UNDERSTANDING SHARED FAMILY MEALS ON THE AUTISM SPECTRUM

BY

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DISSERTATION

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Abstract

There is ample evidence on the positive effects of the family meal for children and families, but few of these studies have examined families where a child has autism. In order to better understand (1) the nature of shared family meals when a child has autism, (2) how families establish useful mealtime routines and meaningful mealtime rituals, (3) what are the barriers to achieving the family meal, and (4) the role mealtime rituals and routines play in family life I analyzed recorded observations of family dinners in the home and interviews with mothers of 16 Midwestern families. Each family had at least one child between the ages of 5 and 14 with autism. The families in this study shared many of the universal features of mealtimes such as using the time to share and problem solve, but they also had features salient to their identities as autistic families. For example, having to anticipate throughout the meal their children's capacities and limitations. The creation of useful routines was enmeshed with the creation of meaningful rituals. Logistical considerations, the ideal family meal, and the family-of-origin-family-meal placed constraints on what the mealtime routine could be. The repetition of routine created symbolic meaning which, in turn, both reinforced and reflected family functioning. Thus, family meals were a symbol unto themselves and the enactment of them had the potential to create connection and communicate closeness; however this was predicated upon the families ability to negotiate a dialectic of acceptance and control.

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Chapter One
Introduction

The shared meal is an iconic family ritual that provides significant benefits to families and its' members. Mealtimes serve as a context for development, rich with experiences and interactions that can promote child well-being, and there is a large body of research supporting this claim. For example, direct and clear communication, flexible adherence to carrying out a meal, and the repetition of roles are characteristics of mealtimes that have been linked to positive child outcomes (Fiese, Foley, & Spagnola, 2006). More frequent shared family meals are related to literacy development (Snow & Beals, 2006), healthy eating habits (Larson, Neumark-Sztainer, Hannan, & Story, 2007; Videon & Manning, 2003), positive values, social competencies, and supportiveness (Fulkerson, et al., 2006). Conversely, a low frequency of shared family meals has been associated with risk behaviors including substance use and depression (Eisenberg, Olson, Neurmark-Sztainer, Story, & Bearinger, 2004). Unfortunately, general research on family mealtimes usually precludes children with developmental disabilities from the sample so much is still unknown about the impact of the shared family meal for children with autism and their families. The research that has examined the connection between autism and food or mealtimes has focused on challenges and deficits, not on mealtimes as naturally occurring family processes.

One of the first representations of autism was by Leo Kanner in his 1943 paper as he described a five year old, "Eating…has always been a problem with him. He has never shown a normal appetite. Seeing children eating candy and ice cream has never been a temptation to him" (p. 217). Although there is nothing specific to food or mealtimes in the diagnosis of Autism Spectrum Disorder (ASD), autism has often been linked to food or mealtimes: theories link diet and nutrition to causes of autism, autism may express itself through different mealtime related behaviors, and mealtime may be used as a site of interventions. Mealtimes have been found to be one of the most stressful caregiving activities for mothers and fathers of children with autism (Plant & Sanders, 2007). But there are reasons to believe that mealtimes are beneficial for these families as well. Some evidence illustrates there is no difference in the frequency of shared family meals among families with children with autism compared to families with unaffected children (Lee, Harrington, Louie, & Newschaffer, 2008). Families with children with autism have to make intentional choices in regards to what routines to make

meaningful in their families lives, and for some families the mealtime is one of these activities. These families describe the mealtime as a place where they can be together and have a conversation (Bagby, Dickie, & Baranek, 2012). Families that are able to sit and eat a meal have reported feeling like a "normal" family (Werner DeGrace, 2004).

Purpose of Inquiry and Research Questions

For autistic families, who are more often viewed in terms of their deficits than their strengths, research is needed to resituate family meals as a place where some foster resilience, without ignoring the real challenges and struggles faced in everyday family life. Social communication and rituals and routines are at the core of how autism is defined and yet a broader understanding of ritual and sociocultural learning are rarely applied to this population. In fact, when ritual is discussed in relation with autism it is almost always understood as pathology. There is almost no effort to understand autistic ritual within the larger cultural conceptions of the form and functions of rituals.

Further research is also needed to better serve families. At this point, too little is known regarding family meals to successfully create programming to ease the stress and challenges that are commonly reported by parents of children with autism. Although there are many anecdotes of mealtimes being both difficult and important for families, a more systematic evaluation of the nature of family meals is needed before program development would be appropriate. This study will provide insights into family meals and strategies that have been successful for parents to have useful routines. This can set the foundation for future programming. Additionally, when parents seek support regarding mealtimes, they are often given recommendations that adapt practices that are commonly used in controlled clinical settings by trained professional staff. These recommendations may be difficult to implement in the family home. Parents will benefit from a program that grounded in the experience of families and strategies that other parents have found useful.

The existing research on shared family meals when a child has autism is limited in several ways. Most studies have not focused solely on mealtimes, confounded the constructs of ritual and routine, relied solely on interview data, and have focused on families under distress. There have been no studies specifically examining families who are successful with mealtimes or how families with children with autism adapt rituals to be inclusive. There also have not been studies that examine how families construct and express identity and cohesiveness in the absence

of "typical" mealtimes. There is no evidence that families with children with autism value mealtime less or are less likely to see mealtimes as a normal part of family life. In fact, they may actively feel an absence of family mealtime as another instance of how they are different or *other*. The purpose of the project is to have a better understanding of the role of mealtimes in the lives of families of children with autism. The specific research questions addressed are:

R1. What is the nature of shared family meals when a child has autism?

R2. How do families establish useful mealtime routines and meaningful mealtime rituals when a child has autism?

R3. What are the barriers to achieving the family meal?

R4. What roles do mealtime rituals and routines play in family life when a child has autism?

Defining Terms

In this section I provide explications for the constructs autism, mealtimes, rituals, and routines as full understanding of each is critical to my analysis.

Defining autism. The American Psychological Association's (APA) definition of autism is the most commonly used definition in the scientific community and it influences, at some level, nearly all understandings of autism. The APA utilizes the phrase *autism spectrum disorder* or *ASD* to refer to what people commonly mean when they say autism and define ASD as a pervasive developmental disorder that originates in childhood and is based on a set of criteria: significant impairments in the domains of (a) social communication and (b) rituals and repetitive behaviors (Wing, Gould, & Gillberg, 2011). This means that children with autism often have deficits in social emotional reciprocity, nonverbal communicative behaviors, relationships, sensory reactions, and motor movements as well as having an insistence on sameness and highly restricted interests.

Conflating the APA's definition of autism with what autism means is problematic in several ways. The first set of problems relate to the use of criteria. Over time the APA has changed the diagnostic criteria for autism and the words used to name autism. These changes have led to confusion about what autism is and if a person has been correctly diagnosed. Additionally, the practice of classification, diagnosis, and naming of individuals based on the APA's criteria is difficult. There are two tools that have been developed and are the gold standard for diagnosing individuals with autism: the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 2000) and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, &

LeCouteur, 1994). If a child receives a score lower than the cutoff, then they are usually diagnosed with autism, however clinicians may vary in their assessment; this has been shown to be especially true when assessing girls (Begeer, et al., 2013). Using these assessments to define who has autism and who does not also presumes that children are equally likely to be referred for diagnostic assessment; however evidence has indicated a racial bias in referral rates (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009). Thus female and African American children may be less likely to be *labeled* autistic even if they meet the diagnostic criteria. Also, not all clinicians use the same diagnostic tools for assessment and even the same clinician may use different tools with different children. This can be especially problematic when doing so yields different diagnoses. For example, a recent study found that four items on the ADOS could differentiate attention deficit hyperactive disorder (ADHD) from ASD but the ADI-R could not suggesting that the same child could be diagnosed as either having ADHD or ASD depending on the clinical tool used (Gradzinski, Dick, Lord, & Bishop, 2016). Difficulties in identifying autism calls into question what it means to *be* autistic.

Another set of problems with the APA's definition is that the way the APA defines autism is inherently individualistic. Doing so fails to address the social aspects of disability; "disability is a culturally and historically specific phenomenon, not a universal and unchanging essence" (Shakespeare, 2010, p. 268). Thus the APA's definition situates impairments related to autism within the individual and does not address how society functions to make specific impairments disabling. The social model of disability draws a distinction between a physical limitation (an impairment) and disability (social exclusion). The imperative for intervention from a social model is to accept the impairment and to change the disability or in other words change the structural and societal factors that impede on the freedoms of individuals with impairments (Shakespeare, 2010). This is much different than the APA's definition that would logically lead to interventions that seek to change the person so that they are less impaired. It is important to note that the social model is not without its' own limitations, the main one being that it can be difficult to interpret in practical application. For example, the Teach, Expand, Appreciate, Collaborate, Cooperate, Holistic Autism Program (TEACCH) is an attempt to affirm the culture of autism and provide culturally sensitive supports; however they define the culture of autism using a list of stereotypes and deficits (see Figure 1).

Figure 1. The "culture of autism" as defined on the TEACCH website (n.d.)

"CULTURE OF AUTISM"
- Relative strength in and preference for processing *visual* information (compared to difficulties with auditory processing, particularly of language)
- Frequent attention to *details* but difficulty understanding the meaning of how those details fit together
- Difficulty *combining* ideas
- Difficulty with *organizing* ideas, materials, and activities
- Difficulties with *attention*. (Some individuals are very distractible, others have difficulty shifting attention when it is time to make transitions)
- Difficulty with concepts of *time*, including moving too quickly or too slowly and having problems recognizing the beginning, middle, or end of an activity
- *Communication* problems, which vary by developmental level but always include impairments in the social use of language (called "pragmatics")
- Tendency to become *attached to routines*, with the result that activities may be difficult to generalize from the original learning situation and disruptions in routines that are upsetting, confusing, or uncomfortable
- Very strong *interests and impulses* in engaging in favored activities, with difficulties disengaging once engaged
- Marked *sensory* preferences and dislikes.

In addition to an individual orientation failing to address the societal issues related to autism, it also fails to address the familial aspects of autism. For families with children with autism, autism often becomes a core feature of the family's identity. Parents report that all of their decisions are affected by their child's autism (Hoogsteen & Woodgate, 2013). Mothers, after receiving an ASD diagnosis, often report a sense that their lives will never be the same (O'Brien, 2007). This suggests a shift in family identity. This shift occurs despite the fact that their child has not changed but rather as a direct response to receiving the ASD diagnosis.

