

FAMILY OCCUPATION: A STUDY IN NEGOTIATED PARTICIPATION

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ABSTRACT

Adrienne Firth Miao: Family Occupation: A Study in Negotiated Participation
(Under the direction of Ruth Humphry)

There is much to be learned about health, wellness, and inclusion from the everyday things that families do. Families with children with disabilities, in particular, are adept at negotiating myriad situational factors as they construct activities together. This study began by examining family research methods and exploring how qualitative designs fit into daily family life. Semi-structured interviews with 13 parent advisors yielded their key motivations for participation in research, reservations about naturalistic designs, and recommendations for improved feasibility. These findings were applied during a subsequent ethnographic phase of the project. This second phase of study employed participant observations with 7 families with one or more 6-11 year old (middle childhood age) children with a variety of disability diagnoses. The researcher accompanied families in their homes and communities to learn about the enactment of family time occupations and shared engagement. Narrative and thematic analyses revealed that families constructed moments together with awareness of the multi-bodied, multi-abled, and multi-preferenced natures of their collective units. Family occupations were inherently manifold, evolving, and negotiated. Several inclusion practices used by families to promote member participation in joint activities are also described. Disability was one of many family characteristics that impacted these activities, supporting the use of relational approaches to family-centered care. Family occupation is a helpful window for exploring daily life, social relationships, and coordinated action among groups.

For my many families.

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“Humankind has not woven the web of life. We are but one thread within it. Whatever we do to the web, we do to ourselves. All things are bound together. All things connect.”

--Chief Si’ahl (Seattle)-Leader of the Suquamish and Duwamish Native American Tribes

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
PAR	Participatory Action Research
PTSD	Posttraumatic Stress Disorder
WHO	World Health Organization
TV	Television
US	United States
UN	United Nations

CHAPTER 1. INTRODUCTION

I am watching a magic show. It is of the homegrown variety, to be sure. A nine-year-old girl stands before assembled family and waves a wand through the air, intoning “Abracadabra” as she makes marbles disappear under colorful plastic cups. She takes her job seriously, a solemn expression on her face and frequent earnest eye contact with her audience. Her father, the designated assistant, perches carefully next to her on a precariously small stool. He watches and listens, passing her magically self-repairing tissues and unknotting ropes when requested. I am part of the audience. We are also taking our role seriously, nodding, and clapping, and audibly expressing our amazement. There is a sassy critic in our ranks as well. A bright-eyed six-year-old girl is sitting in her grandmother’s lap and letting loose loud belly laughs. Her laughter is contagious, tipping us over into collective peals of delight.

To me this brief glimpse captures a taste of the joy, humor, connection, and spontaneity of family life. It is an ordinary scene, a family together at the end of the day. It is an extraordinary scene too, a privileged glimpse of an intimate, unguarded moment.

Studying Family Life

Social scientists study how life is, including investigating how people live in relationships (Daly, 2007). Family relationships represent different things to different people, but the family is generally viewed as a fundamental human social unit, a key identity group, and developmental context (Daly, 2003; Fiese, 2006; Fitzgerald, 2004). Scholars use various definitions to delimit family for the purposes of study design, and a recurring critique is the use of overly narrow, value-laden, or culturally mismatched declarations of what officially counts as

family. For the purposes of this study I used self-described, situationally-specific family groups. Sometimes these families manifested as a parent and child, sometimes as a household, and often as a portion of a household combined with additional friends and relatives.

In order to access family life I chose to look through the lens of daily activities. Family occupations, in short, refer to the everyday things that families do together. These occupations include actions undertaken to get through the day, as well as the sense of connectedness fostered in the process. As Humphry and Corcoran (2004) have suggested, “Perhaps some of the power of occupations in helping families function is not *what* is being done, but through the shared activities in which family members are socially occupied with a loved one in a special way” (p. 488). Exploring daily activities enjoyed by the family together, then, serve as a useful lens for understanding human lives as lived in relationship.

This study examined family occupations as manifold; engagement is shared, but not experienced in the same way by all persons. In order to enter into this complexity the study utilized ethnographic methods, with a focus on the coordination processes revealed through observation. As Lawlor and Mattingly (2014) described,

Family life is dynamic, often compelling, complicated, and multifaceted. Although the term *family life* may imply a unitary construct, understanding family life involves the recognition of its heterogeneity and diversity. Family life is situated in broader sociocultural contexts as well as intergenerational and historical contexts. Family life is constituted through an array of cultural and social practices and lived through engagements in occupations (p. 151).

Family life is also distinguished by the nature of its interdependency, a facet too often overlooked by scholars. Given increasing attention to the need to incorporate family strengths into health and wellness interventions (e.g., DeFrain & Asay, 2007), more research is needed to develop knowledge of everyday family life, including how families “do” things together. Family

perspective is also needed in the research design process to ensure research questions are relevant, and research methods are acceptable.

Overview of the Research

This study aimed to expand the descriptive knowledge about family occupations, with attention to both the methods for studying family life as well as how family groups navigate daily life activities together in relationship. The complexity and intimacy of family relationships help make visible the ongoing negotiation processes involved in enacting successful moments. The research was intentionally undertaken in two phases. The first phase of investigation solicited parent advisors to offer commentary about family research, using personal experiences of family life to reflect on past research participation, as well as offer suggestions for naturalistic research designs (Manuscript One).

The second phase of research explored the coordination of family occupations. Despite the unique array of challenges and characteristics a given family has, every family actively figures out ways to get through the day and make things work. Episodes of family occupation were described and examined to better understand the negotiation processes involved in doing together (Manuscript Two). Inclusion practices to promote the participation of all family members were examined in order to better understand how families successfully enact these occupations (Manuscript Three).

Format

This introduction is the first chapter in my dissertation study of family life. In the second chapter I review existing literature about family occupation, drawing heavily upon occupational science, occupational therapy, and family studies scholarship. I also examine the methodological challenges of conducting research with families, accentuating work related to my interest in qualitative approaches within naturalistic settings. I conclude by explaining current knowledge

gaps and presenting my three primary research aims. In the third chapter I explain my research methods, including conceptual frameworks, study design, and data collection and analysis. In the fourth chapter I introduce the ethnography participants, briefly describing the seven families as well as positioning myself as a researcher. Chapters five through seven are written as three distinct manuscripts highlighting my exploration and findings related to gatekeeper perspectives on family research, coordinated processes (negotiation) of family occupations, and inclusion strategies. In the eighth chapter I offer a reflexive account of the experience of undertaking this dissertation project and lessons learned along the way. Finally, in the ninth chapter I offer integrated implications from the study and suggest directions for future research.

CHAPTER 2. REVIEW OF LITERATURE

Overview

The study of family occupation requires the consideration of several key concepts. There is the immediate question of how to conceptualize family and select participants. Similarly, occupation and family occupation have related but differing definitions that impact the unit of analysis. Much of the existing family occupation literature has a particular flavor in terms of focus, population of study, view of disability, and methodological approach, resulting in gaps in the overall knowledge base. Research into family life also presents unique challenges as well as opportunities for innovation. The aims of this study are presented at the conclusion of the review of the current state of the literature.

Family

“[Families] are a cultural universal and a cultural icon” (Fitzgerald, 2004, p. 489), however, the term “family” is not without controversy. Debate persists about whether the term might better be subsumed or replaced by alternatives such as “intimacy,” “personal life,” or “kinship” (Edwards, McCarthy, & Gillies, 2012). Although “family” may be a flawed term it is widespread in the general lexicon, used daily by a vast variety of people, and therefore quite “real” (McCarthy, 2012). The amorphous concept of family has the potential for endlessly fluid boundaries. Questions of how and by whom family is defined continue to challenge theorists, methodologists, and scholars.

There has also been an ongoing scholarly discussion regarding whether “family” (or “families,” which has been suggested as more inclusive of diverse structures) is best employed as

noun, adjective, or verb (DeVault, 1991; Edwards, McCarthy, & Gillies, 2012; McCarthy, 2012; Morgan, 1996). Contemporary family scholars are increasingly moving towards examining “family doing,” “family being,” or “family display,” as more productive than examining families as “things” (e.g., DeGrace, 2003; Finch, 2007). These expanded foci allow for diverse self-definitions of “family” and “family-like” groups. Finch (2007) noted “displaying” family, in recognition of the fundamentally social nature of family practices: “The meaning of one’s actions has to be conveyed to and understood by relative others” (p. 66).

When it comes to studying families one of the most significant gaps has been an overreliance on sampling from a subset of family types, namely heterosexual married couples with children (Finch, 2007). There is compelling evidence that the family structural norms typically sampled within family studies are outdated. Data from the 2013 American Community Survey indicated that only about 29% of households were comprised of a married couple with children (U.S. Census Bureau, 2013). Globally changing patterns of household composition have been documented; within the 35 member countries of the Organization for Economic Cooperation and Development there have been declining household sizes, decreasing marriage rates, growing divorce rates, and increasing childlessness (OECD, 2011). Likewise, in the European Union changes have been noted “in relation to patterns of family formation, with traditional boundaries becoming increasingly blurred and different types of family nuclei becoming more common” (Eurostat, 2015, p. 1). Researchers must produce scholarship relevant to modern families and able to adapt to changing family types and compositions.

There are obvious limits to definitions that reduce families to social and economic units comprised of some minimal configuration of parent(s) and child(ren) (Fitzgerald, 2004). All recent empirical work confirms the diversity and fluidity of family relationships, which naturally

change across time (Finch, 2007). Family configurations evolve, change, and reconfigure over time, in relation to both specific contexts and major life events. “Although for most societies some ideal family configuration has been identified (and these are often the descriptions we find in texts of families), there is, in any society, a great deal of diversity” (Fitzgerald, 2004, p. 491). For example, Finch also argued that “family” may include connectedness beyond households.

Scholars have taken initial steps towards acknowledging this diversity when focusing on the family as the unit of analysis. In their exploration of occupatio-temporality Larson and Zemke (2003) alluded to the multiple configurations of “family groupings”: “Family as used here constitutes many different configurations of members from heterosexual or homosexual couples, to single-parented families or two-parented families” (p. 85). The addition of the word “groupings” served to expand from traditional concepts of family as a concrete arrangement of relationships, although their definition retained a focus on parents and children. Similarly, in her study of family zoo outings, DeVault (2000) observed various “‘family-like’ groups of adults and children together” (p. 490) rather than attempting to determine any specific kinship structures. As she noted,

I have not adopted the standard methodological procedure in family studies, whereby the analyst decides, however thoughtfully, on some definition for a family—based perhaps on biological or legal connections, perhaps on members’ self-definitions—and includes only those groups that fit the selected model: such procedures seem to insure that some of the diversity of family experience will be lost (DeVault, 2000, p. 490).

In place of a priori definitions DeVault focused on the active constitution of family via socially organized practices. She felt that ambiguity was more authentic to the experience of family relationships, and rejected the precision that researchers impose for the purposes of study. These innovative attempts serve as signposts for family scholars. More research is needed that allows

for ongoing self-definition of the relevant family group out of respect for the dynamic nature of family.

Occupation

The International Society of Occupational Science defines occupations as “the various everyday activities people do *as individuals, in families, and with communities* [emphasis added] to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to, and are expected to do” (Asaba, Blanche, Jonsson, Laliberte Rudman, & Wicks, 2007, p. 1). The concept of “occupation” is an evolving one that continues to be discussed and adapted by scholars, and definitions of occupation continue to be disproportionately dominated by Western philosophy and theory (Hammell, 2009; Ramugondo & Kronenburg, 2015). Within this body of occupational therapy and science literature, several repeated themes have emerged.

Occupation as largely ordinary and familiar. Occupation has generally been written about as “the ordinary and familiar things that people do everyday” (Clark et al., 1991, p. 300). Everydayness and mundaneness are considered key domains for investigation, although special events and occasions have also been counted as occupation (e.g., Shordike & Pierce, 2005). Ramugondo and Kronenburg (2015) foregrounded that occupation is both ordinary and extraordinary, taking place within the context of the everyday. This emphasis on daily life has allowed for the extension of occupational science scholarship examining habits and routines (see Clark, 2000). It is worth noting the emphasis on familiarity, referring to close or family-like acquaintance, which further highlights the need for an expanded knowledge base about how occupations are enacted in family-like ways.

Occupation as chunk of activity. Much has been written about occupations representing fundamental units of activity, often referred to as “chunks” of larger action (Clark et al., 1991; Yerxa et al., 1990; Yerxa, 1993; Zemke & Clark, 1996). The idea of occupation as a unit of

action has presented possibilities for investigating occupation in and of itself (Dickie, 2010; Hocking, 2009). However, the idea of activity chunks also carries the implication of occupation as neatly bounded. While Pierce (2001) wrote that “An occupation has a shape, a pace, a beginning and an ending” (p. 139), the continuity of past, present, and future as part of the transactional nature of occupation has also been described by several scholars (Cutchin, 2004; Cutchin & Dickie, 2013; Dickie, Cutchin, & Humphry, 2006; Wright-St. Clair & Smythe, 2013). More work is needed to investigate how occupations meander, overlap, and morph into one another, especially within the context of daily life. This imperative is amplified when considering the occupations of groups rather than individuals.

Occupation as self-directed, subjective, and individually interpreted. Formative works within the discipline have also conceived of occupation as self-initiated, goal-directed, and socially-sanctioned (Yerxa et al., 1990; Yerxa, 1993). Pierce (2001) theorized, “An occupation is a specific individual’s personally constructed, nonrepeatable experience” (p. 139). However, Hammell (2009) critiqued the ableist assumptions underlying the notion of humans as individual agents. Various scholars have challenged the prioritization of the individual within occupational science; Dickie, Cutchin, and Humphry’s (2006) transactional perspective opened new avenues for examination of the integration and co-constitution of individual and context. In addition to the questionability of agentic humans crafting occupation in personalized manners, the issue of how multiple persons enact occupation (in co-constitution with other contextual features) warrants further exploration.

Family Occupation

The existing definitions of family occupation have clear ties to the foundational occupational science literature and specify additional relational characteristics. Segal’s (1999) seminal work suggested family occupations to be carefully constructed, “culturally meaningful

chunks of activities” (p. 53), occurring when the entire family is engaged together, and often comprising varied aims and happenings for different family members. While her description of the whole family acting together has subsequently been challenged (e.g., Bonsall, 2013), most definitions suggest some degree of distribution as “daily activities and special events are shared among family members” (Jaffe, Humphry, & Case-Smith, 2010, p.109).

Bonsall (2014) theorized family occupations to be “the occupations that build and define families” (p. 305) that are constructed via doing together, exhibit variability of participation, and occur over time with input from family members. Similarly DeGrace, Hoffman, Hutson, and Kolobe (2014) noted that families discussed both doing family things and existing as family, and envisioned these occupations as “the family's capacity to successfully manage everyday tasks and generate opportunities for preservation of family everydayness” (p. 316). By accepting more variation in participants and flexibility in togetherness, occupational scientists will be able to have a larger pool of family occupations from which to draw for study, as well as allow less onerous paths for families to take part in observational research.

Family occupation as “time.” Related to the notion of family occupation is the concept of family time. Quality family time has been conceived of as times of togetherness, emotional closeness, and affection (Evans & Rodger, 2008). However, Daly (2001) critiqued the construct of family time as seemingly universal and desirable, but in actuality complex and problematic. Daly’s qualitative unpacking of the concept of “family time” using interviews with parents and observations of children yielded a striking gap between ideological expectation and lived experience. Parents talked about family time in terms of togetherness, fun, and the creation of memories, however experienced time as scarcity. The divergence between expectation and experience generated chronic guilt for parents that described concern and regret about constraints

and competing demands. Daly (1996) suggested that perceptions of “time famine” are attributed to social changes, particularly changes in family structure, as well as changes to work hours, the scheduling of child activities, and changes in family ideologies. Additionally, the tension between quantity of time and quality of time appears to be high, with families attempting to trade off credit on each variety. Daly likened the challenge to Gillis’ (1996) notion of the tension between the family you live with and the one you live by, suggesting that cultural ideals are always influencing the interpretations of one’s own experiences.

In their study of quality time among working families, Kremer-Sadlik and Paugh (2007) explored the presentation of quality time in both academic and popular literature. Their analysis of web-based discourses revealed the discrimination between “quantity time” as a desirable norm of full-time caregiving, and “quality time” as chunks of meaningful togetherness focused on child preferences and special activities, used as a compensatory strategy by working parents to improve parent-child relationships. Kremer-Sadlik and Paugh proposed shifting the focus from blocks of time to moments of connectedness within everyday life in order to better understanding family well-being. Larson and Zemke (2003) also noted that occupations themselves contribute to the experience of time and time use. Given the perceived busyness of family life, studying occupation as moments rather than large blocks of dedicated family time offers a more practical and less burdensome option for engaging families in research.

A Focus on Barriers to Family Occupation

Many scholars have raised concerns about barriers to participation in family occupations associated with the presence of childhood disability (e.g., Bagatell, 2016; Bagby, Dickie, & Baranek, 2012; DeGrace, 2004; Evans & Rodger, 2008; Law, 2002; Larson, 2006; Marquenie, Rodger, Mangohig, & Cronin, 2011; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Most of the family occupations and disability literature has focused on autism spectrum disorders

(ASDs). DeGrace (2004) found in her study of families with young children with severe ASDs that parents reported fleeting and infrequent moments of feeling like a family. Instead these families reported being overrun by the need to manage the condition and the need to keep children “occupied and pacified.” They reported that their entire family lives revolved around ASD; DeGrace suggested that the family unit’s identity had become “autism.” Similarly, McCann, Bull, and Winzenberg’s (2012) examination of time use of parents of children with complex conditions found that parents overall reported increased burden, which did not decrease as children grew older. Parents spent significant amounts of time engaged in supervision and vigilance duties, as well as care duties extending beyond the “typical” parent role. The increase in burden led to stress as demands exceeded time available during the day. Marquenie et al. (2012) noted that both unpredictable responses and rigid routines of children with ASDs negatively impacted family mealtime and bedtime. Bagby and colleagues (2012) found that parents considered the sensory context of potential family occupations, and made decisions about social participation taking account of negative past experiences as well as the anticipated comfort and potential benefit (or learning opportunity) of the current context. ASD was perceived to impact the degree to which the meaning of the practices was shared. Schaaf et al. (2011) have also noted reduced participation of families outside the home and in unfamiliar spaces including community events, outings, and travel.

Limitations to this literature include a focus on the disruption of family occupations. There is emerging recognition that disability does not have inherently negative or positive effects on family practices, but rather may represent a press for change or adaptation. Koome, Hocking, and Sutton’s (2012) study of family routines in the context of adolescent mental illness found that routines served as health status indicators, with disruption of routines an early warning of

increased stress or decreased coping. Koome et al. also noted that the establishment of new routines (in the face of illness) was perceived as meaningful. Crespo et al. (2013) similarly found that family practices are impacted by chronic conditions, but also function as strategic resources for families offering opportunities to express support, hold onto routines in order to re-establish a sense of normalcy, and as reassurance that the disease has not taken over family life.

These more neutral views of disability are also found in studies that have focused on child perspective. In their study of sibling experience (which used multiple methods adapted for various ages), Connors and Stalker (2007) found that siblings did not view the child with disability as intrinsically different from themselves. These siblings presented all of their family members in ordinary ways, often mentioning mundane family routines. This finding aligns with some of the (limited) work that has been done examining the accounts of children with disabilities themselves. Both Stalker and Connors (2004) and Phelan and Kinsella (2014) found that children with disabilities largely avoided talking about disability and instead presented themselves in terms of similarities or sameness to others. More research is needed that adopts neutral or strengths-based approaches to the presence of disability.

Another gap in existing family occupation literature is the concentration of research on families with children with ASD. Clearly more research is needed exploring disability experiences beyond ASD, as well as families without disability experience. Broadening beyond the use of specific disability diagnosis to explore disability as social (family) experience would also help resist conceptualizations of disability as body-bound. An additional limitation of the existing literature is the use of narrow methodological approaches. Boyd, McCarty, and Sethi (2014) have critiqued the methodological limitations of the ASD and family routines literature for its reliance on interview methods, focus on caregiver perspective, and sampling of families

with young children. These concerns also characterize much of the family occupation literature. Expanded observational research is required to build detailed descriptions of the processes of family occupation.

Studying Families and Family Occupation

Methodological sameness. Methodological sameness within the field of family studies is increasingly being critiqued; Hendricks and Koro-Ljungberg (2015) interpreted the adoption of family “science” labels and the dominance of grounded theory approaches to be indicative of a continued striving for disciplinary legitimacy via a post-positivistic paradigm. Similarly, Daly (2003) felt the field leaned positivistically:

The preoccupation with measurement has meant that most of our research focuses on individuals, not families. Although we purport to study families when we use terms such as family theory and family studies, we are in practice studying individual characteristics, attitudes, and behaviors... The result is that family life tends to be viewed in terms of averages around measures of central tendency, rather than in the diversity and complexity of shared meanings and interrelated perceptions (p. 772).

The legacy of individualizing measures appears to have carried over into qualitative methods, resulting in a strong preference for interview approaches. Furthermore, Handel (1997) emphasized that even when a family focus is claimed, “most family research is not family research but research on one of the component relationships in a family” (p. 342). Handel noted that these studies typically isolate married couple relationship or parent-child relationships.

Interviews. In-depth interviews have been the most frequently used method for qualitative family research, although analyses of artifacts such as diaries or photographs, experience sampling, video analysis, and participant observation have also been employed (Rosenblatt & Fischer, 1993; Mason & Tipper, 2014; Rönkä & Korvela, 2009). Interview methods may be perceived as more readily available, however they have also been critiqued as limited means of gathering information about daily life, and particularly so for children.

“Children are highly fluent in visual, non-verbal, embodied, physical, and tactile modes of communication, and they frequently choose to express aspects of their lives these ways” (Mason & Tipper, 2014, p. 160). Interview methods also obviously exclude or reduce the participation of those with unique communication strategies that may be considered challenging to ask questions to or speak with. In contrast, research in naturalistic settings gets researchers closer to where lives are lived, and thus affords more information about dimensions of physicality, materiality, space and place, sensory environment and other contextual features (Mason & Tipper, 2014).

Challenges to observation. Cultural constructions of “home” have served to reify households and dwellings as private spaces and families as private bodies (Fahey, 1995; Whitman, 2004). Moreover, the concept of home is frequently tied to other aspects of identity and relationships deserving of daily safeguarding. Mallet’s (2004) review of social science literature highlighted the frequent conflation of home and notions of self, family, haven, and journeying: “Clearly the term home functions as a repository for complex, inter-related and at times contradictory socio-cultural ideas about people’s relationship with one another, especially family, and with places, spaces, and things” (p. 84). Collectively these expectations of privacy of family and privacy of home have served to limit researcher engagement within these spheres, reducing enthusiasm for the use observational methods in these contexts.

Methodological innovation. While many methods of study dwell on central tendencies, Rönkä and Korvela (2009) have noted that, “There is, however, an obvious need for researchers to develop new, innovative methods that would be able to get close to daily processes and moments” (p. 98). Ganong and Coleman (2014) have argued for the growth of qualitative approaches to family research, pointing out that qualitative approaches can offer contextualized

information, capture relational and interactive processes, and allow for the expression of marginalized voices.

Qualitative researchers have responded to the challenges of studying family life by testing out new methodological approaches and attempting to include diverse families. Hess and Handel's (1959) groundbreaking *Family Worlds* study involved interviewing each member of two-parented families with children (ages 6 and older). Handel (1997) later reflected, "Obtaining data from each member of each family is the major methodological innovation of our study. That was a departure from prevailing practice, and it remains rare today" (p. 339). Similarly, Stacey's (1990) ethnography of families in postindustrial America was innovative in the inclusion of non-nuclear family members and acknowledgment of the changeable nature of family membership. As Stacey explained, "Like postmodern culture, contemporary family arrangements are diverse, fluid, and unresolved" (1990, p. 17).

In addition to addressing multiple family members and using expanded notions of family, ethnographers have also explored how gender, race, and class impact both family life and family research. For example, Bonsall's (2013) occupational science ethnography of fathers of children with disabilities utilized narrative phenomenology in order to explore occupation and gender experience. Bonsall conducted interviews and observations in order to better understand family occupation through the lens of fatherhood.

Primeau's (1998) grounded theory study of the orchestration of work and play within the daily occupations of families with preschool age children specifically targeted a cultural subgroup based on researcher characteristics. As part of the study design Primeau selected parents with similarity to her own racial and ethnic background in order to try and minimize researcher effects on the data. In contrast, other family ethnographers have detailed the work

they have done to gain access to communities of different sociocultural composition than their own. Mattingly and Lawlor (2000) emphasized the power of narrative interviews and story elicitation to bridge differing sociocultural perspectives. Stack (1974), a white researcher, studied black family life in 1960's America. She and her young son moved into the target neighborhood to live embedded in the study context. Stack noted that often researchers have accessed men of status as community gatekeepers in order to gain entrance to participants. Stack wrote, "I decided instead to try and find my own means of entrée. I decided to circumvent the obvious centers of influence- the pastors, the politicians- and try to reach families without resorting to middlemen" (1974, p. xi). Stack was able to network with a university colleague that had grown up within the community in order to gain direct introductions to families. She built rapport by participating in family tasks such as helping a family fold newspapers for their son's newspaper route prior to explaining her study aspirations.

Newspaper folding is just one example of many diverse activities that ethnographers have engaged in as part of their forays into family life. Ethnographers have employed a broad variety of research activities in order to capture family experience, and continue to experiment with and report about novel techniques. The University of California Los Angeles Center on Everyday Lives of Families (CELFL) study recorded a "Week in the Life" of 32 middle class families using a combination of measures including using visual ethnography (Arnold, Graesch, Ragazzini, & Ochs, 2012), as well as video recordings of family routines (Ochs & Kremer-Sadlik, 2013). Lareau (2003) and her team of graduate researchers joined families in their homes (including overnights), as well as on community outings in their ethnographic study of how race and social class impact child and family life. In a flipped approach DeVault (2000) and research assistants observed public family spaces outside of the home (at the zoo) in order to study the outings of

“family-like” groups. DeVault explained her choice to sacrifice a level of certainty about family membership “as one of the costs of looking at family activity naturalistically in a public setting” (2000, p. 490).

The willingness of family ethnographers to build upon, challenge, and experiment with methods is one reason ethnographic approaches are well suited to studying daily life. Equally, deliberation about researcher roles, impacts, issues of credibility, and efforts to foster successful research relationships are necessary for such studies (Lawlor & Mattingly, 2001).

Additional Considerations

Families with children. Family research has also been limited by conceptualizations of childhood that view children as immature objects rather than autonomous occupational beings. Children have historically been under-considered in research and theory, seen as having limited capacities, skills, and knowledge. Only recently has the “new sociology of childhood” emerged that considers children as social actors and childhood as a distinct social world that differs from the social world of adults (Bühler-Niederberger, 2011). The recognition of children as actors that participate in intentional, meaningful ways that make sense to them has important social justice implications. Cavet and Sloper (2004) suggested that while children have been consulted on limited “children’s topics” in the past, they are able to participate in broad conversations about many more social and political topics. Lawlor (2003b) similarly argued that children are social beings constructing social worlds and that there is a need for researchers to stop merely describing what they do and truly examine them as occupational beings.

There is compelling evidence that children perceive and understand their worlds differently than adults (e.g. Davis et al., 2007), which raises concerns about the traditional research practices of having parents report on behalf of their children. Literature investigating health-related quality of life has long noted discrepancies between the self-report of children and

the proxy report made by parents (Upton, Lawford, & Eiser, 2008). Davis et al. (2007) undertook a qualitative examination of this gap using a think-aloud method and found that children and adults differed in their manner or strategy of responding to questions, in their actual responses (or perceptions of health), and in their interpretation of the terms and concepts used.

Existing evidence likewise suggests that children do not conceptualize family in the same ways as adults. In their studies of kinship Mason and Tipper (2008) and Tipper (2011) have detailed the creative ways children “reckon” family, often including people and animals both living and deceased, as well as spanning multiple households. Tipper noted that children often include pets in describing their families, and emphasize these relationships as emplaced and embodied. Given that children may conceptualize family in different ways than adults, it becomes even more essential to include children when investigating how families “do” family together. Scott (2008) suggested that given all the creative ways in which adults construct and negotiate their social worlds, it is easy to imagine children as equally creative in these endeavors. Morris (2003) found this imaginative social construction also to be applicable to children with communication impairments. To date, however, children remain largely excluded from both quantitative and qualitative research (Scott, 2008).

