with Shandra were conducted in the living room of her home in the morning while her children were in school or child care.

Results

Two hundreds and fifty-seven notable "stories" were identified within the raw data and given titles. Through an inductive process, these stories were reduced and clustered into four emergent themes: the work of mothers, the emotions of mothers, the constraints on mothers, and the supports for mothers. Each of the four remaining sections of this chapter describes one of the four emergent themes and its accompanying subthemes, which are identified in italics and illustrated by relevant photographs and/or quotations provided by the participants.

The Work of Mothers

The mothers who participated in this study performed a number of role-specific activities that supported one primary work task: facilitating the healthy growth and development of their children. This idea is supported in the mothering literature, which posits that fostering the child's growth and development is work that is shared by mothers across cultures (Chodorow, 1978;

Dunbar & Roberts, 2006; Francis-Connolly, 2000; Ruddick, 1989). While many of the nine activities related to this task that were identified in this study may be performed by all mothers, some are specific to mothers of children in therapy. These activities constitute the nine subthemes within this theme: (1) identifying atypical patterns of development in their children, (2) determining the priorities for intervention, (3) pursuing knowledge for the benefit of their children's development, (4) providing enriching experiences for their children, (5) supporting the work of therapists during therapy sessions, (6) completing home programs to support the therapeutic agenda, (7) building bridges between people that provide care for the child, (8) marking the children's developmental progress, and (9) promoting the child/self to others/protecting the child/self from the judgment of others.

One of the ways that the mothers in this study accomplished this task was by *identifying atypical patterns of development in their children*, which they accomplished through scientific processes including observation, experimentation, and consultation. Emma's first indication that her son might have a developmental delay or disability was when she observed his atypical posture:

> I had kind of noticed that he was kind of tilty? Like his head would tilt to one side and he would, when he would sit in his car seat, like he would, his head would always be [tilted to one side].

As he became mobile, she observed that he had atypical movement patterns:

> Oh … he was about, between, I think, like, 7, 8 months, something like that. He started being interested in being upright? and, you know, holding onto things and bearing weight and wasn't, he wasn't bearing weight on his feet equally. He was, he would bear weight on his right foot, but he would only stand on his tippy toes on his left foot and, like, curl

> his toes under and stand on, when he would put weight, it was, it was really disconcerting for a mom to see, um, so I went racing into the clinic.

Shandra also observed differences in her son's mobility, and in his social interactions and play behaviors as well:

> [H]e was about, probably a year old. We would kind of talk to him, and most babies, if you're kind of in their face, and we'd be like, "Lucas! Lucas!" And he'd be looking around and not really paying attention. … Even when, when he first started crawling, we said he had kind of a little pimp crawl. It was really funny. He crawled on one knee and one foot. .. He'd just kind of crawled just different. Um, just not really focusing or paying attention. The babbling, he would babble but just not a lot of back and forth. … [W]hen he would play, he would bang things together and he would bang anything. He did it all the time. It was so annoying. Um, he was very musically inclined. He would hear a song and kind of hum it back to you later? Like, it could be hours later or days later. It was kinda creepy. Um, playing the piano, if you played, not a huge tune, not a long tune, but if you did like a, I don't know, played a couple of notes, he could copy it back. Um, he did a lot of stuff. So, I was concerned with that.

Similarly, Rachel became more concerned about her son when she noticed atypical movement patterns:

> [O]nce he was mobile I started to notice a couple of things. … I was watching him on the playground set out [in the backyard]. … I was watching him climb the wall and I couldn't believe he could climb the wall. And I called my husband and I was like, "He is like, barely walking and climbing this wall." And then I was like, "But he's doing something really weird. He only uses his arms. And then he only uses his legs." And I was like,

> "That's really odd." And I was like, "Hmm, [he's a] baby." But in my mind, I was like, "That's not right." … [T]hat was the first moment I was like, "I love him, there's something wrong." I just knew it right then and there.

When she observed other behaviors that concerned her, she conducted experiments:

> I noticed as he was getting older and more mobile that all the other kids would want to be near their mom, but we would go to a playground and he would just run away. Like, but not run away from me, but he would run away, like, he would keep going. So, one time … I asked [my friend] to stand across a field. And I let him go. And he never stopped. Like, he just went. And like went and went. And he was just lost. And by the time we had him re-evaluated, I was like, I'm a scientist, I just put him in all these situations. I had much more information.

When their children entered the EI system, these mothers helped to *determine the priorities for intervention*. They made decisions about whether or not a delay in their child's occupational performance should be addressed by the EI team. These decisions were influenced by their beliefs about the variability of children's development, the importance of the child's ability to perform the occupation to them, and the success of any attempted interventions.

Initially, Jason's difficulties with feeding were a priority for intervention for Rachel because of the challenges they created in performing her mothering tasks of feeding her children and cleaning up after meals:

> [O]riginally, [mealtimes were] the big issue for us. … [H]e couldn't sit in his chair and was all over and couldn't use utensils and kind of put stuff everywhere. Or he would like eat a little and then be distracted and couldn't sit at the table long enough to like get a full meal in and couldn't get him back again and, just very difficult at times. … It was like

> one of our big things, like, in the beginning, and Linda [the PT] had, like, re-positioned him. In, like, *the perfect way*. And, um, Emily [the OT], we did meals with. So we like *sat* and did *meals*. She came to dinner a few times.

But the interventions weren't helpful because Jason refused the positioning recommended by the PT and did not demonstrate the same performance issues during intervention sessions with the OT:

> [H]e was so interested in [Emily] being at the table, he was focused, you know. … [I]t was one of those things where you bring your kid to the doctor and they're totally fine. You know? … He was like, "You're having dinner at our house!" … And she brought some things, and it was like he wanted to eat it and it was really exciting and he did great. … And we tried in a couple different ways, and it was just always like that. He was so excited to be there with her. … I was like, "There's no way, unless we have like a secret camera."

When the interventions provided were not successful, Rachel re-assessed her need for Jason to improve his performance in this area and determined that as long as his basic needs were met, she could compensate for his difficulties:

> [W]e were just like, "We're going to work on other things and he'll just have to grow into this, and until then, we'll just mop the floor." … [H]e was getting nutrition…. It wasn't like he was starving. And it wasn't hurting anything. It was just really, really messy.

This experience also seems to have led her to revisit her beliefs about Jason's mealtime challenges, ultimately determining they were related to his temperament and would have to be accommodated rather than remediated.

> [Jason] still has trouble focusing on his meals and stuff a little bit. … There were definitely things that we had to work on. … [But maybe this] is just who he is. You know, and that's always hard, when you start looking at life with him. You know, an assessment, we're always like, you know, how much of it you have to really say, "This is just who he is, and that's okay."

After that decision, writing became her priority for OT intervention. This decision was influenced by the impact her daughter's performance in this area has had on Jason's participation:

> I've asked [the OT] to work on writing a little bit more. … Jason's not wanting to engage because Sarah's like being a little ridiculous (laughs) in her development. … [I]t's not that he has to, but I'd like them to start working on grabbing the pen and stuff.

However, helping to establish the priorities for therapy doesn't necessarily translate into active involvement in goal writing. Rachel stated, "I don't set the goals. I'm not the therapists. They have, they both have a very clear sense of what his needs are."

Mothers may also *pursue knowledge for the benefit of their children's development*. The mothers in this study acted as students of development in general and of their own children's development in particular. They actively sought information from professionals and others in order to support their children. During her son's initial evaluation, Emma sought information from the evaluating therapists:

> I talked to somebody, um who had some familiarity with the process, which I had none of, who said, "Even if he doesn't qualify, go through it, soak up as much of it as you can. Listen, try to remember everything, because you'll learn a lot in the process." That was very good advice, and it was very true. … You know, we had learned some in the Baby

> Lab time that we had, um, but we learned a lot more from that OT who taught us more about things that we could do to encourage the right kinds of movements and the right, um, kinds of activities that would help him.

When intervention began, she continued this pursuit:

> I did a lot of asking questions, you know, with all three: the PT, OT, and speech. … [E]verybody, the therapists that I was talking to were *so* knowledgeable. And, you know, I would start asking questions that were directly related to their expertise as a particular kind of therapist and before it was done, you know, I was asking questions that were way out of their, officially out of their wheelhouse, but they just had worked with so many kids and so many families and their own families were so knowledgeable, that it was hard to not ask tough questions.

Shandra similarly asked questions of her son's therapists for his benefit. She stated, "I would sometimes ask little things like, 'Okay, what can we learn next?' If he would pick up on one word one week, I would ask for something else and go from there."

Mothers may also *provide enriching experiences for their children*. This is supported by Lawlor, who said that mothers "create experiences that will propel the desired developmental trajectory (2004, p. 315). These experiences included participation in co-occupations that the mothers considered supportive of their children's development. Dunbar and Roberts (2006) suggested that the way these activities are executed by mothers "indicate[s] the meaningfulness of these activities to her and her children" (p. 63). This researcher would argue that the same could be said for the stories mothers tell about the execution of these activities. Rachel gardens and bakes with her children. She said, "[I]t's really good for them to bake. … So it's like you can have art supplies or you could buy baked goods, so I might as well do that." Shandra bakes with her children as well. She also enjoys reading with them and participating in outdoor leisure activities:

> We'll go, like, if there's snow, sledding over the weekend. And all kinds of stuff. We're always doing stuff. … [W]e travel a lot. And then we do a lot of outdoor activities. We, um, get a park pass every year, so we go to all the different parks just about every day. … And we camp and do all kinds of stuff. … He *loves* it. It's so cute. He loves it. He runs around and gets all excited. I think he's probably one of the last ones to fall asleep. … Actually, we had a tent set up in the backyard for a while. Cause he, uh, he loved to play in and out of it. Yeah. Kids love that.

Emma similarly enjoys hiking and reading with her children. Many of these co-occupations are represented in photographs such as these:

Figure 1. Providing enriching experiences 1. Lucas making apple pies.

Figure 2. Providing enriching experiences 2. Jason and Sarah baking.

The voluntary inclusion of these photographs in the mothers' narratives suggests that participating in these activities is important to these mothers, and not only because they may facilitate healthy growth and development in their children. Their desire to be seen in these activities suggests their performance has value and meaning to them and their identities as mothers.

These mothers also *support the work of therapists during therapy sessions*. They often accomplished this task by assuming a predominately peripheral role, but taking an active role when needed. They tended to see the therapist as the active agent and found it most beneficial to position themselves at a distance that would help the child feel secure but remain engaged in the session. From this distance, they could observe the therapist and assist as needed, and they tended to follow the therapist's lead in determining how involved they should be. Emma stated,

> [T]here were occasions that I would, um, sort of get sort of more hands-on involved in the therapy sessions, but often it was more useful to sort of stay a little bit removed. If I got more hands-on, oftentimes that would distract Greg from whatever they were trying to accomplish or do and, um, or, you know, distract him in a good way or distract him in a bad way. You know, and, that was often sort of counter to what we were trying to accomplish, so that was often … the role that the therapist wanted me to play. There were sometimes I would get involved, but only as it was helpful.

Rachel also found it more useful to remain at the periphery, but adjusted her role as needed:

> I try to stay out of the way. 'Cause Jason is in this phase where he's very "Mommy, Mommy, Mommy!" And so, the best thing I can do is kind of stay out of the way and not participate. Sometimes that changes, and like, participation's really important, but we're not in that stage because he'll just want to sit in my lap and cuddle or read a book and he's just in this stage, not just with Linda but in life. … [Today] I was kind of picking up the play room while they were doing [the session].Just because I was like, around. And trying to stay out of their way. If I just sit, then usually he just comes running over, but if

> I'm busy, he'll, like, do other things. So I'm just, like, organizing the playroom a little, like *there* but not waiting for him to come running over.

Shandra preferred to watch the sessions as well, but helped to manage her son's behavior: "[I] just kind of watched [the session]. And then, if he tried to escape, I'd just kind of sit and grab him."

In addition, these mothers were often tasked by their children's therapists with *completing home programs to support the therapeutic agenda*. Sometimes, this meant adjusting the materials or practices of the mother's routine caregiving tasks, like eating and feeding. Emma stated, "I was getting weekly instructions on, 'Give him something that forces him to bite and pull' or 'Give him different sorts of consistencies of things.'" Similarly, Shandra was given instructions for expanding her son's repertoire of foods:

> But Emily always says to, um, keep trying, keep trying [new foods]. Because people give up? And then, they don't, um, keep trying. And she said it usually takes about seven tries, so try something, like, for instance, keep offering him peas for a while. … I offer stuff to him. Like, the other day, we, um, I cut up a bunch of little things. Grapes. Blueberries. …I had a whole bunch of different fruits cut up small… [I]t was sitting there and it's like, "This is all you can have right now. This is it." So, I took everything else away that he would want to eat and just left a little plate there.

Other times, it meant adding new tasks or routines to the mother's workload. Shandra's son was identified as having tactile defensiveness, meaning he was hypersensitive to tactile input, which impaired his ability to wear shoes and outerwear. To mitigate this impairment, Shandra was encouraged to follow a brushing protocol, which required her to brush her son's skin with a surgical brush according to specific directions and then administer joint compressions every two hours. While this intervention had been reported to help children develop a more appropriate response to tactile input, it also increased demands of the primary caregiver’s time and energy:

> [H]e wouldn’t wear socks or shoes. He would *scream*. Like, I’d put his socks on and he would rip them off. And he would just scream when you would try to, he wouldn’t keep anything on. It was so annoying. … I was like, “Look. He doesn’t keep a blanket on. He won’t keep socks on. He won’t keep shoes on. You know, it’s starting to get cold. He’s got to keep this stuff on. I don’t know what to do.” So she handed me one of these little surgical brushes? … She would do the brushing at all the beginning of her sessions and do the joint compressions and she taught me how to do everything.

Similarly, Rachel was given strategies to help manage her son’s behavior while shopping, but practicing these strategies also required additional shopping trips.

> [T]he mall used to be a very hard place for him, because he would just *pshew*! (noise to signify fast movement) … Linda gave us a strategy to, like, have him play “I Spy” and different things so he’s like engaged. Which makes it really hard to shop. But, like, you know, after working on that a few times, it became successful. We used to practice going to the store. I used to practice at Kohl’s, because it’s always empty and full of little old ladies. We used to, like, drop Michael off at school and go to Kohl’s and walk around and try to find things in the store.

These mothers also supported their children’s development via the therapeutic agenda by *building bridges between people that provide care for the child.* One way they accomplished this role was by building bridges between therapies: informing therapists about the skills being learned in other therapies and encouraging them to reinforce these skills in their sessions. For example, Shandra would share the goals of speech therapy with her son’s OT:

> [I]f they were working on something with speech, I would just say, “Hey, Emily, we’re, this is what we’re doing now” and then she would make that part of the lesson plan. With speech, if we did, like, action words, like pull or push? Then I would say, “Well, this is what we’re working on in speech,” so she would make that part of the plan. So then it kept going.

These mothers also built bridges between the therapists and other family members by informing the family members about the skills being learned in therapy and encouraging them to reinforce these skills in their daily interactions with the child. This role is supported by the work of Lawlor and Mattingly (1998), who found that mothers serve as “culture brokers,” connecting the culture of therapy to the culture of the family. Often, this task involved encouraging the family members to adopt the therapeutic agenda and the home program, which often included encouraging the child to participate in occupations that were challenging for them. For example, Shandra taught her mother and stepmother what the therapists had taught her and explained why it was important:

> [I]t’s just mainly talking to him. And making him ask for stuff, instead of just assuming what he wants and handing it to him. And that’s hard, because I can do it fine, but then he’s got two grandmas who are … just like, “Oh, here!” You know, it’s like, “No! He needs to ask for a drink!” … [And} they’re like, “Yeah, I know! I know!” And then I get frustrated and I’m like, “He’s not going to talk. Why would he ask for anything? … If you hand him everything, he’s never going to ask. He doesn’t have to. He’s never going to talk because you do it for him.”