The final set of problems with the APA definition is the use of a medical model for defining autism. "The medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit" (Linton, 1998). In his history of discrimination and disabled people, Colin Barnes (2010) identifies several problems with defining disability from a medical perspective: normality and impairment are not easily defined and are culturally dependent; people are presumed to be alterable and the environment is assumed to be fixed; it is implied that intervention can and should be used to fix the person with impairments; the people who fail to be adapt are seen as passive and apathetic; and disability and impairment are viewed as static. This mental model can have grave consequences and is inherently linked to the justification of isolation, marginalization, and abuse of disabled individuals across time and space. Joseph Straus (2010) has argued that understanding autism as culture is a more valid paradigm. People become autistic not just through medical diagnosis, but also through "personal choice, and self-identification, and even casual classification by outsiders" and what these individuals have in common is not a disorder but rather "clusters of behaviors, abilities, and attitudes" (Straus, 2010, p. 540-542). While many individuals in our society have been provided

with a label from the medical community, ultimately individuals with autism define what it means to be autistic (Straus, 2010).

Given that using a clinical definition is insufficient, I will give a working definition of autism[1] for this project. *I understand autism to be, primarily, differences in the way children learn: children with autism do not attend, encode, process, and or assess information from the social world the way typically developing children do these things* (Insel & Fernald, 2004). One reason why these children learn differently has biological roots such as gene expressions that lead to structural changes in the brain (Geschwind, 2011). The fundamental differences in learning and thinking can cause a variety of traits including but not limited to idiosyncratic language use and communication, intense and highly focused interests, and moving through the world without being attuned to implicit social rules. Our society has rigid behavioral expectations and therefore individuals (and families) with autism are often sanctioned, stigmatized, and isolated for not fitting in (Locke, Ishijima, Kasari, & London, 2010) and this exacerbates the impairments associated with autism. Autism is a "spectrum." This is often interrupted like a thermometer as "more or less autism" or "higher or lower functioning." I reject this conceptualization of spectrum applied to autism and instead see the spectrum akin to a rainbow. Not more or less on any given dimension, but each individual having a different combination of capacities, impairments, and supports that makes autism look very different among different people. In this project, I define a *family of a child with autism* as a family in which a parent identifies themselves as having a child with autism.

Defining mealtimes. The shared family meal is a cultural site, "historically durable yet transformable, socially organized and organizing, and tempospatially situated arenas, which are laden with symbolic meanings and mediated by material artifacts" (Ochs & Shohet, 2006, p. 35). Breaking down this definition, *historically durable yet transformable* refers to how family meals look different from family to family, across cultures and throughout time, yet they are easily recognized and identified. *Socially organized* refers to the patterned behavior that characterizes family meals. Shared family meals are a "package of reoccurring meaning-laden activities" that are an important part of family life beyond the "coordinated arc of activities" of which they

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[1] Throughout the paper, I use ASD to specifically refer to APA's definition of autism and autism as a medical condition. More often I use *autism* and in doing so I refer to a broader understanding of autism as set of traits that have particular meaning in social and historical context. I also use *person first* language (eg. individual with autism as opposed to autistic person) as consistent with the dominant trends in the current American disability movement except when this terminology is problematic for understanding autism as culture.

encompass (Larson, Branscomb, & Wiley, 2006, p. 2). *Socially organizing* refers to the functions of mealtimes. From this understanding, mealtimes are where novice members of society (usually children) are socialized into being competent, moral, and appropriate full members (Ochs & Shohet, 2006). Shared family meals can serve as an "organized group activity and the symbolic representation of these events [can] provide a link between individual development and system regulation" (Fiese & Parke, 2002). *Tempospatially situated arenas* means that they occur in both time and space although there is wide variation both within and between families and across time and place in where and when shared family meals occur. *Laden with symbolic meaning* refers to the special meaning attributed to routine elements such as seat assignment, manners, role assignment, conversation, and attendance which create a ritualistic element to shared family meals (Fiese, 2006). *Mediated by material artifacts* means that shared family meals are more than an intellectual and emotional endeavor; they happen and objects are necessary for implementing them, for example, in the United States, plates, forks, food, tables, and chairs.

This definition presents a broad scope of what can be considered a shared family meal and defining the boundaries are difficult. For example, to what extent does the meal need to be recognized as such by another, how organized must it be, to what extent do meals need to function as more than just a chance to eat, how frequently and regularly must they occur, to what extent are ritualistic elements necessary, how many members of the family must be present, and in what rooms can they take place, are examples of questions that define the boundaries of a shared family meal.

For the purposes of this project, *I define a shared family meal as having two or more members of the family present and eating within sight of each other at roughly the same time.* The "room" can be any semi-public space where members of the family reside such as the living room, dining room, patio, or family room. I will focus on evening meals and meals where a child member of the family who is participating in sharing the meal has autism and at least one other member present is a parent or legal caregiver. The first research question regarding the nature of shared family meals when a child has autism, will provide grounded insight into what a shared family meal means for autistic families. I will focus on families where the child with autism is in middle childhood (aged approximately 5 to 14). The age range was selected for the following reasons:

- 80.7 % of families with children in this age range eat dinner together four or more times per week (The National Survey of Children's Health; NSCH, 2012) suggesting it is an important time for family meals.

- Most children with autism are not diagnosed until after age four (Baio, 2014) creating a practical barrier to reaching families of younger children.

- In the life course of the family, as intense caregiving for young children diminishes the symbolic elements of family rituals increase (Fiese, Hooker, Kotary, & Schwagler, 1993). This makes middle childhood a more established phase in the family life course as well as a time where children are more active participants (Fiese, 2006). These features of family life may be different for families whose children have unique caregiving needs.

Defining family rituals and routines from a ritual theory lens. Family ritual theory is a lens for analytically understanding phenomena observed in family life: the "ritual as a symbolic form of communication that, owing to the satisfaction that family members experience through its repetition, is acted out in a systematic fashion over time" (Wolin & Bennett, 1984, p. 401). Rituals must be "performed" and to do this the participants must carry out sequences of formal acts, words, or sounds, and use special symbols that derive their meaning from a pre-existing external authority like culture, religion, or society (Rappaport, 1979). A family's sense of collected self may also be a form of external authority (Wolin & Bennent, 1984).

Wolin and Bennett (1984) proposed a typology of family ritual that consisted of family celebrations, family traditions, and patterned family interactions. Each category varies in the degree to which it is practiced (or performed) in the larger society, standardization of the practice, frequency of occurrence, and degree of intentionally. *Family celebrations* include rites of passage, religious holidays, and secular holidays (Wolin & Bennett, 1984). These are widely practiced in a given culture, have a fairly standard practice, occur yearly or to mark specific events, and usually take a great degree of intentionality to carry out. *Family traditions* are more family specific and consist of special events such as summer vacations, family reunions, or birthday parties (Wolin & Bennett, 1984). Most families have some family traditions, but they are not set upon in a given culture, they tend to have some standard practices but also practices that are idiosyncratic to the family, they occur less regularly than family celebrations, and they usually take a great or fair amount of intentionality to carry out. *Patterned family interactions* consist of bedtime rituals, shared family meals, and special leisure activities (Wolin & Bennett,

1984). Although they are practiced in the larger society, they can be highly idiosyncratic to the family, they occur very frequently, and they are the least deliberate of all types of family rituals.

Although family rituals may be more or less distinctive, especially with family traditions and patterned family interactions, variations in the ritual are noted and it may be that an individual involved in the ritual or an outside observer may feel that the ritual was not performed adequately (Parkin, 1992). For example, if a child with autism uses a special kind of chair at the dinner table that allows him or her to bounce throughout the meal, the child's grandmother may not feel like it is a *family dinner* because her conception of what that means does not include children bouncing while they eat. In this way, although family rituals are in some way unique to families, they are also beholden to larger cultural standards.

***The function of family rituals*.** Because human beings are social they must construct their identities in relationship with real and imagined other (LaRossa & Reitzes, 1993). Individuals use ritual as a mechanism for expressing and interpreting meanings among a group (Geertz, 1973). Through ritual, a family comes to have a shared understanding and it is through ritual that meaning is regulated (Kantor & Lehr, 1975). There are two meanings that must be expressed and interpreted by the group that can be conceptualized in terms of questions. The first is *who are we?* And the second is *who is in and who is out?* Put differently, family rituals stabilize identity, clarify roles, delineate boundaries, and define rules for the family (Wolin & Bennet, 1984).

Who are we? Through their special meaning and their repetitive nature, rituals contribute significantly to the establishment and preservation of a family's collective sense of self (Wolin & Bennet, 1984). Rituals perpetuate a family's paradigm and through this paradigm individuals in the family are prepared for and protected from the outside world (Reiss, 1971). A family's identity is both constructed through ritual and reflected by family rituals; "family rituals involve communication with symbolic meaning, establishing and perpetuating the understanding of what it means to be a member of the group" (Spagnola & Fiese, 2007, p. 285).

Who is in and who is out? Rituals reinforce who is in and who is out; they are sites where inclusion and exclusion processes emerge to define and redefine group membership (Gamson, 1997). Many see ritual as promoting belonging, however these theorist were rarely examining ritual from the perspective of the *other* (Oswald, 2001). The family meal is a site where membership in the group is expressed and families intentionally or unintentionally use ritual to

exclude members who make the idealized form of family difficult to achieve (Oswald, 2002). Thus the presence of the child with autism and the ability of the family to incorporate the child into the meaning making parts of a meal is an important part of the process and how the family defines its boundaries and sense of self. A study of 102 children with and without autism spectrum disorder found that children with autism were much more likely than their typically developing counterparts to eat by themselves between the ages of 3 – 11 (Truex, et. a., 2016).

The process of defining who is in and who is out not only applies to individual members of the family but also the family unit as a whole. Here the performance of a mealtime ritual is not so much about the boundaries of a family unit, but rather the family's sense of feeling like it is part of the larger cultural group. This is especially important for families of children with autism. Families of children with autism may feel that they are not a *normal* family and they can perceive this as being isolated from their communities (Woodgate, Ateach, & Secco, 2008). All families likely use an idealized construction of family as a reference for their own family ritual, however the idealized family precludes having a child with a disability and thus families with children with autism are inherently *othered*. Family rituals are important to families with children with autism in constructing a sense of normalcy and of these family rituals shared family meals stands out as being one of the most important (Gray, 1997).

Routines compared with rituals. Previous research has highlighted the importance of distinguishing the functional and logistic aspects of family life as family routines while defining the symbolic and emotional aspects as the ritual. A specific activity, such as a meal, may have both routine and ritual elements. Routines are different from rituals in terms of three dimensions: communication, commitment, and continuity (Fiese, et al., 2002). In a family ritual *communication* refers to problem solving, discussion of sensitive topics, and affective climate instead of the instrumental parts of the task such as requesting desired food items; *commitment* in ritual refers to emotional investment instead of how a task is accomplished; and *continuity* of the ritual refers to intra-family and intergenerational cohesion instead of the frequency of occurrences (Fiese, et al., 2002). An activity may become more than a routine when it moves beyond utility and starts taking on the functions of ritual such as conveying symbolic and emotional meaning and determining group membership. When shared family meals are an important part of organizing family life, creating a sense of family identity, and providing a

space for members to participate in shared meaning making, they are not just a family routine, but a family ritual (Wolin & Bennet, 1984).