Acknowledging child agency requires valuing child voices, choices, actions, and how child perspectives and knowledge are expressed. As Handel (1997) stated,

No member of any family is a sufficient source of information for that family. A family constructs its life from the multiple perspectives of its members, and an adequate understanding requires that those perspectives be obtained from their multiple sources. How this principle is implemented in particular projects will depend on the nature of the project (p. 346).

There is a distinct need for researchers to tap the perspectives of children, who have tended to be either ignored or voiced by proxy. Within families complex power dynamics and social

structures may influence the free choice of members to participate. There are concerns about key informants, gatekeepers, and how to ensure the consent of all persons involved (Zartler, 2010). The “negotiation” of research that takes place within families raises concerns about child assent, power, and how information is communicated to multiple family members. Researchers have noted the need for additional ethical consideration to practices surrounding permissions, disclosure, authority, and representation (Phelan and Kinsella, 2013). Ultimately, the investigation of family experience requires care and attention to the dynamic process of entering and accessing family life, including explicit recognition of children’s experiences as part of family experiences.

Families with children with disabilities. Working with families with children with disabilities likewise raises additional ethical issues. Phelan and Kinsella (2013) called for researcher reflexivity that begins before the study design process and lends a shaping presence throughout the research activities. The treatment of consent and assent as ongoing processes rather than initial steps is especially important when working with children with disabilities (Cameron & Murphy, 2007). As Phelan and Kinsella noted, the act of signing an assent form may hold additional symbolic meanings for a child, such as demonstrating skill or determination; extra caution must be taken to ascertain a child’s understanding of voluntary assent. Spitzer (2003a) has pointed out that there are multiple ways to evaluate ongoing consent or permission, and careful observation may be used in place of linguistic confirmation. Participants with disabilities may need information to be provided in different ways, and may require additional time to make decisions (Cameron & Murphy, 2007).

Problem Statement

There is a need for the development of knowledge about family life in order to support scientific progress, health promotion, and social policy. Existing scholarship has generally been limited by narrow definitions of family, treatment of the family as a private space (with reluctance to engage in naturalistic, participant observation driven research), and overreliance on parental accounts to represent family experience. Furthermore, research on families with children with disabilities has often focused on disruption, dysfunction, and negative aspects of disability experience (with disability itself conceptualized in a restrictive, body-bound manner). These problems have impacted both occupational science and occupational therapy by confining the scope of research and thus restricting the development of family-centered knowledge for the provision of family-centered care.

More research is needed taking family occupation as the unit of analysis, and considering disability as not inherently positive or negative, normative or non-normative, but instead as a relational element within the dynamic flux of daily family life. This study addressed existing gaps and problematic assumptions by adopting a relational approach, in which the researcher entered into the process as a learner seeking the expertise of the family. The adoption of a transactional perspective (Cutchin & Dickie, 2012; Cutchin & Dickie, 2013; Dickie, Cutchin, & Humphry, 2006) enabled exploration of the blurring of boundaries between family members who sometimes act as independent agents, and sometimes as collective units (e.g., van Nes, Runge, & Jonsson, 2009). The aims of this study were to explore how methodological choices impact family-centered research processes, as well as add to current understanding about family occupations, and specifically the experiences of families with children with disabilities.

Aims and Objectives

Aim 1: Investigate how qualitative research methods are experienced and perceived by family gatekeepers.

The *objective of this aim* was to elicit parent advisor accounts and perspectives of the research process with attention to barriers and supports to implementing studies within naturalistic settings.

Aim 2: Explore the coordination and enactment of family time occupations among families with middle childhood age (6-11 year old) children with disabilities.

The *objective of this aim* was to describe processes of negotiation within varied daily family occupations.

Aim 3: Examine how families with children with disabilities support the participation of members during family time occupations.

The *objective of this aim* was to understand how families habitually support the participation of group members.

CHAPTER 3. METHOD

Paradigm

Naturalistic qualitative methods best served my interest in exploring the highly fluid and complex everyday experiences of families. I drew heavily upon the ontological assumptions of social constructionism. The benefit of social constructionist ontology is the recognition of the shared and constructed (negotiated) aspects of social realities (Gergen & Gergen, 2007). The underlying assumption, that socially created experiences are contextually specific, suggests the necessity of naturalistic research. Social constructionism has itself experienced critical, rhetorical, and social turns, and one of its drawbacks is that social constructionists often hold underlying values about the centrality of language to make social worlds intelligible. However, social constructionism also supports methodological liberation, as it recognizes that no form of knowing is more valid than any other (Gergen & Gergen, 2007). In my approach I attempted to deemphasize verbal language in favor of more holistic communication strategies. Gergen and Gergen (2007) called for experimentation, as qualitative methods should reflect the emergent nature of knowing. As an individual graduate researcher within a specific temporal, sociocultural, economic, and political context, I was mindful of focusing on pragmatics and considering feasibility and reasonability as essential design elements (Lewis, 2010).

Conceptual Frameworks

Transactional perspective. The transactional perspective described by Dickie, Cutchin, and Humphry (2006) helped to frame my exploration of family as community, including the influences of multiple family members, and the complex and contextually integrated co-

construction of family doing. The historical roots for transactional perspectives of occupations lie in the work of American pragmatist John Dewey (Cutchin & Dickie, 2012). “Dewey asserted that the emergence of problems in life was something people could not avoid. In a world that changes about them all the time, people find relative stabilities, but also find that the emergence of one state of affairs into another is continuous” (Cutchin, 2013, p. 290). The transactional perspective offers a framework for thinking about the continuous fluctuations of daily experience. It emphasizes the co-constitution of persons and contexts, with neither existing in isolation from the other, but rather continually shaped by one another through occupation (Dickie et al., 2006). A transactional perspective recognizes multiple family members as collectively co-contributing to the experience of family, as well as to family practices. Researchers must elicit the converging, diverging, overlapping, and conflicting “knowledges” of families, recognizing that no singular voice will fully capture a shared experience.

Communities of practice framework. I was also influenced in my thinking about groups by the concept of communities of practice. Wenger (1998) proposed that shared practices build community, which has been echoed in the occupational science literature by Bratun and Asaba (2008). Wenger conceptualized community as centered on mutual engagement, joint enterprise, and shared repertoire. The shared repertoire includes tools such narratives, stories, and artifacts that enable symbolic communication; the repertoire functions as a resource for the negotiation of meaning (Wenger, 1998). Analyzing family occupations offers the opportunity to examine the processes of family as processes of community, and scholars of family occupation are poised to contribute to the development of new methods of community study.

Relational model of disability. In addition, my conceptualization of disability experience as distributed, shared, and intersecting among family members, was influenced by social relational models of disability. Such models, which emerged in the 1980's and have largely been adopted within the field of Disability Studies, call for the examination of socially constructed elements of disability experience, rather than operating on the assumption that disability resides within an individual (Lawlor & Mattingly, 2009; Söder, 2009). Social models describe functional limitations tied to chronic conditions, disease, or illness, as “impairments;” in contrast, “disabilities” are the social and physical barriers to doing or being. The experience of being disabled, then, is the experience of exclusion or discrimination based upon having an impairment (Connors & Stalker, 2007; Söder, 2009). Adopting a social relational model of disability within a family context requires examination of family practices as collective experiences that may be impacted by functional impairment, but are also affected by social support and social experiences.

Study Design

Overview. The basic tenets of qualitative family research include a focus on the family as opposed to the individual, examination of how people act, speak, and feel, and consideration of “details and idiosyncracies” (Rosenblatt & Fischer, 1993, p. 170) as data. Ethnographic methods allow for the use of a broad range of research methods in order to watch, listen, experience, and query human experiences within the context of daily life (O'Reilly, 2008). As Bailliard, Aldrich, and Dickie (2013) have described, “Ethnography is characterized by periods of *hanging out*, during which the researcher remains open to new avenues of inquiry and unanticipated sources of data” (pp. 158-9). It is an excellent choice for exploratory aims.

This type of study design embraces active participation. Wolcott (2008) described ethnographic research as a way of directing attention including “experiencing,” “enquiring,” and

“examining,” and active participation allows the researcher’s body to become a means of collecting data. Similarly, Pink (2009) described sensory apprenticeship, as ethnographers “develop an awareness of how different types of research material might facilitate ways of being close to the non-verbal, tacit, emplaced knowledge that a sensory analysis seeks to identify” (p. 130). This type of embodied knowledge has particular applications to situations in which participants may not rely on lengthy verbal explanations to describe an experience. As Spitzer (2003a; 2003b) has demonstrated, highly individualized communication systems can be built upon shared engagement in daily activities.

Ethnography has the capacity to describe complex processes of change over time and identify holistic patterns and themes. The iterative-inductive nature allows for necessary flexibility and the organic evolution of the research design throughout the research process; “Ethnographic analysis is not a stage in a linear process but an iterative phase in a spiral where progress is steadily made from data collection to making some sense of it all for others” (O’Reilly, 2008, p. 13). Bailliard, Aldrich, and Dickie (2013) have argued for the natural compatibility of ethnography and transactional perspectives of human occupation, offering the ability to examine situated relationships.

I employed a multi-sited ethnographic approach to explore everyday family life, as expressed and enacted by multiple family members within dynamic, fluid, and varied family households. Although there is natural overlap between qualitative methods, the use of ethnography enabled me to focus on families as cultural units with their own languages, practices, and histories, through the exploration of daily life in context (Descartes, 2007). I have retained the word “participants” rather than “informants” throughout to emphasis the active

engagement that characterized the visits. This approach also allowed me to examine linkages across families (Hannerz, 2003), and consider patterns across multiple cases.

Sandelowski (1995) noted that sample size may refer to the number of people, interviews, observations, or events; in this study each family visit included many different people and events. Given that one of the primary contributions of the research was the deep examination of family experiences, the sampling design was chosen to accommodate the anticipated high degree of complexity within family context. The study included elements of within-case sampling, in the examination of multiple experiences of a family group, as well as multiple-case sampling, in the investigation of multiple family groups. This was chosen because “Each setting has a few properties it shares with *many* others, some properties it shares with *some* others, and some properties it shares with *no* others” (Miles, Huberman, & Saldaña, 2013, p. 34).

Recruitment. The parent advisors (Phase One) and families (Phase Two) were recruited from communities in a southeastern state in the United States. Opportunity and snowball sampling are considered appropriate to exploratory investigation (Arksey & Knight, 1999) and were employed during both phases. Cognizant that participation rates are higher when unknown researchers are introduced via trusted entities (Cree, Kay, & Tisdall, 2002), I recruited via existing social networks of parents, professionals, academics, and extant participant databases. Informational materials were also posted in public location such as libraries. Lewis (2009) found that appealing directly to fathers on recruitment materials increased male response after poor initial response to calls for “parents,” and suggested that some participants may feel their contribution is valued if specifically requested. In a similar vein I tailored my recruitment of families of children with disabilities by using strengths-based and positive language (e.g. “family fun”) to appeal directly to this community. Although my recruitment materials used the term

“disability,” I followed family leads in using the term “special needs,” which appeared to be preferred terminology for these families.

Informational leaflets, flyers, and email messages (please see Appendix A) were also available to be passed along (snowball method) to additional contacts that may have been interested in participating, or may have known other likely candidates. Potential participants were asked to opt in to research by contacting me via telephone or email and indicating an interest in learning more about the study. I responded using the potential participants’ preferred line of communication (i.e., phone, email) to provide additional details, describe the consent procedures, and answer questions. All of the families that contacted me were eligible for the study; none were excluded. I recruited families on a rolling basis until seven cases were completed. The choice of seven cases was above the minimal threshold of “five richly researched cases” suggested by Miles, Huberman, and Saldaña (2013). I anticipated that some of the families might need to discontinue participation mid-way through data collection; fortunately none of the families discontinued after enrolling. The families that enrolled in Phase Two were provided with a small monetary appreciation at the conclusion of the visits.

Participant characteristics. The respective study samples consisted of thirteen parent advisors (demographics described in Chapter Five) and seven families with children with disabilities (described in detail in Chapter Four). Phase One inclusion criteria were English fluency and that the participating adult (18 years and older) both identify as a parent and have past research experience. Inclusion criteria for Phase Two were an understanding of spoken English, a parent/guardian participant 18 years of age or older, and at least one child between 6 and 11 years old at the time of the study with a family reported disability diagnosis. This middle childhood age range (CDC, 2016) was chosen because it is traditionally for children a time of

developing self-expression and high participation in family activities (Maccoby, 1984; McHale, Crouter, & Tucker, 2001).

Investigative techniques. The primary data sources for naturalistic research are words and actions; researchers look, listen, and ask to gain understanding about participants' experiences (Lofland & Lofland, 1995). During Phase One of the study I utilized semi-structured interview techniques. This style of interview allows for conversational foci and questions, as well as flexibility for participants to speak about what is of interest or importance to them (Hesse-Biber & Leavy, 2011). Based upon the findings from Phase One, during Phase Two of the study I utilized a flexible, situationally responsive combination of observation, participant observation (via shared occupation), casual conversation, and the more targeted asking of questions (within conversation).

Ethics. Each phase of the study was reviewed and approved by the University of North Carolina at Chapel Hill's Institutional Review Board, and participants completed the appropriate written adult consent, parental permission for minors, and child assent documentation (please see Appendix B). When visiting with families, additional persons frequently took part in activities or were present in community contexts. I let the families take the lead regarding disclosure of the study, and whenever possible, formal consent documentation was also collected for family visitors. When formal documentation was not appropriate or achievable I treated other persons as anonymous collateral participants and monitored for signs of general comfort with my presence.

Data Collection

Phase One. In Phase One of the study I explored family perceptions of naturalistic research processes. This initial phase of investigation allowed me to ask for advice in research design, with particular attention to recruitment, consent/assent procedures and ethical concerns, data collection logistics, and rapport building. Literature suggests that parents are the initial gatekeepers and points of contact between family researchers and participant families (Lewis,

2009), accordingly during this phase I recruited parents to speak to the experience of family gatekeepers. I met with these gatekeepers at a location of their choosing for a single interview, lasting 45-90 minutes; each interview was audio recorded and later transcribed verbatim. The semi-structured prompts were related to how an investigator might best approach families and design research activities. (Please see Appendix C.)

Phase Two. The second phase of research focused on exploring how families successfully negotiate every day occupations. I asked families to select activities that they liked to do together that I could visit during in order to learn about what they did and how they did it. Data collection activities during this phase of research involved joining in home and community settings, hanging out, and actively participating in what families were doing (whenever appropriate). (Please see Appendix D.) Data collection took place in the settings of everyday family life including places of residence, local neighborhoods, and community spaces frequented by participants such as schools, playspaces, ice cream shops, athletic venues, swimming pools, and during transit.

I completed 3-6 visits with each family, lasting between 1.5-8 hours per visit. Total time in the field was approximately 95 hours. The question of how many visits to request was complex. I did not want to hurt my chances of successfully recruiting families by scaring them off with too extensive a time commitment; however, I desired the opportunity to develop depth in my exploration. The range of targeted visits was selected based upon both the feedback of parent advisors during Phase One of the study, as well as based upon the experience of Lareau (2003) in her observational study involving families of third graders. Her research team observed that the first few family visits were inevitably quite awkward, with a noticeable easing of tensions on the 3rd visit. Tension levels then plateaued until the 10th visit. They also found that

children benefited as the visits became more routinized. For this reason, a minimum of three visits was requested with each family.

Data Analysis

“Key to data analysis in qualitative family research is the process of deciding what is important and of managing the data” (Rosenblatt & Fischer, 1993, p. 172). My process included: (1) frequent re-immersion in the data via transcribing, re-reading, and re-listening to prior audio fieldnotes enroute to subsequent visits; (2) more intensive analysis of the first three cases to explore alternative motifs present in the data; (3) coding and themeing via segment analysis, memos, and visual mapping and rearrangement of notecards to examine repetition, evocativeness, and clustering of data; (4) walking, talking, and thinking. Movement across varied environments and contexts was an important element of how I processed the data and shifted perspectives between the local and big picture.

Dickie (2003) wrote about the need for “stepping in and stepping out, seeing things from multiple perspectives” (p. 53), which in her experience often necessitated both immersive and distancing acts when working with data. In addition to many detailed analytical tasks such as marking, labeling, and sorting data segments, Dickie also emphasized the importance of allowing time to reflect and process:

Thinking time is vital. Thinking time might be focused at my desk, but it includes time doing such things as walking, watching the woods outside my window, talking, commuting, taking showers- in other words, activities that allow my mind to wander and puzzle over what I am finding (2003, p. 53).

In my own experience many ideas and patterns were aided by conversations I held with myself while driving.¹ I often talked through various points to clarify my position and understanding

¹ Many aspects of this project were closely tied to driving- whenever possible I would re-listen to audio fieldnotes from previous visits enroute to the next visit with a family. I occasionally recorded audio notes

during daily commutes, and then recorded voice memos upon arrival at my destination in order to summarize these ideas.

One of the critiques of coding techniques is that they fragment data, dissociating it from human experience. However personal narratives and contextualized accounts are critiqued for reifying the authenticity and meaning of individual experiences (Lal, Suto, & Ungar, 2012). I ended up in a middle ground. I found minute line-by-line coding to be ineffective, preferring instead to gradually code scenes or units of activity within the larger episode of an observational visit. This coding actually took place after more detailed segment memo-ing, in which I asked myself questions such as: “What is happening here?” or “Why does this moment feel significant, evocative, or telling?” After re-examining the moments, I was able to better categorize scenes with thematic codes, which primarily served as short hand for organizing and then rearranging data. Practices for making things work ended up being only one of many types of stories and actions that I witnessed, but once I had selected this focus, I revisited the episodes to narrow the number of selections and choose exemplars. The chosen exemplars used in the manuscripts represent middle-of-the road moments that appeared to be within the typical repertoire for the given family. For the coherence and readability of the manuscripts I did look for examples that highlighted different aspects of the occurrences observed, although in practice the negotiation and inclusion processes were densely overlaid.

Thematic analysis. I employed thematic analysis as part of both Phase One and Phase Two data analysis, using an inductive approach adapted from Braun and Clarke (2006) with additional coding strategies described by Saldaña (2015). I included three distinct rounds of

while driving home from a visit (if I was unable to locate an inconspicuous parking lot to stop in or if it was very late at night or extreme weather). I imagine I began to develop some unconscious thinking practices related to the research during the data collection that I continued to engage in later as I continued my analysis and writing.

coding, beginning with action codes. I found that coding actions with “-ing” was helpful to illuminating processes; I also separately coded for moments of emotion (among family members or myself), as well as statements or actions that indicated underlying values, attitudes, or beliefs (Saldaña, 2015). Phase Two data analysis was also influenced by the components of data collection, condensation, display, and concluding described by Miles, Huberman, and Saldaña (2013). The analysis was conducted inductively and across multiple cycles closely following the “Sort & sift: Think and shift” technique described by Maietta and Mihas (2015). A detailed explanation of this strategy is anticipated in upcoming publications, however basic tenets of the method have been elucidated in presentation papers:

The Sort and Sift technique encourages frequent movement between thorough review of data with recording of ideas that emerge during review and stepping back to review and reflect on content and process used during data analysis. The approach is a process that involves two recurrent phases of a cycle of data analysis. The first phase is called “Diving In.” Get into your data as quickly as possible. Read, review, recognize and record. The second phase is called “Stepping Back.” This phase encourages you to stop to review where you are. Reflect and re-strategize. Then dive back into what you have done and recognize what is new (Maietta, 2006, p. 8).

The core activities of using this method included the identification and examination of powerful data excerpts, inventorying and analyzing powerful data segments across each visit, revisiting and monitoring ignored sections, producing episode profiles including diagrams and memos to create a sketch or narrative of each visit, and the use of diagramming to bridge and question across episodes and cases. MAXQDA (Verbi, 2014) software was utilized to assist in management of the data documents and analytic codes and memos, although my initial enthusiasm waned over the course of the project and I found myself reverting to notecards and post-its to support my preferred tactile engagement with the data.

Throughout the Phase Two analysis (please see Manuscripts Two and Three) I returned frequently to the questions: “How is the family activity negotiated and coordinated?” “What makes the activity successful?” “What strategies are the families using to promote engagement and participation?” “What forms of participation are included and validated?” I found the technique of segment analysis via segment memo especially productive in allowing myself to engage in reflexive conversation about my own interpretations and responses to moments within each episode, including consideration of the attitudes and emotions being expressed by participants and myself (partially inspired by my past employment of coding recommendations by Saldaña, 2015). I originally attempted to use thematic coding to also describe the processes of family occupation (Manuscript Two), but found that the themes generated were isolating aspects of person, setting, and action from one another. I next turned to narrative inquiry to examine the data as enacted stories of family life. Narrative analytic techniques better allowed me to examine the arc and progression of episodes of family activity that highlighted the interplay among family members and collective group.

Narrative inquiry. Family narratives are stories of family life. Mattingly and Lawlor (2000) offered a working definition of narratives as “event-centered and historically particular, located in a particular time and place. Stories concern action, more specifically human action, and particularly social interaction” (p. 6). Viewed this way, family narratives relate human social action across nested contexts including specific family moments, broader family life course and identities, as well as larger sociocultural context. Mattingly (1998) noted that one of the function of narrative is to provide meaningful linkages in daily life:

Life is not experienced as one thing after another because actors work to create a story-like quality to their actions. Being an actor at all means trying to make certain things happen, to bring about desirable endings, to search for possibilities that lead in hopeful directions (p. 47).

Family narratives have been conceived of as serving multiple functions including helping acculturate children to language use and social norms, as well as promoting connectedness and sociability (Blum-Kulka, 1997).

Narrative as emergent action. Narratives represent constructive and co-produced processes (Blum-Kulka, 1997; Garro & Mattingly, 2000). Mattingly (2000) described emergent narratives as “improvisational and embodied stories” (p. 189), that are “usually invented more or less on the spot, unrehearsed dramas that spring up in the course of everyday activity... It is a cultural act, and its creation depends upon a complex repertoire of cultural resources” (p. 205). These spontaneous and developing lived stories were the foundation of my analysis. I was most interested in what the negotiated actions were telling me about family life.

My conceptual view of narrative is similar to that of Nyman, Josephsson, and Isaksson (2012), who wrote, “We approach narrative as stories that are both told and performed” (p. 411). In the past I think scholars have tended to ascribe a false separation between acting and telling, perhaps due to frequent research preoccupation with words and text. As observed, I found the telling and acting to be contiguous. Many occupational therapy and science scholars have embraced narrative inquiry as appropriate for analysis of observational data (e.g. Alsaker & Josephsson; 2010; Alsaker, Bongaardt, & Josephsson, 2009; Bonsall, 2012; Josephsson, Asaba, Jonsson, & Alsaker, 2006; Mattingly, 2000).

Occupation as opportunity. I considered the family times that I witnessed as possessing a tangible potential for coordinated action, akin to the “opportunity space” Ochs, Smith, and Taylor (1989) described as “a temporal, spatial, and social moment which provides for the possibility of joint activity among family members” (pp. 238-9). In their cross-cultural study of family time Kremer-Sadlik, Fatigante, & Fasulo (2008) noted:

We have been struck by the presence of what we call ‘quality moments’ in family life – spontaneous, unstructured, everyday moments of shared social interaction between family members. Although individual family styles vary, we find that quality moments occur regularly in the course of everyday activities and routines involving parents and children (p. 288).

These moments appear frequently and unexpectedly within daily life, but are also constitutive of family life. In other words, they are both mundane and extraordinary. They are characteristics of family life, while simultaneously integral to creating the family-like quality of the experience. Family life is a collective journey, with different stages, milestones, unexpected turns, plots, subplots, and rotating cast of characters. There is a sense of past history, present moment, and hopes and possibilities for the future. Within the context of this study I examined how the participant families negotiated occupations together, while concurrently enacting larger narratives about family life, the meaning of family time and togetherness, what constitutes “fun,” the process of growing up, and what it means to be a family. I found that these were largely aspirational narratives about possibilities and benefits of family-ness.

Being part of the story. Narrative inquiry is a relational process (Clandinin, Caine, Lessard, & Huber, 2016). As the solo participant observer my fieldnotes, memos, themes, analyses, and written reinterpretations reflect my own listening, observing, and telling. I was present in the moment, and the data were multiply interpreted through, with, and by me (and my performance of “researcher”) in a spiraling and transactional process. At the same time, when I considered my own presence as a character within the scenes I thought of myself as a somewhat generic “new friend of the family” persona. I attempted to remain a background character as much as possible.

In writing about “enacted togetherness,” Nyman, Josephsson, and Isaksson (2012) noted that “by engaging in everyday activities with someone else, the participants gained access to, and

became part of an unfolding enacted narrative” (p. 411). My goal was similar to this notion of joining in stories acted out via daily occupation. Within each unique family there was always a narrative about family life and what it means to be a family that was being constructed and enacted.

Narrative analysis. My narrative analysis included accessing ongoing action within daily context in order to attempt to capture “real-time situatedness” (Alsaker, Bongaardt, & Josephsson , 2009, p. 1157). I should note that I did not explicitly seek out individual family member interpretations, although they were sometimes expressed by individuals during the unfolding action. Rather, I used my position as a guest to observe and interpret the action processes involved in negotiating occupation, which themselves revealed interconnecting but also diverging meanings, preferences, and goals.

Some of the characteristics I examined included sequentiality, temporality, cast of characters, space frames, symbols, underlying values, plot, subplot, and dramatic turns (Daiute & Lightfoot, 2004; Daly, 2007). I drew from Fraser’s (2004) seven phase analytic process, including “experiencing each other’s emotions,” “transcribing the material,” “scanning across different domains of experience,” and “looking for commonalities and differences among participants.” Fraser highlighted the benefits of intensively listening to audiotaped stories; indeed, I found that re-listening to my audiotaped initial fieldnotes allowed me to attend to the inflections and emotion conveyed in my own retellings of the visits. Transcribing and expanding my audio prompted me to reflect on my habits of memory, interpretive lens, and processes of translation. The initial voice memos, as comprehensive as I attempted to make them, were still akin to shorthand notes, a conversation with myself, cues to trigger my memory. I immediately prioritized certain moments, scenes, and conversations as most memorable and worthy of

recording. The expanded fieldnotes, in contrast, represented a translation and retelling, again primarily for myself as an audience, but this time wearing a different analytic cap. The phased analysis was a mechanism for revisiting the data in hopes of hearing and telling the stories differently to elicit new insights.

Credibility

Davies and Dodd (2002) wrote of the strengths and rigor of qualitative research lying in “terms such as *attentiveness, empathy, carefulness, sensitivity, respect, honesty, reflection, conscientiousness, engagement, awareness, openness, context*, and so on” (p. 288). They felt that these terms represented a more useful evaluation of the qualitative research process as interpretation is woven into all steps of research encounters. Steps to ensure the credibility of the research suggested by Beck (1993) and undertaken during this study included: detailed fieldnotes, reflections on the role of the researcher, and provision of vivid excerpts to the reader. Efforts to increase auditability of the research included: fieldnotes tape-recorded immediately after each visit to increase accurate recall, verbatim conversation included whenever possible, detailed descriptions of the data analysis process, and rich descriptions of participants.

The term “triangulation” originated in land surveys and was adopted by researchers as a metaphor for strength (based upon the geometric principles of triangles) (Patton, 1999). Although triangulation most commonly refers to mixing methods such as interviews, observations, and artifact analysis, it may also indicate the range of sample and inclusion of multiple perspectives. When I began the study I had a specific interest in multiple perspective research. I had read about techniques used for analysis multi-perspective data, although it almost exclusively referred to interview data. In practice these strategies were not readily applicable to my data, although I attempted to keep in mind the possible converging, diverging, and multiplicity of narrative and experience. I do think that group observation differs significantly

from observation of an individual within a group, and my aim was to consider the experience of all group members without prioritizing certain actors or voices.