Rachel connected her son’s nursery school teachers to the therapeutic agenda. She said, “Given the chance, [Jason] will opt to not do like fine motor skill stuff. … Like, at school, I keep telling them, ‘Don’t give him a chance. Just make him do the fine motor stuff.’” In this respect, their work includes not only educating others on the therapeutic agenda, but encouraging them to push it.

As therapy progressed, these mothers continued to observe their children’s development in order to *mark their children’s developmental progress*. In this way, the mothers attempted to determine if their children’s developmental trajectory was improving and if intervention was effective. When their children made developmental gains or if they more closely resembled typically developing children, the mothers celebrated. Shandra was excited by gains in her son’s ability to communicate:

> One big breakthrough that I just loved was when, um, she ... would … she taught him, um, how to say “more” and the sign for “more.” “If you want more, then you need to ask for more.” Um, then like hand him, um, uh, puzzle pieces or whatever. He really likes puzzles. Once I saw that and he recognized he could do it, I thought that was so cool and I just loved it. Um … so, that was really nice, just seeing the progress and like, so that was nice for me.

She was also pleased with his ability to attend to tasks like reading. She says, “He actually sat and paid attention to the whole book, which is …Lucas is a mover, so that was cool.” Emma noted changes in her son’s physical appearance:

> [T]he main sort of outward symptom or thing that sort of brought it to my attention on a regular basis was the asymmetry in his jaw. … That, that got to the point where that, that corrected itself, not corrected itself but corrected to the point where the only time I would ever see it was when, um, towards the very end, when he would do a big, toothy grin for a picture or something. Um, so, on a daily basis, it got to where, I wasn’t seeing it. And

> the only time I would see it was when I was flipping through an album or pictures on the computer, and then it would be like, “Oh yeah! It’s there!” But now it’s gone entirely.

Rachel was pleased with her son’s improved ability to write letters:

> He, like, started drawing H first? And once he got the H down, he made Hs for everybody and handed them out. He was very proud that he was writing something. Yeah, it was really good. It was very dramatic. We took pictures and, it was really good, and then once you feel success with it, it’s easier to try more and see the difference between letters. … There’s nothing else like it, you know?

She was also excited by how much his ability to participate in nursery school had improved and how much more closely his behavior resembled that of his peers:

> I see him, when he was, like 18 months, he was clearly not aligned with his peers. … And now, he clearly is. Like, he’s a leader in school. He sits at circle time. He pays attention. He organizes, like, if you ask him to organize, you know, he’s still three, but he’s really successful. And he knows some boundaries and, you know, the safety issue is less and less because he listens a lot better. You know, he’s good. He’s come a long way. And it’s nice to see him doing so well.

Sometimes, the gains made by the children were remarkable for the way they alleviated mothering burdens. Part of Shandra’s pleasure in her son’s improved ability to attend to books is that she can sit and enjoy the time as well. She says, “[I]t’s getting a lot easier with books because, um, his attention span’s going a little bit longer, so you can actually sit and stay focused for a little bit longer, so that’s kind of nice.” Similarly, Rachel’s son’s improved ability to attend to a task also means more sitting and enjoying for her:

> [A]bout six months after [we started EI], one of my friends … we were at her house and we were drinking tea and he sat and he played with something for, like, five minutes straight. And we couldn't believe it. We couldn't talk, because we were just watching him. Because it had been such an overwhelming … chasing him around had been so overwhelming, I just didn't realize it.

She has also found that her son's improved behaviors means less behavior management for her:

> [H]e's like, really sensory seeking, and he's sometimes with the dog inappropriate. He just like wants to rub the fur all over him. And he kept getting in trouble and we were yelling at him, "Don't do that! Don't do that!" And we were at T.J. Maxx the other day and he picked out a soft brush and was like, "If I use this, I won't hurt the dog." And so, we got it and he uses it. And he's been really good with the brush. He's just started to feel and understand his success and know his limits a little bit. And that's really helpful.

Emma has felt relief as a result of her son's improved sleeping patterns:

> I think [therapy] definitely did help him sleep better? And that was definitely something that was a real hard part of mothering Greg. His sleep was *terrible*. He was up many, many, many times during the night and very uncomfortable and, um, you know, a lot of it was the reflux, but a lot of it was related to the asymmetry and, um, to his, um, discomfort and such., And also, I think, to hunger. Um, related to the choking and eating difficulties and stuff. And so, as we got more into therapy, his sleeping got so much better. … It was both gradual and sort of all, like, all of a sudden. Which, I'm not sure how it's possible to be both. But, like, we, we noticed … little incremental sort of improvements. … But then, there was also sort of a turning point where he just started sleeping. It just kind of clicked. We didn't really realize, um, immediately that it had

> happened that way. Like, after we had caught up on a little bit of our own sleep and we were both feeling a little more sane and rested. Um, we kind of looked at each other and were like, "Do you realize that he's sleeping *so much better*?"

Finally, these mothers facilitated their children's healthy growth and development by *promoting the child/self to others and protecting the child/self from the judgment of others*. They worked to solicit favorable opinions toward their children from the professionals working with their children and from the interviewer. Emma noted her son's positive attributes in this photograph along with the physical evidence of his need for therapy:

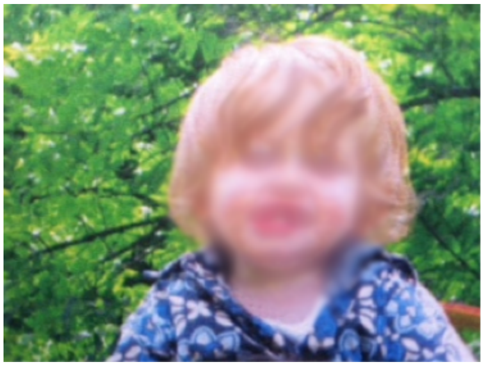

Figure 3. Promoting the child/self to others 1. Greg smiling.

She said, "You can see his sort of happy, vibrant personality, but also the asymmetry of his jaw." Shandra described her son to the interviewer this way: "He's such a sweetheart. … Um, he's just lovable. He's happy. He's funny. He's such a character. He's such a doll. Everyone loves him." Rachel wanted the interviewer and others to understand that her son's difficult behaviors were linked to his difficulty with auditory processing. She said, "[W]hen he's in a big, open space, it's like he can't hear you. It's not that he can't, and it's not that he misbehaves. He actually really wants to be good. It's just that he can't." Sometimes, they predicted negative judgments from others and took steps to protect themselves and their children from these judgments. Shandra tried to shape the way her son's therapist viewed choices she made about letting him explore his environment:

> I really want, um, Lucas to be familiar with his surroundings, so I would let him chew on stuff? Like, you know, just a leaf or bark or stuff. And [the OT] didn't give me crap for it. So that was cool. So, you know, a lot of times, he would pick up and chew pine cones and kind of play and experiment with them, and she was really cool about it. … [I said to her,] "Just let him. We don't make a big deal out of this." … I just didn't want to hear it. … Don't be judgmental and just let him, not necessarily just do whatever he wants to do, but just kind of experiment with stuff, if I know it's not going to hurt him.

Avoiding these judgments is implicit in Rachel's decision not to use devices for keeping young children from wandering. She said, "I just can't leash my kids. Some people are like, 'Just put him on a leash.' And I just can't. I just can't do that." For her, avoiding judgments and the possible negative effects was a reason to pursue intervention:

> [H]e's such a sweet boy and he wants to do good and that's part of it. Like, he was breaking rules, but he really wants to, he really likes the rules. And so, I didn't want him to get to kindergarten and be the bad kid. And be this kid who couldn't function in the class and gets pushed aside for bad behavior.

For Shandra, it was a reason to end a therapeutic relationship. She ultimately decided to end services with her child's SLP when the therapist spoke to him in a way that implied a negative judgment of him.

> [The therapist] was like, "Lucas, you're going to give me a complex." So then, I decided, I'm like, you know what? None of us are happy. And she voiced it again and then finally,

> I was like, you know, if he's giving you a complex, and you're having such a hard time, why don't we take a break?

Like all mothers, the mothers of children receiving EI work to facilitate the healthy growth and development of their children. Many of the activities included in this work are shared by the mothers of typically developing children, while some are specific to these mothers, such as participating in therapy sessions and home programs. These two activities are some of the direct service mothers provide for their children, but they often provide indirect services as well by encouraging those who are in a position to help their children think positively of them and by pushing the child's therapeutic agenda.

The Emotions of Mothers

Facilitating the healthy growth and development of their children was varied and complex work. As such, for the mothers in this study, this work resulted in strong, varied, complex, and sometimes conflicting emotions. This study identified four of these emotions, which comprised the following four subthemes: pride and joy, ambivalence, overwhelmedness and exhaustion, and guilt and regret.

One of the emotions these mothers reported feeling about their work is *pride and joy*. When these mothers were able to complete mothering tasks that were meaningful to them despite their children's challenges, they reported feelings of triumph. This feeling was palpable in these anecdotes and photographs from Rachel:

> I took my three kids and my neighbor's son to [a local pumpkin farm]. And this was right when Jason had started OT. And he is like a true runner. … And so going somewhere like [a pumpkin farm] with three kids was something that was really challenging from a safety issue. … So this day, we went and me and the two older boys had a conversation about

> going … and we pulled it off. … [W]e had an awesome time. We pulled it off. And just worked together like a team. … You know, and so this was just a really great day that I felt very successful.

> [W]e picked this whole garden and we freeze everything. And we picked this whole big thing of tomatoes together. And Jason is holding it up. And he had just, the kids had just finished completely stuffing their faces with these tomatoes that they grew. And it was just, like, a really proud moment for me in that we, like, had this garden and planted it together and just colossally more difficult, especially to do a big one. … But it is huge and I love it and they go in there and see the food and it's part of our family. Um, and I felt really proud of that.

Figure 4. Pride and joy 1. Rachel and children on outing.

Figure 5. Pride and joy 2. Rachel and children gardening.

The fact that these moments were photographed underscored the celebratory feelings that Rachel reports, and the decision to share them with the interviewer and a larger audience suggests a desire on Rachel’s part to be seen as triumphant in her mothering role. Emma spoke more generally of the pride she felt not only in her mothering but in the joint parenting she does with her husband:

> I’m proud of how we, Adam and I both, have risen to a lot of challenges that we’ve been presented with, many of which have either because of or related to parenting. … I’m really proud of the commitment, or the technical term is stick-to-it-iveness. And the willingness to do the hard work that we’ve been engaged in the last few years. Yeah. I think it’s made a real difference in the quality of all of our lives.

In addition to pride, all of the mothers expressed feelings of joy at times during their mothering work, especially during bonding activities like holding their children. Shandra reported feeling joy when she got to nurse her son, who was born prematurely, for the first time, and Emma’s joy was implicit in this description of her son’s bedtime routine:

> Putting Greg to bed at night, that’s sort of my, that’s part of what I do, and Adam often offers to do it and I’m really protective of that time. So, fixing him a glass of milk and getting him to bed, reading stories with him in bed. And I, I climb in bed with him and we read and I wrap my arm around him and snuggle with him for a few minutes until he’s content and says I can go. And, um, and I just treasure that time. I would be really sad if I didn’t get to do that.

The mothers in this study also reported *ambivalence* or conflicting feelings about identifying atypical development in their children and qualifying for EI. While they wanted to optimize their children’s development, having their suspicions validated by professionals and entering the EI system signified for them that their child was not on the typical developmental trajectory, which produced anxiety and grief. One example can be found in Rachel's description of a time when a friend shared some concerns she had about Rachel's son:

> Then one day, we went to a playground with, it was like a Moms Club thing. And there was, like, 20 two-year-olds there. And they were all running around. And I was sitting with a friend of mine, who is a good friend but a little too candid. And, I was watching him. And she was, like, watching me watch him. And she was, like, and I mean, in a helpful candid way. I actually appreciate her candidness. And, um, she was just like, "Hmm." And I was just watching him, and I said to her, I said to her, I was like, "Do you think Jason's functioning, you know, like, playing, moving his body the same way?"And she was like, "Nope. I've been watching him the whole time." And I was like, "Me, too." And we had this really good conversation about it. Like, "I don't think he's playing the same way."

Rachel's initial description of the observations made by a friend as "a little too candid," suggested a negative feeling toward the friend for making them, but her revision of this feeling to the interviewer and her subsequent actions on the part of her child suggests gratitude for and agreement with the observation. Emma was more explicit in her ambivalence about not qualifying for EI services:

> [I]nitially, when he didn't qualify, again it was sort of like a real mixed set of feelings. Like, I really didn't want him to qualify? Part of me didn't want him to qualify. Because I didn't, I didn't want it to mean that he had that much delay…. I was kind of relieved that he didn't qualify but part of me was bummed, too, because I, um … I knew he needed something, you know, clearly, things just weren't clicking for him in the way they were supposed to.

She felt similarly later, when her son did qualify for services:

> I also felt, um, much more confident, although not in a positive way, that he would qualify. Um, so, um, you know … you know, that was disconcerting in some ways, but it was also, um, empowering that, you know, we were, we were going to lick this thing, we were going to figure it out what it was.

This ambivalence was partially resolved when EI services were secured.

> I also remember, um, really strong feelings of relief and, like, "Oh, finally, like, there's people who *know* about this stuff and that I don't and who can help me." Um … and so … so it was useful, um, in that way, and helped me realize that I didn't have to stay feeling this powerless and um, unable to, to … rally whatever forces I needed on behalf of my son.

The mothers in this study felt just as ambivalent about ending therapy as they did about entering it. They were glad for what an end to services signified—that their children's developmental trajectory had improved—but they were anxious about the loss of support for themselves and their children. Emma said,

> I remember being really nervous at that point, so that would be a year later, um, his reassessment yet again. And … um, people, particularly his service coordinator, but also all the therapists that were involved telling me, "You know, he's probably not going to qualify" and at first, I was really anxious about that. But then I began to realize, That's because he doesn't need it. Or he, he's not going to need it. There was a clear need for it right up until the last few weeks. At that point, I began to wrap my mind around the fact that this really, like, we really have gotten past this. We really have. Um … we're really going to graduate from this thing.

Adding to the complexity of the emotion were feelings of gratitude and loss:

> My feelings about the last sessions, those were really hard. They were great. I mean, there was this sort of really contrasting emotional responses. Both feeling super super grateful to them, who had done so much for us, um, and … kind of sad, in a way that I didn't anticipate. I expected only the gratitude and excitement. And the sadness kind of took me by surprise.

At the time of this writing, Rachel's son was still receiving services through the CPSE system, but she was anticipating an end to services after the next evaluation:

> I'm afraid he'll get tested out of the program. … I mean, I'm happy that he will, because it means he's improving, but it's such a positive thing and I kind of wanted to hold onto the developmental support until he was in kindergarten, at least. I also want him to stay a little longer, just to, like, reinforce everything. … I would like him to stay in it as long as possible. Because I only see this as positive for him.

For Shandra, the possibility of losing services produced more anxiety than ambivalence:

> He could be in preschool for two years, and then after that, you're just kind of left for the wolves. And that's the part that bothers me. It's like, thinking ahead, well, we've got to get something figured out and get a handle on this, because after that, there's nothing. … I just don't want to be left hanging.