Need for Further Inquiry

Given that mealtime as a family ritual has been scantly explored among families with children with autism the evidence of the importance of the mealtime ritual is unestablished for these families. There are three specific limits of using ritual theory to understand mealtimes when a child has autism that suggest a need for further theoretical development on this topic: (1) it is unclear to what extent routines and rituals are unique developmental assets for children with autism; (2) it is unclear if the mealtime ritual compared to other family rituals is important for children with autism and their families; and (3) it is unclear the degree to which children with autism are able to participate in mealtime rituals due to the impairments associated with their disability and the parents' ability to adapt.

Routines or rituals. It may be argued that stable routines are more vital than the ritualistic elements of mealtimes for families of children with autism. It has been theorized that children with autism need more predictability and routine than typically developing children (Flannery & Horner, 1994) and many interventions for children with autism focus on teaching them adaptive routines. Daily routines are often the focus of interventions in order for them to continue to be implemented repeatedly over time and so that they can have functional success for the family (Moes & Frea, 2000). Additionally, having set family routines has been found to be important to the functioning of families with children with autism (Larson, 2008). The benefits of routines are well-established in the literature but often routine is not well defined as a construct; this problem may have led to an overemphasis on routine at the expense of ritual. Additionally, in the literature on families with children with autism, ritual and routine are almost always treated as interchangeable terms rather than discrete constructs, thus it is difficult to tease apart if it is an adaptive routine or meaningful ritual that is important. For example, in a qualitative study of families with children with disabilities (not specifically autism), both rituals and routines were associated with resilience; moreover, mealtimes were one of the critical family rituals, but in this study rituals, routines, and rules were treated as dimensions of the same construct (Knestrict & Kuchey, 2009).

There is not clear evidence at this time from the mealtime literature that rituals are beneficial to the family and the child with autism above and beyond that stability that is provided

by the routine, but there is some evidence of the unique benefits of ritual from the religious studies literature. For example, for South Asian Muslim families living in America, children with autism's incorporation into religious ritual was critical to the family's resilience because of how the family used ritual to make meaning of the child's disability (Jegatheesan, Miller, & Fowler, 2010). There is also evidence from the literature on typically developing children. Among the general population, many of the routine elements observed during family meals have been linked to positive child outcomes, but the ritual aspects of the meal are also important for child development(Fiese, Foley, & Spagnola, 2006). For example, through ritualistic aspects of communication, commitment, and continuity of shared meals, families were able to problem solve developmentally salient topics (e.g. peer rejection), process and validate emotions, foster a sense of cohesion, conceptualize the future through planning, and connect the family with the past through the influence of family origin (Fiese, Foley, & Spagnola, 2006). There is no reason to suppose that the processes associated with rituals are any less important to families with children with autism. For example, an important factor for resilience in families with children with autism is how families make meaning of their child's disability and specifically, give up the idea that they can fix or cure their child (King, et al., 2006) which would align with the ritual processes associated with mealtimes.

Another problem with understanding the unique contributions of the ritual components of an activity beyond the routine, is that the distinction between ritual and routine can be difficult to parse apart and they are often interrelated. For example, in examining resilience among families with children with autism, being connected to one another was important; this would be considered part of the function of a ritual. Critical to being connected was the ability to be flexible and communicate clearly; these would be associated with the routine aspects of a family activity (Bayat, 2007). Distinguishing routine and ritual as distinct constructs and how they interact with one another is important for future work in this area and will be attended to in this project. I will examine both the discrete and interrelated components routines and rituals as well as explore outcomes related to the ritual and routine features of shared family meals.

Mealtime compared with other rituals. A small amount of previous work has examined the role of religious ritual for individuals with developmental disabilities and autism. For example, the bar/bat mitzvah ceremony created a sense of connectedness and enhanced self-image for young people with intellectual disabilities, their families and religious communities

(Vogel & Reiter, 2004). In the Navajo community, healing rituals and spiritual philosophy foster an accepting attitude toward autism (Kapp, 2011). Although many types of rituals are likely important for individuals with autism, their families, and communities, it is likely that mealtime plays an important role. Religious rituals are likely important for the family feeling like they are part of larger community and they play a role in defining who is considered part of the family unit (Oswald, 2002), but there is evidence that families with children with autism retreat into a more private spiritual life due to exclusion from formal religious ceremonies. Although parents of children with autism often report having religious beliefs or a faith in God, they are less likely than parents of typically developing children to participate in religious services (Twoy, Connolly, & Novak, 2007). Thus *patterned family interactions* such as mealtimes can be of utmost importance for achieving the functions of ritual especially for families who are excluded or precluded from participation in other forms of ritual.

It has been proposed that family rituals (and routines) are a context for child development. By context it is meant that family rituals, such as mealtimes, are a site where children develop cognitive and social skills as well as the affective bonds necessary for social emotional development (Spagnola & Fiese, 2007). It is unlikely that other types of family rituals such as birthday celebrations or family vacations would have the same degree of developmental impact as they occur less frequently. Other types of rituals such as bedtime and reading rituals have been found to be an important developmental context (Spagnola & Fiese, 2007), however these rituals are much less likely to involve the entire family and therefore may not have the same impact when it comes to the formation of family identity and feelings of family cohesion. I will explore the degree to which this line of thinking is validated for families with ASD in answering research question one regarding the nature of family mealtimes. Additionally, I will explore to what extent mealtimes are important to the family as well as other family rituals in answering research question four regarding the role of mealtimes..

Children with autism's ability to participate in mealtime rituals. Children with autism often display highly ritualized and idiosyncratic behavior; these behaviors are a definitive characteristic of ASD. For children with autism their rituals often exclude them from group membership, isolate them from others, and cause barriers from shared meaning because these

rituals are highly individualistic and rarely draw upon larger cultural meanings[2]. There is evidence that these personalized rituals can be utilized to expand a child's ability to symbolically connect with peers. For example, typically developing children and their siblings with autism can both participate in structured play activities that incorporate individual ritual elements with traditional play thus providing additional opportunities for socialization and developing an affective bond. In an intervention based on this process, the children were able to maintain these connections during mealtime activities suggesting that even highly personalized rituals can be utilized in specific contexts to promote group membership (Baker, 2000). But families may not use the mealtime as an opportunity to engage their child; they may distract the child by turning on the television or dismissing him or her from the table so that the other members of the family can share (Marqueine, Rodger, Mangohig, & Cronin, 2011). I will explore the degree to which the child with autism participates in the ritualistic aspects of the mealtime routine in answering the first research question regarding the nature of mealtimes when a child has autism.

Similar to how a pastor has a leadership role in the execution of religious ritual, parents and caregivers have the role of implementing and facilitating the mealtime ritual. In other cultural practices, parents can have a difficult time adapting to a child with special needs. For example, society has patterns of language socialization that are historically rooted, socio-cultural practices (Ochs & Schieffelin, 1984) and sometimes these patterns create less than ideal conditions for the development of children who have neurological impairments such as autism. For these children, parents may not independently adapt to meet their child's unique needs (Ochs, Solomon, & Sterponi, 2005). To the extent that rituals are naturally occurring family processes, at least some families with children with autism may not be able to participate in mealtime rituals as parents may not be able to adapt rituals to meet their child's needs nor do they have cultural standards for what these adaptions may look like. Some parents, however, intentionally facilitate a mealtime ritual. They may do so independently or have had opportunities to learn strategies to incorporate their child with autism into the ritual experience. For example, when parents were able to use strategies to facilitate socio-cultural perspective taking, children with autism without cognitive impairments have shown evidence of success during dinnertime conversations based around question and answering (Kremer-Sadlik, 2004). I

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[2] This is similar to what Erikson (1968) called a "private ritual" which he analyzed separately from the larger cultural enactment of ritual. I have chosen to contextualize the private rituals of children with autism within the larger cultural functionality of ritual.

will explore how parents facilitate a mealtime ritual and what happens when they do not in answering the second and third research questions regarding how families establish meantime routines and rituals and barriers to doing so.

Chapter Two
Review of the Literature

This review of the literature covers two domains: (1) the relation between autism, food, and mealtimes and (2) parents as facilitators of mealtimes through a sociocultural lens. *The relationship between autism, food, and mealtimes* explores previous research related to mealtimes and autism. *Parents as facilitators of mealtimes through a sociocultural lens* bridges the relation between previous research that has examined mealtimes as deficit area and the potential for mealtimes to be a developmental asset. If it is true that family rituals are critical for child development and family functioning, but do not always occur naturally, especially for families with children with autism, then sociocultural theory can be useful for illustrating how families may achieve the ritual. It is particularly relevant due to the role that culture and symbolic meaning play in both family rituals and sociocultural theory and because of the system level nature of both theories.

The Relation between Autism, Food, and Mealtimes

Previous research has explored eating difficulties, difficulties with mealtime behavior, interventions during mealtimes, using food in interventions, and nutrition as a cause of autism. This review reflects the deficit orientation of most of the research on children with autism and their families. Whenever possible, I have tried to represent research that reflects a more balanced view.

Eating difficulties. Many families of children with autism report difficulty with mealtimes or eating. For example, individuals with autism may limit their diet to a few options (selectivity), ritualistically keep food in the mouth (packing), voluntarily regurgitate and then re-ingest food (rumination), or eat non-edible objects (pica). Although children with autism may have any of these eating difficulties, there is controversy as to whether the presence of eating difficulties is significantly greater in children with autism compared to typically developing youth. Some studies have reported no or small differences between groups (e.g. Martins, Young, & Robson, 2008) and other studies have reported large differences between groups (e.g., Sharp et. al., 2010). Eating difficulties often lead to intentional interventions that may be facilitated by a clinician, parents, or school-based personnel.

Food selectivity. Of all the eating difficulties associated with autism, food selectivity seems to garner the most attention. It is easy to find literature suggesting picky eating is a

common problem for children with ASD.   For example, Sharp and colleagues (2013) have conducted a meta-analysis of feeding problems (most which focused on food selectivity) which found that children with ASD are five times more likely to have a feeding problem than children without ASD. Other research, however, has pointed out inconsistencies when defining food selectivity such as treating picky eating, food refusals, limited food repertoires, excessive intake of foods, and food category selectivity as interchangeable phenomenon (Cermak, Curtin, & Bandini, 2010). Others challenge the methodological validity of studies that find large differences in food selectivity in terms of control groups (e.g. not matching for functional ability) and effect sizes (e.g. only small differences in means that may be statistically significant but not practically significant) (Martins, Young, & Robson, 2008). A comparison of children with ASD with and without issues related to food selectivity found no difference in gastrointestinal symptoms, growth adequacy, or adaptive skills. However, there were differences in terms of parental stress and parent reports of problem behaviors (Postorino, et. al., (2015).