I attempted to tell the story of how the study came to be and unfold as clearly and transparently as possible so that readers will feel better informed to assess the strength and relevance of the findings. In preparation for the study I undertook relevant coursework and workshop training focused on ethnographic data collection and analysis. The findings from Phase One of the study were used to help design the observations in order to increase social validity and capitalize on the expertise of a wider pool of parent advisors. I conducted pilot testing home visits with a family similar to my targeted participants, and completed autoethnographic observations and fieldnotes in order to examine my own assumptions and experiences of family life, as well as practice my technique. I also wrote reflexive journal entries to process what I was experiencing throughout the study and how my thinking was evolving. (Please see Figure 1 for an overview of linked data collection and reflexive processes). The study benefited from talented advisors that served as auditors, pushed me to think about additional avenues of analysis, and served as sounding boards for ideas.

CHAPTER 4. PARTICIPANTS

The Riley Family

I met the Riley family during Phase One of the study. Another participant had forwarded my recruitment email to a parent listserv at her school and the Riley family reached out. We met at a local coffee shop, with parents Alex and Jess, as well as their youngest son in attendance. I left the interview with the impression that they were highly educated couple, interested in science, and protective of their privacy. For example, during the interview they were careful never to say the names of their children. I admit that I was a bit surprised that they were willing to participate in the second phase of the study; however, I had acted upon their recruitment suggestion to create a brochure about the study that they may have appreciated. The Riley family included parents Alex and Jess, and sons Wyatt (6), and Silas (3), as well as cat Slingshot. During Phase Two they had no reservations about scheduling a visit, although they only texted their home address to me immediately beforehand. They lived in a compact single family home within a development. Alex and Jess worked varied and often alternating schedules; often one parent took the children on outings. The Riley family invited me to join them for laundry folding and playing at home, an outing to a local science museum (Alex and the boys), and a trip to the swimming pool (Jess and the boys).

The Riley family appeared to be environmentally conscious, abreast of current events, active in their local community and cultural events, and highly valued and supported learning. During the visits they enjoyed answering questions, explaining how things work, and discussing many topics including science and geography facts with the boys. The boys appeared to enjoy

playing with one another as well as with mom and dad, and were inquisitive about their visitor (me). They were sometimes competitive with one another, particularly in running the fastest. Silas had been diagnosed with a speech delay, and Jess frequently helped to clarify what he was saying. Wyatt had a slight motor delay and Jess also mentioned sensory concerns (as yet undiagnosed). The boys frequently initiated pretend play schemes involving props, stuffed animals, or creative use of everyday objects. The family appeared down to earth, practical, curious about the world, and serious about education. The boys attended year round schools and the visits tended to be coordinated more fluidly, with the family emailing or texting to see if I was free to join. They were the only family that took me up on the offer of a babysitting night at the end of the study, with Jess joking that by then I had been fully vetted.

The Oliver Family

The Oliver family included parents Penny and Paul, and children Haley (18), JD (14), and Ron (6), as well as dog Ralphie. The family was also very close to aide Lydia. The Oliver family was accustomed to having many therapists, aide workers, and friends of their older children coming into the house, and they were very comfortable with my presence. Penny was enthusiastic about research and the family has had students come into the home before. Penny said, “We like to participate in these kinds of things.”

Paul worked full time and Penny worked part time. She also painted as a hobby, and had begun selling her pieces at craft fairs. Haley was preparing to transition from high school to college and spent the summer getting her first work experience. Part of the summer she was away from home working at a camp program. JD was a middle schooler who enjoyed spending time with his peers and was gearing up for his first dance. During the summer he and Paul spent some father-son time out on a camping trip after fixing up an old RV together. Ron was getting ready to start kindergarten in a special needs classroom, a placement Penny had been worrying

about. Ron had been diagnosed with a rare genetic disorder resulting in global developmental delay including visual impairment, neurological deficits, and muscle weakness on one side of his body. He did not use verbal language, although he made other vocalizations. Ron had a huge grin; he was quiet, attentive, and polite. He sought eye contact with others and gave high fives. Ron enjoyed watching what was going on before joining in. He liked songs, music, and playing with his toys. At music class he kicked his legs to the music and gently tapped with his hands.

Penny described Ron as the focus of the family. Ron used a stroller for longer distances and walked with a walker or handhold assistance for shorter distances. Penny said there was a time when he hardly moved independently, but he had made great gains. He was able to reach and hold objects, sit and crawl independently, and help feed himself. Penny was very committed to therapies, interventions, specific diet and vitamin supplements to help maximize his gains. She said the family does not know what to expect as far as his capabilities. Penny was both nervous and optimistic to see what changes school would bring. Penny and Paul ultimately decided to place Ron in a classroom for children with severe disabilities, although Penny was keeping an eye on a moderate disability option.

Penny described Ron as a “surprise baby” and his older siblings were very affectionate with him. Haley gave hugs and cuddles, and JD liked to wrestle with him. Penny felt that Ron helped Haley and JD to be more communicative and affectionate during their teenage years, and that they enjoyed participating more readily in family activities because they loved spending time with him. Penny identified strongly as a family with special needs. She said that she was always planning how to present Ron in public. Some of the choices that she made were intentionally to present Ron in a positive light. She said that she chose toys and supplies that helped him appear smart, age-appropriate, and engaged. She did not want him to be in public

with items that would make him appear younger or less capable than he was. When she experienced stares or impolite questions from strangers she has been very affected.

The family had a very busy summer schedule, and the majority of my visits were focused on Penny and Ron doing things together. I joined the Oliver family for a parent-child music class, play and therapy activities at home, stretching and then a trip to the community pool, and a pool visit and dinner with friends (from the York family).

The York Family

The York family included Alice (6), Chloe (8), parents Lindsay and Cael, dog Spot, and frequently grandparents Grammy and Gramps who live nearby. During the course of the study the family qualified for in-home services but had not yet found an aide. This family was very enthusiastic about the study and was instrumental in putting me in touch with other families. They lived in a spacious home in a beautiful older neighborhood of a large metropolitan area. Lindsay was originally from the area, and Cael came from another southern state to attend a university in the area. They met later while working at the same transportation company, and although they initially lived out of state they returned to be closer to Lindsay's parents after they had children. Cael's family was spread out across the country and they felt that their current location offered the best opportunity for family support since Lindsay's sibling also lived close by. Lindsay's parents frequently dropped by, hosted meals, and helped watch the kids. Lindsay alluded to jokes about living too close to your parents but said: "Any of my friends that I tell this that have kids, think it is great."

Lindsay had been working full time before the girls were born but at the time of the study stayed home full time. Cael had been working extensive hours with a technology company, but within the previous year had been able to shift to a slightly more flexible schedule, starting early in the morning and finishing in the afternoon. The job was intensive but came with good health

insurance. Chloe and Alice attended different schools; Chloe was in a private school and Alice was in a public school. They chose these schools specifically because they were close to one another, but Lindsay and Cael shared that in practice it was hard to coordinate the transport given different start times and Alice's before-school therapy sessions.

Alice had a global developmental delay related to a genetic syndrome. Although extremely rare, the condition was expected to be progressive and associated with a shortened life expectancy. Alice had moderate motor control; she was able to sit up, lie down, and roll over on her own. She used a wheelchair or stroller for longer distances, and a supported walker or handhold assistance for walking shorter distances. In addition to postural support Cael and Lindsay helped feed Alice by cutting the food and lifting it to her mouth. Alice was beginning to learn to use a pictorial communication book with assistance. She tapped and gestured towards pictures with her hands, and was working on head nods for "yes" and "no." Communication continued to be a collective and interpretive process. The family appeared very enthusiastic and attentive to using the book; Lindsay frequently initiated conversations as well as asked Cael and Chloe to "find out what Alice wants." Chloe displayed confidence in her interpretations and definitively announced statements such as: "She has an itch."

Alice had expressive facial expressions and verbalizations. When content she often audibly sucked her thumb. She flashed big toothy smiles, especially when her family members were talking to her or playing with her. She rocked her body enthusiastically to music. During meals she gestured and reached to indicate that she was hungry and wanted more food. When less socially engaged she tucked her head and played with ribbons attached to her walker or watched the rotations of the ceiling fan. Lindsay explained that Alice attended several therapies weekly including occupational, physical, and speech therapy. She also did therapeutic riding and

had recently started going to a small group music class. Chloe was also busy with activities including dance classes, Girl Scouts, musical instrument lessons, and summer swim team. Lindsay confessed: “She has a lot of activities. I know some parents limit their children’s activities, but I don’t. I’m compensating. I know things are going to get hard and I just want her to have a happy childhood.”

Chloe was inquisitive and exuberant. She readily made friends and socialized with peers. She was athletic and enjoyed physical play and trying out gymnastic moves. Her grandparents described her as very creative and spoke of the many pretend games she invented with complex rules and fantasy world elements. For example, Chloe invented a game in which everyone in the family was a garden gnome, with a special name, powers, and animal sidekick. Lindsay was dismayed to be deemed the “cleaning gnome.” Cael was a more reserved and quiet person, observant and often listening to others. He seemed very thoughtful, such as in selecting foods his wife preferred but he did not. He was very gentle with Alice. Lindsay was friendly, talkative, and used frequent wry wit. She made an effort to not gloss over challenges, but appeared to be very adaptable and look for the humor in situations.

The family strongly advocated for Alice, and Lindsay was especially attentive to looking for novel ways to include Alice in activities, such as when she tied one end of a jump rope to Alice’s walker so that Alice could help “turn” the rope for Chloe to jump. Gramps and Grammy were thrilled to get to see the children so much, and Gramps commented that he loved how Lindsay always had Alice dressed in cute outfits and barrettes. He liked that she took such care so Alice always had a nice appearance. Gramps was a former educator and enjoyed speaking with students and explaining mechanical things to Chloe and the rest of the family. Grammy was

present during one visit; she had an easy laugh and enjoyed playing games with the kids and giving cuddles.

I joined the York family for: an outdoor movie event; field day at Alice's school and then lunch; an augmentative communication users family picnic; dinner, games, and a magic show (performed by Chloe); a trip to the community pool, dinner, and then making dessert at home; and another pool visit followed by dinner with friends (from the Oliver family).

The Goddard Family

The Goddard family included Pablo (8), Uniqua (11), and parents, Tasha and Austin, who both work in education. This family picked their pseudonyms based on the Backyardigans television (tv) show. They wanted me to specify that although Pablo picked the name Pablo, he was not Latino. The family was multiracial; Tasha was Black, Austin was White, and Uniqua and Pablo were biracial. Visits with the Goddard family were action-packed, and they appeared to be four relatively independent actors. The Goddard family identified a day and time of the week (Friday afternoon-evenings) as "family time" and invited me to join them consecutive weeks at this time. Each week they chose different activities that took place either within their home or neighborhood. The activities tended to loosely coalesce around a theme that Tasha identified prior to the visit. Tasha was my direct contact and access point to the family; she contacted me after seeing my recruitment email on a large research listserv and we spoke by phone prior to the first visit. Tasha came up with names for each week's visit including: "Game night", "[Wii] Dance party", "Pool party", and "Waterfight." With the exception of the swimming pool, all of the visits took place at the family's home, which was a compact single family home in a development.

Uniqua was quite social, seemed very interested in the study, and was happy to explain things (or "teach" me as a learner). She was constantly helping around the house. Pablo seemed

to be a bit of clown. He was a little shy of me at first, but I think he became more comfortable over the course of the visits. Although he tended to speak less than the others, he often seemed to gravitate into the center of attention. Pablo had a mild orthopedic condition that slightly limited the mobility of his dominant arm. This “disability” rarely appeared to impact the manner in which the family constructed activities together, although Tasha at one point asked him how he was getting on with a video game controller (he said he was fine). Tasha took on the role of primary explainer, with Uniqua frequently chiming in. Tasha tended to keep up an ongoing commentary, verbally addressing the ongoing action of the scene, and she frequently added additional explanation (for my benefit). Although Tasha did not speak to me exclusively, her “out loud” commentary often added details known to Austin or the kids but unknown to me. I sensed that Tasha and Austin were more aware of my presence as a researcher and kept an eye on how things might be perceived, which sometimes prompted Tasha to add a comment (such as about wanting Pablo to carry his own belongings in order to teach him responsibility). I did not sense that they were limiting or changing the activities; rather they were more inclined to add additional explanation.

Tasha and Austin had a gentle teasing dynamic that seemed quite balanced, although Tasha was the louder personality. They originally met many years ago while serving in the military. They appeared to consult one another when making decisions, with Austin sometimes playing a devil’s advocate. This family was very warm and friendly, using frequent humor, nicknames, and inside jokes in their dialogue. This was a multiracial family and they talked openly about race and identity. There seemed to be a running joke about “being racist,” such as when Pablo did not want black beans for his tacos and Uniqua joked that he was racist towards

black beans. The family also appeared to enjoy physical closeness, with the kids often climbing on Austin and Tasha or sitting cuddled with them on the couch.

During my first visit with the Goddard family I made the mistake of not communicating clearly about whether I would partake in their dinner, which led me to feel bad and demur. In retrospect my failure to fully participate in family dinner added an awkward element to the start of the evening (and changed my approach to mealtimes from this point on with all the participant families). Fortunately, this family was quick to warm to strangers, and, given Tasha and Austin's professions, they were keen to help out with a student project. I felt that I gained relatively easy acceptance.

The family seemed to prefer times when all members were engaged in an activity in similar ways, such as rotating turns when equipment was limited or games required fewer players. This family appeared to value egalitarian principles. Within these broader categories the flow of activity unfolded quite organically and with input from different family members. For example during "game night," the choice and order of games was open to suggestion; the kids generally took the lead in choosing the next game; Uniqua instructed the newbie (myself) in the structure of the games; and mom and dad helped younger brother Pedro adhere to the rules.

The Barnett Family

The Barnett family included Madelyn (6), Jasmine (13), and mom Aster. The Barnett family identified a few specific family occupations that they participated in frequently and were meaningful to them. Aster mentioned that attending church together was an important weekly activity; however, once at church the family divided into separate spaces and activities that Aster thought would be challenging for an observer. Instead, as sports held significant meaning for her family, Aster suggested going to a pool, a frequent summertime activity, and attending volleyball practices and games. Aster coached her eldest daughter's volleyball team, and her younger

daughter attended in a mandatory helper capacity. I joined the Barnett family for two trips to their community pool, two volleyball practices (and one dessert outing after), and one volleyball game.

Aster requested a pre-visit meeting, as she considered her family quite different from the norm, and felt there were things it was important for me to know before I met her daughters. The Barnett family was a multiracial family; Aster's ex-husband was Pacific Islander, she was White, and her children were biracial. In the last few years Aster and her girls had all been through significant transitions, and in many ways they were reestablishing themselves as a new family composition in a new place. The dynamic was complicated involving a messy divorce a few years prior and resultant strained relationships. The family moved across the country and into Aster's parents house after the divorce. Aster was always careful to distinguish between her daughters and herself as an immediate family unit, and her parents as part of the extended family unit. Aster talked about the benefits of living so close to her parents (one floor away in the same house), but also stated that because both of her parents were still working they saw the girls for certain scheduled activities. Aster appreciated that her parents enjoyed cooking and would frequently make dinner for everyone.

Jasmine had been dealing with posttraumatic stress disorder (PTSD), and Madelyn had been diagnosed with high functioning ASD. Aster said that Jasmine did not like to talk about PTSD, but that she was doing well and excelled at school. Jasmine was more reserved and often entertained herself texting and playing with her phone. She was a talented athlete and took her sports seriously. Jasmine often appeared impatient with her younger sister but eager to converse with Aster. Madelyn was enthusiastic, talkative, and demanding of attention. She looked up to her older sister and enjoyed spending time with her family. Madelyn was athletic and enjoyed

basketball and soccer. Aster considered Madelyn's condition to be mild. She explained that they had been able to implement many strategies so that Madelyn's "bad days" decreased from several times a week to only a few times per month. Aster talked about the limited time she had to herself. She said she spent most of her time "being a mom," commuting a long distance, and working in education administration. She was laid back and willing to be silly with her girls.

Aster felt that the age gap between the girls made it difficult to plan activities that everyone enjoyed. As a teenager Jasmine was seeking more independence, spending time with her friends and did not always want to do things with her younger sister. Aster believed that Jasmine was sometimes jealous of the attention that Madelyn received. Aster said that Madelyn could not be left alone and often required a lot of her attention. Sports functioned as a time for the family to spend together, offering an opportunity for communication between family members as well as exercise. Aster was able to demonstrate interest in Jasmine's life by coaching her sports teams. While the last few years had encompassed significant change for the Barnett family, volleyball had been an anchoring occupation that allowed them to begin to participate in a new community and establish new friendships and family routines.

The Irwin Family

The Irwin family kept busy with many activities. They enjoyed playing and watching sports, and the family made an effort to support one another by attending team games. The family lived in a single-family house in a quiet neighborhood within a large metropolitan area. The Irwin family included Wilson (7), Luke (9), Callie (14), Jason (18), and parents Cindy and Eric.

Wilson, the youngest, played hard. He brought enthusiasm and physicality to his activities and enjoyed trying new things. He was participating in several different team sports. Wilson and Luke attended the same school and frequently played together at home. Wilson

enjoyed spending time with his parents and siblings. He was chatty and joked often with his older siblings.

Luke enjoyed playing with his siblings, watching video clips, swimming, talking about food and helping plan upcoming meals. Luke had Down syndrome and attended a special education classroom. He enjoyed sports and had played in an adapted baseball league. During the summer he attended a day camp program for children with special needs that included arts and sports activities. Luke was independently mobile, although his family members often took him by a hand to help lead him to the next space. Luke spoke in short sentences and phrases; his speech was sometimes difficult to understand and Cindy appeared to be the go-to interpreter.

Callie was the quietest of the bunch and was the person most likely to be using technology, such as texting on her phone while watching Wilson's basketball game. Like the other children, Callie had been involved in sports in the past. She enjoyed spending time with her friends, and was away on a beach trip with peers during one of my visits.

Jason had recently graduated from high school. He was planning to get a part time job and then enroll in a local or community college. Cindy described Jason's plan as a transitional year to figure out what he wanted to do. Jason and Eric frequently talked about, watched, and played sports (such as golf) together. Jason was very affectionate and patient with his younger siblings; he often was the one to take Luke's hand and gently guide him towards the next activity. Jason also thought about ways to modify activities to make them easier for Luke to access.

Eric worked in construction and development. He enjoyed discussing, playing, and watching sports with his kids and mentioned having played soccer in college. He was an enthusiastic spectator, invested in rooting for his team at sporting events. Cindy had primarily

been a stay at home mom, although she had recently begun working part time in a school setting. Cindy did a lot of transporting of the kids between their various schools and activities. She tended to take on an ambassadorial role, telling me about the family and asking questions. Cindy said that she always thought she would have kids, and that she had a romanticized picture of family life that included baking cookies and having fun all the time. She described the reality as complex coordination. She said: "It's hard to get everybody in the house at the same time. We try to spend time together as a family and take advantage. It means that the laundry and dishes are not maybe getting done, but we are prioritizing this [activity]." Cindy was very gentle and calm, and she would cuddle and whisper to the younger boys when she was trying to get them to do something. She was friendly and social with other parents in group settings.

I joined the Irwin family attending Wilson's basketball game; getting ice cream and playing at a McDonald's playspace; a trip to their community swimming pool; and attending Wilson's soccer game and then going home and playing a pickup football game.

The Vida Family

The Vida family were world travelers. Both parents were originally from different continents, Kevin from Oceania and Maya from Asia. They had lived in Europe and Asia as well as the United States. Maya and Kevin met on their first day of work; they both worked in biotechnology. They dated internationally for a while and eventually got married. Of their time before having children Maya said, "We recommend it. We had fun. We traveled a lot." The Vida family included three children: Todd (10), Evie (7), and Sasha (2); grandmother Nana and her personal aide Carmina were also staying with the family on an extended visit at the time of the study. The family also received part-time in home services from aide Louisa. The family continued to highly value travel. Maya joked: "Everywhere we go, we're critiquing accessibility."

Todd often took on the role of helper and was especially close to Sasha. He dedicated a lot of his attention to her and seemed to enjoy playing with her. He told me that he was the one that taught her how to do a fist bump. Todd liked Star Wars, Legos, soccer, swimming, and playing Wii games. Sasha was the baby of the family. She loved running, climbing, jumping, and being barefoot. Sasha was very expressive, both in her countenances and gestures. I frequently saw her use a quiet voice and a face of consternation to order the other kids (and adults) around, exert ownership, or give directions: “You can’t go that way! My soccer ball! You can’t use it. Get off!” Sasha had a habit of wagging her index finger when she was warning someone off. Kevin joked that Sasha’s favorite saying was “Don’t do that! Don’t do that, Todd!” She seemed very at ease with adults and other children, enjoyed checking out where the action was happening, and trying out activities.

Evie was the middle child. Maya said that Evie liked books, and that Evie and Sasha enjoyed doing art projects together such as finger painting. Evie played on an adapted baseball team, attended both summer school and a day camp (in the summer), and participated in several weekly therapies. Maya said that they knew in utero that there were some health concerns for Evie, and she surprised the family with a premature arrival. Evie had a diagnosis that fit under the cerebral palsy (CP) umbrella. She had some associated seizure activity, and was suspected of having visual impairments (they were waiting for a full assessment through the school system). She also had some diminished pulmonary function and because she was unable to clear the phlegm from her lungs very efficiently, she used a vibrating vest daily. Maya described Evie as being in pretty good health; Maya felt that the vest had reduced Evie’s susceptibility to colds and frequency of seasonal illness.

Evie had some independent trunk control and could lift her head up for short periods; she also did some swiping, reaching, and grasping movements with her hands. Evie moved her entire body with support. She used a wheelchair or stroller for longer distances, and practiced standing and walking using a supported walker and orthotics. Evie received most of her nutrition through tube feeding. Maya said as far as academics they were not sure what to expect, but at the time they were working very actively on communication. Evie used visual gaze and head turns to make some choices and was beginning to work with a pictorial communication book. She moved her eyes a lot to look at what was happening around her. Part-time aide worker Louisa commented, "Evie doesn't miss anything. She's very aware."

Maya and Kevin were a laid back couple who enjoyed socializing with friends, telling stories, and entertaining. Kevin was very animated and had a ready laugh. He was always happy to help move Evie and was especially affectionate with her. Maya was warm, friendly, and in frequent motion helping the kids. Maya would often add details to Kevin's accounts of their past experiences. They both had hard science backgrounds. When I asked Maya about learning so much about CP, neurology, and medical interventions she said: "Oh, yeah. Kevin and I both love it. We find it really interesting." Maya said she and Kevin love to go to the doctors and ask lots of questions to try and understand things better. For them, thinking through all these different facets of Evie's care is an engaging topic. Maya said therapies have become a family thing.

Kevin was currently working full time and traveled frequently on business. Maya had not been working full time since Evie was born. She had taken on a few side projects, and was thinking that after Sasha started preschool she might pick up a little bit more. Maya's scientific orientation was evident in her "confession" of interest in a non-evidence based listening therapy, as well as the familiar way in which she explained assent to Todd; she told him he could "toot

and burp” and do all his normal stuff and not worry about it. Maya’s mother, Nana, was present during the first two visits. She was accompanied by a personal aide, Carmina, who acted as a bit of an auntie to the kids. At the time Sasha really enjoyed spending a lot of time with Nana. Maya said that when they lived in Asia they had the benefit of nannies. The family did not have any live-in helpers at their present home, but did receive part time caregiving services from Louisa.

The family had been living in Asia for several years before moving to the US a year and half prior. Maya said when it was time for the next project, Kevin’s company gave them the choice between Europe and the US. They chose the US in part for the more inclusive school programs. The family lived in a spacious single family home with a large yard in a quiet, tree-lined neighborhood. Kevin said that this was the least populated place he had ever lived. Maya said living in the US has presented them with the new issue of not having any family close by. She said they were asked to list emergency contacts on a lot of paperwork for Evie. “I don’t know who to put. Those who understand Evie’s care, it’s really just Louisa and maybe her teacher at school. You know, we have neighbors here, but they don’t know how to take care of Evie. So it’s something I’ve been thinking about a lot, is just we don’t have close support here, although we have resources.”

I joined the Vida family for a BBQ; physical therapy session; children’s museum outing; and one of Evie’s baseball games.

The Researcher

I grew up part of a small nuclear family that fits many conceptions of “traditional”: two married parents, a younger brother, a suburban home, and mandatory family dinners. We lived for most of my childhood in a middle class suburban neighborhood in New England, filled with other (fairly similar) families, and we participated in the community a lot. I walked to and from public school everyday. My family diverged from traditional norms in other respects: a

multiracial, multicultural family, we had lived abroad and had extended family distributed across the globe. My mother became the legal guardian of her sister, my aunt, who had intellectual and physical disabilities and lived in a group home in a nearby town. Overall I had a very stable family structure throughout my childhood. My family held clear values of education, volunteerism, and the importance of travel and “having experiences.” My childhood was safe and comfortable, my family generally got along well, and I continue to highly value these relationships today. I feel extremely fortunate and grateful.

When I began this dissertation I brought my own life histories and experiences, which impact my perspectives and everything from my style of interaction to my habits of thinking. I brought expectations, hopes, and motives. I acknowledge that position is not merely something an individual can exert upon the world, or upon a research project, or stake out within a community. I think of position as the theoretical interpretation of situatedness. The aforementioned are some of the ways I position myself *within* family, although of course there are many other ways of defining family and living in community. I also position myself *without* family. My focus is on the families of school-age children, and I live outside of this type of family. I do not have the roles or responsibilities of being a parent, nor of being a partner in a union. I currently live in community with other graduate students. I am cognizant of the potential benefits and hindrances of not living in the type of family I accessed in terms of communication and interpretation of family talk and family doings.

I should also note that when thinking about working with families as well as studying everyday family life I did often rely on schema of families with children. DeVault (2003) called this “a taken-for-granted association of family with children” (p. 1296). Despite deep reading and discussion of the construct of family, the relational language of family, and cultural motifs of

idealized families, I still noticed within myself a tendency to think first of this “type” of family unit before thinking of other compositions. Working alongside this persistent and pervasive norm was sometimes uncomfortable. My research focus in this study was to examine families with children, but I acknowledge that the use of titles and language related to family is imperfect and often excludes other configurations that offer equally valid and important enactments of family occupation.

I identify as a woman, and I work and study within a profession and discipline with a high proportion of women. I think that many people see it as a natural fit for female researchers to be interested in families, stemming from cultural conceptions of women having inherently nurturing characters, interest in children, or concern with families as largely (historically) women’s domains. While I resist this stereotyping of women, I benefit from access to symbols, metaphors, and language about families that are directed towards women. I believe that I also was aided by a prevailing cultural comfort with women and children doing activities together, and that I was readily viewed as a non-threatening addition to the families I visited. I assisted with physically carrying children at times, and on occasion also accompanied mothers and children into swimming pool locker rooms or was present during dressing activities.

Ultimately I took the most advantage from my identity as a learner. I have taken coursework in my graduate occupational therapy and occupational science programs related to research theory, participant observation, and interviewing techniques. I have pursued additional training in coding and analyzing qualitative data. The steps have been helpful, but I entered into the field as a novice, the dissertation project my most serious foray into research to date. I advertised the study and recruited in such a way as to emphasize my positioning as a student, keen to learn about research methods and family experiences.

CHAPTER 5. MANUSCRIPT 1: ACCESSING FAMILIES IN CONTEXT: PARENT PERSPECTIVES ON STUDY DESIGN

Introduction

The conversation about the challenges to studying family life has spanned decades, and no single method has emerged as most appropriate (Rönkä & Korvela, 2009; Rosenblatt & Fischer, 1993). Throughout much of the 20th century the field of family science within the United States has allowed for a dichotomy between the exterior public and interior private spheres of family life (Doherty, Boss, LaRossa, Schumm, & Steinmetz, 1993). The ordinary activities of family life remain largely understudied; Daly (2003) described everyday family life as existing within the equivalent of an artistic negative space, “the recessive areas that we are unaccustomed to seeing but that are every bit as important for the representation of the reality at hand” (p. 771). Health researchers are also concerned by the systematic underexamination of families in healthcare given the widespread endorsement of family-centered care for improving health outcomes and health system utilization (Kuhlthau et al., 2011; Lawlor & Mattingly, 2009). Family theorists and researchers have called for more attention to be paid to the interactive processes of everyday life and have acknowledged the need to develop innovative methodologies in order to capture its complexity (Cummings, Bergman, & Kuznicki, 2014; Daly, 2003; Gabb, 2009; Rönkä & Korvela, 2009).