Despite any ambivalence or anxiety they may have experienced along the way, the mothers in this study reported feeling grateful for the services their children received through the EI system. Emma said, "[I feel] intense gratitude for the expertise of the people who were now involved in his life and helping him to sort of put all the pieces together," and Shandra stated "I'm grateful that we were eligible and that we have it. Definitely fortunate, because I'm sure there are a lot of people who may not think that they need it or have access to it, and I’m thankful for that. Very thankful for that.” And Rachel’s gratitude was implicit in this statement: “Anyone who will come to your house to help make your kid stronger is, like, every time. That’s an amazing thing.”

These mothers also reported feeling *overwhelmed and exhausted* at times by mothering, and by balancing their role as mothers with their other roles. All of the mothers in this study had professional work roles. They were also mothering children other than the child receiving EI, and they were dealing with stressors beyond their professional and family lives. The multiplicity and constancy of these tasks sometimes resulted in physical, emotional, and spiritual fatigue. Their experience is validated by the experiences of others included in the mothering literature (Bateson, 1996; Francis-Connolly, 2000) and the EI literature (Case-Smith et al., 2007; Hastings, 2002). In this anecdote, Shandra illustrated the kinds of experiences that produce these feelings:

> [I]t’s hard to, like, divide your time between kids and figuring out, you know, helping and giving support when, where it’s needed. … Lucas likes, well, *demands* a lot of attention, so you really have to be on the floor laying there, on his level, playing trains or whatever he... So that’s kind of, you kind of have to do a little bit of *everything*. … Ariel might be sitting at the table doing her homework. I’m making dinner and then in-between stuff, I might run over to appease Lucas. He wants to help make dinner, but I don’t want him near the stove, so we’ll grab like a pot or a pan or some bowls and pretend to cook? …I’m sitting on the floor, Ariel has a question and I’ll go help her, and then I’ll stir up whatever. Just constant. Yeah, constant. Non-stop. It’s exhausting. … It’s like running 24-7.

Rachel described the experience of being overwhelmed and exhausted this way:

> [M]y son got off the bus at 3, and I like pushed him in the car, and he just wanted to unwind, and there was like a fight the whole way, and then you dump him at your friend's house, and it's like, "Hi! Hi! I don't want to overwhelm you, but, you know, I don't want to impose them, but I love you! Goodbye!" And then you run into class and you teach for an hour and you have fifteen minutes and you go and you pick them up and you run them home and they're hungry and you go and you make them dinner and you sit down and go (breathes heavy) "oh crap, now I have to go do all the other things I didn't do because I was so busy." And so it's very overwhelming and, um, hard to do all those things very well. And that's where the challenge is.

This experience was made worse by the constant vigilance her son required:

> [A]t first, it was very challenging, because he couldn't hear when you yelled, when you told him to stop. And that was hard, but he really couldn't. So when we were out, he would just run away, and that was really hard. Especially with a twin and another sibling. Like, I never could sit down or take my eyes off him. I was always afraid he would hurt himself. And like, that was really the biggest challenge. By far. Like, he was gone.

This experience was shared by the mothers of children with autism spectrum disorder (ASD), whose well-being is negatively impacted by this need for "intense vigilance" (Larson, 2010). For Emma, her feelings of being overwhelmed by the addition of a second child were exacerbated by having her home flooded:

> [A]nd then three weeks later, the, um, flood happened in [town name], um, and our home and our cars and most of our belongings were *lost* and it was a really, really stressful time, what with a new baby. … [W]e were living in somebody's basement apartment temporarily while we were trying to sort through muddy stuff and figure out, you know,

> what was next and look for an apartment and all of that … and, um … we, you know, we didn't have enough hands on deck and it was just a really, really busy time. … [W]e had a two year old as well who was trying to wrap his mind around this whole new baby thing. … My husband didn't have a lot of time off work and, um … it was a really special time, it was also a really sort of *Aaaah!* crazy, crazy time.

Mothers could also be overwhelmed by their anxieties over their children's future. Emma said,

> [I had] feelings of … fear, um, you know, what is this? How is this all going to turn out? Is he going to overcome this? Is this something that's going to, you know, he's going to really wrestle with? As well as anxiety. Am I doing enough? Am I following through enough outside of the sessions? Are we doing enough daily work to make this all pay off?

For her, these anxieties contributed to feelings of powerlessness:

> [A]nd then there were, there were, you know, times on the other side of the coin, when he was *sooo* uncomfortable, just *so* uncomfortable. We were still trying to figure out, for quite a while we were trying to figure out what was going on and what was … long before we were ever clued in to the torticollis stuff, um, he would just scream and yell and he was so unhappy and he wouldn't sleep. And I was trying to figure out, what is it? What can I do to make him comfortable? And I just felt very, very powerless … and, um … just not sure of where or how to go or what to do or how to deal with it.

The mothers in this study also reported feelings of *guilt and regret* over decisions and actions regarding their children's development. For example, Emma expressed feelings of guilt about her son's difficulties:

> It, it's possible that [the reflux] started earlier and we were so distracted by the flood and everything that we didn't pick up on the cues. … I experienced a lot of guilt, too, around,

> you know, were there things that I should have picked up that I didn't because I was, you know? … Um, and two, he probably spent a lot more time in his car seat, or in, you know, some holder or something, undoubtedly than he would have otherwise. Had we not been, like, you know. … So, you know, I felt guilty for like, not, not holding him, or for him spending too much time in his car seat caused the torticollis and the sort of head cocking and stuff that might have led to it. … I mean, intellectually, I know that, like, it was what it was, and I was an attentive mother and there wasn't anything I could have done under the circumstances, but emotionally, that's hard to, you know.

She also reported feeling guilty when she did not complete assignments from the therapists.

> [T]here were some weeks when I felt like we did a really good job at it, and there were some weeks when we would get a homework assignment and, or suggestions for things that we could do and we would go back to the next session not having even thought about it again, you know, and, um … on those weeks, I often felt guilty, I'm really skilled at feeling guilty. Um, but you know, I felt like I hadn't, we hadn't done what we needed to do and *they're going to be able to tell right away!*

Shandra's regrets were about not asking for a different SLP for her son sooner than she did. Despite her differences with the SLP, she continued the relationship because she felt her son was making progress. Ending the relationship had led her to reassess his progress and regret this decision.

> I probably should have changed his speech teacher a long time ago. That would have helped (laughs) quite a bit. So. He was just kind of stuck for a while. … [I]t really stinks, because they make a little bit of progress, and you're like, "Okay, well, this is good," and then, but then it's like, "Well, maybe he could have been making more progress with,

> with a different speech teacher." … You definitely have to give it time, but there were things that he would do for the other teachers and not for the speech teacher.

She also seemed to have some regret over not referring Lucas to EI sooner. That feeling was implicit in this statement: "If I had noticed stuff before or I had gotten him evaluated earlier, then I think we probably would have gotten services before, but … it's so hard." The idea that mothers of children with health concerns may feel guilt or regret for decisions regarding their children's care is supported in the work of Lawlor, who says a mother may "anguish over regrets that [she] did not challenge professionals or care decisions sooner or harder" (2004, p. 319).

The work that these mothers do to facilitate their children's healthy growth and development appears to result in emotions that fall within four categories: pride and joy, ambivalence, overwhelmedness and exhaustion, and guilt and regret. It is notable that there appears to be more support in the literature for the more difficult emotions than the positive feelings of pride and joy that these mothers feel when they are successfully connecting with their children or completing their work. Some of these more difficult emotions may result from the constraints that make it difficult for these mothers to support their children. Some more difficult emotions were also described by these mothers in the following section.

The Constraints on Mothers

There were many factors that made the work of mothering a child who is receiving services through the EI system more challenging. Three constraints were identified in this study: the variable and non-linear nature of development in young children, the practical challenges of completing therapy sessions and home programs, and the lack of time and family support for mothering and other roles.

One of the constraints on these mothers was *the variable and non-linear nature of development in young children*. Because there is such a wide range in what constitutes typical development in the early years, regression can occur in typical development, and the achievement of developmental milestones often happens in fits and bursts rather than in slow, steady progress (Brazelton, 2006), it may be difficult to determine whether or not a child is on a typical developmental trajectory. Because of this, mothers and other professionals may have a hard time determining whether or not there is a need for EI or if intervention is working. For example, Shandra's beliefs about the variability of development made it difficult for her to decide whether or not to pursue an evaluation through EI.

> [I]t's really hard when someone tells you, "Your child's supposed to know 20 words" and it's like, "Are you kidding me?" Two kids aren't the same, number one, and number two, well, I don't know. It's like, a lot of things, they need to learn at their own pace, but, at the same time, you don't want them to be, you don't want them to fall too far behind.

These beliefs also informed her opinion about her son's atypical crawling pattern, which was more worrisome to others in her support system. The conflict between their assessment and hers was distressing to her.

> [H]e wouldn't crawl. He had like a, I called it his cripple crawl or his pimp crawl. You just imagine him kind of walking and, not walking, but he would kind of step out and then one knee, so, he didn't crawl on two knees. He just crawled on one. Everyone made such a big deal out of it, and I was like, "You know, this is what he wants to do." And they were telling me, I don't know exactly who it was who told me, but, "Oh, he might have to get braces for that" and all kinds of stupid little stuff. And I'm like, "No, this is just how he wants to crawl." So I was just like, "You know, … I know that this isn't how

> most kids crawl, two knees down, but this is how he wants to crawl and this is how he does it, and I don't think that there's a problem." … I remember getting really upset and thinking, "Just because he crawls like this doesn't mean he's going to walk like this." … And, I remember someone had said, maybe it was the doctor's office that said, "If he doesn't crawl correctly, then he's not going to walk correctly" or something. And, um, he did just fine. So that really kind of bothered me. It just really stinks when people tell you or they say, "This is what needs to happen to have this outcome." And, I understand that, but I just, I don't know. Sometimes I think you need to just leave these things alone and let them kind of go the way that they need to go.

The difficulty of distinguishing between a variation in development and a true delay was true for the professionals as well and, in Jason's case, may have delayed the start of EI services.

> You know, and [the people on the evaluation team] were just overwhelmed by how social he was, and they were just like, "This is totally awesome. He's going to grow out of it. Let's see if he grows out of it." And he didn't. And we're like, "Uhh." And then the next time, they're like, "Okay, so he didn't grow out of it. Let's check out what's going on."

The mothers in this study also had difficulty determining if their children were improving with therapy because gains were not always apparent or were lost. Emma described the changes as "slow going" and said:

> [There was] not a lot of black and white to the various therapies that he's been in. I mean, yes, there is black and white in the sense of when he started, he had a lot of challenges, and now he doesn't, but it's such an incremental process and, um, so many, like, two steps forward, one step back that it, it was hard for me to see the forest for the trees, a lot of times. And, so, I, I would get discouraged. … I remember never sort of getting up from

> the floor ever and sort of feeling like, “That was a win!” or “That was a total defeat.” I mean, it was always like a total mixed bag. And so it was hard for me to *know*, like, how much of the work we were doing was beneficial or useful

For Shandra, the slow rate of progress was disappointing. She said, “I feel that … he is making progress, um, with the early intervention, but I feel like he’s plateaued and I just… I don’t know. It’s not going as fast as I’d hoped.” This feeling of being “plateaued” produced some suspicions in her that her son might have a developmental disability such as autism spectrum disorder (ASD). She said,

> I’d planned on getting him tested way back in May? Well, I wanted to look into it because of the behaviors that he was doing. But they were like, “Just wait it out and see what progress he makes.” And he’s been making progress, but it’s been slow and he’s not been making leaps and bounds.

Contributing to the difficulties of determining whether or not there was a need for intervention was the fact that mothers sometimes had difficulty determining which behavior challenges were simply part of typical development and which ones were causes for intervention. Shandra highlighted the problem in this anecdote:

> [We’re a]t … his great-grandmother’s birthday party, and there’s a lot of people there and the way that the tables and chairs were set up, it’s pretty crowded and, I don’t know, I think he didn’t really want to be in there, so he kept running into the hallways. And I’d say, “Lucas, come!” and he would like turn, look at me, and he would just haul, just run. So, I’m like, “Oh, come on!” It was just annoying, because he kept running out, which, I mean, that’s his age as well, so I can’t really get too upset about that. But we didn’t even

> really get to enjoy the party, because he was all over the place. … It's just tough, because their age, you just never know what's, you know. How to decipher the two.

Emma felt similarly challenged by the behavior of her older son, who did not receive EI:

> [My older son] is *soooo* active. Like, he is always on the go. He literally cannot sit still for five minutes for a bowl of cereal. Like, he is *always* going, he is *always* talking, usually loudly, he is always into something. … I mean, sometimes, um, it, sometimes it's a cause for worry? Adam and I both, like, Adam as a child had a diagnosis of ADHD and had a lot of struggles as did his parents around should they medicate? And he did, for a period of time, take medication for it and that was a sort of disaster, and so we have a lot of worry around is this the road we're headed down? And how are we going to do this?

Mothers are also constrained by *the practical challenges of completing therapy sessions and home programs*. The mothering literature suggests that in order to complete their work, mothers must rush through their activities, attempt to complete multiple activities at once (enfolding), enlist others to do their work for them (unfolding), or simply not complete their work (Bateson, 1996), while the EI literature suggests that therapy and home treatment programs may make untenable demands on a mother's already limited time and energy (Bailey, 1987; Edwards et al., 2003; Llewellyn, 1994). This idea is supported in the testimony of these mothers. For example, Emma had difficulty just getting her child to therapy sessions. She said,

> Multiple times a week, it meant we had to fit another activity in our day, or I had to be at daycare to drop him off early, or he had to stay late, or we had to coordinate, it was especially tricky when we were doing the OT here on campus, because we were sharing a car at that point. Um, and … so, I would have the car up here at work and I would have to drive down to … [the children's museum]. And, um, pick him up and get him back up

> here for our appointment, which was the last appointment of the day, but still, you know, what was it, like four or four fifteen or something like that. Then after the appointment, would have to go back down and get Chris because I could not, I could not have Chris with me at the appointment. That's just not the kind of kids I have. … That was a challenge. Just on a very practical level.

She and Rachel were sometimes challenged to complete assignments given by their therapists because of their children's unwillingness to participate in the activity or use the recommended positioning. Emma described the problem this way:

> I remember a lot of um, sessions, times, like, sitting on the floor with him, trying to recreate situations, um, doing the homework, um, where, the, like, because the, um, muscle tightness was on his left side, it was always activities designed to get him to orient to his left. … [H]e's not a kid that's going to do what he doesn't want to do? You know? Um, so, a lot of times, I remember just feeling like, "Please, would you just cooperate *once*? Please, just, just do this for me!" Um, and, and he… he would or he wouldn't. You know, sometimes he'd be in good, more cooperative moods, and we would get a lot of good, um, effort in and other times, we wouldn't.

It was also difficult for her to carry out the feeding assignments given to her by her son's SLP. She said, "[I]t was a challenge in large part because he's a super duper picky eater. And, so, already, in terms of feeding, I was challenged in terms of finding foods he would eat." Rachel's difficulties were in implementing the positioning suggestions her PT gave her for seating her son for mealtimes:

> [Jason] didn't want to be in a high chair because his sister, nobody *else* was in a high chair and it was for *babies* and he kind of *needed* to be in a high chair and we tried a *pillow* and he fell *off*, so. He just sat on his knees.