If there are differences in patterns of food selectivity among children with ASD, it may be that families of children with autism are different in important ways from families with only unaffected children. Parents of children with autism may be more likely than parents of typically developing children to believe that there is a relationship between nutrition and behavior (Raiten & Massaro, 1986) and therefore may have more rigidity with food selection. The relationship between child food selectivity and parent behavior is dynamic; parents may perpetuate picky eating by preparing their children special meals regardless of whether they have autism, other special needs, or no formal disability status (Hendy, Williams, Rigel, & Eric, 2010). Parents of children with autism may have more negative perceptions of their child's eating behavior than parents of typically developing children. In a study that compared the two groups, despite children from both groups eating the same amount of food, parents of children with autism were more likely to consider their children picky or difficult eaters (Lockner, Crowe, & Skipper, 2008). Food can become a symbol of stress for families with children with autism that can lead mothers to dread mealtime (Marquenie, Rodger, Mangohig, & Cronin, 2011). Furthermore, mothers of children with autism may have stress related to mealtimes such as being concerned about diet or being worried about their spouse's stress level (Anderson, Must, Curtin, & Bandini, 2012). Food selectivity may lead to other problems. For example, regardless of whether children had ASD or not, food selectivity has been found to be associated with mealtime

behavior problems (Curtin et al., 2015). Other research has called into question the stress caused by food selectivity. A study of co-parent quality found that, although picky eating was the most common challenging feeding behavior, it was not associated with parenting stress (Thullen & Bonsall, 2017).

        Difficulties with mealtime behavior. In addition to picky eating, families report difficulties with other behavior related to mealtimes. Many families use mealtime as an opportunity to talk about their day, but have difficulty doing so and attending to their child with autism; they may distract the child by turning on the television or dismissing him or her from the table so that the other members of the family can share (Marquenie, Rodger, Mangohig, & Cronin, 2011). There are other symbolic forms of communication that can be difficult for families with children with autism. When observing families at dinnertime and in other settings, children with autism had difficulty improvising prayers, co-telling stories about their day, and understanding the conversation. There were strategies, however, that parents were able to use to promote social coordination: speaking the same first language as the child[3], using short conversational turns, talking about objective knowledge, sitting side-by-side (instead of face-to-face), using objects, writing, pointing, restraining affect, and keeping a fast tempo (Ochs & Solomon, 2010).

        Parents of children with autism reported being flexible with routines and having more success with routines executed in familiar space. Despite this, families found mealtime routines could be difficult to complete on a regular basis, especially in a way that families perceived as relaxing or met their perceptions of a typically shared family meal (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). It may be that there is no difference in the routine elements of actually having a meal occur, but that these meals do not sufficiently serve to reinforce intra-family connections and there is some evidence that this is the case. A very small sample study found that there was a lesser degree of ritualization of shared meals for families with children with autism compared to families with unaffected children despite having fairly comparable levels of adhering to family routines (Rodger & Umaibalan, 2011). Another small study found that the markers of mealtime recognizable in all families were present in families

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[3] In the United States, it is not uncommon for non-native English speaking parents to be advised to only speak English to their child with autism regardless of the parents' proficiency in English. In this study, for one of the families the parents only spoke Chinese yet their son with autism only spoke English which led to significant barriers for meaningful mealtime conversation.

with children with autism such as preparing the meal, setting the table, sitting at a table, eating a meal, and cleaning up, however in this study the mothers were often preoccupied with the child with autism and his or her unique behavior rather than the meal itself. Often the child would not participate in many of the markers of the meal; for example, the child with autism may not sit at the table or not eat the food (Marquenie, Rodger, Mangohig, & Cronin, 2011). This suggests that sometimes when a family is defining a shared family meal they may report that they eat together even if the child with autism's participation is limited at best. Another study has found, that even if it is a sporadic occurrence, when families were able to sit and eat a meal, especially out in public, they have reported feeling like "normal" family and this was something that the family very much looked forward to (Werner DeGrace, 2004).

Intervention during mealtimes. Because mealtime is a functional and natural part of a family's day, it is often the site of interventions. These interventions may be addressing mealtime behavior or may be targeting social or functional skills more generally. For example, a parent may be taught how to use picture communication tools to facilitate conversation during mealtimes. Although there is usually a clinician involved in teaching the parent the skill, the strategy is implemented during family mealtimes. Mealtime may also be used to generalize a skill taught in a different context; for example, in a study of pre-school aged children, non-affected children were taught how to interact with children with autism on the playground. They then successfully used mealtimes to see if these practices would generalize (Trembath, Balandin, Togher, & Stancliffe, 2009).

Using food in interventions. Along with mealtime being a site of autism interventions, food is often used during interventions as a tool for instruction with children with autism, for example, mothers of children with autism may be more likely to use food as a reward (Anderson, Must, Curtin, & Bandini, 2012). Applied behavioral analysis (ABA) is specific type of intervention often used to teach skills to and modify the behavior of individuals with ASD in which food may be used as a reward. With the use of such techniques, desired behavior is reinforced, often with edible items, and non-desired behavior may be punished (called response cost in the literature) also with edible items (Cooper, Heron, & Heward, 1987). Although ABA may be used to address eating difficulties specifically, the use of food as a reward (or response cost) may be used to teach skills not directly related to eating such as speech, academic, or functional skills. The use of food in intervention adds a layer of complexity to the concept of

mealtime for a child with autism. Often ABA tasks are carried out at table thus sharing many of the same physical elements of mealtimes (e.g., food, table, chairs, and partner).

Nutrition as a cause of autism. In addition to food and mealtimes being used in a targeted way, diet has been used to address the core symptoms of ASD. In 1968, Linus Pauling wrote a paper suggesting that deficiencies and abnormalities of the "optimum concentrations of important normal constituents [vitamins] of the brain" can cause "mental diseases" (p. 265); since then, the relationship between autism and vitamin deficiencies has been studied extensively in the literature (see Pfeiffer, Norton, Nelson, & Shott, 1995, for a review). Such studies have led to dietary treatments in hopes of reducing the severity of ASD or curing it all together. From watching intentionally opiated animals which he believed behaved like children with autism, in 1979 Jaak Panksepp hypothesized that autism may be caused by over activity of the endogenous system. Later researchers observed that gluten and casein have proteins similar to opiate molecules and from this observation drew the conclusion that gluten and casein should be avoided. Others have proposed different theories that supported the same conclusion (see Christison & Ivany, 2006 for a review). Thus the gluten-casein free diet become popular in the autism community despite being ineffective, posing health risks, requiring a high amount of effort to implement, and inducing stigma (Mulloy et al., 2010). It is unclear how many children with autism are on special diets but one study estimated 17.3% were taking specialized vitamin supplements and 15.5% were on a special diet as the primary *treatment* for the disorder (Witwer & Lecavalier, 2005). Many more may be using diet as a supplemental treatment.

Gaps in the literature on mealtimes and autism. What is absent from much of the research on food and mealtimes in the autistic community is a recognition that children live and often eat within the family system. Each of the previous connections between autism, food, and mealtimes focuses on the child and not the family as the unit of analysis. There is some research that looks at the family unit or at least a sibling or parent-child dyad, but it is not part of the dominant conversation in the scientific autism discourse.

Parents as Facilitators of Mealtimes through a Sociocultural Lens

To further the case of the need to explore shared meals as a relevant phenomenon and the family as the appropriate unit of analysis, I draw upon a sociocultural theory. Sociocultural theory seeks to explain the physical and social relationship between human beings and their environment; labor as the means for relating human beings to nature and the consequences of

this relationship; and how *tools,* both psychological and technical, are related to the development of language (Vygotsky, 1978). In doing so, sociocultural theory explains the presence of culture in thinking, the nature of learning, and the relationship between development and instruction (Kozulin, 2012). Sociocultural theory was developed by Lev Vygotsky (1896-1934) to describe human development in terms of four domains:

> *Phylogeny* (the evolution of the human species), *history* (the development of cultural tools and sign systems, including languages, forms of literacy, mathematics, mythology, and science), *ontogeny* (psychological development), and *microgenesis* (the moment-to-moment changes of understanding when performing some task). (Edwards, 1997, p. 44)

These domains come together in social interaction (Wertsch, 1985) where social means both between two or more people and embedded in a sociocultural context (Wertsch, 2000). Most of developmental psychology examines the child as the smallest unit of analysis; however from a sociocultural perspective the child participating in an event embedded within a cultural context is the smallest unit of analysis (Miller, 2002). From a sociocultural perspective, one would not conceptualize the meal, the child, and the parent as distinct entities but rather as a single unit. Mealtime provides a rich sociocultural-historical context in which children are fused in activity with other people (typically their families) and a unique opportunity to examine development from a sociocultural theoretical perspective. There are many facets to sociocultural theory, but for the purposes of this review, I have focused on the zone of proximal development (ZPD) and mediation. After defining ZPD and mediation, I explore language as a psychological tool for cognitive development.

> ***Zone of proximal development and mediation.*** ZPD is the difference between what a child can do independently and what a child can achieve through guidance and collaboration with more skilled individuals (Vygotsky, 1978). Critical to this learning process is the adult (or more skilled peer) building on the child's competencies to facilitate the child developing new skills (Vygotsky, 1978); the adult building on the child's abilities is an example of a human mediator. As the child and the adult work together to solve a problem, the child and the adult engage in intersubjectivity, or shared understanding, and through this there is a "internal reconstruction of an external operation (Vygotsky, 1978, p. 56) or in other words, the child internalizes the adults' culture (Rogoff, 1990). This process is happening as children learn from instruction by adults and more skilled peers as well as through observation (Rogoff, 1990).

Whereas ZPD describes a range of developmental potential, mediation describes the processes by which a child moves through said range (Kozulin, 2003).

For example, at dinner a young child may bang his utensil on the table and be pleased at the noise. At first, his mother may smile at his playing, but after some time, she guides his hand to use the utensil to scoop his food. When he uses the utensil on his own, she smiles and coos at him saying, "That's my big boy, look how good you eat with your spoon." In this moment the mother is teaching him how to use the spoon. She has *scaffolded* his learning by using a physical prompt when he did not use the spoon as an eating utensil independently. She is teaching him a word by naming the utensil as a spoon. She is also communicating to the child cultural expectations about what tasks are done at the dinner table (eating and not playing), the value of independence (encouraging him to eat on his own rather than feeding him and by encouraging him to be a big boy rather than remaining a helpless baby). The child is physically capable of using a spoon and may even have somewhat of a conceptual understanding of what a spoon is and although he does not use it independently, he can use it with his mother's support. This task falls squarely within his ZPD. In time, so will using the word spoon as a symbol for an actual spoon and the internalization of cultural values related to using a spoon. The child does not learn to use the spoon independently, but rather the child's learning is mediated through the actions of the mother to facilitate the task. These facilitated learning actions are called scaffolds or scaffolding (Bruner, 1975).