Collaborative inquiry represents the push towards employing research techniques that are “participatory, democratic, and reflective in design, methods, and dissemination” (Bridges & McGee, 2011, p. 213). The idea of collaboration extends beyond data collection activities to include study design and bringing relevant stakeholders into the planning phases of research.

Turnball, Friesen, and Ramirez (1998) outlined a continuum of family participation in research, ranging from families as research participants to families as research leaders. As Turnball et al. explained, the goal of participatory action research (PAR) is to move towards increased researcher and stakeholder partnership. Specifically highlighted benefits of such cooperative research approaches included increased rigor, relevance, and utilization of the research results. They noted that PAR techniques may help increase feasibility and acceptability of research procedures, and may provide logistical advantages, such as when families enthusiastically spread information about the study across social networks, thus speeding the recruitment process.

Recent attention on the gap between research and practice has shed light on the importance of increasing social validity, (the acceptability and satisfaction of consumers and with the research), by involving key stakeholders in research design and decision-making (Dingfelder & Mandell, 2011; Small, 2005). Researchers need to involve stakeholders that do not have financial involvement or conflict of interest in design decisions (Ioannidis et al., 2014). Vander Stoep, Williams, Jones, Green, and Trupin (1999) were relatively early adopters of family researcher partnerships using participatory research strategies to explore family engagement in children's mental health services research. They argued that partnering with families improved the relevance of the research and helped them design research to produce meaningful knowledge. Their family partners contributed passion and energy, healthy skepticism, clarity, validity, and alternate perspectives that enhanced study design and analysis (Vander Stoep et al., 1999).

Much of the literature about the experience of research focuses exclusively on the reflexive accounts of researchers, resulting in a critical gap in the perspective of participants (Hadfield-Hill & Horton, 2014). While it is understood that parents typically serve as facilitators

of children's participation in research studies (Broome & Richards, 2003; Margolin et al., 2005), there is limited literature about the experience of participating as a family. One of the few studies examining how families make decisions about participation in research was Lewis's (2009) study of Scottish parent-child communication about sexuality. She found that mothers typically adopted the gatekeeper roles by virtue of taking charge of communication and making arrangements with the researcher. If the main gatekeeper was inclined to participate, she tended to influence the participation of other family members. Lewis noted that the negotiation process mostly took place privately and did not involve discussion with the researcher. Her work suggests the need for more research into how gatekeepers perceive and interpret information about research studies as a point of entry for learning more about family experiences of participation in research.

Spoth and Redmond (1992) used surveys and telephone interviews to examine barriers to family participation in prevention research. They found that time and schedule factors were most frequently cited as obstacles to recruitment for what was perceived to be an intensive intervention study. Lesser barriers included hesitation to be the subject of research, and reluctance to be videotaped. More recently Frueler et al. (2013) used semi-structured interviews with parents of children who had participated in a randomized controlled trial intervention study to investigate how it was experienced. They found that participating in the study conferred feelings of validation for some parents with concerns about their child's development, educated parents about community resources available, and laid a foundation for future therapeutic interventions. All the participants had hoped to be randomized to receive the intervention, highlighting the issue of reciprocity in research and the desire for useable knowledge outputs.

At present there is limited published literature available to help scholars design accessible studies, understand factors impacting participation, and recruit broader and more diverse samples. More research is needed to expand our understanding of how and why families become participants in studies inclusive of a variety of families and methods, particularly for studies within naturalistic contexts. The current study was nested within a larger dissertation study about family life and aimed to explicitly seek stakeholder input and expertise for the design of a subsequent phase of investigation. This study had two aims: (1) Explore participant perceptions of past research experiences, including why they chose to be involved, as well as barriers and supports to participation; and (2) Explore participant recommendations for naturalistic study design.

Method

Sampling. Parent advisors were recruited using opportunity and snowball sampling methods, utilizing local therapist and parent networks and listservs, as well as social contacts. Informational flyers were posted in public spaces including community centers, libraries, and university bulletin boards. Most of the parent advisors contacted the researcher after being forwarded an informational email by a mutual acquaintance. All participants were provided with informational emails and researcher contact information that they were welcome to pass along to other parents they knew that might be interested in learning more about the study. One parent replied to an informational flyer hung on a public bulletin board.

Inclusion criteria. The parent advisors were required to be 18 years of age or older with conversational English language ability, parents to children of any age, and to have had previous involvement in research activities. Involvement was broadly defined to include experience as a direct participant in a previous or ongoing study (or parent of a participating child), or as an investigator that had gone through the process of contemplating appropriate methods for the

scholarly pursuit of knowledge. Recruitment materials explained: “This is the first phase of a larger study about family life, and information from the interviews will help shape the design of the study in order to try and make it as ‘family-friendly’ as possible.”

Participants. 13 parent advisors, representing 12 distinct family units participated in the interviews (one husband and wife participated together). Parent advisor demographics are described in Table 1. All of the parent advisors were married and living in the same household as their spouses and children, and had children ranging in age from 3 months to 17 years old. One parent was part of a same-sex couple. These parent advisors represented a sample with high educational attainment and paid employment in fields related to science, academia, or healthcare. Unanticipated but also of note is that all of the parent advisors were also research consumers, and most had been involved in some form of data collection either during graduate school or as part of professional employment.

Researcher. As the solo researcher I leveraged my graduate student identity and positioning as a learner that was “new to research.” I explained that the research would assist with my dissertation and personal learning. I also expressed that my interest in family research methods had developed as I began the process of trying to design a study, and had even come to surpass my original interests in daily family life. I briefly shared that I had past work experience with children and families that had led to my interest in the life experiences of families with children with disabilities and my long-term goal of supporting family health interventions. When asked, I readily disclosed that I was not a parent and expressed my desire for parental input.

Ethical considerations. This study submission was approved by the University of North Carolina at Chapel Hill Office of Human Research Ethics and included documented consent, safe data storage, and the use of pseudonyms to protect participant privacy.

Data collection. Interviews were scheduled at locations selected by the parent advisors. Most meetings occurred in coffee shops, one took place in the parent advisor's home and one interview was conducted while walking outside. A semi-structured interview approach was chosen to allow for a balance of directed questions and participant-driven topics. I adopted an "interviewee-centered" approach including a non-interruptive style of conversation and nonjudgmental attitude (Hesse-Biber & Leavy, 2011). Each parent advisor completed one interview lasting 45-90 minutes. All parent advisors consented to audio recording of the interviews; the audio recordings were later transcribed verbatim.

Data analysis. Data analysis followed an inductive thematic approach adapted from Braun and Clarke (2006) and utilized coding strategies described by Saldaña (2015). I began by re-reading the data and posing questions such as, "What messages about the research process is this gatekeeper attempting to convey?" and "What are the implications for study design?" Multiple cycles of coding were undertaken to synthesize the data and search for themes, including first cycle descriptive, in vivo, and process coding, and second cycle affective coding including emotions coding and values, attitudes, and beliefs coding. The resultant codes were then condensed into three overarching themes with related sub-themes.

Results

The interviews revealed prevalent themes related to the broad topics of: (1) motivations, (2) reservations, and (3) recommendations. Motivations included parent advisors' reflections on their rationale for involving themselves, their children, and families in research studies. Reservations described concerns parent advisors anticipated when thinking about participation in naturalistic research given the current realities of their daily lives. Recommendations offered suggestions for future naturalistic family study design.

(1) Motivations: “A ‘wanting to help’ sort of thing.” When I asked about why the parent advisors had decided to involve their children and families in research they reported several motivating factors including the inherent value of science, professional interest, the opportunity to expose their children to research, and as a means of helping improve the lives of others. Monetary incentives were mentioned as a secondary perk.

Positive view of science. The parent advisors spoke readily about their professional ties to research and their broad support of scientific work. For example, couple Jess and Alex spoke of how they both valued science. Jess came from a natural sciences background, and Alex was a healthcare professional. Jess spoke frequently of the need for broader samples to increase good factual data. Alex spoke about employing evidence-based practices in his daily clinical practice rather than “stabbing around in the dark.” This positive view of science as helping society was mentioned by nearly all of the participants. Michael, also a healthcare professional, described himself as loving medicine and science. Michael expressed that he and his wife have the mindset to involve their kids in research because they “come from research” and thus appreciate the knowledge gained from past studies as well as respect the need for participants. He explained that the decision to participate is natural: “We know that science doesn’t move forward without people participating.”

Many of the parent advisors described professional involvement in conducting research studies and recalled the challenges of recruitment as one of the most difficult parts of doing research. They were sympathetic to fellow researchers and open to being involved when possible. Andi captured this sentiment as she explained her dual rationale: "One, knowing how difficult it is to recruit people, and then the other thing is just wanting to help further science. So I feel sort of that - obligation's kind of a strong word - but, you know, kind of a ‘wanting to help’

sort of thing." Andi participated in studies because she felt that understanding how things work helps people improve their lives.

Educational opportunity for children. Given that the parent advisors viewed science as a positive endeavor, they also felt that exposure to science had educational value for their children.

[Speaking about witnessing a father and daughter coming to the lab to take part in a research project:] He said that the whole reason that he brought her was that he wanted to show her what it's like to do science. And that people do science as a career, and that, you know, it can be interesting and fun. And I loved that that was what he wanted to expose his daughter to, so there's some of that in me too. Like, I want to show my kids that, you know, you can do this interesting stuff. (Sabine)

And I think it's interesting maybe later to tell them, hey, you contributed to this study. Maybe they'll find some of it interesting.... And I want my kids to also know that research is important, and that if we can take the time to do it... Being in the moment it's just hard to find the time. (Hannah)

The parent advisors felt there was some potential benefit to involving their children in research from an early age. Sabine talked about being inspired by father-daughter participants in one of her own studies, as well as her own desire to introduce her children to scientific processes and careers. Hannah also saw studies as teachable moments to instill the value of science in her children. She envisioned that she might revisit the experience later with her children when they were older and might be more interested in the study outcomes.

Helping others. Charlotte, a new mother who had been involved in prenatal studies as well as professionally involved in research explained that she would become involved in studies if they related to "things that are important to me, and my sense of community, and I feel like I'm part of the general community of mothers with young children and just helping." Olivia similarly was most interested in studies that had some kind of family focus or related to a need that she felt her own family shared. The parent advisors spoke about engaging in research as a means of being a good neighbor by contributing to science that might help the general good. Michael and

Susan described that they were happy to have their families or children serve as comparisons for investigations or interventions that aimed to help families with children who might have disabilities or health problems. Michael mentioned the potential of such studies to bring extra attention or treatments to families that might benefit from them. The parent advisors felt that general benefit to the community was a motivating factor even if their own family might not benefit directly.

Compensation. The parent advisors I interviewed specified that monetary compensation was generally a secondary incentive to their support of science in general. Several mentioned that they felt that for some families the financial considerations would be more important, and expressed that because they were financially stable they were able to choose to participate based first and foremost on their interest. However they also acknowledged that compensation was considered a perk, and was usually exciting for their children. As Michael pointed out: “I do think money talks when it comes to kids.” Olivia spoke about small monetary compensations having great resonance with her kids, and stated that the research activities felt like a little job for them.

(2) Reservations: "It would be taking up space in my mental list of things to do."

The biggest reservations the parent advisors spoke about included (1) *fitting it in*, and (2) *emotional vulnerability*. These factors were identified as playing a significant role in their determination about whether they would be willing or able to sign onto a naturalistic research study.

Fitting it in: Temporal, emotional and physical considerations.

Temporal.

Now that Noelle is in school mornings are kind of complicated and they're totally out for her... And now she is starting to have more afternoon activities, and then there's homework and stuff, so weekdays are actually pretty tough. And then, you know, they go to bed pretty early. So, evenings are kind of out. (Sabine)

All of the parent advisors described perceived logistical challenges to scheduling research activities. As Melody noted: "It's just very day-dependent." Many of the parent advisors recounted their typical daily schedules to illustrate the narrow bands of time in which everyone was together in the home. Generally mornings were described as operating on a tight schedule with a slim time cushion, afternoons were often filled with children's activities or sports, and evenings included dinner preparation, homework for school-aged children, bathing and bedtime routines. Weekdays were described as tightly scheduled but more predictable, whereas weekends tended to be more relaxed but less predictable. Parent advisor preferences for scheduling were extremely varied including time of day, season, weekdays vs. weekends, and duration and frequency of visits. The timing and duration of each visit was often dependent on the age of the child, and naptimes were mentioned as a significant planning factor. The parent advisors suggested durations of visits ranging from 30 minutes to all day. Some parents advisors suggested once a week visits for a set number of weeks, such as four to eight weeks. Other parents felt that daily visits for a shorter duration such as everyday for one week would be more feasible.

Emotional.

I feel like honestly I would hesitate to sign up for something that involved... really more than a couple visits... But that's mainly because when I sign up for something I feel really compelled to follow through, and then I feel like if I had sort of committed to six visits- like once a month over the span of six months- I would sort of feel like, oh, we can't back out. And then if something came up...

Scheduling, and then just like, mentally. It would be taking up space in my mental list of things to do. And I tend to already feel a little overwhelmed by just, I don't know, all the things on our plates. (Laughs)... (Melody)

Melody expressed the frequently cited sentiment that research participation represents a family commitment and adds to the already busy family schedule. Although Melody had conducted research projects and spoke of being better informed of her rights to discontinue a study at any time than the general public, she stated that she would feel guilty if she had to “back out.” In addition to the challenges of accommodating the research into the family schedule, Melody also pointed to the mental burden of adding another task to the “to do” list. In this sense research participation could compete with other daily tasks and potentially be an energy-depleting endeavor. The emotional space needed to accommodate signing up for research activities added to the temporal pragmatics.

Physical. Several of the parent advisors mentioned the challenges associated with having a researcher come into the home. A few parent advisors mentioned specific concerns about family pets that did not react well to strangers. Krista described how her apartment quickly shrunk with the addition of more bodies in a smaller space. Michael mentioned that his house could feel small with immediate family members present, and that his children often preferred to be in the same space as his wife and himself, thus concentrating everyone within a single room. Similarly, Sarah described her family at home as a system that needs to function like a well-oiled machine and might be vulnerable to the disruption of a researcher presence. In addition, Sabine commented that the novelty of a visitor is especially problematic at the end of the day when she is trying to settle her children down in preparation for bed. Many of the parent advisors expressed that researcher flexibility in location of observation and openness to both home and community spaces was perceived to be less logistically taxing.

Vulnerability: “Deep feelings of self protection.” In addition to the pragmatics of coordinating schedules and fitting the research (and researcher) in, the parent advisors also frequently talked about emotional barriers to participation. Sarah mentioned how parenting and family life is politicized and scrutinized, and said that she would be nervous about a researcher walking away with misperceptions about her family. She said, “That would be my number one concern, that you would judge my parenting. Cause that's like... (laughs)... that's a big button for a lot of us I think.” Sarah talked at length about the emotional complexities of parenting, including feelings of shame and inadequacy. She felt that she would be more comfortable that a researcher who was also a parent would understand that complexity. Other parent advisors felt less strongly about whether the potential researcher was a parent or non-parent, but requested that the researcher enter as a learner and give the family multiple opportunities to show their strengths.

When asked about concerns associated with having a researcher doing observations the parent advisors cited judgment of parenting and daily family operations. Parent advisors readily envisioned scenarios in which a researcher was present when things were not running smoothly: “[If] this wasn't bad enough, now I've got somebody observing me, critiquing me, my parenting skills, and I'm tired, and it's the end of the day, and my kids aren't behaving well” (Susan). Parent advisors talked about the uncertainty of how children might behave and that when folks were tired or hungry things might “get ugly.” Melody felt that home visits would portray a much more accurate view of family life than clinic observations, but acknowledged:

You want to put your best foot forward. And it's hard too, when you have kids you want them to put their best foot forward. So there's kind of this anxiety about- will your child be perceived in the way that you want them to be? Or will they not sleep the night before and be bouncing off the walls or whatever?

Parent advisors articulated the tension between offering realistic representations of daily life and assuring that their families had the opportunity to demonstrate some of their strengths. Hannah confessed she would try to ensure everyone was rested, fed, and that the house was tidy before a researcher arrived. She said this with a guilty smile, indicative of the competing desires to present the family in a favorable light but also to be authentic to everyday hassles and not “sugarcoat” life.

(3) Recommendations. Ultimately the comfort with a specific research plan is culturally situated within each family. However, the parent advisors offered several recommendations about study design as well as approaching and recruiting families. These included suggestions for coordinating to fit research activities into family life, researcher sensitivity and humility, and “being real” by utilizing social connections as well as developing a research relationship prior to commencing study activities. Emily summed it up: “I think that if it was a subject that I was interested in... if it was small amounts of time. And if I had good rapport with the interviewer.”

Methodological flexibility: Settings, schedules, activities.

I was lucky when I was a participant, because [the study] was pretty convenient as far as working around my schedule, especially since the entire family had to be there. I could see where that would be a challenge, because if it would've been over the last 4 months I wouldn't have been able to participate. (Laughs.) But at the time there was a lot of flexibility given, and that was able to work out well. (Krista)

As mentioned previously, the parent advisors confirmed that no “one size fits all” when it comes to planning and coordinating schedules. The parent advisors suggested that weekdays and weekends offered different glimpses of family life, with certain options working better depending on the family. Similarly they counseled patience and flexibility with study duration; most of the parent advisors felt repeated visits would be necessary and reassuring, however should be weighed against the difficulty of finding time. The parent advisors recommended

offering a range when it came to number of visits, as well as the option to customize preference for frequency when the study question would allow it. The parent advisors suggested offering flexibility in settings including home and community settings when possible and leaving the choice up to the participant families. Likewise, the parent advisors communicated that flexibility in research activities rather than rigid protocols might encourage more families to participate.

The parent advisors were generally open to participant observation with the recommendation that everyone review expectations. They articulated a clear preference for repeated visits to ensure that their children and families had multiple opportunities to display their abilities. As Sarah stated, “You’re going to have ample opportunities to see me screw up, and see my kids screw up, but to see us get it right the next week.” The increased parental confidence in repeated visits was acknowledged to juxtapose with the hassle of a longer time commitment. The parent advisors supported the idea of repeated visits within reason.

Relational approaches. Parent advisors shared that the researcher needed to be personable in order to make the family feel more at ease with having them around; they envisioned the researcher entering into daily life like a family friend. They mentioned the researcher’s ability to engage with their children as an important determinant of study success. Humility and respect for the challenges of parenting were also highlighted as conveying a non-judgmental approach. The parent advisors did not feel that researchers needed to share characteristics of life experiences with their families, but that the researchers bring an open attitude. Researchers’ ability to explain why they wanted to do the study, what they hoped to learn, and a genuine interest in the topic were viewed as important predictors. The parent advisors also appreciated researchers that were not strictly deficit-focused and were interested in seeing the abilities of their children and families as well.

Social connectivity. It was also important to parent advisors that the researcher be both a known entity and willing to establish a good working relationship. The parent advisors stated that they would be much more likely to entertain the idea of participating in a study if the researcher were somehow socially connected to someone they knew and trusted. As Jess explained, it was not enough to just be a “real” person, but a researcher asking to come visit with her family must also be “real to me.” Academic credentials and university affiliations helped reassure the parent advisors that the study was officially sanctioned, but in isolation were insufficient to convince them that a researcher would be a good fit with the family. The parent advisors suggested that researchers recruit via social networks to increase the likelihood of reaching participants with whom they shared a mutual acquaintance.

After establishing a social connection, the parent advisors suggested offering additional information and contact opportunities to further build and evaluate the working research relationship:

I'd at least want to probably talk to them. It could probably be just on the phone.... How involved were they and everything else, and how their personality was. I think that's where talking to them for a bit ahead of time- because I think that personality- I mean they can say that they're not going to judge you, but sometimes you get that sense when you talk to people (Krista).

For other parent advisors the extended introduction was as simple as sending a link to a photograph so that they would know whom to expect in person:

Like you sent me [a link to] your picture, right? I mean that meant something to me. That was good. I go to [the university website]. I see your picture. I see your interests. Actually that was very good. Cause that validates that you're not just making this up, you know? (Susan).

Charlotte admitted that during a previous study she had gone online and looked up all of the investigators prior to enrolling, which helped her feel better prepared to make a decision. For this

technology savvy group of parents, computer and internet-based methods of communication were frequently cited as mechanisms of information gathering and exchange.

A final sentiment: encouragement. The parent advisors were supportive of the idea of collaborating on study design and were encouraging of the proposed next research project. They offered a significant amount of specific advice for local recruitment as well as general reassurance that I could be an adequate researcher despite my relative inexperience.

You're thinking about this stuff. And you're never going to do it right. But that you're even aware of... that design is going to impact which families are willing to participate... and that you're thinking about this ahead of time, you're ahead of the game (Sarah).

Discussion

The parent advisors in this study consistently cited the value of science, educational opportunity, and the potential to help other families as motivators for participating in research. While there is limited literature examining this topic, these results align with Lewis's (2009) findings that parents wanted to contribute to the general expansion and growth of scientific research (and the training of new researchers) and hoped that their involvement would benefit other families. While Lewis posited that parents' reported feelings of social obligation to participate might relate to public discourse and sensational news stories, in this study parents reported a sense of professional obligation related to being consumers (and thus beneficiaries) of research.

A novel contribution of this study is the finding that parents use research participation as an opportunity to teach their children about the scientific process and the value of contributing to the development of new knowledge. This rationale may suggest new avenues of recruitment for family researchers, such as offering to share more about their work or training with child participants. Additionally, this reasoning accounts for the desire that the research experience be especially enjoyable or positive for their children (with some parents perhaps hoping their

children might be inspired to entertain scientific careers of their own). Thus, as a community, family researchers need to be sensitive to making participation engaging for all family members, but particularly children, who have historically been overlooked or undervoiced within the family context (Lewis, 2010). Encouragingly, many contemporary researchers are embracing updated conceptualizations of children as social actors, and looking to collaborate with and involve children in research about children's lives (e.g., Mazzoni & Harcourt, 2013; Phelan & Kinsella, 2014). This finding lends additional support to the inclusion of children in research about family lives.

The fact that monetary compensation was viewed as a secondary motivator likely spoke to the relative financial stability and comfort of these parent advisors; however money may be perceived as symbolically meaningful. Murry and Brody (2004) described the steps they took to establish strong working relationships with participants in a study of rural African-American families, a population previously documented to have lower participation and higher attrition rates in research and intervention programs. They wrote that paying participant families helped to establish good faith relationships and demonstrated that researchers valued the participants' time. Although there are diverse cultural attitudes towards money, in smaller amounts approved as non-coercive by institutional review boards monetary compensations may serve as convenient symbolic means of recognizing the contributions of participants.

The parent advisors' concerns and reservations about embarking on a naturalistic study voiced in these interviews echo findings from one of the few studies that has examined nonresponse in family research. Rönkä, Sevõn, Malinen, and Salonen, (2014) found in brief non-response questionnaires that "lack of time" was the most oft-cited reason for refusal (53%), closely followed by the perception that the study required "too much effort" (44%). Similarly in

the current study the parent advisors noted that finding time to participate together could be challenging. Their families were constantly navigating differing family member preferences and goals. In part, the issue of uncovering family life had to do with the difficulty of isolating spontaneity within taxing collective schedules. Often family life was experienced in moments, rather than lengthy chunks, which made the idea of scheduling visits and predicting when family time together would occur challenging. These parent advisors implied that a partial solution for planning research is to maximize flexibility about who needs to be present, short notice scheduling, and being open to including different activities within the realm of family life whenever possible (as opposed to narrow foci on particular family activities). Traditionally many qualitative researchers have attempted to address issues of trustworthiness and credibility by highlighting their prolonged engagement in the field. However, in this study the parent advisors voiced apprehension about signing up for lengthy or overly taxing time commitments. Interestingly, the desire for brevity of study duration was counterbalanced by the desire for multiple opportunities to generate a representative snapshot of family life. Parent advisors suggested repeated but not excessive visits, customized to work within the parameters of the specific family's schedule.

This study also further explicates concerns about the emotional burden of participation and the vulnerability that parents may feel about sharing the intimacy of daily life's ups and downs with a researcher. The most significant concern voiced by the parent advisors was the perceived risk of being negatively judgment of their parenting or family practices. Most existing literature about research participation and the potential for emotional harm has been specific to working with vulnerable populations, such as persons with terminal cancer or persons with addictions (e.g., Alexander, 2010; Fry & Dwyer, 2001; Tait, Voepel-Lewis, & Malviya, 2004).

Nursing research has probed the question of whether it is ethical to include people approaching end of life in research that might be distressing and has found strong evidence that such participants perceive research involvement to be rewarding, validating, and a means of helping others. Families have not usually been included as vulnerable populations, however the emotional burden of family research warrants further investigation.

Scholars have previously argued that vulnerability may serve an important function in building research relationships. In her analysis of how occupational therapists might develop an ethnographic research stance, Lawlor (2003a) highlighted the significance of vulnerability: “Vulnerability is not merely a form of emotional fragility, but is a way of participating in aspects of informants’ lives that enhances understanding. It is a vehicle for participation and an essential ingredient to building relationships” (p. 33). In this case Lawlor was arguing that investigators must enter the field with openness to being vulnerable as a means of being more authentically invested research partners. In the current study parents expressed their perceived vulnerability in entering into participant roles. They emphasized the need to consider the emotional labor of research for all parties. Hatfield-Hill and Horton (2014) noted that “emotions in research emerge from being and working together” (p. 149), and “the emotions experienced during fieldwork are seldom just emotions-about-research” (p. 148). Family researchers must acknowledge and respect the vulnerability they inherently are asking participants to engage with, and take seriously the spirit in which it is offered. Research is not discomfort-free, and avoidance of such feelings is not justification to ignore more intimate aspects of daily life.

Study limitations. The opportunity and snowball sampling methods drew parent advisors from a small geographic area; all participants were White, the majority were female (11 of 13), and with high educational attainment. The researcher was not able to offer any financial

incentives, which may have restricted access to gatekeepers with a wider range of socioeconomic status. Additionally the households represented by this sample represented two married parents and one or more children living in a family home. The parent advisors reported being either employed or full time students. As emerged during data analysis, close ties to research production were often cited as a rationale for research participation, and this group of parent advisors all reported interest in scientific knowledge related to their professions.

This group in many ways reflected the highly motivated band of research participants. Their insights add tremendously to the understanding of participant self-selection, however, this group was not able to speak to hard-to-access groups and underrepresented populations. Much more research is needed to understand the perspectives of parents across the range of household types, education levels, geographic settings, and professions. Additionally those that chose to participate in this study had professional ties to education, healthcare, or science. This appeared to be a strongly motivating factor for these participants. There is clearly a need to develop more targeted understanding of how persons less directly involved in research decide to participate.

Conclusions and Future Directions

Research with families inherently reflects co-constructed experiences among investigators and participants. The findings from this study suggest the importance of approaching research as a negotiated endeavor and the potential of including relevant stakeholders in collaboration early in the process. These parent advisors were willing and readily able to offer suggestions and considerations to ensure the research study was more feasible and accessible to a variety of families. Cooperative processes allow researchers to begin building working relationships and relevant social networks that may aid participant recruitment, as well as offer valuable advice about local contexts.

Exploring motivations for participation in research may be an avenue to better understand and design recruitment materials as well as to consider expanding relevant outputs. For instance, this group of parents indicated that they were invested in research as an exemplar of scientific process and enjoyed role modeling to children the options of research careers. Thus, one non-traditional product that was appealing to these parent advisors was the opportunity to use research participation as a learning opportunity for their children. This finding suggests that complementary age appropriate informational materials about scientific exploration might be appealing to these parents. The study supports general recommendations for translational and PAR research including consideration of novel products and action outcomes.