The mothers in this study were also challenged to meet the other demands of their mothering roles, such as attending to the needs of their other children and/or preparing a meal. Emma illustrated the problem this way:

> [A]t other times, some of the things that she was able to do just weren't at all realistic for me to try to replicate. … [A] really classic scenario would be Greg sitting in his high chair and I would be in the kitchen sort of trying to figure out what I could give him that would be what Sheila was wanting him to have access to, and I'd be sort of trying to coordinate getting the rest of the dinner on the table because it was always something different and the … Greg's older brother, Chris, would, transitions are difficult for him. So we would get home from day care and he would have this really difficult sort of hour, um, as he would get settled back into, sort of, home life. Um, so he would be screaming or yelling or hanging on the ceiling or, you know, who knows? It was just be a tough time for him as well. And, so I just remember sort of feeling … pulled in a lot of different directions and stressed out. And then very predictable, and it probably makes sense that under those circumstances, Greg would just be like "Whatever!" and I would give him something that I tried to prepare that was consistent with instructions and it would just get knocked off the high chair or whatever, and I would just be like, "Ughhhhhhhhhhhh!" So, you know, that was challenging. Um, I, I wished often that I had the kind of time to give it sort of concerted energy and attention, um, absent all the other stuff, but the reality was that I didn't.

Rachel expressed a similar frustration:

> [I]t's just hard. We have three kids. And [Jason] may need some help with, like, eating, but, you know, the other ones need help, too. It's just really hard to just sit one-on-one with him when you have three kids.

To a lesser degree, Emma was challenged by the lack of clarity in the therapist's instructions:

> And she would write these, like, she would give us homework assignments and she would draw these little stick figures? on little sheets of paper. Like, and there was a mom stick figure and a baby stick figure and I remember getting home from those sessions and having a good laugh with Adam, because we would look at this and be like, "What the hell is this? I have no idea what I'm supposed to do."

And while Shandra did not express any difficulty with performing the brushing protocol recommended by her son's OT, she was frequently unable to complete it for one reason or another:

> [The brushing], I've been slacking a little bit on. … [W]e were doing really good for a while, but I've just been feeling like *crap*. … He gets a brush here, a brush there. Usually we've been really consistent with that. Especially after we ordered more brushes?... [W]e did for quite a while. We did for months. We were doing really good until the last brush was lost.

The mothers in this study were also challenged to schedule therapy sessions at times were convenient for them and the therapists. Sometimes, these were minor inconveniences and could be handled with a little flexibility on the mother's part.

> The one "challenge" … was around scheduling. … [W]e had a set time, but sometimes it didn't work out that way. Sometimes Linda couldn't come on whatever time she was

> scheduled to come, … or … something was going on, and for the next few weeks, she needed to come an hour later. … [S]ometimes those changes were communicated early and we could plan for them easily and it wasn't a big deal. Other times, they came up and we never felt like that had anything to do with, other than just … our therapists are really at the mercy of parents and the people that they're working with, and sometimes, people change things. You know, we weren't put out by that. We tried to be really flexible, and I think we succeeded in doing that and, you know, if it meant that Linda saw Greg by himself and we just touched base by email in, you know, a day or two after the session, then, or text message.

Other times, they were more egregious and difficult for the mother to manage.

> The only thing Emily had, we had an issue with, she's, she's late a lot. And it's like really problematic. Especially when you're a parent and, like, for Jason, I always have to get him to eat first so that he's engaged and we're kind of lining it up and they're waiting at the window and they get excited and they don't show up and it's like disheartening for him? And as a parent, and I work a little, it's like, you rearrange your schedule for an appointment and, like, there are times when she's 45 minutes late without calling, a long time. And then one time, we had a session, it was like the first appointment of the day. … And the service coordinator was coming? And she waited for her for 45 minutes. And she was *furious*. And she was like, and another time, she was like an hour late to Linda, like a dual appointment. And like came in and was like, "Oh my god! I overslept! I was talking on the phone!" You know, and not, and you're just like, "You don't understand. We all rearranged our worlds to be here at this moment." … [I]t kind of was like, "This is

> getting to a point where I can’t continue if it’s like this. Not because we don’t love you, but because, like, it’s too hard.”

Thankfully, Rachel successfully dealt with this challenge by having a conversation with her therapist, which resulted in changed behavior.

> I would say I wasn’t really scared, and she was, um, really receptive and we had a good conversation, and nothing was, like, yelling, it was just, “Okay. Moment of truth here. I’m telling you this because this is something I can’t manage. If you can’t change, then we need to change something, because this is something we can’t…” … She was really responsive. She was like, “I’m, I’m thinking about it, and I can’t believe I was doing that, and I see how I was…” and it’s like, “How did you not know you were doing it?” But she really didn’t, and I really believed her that she just wasn’t aware of it? But I don’t know. So, but we’ve moved forward, and she’s much better. I mean, she’s still, like, a good ten minutes late, often, but I kind of can deal with that.

Part of what made scheduling challenges particularly stressful for these mothers was their *lack of time and family support for mothering and other roles*. All of the mothers in this study reported feeling that they did not have enough time to meet all of their responsibilities. Rachel said, “[It]’s really hard. I often have to prep at night after they go to sleep but I also have to make dinner and I also have to do the grocery shopping and my house is just not clean and that’s okay. I’m okay with that.” In order to help her son progress with his feeding skills, Emma was tasked by her SLP to provide her son with foods that would encourage him to “bite and pull.” She described the challenge of trying to complete this assignment when her schedule was already full this way:

> I remember a lot of grocery shopping trips when I would … um, I would, I would just have “bite and pull” written on the grocery list, like, just to remind myself while I was there, and grocery shopping trips these days feel really hurried. Like, you know, “I’ve got to get through and get everything I need quickly so I can get home and get to the next thing and, um, feeling sort of hurried to find the right things, the right new things, and um, that was a challenge. Sometimes successful, sometimes not.

This problem was exacerbated when mothers did not have the family supports they needed to complete their tasks. While Rachel was quick to acknowledge the work her husband does for their family, she reported that caregiving responsibilities fell mainly to her.

> I work almost half-time but the kids are only in child care 9 hours a week and [my husband] comes home and helps, but if there’s like a school break, he will never take off work, but I just lose my child care time. And I have to manage that. So if someone gets sick, he still goes to work, but it’s me who has to find a way to make up the slack.

A recent loss of support—her father and father’s girlfriend had helped provide transportation for her daughter—made it difficult for Shandra to complete her mothering tasks:

> My dad and his girlfriend were helping…to transport my daughter, but they’re in Florida now? They go to Florida for the winter. … [Now I’m] just running around like crazy. Um, it just stinks because, um, [my daughter will] dance, she’ll have two or three classes back to back, so I’ll be stuck in [town] for 2 or 3 hours? with nothing to do and then and I turn around and come right back home. And there’s no point in dropping her off and then coming back home and then picking her up and coming back, so. … It was just nice before, having someone drop her off? Because then I could be home, making dinner, doing whatever, and then go and pick her up. … Now we’ve got the mad house.

For Shandra, the lack of time and family support made a pending transition to CPSE more stressful and her desire to know whether or not her son had ASD more urgent.

> [H]e's two now, and I'm always like, I'm a big planner. Single mom, you always have to worry about everything. Thinking ahead. … [W]e've got eleven months to go, but is that going to be enough time or, if he needs additional help? I just want that kind of cushion to follow him through. Because once [EI] stops, or if he goes to school or whatever. I want to know what's going to happen after that.

Lack of time contributed to Shandra's sense of urgency around this progress in other ways as well. Her anxiety seemed to be exacerbated by her beliefs about the importance of the early years to a child's overall developmental trajectory. She said,

> And I think it's all about if they have a good start. And if they have a good start, then they're okay after that. If you don't have a good start, then it's just harder to play catch-up. …If you don't have the foundation, but then everything falls apart. But if we can give him a nice, strong start before school, and then, once he's into school, if he has those things in place, then after that, you know. He'll be fine. We've got 11 months. Not even that, because he'll be going to school, but we've got a little bit of time to get things in place, but I think it's all about a good start.

Because of this, her son's failure to progress more rapidly within the window of time in which EI services are provided signified for her not only an increased possibility of ASD but also the decreased possibility of providing the "good start" that might prevent "everything" from "fall[ing] apart." For this reason, a pending turnover in therapists—at the time of her final interview, she was preparing for her son to begin services with a new special education teacher—was felt by her as a loss of precious time.

> You feel like you're starting all over. It's like, all right, you get to a happy place and then it's like, ugh. You have to start all over. … It just seems like it takes a while to get going when you have to start from scratch.

These mothers' ability to facilitate the healthy growth and development of their children was constrained by at least three factors: the variable and non-linear nature of development in young children, the practical challenges of completing therapy sessions and home programs, and the lack of time and family support for mothering and other roles. Of particular note is the way that time constrained mothers in a variety of ways. When it comes to mothering, it seems that there is never enough time for all that must be done, which becomes even more true when the services provided by EI demands even more of a mother's time. On top of this, EI is a time-limited service, one that is provided during a period that is considered critical for development but is also a time of great variability, which may make it difficult to predict (and thereby adequately support) a child's developmental trajectory. However, these constraints may be mitigated by therapists and others who provide supports for mothers. These supports are detailed in the following section.

The Supports for Mothers

The mothers in this study identified 14 supports provided by therapists and others which helped them deal with the more difficult emotions produced by their work as well as the constraints on their work. 13 of these supports were provided by therapists and comprise the following subthemes: navigating and utilizing the EI system; creating meaning from their observations and taking action based on these understandings; projecting the child's developmental trajectory via therapy; making connections between the therapist's actions and intentions; making connections between the child's behavior, its cause, and the appropriate intervention; helping them to "see" the child's successes and progress; confirming their positive view of their children, recognizing the complexities of their family, and accepting their family without judgment; teaching, coaching, and modeling strategies for supporting the child's development; support for dealing with parenting challenges that arose secondary to home programs; sharing experiential knowledge gained through mothering their own children, responding to the needs of their children and themselves; providing extra hands and/or engaging sessions so they could rest, observe, and/or get other mothering work done; and validating their role as mother and the mothering work that they do. The final support was provided by family members and others who help with mothering tasks and provide emotional support.

One of the ways the mothers in this study felt supported was when therapists and others helped them *navigate and utilize the EI system*. Many of them reported feelings of anxiety at beginning the EI process and appreciated information about how the process would go. Emma described her experience this way:

> [T]here had been … a service coordinator … from the county, who I'd had some interaction with from the beginning. And it was the same one who … reactivated when we referred a second time. She was *fantastic*. Um, and even though we had been through it once before, she didn't assume any sort of level of knowledge. She just came in and really just met us where we were and walked us through the process.

Shandra received similar assistance from the visiting nurse who began coming to her home when her son came home from the hospital after being born prematurely.

> [The visiting nurse] let me know what was going to happen. She was like, "First, you're going to have a meeting, and then you're going to have to fill out a bunch of paperwork, and then they're going to send maybe a couple of therapists and have him evaluated and

> they may have to have him evaluated twice" and she just kind of let me know everything that was going to happen ahead of time. She just let me know, like, it may not just be speech. He may qualify for other services as well. And he did, so she was pretty on point with just about everything.

They also appreciated it when therapists recruited new team members and shared information with existing team members. Shandra expressed appreciation for therapists who shared information to create consistency and increase carryover:

> I think it's very important if the child receives other services [for the therapist] to just kind of, you know, say, "Hey, do you mind if I get in touch with so-and-so, just so we can all be on the same page?" I think that's really important. Really, really important. Definitely being on the same page just so that, you know, you can all work on the same thing and that's one thing that I would do with Lucas's speech. I would say, "Well, we're working on marching right now." And she would add marching into the play and same with Alex and so on and so forth. So it's like, okay, now he's getting a bunch of it, you know?

Emma appreciated her PT for encouraging her to bring in OT and SLP to help with Greg's feeding issues.

> I remember [the PT] saying something like, "It could really *only* benefit. It could *only* help." Uh. And, you know, "If OT is available to you, it would be a really great addition" to the work that she was doing. And, also, because I was reporting to her the things we were seeing at home and one of the, um, biggest things that I was reporting, challenges, was that he was choking on his food. And, you know, that came about as he developmentally started going from formula to more solid foods. And so, the more

> complicated the consistency and structure of the different foods that he was getting, the more we were picking up on the fact that he was having trouble with it. So that then brought the recommendation that we do the speech for the feeding and that the OT could also help.

The mothers were especially grateful when therapists guided them not just to a specific discipline, but to a specific therapist she personally endorsed. Emma described her experience this way:

> I was thrilled to get hooked up with Linda [the PT] early on, and that was by referral from Hannah [the OT]. … Hannah had said, "She's absolutely terrific!" … And really quickly, … I came to feel that way myself? And we ended up when Linda started making suggestions for additional therapies, um, she was guiding us to kind of hand-picked therapists as well. So, you know, again, Sheila the feeding therapist came *really* highly recommended and, um, Linda actually helped make that happen. Um, helped to make sure it was Sheila that got assigned to our case and not somebody else. … [W]e got connected to the best, so we felt really in good hands. (Emma, 2)

When Shandra ended services with her son's SLP, the other EI professionals helped to point her to one they felt would be a better fit.

> Shirley, who is, like, the coordinator, she just thought [Susan, the SLP] would be a good fit for him. So she decided on Susan. … And then she told me that Susan and Emily [the OT] worked with him. Or, Susan and Emily had worked with a lot of the same kids. They know each other. … And, um, so she was like, "Well, if you ask Emily about her," so I asked her, and she said she was great and works really well with kids like Lucas. So after she said that, I was like, "That's good."

Mothers also reported feeling supported by therapists and others who helped them *create meaning from their observations and take action based on these understandings*. While all of these mothers were able to recognize that some of the ways their children moved and behaved was different from the typical developmental trajectory, they were not always able to determine what these differences meant for their children's development or what course of action they should take as a result. Because of this, they appreciated therapists and other health professionals who helped them put their child's development into context, identify typical and atypical development in their children, and make thoughtful decisions to support their children's development. Shandra received this help from her visiting nurse:

> And [the visiting nurse] was always saying that, you know, they take, you know, [a developmental assessment] might take, like, 100 babies and say this, all the babies, this is what, this is what they need to do. You know, and, it made me feel a lot better about, not all two babies are the *same*, not all babies are going to walk the same or crawl the same or, you know. They're going to do things are their own rate. And, um, you know, she just made things a lot easier to deal with, not having such a *harsh*, um … not making everything so harsh.

For Rachel, this support came from her friend, Hannah, who was also an OT.

> And she was watching him [during a play lab in her clinic], and she was like, "I see it." In that environment, with all those skilled things set up, you can really see it. And so, um, she wrote me down some notes, I went back to my pediatrician and we got him reevaluated with different people. And the people who evaluated him said, "Yes. I see this, this moment." And you could have missed it. … Like, so they were like, "You could have easily missed this, but this is clearly, like, he's not, like, something's wrong."

Emma received this help from a PT and PT students who worked at the college where she taught:

> [A] few months in, we, I brought him [to the PT program at a comprehensive college in the Northeast] for the Baby Lab project. … I mentioned [my concerns] and they looked him over and the student said, "Yeahhhhh, I'm going to call in…" So the professor came over and looked into it and the professor suggested the possibility that he had torticollis and, um, and suggested that we (1) refer ourselves to the early intervention program and (2) um, they taught us a number of different things that we could do. Like, the football hold and different things that we could, um, do to try to stretch him out and get him more symmetrical. Um, we referred to early intervention at that point.

And, like Rachel, she also had help from Hannah the OT:

> I ended up getting connected with Hannah and, um, she was a really, really useful resource because she had familiarity with torticollis specifically and, um, so we talked about it quite a bit, um, and she suggested two things: (1) that we re-refer? to early intervention, and (2) that we, um, see about the possibility of getting him started with some private therapy even if we didn't get qualified for early intervention, that we get private through our insurance. So we did both of those things and he qualified for early intervention at that point and, um, in the meantime, because that's a process to get started, we, um, started seeing a physical therapist, Linda, privately, um, at the [local PT clinic] and, um, then, once he was qualified and enrolled in early intervention, then we started, um, with physical therapy there.