In this example, the child not only learns from the mother's intervention, but also from watching what is happening at the dinner table, however the ability for children to learn through observation is not equally true for all children in all contexts; children with autism often have difficulty learning without intentional instruction especially about social relationships. But the role of intentionality on the part of the parent, more skilled peer, or practitioner makes sociocultural theory an important paradigm and ZPD and mediation are a central concepts for most interventions for children with autism. For example, in ABA (described earlier) each task is categorized within a developmental sequence. Children are taught tasks in order, starting just beyond what they can already do independently and moving through tasks that they can do with support until these tasks become independent. As each task is taught the scaffolding (which takes the forms of various levels of prompting and reinforcement) is reduced and through this systematic reduction of scaffolding, the child moves through the ZPD gaining more and more

independence. Techniques such as *Floortime* (Greenspan & Wieder, 2006) also draw from the ZPD and mediation. With Floortime, the parent follows the child's lead and slowly and systematically the parent expands the child's ability to engage, relate, and develop their symbolic world through play and thus the parents have mediated the child's learning experience and also facilitated the child developing symbolic mediators. Symbolic mediators are psychological tools that shape mental functioning (Kozulin, 2003).

   ZPD and mediation applied to mealtimes. For the most part the ZPD and mediation have been studied in instructional contexts and during play, but there have been few attempts to apply the ZPD or mediation to mealtimes. One such study focused on 28 American middle class 10 to 15 month old typically developing infants and their mothers during lunch. In this study, the structure of the learning environment was conceptualized as the "*zone of free movement*… a socially constructed cognitive structure of child-environment relationships" with the function of limiting the child's actions (eg. a high chair) and the "*zone of promoted actions*…the sub areas of the [zone of free movement] the child's caregiver attempts to promote" (eg. using a spoon) (Valsiner, 1984, p. 67-68). One of the focuses of this study was the variety of different instructional pathways mothers utilized to encourage the adoption of using the spoon, but as this study only included typically developing infants, it remains unclear what strategies parents of children with autism may utilize.

   The role of language. Adults help children to develop the inner structure of the mind by teaching them to use psychological and technical tools (Kozulin, 2003). Both technical and psychological tools are embedded within culture but whereas a spoon is an example of a technical tool and externally oriented, a psychological tool will be internally oriented with the goal of organizing and controlling thinking and behavior (Miller, 2002). To Vygotsky, language was the most critical or valuable psychological tool; language is the foundation for thinking, organizing reality, controlling behavior, understanding memory, and problem solving (Miller, 2002).

   Children with autism vary to the degree they develop language. The example of a child and the spoon utilized above can illustrate why this may happen. At dinner a young child may bang his utensil on the table and be pleased at the noise, but he does not attend to his mother's response nor her attempt to guide his hand to use the utensil as a spoon. She has nothing to praise and even if she did praise him, perhaps after eating from his spoon when she has guided it

to his mouth, he may not attend to this either. Even if he does process that she has spoken to him, it may not evoke in him pleasure and therefore even if the content of her words are praise, they are not functionally praise in line with its use to positively reinforce desired behavior. It is unclear whether the task of using a utensil to eat, using a cultural tool, symbolically using the word spoon to represent an item, or understanding cultural expectations are within the child's ZPD.

If the child does not learn language he will be limited in his ability be successful in the day-to -day functions of living and also in his ability to connect with others as language is instrumental to how most people achieve both these goals. But there is another problem. Not only is the child not connecting the word spoon to the object, he may not be developing symbolic mediators; the child may not be connecting the object to a function that exists within his mother's mind rather than the function that exists solely within his own. Without the tool of language, it is unclear if he would develop other psychological tools necessary to process and organize the more abstract cultural lessons that are embedded in the exchange. The absence of symbolic mediators also will greatly impair the child's ability to be independent with the skills of daily living and with developing human connections because symbolic mediators are the tools that organize the mind and behavior. What makes this more complex for children with autism is that it appears that some children with autism develop language but that language does not serve as a psychosocial tool in the same way it does for typically developing children.

Internalization. Although Vygotsky proposes that instrumental and psychological tools are important for internalizing the "intermental to the intramental (Vygotsky) or appropriation of shared activity (Rogoff)" the exact processes remain unclear (Miller, 2002, p. 410). The exact role language plays in this process is also unclear. For example, family rituals imply the internalization of cultural values and family identity, however this happens not just through the language of the ritual, but also the use of objects associated with the ritual and the patterns of behavior that encompass the ritual. In instructional settings, objects can be extremely important for teaching new activities and establishing joint attention (Korkiakangas & Rae, 2013). I speculate that, for children with autism, objects and patterns of behavior may be critical for internalization and may be more important symbolic mediators than language. Child development is embedded in culture and this culture is constantly expressed in the child's immediate setting thus as a child is learning the more functional elements of the meal they will

also be learning some of the symbolic elements of the meal. The child's ability to develop symbolic meaning will be mediated by the child's ability to develop psychological tools, but participation in ritual also connects the child to his or her larger culture and family culture through the symbols and actions of the meal. The symbolic (ritual) and instrumental (routine) elements of the meal are embedded and intertwined with one another, even if they are related to different developmental outcomes. As the child learns functional tasks such as sitting at a chair and using utensils (tasks that may be no small feat for families with children with autism) the child and the family will co-create their identity and what they value. As an example, the very symbol of all members of the family being at the table sends a powerful message of inclusivity and that concept is likely to be within the ZPD for many children with autism even if they cannot put that message into words independently.

Sensitizing Concepts

Sensitizing concepts "give you initial ideas to pursue and sensitize you to ask particular kinds of questions about you topic" (Charmez, 2006, p. 16). Family ritual theory and sociocultural theory shape why I am interested in shared family meals when a child has autism, the types of research questions I ask, and how I have structured a plan of inquiry for answering them. Additionally, I tend to see autistic families from a resilience stance and tend to take a critical stance to previous research on these families. By a resilience stance, I mean that I see *doing family* when a child has autism as, "a dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar, Cicchetti, & Becker, 2000, p. 543) where adversity is the lack of appropriate supports and societal acceptance of difference. By a critical stance, I mean that I see much of research on autism as an effort to impose *Truth* "by those who control the power to shape knowledge" in order to ""maintain the prevailing power system" (White & Klein, 2015, p. 26).

These perspectives applied to my work mean that I attempt to *write without othering* (Fine, 1994; Krumer-Nevo & Sidi, 2012). Othering is "the risk of portraying the other essentially different, and translating this difference to inferiority" (Krumer-Nevo & Sidi, 2012, p. 299). As I integrate concepts into a theoretical model I must "struggle to find an interpretation that is rich, esthetic, and serving a social change agenda without violating or being disrespectful toward the people involved" while simultaneously rejecting "romanticization, forgetting, or ignoring the difficult aspects of their reality and behavior" (Krumer-Nevo & Sidi, 2012, p. 192).

Put differently, I take seriously the consequences of inquiry. In studying disability, I take responsibility for creating truth that is valuable to the extent that it has meaning in the context of real life, that it is useful for relieving the burdens imposed by aspects of an impairment, and that it does not perpetuate stigma and marginalization. In summary family ritual theory, sociocultural theory, family resilience theory, and critical theory are sensitizing concepts in my work. For a full reflexive statement of my biases and training, see Appendix A.

Chapter Three

Methodology

In this chapter I outline my mental model in terms of paradigm and how that led to my methodological framework, grounded theory. I then articulate my recruitment and sampling strategies followed by a description of the participants in this study. Finally, I outline the data collection procedures and analytic plan.

Paradigm

Pragmatism is a philosophy that resulted from a reluctance to accept the realist ontology of experimental inquirers as well as a desire to expand the scope of the field of inquiry beyond the *natural* world. Pragmatism rejects the dialectic of the ontological divide between (post)positivism and interpretivism- the idea that the nature of reality is singular or plural and knowing is an objective or subjective act. Pragmatism focuses on nature as a "moving whole of interacting parts" in which the indefinite interactions and not the mind is at the center of knowing (Dewey, 1925, p.232). Fundamentally this challenges our understanding of the nature of reality and how we come to know about reality. Reality is not something that you discover; rather it is something that you make (James, 1907). From a pragmatic worldview, when a researcher utilizes methods from positivist or constructivist traditions, he or she is not choosing between different ontological frames. The objects of knowledge are not things that exist (subjectively or objectively) but rather "outcomes of the process of inquiry" (Biesta, 2010, p. 109).

The methodological implications of pragmatism are unclear. Pragmatism explores issues of ontology much more than it does questions of epistemology (Biesta, 2010). Early pragmatists affirmed the role of the scientific method that has firm roots in positivism (West, 1989). Pragmatists such as George Hubert Mead are also cited in the constructivist tradition due to their rejection of pure objectivity and their exploration of how the self is created through engagement with the world (Lock & Strong, 2010). William James saw the role of pragmatism as a mediator and viewed the amiable reconciliation of two extremes to be the best solution (West, 1989). Pragmatism does not prescribe specific methods and preclude others; rather it opens the door to utilizing multiple methods as long as there is an integration of theory, question, and phenomenon with method (Feilzer, 2010). Thus, from a pragmatist paradigm the method or methods that have the best utility should be utilized. When adopting a pragmatist approach one is embracing ambiguity (Feilzer, 2010); what action (method) one takes depends on the ability to shed light on

the phenomena (Johnson & Onwuegbuzie, 2004). Pragmatism does not privilege one set of methods, but rather suggests that "different knowledges are simply the result of different ways in which we engage with the world" (Biesta, 2010, p. 113) and thus the methodologies a researcher chooses will depend on the kind of connections he or she is trying to make.

Grounded Theory

Pragmatism is not inconsistent with the ontological underpinnings of grounded theory; grounded theory is rooted in both pragmatism and symbolic interactionism (Charmaz, 2006). I follow most closely the work of Corbin and Strauss as described in the third edition of <u>Basics of Qualitative Research</u> (2008) although other editions of their work and interpretations of grounded theory by other methodologists are integrated. I choose this version of grounded theory to be my primary source because they approach grounded theory from a pragmatic paradigm (Corbin & Strauss, 1990; Corbin & Strauss, 2008) which is consistent with my mental model and purpose of inquiry. I believe grounded theory is the most appropriate method for answering the "how and why" types of questions needed at this stage of research on mealtimes in families of children with autism. My research questions are exploratory, hypothesis generating, and have the flexibility to incorporate concepts that have not yet been identified (Corbin & Strauss, 2008). My research questions are:

R1. What is the nature of shared family meals when a child has autism?

R2. How do families establish useful mealtime routines and meaningful mealtime rituals when a child has autism?

R3. What are the barriers to achieving the family meal?

R4. What roles do mealtime rituals and routines play in family life when a child has autism?

Grounded theory is a method that can be useful when no theory exists or when existing theories are inadequate for the purpose of understanding processes, action, and interaction (Creswell, Hanson, Plano, & Morales, 2007, p. 241) such as in this case. There is not enough evidence in this area to suggest what outcomes are related to mealtimes for families with children with autism. It remains unclear to what extent families with children with autism participate in shared family meals, to what extent the child with autism participates in meals and with what other members of the family, how families are able to achieve family meals to accommodate their child with autism, and the role of mealtime rituals in the development of family identity. In the current literature there has been a lack of attention to the constructs of

routine and ritual and how these constructs operate together yet distinctly relate to child and family outcomes. Without understanding the process of family meals it is difficult to establish the link between mealtimes and specific outcomes.