The parent advisors in this study revealed that they were more concerned with the issue of self-protection than the idea that home life should be private. Despite the strong cultural discourses about the privacy of the home, families are also interdependent and in many ways are primed to have others involved in their home, interacting with their children, and helping them out in various ways. Family research requests that families allow a lens to be held up to them, entering into their own reflexive process as well as disclosing personal information to the researcher. Vulnerability is about exposure, risk, trust, and emotional candor, and not bringing judgment that might harm a family's identity or question the choices they are making in everyday living. These parent advisors reported that family life is challenging, difficult, messy, and humbling. They wanted reassurance of researcher humanity too. In contrast to previous ethnographic discussions of the possibility of being an objective observer, these parent advisors talked about researchers entering into daily life as friends of the family. The interviewees in this study represent highly motivated parents amenable to research participation, however concerns about self-protection featured heavily in their considerations. When attempting to access hidden,

or “vulnerable” family populations researchers must be even more mindful. Collaborative inquiry is especially useful for family scholars because of its emphasis on relationships, mutual respect, and partnership.

The parent advisors emphasized several recommendations for future study design. Recognizing that families are accessed via gatekeepers, researchers must be able to approach and explain their interests to these representatives. First impressions matter; relationship-based research depends on the establishment of rapport. Investigators must be personable, authentic, and nonjudgmental. Leveraging social networks and snowball sampling methods may be especially helpful to make contact as a known entity. Family life is complex, and proposed study activities and commitments are assessed pragmatically. Whenever possible, research teams should consider customizing approaches to best fit the availability and preferences of the family. Recognizing that research is shared activity reminds us that the concerns, hopes, contexts, and abilities of all parties require ongoing coordination; research is a collective process.

CHAPTER 6. MANUSCRIPT 2: “WE TRY TO SPEND TIME TOGETHER”: THE NEGOTIATION OF FAMILY OCCUPATION.

Introduction

Most occupational science and therapy definitions of family occupation build upon Clark et al.’s (1991) definition of occupation as “chunks of culturally and personally meaningful activity in which humans engage that can be named in the lexicon of our culture” (p. 301). Indeed, family occupation has been described as purposefully constructed, culturally meaningful activities and events shared by family members (Jaffe, Humphry, & Case-Smith, 2010; Segal, 1999). The purposes of family occupation have been found to include the pleasure of being together, sharing values and expectations, and providing learning opportunities for children (Segal, 1999). Recent scholarship has also considered how family occupation might help build families or represent their ability to manage daily tasks (Bonsall, 2014; DeGrace, Hoffman, Hutson, & Kolobe, 2014). However, most descriptions of family occupation have focused on the interactions of individuals comprising a family unit, rather than the coordinated actions of a collective.

Family occupation studies have also largely been limited by a focus on disruption attributed to the presence of childhood disability. For example, ASDs have been associated with the disruption of mealtimes and bedtimes (Marquenie, Rodger, Mangohig, & Cronin, 2011), changes in how families plan and participate in activities together (Bagby, Dickie, & Baranek, 2012), reduced travel and participation in community events (Schaaf et al., 2011), and decreased frequency of feeling like a family (DeGrace, 2004). There is, however, an emerging recognition that disability is not inherently negative, and may instead represent a press for change or

adaptation. Koome, Hocking, and Sutton's (2012) study of family routines noted that these coordinated activities served as early indicators of adolescent mental health status, and that the establishment of new routines in the face of illness was perceived to be meaningful. Crespo et al. (2013) similarly found that family activities had the potential to function as strategic resources offering opportunities to express support and re-establish a sense of normalcy in the context of chronic health conditions. Given the need to support family well-being within context, more research is needed that examines disability as a neutral factor influencing family life in situationally-specific ways.

The other significant gap in family occupations literature is the heavy use of individually-focused methodological approaches such as maternal interviews (e.g., DeGrace, 2004; Segal, 2000; Larson, 2000; Marquenie, Rodger, Mangohig, & Cronin, 2011; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Boyd, Harkins McCarty, and Sethi (2014) have critiqued the aforementioned ASD literature for its reliance on interview methods, focus on caregiver perspective, and sampling of families with young children; indeed these concerns characterize much of the broader family occupation literature. Individual interviews prioritize singular voices and unintentionally obscure the complexity and diversity of family experience. Parents and children experience both daily life and disability differently (e.g., Connors & Stalker, 2007; Mason & Tipper, 2008; Scott, 2008), and children's experiences are largely missing from the understanding of family occupation. Methods that are more compatible with the inclusion of multiple family members, such as observational approaches, offer the opportunity to examine processes as they occur, and thereby expand knowledge of how occupations change, coordinate, and diverge.

The intent of this study was the observational investigation of family occupation in order to develop understanding of this group process. I drew upon Rönkä and Korvela's (2009) definition of "everyday family life" to represent my understanding of family occupation as "a process that family members constantly create and construct in time and space, together and separately, by material, mental, and social means" (p. 88). Given the observational nature of this study I focused on the subset of family occupations that occur when parts of the family share a degree of togetherness via proximity. The study aimed to describe processes of negotiation inherent to the coordination of family occupation, centering on family time activities among families with one or more children with disabilities.

Method

Research activities. The study utilized an ethnographic approach involving participant observations in home and community settings. Families were recruited from communities in a southeastern U.S. state, using a combination of purposive, opportunity, and snowball sampling techniques. This study was reviewed and approved by the University of North Carolina at Chapel Hill Office of Human Research Ethics. Pseudonyms have been substituted to protect the privacy of family participants.

Inclusion criteria. "Family" was considered a fluid, flexible, and contextually-dependent construct; I followed the lead of participants and utilized their self-definitions of family. I placed no limitations on structure beyond the initial recruitment of English-speaking "families" with at least one adult and one child with a (family reported) disability between 6 and 11 years old. The age range was chosen to correspond to the Center for Disease Control's categorization of middle childhood, a time of high family activity participation, as well as maturing child self expression and experience interacting with non-relative adults (CDC, 2016; Maccoby, 1984; McHale, Crouter, & Tucker, 2001).

Participants.

The Irwin Family. The Irwin family was one of seven families that participated in the study. The Irwin family included Eric (dad), Cindy (mom), Jason (18), Callie (14), Luke (9), and Wilson (7). The family lived in a single-family home in the suburban neighborhood of a major metropolitan area. Eric worked in real estate and Cindy worked part-time in education. Jason had recently graduated from high school and was living at home, looking for a job and hoping to enroll in community college classes. Callie, Luke, and Wilson were full time students. Luke, who had Down syndrome, attended a special education classroom. He communicated verbally although it was sometimes difficult for non-family members to understand his speech. The family was active in the community and usually busy with sports including soccer, baseball, football, and golf. Cindy reported that it could be challenging to get everyone together at the same time. She used the term “complex coordinating” and reported that it was a family priority to spend time together: “We don’t always do it but we try.”

Researcher. I was the sole researcher in the field. Throughout my engagement with the participant families I leveraged identities related to being a graduate student and beginning researcher who wanted to be seen foremost as a learner. I openly disclosed that I was not a parent and I thanked the families for helping with my personal learning as well as contributing to larger academic understanding. I did not obscure that I was an occupational therapist, but I did also share that my interest in the research stemmed from a range of experiences working with children and families with and without disabilities. During the rapport building process I briefly shared other details about my life experiences that led to my living in the local geographic area and studying at my university.

Data collection. Families were asked to choose activities representative of things they liked to do together within daily family life. Data collection consisted of 3-6 visits with each family at times, locations, and for durations of their choosing. I occasionally rode with families in their cars to secondary locations if convenient. Most visits occurred in the family home or at community venues such as swimming pools or museums. Throughout the visits I strove to adopt a “guest position” as described by Alsaker and Josephsson (2010); I entered as a visitor “interested in the everyday life of the participants” and I “followed the participants’ initiatives regarding how to do things and the subsequent conversational themes” (p. 60).

A condensed audio account was recorded immediately after the conclusion of each visit and including as many verbatim conversations as I could recall; expanded fieldnotes were written as soon as possible after each visit. Fieldnotes included attention to the nine dimensions of social situations identified by Spradley (1980): Space, actor, activity, object, act, event, time goal, and feeling. In addition, fieldnotes contained information about the sensory features of the episode (Pink, 2009), as well as the potential implications of silence (Lewis, 2010).

Data analysis. Multiple techniques and cycles of analysis were employed following an iterative-inductive approach. I utilized data management and accounting logs derived from the recommendations of Miles, Huberman, and Saldaña (2013). Primary analytic activities included examination of powerful data excerpts, inventorying data segments across each visit to develop episode profiles, reexamining disregarded sections, composing diagrams and memos to trace narrative arcs, and visualization techniques to connect and disrupt cases and episodes (Maietta & Mihas, 2015).² A narrative consideration of significant scenes allowed for the exploration of

² The ‘Sort & sift: Think and shift’ method described by Maietta and Mihas (2015) is one of many extant guides to the longstanding ethnographic analytic practices of pulling apart and drawing together data in different ways during repeated and evolving interpretations.

processes of negotiation,³ which I conceptualized as an ongoing and collective process of perspective and priority-shifting in order to collectively enact occupation. I examined meaning as embedded in everyday occupation (Alsaker & Josephsson, 2010), and explored emergent, enacted, and co-produced narrative events of family life (Alsaker, Bongaardt, & Josephsson, 2009; Blum-Kulka, 1997; Mattingly, 2000). The applicability of narrative analysis to participant observation of action has been previously articulated by occupational science and therapy scholars (e.g. Alsaker & Josephsson, 2010; Alsaker, Bongaardt, & Josephsson, 2009; Bonsall, 2012; Josephsson, Asaba, Jonsson, & Alsaker, 2006; Mattingly, 2000).

The Pickup Football Game

The following vignette illustrates complexity and tension inherent to how families navigate and coordinate occupations given their multi-bodied, multi-abled, and multi-preferenced nature. I have attempted to employ Kremer-Sadlik and Paugh's (2007) recommendation to focus on moments of connectedness within the larger flow of events. This vignette was selected as a unique scene that nonetheless exemplifies common patterns of negotiation among my participant families as they engaged in occupation together. The following scene took place within much larger sociocultural frames; I have limited the description to the most immediate contextual frame for the sake of brevity.

³ Common English language meanings of the word 'negotiate' are "1) obtain or bring about by discussion, 2) find a way over or through (an obstacle or difficult route)" (Oxford Dictionaries, n.d.). In describing negotiation, I do not consider conversation and action to be separate processes. du Bois-Reymond, Büchner, and Krüger (1993) wrote that modern intra-family relationships are characterized by "situationally grounded processes of negotiation between parents and children" (p. 87). While they were studying the culture of negotiation within family life course biographies (see also Krüger, Büchner, & du Bois-Reymond, 1994), I found contextually-situated negotiation to be a facet of moment-to-moment and day-to-day family life.

Persons: *Wilson (7), Luke (9), Callie (14), Jason (18), Cindy (mom), Eric (dad), Adrienne (visitor).*

Setting: *Saturday afternoon. The scene took place in the front yard at the Irwin family home. The family had recently returned home after attending Wilson's soccer game. Various family members were relaxing in different parts of the house, putting items away, and watching TV. The younger boys were milling around between the living room and the kitchen, where Cindy and Eric were talking.*

Scene: *Cindy announced to the younger boys that it was time to go outside. She told Luke, "You want to go outside and we will play football." Luke said no. Cindy sat down and took Luke onto her lap; she had his shoes in her hands to help him put on. Luke picked up a shoe and threw it on the floor. Cindy used a pet name for Luke and cuddled him on her lap while she asked Wilson to hand her the shoe. She quietly coaxed Luke into his shoes. Then she gently held him by the shoulders with two hands and guided him towards the door, walking behind him and nudging him along with her body. She said, "You can get some fresh air. Jason can get some fresh air. It's a nice day out; we have sunshine."*

The impetus for going outside to toss the football around stemmed from a moment of relative quiet after the transition home as everyone tried to figure out what to do next. Cindy took the opportunity to direct the action outside in order to take advantage of the good weather and promote general health and "fresh air." The intimate quality of the interaction between Cindy and Luke as she coaxed him into going along with her request typifies the physical closeness and affectionate inflections of voice and tone that I frequently observed among family members. Cindy held Luke on her lap both to physically assist him putting on his shoes, and also as means of whispering directly into his ear and offering reassuring squeezes. The embodied familiarity of

this family dyad is evident in the comfort with which Cindy and Luke shared space, touched, and manipulated one another's bodies. Cindy was attempting to guide Luke outside, even using her own body to guide Luke's body in the direction of the door. She also expanded on her initial vision of Luke and Wilson going outside by announcing that Jason would be joining them as well.

(Cindy, Eric, Luke, and Adrienne are outside.) Wilson came barreling out wearing a football helmet and he looked ready to play. We formed a loose circle and tossed the ball back and forth. Luke and Wilson were doing a lot of tackling- Luke grabbing Wilson around the waist or Wilson grabbing Luke or Eric or Cindy. We were practicing catches and defense. Jason came out and joined in. Jason threw some fast tosses that Eric and Cindy called "bullets" that Wilson was having difficulty catching. When he did catch one everybody congratulated him.

Jason threw softer and shorter passes to Luke, having him get into a catching stance first and counting aloud before he tossed the ball. Jason and Eric debated whether a less inflated ball might be easier for Luke to catch. Jason said: "Let's try using a flat football with Luke and see if he likes it better." Cindy helped Luke physically position his arms, and then reminded him when to look up to see the ball coming.

Wilson displayed considerably more enthusiasm for playing football than Luke initially did. He found some authentic football equipment (in this case a hand-me-down helmet), and appeared dressed for the part when he arrived outside. Jason challenged Wilson by tossing him more difficult passes that the family referred to as "bullets," and which appeared to elevate Wilson's effort and engagement. Wilson struggled to catch these passes, but expressed a heightened sense of accomplishment when he was finally successful. Shared cultural knowledge is evident in the mention of using an underinflated football, with both Eric and Jason

understanding that such a ball might be easier to grasp and handle. Jason appeared to employ a different approach in his passes to Luke than those to Wilson. Jason threw shorter and softer passes to maximize Luke's chance of catching them successfully. He offered additional verbal cues and Cindy offered physical and attentional cues. The net effect was Luke's increased engagement in the moment and the likelihood of his continued participation and enjoyment. Jason was able to easily interweave these different strategies based upon his sense of the bodies, capabilities, and interests of his various siblings.

After a bit of practice Jason asked Eric if we were going to play a game. Cindy said: "Well if we're going to play a game let me go see what Callie is doing; she might want to be part of this." Cindy went inside and returned a few minutes later with Callie in tow. When Callie first came out she had a neutral look on her face and I was unsure if she was being dragged into it.

Despite some initial reluctance on Luke's part, the outdoor play and football tossing proceeded well with no one protesting, complaining, or refusing to participate. It appeared that the activity might be coalescing into a more significant game, and Cindy expressed a desire to involve Callie as well. I interpreted the moment as Cindy not wanting Callie to miss out if the rest of the family was playing the game together. In the moment it was unclear to me what Callie's own interest level was, but she appeared to be amenable to the game and readily joined in. The varying interests of different family members is a natural part of the way family occupations develop, which may be manifested as a detectable or implicit tension in the way various elements of family are pulled along in activity. In this case Cindy exerted a strong pull for the family to play outside. Wilson exerted pull through his enthusiasm, whereas Luke exerted some resistance. Jason further exerted pull by organizing the play into a more structured game.

Wilson split us into two teams with suggested input from just about everyone else. There was some discussion of the downward slope of the yard and possibilities for an end zone as well as protecting the van in the driveway from contact. The older family members debated briefly and decided that each team would run plays towards a single end zone at the far side of the yard.

The football game cannot be extracted from the environment, as the physical and social contexts continue to co-constitute the unfolding action. In this case the physical parameters of the yard (including slope, shape, and size) influenced the rules and structure of the game (everyone will move towards a single end zone), and the adaptations of the gameplay throughout (not throwing passes longer than the yard, avoiding tossing or running into the street or into the family van parked in the driveway).

We started to play. Eric, Cindy, Jason, and Callie occasionally called aloud reminders about passing direction and offside rules. Eric and Cindy both ran pretty fast; Jason ran especially fast when his dad was defending, and Wilson appeared to be playing all out. Callie was occasionally playing hard, occasionally letting Luke tangle her up in a tackle, and frequently watching the plays with a bemused expression.

As we played I saw the family make certain accommodations to support Luke's participation. His teammates would frequently call his name before passing to him. Sometimes Luke accidentally passed to someone on the opposite team. That player or another family member might call aloud that it was a fumble, an incomplete, or a down in order to return possession of the ball, or they might temporarily accept Luke as a member of their team and continue to play. Part way through the game Luke announced that he wanted to "hike" the ball and that became a part of many of the plays. Members of both teams would help him orient if he started facing the wrong direction. Some of his hikes did not get off the ground but someone

would pick the ball up and keep the play going. Luke also liked picking who he was going to tackle. Often it was Callie and players from both teams would remind him: “OK, you are going to guard Callie,” and then Luke would run towards her.

Individuals adjusted their strategy and style of play alongside their fellow players and with an awareness of the impact on the group. A player might have chosen to protest every rule violation, but this would have been disruptive to the overall flow. Sibling encouragement and in-the-moment inclusiveness was thus displayed as players accepted the fluidity of the rules and norms. For example, youngest brother Wilson’s lack of concern about the exact “sameness” of the application of game parameters contributed to success of the occupation within the moment of the play. The family players used flexible strategies to facilitate the continuation of game and the enjoyment of others, including supporting Luke’s participation. Depending on the moment and who was responding the player sometimes called the play one way or another, and occasionally other members of either team suggested aloud a course of action to take. These small improvisations were then validated by the larger group as the game continued.

Additionally, Luke’s preferences were incorporated into the game play as he was able prioritize doing his favorite parts (snapping the ball or tackling) for many of the plays. These adjustments increased Luke’s enjoyment, and also enabled the game to continue without disruption due to complaint or disengagement on his part. It was not the presence of disability that arose as meaningful within the family narratives, but rather the importance of enacting family closeness through shared time and action. The family collectively navigated as a multi-preferenced but still largely united group despite the overt divisions between two competing teams. In this way the game unfolded and was constructed with incorporation of varied,

changing, and complex relationships, with moments of person vs. person challenge, as well as person vs. group and group vs. group (team vs. team).

There was one moment when Wilson teared up after bumping his head on his slightly too big helmet when he tripped, which prompted Jason to exclaim: “He hit his head on his own helmet, that's why you don't wear helmets.” But later when the football fell into prickly holly bushes past the end zone, Wilson dubbed his helmet “armor” and rescued the football with Eric helping to hold back the branches.

Eldest sibling Jason poked fun when Wilson bumped his head, pointing out the irony of hitting one's head on head protection equipment. The momentary tears did not derail the entire game, but merely elicited a pause to recover. Given Jason's critique, Wilson appeared even more determined to prove that he was playing football in an authentic and competitive manner.

Wilson's helmet choice reemerged as a conversational topic later in the game, when it enabled him to extract the football from the holly bush where it had fallen (thus pausing the game), and Wilson appeared vindicated in his choice to wear it.

We played for a while; Cindy went inside at one point and returned wearing a Miami Dolphins t-shirt. The kids teased, “Oh, Mom's got her Miami shirt on. It's getting serious.” The next time Cindy ran a touchdown Luke ran up and gave her a big hug and then they both started to do a victory dance holding hands.

We were not really keeping score. When Luke asked, “Who is winning?” Cindy would say, “Oh it's hard to tell.” The game dissolved when people began to get thirsty. Luke sat down in the driveway and Jason asked him, “Are you tired?” Luke confirmed. Cindy suggested popsicles and escorted Luke inside to the kitchen table. Jason and Callie disappeared into the

living room to watch a football game on TV, while Eric and Wilson stayed out to run a few extra plays.

As the game continued to go well and build momentum, Cindy built upon the spirit of the activity and put on a football shirt. This action prompted teasing from the kids and served to heighten engagement further by raising the stakes. Symbolically the shirt appeared to represent increased investment in the game, although not necessarily increased competition. Luke responded to Cindy's enthusiasm, joining her in a victory dance after her next big play. Cindy's comment about the score denoted the recreational nature of the game and the focus on play and enjoyment rather than points. Her comment was also accurate; given the many adaptations of the game to the setting, the fluid nature of the teams, and the lack of anyone calling out scores aloud, it was hard to evaluate the game play in standard scoring terms. The game began to dissipate as family members expressed readiness (such as Luke sitting in the driveway, or Cindy mentioning being thirsty). The flow away from the activity was varied, with some family members departing more suddenly and others more gradually. The game transitioned into several related activities: eating popsicles and watching football on TV. Meanwhile Eric returned to what I perceived to be one of his original intentions (using football practice to help Wilson improve certain sporting skills) as he and Wilson stayed outside to practice a few additional plays.

Discussion

Continuity and flow⁴. Some of the most prevalent features of the football vignette include the unfolding and flow of the occupation across time, the dynamic negotiation of the occupation, and efforts by various family members to ensure the continuity of the occupation. The multidirectional influences of time are apparent in the way the football game unfolds after the participation of the family in sports earlier in the day, as well as continued participation in sports-watching after the football game ends. The family has a strong connection to sports that is detectable in their ease and familiarity with the language, accessories, rules, and forms of multiple sports including football, as well as their frequent conversations about sporting events. There is a sense of ongoing connection to sports, the desire for the children to participate in sports and gain athletic skills, and the significant impact of sports event scheduling on the overall family schedule.

This episode also illustrates the subtle ways various family members promote continuity of engagement and action, and thus influence the sustainability of the occupation. In writing about intersubjectivity and engagement, Lawlor (2012) suggested several “vehicles of engagement” to promote the participation of social actors, including the use of “solicitation cycles,” which she described as repeated invitations within the flow of activity into more connected action. Although Lawlor wrote specifically about occupational therapy sessions, I found solicitations to be a prevalent feature of family engagement, offering the opportunity for children and adults alike to prolong, intensify, and alter occupation-in-action.

⁴ I should also note that in describing and interpreting the sequence of action and activity in the scenes that follow, I often use words such as flow, unfolding, and negotiation to try and capture the dynamic processes I observed. My use of the word flow is to indicate ongoing sequences of activity across time, and is not associated with Csikszentmihalyi’s (1975) theory of flow. Similarly, I use unfolding to describe the shifting sequence of activity, which differs from the way Segal (2000) described the maternal time-use strategy of enfolding and unfolding occupations.

Consensus action. It is also apparent from the start of the episode that not all family members share the same degree of interest, enthusiasm, or even willingness to participate in the football game. These findings align with Morgan's (1975) recognition of contradictions as a natural part of family experience and Daly's (2001) findings about the sometimes discordant nature of family time. Luke expresses through his words and actions (e.g, throwing his shoe) that he is a reluctant participant, a stark contrast to Wilson, who runs off to find a helmet. The many threads of connection among family members construct a collective entity that is continuously pulled in multiple directions by the different ideas, desires, motivations, interpretations, and actions of the various actors, resulting in ongoing and active negotiation. In the beginning of the episode Cindy's strong preference and adult power drive the activity, but the game evolves and the enthusiasm of others takes over to the degree that Cindy does not need to be continually present in order for the game to proceed. Indeed, Cindy takes short breaks in order to find Callie and later to put on a football t-shirt. At various moments Jason, Wilson, or other family members take the lead in nudging the action (such as announcing the start of the game, or needing a break to nurse a bumped head). The tension among these connective threads elicits ongoing motion, discussion, and co-construction.

Intimacy. The episode highlights the frequent touch, closeness, physicality, and intimate quality of how the family acts as both individual and collective bodies. This intimacy corresponds to the findings from Sachs and Nasser's (2009) unique study of family occupations within the context of an institutional setting:

It is interesting that intimacy, as a major characteristic of family occupations, was not mentioned in other studies. Presumably the reason is that in those studies, family occupations were investigated only in families of children living in their natural homes, where intimacy is taken for granted and permanent (p. 459).

Sachs and Nasser noted intimacy to be a key feature of family occupations, and indeed in this vignette the Irwin family demonstrate a high degree of comfort with one another. Including all bodies and the sharing of personal space are notable aspects of the football game, as well as how the members of the family move and act inside their home. At times, the closeness serves to help spur action (such as when Cindy takes Luke onto her lap to help him put on his shoes), but at other times appears more to be part of how the family plays and acts together (such as grabbing hands for a joint victory dance). van Nes, Runge, and Jonsson (2009) described the blurring of individual bodies among a couple out of necessity after one member experienced a stroke; among the Irwin family I frequently witnessed routine and ongoing blurring of bodies as they collectively navigated situations, tasks, and environments with a keen sense of their multiple bodies and abilities.

Varied participation. The validity of multiple modes of participation is manifest throughout the football game, a result that aligns with Bonsall's (2014) findings about variability in types of engagement in family occupations. It is not the exact duplication of action, the equity of roles, or matched level of attention that mark this as a shared activity. A range of participation is essential to successful family occupation, a finding that echoes some of the conclusions from Segal's (1999) study of families with children with special needs. In the football vignette engagement is rarely parallel or equal given the differing ages, abilities, and interests of the persons involved. Rather, the game accommodates the waxing and waning of individual participation from moment to moment, instead promoting a sustained collective engagement that allows family members to share a sense of enjoyment from being together. This sense of connection was described by DeGrace (2003) as "family being" and highlighted the collective construction of meaning from engagement in daily living.

Family occupation as transactional. The transactional perspective (Cutchin & Dickie, 2012; Cutchin & Dickie, 2013; Dickie, Cutchin, & Humphy, 2006) offers a framework for thinking about the continuous and complex fluctuations of daily experience. It emphasizes the co-constitution of persons and contexts, with neither existing in isolation from the other, but rather continually shaped by one another: “The transactional view means that what we would typically see as separate from each other are really *part of each other*” (Dickie et al., 2006, p. 88). Drawing upon Deweyan philosophy, this relational theory emphasizes the connectedness of situations, including the continuity of humans and environments, as well as social and temporal continuity (Cutchin, 2004; Cutchin & Dickie, 2012; Dickie et al., 2006; Wright-St. Clair & Smythe, 2013).

Continuity of humans and environment. In this vignette the situational context, including aspects of the physical environment, continually influences the creation and unfolding of the occupation. The actors are not merely social actors, their bodies and the intimate qualities of their communication, movements, relative closeness and distance, and styles of doing reflect an embodied experience of both place and relationships. DeVault (2003) wrote:

I want to suggest that in some sense family is (in part) a place that people inhabit momentarily - space we move through in quite literal ways. Family members come together, spend time, separate for activities that connect them differently elsewhere, come together, separate, and so on” (p. 1298-9).

Just as humans cannot be separated from their environment, neither can individuals be separated out from their family group. The individuals do not exist in isolation; nor is there a singular unified larger unit of family. Indeed words, bodies, ideas, interests are in continual dialogue to the point that the boundaries between individuals blur.

Continuity of past, present, and future. The past, present, and future coexist within the moments captured within this scene. The past is evident in the very idea of familiarity; this ease

is based upon a knowledge and experience rooted in some degree of shared history. The intermingling of past, present, and future is also apparent in the mix of planning and spontaneity revealed as the scenes unfold. The intentional structuring of educational opportunities (such as noted by Segal, 1999) is not explicitly articulated during the vignette. However, there is a tacit awareness of the future and the desire that Cindy and Eric have for their children to learn and grow, as well as the desire to continue building memories as a family.

Occupations co-constructing relationships. Family occupations offer an excellent vantage point for this tenet of transactional perspective. Family occupations bring a sense of “family-ness” to everyday doing, and continually create family relationships. This quality aligns with Finch’s (2007) work on how families in part display and affirm their relationships through the ways and manner that they do. Thus families help us to uncover and “see” how humans live interconnected lives. Families are an excellent entry point for investigating relational processes, and the strong presence of the family unit in discourse across cultures make families a compelling focus for social and health scientists. Family occupations are socially embedded, contextually emplaced, and multiply embodied, and offer useful exemplars of transactional processes within everyday life.

Strengths & limitations. The Irwins represent a distinct cultural unit with their own history, identities, practices, and vocabularies, however they share characteristics with frequently sampled populations. The family is White, and includes married, college-educated, heterosexual parents and their four biological children. The occupation described took place at their home in a quiet suburban neighborhood with privacy, space, and material resources to support the outdoor play. Data were collected by a single researcher, which allowed for consistency in data collection and documentation, but also reduced the opportunity for discussion of various perspectives.

Conclusions and Future Directions

Previous studies have attempted to identify coordinating features of family occupation (e.g., Larson, 2006; Larson & Zemke, 2003; Primeau, 2000; Segal, 1999). However, this study analyzed family occupation through a transactional lens in order to examine coordination as a relational process. The findings suggest that family occupation is negotiated in ongoing, highly situated, and complex ways.