When EI services began, the therapists provided further support by *projecting the developmental trajectory for the children via therapy*. Lawlor suggests that mothering includes "envisioning possible futures for their children" (2004, p. 315), but this work may become more difficult when a child develops differently than his or her peers and the mother is unsure how to interpret this difference and what it might mean for the child's future. Therapists who have more experience with children with developmental delays and disabilities may have a better frame of reference from which to envision the child's trajectory, which may help to provide a more positive picture of what the future might hold for the children and their mothers as well as a plan for how they might reach that future, which helped to alleviate the mothers' anxieties. Emma received this support from Linda, her son's PT:

> I remember her … um, her attitude and her disposition being *really* positive and upbeat and that was *so* useful at that time. Um, like, you know, combined with the reflux, which at that point was full on, and the torticollis and all of it, I just often remember feeling so, like "We're never going to get through this. We're just never going to make it." And, um, and she was just like, "We're totally going to do this! We can get through this! We can, and here's the little piece that we can do this week. You know, this is what we can do this week. Here's what I want you to do."

Rachel received a similar message from Linda, who was also her son's PT:

> [S]he made me feel like, like we could be successful. Like this was something we could work on and get through, and that was really important. … It was just, like, you know, it wasn't false. She didn't walk in and say, "No problem!" She met him, and at the end, was like, "We've got work to do, but it's cool. We'll work through it. … [S]ome things I don't really understand yet, but there's a lot we can do." And that felt really good.

And while all of the EI professionals involved in Lucas's care have cautioned Shandra that they cannot make diagnoses, she has taken comfort in their predictions that, if he is diagnosed, he will likely be found to be on the more mild end of the spectrum and will be able to achieve many of the typical markers of success in life.

> Shirley said [having Lucas evaluated for ASD] is great if that makes me feel better, but if he is diagnosed, it's going to be on the very mild end. … But if he's anything at all, he's on the very mild end, because he's, he, uh, I don't know. He does have eye contact, he does do a lot of, um, he's easily calmed, he's happy. … With Alex, I did talk about it a little bit, and he just said, "If he is on the spectrum, then he's high functioning." And actually, Emily said the same thing. That he is high functioning, and he'll probably function like as a perfectly normal adult and go on to college and all of that stuff." So that made me feel really good.

During evaluations and therapy sessions, the mothers in this study wanted to understand why their children's therapists took the actions they did, what therapists were observing as a result of these actions and/or how these actions supported their children's development. They were appreciative of therapists who helped them *make connections between the therapists' actions and their intentions*. Emma described this experience during her son's initial evaluation:

> [A]t the first assessment for early intervention, … I don't even remember the OT's name, I think it was Karen. Um, she and the nurse and myself and Greg were all sitting on the rug on the floor and doing a lot of activities. You know, she would put balls out or things out and get him to like reach for, um, the various activities and I remember … being grateful for her explaining exactly what she was doing each time. You know, what she was looking for and what she was trying to determine whether he was able to do or not, and explaining. And I don't remember specific explanations she offered, but I remember her saying, "You know, I'm looking to see if he can do X and that's meaningful or useful

> because it tells us," you know, and would translate that into everyday, like, life of a baby activities and that kind of thing. I remember being able to connect those dots being so … useful.

Rachel expressed appreciation toward her son's PT for "connecting the dots" during treatment sessions:

> Linda's really good about laying it out as she's going. "This is what we're working on." [S]he articulates it. And I can see it in the activities, how she's like doing the same kinds of things in different ways, and it's very clear. … [O]ne of the very big things that she does is this, was this getting him to do obstacle courses. Like, at first, you could say to him, "Get that, and come back here." And that was kind of tricky. And then, it would be like, "Get this, put it over here, and then come back to me."And also moving it from a small space into a bigger space. And, um, and you could see it. Like, she came in and was like, "Okay, this isn't working, so we're going to try to put this physical thing into it." But you could definitely see that it was a very clear thing, another step into this broader process of skills that she was working on.

Rachel was able to understand what her son's PT was working on not only because the PT expressed it verbally to Rachel, but because she approached intervention in a systematic way that made her intentions visible. By completing the same activity—an obstacle course—over multiple sessions and making it more challenging over time by expanding both the amount of directions given and the physical space in which the course was created, the PT made it clear to Rachel how the interventions were helping her son's ability to understand and attend. For Rachel, the PT's ability to "connect the dots" provided support for her claim that Jason's developmental trajectory will improve with therapy.

> And when you’re on the receiving end as a parent, you can just very much see that Linda has this path, and she’s like, “We’re going to do this, and this skill’s going to build on that, and we’re going to do that” and it’s very easy to see where those outcomes are more measurable. … Like, there’s definitely, like, in Linda’s path, I think it’s more measurable and we’re pushing in a certain way and that’s really good.

Conversely, mothers may feel frustrated when therapists don’t make explicit the connections for them. Rachel was challenged to see how Jason’s OT’s actions fit into a larger plan of care for her son.

> With Emily, sometimes, they’ll do one thing, and sometimes they’ll be working on something else, and it’s just not clear to me what the plan, what the flow chart looks like. … She will do something for a while, and it will just kind of drop off and it won’t come back. And you’re like, “What happened to that?” For a while, she was using this music, so she would put music on and it would distract him while he was doing tasks, and it actually to me would seem success, like, it was one of the few things we talked about that was really successful, and then she just stopped doing it. But it seemed that it was something he really liked. I mean, I don’t know. Maybe it got to a point where she just didn’t think it was beneficial? But, like, I don’t know. … I don’t see the flow of skills. She’ll just have these three [activities], and I’m like, “What do these three things have to do with each other?” … [T]hey’re all appropriate things, you know. But it doesn’t seem like, but she may have this grander plan. I just don’t know it. …[S]he’s not making that link for me, and since she’s the professional, I’m not going to make it on my own.

Because the OT doesn’t interpret her actions for Rachel, Rachel was left to interpret them on her own. As a result, she didn’t have complete confidence in this therapist’s more responsive approach. While she saw benefit in this method, especially her son's feelings toward the therapist, she wondered if the therapeutic agenda was being somewhat lost.

> Linda's like hyper-organized and hyper-prepared and I find Emily to be less so. But it's not always a bad thing. Like, she has ideas, but they're like, and I don't know if you want me to compare them, but, like, um, uh, when Linda looks at things, she's like building on this whole project. And like Emily kind of comes day to day. And she's like, "I'm here today, and we're going to work on this today" and it's kind of like "This is what we're working on today." And with Linda, it's kind of like a longer sequence of things that she's working on, and we slowly build it. … Emily is more *fun*, but Linda gets more work done. … And so, there's good and bad things about that. The good thing is that it's always fun when [Emily's] there. The bad thing is that, I don't know if this is true, but I wonder if he doesn't want to do things, then it's not getting pushed as much then if you come in and, I think there days when Linda comes in and he's just like "No way" and, you know, you have to be flexible? But there are two different styles, and I wouldn't even say one is better than the other. But one of them is more proactive with the plan and one of them is more responsive with what's going on with the kid.

The mothers in this study also felt supported in their work by therapists who *made connections between the child's behavior, its cause, and the appropriate intervention*. They appreciated therapists' explanations for their children's behavior and as well as the concrete strategies for dealing with the behavior in an appropriate and effective way. Rachel expressed appreciation with her child's PT for persistently pursuing the underlying cause of his lack of safety awareness:

> [W]e were doing the sessions in the house, and he was really improving. … And then … I took him to a playground he had never been before and it was like old him. All of the things that, like, we realized there were depth perception issues. Like, he just wasn't using his peripheral vision on the playground structure. Unless he knew the playground, he would just kind of step off of it. It was really stressful, you know? And, so we'd been working in our house setting, and then we went to a playground that he knew, and she was like, watching him and thinking about it. … And she's like, "Are there any playgrounds you've never been to before?" And she just totally nailed it. … [S]he's like, "Let's meet there next week. Not now. We're kind of warmed up." And so we went there, and all his stuff came back. And it was like, "Ugh." And she was like, "Aha!" And he was, like, running. He does this, he used to do, it stopped more now, but he does this thing where he throws his head back and forth and kicks his heels out when he runs, and I always thought it was so cute. And she was like, "That's what it was!" And she was like, all of these things that I couldn't articulate from this moment, and it was from many sessions of putting it together. And I was like, at that moment I was like, "You *know* him." … And she kind of did a 180 and, like, we went right after that to the hearing specialist, and she was like, "I want to get his hearing tested." And I was like, "But it was tested in the doctor's office." And she was like, "No, no, no. I want *this* done." And we went to the hearing specialist, and so, she was like, "He's hearing fine. Everything's fine. Everything's working." And then she put us in a sound booth. … So, there's like a duck and a monkey, and they, like, clap and make noise. And I'm sitting there with him on my lap, and we've gone through, like, 10 types of hearing testing, and he's fine. He's *fine*. And she plays it, and he can't see it. Like, it's loud, and it was just in his periphery Like,

> in that moment, that’s when we figured that he had really no periphery. He was, like, suppressing it. Like, he really wasn’t using it, and everything was like a tunnel for him. And, from there, we made really great progress.

Shandra shared multiple examples of how her son’s OT explained her child’s sensory-seeking and sensory–avoiding behaviors and gave her effective strategies for dealing with them.

> [T]he other day, well, last week, we met at the library, and he was all over the place. He wasn’t having it. …And so, we were getting ready to leave and I was trying to get his mittens on and he didn’t, you know, the whole texture thing, he doesn’t like things on him. So, we ended up, I put him in the stroller and said, “Lucas, it’s freezing out.” This is when it was, like, it was in the teens. It was freezing! And it’s like, “You really need to have your gloves on.” But once I started kind of pushing him, he stopped. And then I was able to put his gloves on. And she was like, “Do you see how once you started pushing him in the stroller, he was okay, he was able to focus because you were moving?” And, um, you know, it was just nice. Like, “Wow, you’re right. I’d never noticed that before.” Something so simple. We had pushed, I’d pushed him probably five feet and he was like, “All right.” You know? He put his gloves on. He was just like, “Ahhh!” You know? He was calm and cool and I was like, Oh. That’s so simple.
>
> I just asked her, “Why does he always chew on things?” He’s not teething, because he’s not, he’s all done with teething? And she said, um, oral motor calms his body down, especially for kids who are very active. And that’s why, uh, it makes it a lot easier for him to stay focused. Simple things like, uh, if he has, like, a juice box with a straw, and

> he's sucking on the straw, he'll make good eye contact after that, just because he's had to focus on sucking. And he's…he's right there with you.

This knowledge not only helped her to deal with her son's behavior but also led her to revisit past actions with new understanding and create new meaning from them.

> My daughter had a dance workshop and competition in Long Island. Um, we, well, the bus kept breaking down, but the whole trip ended up to be seven hours and he was perfect. The only kid on that bus that was quiet, calm and collected. I could have choked all these little girls. They were *awful*! It was so bad. But he was perfect. He didn't give anyone any problems. He was calm, cool, happy. It was great. So, looking back to that, I'm like, "Oh, yeah, you're right!" All the other kids were going crazy and he was just, you know, kind of hung out and got passed around a little bit and just sat there looking out the window. It was moving. He was happy.

These examples help to highlight why effective communication is considered an important quality of FCC (Case-Smith, 2010; Myers et al., 2010; Rosenbaum et al., 1998). When therapists share their observations, interpretations, and plan of action with mothers and with each other, they help to build the mother's skill set as well as her confidence in their skill set. When these things are not shared with the mother, there is more room for doubt to form.

The mothers in this study also valued therapists who *helped them to "see" their children's successes and the progress their children had made* when it was not apparent to them. Emma shared this experience:

> I think, for me, being able to go to the sessions on a weekly basis … that was where I was getting the feedback that the work that we were doing was useful, or the work that we were, um, doing was getting him moving in the right direction … [T]hrough the session,

> as they got to work, she would say, “Oh, I can *feel* he’s, you know, he’s not as tight,” or, “He’s”—um, you know—“He’s really in line today,” or “He’s”—um—“well coordinated.” Or, you know, she would just, as she was observing him, she would just, um, vocalize those [observations].

Similarly, Shandra felt discouraged after a particularly difficult treatment session, but her son’s OT was able to help her see the skills her son had demonstrated despite his challenging behavior.

> I didn’t think the session went that great and [she’s] like, “Oh, it went great!” … I was like, “What? What are you talking about?” [She’s] like, “Well, he had great eye contact” and then pointed out little things. I was like, “Okay, you’re right”

These mothers also reported feeling supported in their work by therapists who *confirm their positive view of their children, recognize the complexities of their family, and accept their family without judgment*. Recognition and acceptance of the family’s cultural and child-rearing practices is considered a critical element of FCC (Case-Smith, 2010; Case-Smith et al., 2007; King et al., 2004; Myers, Stephens, & Tauber, 2010), and the testimony of these mothers underscores its importance. By demonstrating acceptance, empathy, and even love for the child and mother, therapists help to foster the kinds of relationships with mothers that allow for effective partnering. For example, Emma appreciated the positive language her child’s OT used to describe her son’s behavior:

> Hannah, in the OT clinic, described him as “spicy” which was, I’d never heard anybody describe that sort of personality before, but that’s just a *perfect* way of describing his personality without a negative connotation. Um, he, he’s just a really spicy kid.

The positive way in which Linda described Jason in his first treatment session helped Rachel see Linda as compatible with her family:

> [Our first PT session] was really positive. The session came and he was really excited to play, and engaging. And [the PT] was like, “Oh, yeah, he definitely has needs, he has, like, concerns, but he’s like a really bright kid” that, like she thought would be responsive. It was clearly a good fit for her and me and him and her. It was like a really nice match and it felt really good.

Emma feared judgment from her child’s initial evaluation team because of their living arrangements and grew teary when she expressed her appreciation for their understanding and acceptance.

> So, I remember, like, being really self-conscious, um, and, like, worried about people coming into my home and, like, you know, what level of scrutiny there would be. But, but I remember, too, like, very early on in that visit, feeling like, all of that sort of washing away, like, um, not, they just made me feel very comfortable. They made it really clear that, um, they had a purpose for being there and it wasn’t to judge. And they were also, like, very empathic and, um, understanding, and we, they knew the circumstances of what had led us, what had happened over the course of the last few months and, um, so it was, um … it was, um, it was a relief to feel that level of acceptance and from them.

This “level of acceptance” was one of the things she missed about being in the EI system:

> [O]ne of the things I miss about therapy is the sort of validation that it provided. The therapists that we saw didn’t, you know, helped me realize that my kids were really normal and that all kids were wild and that’s easy to forget, but, yeah, it was a regular source of validation…[I]f we were having a really hard drop off and then we went immediately to a session with Linda (the PT), she, … I wear my emotions on my face and

> my sleeve, and I, I don't, um, do a very good job of containing them, so Linda would know if we were having a hard morning and that kind of thing, and she would often, she could often tell exactly what was going on because she would observe the behavior of the kids or Greg, and she would … without going into too much detail, she would often share a little bit about her experience as a mother. About times when her kids, who were older, but times when they were younger, particularly difficult moments she would have that were things that were similar to what I was going through, and she would talk about how they would make her feel. And that was helpful.