Recruitment & Sampling Strategy

The family where a child has autism was the primary unit of analysis for this study. I considered a family to be at least two people: a parent or legal guardian and their child. In order to participate in the study, the child must have had autism according to the parent and be elementary or middle school aged.

I recruited families through service networks, personal networks, mental health clinicians, community providers, and parent support groups. I posted flyers in locations throughout the community that would likely serve individuals with ASD and sent emails to providers likely to serve children with ASD or their parents. I asked researchers and providers that I know to contact individuals they knew who may qualify. Participants in the study were asked to pass along information to their networks. See Appendix B for examples of recruitment materials. Interested individuals either registered to participate in the study online or contacted me directly. Once registered, participation was confirmed via phone call or email. The confirmation outlined the study procedures, provided an advanced copy of informed consent (in the case of a phone conversation this was emailed after the call), and established a date for the observation. The interview time and location were scheduled after the observation. I started data collection on September 29th, 2015 and ended data collection May 24th, 2016 with 16 families participating in the study.

Rationale for ending sampling. Glaser and Strauss (1967) use a concept they call theoretical saturation to explain when sampling should end – when, "no additional data are being found whereby the sociologist can develop properties of the category" (p. 61). Corbin and Strauss (2008) go on to say "saturation is more than a matter of no new data. It also denotes the development of categories in terms of their properties and dimensions, including variation, and if theory building, the delineating of relationships between concepts" (p. 143). Simply, data collection ends when there is enough data to meet the goals of the project. The goal is to produce a *theory*, an abstraction that enables us to organize, simplify, and comprehend a phenomenon. There must be enough data to do justice to the complexity and not to distort the interpretation through the process of simplification (Strauss, 1993).

Thus in order to understand saturation, one must clearly articulate the goals of the project. For this project, as consistent with the typical goals of grounded theory my goals were: (a) a theoretical model that explains a process, (b) a visual representation of the model, and (c) a discussion of the components of the model and how they interrelate (Creswell, Hanson, Plano, & Morales, 2007, p. 252). Using this standard, data collection ended when I (a) developed a framework of the nature of mealtimes and the role that mealtimes play in family life when a child has autism; (b) could represent that framework in words and images; and (c) was able to discuss how families established useful mealtime routines and meaningful rituals as well as the barriers to shared family meals and the role of mealtimes. Having said that, enough data to complete the goals of the project is still a vague criterion for judging that saturation has occurred. In the absence of set criteria, the following concepts guided my discernment of saturation. Variation, fairness, and grounded in examples have been identified as markers of trustworthiness for qualitative inquiry. I used these markers as guidelines for saturation. Each concept is discussed separately, but they were iteratively connected in the process of determining saturation.

Variation. In understanding a phenomenon it may be tempting to look for typical reports, however, for the purpose of saturating, variation gives more insight into the boundaries and dimensions of categories, themes, and codes (Morse, 1995). It is critical to be reflexive as limited variation could easily be a product of weak interview questions, but, in general, an indicator of saturation is that the data seem to yield no new variations. In my work this looked like not needing to add new concepts to the code book and determining that each concept had been outlined in terms of its dimensions. For example, with the concept "control" that I was not finding any additional strategies for control. It also meant that I felt I had enough variation to fully understand what control meant and how it was enacted.

Fairness. "Fairness may be defined as a balanced view that presents all constructions and the values that undergird them" (Lincoln & Guba, 1986, p. 20). In order to be fair, data must be gathered to the extent that persons from different value systems are *included* and *understood*. In this study, an indication of saturation because the work was "fair" was determined in two ways. To establish the *included* component of fairness I sought a diverse sample thus recruitment could end when we had a diverse sample. I looked for diversity in terms of family structure, sexual orientation, race, socioeconomic status, and the intensity of support needed by

the child with autism. Simply having a diverse sample does not ensure that the participants are *understood*. One tool that Lincoln and Guba (1986) suggest for ensuring fairness is the use of member checks, but the use of member check is not without controversy. Participants may be limited to their own experience when the researcher may be abstracting across accounts (Morse, 1998; Sandelowski, 1993). In other words an individual participant may not feel their story is fairly represented because the results are more abstract than their own experience. In terms of establishing the *understood* component of fairness I was in the unique position of having both interview and observational data. Instead of using member checks, I sought to understand our interpretations of the interview data in the observed mealtime experience. As part of the interview protocol, participants watched excerpts from their own mealtime observations and interpreted their own behavior. I determined we were saturated when the theoretical process could be understood in the lived experience of families.

In my initial recruitment, all the children in the study had some verbal language skills: at the very least they could speak in short sentences or phrases that were understandable to people they knew well. Although several had impairments of functional reciprocal communication, the presence of verbal language has significant implications for family meals. Additionally, no children in the study used augmentative communication at home, although several used I-Pads at school as a secondary communication tool. Recruitment of families with children who have significant verbal impairments and who use augmentative communication devices as a primary communication strategy was not possible within the practical constraints of this project. Thus my theoretical model is limited to families of children with autism with some verbal language ability.

Grounding in examples. In order for the data to be saturated, I should be able to provide "data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them" (Elliot, Fischer, & Rennie, 1999, p. 222). Through the process of grounded theory, I engaged in an act of interpretation, and as such, pieces of data may contribute to an understanding above and beyond their face value. Given that not every piece of data may resonate with readers, one indicator of saturation was that I had sufficient data to yield exemplars of the codes, categories, and phenomena that I discuss. As I was analyzing the data as I was collecting it, and I had the ability to determine that I had sufficient data to ground my results in examples.

Participants

Sixteen families participated in the study. Participants varied in terms of the presence of other children in the home, the presence of other individuals with autism in the home, type of home, commuity, race and ethnicity, family structure, mother's highest level of education, the age of the target child (TC), and mother's age. See Table 1 for participant demographic information and Appendix C for a more detailed participant guide.

Table 1

Participant Demographics

Demographic Variable		N = 16
Number of Children in the home		1 to 3 (largest family had 5 children with only 2 at home)
Additional Immediate Family Member with ASD	None	10
	Parent	2
	Sibling	2
	Both Parent and Sibling	2
Home type	Apartment	6
	Single-Family Home	10
Community	Micro-Urban	11
	Small Town	5
Number of different communities		8
Race/Ethnicity of TC	White/European American	10
	Black/African American	1
	Latino/Latina	1
	Asian	1
	Multi-ethnic	3
Family Structure	Two-parent	6 (all heterosexual couples)
	Blended	6 (5 heterosexual and 1 lesbian couples, 3 of whom share custody with former husbands)
	Single-parent	4 (all mothers, 1 of whom shared custody with former husband)
Mother's Highest Level of Education	High School	1
	Some College	5
	Bachelor's Degree	6
	Advanced Degree	4
TC's Age Range		5 to 14
Mother's Age Range		30 to 53

Data Collection and Procedures

        I collected two types of data with each family: (1) a dinnertime observation and (2) a parent interview. For each family, two types of informed consent were collected: one to participate in the study and one to use their digitally recorded mealtime from the study for presentation and educational purposes. Use of recordings for presentation purposes was not necessary for participation in the study (see Appendix D for consent and assent forms). The participant received a reminder the day before their scheduled appointments. The first two families were considered "pilot" families and the data collection procedures were scrutinized. There were no major changes to the data collection procedures based on the piolet families although the interview protocol changed slightly throughout the study.

        Dinnertime observation. Observations were used as they are an excellent tool when "the preconceived image we have of the settings and people we intend to study may be naïve, misleading, or downright false" (Taylor & Bogdan, 1998, p. 25). This is the case for families of a child with autism. The mealtime observations took place on an evening of the family's choosing and were observed through digital recording. For providing consent, only children for whom the adults are the parent or legal guardians were asked to be present during the meal. We also asked that all members of the family who usually eat dinner together be present. Either myself, or a research assistant and myself set up the recording equipment and acquired consent. In regards to timing, we came 40 minutes prior to when the parent indicated that someone would start eating. On one occasion the family started eating before I left (it usually took me 10 – 15 minutes to set up the recording) but for all the other families we have approximately 30 minutes of pre-eating recording. We used three to four video cameras and two audio recorders for each home. The placement of the recorders was based on where the family indicated that they ate and any other space in the home easily adjacent that could be captured. For example, in an open floor plan house, one camera may have been pointed toward the living room space but in a more closed floor plan house this may not have been feasible. Before leaving the home, we ensured that the family knew how to turn off the video recorders if they would like to end the observation and that they had the correct phone number to call when they were finished with the meal. Once contacted, I returned to the home to collect the recording materials (which took approximately 10 minutes), gave the family $25, and scheduled the interview. I usually did this on my own unless the timing of the meal precluded bringing the research assistant home. One family contacted me

when they had finished eating their meal, but they were still planning on making and eating dessert. For all other families I have at least 10 minutes of post eating activity. The family observations ranged from 37 minutes to 152 minutes.

The day following the observation, all of the recordings were saved onto a share drive and an external hard drive. The video and audio files were merged and the video was edited to create one view that was used for coding purposes. A five to six-minute excerpt of the meal was selected to be used during the interviews. These clips usually highlighted particularly nice interactions during the meal. There was one family where there was almost no conversation during the meal and the meal was prepared before we arrived to set up the cameras. An excerpt was not created for this family.

Field notes. For each mealtime observation, I wrote a field note memo which included the basic sequence of events, details about who is in the home and how dinner was served, how I felt after watching the meal, and what stood out to me. For each family, I created a floor plan diagram of the home based on the observation. This diagram was used in conjunction with the video to help understand the flow of movement during the observation.

Interviews. Interviews were used as they are an excellent tool for eliciting how people view events and the meanings that they attribute to them (Rubin & Rubin, 2012). The parent could select where to do the interview: in their home, at the library, or at Christopher Hall. Although most families choose to do the interview at home, we did interviews in all three settings. A research assistant went with me and interviewed the child with autism (this data is being used for another project). No sibling childcare was offered. On one occasion, a sibling was present during the parent interview. The interviews were recorded using an audio recorder. The interviews ranged from 0:52 hours to 3:00 hours, however most of the interviews were between 1:05 and 1:30 hours. There were three different interviewers for the project. The interviews were transcribed for use in analysis by eight amateur transcribers and one professional transcription service. The raw audio and transcripts of the interviews where saved on the share drive and an external hard drive. Although participation was not limited to mothers, only mothers participated in the interviews.