I was particularly struck by the ways families negotiated occupation as multi-personed entities. This does not discount individual needs and wants, but suggests that individual bodies, capabilities, and feelings exert ongoing pull and tension within larger collective units. Families act as multi-bodied, multi-abled, and multi-preferenced groups with shared knowledge and ways of doing. Each family unit negotiates both within and among itself, among the actions, and among the larger social and environmental contexts. Embodiment in multiple bodies lends an intimate quality to family occupation. Multiple preferences prompt ongoing negotiation and consensus action. Multiple abilities are manifest in the varied modes of participation.

This study contributes to the conceptualization of the social nature of occupation. The complex negotiation of daily family occupation also prompts us to reexamine our approaches to the study of disability experience, rejecting notions of bounded individual body experiences that respond to socially isolated interventions. The findings also prompt a reexamination of the concepts of independence and family-centered care. If occupational therapy aims to promote and support participation in daily living, more nuanced examination of goals concerning functional interdependence may need to be prioritized. Likewise, the centering of the family in the delivery of care may necessitate moving beyond the acknowledgement that individuals exist alongside family to actively reimagining how families do collectively, and the opportunities therein.

There is a need for more descriptive accounts of family occupation to broaden our understanding of participation in daily life across the family life course. Occupational science scholars need to investigate occupation processes among more varied families and contexts, as well as in non-family identity groups that similarly blur the lines between individual and collective. Observational studies help to capture the moment-to-moment actions that comprise family occupations and are an excellent illustrative complement to the way family occupations are told. Future studies may more intensively examine the navigation of disagreements, competing ideas, and shifting priorities.

CHAPTER 7. MANUSCRIPT 3: BOOSTING PARTICIPATION: FAMILY OCCUPATION INCLUSION STRATEGIES

Introduction

The World Health Organization broadly defines participation for both children and adults as an individual's involvement in everyday activities and life situations (WHO, 2001; 2007). The American Occupational Therapy Association views participation as the root of the profession: "In its simplest terms, occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do" (AOTA, 2016), and Law (2002) considered the facilitation of participation in everyday life to be occupational therapy's "unique contribution to society" (p. 640). Much of the literature on participation has focused on adult participation in work or leisure activities, and child participation in school or leisure activities, with beneficial health and developmental outcomes associated with such involvement (Freysinger, Alessio, & Mehdizadeh, 1993; King, 2001; King et al., 2003; Law, 2002; Renwick, Brown, & Nagler, 1996).

One primary focus within the research community has been to examine the relationships between participation and disability, with questions about physical and social accessibility as well as person and family factors such as activity preferences and attitudes. King et al. (2003) drew from the literature of several disciplines including rehabilitation sciences, psychology, recreation, and exercise science to develop their conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. This model helpfully considered the impact of person, environmental, and activity factors, and further aimed to extrapolate causal relationships through nonreciprocal pathways. However gaps remain in understanding how to

promote and support the successful participation of children with disabilities (Mancini, Coster, Trombly, & Heeren, 2000). The question of how to evaluate success in participation is equally challenging. The work of Heah, Case, McGuire, and Law (2007), based upon qualitative interviews with children with physical disabilities, suggested that children may perceive having fun, being with others, and doing things independently as representing successful participation.

Strategies for promoting participation in family activities have typically been studied within specific populations, much of it related to children with attentional and neurodevelopmental disability diagnoses. Segal (1998) explored the enabling and adaptive strategies of mothers of children with attention deficit hyperactivity disorder (ADHD). Autism researchers have described the importance of the establishment of functional routines, advanced preparation, occupying and pacifying children, using reinforcers, deferring to children's preferred activities or linking family occupations to children's interests, and sometimes tricking children into participating (Bagby, Dickie, & Baranek, 2012; DeGrace, 2004, Larson, 2006, Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). A parent in Bagatell's (2016) study of routines in families with adolescents with ASD described "bribing and begging" (p. 56) as an engagement strategy.

One of the biggest limitations of the existing literature is the focus on the participation of individuals. Despite the recognition of family as a fundamental social unit (UN, 1948), limited literature has examined families' collective participation occupations. Most studies have represented the perspective of a parent (usually a mother) and focused on restricted opportunities for participation related to the presence of childhood disability (Bagby, Dickie, & Baranek, 2012; DeGrace, 2004; Law, 2002; Marquenie, Rodger, Mangohig, & Cronin, 2011; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Law (2002) wrote, "Families who live with

persons with disabilities experience increased demands on daily occupational routines, leading to changes in patterns of family participation” (p. 644). However, social psychology research has increasingly acknowledged that families of children with disabilities also report employing many successful adaptations, and that families of children with disabilities have similar variability in outcomes as families of children without disabilities (Ferguson, 2002).

Further exploration of participation in family occupations and investigation into successful adaptations is needed to better understand the range of daily experiences of families with children with disabilities. Disability must be examined not as an inherently positive or negative individual trait, but rather as one of many family characteristics that might impact occupation. This paper offers a description of inclusion practices employed by families with children with an array of disabilities (as well as with siblings with typical development). The study aims to add to the understanding of family functioning, health, and well-being.

Method

Research activities. This study used an ethnographic approach including participant observation within naturalistic settings. The design included 3-6 visits with each participant family with (each visit 1.5-8 hours in duration).

Sampling. Families were recruited from a southeastern state within the United States, via a combination of purposive and snowball sampling. Families were initially recruited through existing research listservs and professional and social networks, which yielded four families. These families were then provided informational materials and researcher contact information that could be passed along to other acquaintances that might be interested. This process was continued until seven families were enrolled.

Inclusion criteria. The inclusion criteria were families comprised of one or more parents or guardians over 18 years of age, and one or more children 6-11 years of age with a disability diagnosis (as family reported). In the context of this study “family” was self-defined and considered a fluid and situationally-linked construct, however with a specific focus on families with children. The middle childhood age range was targeted due to this being a time of high family activity participation as well as increased child experience with non-family adults (such as in school settings) (CDC, 2016; Maccoby, 1984; McHale, Crouter, & Tucker, 2001). The study aimed to investigate disability as experienced by family groups and no limits were placed upon diagnostic classification or severity.

Participants. Seven family groups enrolled in the study; all enrolled families completed the study. Two additional families expressed initial interest but were unable to be reached for ongoing contact. Three of the seven families represented multiracial families. One family was a single-parent household; six families included cohabitating spouses. All of the families had fulltime custody of two or more children, lived in single-family homes (one shared with extended family members), and included parents that had completed some college education. Each family represented a unique cultural group, and families incorporated various additional friends, family members, aid workers, and professionals in their contextually specific family groups.

Researcher. Josephsson and Alsaker (2015) have noted the need for mindful researcher positioning, suggesting that “One potential position is to be a learner, a guest or someone who is new to this situation, something that will provide ways to communicate easily within the situation” (p. 75). I approached families as a student and beginning researcher, with much to discover about both family life and the research process. Although I had training and work

experience as an occupational therapist, I tended to bundle that experience along previous work with children and families (such as adaptive sports, teaching, or camp counseling). While I believe that my occupational therapy training increased my comfort in observing and participating “alongside” as Josephsson and Alsaker have suggested, I hoped to be seen as a learner first. I attempted to convey an ongoing and genuine interest in children and families, but that I did not possess any particular expertise. I chose to disclose anything the families asked about in conversation with regards to my home situation, my progress as a student, and the fact that I was not a parent. I found disclosure to be within my personal comfort zone, as well as natural and helpful to the “getting to know you” and rapport building process.

Ethical considerations. This study operated with approval from the Institutional Review Board at the University of North Carolina at Chapel Hill, and ongoing assent of all participants was monitored throughout all study activities. Additional persons in public spaces were considered collateral participants, treated anonymously, and monitored for general comfort with my presence. Minor biographical details have been modified and pseudonyms substituted to protect participant privacy.

Data collection. A summary of the research visits is provided in Table 2. The duration and location of visits were scheduled flexibly with each family. I accompanied families within the home or yard, at local venues such as schools, restaurants, recreation facilities, community swimming pools, and in cars or during transportation. I attempted to act similarly to Alsaker’s description of the frequent guest (Alsaker & Josephsson, 2010) and to follow the conversational and occupational leads of the participants, joining in activities but striving not to direct or strongly shape the action. Audio notes were recorded at the conclusion of each visit including

verbatim conversations whenever possible, and then transcribed and expanded into full fieldnotes.

Data analysis. Data were analyzed following an iterative-inductive approach including emotions, values, attitudes, and beliefs coding (Saldaña, 2015), and the “Sort & sift: Think and shift” method (Maietta & Mihas, 2015). The core analytic activities included the identification and examination of powerful data excerpts, inventorying and analyzing data segments across each visit, revisiting and monitoring ignored sections, producing episode profiles including diagrams and memos to create a sketch of each visit, and the use of diagramming to bridge and question across episodes and cases. These tools were used in conjunction with thematic examination derived from Braun and Clarke (2006) in order to identify frequently utilized practices related to the promotion of participation in the coordination of family occupation. MAXQDA (Verbi, 2014) software was utilized to assist in management of the data documents, analytic codes, and memos.

Results

Please see Table 3 for descriptions of the participant families. Across families, several common practices emerged that promoted the participation of various family members in shared activities. These practices were present during times of relaxed family recreation and play, as well as during specific tasks such as household chores, sport practices, or learning activities. The family practices boosted successful engagement in occupation by integrating the diverse ages, abilities, and interests of the relevant parties. Family inclusion practices included: 1) planning; 2) using a hook; 3) centering; 4) bantering; and 5) improvising.

1) Planning. Families had regular practices of thinking ahead and planning for activity options. They considered the logistics of what might be needed to increase the likelihood for success. This planning included assessment of transportation, weather, materials, expense,

supervision and group composition, accessibility, and timing. Family members advocated for activities that could be matched to their family group in terms of both interest and feasibility, and inclusive of some form of participation for the persons that would be present. They were willing to juggle some adaptations and take advanced steps to promote positive outcomes. Sometimes the planning process was clearly demonstrated by advanced actions:

When I arrived the kids were on the front lawn filling up water balloons from a hose. They were excited to show me the various water toys they had assembled in anticipation of having a big battle. Uniqua (11), Pablo (8) and Austin (dad) had gone shopping earlier and purchased a new water gun so that there would be one for each person. Pablo told me about how they had picked out a water gun for his friend Cam, who would be arriving shortly. As Pablo recounted the shopping trip, (mom) Tasha raised her eyebrows and commented on how expensive these kinds of toys are. Austin gave her a pleading look and interjected: "You can't leave your friend without a water gun." Pablo nodded enthusiastically.

In this case Pablo's friend, Cam, was accounted for as a member of the family group when they planned earlier in the day for an evening waterfight and secured an additional water gun for him to use. Austin and Pablo justified the value of purchase as aligning with family values of fairness, inclusivity, and friendship. The kids further prepared to enable jumping immediately into the gameplay by filling the water implements prior to Cam's arrival.

Extra supplies were a frequent part of planning, especially for outings away from home. Families used extensive planning and preparation to ensure that family members, and thus the family collective, had relevant supplies on hand to keep everyone comfortable. Sometimes these supplies related specifically to a disability (i.e., specialized mobility equipment), or to a child's age (i.e., diapers), or to interest (i.e., a coloring book to keep busy). Supply availability reflected awareness of, and access to family and community resources.

Equally important to material, physical, environmental considerations, was drawing up a mental strategy or action plan. For example, Penny (mom) explained that she takes her son Ron

(6) to the neighborhood pool in the evening because the sun is less intense, which is beneficial given his visual impairment. Penny was also more likely to choose evenings when she knew the swim team was at an away meet and it would be quieter. She mentioned the comparative challenges of taking Ron to an aquatic program at a new pool:

I'm still getting used to it. Right now it is such a big process with having to take him there and change him and then swim and change him again and then come home and do a bath. But I'll get better at it.

Although Penny had not yet figured out the most efficient tricks for this new variation on swimming, she was mentally cataloging ideas for the next attempt. Planning as a regular and ongoing practice enabled the families to feel more confident in attempting activities and allowed them to incorporate lessons learned from past experiences to increase the likelihood of future successes.

2) Using a hook. Families prioritized activities that would build upon the known interests of one or more family members and were adept at finding “hooks” to make the events enticing or at least acceptable to others. Often additional interest was generated by pairing the family activity with other perks such snacks, special treats, or the promise of preferred activities later. For example, the Irwin family chose a midday outing to a local McDonald’s as a treat to break up the other errands and tasks they needed to do. They selected a particular restaurant in part because there was an indoor playspace that Cindy (mom) predicted the younger boys would enjoy climbing around on. She knew that son Luke (9) had previously enjoyed going to the playspace with his class from school. Although the play equipment was geared towards younger children, Cindy, her husband Mark, and oldest son Jason (18), enjoyed having an ice cream cone and taking a break in a cool space on a hot day to sit around a table and relax in between other activities.

A particularly effective hook for teenagers and older children was the ability to invite a friend to join in a family occupation. For example, Jasmine (13), who lived with her mother, younger sister, and grandparents, was often reluctant to join in activities with her younger sister. Jasmine explained that going to the pool with her family was often boring for her. On an occasion when she was allowed to invite her friend, Rachel, Jasmine appeared much more enthusiastic. She stepped into a hostess role showing Rachel the facilities and encouraging her during the deep water admittance test. The teens were having fun together and Jasmine asked her mom, Aster, if Rachel could sleep over that night:

Aster asked Jasmine if [the sleepover] meant that Rachel was going to go to church with them in the morning? Jasmine looked over at Rachel; Rachel said, "Sure." Rachel started texting her dad to get permission. Aster asked Jasmine to text or call her grandpa and let him know that there would be another person for dinner.

In this moment Rachel served as an effective hook, boosting Jasmine's participation and willingness to include herself in additional family occupations (dinnertime and going to church) as long as she was able to have her friend along.

3) Centering. Families habitually organized themselves among home and public spaces, centering group action to a high circulation hub. This central space served as a home base for the family group, a focus of movement and social action. For example, during a large backyard barbeque the Vida family set up the patio as a centering location. They made sure daughter, Evie (7), who has multiple disabilities and was seated in a wheelchair, was proximal to the action:

During the barbecue Evie was centrally located amongst the family and guests, sitting in the shade on the patio that served as a consistent site of activity, eating and conversation. One thing that struck me about the general scene was how physically familiar and comfortable different parties were with getting to close to various children and touching them, lifting them, or holding them - particularly with the kids with more significant physical disabilities. Adults and children would talk to Evie as they were passing her: "Evie, can you believe all these people are at your house?" One little girl who looked about Evie's age repeatedly walked up and quietly held Evie's hand for a few moments. Karen (Evie's teacher) sat with her a while and gently pinched her cheeks. Whenever

Kevin (dad) passed by he would lean down and kiss her forehead or say something like: "Evelyn Marie! How are you my beautiful girl?"

Evie's participation in the barbeque was supported in several ways by her physical centrality. As Evie relied on support for mobility and was sensitive to heat and fatigue, this positioning allowed her parents and siblings to easily check on her. Her centrality allowed for frequent conversation, touch and physical affection with other family members and friends. Evie's presence as a familiar person in a predictable location also helped establish the patio as a family space and gathering location. Evie's younger sister wandered through, barefoot, helping herself to other people's sodas and climbing the back of Evie's wheelchair to reach the table. Her older brother stopped off for a snack and to ask his dad for assistance setting up a game. As a centering space the patio was at times where the most exciting or enthusiastic action or conversation was happening, but at other times was the safe space where family members retreated to pause, rest, recover, or take a break from the larger arena of action.

4) Bantering. Bantering was frequently utilized to offer entry and heightened engagement during activity. This humorous talk also served an important function in establishing comfortable social spaces, both at home and in the community. Each family had the potential to draw extra attention due to the actions, commentary, behaviors, characteristics, or equipment of family members in a given situation. Bantering helped families carve out socially normative spaces by applying familiar patterns of engagement and interaction such as inside jokes, gentle teasing, and using nicknames and terms of endearment. The creation of familial social spaces through such culturally nuanced communication allowed for the expression of support among family members. Banter was often employed to include children who were non-verbal in conversations, such as joking about a child with a walker being a "bad driver" when they bumped against an obstacle, or imagining that a head turn indicated a child was mad. One father

teasingly admonished his daughter as she leaned over a peer: *“Don’t drool on her head. That’s not very nice.”* In these examples family banter normalized the issues of drool or silence or mobility aids, making them just another facet of family life, rather than a differentiating characteristic to worry about.

In other instances bantering helped normalize other characteristics of family life unrelated to disability. Sometimes this humor was used to encourage play, and other times to introduce more serious conversation topics. The Goddard family, a multiracial family with a Black mother, Tasha, a White father, Austin, and biracial children, Uniqua and Pablo, frequently bantered about race in their communication: *Uniqua asked everyone what flavor ice cream they wanted- chocolate or vanilla? Tasha said, “I’ll have the white one.” She joked, “I like the White ones.” Austin and the kids laughed.* During this mealtime activity bantering helped introduce discussion of an important topic within the family dialogue. When the children were out of the room Tasha commented about a recent hate crime she had been watching coverage of on television: *“This is about race, and it’s scary, and serious.... I’m just so glad that Austin and I are together and we can talk about this with our kids. In our family we can talk about these things.”* Tasha and Austin were very aware of racial identity as an important characteristic within their family and offered frequent low stakes and positive opportunities for the kids to think and talk about their perceptions, ideas, and experiences related to race.

5) Improvising. Another inclusive support to participation in family occupation was the practice of improvising. For example, when the York family went to an outdoor movie they encountered an unexpected disruption that threatened the success of the outing:

About two-thirds of the way through the (outdoor) movie the projector suddenly cut out and the screen went dark. Lindsay (mom) took the opportunity to point out the stars to everyone: “Hey, everyone look up at the stars. Do you see the Big Dipper? Can you see it Chloe (8)?” Lindsay and the girls lay back on the blanket trying to find the Big Dipper.

Chloe said she could see it but Sarah (friend) needed help finding it. Lindsay cued Cael (dad) to help, saying: "I think Dad wants to teach you the constellations." Cael immediately stood up from his lawn chair to help point. The skywatching continued until the projector was rebooted and the movie resumed, at which point everyone returned their attention to the screen.

In this unscripted moment during a disruption to the movie screening, Lindsay took a primary role in redirecting the group's attention to an interim activity (looking at the stars and identifying constellations). She invited the family group into a playful new game of identifying stars and constellations. The assembled group accepted Lindsay's invitation by entering into the game and expanding upon it (leaning back, looking, and beginning to converse about the stars). The girls were immediately interested and willing participants; Lindsay prompted Cael to increase his participation by more actively assisting with the hunt for constellations.

Improvising frequently sustained effort through trial and error experiments. For example, on another visit to a swimming pool the York family played game they called "Daddy Surfing." Older daughter Chloe would try to balance in standing on Cael's back as he floated on his stomach serving as a human surfboard. Younger daughter Alice (6), who had a global developmental disability, was still working on her standing and walking skills. When it came time to include her in a turn, the family had to improvise a few different options:

Alice was making happy sounds and Lindsay said: "I think Alice wants a turn." Cael said, "Okay, how are we going to do this?" Lindsay attempted to support Alice standing on Cael's back, but Alice flexed and retracted her legs. Lindsay and Cael tried again with Alice sitting instead, which required Cael to stand more upright but enabled him to keep his face out of the water. Cael commented: "Oh, I like this. This is much easier for me." Chloe cheered and announced she wanted to try sit-surfing next.

In this instance the buy-in from family members was quick and successive, as Alice, Lindsay, Cael, and then Chloe became engaged in the improvisation and experimentation. The game adaptations not only allow Alice to participate, but were also more comfortable for Cael, and

represented an interesting variation for Chloe to try. The improvisation opened up new possibilities for the participation all the family members.

Discussion

As the observer researcher, I have chosen to call these elements of daily occupation “inclusion practices.” These were not named strategies that family members described to me. Rather, they were seemingly habitual actions and ways of doing that were regularly and repeatedly incorporated into family activities. Although planning might represent an intentional step, I more often observed it to be an ongoing process of predicting, acting, and reflecting applied to dynamic situational moments. Using a hook was a similarly flexible practice, which sometimes included advanced negotiation, but also necessitated continued reminders, reevaluation, incorporation, and adaptation. Centering was a physical and social practice that appeared to emerge spontaneously through the coordinated action of the family group. I watched this process unfold repeatedly across a variety of contexts. Bantering was a nearly omnipresent facet of family communication and closeness. Similarly improvising was a regular practice that highlighted the shared knowledge that enabled families to successfully adapt to changing situations to maintain engagement and facilitate opportunities for participation.

The practice most extensively discussed in the existing literature also prevalent among the families in this study was planning. Bedell, Khetani, Cousins, Coster, and Law (2011) found parents of children with disabilities reported using preparation and previewing with their children at home prior to the activity outings, and modifying environments and activities to better suite their children’s abilities and interests. Similarly, Bagby, Dickie, and Baranek (2012) found that parents of children with ASD used increased preparation to manage the sensory-rich settings in order to facilitate successful family occupation, and Bagatell (2016) found families of adolescents with ASD used preparation and had exit plans ready. In this study I observed

disability to be one of many factors that the families planned for, sometimes a primary consideration and sometimes not. Accessibility, equipment, and supports related to disability needs were incorporated into everything that families did throughout the day, and this ubiquity meant that families were quite practiced and adept at managing them. Families attempted to plan for the needs of all family members and the group, and special supports might equally relate to nap times, food preferences, how many people could fit in one car, or who had been having a runny nose that day.

Successful participation required getting relevant parties to the table, a process that often demanded creativity and adaptation. Primeau (2003) described a hook phenomenon when discussing the tradeoffs she offered to entry with families during research. I have used a similar term, but with a different application when I describe families “using a hook” to coax participation. One aspect of “being part of a family” is doing things that one does not personally want to do. There is an expectation that one will show support to other family members. Often children will be pulled into things they are not enthusiastic about, and during this study I observed a variety of “hooks” to enhance cooperation and engagement. These hooks took the form of attention, treats, material goods, tradeoffs with regards to prioritizing interests, and frequently the inclusion of friends or social supports.

The organic and ready ways that families incorporated other people into the family group during family occupation suggests the potential for social supports to positively impact the success of the family activity. Caregiving literature has developed the notion of informal support as a resource for caregivers to children with disabilities (Linblad, Holritz-Rasmussen, & Sandman, 2007). It is important to note that family members are also well poised to offer one another both formal and informal support (such as normalizing situations with humor) with a

keen attention to changing family needs. The practice of hooking additional people into the occupation points to the significance of social connectedness not just among family members but also to larger social networks.

As families navigated social arenas in both at home, and particular during community outings, they created centering hubs of activity. These focal (physical and social) spaces appeared to ground activity, establishing safe, accepting, and reassuring home bases for family members to gather. This finding aligns with the coordinated movements observed by DeVault (2000) in her study of families at the zoo. DeVault found that families positioned themselves in clusters and maintained proximity in public spaces, sometimes staking out physical spaces and infusing them with a more familial and private nature. She also noted movement patterns centered around specific persons, often with children “buzzing” around the adults. Similarly, I observed centering around an “anchoring” adult or child was a means of including persons by having them at the core of the activity, which increased the opportunities for participation in a central versus peripheral way.

Family activities were also marked by teasing and bantering. Although rarely discussed in occupational science literature, the use of humorous talk during family occupation aligns with prior family communication research. As Everts (2003) noted, family members often share immediate environment and history as well as culture. Family members often communicate the most with one another, especially during children’s periods of language development. Everts suggested that families develop their own collective conversational and interactional style. In her case study microanalysis she found “the family uses humor to accomplish various interactional goals, the foremost of which is a relational harmony, which is achieved largely through drawing all members into involvement in the interaction through humor” (Everts, 2003, p. 369).

Based on interviews and participant observation of family outings, Rieger (2004) similarly found that wit served many functions, including as a communication tool, means of social connection, and coping strategy for families with children with disabilities: “The families’ sense of humor dealt with everything that was real and authentic and most of all everything human within their immediate family realities” (p. 206). Conversation is a key site for humorous interactions within a group, representing the opportunity for the co-construction of verbal play. As Coates (2007) stated, “Where conversational co-participants collaborate in humorous talk, they can be seen as playing together. Their shared laughter arises from this play and is a manifestation of intimacy, with the voice of the group taking precedence over the voice of the individual speaker” (p. 31). Coates noted that this type of banter rests upon shared norms and knowledge. I observed family bantering promoting conversation and communication, including of more sensitive or serious topics, and helping to normalize situations, especially feelings of otherness.

Shared knowledge also supported the family’s ability to improvise. Improvising requires the use of whatever is available in order to create new possibilities. Within the theater world, improvisation or improv styles of performance refer to collaborative performance that is not scripted or rehearsed. Sawyer (2002) elucidated several key tenets of improvisation including collaboration, the moment-to-moment contingency of the unfolding action, the unpredictability of the outcome, and being rooted within the performative social context. Gale (2004) noted that improv practices allowed actors to move away from more individualistic approaches to more collective ones. This relational action is dependent upon trust as well as the ability to enter into shared scenes and realities, often exemplified in the theater exercise “Yes, and...” in which one actor takes the lead in constructing a scene and additional actors accept and build upon that lead

(Gale, 2004). The developing activity represents not singly the initial sponsor's ideas, but rather "collaborative emergence" (Rowe, 2004; Sawyer, 2002), a process of unfolding action constituted collectively by the social group.

Likewise family improvising saw members reimagining participation by changing the shared reality, generating new possibilities by drawing upon knowledge of the family group. Often one family member extended an invitation for everyone else to join in a new or modified social scene, and then other family members either accepted the invitation and participated in that social world, or rejected the invitation and the proposed activity faltered. The practice of improvising promoted inclusion as it allowed the family to spontaneously adapt to changing variables, environmental features, and social situations in a flexible manner and with a high likelihood of success.

Limitations. The practices described were situated within distinct families and family cultures, and should not be taken as representative of the larger population. The dominance of family within public discourse tends to obscure the personalized and interconnected family ways of doing. Within this sample there were several traits shared among the families, including Southeastern US geographic area, middle to high socioeconomic resources, living in single family homes, and having access to a personal vehicle. Each family experienced some form of childhood disability, although the presentation and impact of the disability varied widely. The parents had a favorable view of science in general and were happy to assist in my educational process. To this end they attempted to comment, explain, and demonstrate various facets of daily life together, which likely influenced the occupations I was invited to see and join. The families also had many differences, including in composition, identities, preferences, time availability, practices, routines, and vocabularies. Three of the families were multiracial families, an

understudied but growing segment of the population. The observational nature of the study allowed for exploration of the family as a unit, rather than relying on representatives to speak for family experience. I recognize that my presence as researcher is not always fully described in the excerpts selected. As a solo researcher on this project all data were collected and interpreted through my own body and experience, although extensively supported by a much larger community of scholars. I certainly impacted the scenes, however, I found that attempting to merely observe rather than participate was far more disruptive to establishing rapport. My intent was to be a “follower” as much as possible, rather than leading the action.

Conclusions and Future Directions

Inclusion practices. The inclusion practices of planning, using a hook, centering, bantering, and improvising promoted participation in family time occupations. These practices were observed to be a highly integrated and natural part of everyday doing. The practices related to anticipation of occupation, coordination and structuring of occupation, adaptation during occupation, and ongoing reflection. As collectives, families accounted for group needs in planning and preparing for occupations, recognizing the multiple ages, abilities, and interests within the group. Using a hook helped get relevant parties to the table and sustained involvement, particularly in non-preferred activities. Centering promoted engagement by establishing core family sites within occupation. These highly trafficked hubs allowed members to gather, observe, check in, rest, and keep physically close to action. Bantering was an additional means of heightening enjoyment and normalizing family experiences. Improvising was used within the moment to adapt to unanticipated events, and built upon shared knowledge and history. These inclusion practices represent one small set out of the large and creative range of ways that families adapt and enact occupation. More research is needed to identify other

practices, examine the relevance of practices across different populations, and investigate child and family perception and interpretation related to such practices.