Mothers are also supported in their work by therapists who *teach, coach, and model strategies for supporting their children's development*. The mothers in this study acted as students of their child's strengths and needs. They wanted to know how to best support their children's healthy growth and development and valued therapists who helped build their skill set. This underscores the need for support for the family as well as child, which is considered an important component of FCC (Case-Smith et al., 2007; Fingerhut et al., 2013; Kaiser & Hancock, 2003; King et al., 2004). Shandra expressed appreciation toward her son's OT for teaching her signs which helped her better communicate with her son:

> And the best thing with Emily is she taught me a lot of signs so that I could work on it with him at home. So, that was really nice because I didn't know anything and she taught me probably 90% of the stuff that we learned was from her. I would ask, "Well, what are all the little things that I can, you know, teach with him? Teach him?" And, so she taught us quite a bit of stuff, like how to say "eat" and "drink."
>
> for the direct education she received from her son's therapist:

Similarly, Emma was grateful to her son's PT for her parent education:

> I think she probably spent as much time interacting with and teaching me as she did interacting with him, which was really, um, I think important and time well spent, because then I was able to go home and both teach Adam what I was learning and, um, work with Greg at home, which I think was a really critical piece of it.

She also learned by observing the therapists as they modeled strategies. She said, “I tried to replicate what I was seeing and in a lot of ways I was really glad I could be at a lot of the sessions so I could see the tricks of the trade and what she was doing that I could try at home.”

These mothers also felt supported in their work when therapists *helped them deal with parenting challenges that arose secondary to home programs*. The implementation of home programs can cause disruptions in the routine which can cause new parenting challenges. In the following three instances, Emma was able to deal effectively with these challenges with help from Sheila, her son’s SLP:

> [Sheila] made the suggestion … as we got home from work and dinner, was to, um, delay dinner a little bit? And try giving Greg a bath? And getting him in his jammies before dinner? Which was … sometimes a little bit challenging, to mix up the routine in that way. But we discovered pretty quickly that it was pretty effective, too. Some nights, it wasn’t effective at all. But many nights, it gave Chris some more transition time to sort of come down a little bit, and it gave Greg, like, it relaxed him and put him in a sort of more agreeable frame of mind. Um, and then he would be more open to whatever I was suggesting he try or do differently.

Emma found that that Sheila’s experience helped in managing more than just the concrete skill development.

> I can remember so many times when I would … come into a session and … [the SLP] would both be working with him on a session, but also listening to me talk about … frustrations or difficulties or challenges … specific to his feeding, but also far beyond that. … [O]ften times, it would be, it would start related to the feeding, but turn into a challenge … with, sort of, Chris and Greg. … I think sometimes, you know, Chris got sort of jealous of the attention that Greg got because of the … the reasons why he needed therapy. And so he would sort of create extra fuss? To get attention or draw attention away from Greg. So, so we had a lot of challenges related to that, and Sheila was experienced at the concrete sort of feeding stuff, but she also had so much wisdom and experience to offer to, how do you manage those things? Because it's a lot more complex than just "bite and pull," getting him to eat on the left side. And all that stuff.

And, like any parenting challenge, the changes wrought by the addition of home programs can cause friction between the mother and her parenting partner if there are philosophical differences in their approach to parenting. Emma shared that she sought the help of the EI professionals in resolving some of these disagreements.

> [S]ometimes, and especially as our relationship progressed and I felt even more comfortable with them, Adam and I would have a disagreement about how we would approach a particular challenge that we were having. Or, and he would feel very strongly that we should approach it one way, and he would feel strongly that we should approach it a different way. And so sometimes I would look to them for, um, some, you know, professional viewpoint on a particular issue.

Emma found that Sheila's professional knowledge coupled with her familiarity with their family made her a valuable resource when negotiating these differences in parenting styles.

> So, getting input on, sort of, developmentally, what's realistic to expect of him or, how lenient or … the other way should we be in response to [behavioral challenges related to feeding]. And, um … you know, and sometimes there was a clear answer, and sometimes there was a "Well, you kind of have to know your kid." And, she, she knew our kid, so she was able to, um, weigh in on it, but never said, "You should do it this way" or "Do this." You know, in those respects. There were instructions, "Do this," but they were related, more directly related to the therapy she was doing with him. This was, sort of listening or offering suggestions or thoughts or insights, but never telling us how we should do it ….[This] helped give Adam some more information that sort of allowed him to be sort of less, authoritarian's not the word, but, um … to sort of let go of some of that. Um … and sometimes, it also helped me to be more structured in my response..

Relatedly, Emma expressed appreciation for therapists who s*hared the experiential knowledge they had gained through mothering their own children*.

> Sheila really got it. And she, and also had raised two kids of her own. So, you know, knew a lot about "How do you get two kids to cooperate?" How do you, you know, so there was a lot of just real practical parenting advice and wisdom that I got from my interactions with her that were really useful.

> [S]he didn't talk a lot about it but Hannah (the OT), one of her children, um, had torticollis as well? And so, um … one, she shared that with me very early on, I think in part because I was asking questions about, you know, "Is there a pediatric gastroenterologist around?" And, yes there was, and she knew that because her child had

> seen him. … [I]t also helped me to rest easy in her level of expertise and knowledge, knowing that she had been through it both professionally and as a mom.

It seems that for these mothers, it was important not only that the therapists could offer support for their parenting challenges, but that the support they could offer was developed through their own experiences of mothering. This helped to establish the therapists' expertise and gave their advice more authority. In addition, it created a point of connection between them that gave the mothers a greater sense of being understood and empathized with by their children's therapists.

Mothers also reported feeling supported by therapists who *responded to the needs of their children and to their needs*. The mothers in this study were appreciative of the flexible, responsive, individualized care their children received from therapists, which provides support for the inclusion of flexible and individualized services in the tenets of FCC (Fingerhut et al., 2013; King et al., 2004; Myers et al., 2010). Shandra was grateful to her son's OT for adjusting to her son's rhythms:

> Emily, as soon as she walks in, she's so happy to see him and, "Hi, Lucas!" and it's just a different energy. You know, so he kind of lights up and he's excited that she's here and ready to play and, um, she gives him choices, so it's not like, um, he's stuck with one thing. She'll say, "What would you like to do today? Would you like to do this or this?" And so then, they'll try something, and then if he was done with that sort of thing, she would say, "Wait, you've got to say 'All done!' and so, you know, kind of get him to say, "All done!" and if he wouldn't say "All done!" then she would sit with him and kind of hold his hands and say, "All done!" Just so that, you know, letting him know, all right, if you want to be done, that's fine, but this is how we're going to do it. … If he doesn't want to stay on task with one thing, she would try something else. It was a constant, you

> know, movement. Changing. Um, if he needed, if he was getting stressed out and wanted to do something different, she would recognize that and it's like, all right. Do you want to run around for a little bit, or do you want to, um, swing, or, you know, do whatever? She just kinda would get up and bounce him around and do stuff. I think that little physical break up from constantly working was nice for him.

Her positive response to her son's new SLP could at least in part be attributed to the SLP's flexibility and responsivity:

> [The SLP] gets on the floor and does what he does. For instance, if he's down on the floor playing around with cars, she gets on the floor and plays around with cars, with the similar sounds that he was making. So she just plays and does what he does, so. If he's making silly noises, then she makes the silly noises. Um … she just brings out her little toys and just watches him and does what he does and then, you know, she just has different little things. So, you know, it's just way different. It's not like a structured setting where, you know, "This is how we're going to start things. This is what goes on from there to there and on there." … [T]his was more, like, free play, but she had specific words and things that she wanted to work on and that's what they did…"

Rachel expressed a similar feeling toward her son's PT:

> [Linda] just gets into it. She gets right on the floor and laughs and, even though she's controlling the play, she really lets him feel like he's leading it, and it's like a relationship. It's like she's not just there to treat him…[S]he works with him instead of telling him what to do. So I thought that was good. Especially for his personality, that was really important. … She just gets in and starts off with something fun to capture his attention, which is really important. And I imagine, I'm sure that she's different with

> different kids. … [I]t doesn't seem like she has like a canned thing. … And there are times when he doesn't feel good or, there are hard things that we've gone through, and she'll change her tune and be responsive to that. And I think that's what's made her be extremely successful, is that she doesn't, it's not one thing that she does.

And while she sometimes felt that the therapeutic agenda was lost to the OT's overresponsivity, as noted earlier, there was at least one instance where she saw merit in the OT's approach:

> [T]oday [the OT] came in and sat down and he and Sarah were playing a game, and she just went with their game. And incorporated it, and definitely did do tasks they were working on. They did cutting and, you know, doing those skills that were important. And they did letters, because I've asked her to work on letters with him, and that was really great. And today, yeah, she just kind of threw her plan away and jumped in their game. And that was really great. … They were trying to make a parade out of ribbon. Like, do you see that ribbon on the floor? Those cut pieces? They had that ribbon, and they wanted to make a parade, so they just went ahead and they took scissors and started cutting confetti and they made a banner and like went with the whole parade idea. And it was great. It was really good. … It was incredibly successful, as you can see by the floor.

Emma appreciated that her therapists would solicit information about her son's preferences in order to tailor their interventions toward him:

> Sheila, for example, all the time was asking questions about particular kind of foods that he liked or tastes that he had or, you know, as a way to sort of get to know him better? And tailor his therapies? …[T]hat happened in the context of the OT sessions as well. Hannah and the students asking a lot of questions about who he is and what makes him tick and what he likes and what he doesn't like. And in PT as well. … Sheila almost

> every session would show up with a bag. Either something she had prepared at home in anticipation of our session or up stopped at [the local food co-op] to get. And, so what she would get was informed by that. [I]n the OT sessions … I remember mentioning he really liked playing with little animals, that kind of thing. So, the next session, they had set up like a table that had, like, you know, it was kind of his level table that had lots of toys hidden in other things for him to find. And they had specifically chosen the things that they hid based on what I had told them about his preferences.

Conversely, mothers may be troubled by therapists who seem rigid in their practices and unable to respond to the needs of the child. Shandra was frustrated by her son's previous SLP's rigidity in the way that she performed her sessions..

> I think, she's very forceful. Like, for instance, she wanted him to sit and do certain things and, it's kind of like, well, he doesn't want to do these things, so he's not going to cooperate where you're trying to force him to stay on task to do whatever. You know, he's not in preschool. He's not three or four. At this time, he's like a year and a half. You know, he's not going to sit and do anything. You know, you kind of have to keep him engaged. Maybe even give him choices. And, I don't know. I don't think she was willing to do that. She wanted him to sit and "This is what we're going to do" and she kind of wanted to set up a little bit of a routine. She wanted him to be able to start, um, a project. Be able to work at it, complete it, and then finish the task. Which is understandable, but you're not going to get that in the beginning. It might take quite a while and, you know. I don't think she was very patient with him at all. I think it was frustrating for all three of us.

In addition to appreciating therapists who respond to their children, the mothers in this study appreciated therapists who were responsive to their ideas and concerns. They valued therapists who worked on skills that were priorities for them. For Rachel, this meant shifting the focus of OT intervention to letter formation:

> Sarah [Jason's twin] kind of got, really quickly, like, overnight, she got letters, started to write them, and then Jason really wanted to catch up, so we did that. … I let Emily [the OT] know and I asked her to incorporate it, and she did, which was really good. Yeah, it's just been really successful.

Collaborative decision-making has been identified as an important component of FCC (King et al., 2004, Myers et al., 2010), and these findings suggest it is indeed valued by mothers. The mothers in this study also felt supported by therapists who listened to their ideas about how to best engage with their children. Shandra described her experience this way:

> And she would get up and sing to him and I, she was just open to suggestions. It was nice to be heard. And it was like, "Okay. This is what he likes and this is what he doesn't, and this is what works best for me." So, she would, um, listen to me. I felt like, "All right. She's paying attention. She, you know, respects my opinion and she's open to suggestions and it's working."

Conversely, mothers may feel frustrated when their ideas and concerns are not heard. For example, though Lucas's SLP verbally acknowledged Shandra's concerns, she did not adjust her therapy in response to them. This led to friction that ultimately led to a severance of the therapeutic relationship.

> Sometimes he just wouldn't want to stay with one project for a certain amount of time. He would work on, you know, she just wanted him to start something and finish it all the

> way through. And I'm like, "He's not going to sit for you for fifteen minutes. Like, any toddler is not going to sit for you for that long. You kind of have to switch it up a little bit. Give him some options. Figure out what he will do." [And] she would say, "Well, he needs to, you know, I understand your concerns." She would welcome your feedback. But it's kind of like, you say this, but it's not, like, you're not doing any of my suggestions.

These mothers also valued therapists who were responsive to their practical challenges. They appreciated flexibility with the location of therapy, the schedule for therapy, and the execution of home programs. Rachel felt supported by her PT's willingness to change the location of her son's sessions:

> [The PT] started going to his school, and he didn't like that. Like, he was like, he was too on display, I think. He got pulled out of things and he felt like he was missing stuff at school. He doesn't like that. Like, he really likes school. And didn't want to get pulled out. So we just worked it out for her to come here. … [W]e kind of came together and said, "We need to change something!" He was clearly, like, she came to school a couple of times and he resisted, and then she came to the house, and for the first time, he was like, "I don't want to play with Linda! Humph!" … And we were just like, "Whoa!" And he was just like, crossing his arms in the corner and, like, we talked it through, on the phone. And we realized he just didn't, it was too putting him on display. And, um, and so we, we switched it.

Shandra appreciated her OT's flexibility around implementing the brushing protocol:

> And so, she was like, “Well, I want you to do it 3 times a day. We’ll try it for a couple of weeks and if he’s making progress, then we’ll continue it. If you notice that it’s not working, then, you know, I’m open to a suggestion if you’d like to try something else.”

Emma also appreciated flexibility around the implementation of home treatment programs. She stated, “[The homework] was hard. Um, but at the same time, it was a pretty forgiving process. It was ‘Do the best you can.’” These examples align well with the findings of Crowe, Van Leit, & Berghmans (2000) who suggest that mothers appreciate when therapists recognize the additional burden placed on them by home therapy programs. These mothers also appreciated *extra hands and/or engaging sessions so that they could rest, observe and/or get other mothering work done.* For Emma, the extra hands came from OT students, which gave her more time to talk with their supervising OT:

> [H]aving the [OT] students, um, involved was, um, useful as well. Um … from the perspective of, like, helping keep him focused? and, like, allowing me to be in the sessions and *really* pay attention to Hannah and try to soak up as much as I could … while not having to chase him around and keep him occupied and that kind of thing was really helpful. …[I]t was just nice to have a lot of hands on deck.

For Shandra, extra hands were only available when therapists conducted co-sessions. She said, “Co-sessions work out really nice. It’s nice to have two people just kind of on him because he’s like, ‘*Whoosh!* I’m out of here!’” However, she also felt freed up by individual sessions that kept her son engaged. She described one of her son’s sessions with an SLP this way:

> [T]hey actually played really well the whole session. It was nice, because I was able to cook and kind of do both and I didn’t have to focus solely on them. … I got to sit right

> there. … I don’t mind [participating], but there are times when you want to cook dinner or get things together.

Mothers also feel supported in their work when therapists and other health professional *validate their role as mother and the mothering work that they do*. Sometimes this involved validating the mother’s role in determining the need for intervention, as was the case for Shandra:

> If he wasn’t doing something, I would get all upset and disappointed and [Joan, the visiting nurse] would say, “Don’t worry about it. He’s going to be just fine. And if you feel concern, or if you don’t, it’s up to you. You’re the mother and you know what’s best.” … She left everything up to me and didn’t make a huge deal out of stuff.

Similarly, she appreciated how the members of her child’s team underscored the primacy of her role in seeking (or not seeking) a formal evaluation for her child. She said, “[The service coordinator] is just like, ‘Well, we’ll work with whatever you want to do.’ You know. She just wanted to assure me.” Her son’s OT made the same point. “[S]he just said, ‘I think that, you know, you should go with your gut feeling. And if you feel that he should be tested, then maybe he should.’” For Shandra, this support also involved helping her to privilege her need to care for her child above others’ needs:

> [I]n the beginning, I remember, Lucas was colicky for a really long time. It was *really* hard, and I didn’t understand. [The visiting nurse] was one of the people who told me, she just said, “You just pick your baby up and you rock him and you hold him and you love him. And if people are in your house and complaining about the baby screaming and crying, then tell them to get out. This is the way it is. It’s not going to last forever. It’s hard to get through it, but,” she was just like my little mentor. It made things a lot easier.