Interview protocol. The interview protocol changed throughout the project as I identified new themes and ideas. The protocols were unique to each family and referred to specific details from the mealtime observation. The interview used a combination of general interview guide

approach and a standardized open-ended interview (Patton, 1990) to create a natural flow so the order changed depending on the respondent. I did not ask every question, added additional questions on the spot, changed the wording of the questions, changed the order questions were asked in, and probed for follow up information. Keeping that in mind, the general outline for the interview consisted of five parts: (1) family description, (2) the form of family meals, (3) the function of family meals, (4) reaction to observation, and (5) the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). See Appendix E for an example protocol. Each of the topic areas refer to the type of questions asked, not the flow of the interview.

Family description. Although most of the meal focused on mealtimes, some questions asked about the family more generally such as daily routines. At the end of the interview the parent was asked if there was anything that she felt was important to share in order for me to understand her family. We also asked about the influence of autism on the family.

The form of family meals. Questions were rooted in a family rituals perspective especially the dimensions of commitment and continuity that cannot be observed. As such, the interviews included questions about the parents experience with mealtimes growing up and also focused on mealtime routines. The interviews covered how the family meal has changed over time, accommodations used to support the child with autism, and exceptions to the typical routine. When appropriate, questions focused on connections between autism, food, and mealtimes that have previously been explored in the literature such as eating difficulties, interventions that take place during family meals, receiving therapeutic services during family mealtimes, and special diets.

The function of family meals. Questions in this section addressed the roles that different family members hold, desires of what the mealtime should be, feelings that the parent has about family meals, how sharing and problem solving happen within the family, and what the parent thinks family meals mean.

Reaction to observation. The timing of when to introduce the excerpt of the mealtime usually came at the end of the interview. After watching the excerpt, I asked the parent to clarify aspects of the observation that were unclear. I asked why specific actions happened and if specific actions were typical. I also asked the parent how they felt in response to watching their family's mealtime and why.

Social Communication Questionnaire. The parent was given the SCQ (Rutter, Bailey, & Lord, 2003). The 40 item screening survey took approximately 10 minutes to complete. It parallels the content of the ADI-R, is often used as a screening tool, is an indicator of the intensity of behavioral indicators used to diagnosis autism, and is generally considered reliable and valid (Chandler et al., 2007). As scientific discourse is predominated by the medical model of disability the screening tool was used to establish credibility for this audience. Additionally, as mothers filled it out, many took it as an opportunity to talk about what autism looks like for her child. There were demographic questions at the end of the questionnaire such as each person in the family's age, highest degree achieved, racial or cultural background, occupation, as well as who else lives in the household, if there is anyone who does not live in the household who they feel is an important part of family mealtimes, and if anyone other than the target child has autism. Two participants choose not to complete the SRQ and demographic questionnaire due to time, however much of this information also came out during the interview. Children's current scores on the SRQ ranged from four to seventeen with lower scores indicating lower incidents of autism phenotypic behavior. Of the eight children who scored below fifteen (which is the cutoff for autism on the life time version of the questionnaire), two children were co-diagnosed with ADHD, two children were co-diagnosed with intellectual disability, two children were female, and two children were non-white. Each of these features would be taken into consideration when making clinical decisions.

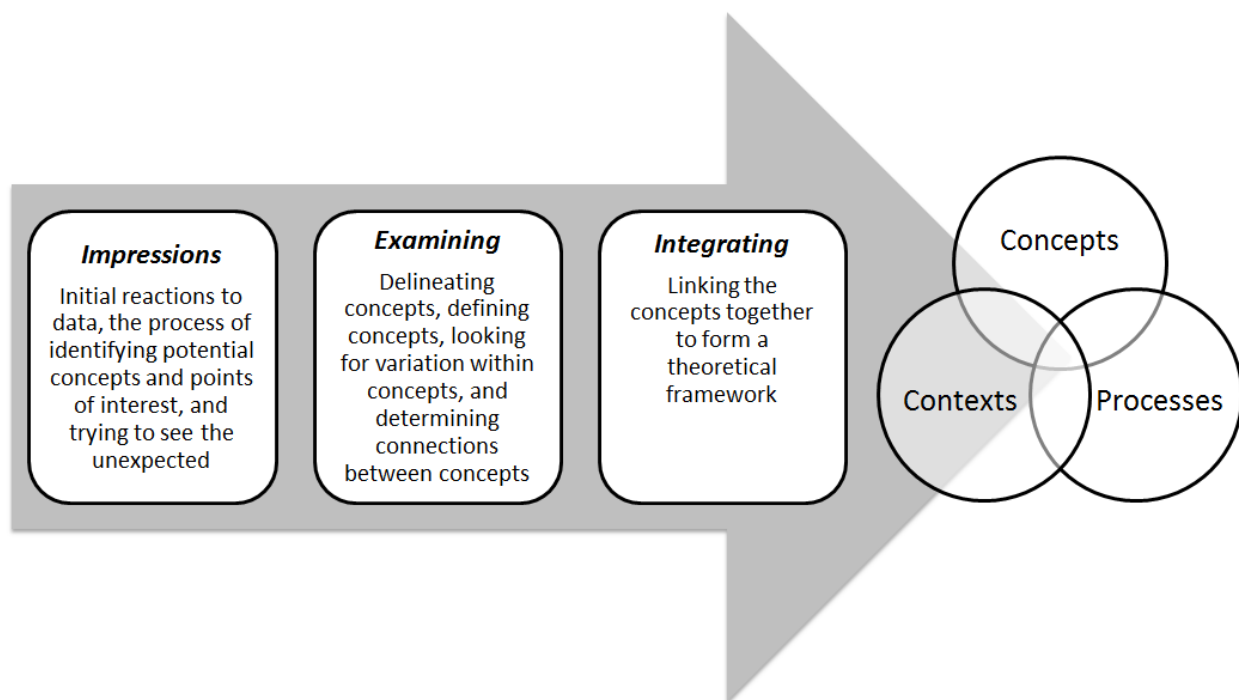**Analysis Plan: Representing Analytic Products and Process**

Grounded theory is an interpretive process- a meaning making process. Corbin and Strauss suggest several analytic strategies (tools) for enabling, "description that embodies well-constructed themes/categories, development of context, and explanations of process or change over time…[in order to] generate new knowledge and deeper understandings because [the analysis] tends to go beyond what everyone knows" (2008, p. 51). Analysis is a process by which ideas must come from the researchers' mind to the outside world and in order for this to happen these ideas must be represented. Below I have outlined how I did this.

Key terms. Based on the work of grounded theory scholars and my own distinction between mental and behavioral processes, I use the word concept to refer to a theoretically meaningful or interesting idea and code to refer to the word, phrase, or description that signifies it. Concepts are the interpretive understandings of the data. They group and organize the data.

They aid in keeping interpretations grounded in the data (although they can be more or less abstract). Concepts are developed, verified, expanded, revised, interrelated systematically, and then organized to explain a phenomenon. I use the word coding to refer to the behavioral process of assigning codes (words, phrases, or descriptions) to raw data. Coding is the verb used to describe this processes of abstraction, "taking raw data and raising it to a conceptual level" (Corbin & Strauss, 2008, p. 66). Once data is at the conceptual level, it is possible to explore context – the "structural conditions that shape the nature of situations, circumstances, or problems, to which individuals respond by means of action/interaction/emotions" (Corbin & Strauss, 2008, p. 87). In addition to context, once data is at the conceptual level, it is possible to explore process, "the identification of patterns as one looks for similarities in the way persons define situations and handle them" (Corbin & Strauss, 2008, p. 100). Although, elevating the data to the conceptual level is a necessary precursor to exploring context and process, each of these spheres is iteratively connected. Processes are situated in contexts and the relationship between them provides connections between the concepts that are essential to the phenomenon. To this aim, concepts are foundational. If understanding concepts, context, and process are the "what" of grounded theory, the next question becomes "how" to achieve this goal which I call analysis. I use the word analysis to refer to two things: (1) the interpretive processes of defining concepts, determining connections between them, understanding context, and identifying processes and (2) the behavioral processes of writing and diagraming in order to facilitate the interpretive process and to create a product that can then be shared.

Phases of analysis. Corbin and Strauss (2008) do not lay out clear phases of analysis, but through my interpretation of their work, I have conceptualized my analytic plan as having three levels (Figure 2). The first phase consisted of *impressions*: initial reactions to observations and interviews, identifying potential concepts and points of interests, trying to see the unexpected and challenging assumptions of what actions and statements mean. The second phase consisted of *examining*: delineating concepts, defining concepts, looking for variation within concepts, and determining connections between concepts. The third phase consisted of *integrating* the concepts: linking the concepts together to form a theoretical framework. The data from each family was analyzed at all three levels but the phases are iterative. Each of the phases will be discussed in more depth.

Figure 2. Analytic conceptual plan

Impressions
Initial reactions to data, the process of identifying potential concepts and points of interest, and trying to see the unexpected

Examining
Delineating concepts, defining concepts, looking for variation within concepts, and determining connections between concepts

Integrating
Linking the concepts together to form a theoretical framework

Concepts

Contexts

Processes

Forming Impressions. There are several strategies to move from raw data to coding, most notably microanalysis (Corbin & Strauss, 2008) which means to explore data at the word, line, sentence, or paragraph level to generate initial codes, categories, and relationships. I departed from this traditional approach and instead followed the method developed by Maietta, Petruzzelli, Hamilton, & Mihas (2016) who suggest an episode profile approach. I conceptualized this phase as coding within each family, although, as coding progressed we began to make connections across families.

What this looked like. Beginning with the transcript either myself a research assistant would first read the transcript in its entirety without taking any notes. Then we would go back and select 10 to 15 selections of the transcript that stood out us. We would then write a memo explaining why that selection was important and interesting. Another member of the research team read the transcript without taking notes and then examined the first set of passages and memos. This person would write a response to the initial memos, edit the memos, modify passages, delete redundant passages, and add new passages. They would also create a quote inventory: the sentence from each highlighted passage that captured the essence of that passage (see Appendix F for an example of a quote inventory and episode profile). Impressions of the

observations followed a similar pattern. Instead of highlighting pieces of text from the transcripts we focused on meaningful scenes. The greatest difference is that we did not create a parallel scene inventory.

  Examining. The process of examining the data had several goals which are consistent with the Corbin and Strauss' definitions open and axial coding (2008, p. 195). The first goal was to delineate concepts that are at the core of blocks of raw data: "attach[ing] labels to segments of data that depict what each segment is about" (Charmez, 2006, p. 3). The second goal was to qualify the concepts in terms of *properties* and *dimensions*. Properties are "characteristics that define and describe concepts" and dimensions are "variations within properties that give specificity and range to concepts" (Corbin & Strauss, 2008, p. 159). In order to do this, I examined the data to answer the questions when, where, why, who, how, and "with what consequences" (Strauss & Corbin, 1998, p. 125). The third goal was to relate concepts to each other. To do this I identified categories or themes, "higher-level concepts under which analysts group lower-level concepts according to shared properties" (Corbin & Strauss, 2008, p. 159) *and* "linked categories with subcategories and asked how they are related" (Charmez, 2006, p. 61). I thought about examining the data as a process of coming up with and exploring hunches related to the data. These hunches were then verified through going back to the data and collecting more data. Through this process the concepts and the relations between them were accepted, modified, and rejected. Through delineating concepts, qualifying concepts, and relating concepts, I began to determine the context and process(es) related to mealtimes which came together in the next phase of analysis: integration. I conceptualized the examining phase as between family coding, although at times, to gain a deeper understanding of the data, we maintained family level analysis.