Practicing inclusion. The description of these inclusion practices within family life helps extend the conceptualization of inclusion and disability experience. Currently, most literature relates to the inclusion of children with disabilities in school settings, with the intent of inclusion being “to create a community in which all children work and learn together and develop mutually supportive repertoires of peer support” (Stainback, Stainback, & Sapon-Shevin, 1994, p. 486). The idea of inclusion within family life may at first seem to be redundant to the notion of family membership, however this study found that in fact families together practice inclusion in numerous ways as a means of supporting one another’s participation, and therefore supporting the group experience. This finding partially aligns with the limited literature looking at the perspective of children with disabilities about inclusion that has highlighted the importance of social acceptance and relationships (Spencer-Cavaliere & Watkinson, 2010), and also backs Finch’s (2007) premise of the inherently social nature of family activities. In the future family scholars might examine how practices of exclusion emerge in daily occupations and impact group participation.

Learning from families with children with disabilities. Given that families are collectives and not merely unified entities, they are always confronting the actuality that not everyone in the group wants or is able to participate in occupations in the same way. Barriers to participation in family occupations depend on the situation. In many of the examples given disability experience was a relevant factor; in many of the examples it was not. The inclusion practices bridged both types of scenario; they were largely subconscious group habits and processes that were a regular feature of family life.

Learning from families with children with disabilities about promoting participation and enacting successful occupations offers scholars a deepened understanding of families as complex groups that in every moment are coordinating and negotiating many different traits, characteristics, and motivations. This study has implications for both family-centered interventions and the broader promotion of family health. The lens of family inclusion may aid in the discussion of family coping, adaptation, and emotional well-being, as well as support the design more comfortable family spaces and activity programming. Information about participation in family occupation also has the potential to improve the implementation and integration of occupational therapy home treatment programs (Segal & Hinojosa, 2006). Continued research is needed to investigate similarities among the experiences and practices of families with and without disabilities, in order to promote collaboration and the sharing of strategies and ideas.

CHAPTER 8. REFLEXIVITY

Confessions of a Novice Researcher

I never set out to do this study. When I started graduate school for occupational therapy I had no idea that it would lead me into an occupational science doctoral program. By then I was something of a “peds person.” It might have been something to do with seven summers of being a camp counselor. All of my work experience related to children. When I started to think about research topics, I gravitated towards child disability experience. However, as my professors reiterated, there is no child in isolation. Attempting to study a child apart from social context would be a missed opportunity for a much richer understanding. I came to realize that I was more interested in children’s experience as part of a family experience, and in disability as a family experience.

The phase that nearly wasn’t. Phase One almost never happened. It was a late addition to my proposal, a silver lining attempt to incorporate an unexpected injury that I felt necessitated a delay in commencing participant observation visits. It was fortunate that interview methods fit the aims. However, the change gifted me the opportunity to take a more translational approach to family research, as well as provided immediate advice and recommendations for study design and implementation. It boosted my rationale, my confidence, and my emotional investment in the project. During the Phase One interviews I could tell that the parents wanted me to succeed and were attempting to provide pertinent expertise. My main takeaways from this phase of research were that families use gatekeeper representatives for the sake of efficiency, and researchers must be able to articulately approach and explain their interests to these gatekeepers first. This is

usually a parent, often a mother. It is essential to be friendly, nonjudgmental, and practical. Throughout the Phase Two family visits I did feel that helpfulness was much more highly valued than credentials. I strove to be the extra set of hands to carry stuff, the extra adult eyes to watch for general safety, or the guarder of belongings while everyone ran to the bathroom. I also felt that being an added person that valued the family and its membership, and particularly any children with disabilities, put me in the position to help validate and normalize the family in public settings.

Disability spectrum. Given my use of a relational model of disability, I was theoretically primed to investigate the social, shared, and distributed aspects of disability. In order to investigate disability as social experience I found it more helpful to draw upon the experiences of families living with a variety of disabilities (although I acknowledge that my own conceptualization of disability is influenced by the Individuals with Disabilities Education Act (2004) categories).

Three of the seven families had children with more significant disabilities; all of these children used mobility and communication aids (and would be considered nonverbal). These children were attending special education classrooms, and the families qualified for part time in-home aide services and Medicaid coverage. These children generally participated in activities with substantial support. Three of the families had children with more mild disabilities involving sensory processing, language, and orthopedic conditions that did not impact mobility. These children were attending general education classrooms at school, and participated in activities with minor support. One family fell in the middle; their son had Down syndrome, attended a special education classroom, and participated with moderate support. He had some verbal

language and was fairly independent for general mobility, although he had assistance with some of his personal care and for precision tasks.

Disability was not as dominant a theme as I expected. There were times when disability was more prevalent in the execution of the family activities, but it was context specific. A child might have needed more support from an adult or sibling due to disability-related mobility limitations, or because they were having a bad day, or they were two years old and lacked safety awareness. Several of the parents of children with more significant disabilities described the experience as being akin to having a younger child needing closer supervision. There were also body traits that required similarly accounting for in negotiating occupation, such as a family member having food allergies, being prone to migraines, or being susceptible to sunburn. As with disability, these other traits are things we might classically think of being tied to the individual, but they were incorporated into general family-level awareness and accommodation.

I was interested in blurring disability lines between bodies within the family, but in practice I think the entire concept of disability was blurred. It was not something explicitly experienced in many moments, although there were some moments when it seemed very significant. I did not delve into the domain of disability and identity, although I saw indicators that some of the families, and particularly the parents of children with significant disabilities identified more strongly as “families of children with special needs,” as well as part of a larger special needs community. (My instinct would be that these identities were closely linked to the occupations of these community groups - such as the therapy activities, the support groups, the special education programs and the adapted sports and recreation events.) Families with disability experiences have much to teach other families about adaptation in navigating daily life.

I should also note that while I only studied families with children with disabilities, all of these families also had many members with typical development.

Recruitment. During Phase One of the study I was surprised by the positive response I received to standard flyers, emails, and word of mouth announcements. It was not too difficult to find parents with research experience willing to talk to me for a single interview. Most of the participants were passed along an email by a mutual acquaintance. One mother reported she had seen a flyer and had been meaning to get in touch, and was reminded again when she was forwarded an email from a friend. (I had been monitoring flyer tear-offs and feel she may have accounted for the only one taken.) Phase Two recruitment, which called for a larger time commitment, participant observations, family member and child involvement, and disability experience, was a different story.

Phase Two recruitment was a practice in patience, optimism, and occasional despair. It lacked the systematic, procedural feeling of other parts of the research process. I ended up recruiting two families from a university research recruitment listserv, and the other five through snowball sampling after networking with an enthusiastic and connected mother via a mutual acquaintance. In the thick of it I once described snowball sampling to a friend as feeling like I was standing outside in my mittens, staring intently at the sky, hoping it would snow. However, once I gained the buy-in of a linchpin mother, she expended considerable effort to help me enroll other families, which led to other families. Most of these families had originally met through disability-related support groups or activity groups. The other important facilitator for recruitment was timing. I was much more successful enrolling families during the summer than during the school year. Families reported too many scheduled obligations while school was in session, but a willingness to commence research visits after school was over.

Consent and assent. I was disappointed by how perfunctory consent and permission form completion was. To me it felt like a mere liability clause, akin to the forms you sign at a doctor's office. It was slightly better with the assent forms, as both the children I were more careful. Children, likely because it was not as common for them to be asked for their signature, took the whole process more seriously than adults. I did too, as I sought to be a responsible researcher and explain the study in age appropriate language. When I read the forms to the children, or explained the sections of the forms I felt that we had at least more directly addressed the ethical issues. I know that parents had to sign repetitive forms, but it was still disheartening to watch them sign with barely a glance. In part it probably spoke to the fact that recruitment processes cater to adults, and once successfully recruited they felt that had already weighed the possible risks or benefits. The formal assent was more symbolic for children who were generally less familiar with how research relationships worked. To me, assent was everything. Consent was the requisite check mark. Ongoing assent was the living process that signaled researcher diligence.

Participant observation. Lareau (2003) wrote: "It is very unusual to study families in a 'naturalistic fashion,' observing them within their homes. Many people are deeply curious about the process" (p. 259). Participant observation has pros and cons (Margolin et al., 2005), but my rationale for choosing this method was its match to my onto-epistemological assumptions about socially constructed experience, its relative accessibility to a novice researcher (compared to child interviews), its ability to accommodate nonverbal participants, and its capacity for dealing with the collective experience of multiple persons. I was pleasantly surprised by how well it went overall. Despite a (Phase One) parental advisor's assurance that I did not "look like a mass murderer," I was still unsure how awkward entry would be and I was pleased with how quickly

working rapport developed. I was equally satisfied by how much detail I was able to recall when I recorded audio fieldnotes immediately after each visit. I found that the families easily acted as advisors for customizing the process to their own needs.

I also noted that in my experience no organic opportunities arose to introduce artifact generation or novel “child friendly” research activities. I was glad that I chose a broader observational approach. This project has made me rethink the idea of research as a family occupation. In some ways I still think it is, but in others I am less sure. For these participants research did not seem to represent a new occupation, as much as an adjustment to ones they were already doing.

I attempted to be a “playful” adult, or at least a “willing to be silly, willing to play, willing to enter pretend games” adult. I tried to be very careful not to convey judgment of parenting styles. There were a few moments when I could see parents make different choices than I imagined (with the hubris and naiveté of a non-parent) that I would make. (I was lucky in this regard in that these were largely successful activities and there were no serious issues or incidents that arose during my visits.) I think I was able to largely to avoid negative parenting judgments; I was most struck by the sheer physicality and emotionality of parenting.

Certainly there were flaws to being a participant observer. But being a non-participating observer was far worse. I do feel some frustration that a common refrain or question I have heard from various bystanders throughout the study is to wonder about the influence of the researcher on what would otherwise be naturally occurring. I see that as a known aspect of the method, and in my case far outweighed by the benefits of seeing life in natural settings. I have attempted to counteract the lingering suspicions that participant observation is not objective enough by being as transparent as possible about my lenses and limitations, trying to establish authentic visitor

relationships with the families, and attempting to be a follower-participant rather than leader. I certainly could not have anticipated at the start of the study how much data collection would take place from within swimming pools. I had to let go of my inclination to dress up for the observations; instead I was most comfortable when I attempted to wear clothing of a similar “casualness” as the families. I spent quite a bit of time considering modest swimwear and cover-ups, which became something of an unofficial research uniform.

It was often fun participating in the family activities. I was usually less adept than the family members at these activities, be they games, operating electronics, or athletics. Hsiung (2010) wrote about “weaknesses as opportunities,” and I think my inexperience prompted family members to more clearly explain what they doing or the expectations of the activity. I think it also reassured younger children that I truly was not an expert (at anything), which increased their enjoyment of the play and sense that they could help teach me things. One of my funnier memories was when I attended a volleyball practice with the Barnett family. Sports practice offered one of the rare opportunities for a more classically observational role, as I often sat with other spectators in the bleachers. But when Coach Aster needed a team for her girls to scrimmage against, she surveyed the bleachers and declared the spectators the “Moms’ team.” Suddenly I found myself not only attempting to play volleyball, but also grouped in with mothers. (Needless to say I experienced more than one moment of imposter syndrome.)

Variety. I had expected participant families to choose an activity that they enjoyed doing together that I would be able to observe a few times. In my communication about the study I listed examples of activities and suggested that they think about activities their family liked. In practice, only the Barnett family chose specific activities. They selected two sports activities, which I was able to see across multiple visits. They were also the only family that I exclusively

joined in the community (away from their living space). Every other family did different activities each time I saw them. Certain components might be repeated (such as eating or some form of game), but the theme of the get-together varied greatly. I feel the parents were intentional about wanting to share a taste of many of the different types of things that their families did together. They also expressed a desire not to sugarcoat family life and to show an authentic picture of a range of experiences including more successful and less successful moments of togetherness.

The families (and particularly the parental gatekeepers) also considered my needs and preferences within the family occupation and were attentive to my goals for learning about daily life. Alex commented about balancing the chore and necessity of laundry with a more “fun” outing the next visit. Maya talked about how family occupations spontaneously arise and the inherent unpredictability of “hanging out” with her family, and similarly Lindsay figured her family would do “something” (to be determined) after a meal together. Penny described her family as being an “open door household” and highlighted an ongoing daily hum of comings and goings and extra people. Tasha purposefully planned different activities so that I could have a broader understanding of the kinds of things their family does together. In these cases we can see the co-constructive influence of the researcher and research context on the choice of family occupation. Because I had been adopted into the family context in a learner position, the families took upon as their “duty” to help teach me about family life. They wanted to show multiple things that the family did in order to help me learn more in a certain way.

Confidentiality. While family ethnographers have raised the issue of confidentiality and concern about the likelihood of hearing secrets about other family members (Hall, 2014), I spent relatively little time with individual family members apart from the larger group. I did spend

time with just the children, but quite often this was at parents' request while they ran to the car or the bathroom and I took up an adult supervisory role. In general I felt that that I was perceived as an adult friend (to the family), and simultaneously a friend of the grown-ups.

Hall (2014) talked about the issue of families recruited via the same gatekeeper knowing one another and frequently asking about, commenting on, or sharing about their social acquaintances. She wrote about the tension between not wanting to offend participants or make a big deal out of "harmless" questions, while simultaneously feeling apprehensive about preserving confidentiality. Three of the families in my study knew one another from a parent support group. This added an additional layer of vulnerability, in that one parent revealed that connection to me. A support group in and of itself connotes a certain type of shared experience. This one was described to me as existing for "moms of kids with special needs." The families all disclosed mutual participation to one another when I was present; on one occasion I met with two families together, and we ran into the third by chance at the same venue. What I do not have a sense of is what questions they may have asked one another about their decision to participate or not when I was not present. These mothers were likely in fairly regular contact.

The study participants would readily be able to identify themselves in research products such as this dissertation. They had the option to pick their own pseudonyms, and they will recognize the activities that we did together. Surprisingly, this never really emerged as a significant concern. I invited all of my families to my defense, which increased my apprehension a little, but only in that I hoped the findings would meet their expectations. I offered to families that I could change details about them, but they were not concerned and left it up to my judgment. Looking back, I think once we passed the photo permission it was pretty open access. I actually see potential benefits in increased accountability from having such a direct link to the

“sources” themselves. I know that this level of transparency and identifiability would not be prudent (or relatively painless) for all types of research. I entered into this research with a (strategic) emphasis on a strengths-based, rather than deficits-focused approach, which is part of how I positioned myself to be able to reassure parents that I did not intend to judge their parenting skills or criticize their families.

Child perspective. It was an ongoing struggle for me to try and give “equal” weight to child perspective in my analysis. I ended up with a larger overall volume of parental conversation, stories, and anecdotes, in part because parents were likely to try to explain and contextualize activities for me by telling me additional details, history, or explanation. I found that both my analysis and writing kept veering towards adult accounts, and that it was harder to find child initiated examples. I think this partly reflects my enculturation as an adult. I spend more of my time with adults and relate to adult styles of conversation more readily. I was continually in tension with a desire to foreground child perspectives, but a simultaneous attempt to provide a birds eye view of inherently uneven, unequal, varied and dynamic expression.

Compensation. For three of the seven families I felt that the monetary appreciation was a motivating factor for participation, although not the primary reason. It was interesting to me that several families shared (unprompted) their plans for use of the money with me, which I felt was in part was to include me in enjoying how it “helped” the family and how it was being distributed to include the children. One family put it towards a vacation and sent me a photo telling me what a good time they had. Another family used it to buy a replacement ipad for therapeutic uses with their son. I had a moment of ethical tension when the mother in a third family tried to hand me \$20 back “to take myself out to dinner.”

A few things I like about studying families.

- 1) Someone will usually talk. This means not everyone has to talk, which helps get around frequent language and communication barrier issues.
- 2) Playfulness. There just seems to be a lot of it. I think I have established that I enjoy play and how people relate to one another and the world through play. Play also helps break down barriers of formality. For my research purposes I think it gets to the good stuff faster.
- 3) Family members ask and answer questions of each other. And many of these questions are about really mundane things. What is happening? Why is it happening? How is it happening? Is it important? As an occupational science researcher, these are often my questions as well. Watching family members assessing, articulating, and shaping these everyday topics makes my job much easier. Because kids are often questioning the everyday, it makes it easier to consider, reflect, and reimagine everyday things as well.

Post script. People usually do not end amicable relationships abruptly, and therefore strict exit points felt artificial. I have been in contact with nearly all the families since the visits ended, and one family joked that they wanted to hire me as their aide worker. Much of the communication has been family updates, which is similar to Hadfield-Hill and Horton's (2014) experience. The learning point for me has been about the feasibility and likelihood of developing genuine relationships via research encounters, to the extent that I sometimes felt adopted into the families. I can see why scholars establish long-term research relationships with participants; there is appeal in that. I can imagine working with these same families to explore other topics (such as the issue of schools-family interface) that emerged in the data but were not explored for this dissertation.

CHAPTER 9. IMPLICATIONS AND FUTURE DIRECTIONS

Overview

Together, these three manuscripts present a chronologic overview of the study process. In Manuscript One, I began by examining how we study family occupation, and what we can do as scholars to develop accessible, collaborative, and practical methods. Manuscript One asked the question *where do we begin?* The findings suggest how methodological flexibility, relational approaches, and social connectivity may benefit family research endeavors. In Manuscript Two, I examined the coordination processes of family occupation. The narrative description of negotiation processes helps answer the question *what does family occupation look like?* The results emphasized the multipleness yet closeness of family doing. In Manuscript Three, I investigated how families promote member participation in occupations. The inclusion practices identified expand our knowledge of *how families 'do' together*. Collectively, the manuscripts offer evidence to support methodological innovation, unpack the complexity of occupation, and suggest opportunities to support family doing.

Methodological Implications

Translational and participatory family research. When I began conceptualizing this study, I realized that asking questions about family life necessitated taking a hard look at methodological issues. As much as I yearned to jump into the investigation of daily experience, a review of the literature indicated ongoing unresolved issues in the study of families. In particular, researchers often opted to interview family representatives rather than more holistic exploration of family-in-relationships-in-action. I wondered what steps could be taken to make participant

observation more feasible, which led me to ask for stakeholder input from parent advisors. I was surprised how manageable it was to incorporate this initial phase of research into the overall study, and the degree to which it increased my confidence heading into the field. In Manuscript One, I presented general themes relevant to family research; however I should note that the parent advisors also offered many suggestions specific to my study and local context. Another benefit of these interviews is that they provided additional opportunities to practice the language of the study and listen to how parents talked about family life. Their interweaving of discussion of occupations throughout many time scales of family life helped to better contextualize the inherently partial glimpses that observations of parts of a day might yield.

I would encourage other family researchers to consider incorporating translational processes into study designs. There are many possibilities for stakeholder involvement ranging from informal advising to participatory collaboration. Bringing this expertise into early phases of conceptualization and design of the study at a minimum enhances researcher reflexivity, and may improve the planning, execution, and social validity (consumer acceptance) of the scholarship. Throughout the observational visits, the participant families were able to indicate design adjustments that would best suit the situation. Families are accustomed to problem-solving, and these participants were willing to strategize with me to make the research project work. I would encourage family researchers to embrace participant observation within naturalistic settings as a means of tapping into the multiplicity and intricacy of lived experience, and particularly the communal lives of families.

This study affirmed using flexible definitions of family unit, as well flexible conceptualizations of occupation. It was not necessary to limit the observations to only certain categories or labeled occupations in order to learn about the processes involved in co-created

activity. The study also supported the examination of family members in relational contexts. Single perspective interviews would not have yielded data with the same richness and complexity. The research demonstrated the co-constructive impact of children as social agents, supporting the turn towards examining children's lives and acknowledging the importance of children as research participants.

More research is needed to build understanding of children's views of research methods (e.g., Hill, 2006), and elicit children's reflections on participating in research studies (e.g., Hadfield-Hill & Horton, 2014). Additionally, there are many more diverse subsets of families whose expertise should be tapped. For example, as financial resources have been found to influence family member well-being (i.e. Park, Turnball, & Turnball, 2002), further study of the relationship between financial resources and how families do activities together is warranted.

Occupational Therapy Implications

This dissertation project may also contribute to practitioner understanding of working with families. The ways that parents articulated concerns and vulnerability about research situations within the home (Manuscript One) equally pertain to therapy situations within the home. As Lawlor and Mattingly (2014) described,

Health care encounters, once characterized by dyadic communication between a patient and doctor, are now complex social areas in which multiple social actors, including family members, convene. Health care encounters involving family members are sites of intense **boundary crossing** where families and practitioners create, negotiate, contest, and/or modify perceptions, perspectives, and caregiving and treatment practices (p. 153).

Home-based therapists (and particularly pediatric therapists) deliver services to individuals embedded in complex family contexts. Occupational therapy practitioners strive to be client-centered, with the recognition that clients may be more than individuals, and that no individual exists in isolation. Clinicians must attend to the situational whole and consider the impact and integration of interventions to family life, recognizing the entwinement of health outcomes

among family members. The current challenge is the continued predominance of therapies to address impairment at the individual level. The potential benefit of instead taking a family health experience approach is the opportunity to promote individual family member wellness and group function and quality of life. Expanded descriptions of family occupations, such as those offered in this dissertation, also suggest new areas and opportunities for activity modifications and adaptations.

Family support is recognized as a strong predictor for implementing habit changes, and family-centered care has been shown to improve health outcomes (Fiese, 2006; Kuhlthau et al., 2011). Blending therapeutic interventions into daily life necessitates attention to the complexity of family doing. Families are culturally-specific groups and require customized supports and health interventions (Freund, Boone, Barlow, & Lim, 2005). While occupational therapists are accustomed to embedding occupation into daily life, an additional implication from this study is that families rarely have singular aims, foci, or forms of action. It may not be enough to carve out a dedicated time of day or week in which to “fit” health interventions; practitioners may also need to consider how these interventions can be overlapped, intersected, and distributed into the general milieu of activity. The inclusion practices of families (Manuscript Three) might also be employed by therapists to promote participation in therapeutic activity.

Additionally, the findings of this study may be of use to other family professionals outside occupational therapy. Strengths-based approaches might be developed that build upon the patterns and processes observed among these families to elicit engagement in other settings. The families in this study demonstrated high engagement in activities, inclusive of children that had significant developmental and physical disabilities. Special educators work to elicit this same type of engagement in learning activities, and schools are especially attuned to the need for

inclusion across settings. Previous literature has found free play settings to be especially challenging for the inclusion of children with physical disabilities with their peers (Taub & Greer, 2000). However, I observed unstructured play to be frequent within family activities, which may offer lessons for expanding participation opportunities. Another prior finding demonstrated by Spencer-Cavaliere and Watkinson (2010) was that adult intervention was sometimes perceived by children with disabilities to be unhelpful or even detrimental to inclusion with peers (in the context of sports, games, and play). Although I observed parents practicing inclusion within family activities, these practices may not carryover to school or peer settings. Siblings, however, often traverse similar school and home contexts. Further study with siblings of children with disabilities may yield new and important insights into how children include one another in peer play.

Occupational Science Implications

From its inception occupational science has been tasked with developing a distinct knowledge base focused on the forms, functions, and meanings of occupation (Yerxa et al., 1990; Yerxa, 1993; Zemke & Clark, 1996). Occupational science has been shifting from an individual focus to address population level problems, including “new macro goals for developing science that are related to notions of social justice and social reform” (Molke, Rudman, & Polatajko, 2004, p. 276). As occupational science scholars have embraced the call to build the knowledge base, they have been increasingly seeking out accounts that expand beyond individual perspectives on individual occupations. As Dickie, Cutchin, and Humphry (2006) suggested, “an understanding of individual experience is a necessary but *insufficient* condition for understanding occupation that occurs through complex contexts” (p. 83), and the discipline has continued to move the consideration of occupation from individual, to dyad, to group, to community experience.

Several scholars have explored families within the context of mothering, fathering, and caregiving (e.g., Bonsall, 2013; Esdaile & Olson, 2004; Hamilton & de Jonge, 2010; Larson, 2000; Marquenie, Rodger, Mangohig, & Cronin, 2011; Segal, 2000; 2004). Another progression has been the examination of co-occupation to represent the joint engagement of more than one person, most often referring to the interactions of a mother and infant or child (i.e., Pickens & Pizur-Barnekow, 2009; Pierce, 2009; Price & Stephenson, 2009; Zemke & Clark, 1996). Segal's work on family occupations (1998) introduced the notion of shared occupations, and additional terms have been added to represent the occupations of larger entities. "Other terms to describe occupations that are not individual and are more collective include *shared occupations*, *joint occupations*, and *co-created occupations*. The theoretical basis for these terms is not yet well theorized but reflect recent attempts to develop a more social, dynamic, and transactional approach to understanding occupation" (Lawlor & Mattingly, 2014, p. 152). Scholars are also increasingly interested in the relationships among communities and occupations, including community development (Leclair, 2010), and even projecting "an intention towards social cohesion or dysfunction, and/or advancement of or aversion to a common good" (Ramugondo & Kronenberg, 2015, p. 10). Leclair (2010) has suggested the need to ask: "Are we enhancing participation in shared occupations?" (p. 19). The questions of how science might drive social change, and how to foster effective communication within both academic and public realms remain extremely relevant, and demand continued innovation and collaboration.

The work scholars have done with individuals has helped the discipline recognize and learn about the social; studying the social can help us learn about the individual in new and interesting ways. Families represent a useful stepping stone between individuals and larger communities and societies. The momentary composition of a family group can range from

compact to quite expansive. As common but complex groups, families accommodate examination beyond specific biological, legal, or kinship relationship, across cultures as well as in many life arenas. Humans create family-like groups that act in family-like ways in many different contexts. Family occupation reveals the social within the mundane, the collective within the individual (and the individual within the collective), and the ongoing negotiation, change, and fluidity of these elements. Family occupations are an excellent exemplar of transactional processes, resisting the isolation of individual actors and acts, while concurrently refusing distillation into simple unitary wholes. The examination of these occupations and the development of new methods for such study contributes to disciplinary understanding about the nature of human life and the social production of daily existence. There are also many other social and activity groups might better be studied using methods that allow for this type of multiple-yet-collective experience.

I have described families as highly fluid, with dynamic composition that changes moment-to-moment, adding and subtracting members, and frequently incorporating “non-family” persons into the “active family group” during activities. This is more akin to DeVault’s (2003) ideas about families repeatedly coming together and moving apart as they “inhabit” together. Although DeVault emphasized the spatial dynamics of convening and dispersing rather than affective components of the family experience, I suspect that this ebb and flow pattern also applies to experience of cohesion, togetherness, and sense of belonging often associated with family occupation. This fluidity in family structure and family doing suggests the importance of ongoing models and perspective that consider family as dynamic and changing rather than static and stable (i.e., life course perspectives).

I do not, however, want to fully dismiss the notion of body when thinking about family experience. I have suggested that families act as embodied collectives that together navigate the different capabilities of the bodies of their members in any given situation. This navigation does not merely require an initial survey of participant member bodies. As bodies in transaction the individual corporeal capabilities and functions are less important than the interdependent and cooperative ways that bodies are being used during family occupation. This transacting, situational, and multiple embodiment of family group, then, suggests the need for new assessments able to examine family health or occupational performance at a combined level.

The findings illustrate occupations as complex, transactional, negotiated and socially constructed processes, and describe several qualities associated with family time activities. For the purposes of this study I looked at what might be considered successful enactment of family occupations, in part because I think interventions need to build upon existing strengths. It is also important, however, to examine unsuccessful aspects of family occupation. This might include focused investigation of moments of disruption or dissatisfaction during occupations, exploration of discontinuation or nonparticipation in desired occupations, or examination of different family member experiences and accounts of least preferred parts of the family day. There is also evidence to suggest that child behavioral challenges negatively impact family quality of life (e.g., Davis & Gavidia-Payne, 2009), and more research is needed looking at family occupations in relation to these types of experience.

I have offered an account of situated disability experience. In this study I did not explore the intersections among disability and identities, rather I observed disability as a (situational) family variable (see Stone, 2013, for further discussion of the situated nature of disability). My work embraced the social-relational model of disability. I observed disability to be a shared

experience, but the findings extend beyond disability as part of shared social experience to describe disability as a part of shared active daily life experience among family members.