> Um, boy, that colic bout was really hard. We had a hell of a time with that. But she's been a nice support system all the way through.

Shandra also appreciated receiving praise and encouragement for her work as a mother. She said, "[W]hen I asked [the SLP] what she wanted us to work on, she just said, 'Continue doing what you're doing.'… So it was nice." She described more specifically the value of the praise she received from her son's OT:

> Emily always gives compliments when compliments are due, which is nice because it's nice to know when you're doing a good job. … We used to go to the park all summer? And she'd always say, "Oh, you're such a good mom and he does really well with you and" you know. She could tell that I was working with him even after the session was done and it was nice to be encouraged and to be noticed for doing something. It's not like I need a big pat on the back, but you work so hard. It's just nice for someone to acknowledge something.

Rachel similarly appreciated praise from Emily:

> We didn't talk about this, but I just gave him square pieces of paper. Like, kind of Post-it size. And he was filling the space with the letter? And when I showed it to her, she was like, "That's exactly what I would have told you to do, because it's really good to define the space." It was kind of accidental. That's just the paper I have. But then, I realized she was doing that just on a piece of paper, drawing a grid system so that it was easy to see. So it was cool. It worked out really well.

When this positive view of the mother's work was coupled with a positive view of the child, it provided even stronger support. Shandra says, "[The visiting nurse] would say what a good mom I was and what a doll he was and it was just nice to have somebody on your side."

For mothers with children in EI, it was as important to receive support from people other than therapists, especially other family members. The mothers in this study reported feeling supported by *family members and others who help with mothering tasks and provide emotional support*. For example, Emma's husband attended their son's PT sessions, which eased the time and scheduling constraints therapy placed on her.

> [T]here were two feeding therapy sessions and one physical therapy sessions a week. And we, the way we had it set up was a parent would be at one feeding therapy session and not the other, and the, um, we would come to the physical therapy session… [I]t just wasn't realistic for me to try to be at everything? So it was helpful to divide the responsibilities in that way.

In addition, it seemed to increase her husband's understanding of their son and investment in the therapeutic agenda.

> Um … and I think it was also helpful for Adam to participate. I think it gave him a little more … [o]wnership, maybe, of the process. I think he learned a lot? In, um, those sessions with Linda, both about Greg's condition and the ways in which the therapists were working with him to try to overcome them, but also, observing [the PT's] interacting with Greg, I think shaped some of the ways in which he, um, interacted with Greg at home. … [B]efore [attending therapy sessions], his tendency was to sort of do things for him, or, you know, to sort of pick him up and carry him down the stairs, or to, um … put him in a stroller and take him somewhere that he could walk. … I think there was increased emphasis on, "How can I help him to do this for himself?" from his Dad rather than, moving away from sort of doing it for him.

This change in Adam's attitude meant Emma did not have to work as much at home to carry over the therapeutic goals.

Though Rachel's husband wasn't able to directly support her by participating in therapy sessions, attending meetings, or performing home programs, he contributed by staying informed and involved with his children.

> [H]e's really supportive. And now, during the school year, he's there when Emily comes in the afternoon sometimes. He's really supportive and just like a good part of the process. I manage most of the logistics of it, but, and I go to the meetings, but. I mean, he would, but he works full time and I work part-time. So I'm the one making the schedule and attending the meetings and stuff. … He's always interested in it. Like, he's definitely interested in Jason. … The times he's with them, he's just playing, and it's very positive and that's good, too. You know? And I think he would do anything. And we'll do play dough together, and I mean everything he does is good for him, so it's like, playing play dough and stuff like that. He helps him out and he's definitely interested and supports him.

Shandra's mother also didn't play an active role in therapy, but she babysat Lucas so that Shandra could have some respite from caring for Lucas. She used this time to participate with her daughter in leisure activities that are meaningful to them.

> [D]uring a pay week, Ariel and I either go to the movies or we go out to dinner, so she gets to pick one that she wants to do without Lucas. My mom will watch [Lucas] while we go do something. … It is needed. It is needed. Not having to rip and *run*. That's nice.

While the work of mothering a child with special needs and some of the related emotions can be considered difficult, therapists and others can provide effective supports for this work.

This study identified 13 specific ways in which therapists and others can support mothers in facilitating the healthy growth and development of their children. Much of what these mothers reported aligns with the tenets of FCC, which suggests that (1) many therapists are including many FCC practices in their work with the mothers of young children, and that (2) these mothers find these practices supportive. In addition, the testimony of these mothers provides more detail that can help develop these practices. For example, saying that mothers appreciate “effective communication” is vague and may not be especially helpful to therapists; however, if therapists understand the kind of insights and information that mothers value, they may be better equipped to communicate effectively with mothers.

Chapter Five: Discussion

Discussion

The results of this study support many previous investigators' findings related to the work that mothers do, the emotions related to that work, such as feeling overwhelmed and exhausted or guilty and regretful, and the constraints on that work, most notably lack of time and support. Additionally, some of the findings contribute novel information to the literature. The mothers' comments also validates that some of the tenets of FCC, especially flexible, responsive service, are implemented by therapists and valued by mothers.

Within the first theme of the work of mothers, there is ample support in the mothering literature for the idea that the primary work of mothers is to facilitate the healthy growth and development of their children (Chodorow, 1978; Dunbar & Roberts, 2006; Francis-Connolly, 2000; Ruddick, 1989). Previous research also supports the idea that mothers provide enriching experiences for their children (Lawlor, 2004), and that the execution of particular experiences underscores their meaningfulness to the mothers (Dunbar & Roberts, 2006). It also suggests mothers of children receiving therapy facilitate connections between their family and the therapists by acting as "culture brokers" (Lawlor & Mattingly, 1998). The literature also acknowledges the additional work of the mothers of children receiving therapy, such as the execution of home programs (Crowe, Van Leit, & Berghmans, 2000). The findings of this study both confirm and illuminate the work that mothers do in support of their children's development.

Regarding the emotions of mothers, previous researchers have also found that mothers feel overwhelmed and exhausted (Bateson, 1996; Case-Smith et al., 2007; Francis-Connolly, 2000; Hastings, 2002; Larson, 2010) as well as guilt and regret (Lawlor, 2004). However, the literature has not always captured the ambivalence these mothers may feel toward therapy, or the positive emotions the experience of mothering a child with a developmental delay or disability may create, or the value and meaning this work might have to their identity as mothers. This study suggests that mothers with children in EI experience pride and joy when they accomplish their work, so much so that they will create work for themselves despite the limits of their time and energy.

As for the constraints on mothers, the practical challenges of limited time and completing therapy sessions and home programs has been well documented (Bailey, 1987; Crowe, Van Leit, & Berghmans, 2000; Edwards et al., 2003; Llewellyn, 1994). However, while Brazelton (2006) has described the variable and non-linear nature of development, the literature review did not reveal anything about the difficulties this might pose for mothers who have concerns about their children's development. Relatedly, it also did not reveal anything about how the time-limited window of early intervention services and/or the belief of the first three years of life as being a "critical window" of development may create perceptions of additional time constraints for mothers, especially those of children for whom the possibility of autism spectrum disorder (ASD) has been raised. This study suggests this multiplicity of time constraints can create a feeling in these mothers that they are in a race against the clock.

The fourth theme dealt with supports that mothers received from therapists and others. There is ample support in the literature regarding the value of effective communication between parents and therapists (Case-Smith, 2010; Myers et al., 2010; Rosenbaum et al., 1998); however, the results of this study suggest what specific content mothers found helpful, such as (1) projecting the developmental trajectory of the child via therapy, (2) making connections between their actions and intentions, (3) making connections between the child's behavior, its cause, and the appropriate intervention, and (4) helping mothers to "see" the child's successes and progress. There is also evidence to support the findings that recognition and acceptance of the family's cultural and child-rearing practices (Case-Smith, 2010; Case-Smith et al., 2007; King et al., 2004; Myers, Stephens, & Tauber, 2010), the provision of flexible and individualized services (Fingerhut et al., 2013; King et al., 2004; Myers et al., 2010), and support for the parents through teaching, coaching, and modeling (Case-Smith et al., 2007; Fingerhut et al., 2013; Kaiser & Hancock, 2003; King et al., 2004) are valuable to mothers. However, the literature was less revealing about the specific practical supports from therapists that mothers find helpful, such as navigating and utilizing the EI system or freeing up mothers to observe or do other work during therapy sessions. The outcomes of this study suggest that mothers may place less importance in being involved with goal setting or the implementation of therapy sessions than the tenets of FCC would suggest. While it was important to them to have input in a less formal way, they were often content for therapists to take on the more formal goal setting. And while they wanted to have a peripheral role during treatment sessions, they wanted to be able to enfold other work into therapy sessions and/or use this time as respite from some of their more demanding work, such as managing their child's behavior. There was also little in the literature in regard to the value of therapists' providing support for additional parenting challenges or sharing their mothering expertise. These findings suggest that mothers have a special appreciation for "other mothers" who are, in fact, other mothers.

Study Limitations

There are a number of limitations to this study. First, this research project was the first study conducted by the researcher who had had limited experience in interviewing, coding, and analyzing data. Second, while the results were checked by the researcher's thesis advisors, due to time constraints, they were not checked by the participants themselves, which would have improved their trustworthiness. Finally, even with the most careful methods in place, exploring the perceptions of individuals is difficult; and capturing the complexity of the experiences these three mothers have lived proved challenging.

Chapter Six: Summary, Conclusions, and Recommendations

Summary

Mothers of children receiving EI services participate in activities that are similar to the activities of all mothers, but they also take part in activities that are specific to them, including therapy sessions and implementation of home programs. All of these activities support one primary work task: to facilitate the healthy growth and development of their children. Many of these activities include providing direct support to their children, but some of them serve their children more indirectly by encouraging therapists and others to connect with their children or connecting their family members to the child's therapeutic agenda. These activities often produce strong emotions, which in turn may impact mothers' ability to do the work. For example, mothers who are overwhelmed and exhausted by mothering and other roles may have difficulty implementing home treatment programs in the way that therapists envision them; however, they may also make time for leisure activities like baking and gardening with their children because it gives them a sense of pride and joy. Sometimes, mothers feel conflicting emotions about their work. In particular, the initial period of identifying atypical development in a child, evaluating the child for EI services, and beginning services may be a time of ambivalent feelings for a mother, as may be the transition from services.

The mothers in this study felt constrained in their ability to facilitate their child's healthy growth and development by the variable nature of development in the first three years and by a number of practical challenges, not the least of which is a lack of time for mothering and other work. Lack of time sometimes requires mothers to rush through their activities, enfold their activities, unfold their activities, or simply not complete their work. For one mother in particular, who had few adult family members with whom she might unfold her work, the lack of time for mothering activities was further compounded other time constraints. This mother also felt challenged by the time limits of the EI system and the critical window of development that these early years of development constituted for her, which gave her a sense that she had a limited amount of time in which to optimize her son's development.

For these three mothers, the difficult emotions that resulted from their work and the constraints on their work were mitigated by therapists and others who supported them. In particular, mothers felt supported by therapists who made their thought processes and actions transparent and who helped them hone their own abilities to observe, understand, and intervene. In other words, the mothers in this study appreciated therapists who were not only competent in their work, which, in its facilitation of healthy growth and development closely resembles mothering, but who helped these mothers become more competent in their mothering work. However, these mothers also felt supported when therapists empathized with their challenges, responded to the needs of their children and themselves, and accepted them without judgment. They mothers valued the emotional support they received for the intensely emotional mothering work that they did. It seems that in order to do their work effectively, mothers want to see, hear, and know, but, in order to partner effectively with others, they need to be seen, heard, and known.

Implications for Practice

The findings from this study have several implications for OTs and other health professionals working in the EI system. First, these professionals must recognize that EI provides instability as well as stability for mothers and families. While evaluating for and implementing services can provide mothers with emotional and practical support, it can also produce difficult emotions and constraints on already limited resources such as time. Professionals need to recognize the emotional and practical burdens their presence places on families and seek to minimize these to the degree possible with emotional support and flexible, responsive service.

Second, EI professionals should complete evaluations that take into account the mothers' role, values, and occupational performance and provide interventions that support these. Mothers facilitate their children's healthy growth and development in ways beyond the therapy services and home programs that therapists provide, and they are motivated to engage in leisure activities and other co-occupations with their children that they believe have value for their children but also have meaning to them in their roles as mothers. Gathering information on what occupations are valuable to the mother and incorporating therapeutic goals into those occupations may increase compliance with home programs, and ease time constraints on mothers by helping them enfold these programs into their regular activities.

Professionals should also be careful to demonstrate a positive opinion of the child and family through words and actions. The mothers in this study appreciated language used by therapists that had positive connotations about their children. Moreover, the one severance of a therapeutic relationship that was detailed in this study occurred when the mother came to believe that the therapist had a negative opinion of the child, a factor which outweighed all of her other considerations. This finding suggests two points : (1) the mothers in this study placed a lot of importance in the therapists' attitude and feelings toward their children, and (2) they were "reading" the words and actions of their therapists in order to determine how the therapists felt toward their children. In order to partner effectively with mothers, therapists may need to not only develop positive feelings toward the child but demonstrate these feelings in a way that makes them evident to the mother.

Professionals should also provide opportunities for mothers to ask questions and express concerns. The fact that mothers did not always express their concerns or act in accordance with their concerns suggests that therapists may not always be aware when a mother feels uncertain or even disapproves of a course of action. To minimize this possibility, professionals should make every effort to create a safe climate for mothers to raise questions, share thoughts, and express concerns. One way to achieve such a climate is by developing and utilizing the interpersonal skills that mothers appear to find supportive, such as empathy and acceptance. When mothers feel that the professionals they work with understand the complexities of their lives and accept them without judgment, they may be more willing to express their concerns.

Professionals should also make their observations and actions transparent to mothers by talking before and after sessions and narrating during sessions. These findings suggest that mothers want to know what the therapist is thinking and doing, not only so she can evaluate the therapist and therapy but also so she can strengthen her own skill set.

Finally, professionals should recognize the demands, emotions, and constraints on the mother and mitigate these with flexible, responsive services. This approach includes power-sharing with mothers on decisions regarding the priorities of the intervention, what the mother’s role should be during treatment sessions, and what home treatment programs are implemented. On a practical level, it means scheduling sessions at the times and places that are most convenient to mothers and being respectful of mothers’ time by being punctual. This particular tenet of FCC seems to be especially valuable to mothers and should be implemented as fully as possible.

Future Research

Future research on the lived experiences of mothers of children receiving therapy might focus on a narrower group of mothers, such as those whose children have successfully concluded

EI services or mothers of children with a particular developmental disability or challenge. In particular, practitioners would benefit to know what might be particular to mothers of children who have some features of autism spectrum disorder but who have not yet been diagnosed. Also, observations of therapy sessions involving young children, therapists, and mothers might help develop descriptions of specific strategies for interacting and communicating with mothers in ways that they find valuable, such as narrating during sessions. With these descriptions in place, research could be done on the efficacy of these strategies for child and family outcomes.

Appendix A: Recruitment Letter

Hello,

My name is Angelina Mirabella. I am currently conducting a study about the experiences of mothers whose children are receiving occupational therapy (OT) through early intervention (EI) in Tompkins County. I have asked local OTs to give this letter to mothers who are eligible and may be able and willing to participate. By interviewing mothers, I hope to learn more about what it is like to care for a young child who is receiving OT, what OT services are like for these mothers, and how OT services affect the way that they care for their child. Your child's OT has given this letter to you because you meet all of the criteria: you are 18 years or older and you are the primary caregiver of a child who has been receiving OT through EI for at least two months. Your OT has not identified you to me. I will not know anything about you or your child unless you contact me and tell me you would like to participate.