Family life and disability are important areas for continued research. While there is a large body of literature examining disruption and disability, Ferguson (2002) also noted,

There is increasing recognition and growing research that a significant number of parents actually report numerous benefits and positive outcomes for their families associated with raising a child with disabilities. These include coping skills (adaptability), family harmony (cohesiveness), spiritual growth or shared values, shared parenting roles, and communication (p. 129).

The fact that previous literature has found both positive and negative associations between childhood disability and family quality of life suggests disability is indeed just one additional ingredient in the unique family mix. However, reports by parents of children with disabilities of the need for additional participation supports (i.e., Poston et al., 2003) prompt continued work to examine how and when families experience successful participation.

Families with children with disabilities, like all families, manage varied member needs and skills. While the compartmentalization between families with children with disabilities and families with children with typical development is overemphasized, families with disability experience are perhaps especially adept at negotiating changing abilities within the flux of daily life. As such, research with these families offers much to help scholars think about everyday participation. The occupations of families such as those in this study allow room for differences with the realm of ‘acceptable’ participation, helpfully expanding notions of participation beyond restrictive roles or expectations. I think that these families allow researchers to more readily examine creative ways of doing and broader conceptualizations of equity and belonging.

Retrospect

Mistakes are valuable to the learning process, and I find it difficult to imagine what I would have done differently and still been able to reach a comparable outcome. Since the research design was intentionally fluid, I was not cognizant of needing to make any official changes in my approach to the observations. There are a few specific moments I would change if given a do over; I would definitely have eaten dinner with the Goddard family on my first visit rather than awkwardly sitting at the table not eating. As I continue to develop as a researcher, I will continue practicing my observation skills. I entered into the Phase Two fieldwork with the intent to attend carefully to the sensory experiences of each family member, but I mostly jotted general notes about the sensory features of the setting. I experienced similar difficulty in my attempts to tackle silence during the visits; I found it difficult to notice partial silences within the larger multiphonic flurries of activity, such as when another person was speaking. After each visit I jotted cumulative notes about silence related to the participation of individual family members, but I struggled to situate silence within the family unit. I think this challenge reflects my attentional habits- my first instinct is to gravitate towards words and speakers. I am interested in silence as transactional, not mere internal process or intentional external communication, but as of yet I am still working on how to capture it.

Researcher Future Directions

This dissertation project enabled me to practice both of the mainstay ethnographic family research methods; I did (mostly maternal) interviews as well as family observations. I was never in a quest to find the better method, as no such thing exists. But in my own learning process I was able to reflect on the different types of information yielded by each. I would be interested in more explicitly blending the two in future investigations, as I felt that “talking while doing” offered rich information about both process and meanings. For the purposes of this study I

attempted not to take the conversational lead, and I would be curious to try asking for more targeted explanations. I also continue to be interested in issues of voice and representation, particularly of children with disabilities that may not use language in typical ways. I remain interested in the many nuanced forms of communication that these children use to express themselves directly, but I am also fascinated by the multiple ways they are voiced within family groups (both as individuals and collectives). I felt that these children were polyvocal in a heightened way as their other family members spoke of them, to them, and for them. Life history storying, discourse analysis, and artifact generation and analysis are other methods I remain curious to explore in the future.

In the short term I would like to use the study data to write about participant observation as a method of family research, as well as to illustrate how family occupations interweave across various activities and events in daily life. The data has also prompted an interest in the interface between school and family. I was surprised to hear participant families, who overall demonstrated a high degree of success and stability in daily life, express intense emotions and often dissatisfaction with their perceptions and experiences of special education classrooms. Thinking ahead to the longer term, the results of this study continue to pique my interest in policy work and the question of how we provide social supports to families. I am interested in the ways people create relationships through occupation, as well as why the motif of family arises so often in the ways people order their social worlds. I believe that increased understanding of this structuring and experience of connectedness has the potential to help us know and relate to one another in positive ways, and create social systems and stewardship for a better shared world.

Table 1. Phase 1 Participant Demographics

Name	Age	Children	Profession
Susan	40's	14M, 17F	healthcare
Melody	30's	2F and expecting	science
Charlotte	30's	<1M	healthcare
Michael	50's	9M, 11F, 12F	healthcare
Hannah	30's	4M, 1M, 1M	academia
Emily	20's	2M	student
Olivia	30's	5M, 7M	student
Sarah	40's	6M, 9F	student
Andi	30's	5M, 1M	policy
Krista	30's	9M	healthcare
Sabine	40's	4F, 6F (lang. disorder)	academia
Jess and Alex	30's	3M (lang. disorder), 6M (sensory)	science & healthcare

**All of the participants were White, had some college education, married and cohabitating with their spouses and children. One participant was the member of a same-sex couple. Three of the parents explicitly mentioned pets (cats and dogs) when describing their families.

Table 2. Summary of Phase 2 Study Visits

Family	Initial	Visit 1	Visit 2	Visit 3	Visit 4	Visit 5	Visit 6
Riley	Pre-study meeting	Laundry and free play	Museum	Swimming			
Oliver	Pre-study phone call	Music Class	Playing at home	Swimming	Swimming		
York	Email	Outdoor movie	Field day at school and lunch	Family picnic	Dinner and magic show	Swimming and dessert	Swimming
Goddard	Pre-study phone call	Dinner and board games	Wii dance party	Swimming	Waterfight and games		
Barnett	Pre-study meeting	Swimming	Volleyball practice and ice cream	Volleyball game	Volleyball practice	Swimming	
Irwin	Email	BBQ	Physical therapy session	Museum	Baseball game		
Vida	Email	Basketball game	McDonalds	Swimming	Soccer game; pick-up football and popsicles		

Table 3. Phase 2 Participants

The Riley Family	<ul style="list-style-type: none"> ❖ Silas, 3 y/o, (language delay) ❖ Wyatt, 6 y/o, (motor delay, possible sensory) ❖ Jess, mother, 30-40 ❖ Alex, father, 30-40
The Oliver Family	<ul style="list-style-type: none"> ❖ Ron, 6 y/o, (global developmental disorder, visual impairment) ❖ JD, 14 y/o ❖ Haley, 18 y/o ❖ Penny, mother, 40-50 ❖ Paul, father, late 40-50 ❖ Lydia, aide worker, 40-50
The York Family	<ul style="list-style-type: none"> ❖ Alice, 6 y/o (global developmental disorder) ❖ Chloe, 8 y/o ❖ Lindsay, mother, 40-50 ❖ Cael, father, 40-50 ❖ Grammy, grandmother, 70-80 ❖ Gramps, grandfather, 70-80
The Goddard Family	<ul style="list-style-type: none"> ❖ Pablo, 8 y/o (mild orthopedic upper extremity disability) ❖ Uniqua, 11 y/o ❖ Tasha, mother, 40-50 ❖ Austin, father, 40-50
The Barnett Family	<ul style="list-style-type: none"> ❖ Madelyn, 6 y/o (ASD) ❖ Jasmine, 13 y/o (PTSD) ❖ Aster, Mom, 40-50
The Irwin Family	<ul style="list-style-type: none"> ❖ Wilson, 7 y/o ❖ Luke, 9 y/o (Down syndrome) ❖ Callie, 14 y/o ❖ Jason, 18 y/o ❖ Cindy, mother, 40-50 ❖ Eric, father, 40-50
The Vida Family	<ul style="list-style-type: none"> ❖ Sasha, 2 y/o ❖ Evie, 7 y/o (CP, global developmental disorder) ❖ Todd, 10 y/o ❖ Maya, mother, 40-50 ❖ Kevin, father, 40-50 ❖ Nana, grandmother, 70-80 ❖ Carmina, aide worker (to Nana), 50-60 ❖ Louisa, aide worker, 40-50

The Goddard, Barnett, and Vida families are multiracial (African-American, Asian, and Pacific Islander). The Riley, Oliver, York, and Irwin families are White.

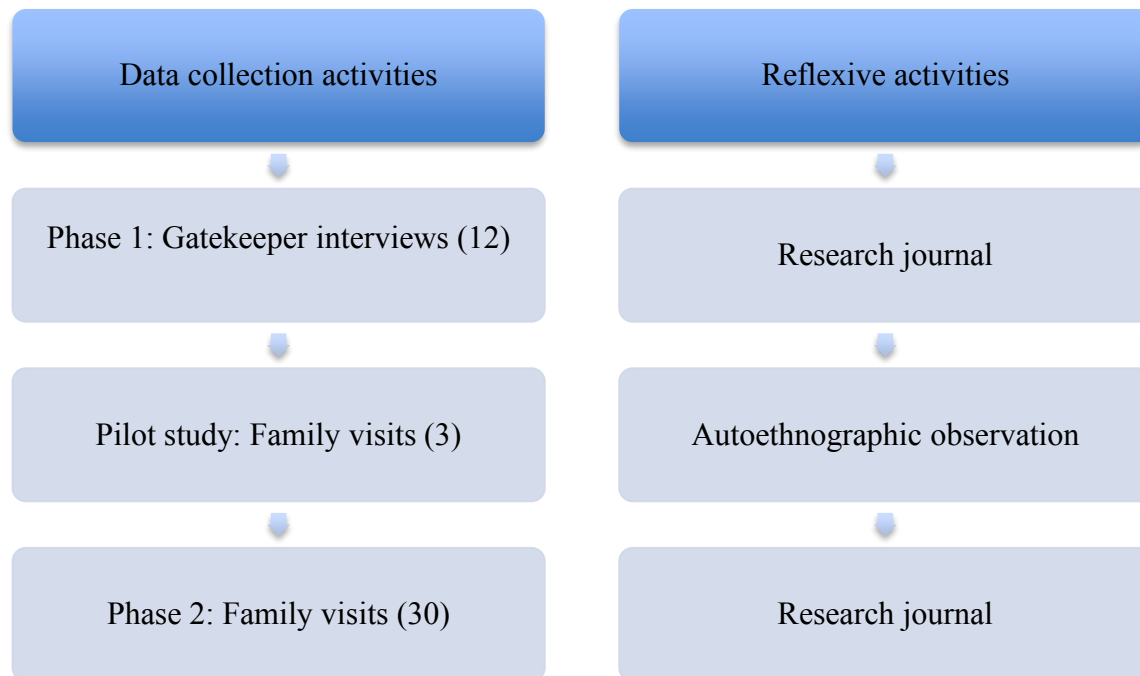


Figure 1. Data Collection and Reflexive Activities

APPENDIX A. RECRUITMENT MATERIAL SAMPLES

A.1 Informational Email

[INFORMATIONAL] Families of children with special needs sought for research study about family activities!

A doctoral student from the Department of Allied Health Sciences seeks participants for her observational dissertation study about family activities.

Objective: To learn about how families coordinate to make family time activities happen.

Participants: Families with one or more children 6-11 years old with any kind of disability diagnosis.

Study activities: 3-6 observational visits. Your family will be asked to choose an activity you enjoy doing together that a researcher can tag along for and learn more about. This activity might take place in your home or be an outing in your community.

Compensation: Families will receive a \$100 cash appreciation at the conclusion of the study visits.

If you would like to learn more about the study, have questions, or might be interested in participating, please contact Adrienne Miao by email at adrienne_miao@med.unc.edu, or by phone at xxx-xxx-xxxx. Please feel free to pass along to others that might be interested. Thank you!

This message & study approved by the UNC Non-Biomedical IRB - Study # 14-1024 Family-centered research: Exploring the perspectives of children with disabilities and their families on everyday occupations.

A.2 Informational Brochure

"A family is a unit composed not only of children but of men, women, an occasional animal, and the common cold."
~Ogden Nash



This study is interested in the everyday experiences of children in REAL families. I am interested in whatever YOUR family likes to do together and however YOU define family.

We need to hear more from children about their lives, and the scientific community needs to listen to the many ways children communicate.
Observation is key!

The Nitty Gritty

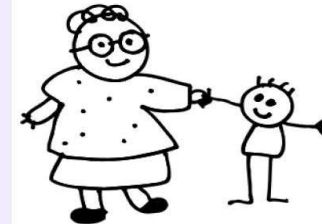
This research study is operating with approval from UNC's Institutional Review Board and family information will be safeguarded. There is no cost to participate. A small monetary appreciation will be provided to participants.

If you might be interested in participating and would like to receive more information about this study, please contact Adrienne and she would be happy to tell you more. If you know of anyone else that you think might be interested please feel free to pass along my contact information.

Thank you for reading!

"Family life is a bit like a runny peach pie — not perfect but who's complaining?" ~Robert Braullt

The Family Fun Study



Learning from children with disabilities and their families about doing fun things together.



- 6-11 year old children
- Any type of disability diagnosis

What is the purpose of the study?

The goal of this study is to add to our understanding of everyday family life. We actually don't have many descriptions of how families go about making things work and having fun. We also need to recognize the many voices within families. I am interested in disability as a shared social experience that is neither inherently positive nor negative, but just another facet of family life.

Ultimately this study hopes to aid the development of health interventions that build upon family capacities and strengths, with the long-term goal of improving services for children with disabilities and their families as they grow and learn to express themselves, build skills and develop their many talents and capabilities. I am interested in the experiences of children with a variety of physical disabilities, intellectual disabilities, and mental health diagnoses.

What your family can expect

This study is designed to be flexible, and everything is negotiable! The primary method is observation as you and your children go about your daily activities. I will ask your family to choose one or more 'family activities' that you usually enjoy doing together. I am especially interested in what makes activities fun or successful.

- 3-6 visits
- Wherever the activity takes place: your home, neighborhood, or out and about
- Observation and casual conversation with you and your children about the activity
- If your children prefer to express themselves through play, drawings, or other means that is great too!
- I will work with your schedule: weekends, evenings, last minute scheduling are all possible.

I consider children to be experts about their own lives, and I am looking forward to learning from the experts. My goal is not to judge parenting or behavior, but rather to try and learn more about how family activities are negotiated, constructed, and made to work. I believe 'health' is in the doing!

The researcher



My name is Adrienne and I am a graduate student in allied health science at UNC Chapel Hill. This study is a part of my dissertation and I will be the contact person as well as the one doing all of the observations. I have worked with children and families in the past as a camp counselor, teacher, adaptive sports instructor, and occupational therapist. I am especially interested in what families do for fun!



I am happy to provide local references/background check.

APPENDIX B. SAMPLE CONSENT, PERMISSION, ASSENT FORMS

B.1 Phase 1 Adult Consent

University of North Carolina at Chapel Hill Consent to Participate in a Research Study Adult Participants

Consent Form Version Date: _____

IRB Study # 14-1024

Title of Study: Family-centered research: Exploring the perspectives of children with disabilities and their families on everyday occupations.

Principal Investigator: Adrienne Miao

Principal Investigator Department: Allied Health Sciences

Principal Investigator Phone number: xxx-xxx-xxxx

Principal Investigator Email Address: adrienne_miao@med.unc.edu

Faculty Advisor: Ruth Humphry

Faculty Advisor Contact Information: xxx-xxx-xxxx

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to better understand how to design family research that is reasonable and feasible for families to participate in. The study aims to learn from families what considerations are most important when planning naturalistic studies, including how to approach and recruit families, how to schedule visits, what is a reasonable time commitment, how to establish rapport, and how to include different family members. The feedback collected during this study will help to inform the design of a more in-depth study of family well-being and everyday family life.

You are being asked to be in the study because you are both a parent and someone who has had experience with research. Your opinions and comments are especially helpful in thinking about research design.

Are there any reasons you should not be in this study?

You should not be in this study if you are unable to take part in an interview.

How many people will take part in this study?

There will be approximately 10-20 people in this research study.

How long will your part in this study last?

Your total involvement is expected to be 1-2 hours, and will be comprised of an interview. It is not anticipated that there will need to be any follow-up visits.

What will happen if you take part in the study?

If you choose to take part in the study, you will be asked to choose a convenient time and place to take part in an interview. There will be some guiding questions, but you are welcome to speak about anything you think is important or relevant. You may choose not to answer a question at any time and for any reason. If you give permission, this interview will be audio-recorded.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being in this research study.

What are the possible risks or discomforts involved from being in this study?

The research is not predicted to cause any harm, but it is possible that you might experience discomfort when thinking about past experiences with research that were frustrating or upsetting. You are welcome to stop the interview, change the topic, or take breaks at any time. The researcher will try to avoid any topics that are too sensitive. There may be uncommon or previously unknown risks. You should report any problems to the researcher.

What if we learn about new findings or information during the study?

You will be given any new information gained during the course of the study that might affect your willingness to continue your participation.

How will information about you be protected?

- The records from this interview will be stored securely in a double locked cabinet. Electronic records will be encrypted and securely stored.
- Only the researcher and her mentor will have access to this data.
- Pseudonyms will be used for all data analysis and representation.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

- Audio recordings from these interviews will be transcribed into written format (using pseudonyms).
- Both the original audio files and the transcripts will be stored securely.
- The audio files will be destroyed within 3 years after the conclusion of the study.
- You may request that the audio recording device be turned off at any time during the interview.

Check the line that best matches your choice:

_____ OK to record me during the study

_____ Not OK to record me during the study

What if you want to stop before your part in the study is complete?

You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

Will you receive anything for being in this study?

You will not receive anything for being in this study.

Will it cost you anything to be in this study?

It will not cost you anything to be in this study.

What if you are a UNC student?

You may choose not to be in the study or to stop being in the study before it is over at any time. This will not affect your class standing or grades at UNC-Chapel Hill. You will not be offered or receive any special consideration if you take part in this research.

What if you are a UNC employee?

Taking part in this research is not a part of your University duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Date

Printed Name of Research Participant

Signature of Research Team Member Obtaining Consent

Date

Printed Name of Research Team Member Obtaining Consent

B.2 Phase 2 Parent Permission Form

University of North Carolina at Chapel Hill
Parental Permission for a Minor Child to Participate in a Research Study

.....

Consent Form Version Date: 11/24/14

IRB Study # 14-1024

Title of Study: Family-centered research: Exploring the perspectives of children with disabilities and their families on everyday occupations.

Principal Investigator: Adrienne Miao, Department of Allied Health Sciences, xxx-xxx-xxxx

Principal Investigator Email Address: adrienne_miao@med.unc.edu

Faculty Advisor: Ruth Humphry, Department of Allied Health Sciences, xxx-xxx-xxxx

Funding Source and/or Sponsor: Society for the Study of Occupation: USA

.....

What are some general things you and you child should know about research studies?

- You are being asked to allow your child to take part in a research study. To join the study is voluntary. You may refuse to give permission, or you may withdraw your permission for your child to be in the study, for any reason, without penalty. Even if you give your permission, your child can decide not to be in the study or to leave the study early.
- Research studies are designed to obtain new knowledge. This new information may help people in the future. Your child may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.
- Details about this study are discussed below. It is important that you and your child understand this information so that you and your child can make an informed choice about being in this research study. You will be given a copy of this consent form. You and your child should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

Purpose of Study

- The purpose of this research study is to better understand how families negotiate and enjoy shared family activities. I am interested in learning from the many voices in your family about what your family enjoys doing together and how you make things work.
- The long-term goal of this research is to contribute to the development of health interventions that build upon family capacities, strengths, and daily experiences, in order to improve the provision of family-centered services that apply to real life.
- Ultimately, this research may be presented as part of a dissertation paper, poster, or conference presentation, or published as a journal article.

Description of the Study Procedures

- If you choose to allow your child to take part in the study, you will be asked to choose a family activity that you would be willing to have an observer join you for. The researcher may watch, participate, or assist with the activity as you deem appropriate.

- The researcher will ask to schedule several (3-6) visits to observe the chosen family activity. It is estimated that each visit may last a few hours. Your child will be encouraged to speak about or demonstrate anything they think is important or relevant. If you are willing, the researcher may ask your child questions about the activity and what it means to you.

Risks/Discomforts of Being in this Study

- The research is not predicted to cause any harm, but it is possible that your child might experience discomfort with having a researcher present or trying to explain the activity. Your child is welcome to stop the observation, change the conversation, or take breaks at any time.
- As with any adult in the state of North Carolina, the researcher is bound by mandatory reporting requirements in the event of witnessed or suspected child abuse or neglect. In the unlikely event that the researcher is required to make a report, she will work with your family to seek out appropriate resources and supports.

Benefits of Being in the Study

- Research is designed to benefit society by gaining new knowledge. Your child may not benefit personally from being in this research study. Participation may provide the opportunity for various family members to share their unique perspectives on family activities with one another.

Confidentiality

- The records of this study will be kept strictly confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file. Only the researcher and her mentor will have access to this data.
- The researcher will not include any information in any report she may publish that would make it possible to identify your child.
- If you give permission for audio recordings, they will be transcribed into written format (using pseudonyms) and will help the researcher remember details about the way you describe or explain the family activity.
- Both the original audio files and the transcripts will be stored securely.
- The audio files will be destroyed within 3 years after the conclusion of the study.
- Your child may request that the audio recording device be turned off at any time during the interview.
- Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your child's information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

Will your child receive anything for being in this study?

- Your child and family will receive a small appreciation (valued at \$100) for participating in the study. This appreciation may be in the form of cash, gift card, or activity passes according to family preference. This appreciation will be provided at the end of the study

visits, or may be mailed in the event that you choose to discontinue the study. Your family will still receive the appreciation if your child chooses to discontinue the study early.

- There is no cost for your child to participate in this study.

What if you or your child wants to stop before your child's part in the study is complete?

- You can withdraw your child from this study at any time, without penalty. The investigators also have the right to stop your child's participation at any time. This could be because your child has had an unexpected reaction, or has failed to follow instructions, or because the entire study has been stopped.

Right to Ask Questions and Report Concerns

- You and your child have the right to ask, and have answered, any questions you may have about this research. If there are questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, contact the researchers listed on the first page of this form.
- All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

.....

Parent's Agreement: I have read the information provided above. I have asked all the questions I have at this time. I voluntarily give permission to allow my child to participate in this research study.

Printed Name of Research Participant (child)

Signature of Parent

Date

Printed Name of Parent

Signature of Research Team Member Obtaining Permission

Date

Printed Name of Research Team Member Obtaining Permission

Check the line that best matches your choice:

____ OK to record my child during the study
____ Not OK to record my child during the study

B.3 Phase 2 Child Assent Form (7-14 years old)

**University of North Carolina at Chapel Hill
Assent to Participate in a Research Study
Minor Participants 7-14**

.....
Consent Form Version Date: 11/24/14

IRB Study # 14-1024

Title of Study: Family-centered research: Exploring the perspectives of children with disabilities and their families on everyday occupations.

Principal Investigator: Adrienne Miao, Department of Allied Health Sciences, xxx.xxx.xxxx

Principal Investigator Email Address: adrienne_miao@med.unc.edu

Faculty Advisor: Ruth Humphry, Department of Allied Health Sciences, xxx.xxx.xxxx

Funding Source and/or Sponsor: Society for the Study of Occupation: USA
.....

I am doing a study to learn about what activities families like to do together!

I am asking you to help because I don't know very much about how kids and families figure out how to have fun together.

If you agree to be in my study, I will ask to come visit your family and learn about the things your family likes to do.

What I learn in this research may help other families figure out ways to have fun together.

Its possible you will feel uncomfortable having a researcher hanging out with you.

You may ask me questions at any time.

You may ask to stop at any time.

The questions I ask are only about what you think. There are no right or wrong answers because this is not a test.

When I tell people what I have learned, I will use made-up names for you and your family. I will not tell anyone who you really are.

Your parent needs to give permission for you to be in this study. You do not have to be in this study if you don't want to, even if your parent has already given permission.

If you sign this paper, it means you have read / have been told about our study and you want to be in it. If you don't want to be in the study, don't sign the paper. Being in the study is up to you, and no one will be upset if you don't sign the paper, or if you change your mind later.

Child's Signature _____ Date _____

Investigator's Signature _____ Date _____

Sometimes I like to audio record what you talk about to help me remember what you said. These recordings are deleted after the study.

Check the line that best matches your choice:

_____ OK to record me during the study

_____ Not OK to record me during the study

APPENDIX C. PHASE 1 INTERVIEW GUIDE

Interview # _____
Date _____/_____/_____

Interview Protocol

Script

Welcome and thank you for your participation today. My name is Adrienne Miao and I am a graduate student at the University of North Carolina at Chapel Hill, conducting my research in partial fulfillment of my doctoral degree in Occupational Science. Thank you for participating in this interview, which is projected to take about 60 minutes but can be stopped at any time. The interview aims to help family researchers better understand what research experiences are like for families, as well as to problem solve how to get families involved without being too much of a burden. If you are willing, I would like your permission to tape record this interview, in order to more accurately document the information you convey. If at any time during the interview you wish to discontinue the use of the recorder or the interview itself, please feel free to let me know. All of your responses are confidential. Your responses will remain confidential and will be used to develop a better understanding of how a doctoral student (and family researchers in general) might go about creating a respectful, collaborative, family-centered research process. The purpose of this study is to increase our understanding of how families decide to participate in research, and what methods families see as appropriate and acceptable to garner authentic and meaningful accounts of family experience.

At this time I would like to remind you of your written consent to participate in this study. I am the responsible investigator. You and I have both signed and dated each copy, certifying that we agree to continue this interview. You will receive one copy and I will keep the other under lock and key, separate from your reported responses. Thank you.

Your participation in this interview is completely voluntary. If at any time you need to stop, take a break, or adjust our scheduled time please let me know. You may also withdraw your participation at any time without consequence.

Do you have any questions or concerns before we begin? Then with your permission we will begin the interview.

To get us started, would you mind telling me a little bit about your family?

How have you been involved in research activities?

What do you see as the benefits of research?

What are the challenges?

What are special considerations researchers should take into account when working with families?

Imagine a researcher wanted to come into your home/life to learn from your family.

What are your first thoughts?

Concerns?

Possibilities?

What would you want to know about the researcher to make you comfortable having them in your home/around your family?

How can a researcher effectively communicate non-judgment?

Please share any opinions, comments, or suggestions about the research process for families.

Approaching families?

Recruitment?

What kinds of incentives or appreciations might a (grad student) researcher offer?

Rapport building?

Scheduling- how much is too much? What times of day/days of week?

What would be your concerns or suggestions about scheduling visits?

Duration?

How would your children react?

How can we tailor study information and activities for children?

Indicators of child assent?

The use of video-taping and audio-recording?

How can researchers better work with families?

What kinds of questions should family researchers be asking?

What kind of family research would you like to see?

Interviews vs. observation- how do you feel about the methods of gathering information? Would you be comfortable if the researcher did not ask questions?

Artifact collection/production- how do you feel about the creation or use of drawings or photographs in research with families?

What activities would you welcome a researcher to join? Which would you rather not?

Other comments?

APPENDIX D. PHASE 2 DATA COLLECTION GUIDES

D.1 Observation Guide

Field Note # _____
Date _____/_____/_____

Observation Protocol

Confirm/reconfirm consent & assent:

Your participation is completely voluntary. If at any time you need to stop, take a break, want me to leave, or don't feel like talking please let me know- that's no problem. You may withdraw your participation at any time without consequence.

Thank for helping to teach me more about this activity that your family does.

I am learning about _____ and if there is anything that you think of that you want to show or tell me, I would appreciate as much information as possible.

Check for questions/understanding:

Do you have any questions or concerns before we begin?

9 Dimensions of descriptive observation (Spradley, 1980)

1. SPACE - layout of the physical setting; rooms, outdoor spaces, etc.
2. ACTORS - the names and relevant details of the people involved
3. ACTIVITIES - the various activities of the actors
4. OBJECTS - physical elements: furniture etc.
5. ACTS - specific individual actions
6. EVENTS - particular occasions, e.g. meetings
7. TIME - the sequence of events
8. GOALS - what actors are attempting to accomplish
9. FEELINGS - emotions in particular contexts

D.2 Conversation prompts

Conversation #:

Date:

Actors:

Conversation Prompts

Thanks for talking with me. As you know, I am trying to learn about how families do activities together. Your family has been teaching me more about _____ (chosen activity).

What did you think of doing _____ today?

- How did you think it went (evaluation)?
- Is it usually like this (comparison)?
- How did you feel before you started (emotion)?
- How did you feel during the activity?
- How did you feel after the activity?
- What is your favorite part (preference)?
- What is your least favorite part?

When does your family do _____ (time/routine)?

How does your family decide to do _____ (negotiation)?

Who usually takes part (actors)?

How long has your family done _____ (time)?

When/why did your family start (time/goals)?

Other comments?

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