If you decide to participate—and I hope that you do!—I will interview you three times, with one month breaks between the interviews. Each interview will last about 60-90 minutes. All of our interviews will occur at days, times, and places that work best for you and where confidentiality can be maintained. During these meetings, I will ask you questions about your experiences as a mother and with your child's OT. By talking to you three separate times over a period of two months, I hope to get a full picture of what these experiences have been like for you. I will use an audio recorder to record our conversation.

To help us get started with our first interview, I would like for you to give me five images that tell me what it is like to be the mother to your child. These images can be photographs of you and/or your child, stock images of families available online, or images that symbolize something important to you, such as an image of a bear to symbolize a mother's protectiveness of her children. These will be used in my study and, with your permission, may also be used in papers and presentations, so they should be images that you are willing for me to scan or that you are willing to send me by email during or immediately after our first interview. Providing me with these images is completely voluntary. If you do not wish to do this, you can still participate in the study.

There is very little risk to participating in this study. Your participation will be kept confidential and will not affect your OT care. However, mothering children with special needs and working with other professionals who work with these children can be emotional experiences for many women. It is possible that talking about these experiences in depth will bring up emotions that are difficult for you.

When I have finished the study, I will share my findings with you to get your feedback. Anyone who participates in the study will receive a $50 gift certificate to Wegman's. If you are interested in participating, or if I can answer any questions, you may contact me by email at amirabella@ithaca.edu or call me at 607.339.6038.

Thank you for considering. I hope to hear from you!

Sincerely,

Angelina Mirabella, OTS

Appendix B: Informed Consent Form

Purpose of the Study

I am conducting a study about the experiences of mothers whose children are receiving OT through early intervention (EI) in Tompkins County. I am interested in learning more about what it is like to be the mother of a young child who is receiving OT, how OT affects the way mothers care for their child(ren), and how mothers and occupational therapists (OTs) work together. I also want to know if OTs provide mothers with direct support for some of their tasks, such as feeding their children, helping their children get to sleep, and teaching their children how to use the toilet.

Benefits of the Study

By participating, you will provide information that may help OTs and other professionals that work with young children partner more effectively with mothers. There is no guarantee that participating in the study will benefit you directly. However, you may gain insight into your partnership with your child's OT that may help you strengthen this relationship and advocate for yourself and your child(ren). Anyone who participates in the study will receive a $50 gift certificate to Wegman's.

What You Will Be Asked to Do

You will be interviewed three times. These interviews will last about 60-90 minutes each and will be spaced about one month apart. These interviews will be conversational and will include questions about your experiences as a mother and with your child's OT. By talking to you three separate times over a period of two months, I hope to get a full picture of what these experiences have been like for you. All interviews will be audio recorded and transcribed. All of our interviews will occur at days, times, and places that work best for you and where confidentiality can be maintained. When I have finished the study, I will share my findings with you to get your feedback.

To help us get started with our first interview, I would like for you to give me five images that tell me what it is like to be the mother to your child. These images can be photographs of you and/or your child, stock images of families available online, or images that symbolize something important to you, such as an image of a bear to symbolize a mother's protectiveness of her children. These will be used in my study and, with your permission, may also be used in papers and presentations, so they should be images that you are willing for me to scan or that you are willing to send me by email during or immediately after our first interview. Providing me with these images is completely voluntary. If you do not wish to do this, you can still participate in the study.

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Please Initial Here

Risks

There is very little risk to participating in this study. Your participation will be kept confidential and will not affect your OT care. However, mothering children with special needs and working with other professionals who work with these children can be emotional experiences for many women. It is possible that talking about these experiences in depth will bring up emotions that are difficult for you.

Compensation

If you suffer an injury that requires any treatment or hospitalization as a direct result of this study, the cost for such care will be charged to you. If you have insurance, you may bill your insurance company. You will be responsible to pay all costs not covered by your insurance. Ithaca College will not pay for any care, lost wages, or provide any other financial compensation.

If You Would Like More Information about the Study

Please contact the principal researcher, Angelina Mirabella, to get more information about this study or to get a copy of its results. Angelina can be reached at 607.339.6038 or amirabella@ithaca.edu. You can also get more information from the researcher's thesis advisor, Kim Wilkinson. Dr. Wilkinson is a member of the faculty in the Ithaca College Department of Occupational Therapy. She can be reached at 607.274.1973 or kwilkinson@ithaca.edu.

Withdrawal from the Study

You may withdraw from the study at any time without penalty. If you withdraw, you will still receive the gift certificate. You may also decline to provide images and/or answer questions you do not wish to answer.

How the Data Will Be Maintained in Confidence

Every effort will be made to protect your confidentiality and privacy. Pseudonyms will be used to identify you in all written products, including transcripts, thesis, research articles, PowerPoint presentations, and poster presentations. When not in use, audio recordings will be stored in a locked file cabinet in the primary researcher's home, as will Informed Consent forms. All electronic data will be stored on a password-protected computer. If you do not want to provide photographs of yourself or your family, you may use stock photos or symbolic images. You can also decline to provide images.

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Please Initial Here

I have read the above and I understand its contents. I agree to participate in this study. I acknowledge that I am 18 years of age or older and I am the primary caregiver of a child who is receiving occupational therapy through the early intervention system in Tompkins County.

Name (PRINT): ________________________________

Signature: ____________________________________ Date: _________________________

I agree to be audio-taped.

Name (PRINT): ________________________________

Signature: ____________________________________ Date: _________________________

I consent to the use of the five images I provide to the researcher for this study.

Name (PRINT): ________________________________

Signature: ____________________________________ Date: _________________________

I consent to the publication of the five images I provide to the researcher in any research article, PowerPoint presentation, and/or poster presentation that results from this study.

Name (PRINT): ________________________________

Signature: ____________________________________ Date: _________________________

Appendix C: Interview Questions

According to Creswell (1998), the interview questions in a phenomenological study should "explore the meaning of [the] experience for individuals and [ask] individuals to describe their everyday lived experiences" (p. 54). In keeping with this approach, these interviews will be conversational and discursive. Rather than attempt to standardize interviews with each participant, the researcher will allow the conversation to move organically while staying within the parameters of the objectives of the study (Mischler, 1986). A list of sample questions that may be used during interviews is below. Using an iterative process common to qualitative data collection, more questions for the interviews may be generated based upon the answers given during the previous interview and any emerging themes.

- Tell me about the pictures you brought with you today. I'd like to know why you chose these pictures and what they mean to you.
- Tell me about your family.
- Tell me about (child's name).
- Mothers have a lot of work to do in order to care for their children, but that work is a little different for every mother. Describe for me your work as a mother. What kinds of things do you do to care for your child?
- Can you give an example of a time when you felt that something you were doing as a mother was very meaningful?
- Can you give an example of a time when you had difficulty doing something for your child or family?
- What goals do you want your child to accomplish in the near future? Is your child's occupational therapist supporting these goals? Can you give me an example of how?

- Are there any other goals that your therapist is working on with your child? How did these goals get established? What are your thoughts about these goals?
- Tell me about an occupational therapy session with your child that stands out in your mind.
- Tell me about your child's most recent occupational therapy session. What happened during the session? What did you do during the session?
- Can you give me a specific example of something you have done outside of therapy time that was recommended by the occupational therapist?
- Can you tell me about a time you disagreed with your child's occupational therapist about something? What happened?
- Can you give me an example of a time that your occupational therapist gave you direct support for your tasks as a mother? Are there other things would you like your child's occupational therapist to do to help you with these tasks?

References

American Occupational Therapy Association (AOTA) (2008). Occupational therapy practice framework: Domain & process (2nd ed.). *American Journal of Occupational Therapy, 62*(6), 625-688.

Arendell, T. (2000). Conceiving and investigating motherhood: The decade's scholarship. *Journal of Marriage and the Family, 62*, 1192-1207.

Bailey, D. (1987). Collaborative goal-setting with families: Resolving differences in values and priorities for services. *Topics in Early Childhood Special Education, 7*(2), 59-71.

Banks, M. (2007). Using visual data in qualitative research. Thousand Oaks, CA: SAGE Publications.

Bateson, M.C. (1996). Enfolded occupation and the concept of occupation. In R. Zemke & F. Clark (Eds.). *Occupational Science: The evolving discipline* (pp. 5-12). Philadelphia: F.A. Davis.

Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry, 7*, 345-374.

Brazelton, T.B. & Sparrow, J.D. (2006). *Touchpoints birth to three: Your child's emotional and behavioral development* (2nd ed.). Cambridge, MA: De Capo Press.

Brown, G. (2004). Family-centered care, mother's occupations of caregiving and home therapy programs. In Esdaile, S.A. and Olson, J.A. (Eds.). *Mothering occupations: Challenge, agency, and participation* (pp. 346-371). Philadelphia, PA: F.A. Davis.

Brown, G. (2007). *The parent's experience of learning about their child*. Paper presented at Australian Occupational Therapy Conference, 1997, Perth, Western Australia.

Brown, S.M., Humphry, R., & Taylor, E. (1997). A model of the nature of family-therapist relationships: Implications for education. *American Journal of Occupational Therapy, 51*, 597-603.

Case-Smith, J. (2010). An overview of occupational therapy for children. In J. Case-Smith & J. O'Brien (Eds.), *Occupational therapy for children* (6th ed.) (pp. 1-21), Maryland Heights, MO: Mosby Elsevier.

Case-Smith, J., Sainato, D., McQuaid, J., Deubler, D., Gottesman, M., & Taber, M. (2007). IMPACTS project: Preparing therapists to provide best practice early intervention services. *Physical & Occupational Therapy in Pediatrics, 27*(3), 73-90. doi: 10.1300/J006v27n03_0673

Chase, S. (2011). Narrative inquiry: Still a field in the making. In Denzin, N.K., & Lincoln, Y.S. (Eds.), *The SAGE handbook of qualitative research* (pp. 421-434). Thousand Oaks, CA: SAGE Publications.

Chodorow, N. (1978). *The reproduction of mothering.* CA: University of California Press.

Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.

Crowe, T.K., Van Leit, B., & Berghmans, K.K. (2000). Mothers' perceptions of child care assistance: The impact of a child's disability. *American Journal of Occupational Therapy, 54*(1), 52-58.

Dunbar, S.B., & Roberts, E. (2006). An exploration of mothers' perceptions regarding mothering occupations and experiences. *Occupational Therapy in Health Care, 20*(2), 51-73.

Edwards, M.A., Millard, P., Praskac, L.A., & Wisniewski, P.A. (2003). Occupational therapy and early intervention: A family-centred approach. *Occupational Therapy*

International, 10(4), 239-252.

Egilson, S.T. (2011). Parent perspective of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences, 25*, 277-284.

Fingerhut, P.E., Piro, J., Sutton, A., Campbell, R., Lewis, C., Lawji, D., & Martinez, N. (2013). "Family-centered principles implemented in home-based, clinic-based, and school-based pediatric settings." *The American Journal of Occupational Therapy, 67*(2), 228-235.

Francis-Connolly, E. (2000). Toward an understanding of motherhood: A comparison of two motherhood stages. *American Journal of Occupational Therapy, 54*(3), 281-289.

Haltiwanger, E.P. (2012, April). Experiences of Mexican American elders with diabetes. *Occupational Therapy in Health Care, 26*(2/3): 150-62.

Hastings, R.P. (2002). Parental stress and behavior problems of children with developmental disability. *Journal of Intellectual & Developmental Disability, 27*(3), 149-160.

Helitzer, D.L., Cunningham-Sabo, L.D., Vanleit, B., & Crowe, T.K. (2002). Perceived changes in self-image and coping strategies of mothers of children with disabilities. *The Occupational Therapy of Journal of Research, 22*(1), 25-33.

Hinojosa, J. & Anderson, J. (1991). Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *American Journal of Occupational Therapy, 43*(3), 273-279.

Kaiser, A.P., & Hancock, T.B. (2003). Teaching parents new skills to support their young children's development. *Infants and Young Children, 16*(1), 9-21.

Kellegrew, D.H. (2000). Constructing daily routines: A qualitative examination of mothers with young children with disabilities. *American Journal of Occupational Therapy, 54*(3), 252-259.

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology, 11*(1), 78-86.

Krieger, M.H. (1996). A phenomenology of motherhood. In R. Zemke & F. Clark (Eds.), *Occupational science: The evolving discipline*. Philadephia, PA: F.A. Davis Company, 243-246.

Larson, B. (2010). Ever vigilant: Maternal support of participation in daily life for boys with autism. *Physical & Occupational Therapy in Pediatrics, 30*(1), 16-27.

Larson, E.A. (2000). Mothering: Letting go of the past ideal and valuing the real. *American Journal of Occupational Therapy, 54*(3), 249-251.

Lawlor, M. & Mattingly, C. (1998). The complexities embedded in family-centered care. *American Journal of Occupational Therapy, 52*(4), 259-267.

Lawlor, M. (2004). Mothering work: Negotiating health care, illness and disability, and development. In S.A. Esdaile & J.A. Olson (Eds.). *Mothering occupations: Challenge, agency, and participation* (306-323). Philadelphia, PA: F.A. Davis.

Llewellyn, G. (1994). Parenting: A neglected human occupation. Parents' voices not yet heard. *Australian Occupational Therapy Journal, 41*, 173-176.

Mattingly,C. (2010). *The paradox of hope: Journeys through a clinical borderland.* Berkeley, CA: UC Press.

Maxwell, J.A. (2013). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: SAGE Publications.

Mischler, E.G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.

Myers, C.T., Stephens, L., & Tauber, S. (2010). Early intervention. In J. Case-Smith & J. O'Brien (Eds.), *Occupational therapy for children* (6th ed.) (pp. 681-711), Maryland Heights, MO: Mosby Elsevier.

Oleson, V. (2011). Feminist qualitative research in the millennium's first decade: Developments, challenges, prospects. In N.K. Denzin & Y.S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 129-146). Thousand Oaks, CA: SAGE Publications.

Polkinghorne, D.E. (2007). Validity issues in narrative research. *Qualitative Inquiry, 13*, 471-486.

Ridgley, R. & Hallam, R. (2006). Examining the IFSPs of rural, low-income families: Are they reflective of family concerns? *Journal of Research in Childhood Education, 21*(2), 149-162.

Rosenbaurn, P., King, S., Law, M., King, G., Evans, J. (1998). Family-centered service: A conceptual framework and research review. *Physical & Occupational Therapy, 18*(1), pp. 1-20.

Ruddick, S. (1989). *Maternal thinking: Towards a politics of peace.* Boston, MA: Beacon Press.

Ruddick, S. (1994). Thinking mothers/conceiving birth. In D. Bassin, M. Honey, & M.M. Kaplan (Eds.), *Representations of motherhood* (pp. 29-45), New Haven, CT: Yale UP.

Shonkoff, J.P. & Phillips, D.A. (Eds.) (2000). *From neurons to neighborhoods: The science* *of early childhood development.* Washington, DC: National Academies Press.

Sutton, D.J., Hocking, C.S., & Smythe, L.A. (2012). A phenomenological study of occupational engagement in recovery from mental illness. *The Canadian Journal of Occupational Therapy, 79*(3), 142-50.

Winston, K.A., Dunbar, S.B., Reed, C.N., & Francis-Connolly, E. (2010). Mothering occupations when parenting children with feeding concerns: A mixed methods study. *Canadian Journal of Occupational Therapy, 77*(3), 181-189. Doi: 10.2182/cjot.2010.77.3.8