  What this looked like. For each family we wrote a memo answering the questions "what did I learn from this family" and "why is this family important to the study?" After five impression profiles were written we created a code book consisting ideas that we wanted to explore more in-depth across families. The codes changed throughout the study, but there were four that I determined to be critical: harshness, closeness/togetherness/cohesion, control, and warmth/love/acceptance. For each family we wrote a memo for each of these concepts. We also did focused coding for both interview transcripts and observations using the entire code book. After the focused coding was done for a family we would write a coding memo and adjust the

codebook accordingly. We did matrix coding where we looked across families at who was present during the meal, where the family was in the family life cycle, how often meals like the observation took place, when in the day they ate, where they ate, the events that comprised the mealtime, what made the routine useful for the family, what was un-useful about the routine, what made the meal meaningful, what made the meal not as meaningful as the family wanted it to be, and what we still did not understand. I wrote family narratives, or vignettes, that tell the story of a specific family's mealtime but also illustrate and important theoretical concepts or processes. I also visually diagramed processes and connections between concepts.

　　　　Integrating. Integration is the process of refining and trimming coding resulting in theoretical construction (Corbin & Strauss, 2008). Integration involves "pull[ing] all of the research threads together to construct a plausible explanatory [or predicting] framework" (Corbin & Strauss, 2008, p. 264). One way to conceptualize integration is as defining a framework that explains mealtimes when a child has autism in specific contexts and the important processes related to those meals, then using the concepts determined through examining the data to tell that story. In addition to bringing concepts together into a unifying framework, the integration phase is also a refining phase: checking for gaps in logic, reworking areas that seem to have gaps, and filling in the framework (Corbin & Strauss, 2008). The goal is to generate "a theory that is integrated, consistent, plausible, [and] close to the data" (Glaser & Strauss, 1967, p. 103). Glaser and Strauss go on to suggest that the theory should lead to future quantitative work and I would agree that this may be a possible outcome, but would disagree that it is an essential component to my own analysis. Glaser and Strauss seem to be using a classical definition of theory- theory as a series of prepositional statements about how variables relate to one another (Burr, Hill, Nye, & Reiss, 1979). The theory produced through this analysis has some of these elements, but is often more consistent with an of understanding theory as a lens or as "say[ing] something about empirical phenomena in the social world …[that may] shed new light on an empirical problem, help us understand some social process, or reveal what 'really' went on in a certain conjecture" (Abend, 2008, p. 178).

　　　　What this looked like. In various ways Corbin and Strauss (2008), Charmaz (2006), and Glaser and Strauss (1967) discuss the role of writing and presenting results as an important step in the process of analysis.

> "It is in the act of reading and writing that insights emerge. The [work of writing] involves textual material that possesses hermeneutic and interpretive significance. It is precisely in the process of writing that the data of the research are gained as well as interpreted and that the fundamental nature of the research question is perceived (Van Manen, 2006, p. 715).

I started writing the results as we were analyzing the data and continued to revise as the analysis developed. As I finished a chapter I received feedback and revised. First I wrote about what mealtimes looked like as this is the most surface level of analysis I conducted. Then I wrote about how mealtime rituals and routines were created and the barriers to achieving both. These are processes oriented questions that represent a deeper level of analysis beyond what is happening. Finally I wrote about the role of mealtimes in family life as the fully integrated theoretical model. The results are presented in this order.

Analytic tools. Analytic tools are the mental and behavioral strategies the researcher uses to elevate concepts derived from the data, and then understand the context of a phenomenon and the processes related to it, in order to articulate theory. Corbin and Strauss (2008) (as well as Charmez (2006) and Glaser (1978)) have identified many analytic tools to aid in the process of analysis. I have highlighted several strategies that were central to my process. Each of these strategies was used throughout the phases of analysis.

*Representation***:** Representation can be written in the form of *memos* that record analysis or visual in the form of *diagrams* that depict relationships between concepts (Corbin & Strauss, 2008). Memos and diagrams were used to explore data, identify and develop the properties and dimensions of concepts, make comparisons, ask questions, elaborate, and explore relationships. Memos and diagrams were the foundational analytic techniques by which the products of all other analytic tools were represented.

Constant comparative analysis. Glaser and Strauss (1967) first introduce the *constant comparative method* as jointly coding and analyzing data in four stages "(1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory" (p. 105). Later Corbin and Strauss (2008) refer to *constant comparisons* as "the analytic process of comparing different pieces of data for similarities and differences" and *theoretical comparisons* as "an analytic tool used to stimulate thinking about properties and dimensions of categories" (p. 65). This definition seems to diminish the

distinction between coding and analyzing while maintaining the distinction between levels of analysis. Meanwhile, Charmez uses the term *constant comparative methods* (citing Glaser and Strauss) to mean the process of coding "to establish analytic distinctions- and thus make comparisons at each level of analytic work" (p. 54). Although she acknowledges that there are levels of analysis, she seems to diminish the clear distinctions between levels while maintaining the distinction between analyses and coding. I compared data throughout the analytic process; both within data from particular family units and across family units. I would intentionally compare across families that were similar and dissimilar on specific dimensions.

      Rich description. Description can be a tool in analyzing data. In ethnographic observational research, field notes are a primary data source. This analysis did not rely on field notes as the recorded observations were directly analyzed; however, writing rich descriptions was part of the analytic process. These descriptive memos included "descriptions of people, events, and conversations as well as the observer's actions, feelings, and hunches or working hypothesis" (Taylor & Bogdan, 1998, p. 67) which parallel what is done when taking field notes. Writing rich descriptions will aid in the analysis because they are a tool for helping the researcher to pay attention and give insights into the nature of activities and patterns of behavior (Taylor & Bogdan, 1998).

      Analysis through questioning. Questioning is a tool that allows researchers to (a) *become familiar with the data (*what is going on here?); (b) *probe (*what is the relation between these two concepts?); (c) *think outside the box (*what would happen if…?); and (d) *facilitate process (*have I researched saturation?) (Corbin & Strauss, 2008). This type of questioning is referred to as one analytic tool by Corbin and Strauss (2008), however, many of the other tools they introduce are achieved through asking questions of the data: what are the various meanings of this word?; what would happen at the opposite end of this extreme?; how is language being used?; how are emotions expressed?; how are metaphors used?; what is the negative case?, and asking "so what"? In some versions of their work, Strauss and Corbin (1998) describe a coding process (axial coding) in which the goal is to answer the questions "when, where, why, who, how, and with what consequences" (p. 125). Using the data to answer these questions and ones like them was critical to my analytic process.

      Charmaz & Mitchell (2001) articulate many questions that may be useful specifically for observational data:

What is the setting of the action? When and how does action take place? What is going on? What is the overall activity being studied, the relatively long-term behavior about which participants organize themselves? What specific acts comprise this activity? What is the distribution of participants over space and time in these locales? How are actors organized? What organization affects, oversees, regulates or promotes this activity? How are members stratified? Who is ostensibly in charge? Does being in charge very by activity? How is membership achieved and maintained? What do actors pay attention to? What is important, preoccupying, and critical? What do they pointedly ignore that other persons might pay attention to? What symbols do actors invoke to understand their worlds, the participants and processes within them, and the objects and events they encounter? What names do they attach to objects, events, persons, roles, setting, and equipment?   What practices, skills, stratagems, and methods of operation do actors employ? (p. 163)

These types of questions also played an important role when analyzing observational data.

Through constant comparative analysis, rich description, and analysis through questioning I explored the concepts, contexts, and processes that are important to understanding the phenomena of shared family meals when a child has autism. This analysis provided insight into the nature of family meals, how families established useful mealtime routines and meaningful mealtime rituals, barriers to functional routines and meaningful rituals, and the roles that mealtime rituals and routines play in family life.

Chapter Four

Overview of Results

The results are presented in three chapters. The first, "The Nature of Family Meals: A New Vision", answers research question one: *what is the nature of shared family meals when a child has autism*. This chapter is largely phenomenological. It paints of picture of what mealtimes look like, how mealtimes feel, and aspects of mealtimes that were interesting and unexpected. The second results chapter, "How Functional Routines and Meaningful Rituals Were Established and Barriers to Achieving Them" answers research questions two and three: *how do families establish useful mealtime routines and meaningful mealtime rituals when a child has autism* and *what are the barriers to achieving the family meal*. In this chapter I posit that ritual and routine are enmeshed processes that cyclically co-create on another and articulate how each is established. The processes I identify in establishing routines and rituals are then pulled together in the third and final chapter of the results section: "The Role of Mealtime Rituals and Routines: Negotiating the Tension between Expression of Love through Control and Acceptance." This chapter answers the fourth research question: *what roles do mealtime rituals and routines play in family life when a child has autism*. In this chapter, I assert that the role of meals is to reflect and reinforce family functioning which I define as negotiating a dialectic of acceptance and control. The model will build throughout the results chapters so I will not define each piece initially; however, I have presented the visual diagram here (figure 3) as a heuristic for how the pieces will come together.

Mealtime as a Window into Family Life: Paula's Family

Observing family mealtimes and talking to mothers about their mealtimes did more than just shed light on one aspect of a family's day. Through mealtimes I was able to peak in and see how mothers thought about their parenting role, how they understood autism, what they value, what their goals were, what was meaningful about their relationships, and how they made decisions. Paula's[4] family is an example of mealtimes as window into family life.

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[4] Paula is a 51-year-old European American woman with a bachelor's degree. Her husband, Travis, is a 50-year-old European American with a bachelor's degree. They both work full time outside the home. He has three children from a previous marriage who are European American. He shares joint custody for the two younger sons Mark, 12, and Chris, 13. Paula also has joint custody of her son, Brian who is a 10-year-old European American who has been diagnosed with ASD. Paula identifies her ex-husband as having ASD. Paula's house has an open floor plan and is in a small community. They rarely all eat together.

You would never know that Paula's family does not usually sit and eat dinner together unless you noticed that there were not enough chairs around the table for everyone to sit down. Usually Paula's husband cooks but when she cooks (as she did during my observation), her son, Brian, likes to pitch in; he likes to help her with whatever she is doing. When everyone sits down the conversation is natural and everyone shares their thoughts. Brian's step-brothers, Mark and Chris, are both older and occasionally react with confusion when Brian tosses out a seemingly random conversation topic like "let's talk about beef jerky" but then they just go with it. When dinner is over everyone helps clean up and all the boys clear their plates and load them in the dishwasher without needing to be reminded. Nothing feels forced.

They chose to sit at the table for the study and Brian did need a little coaxing, but it is pretty rare for Paula's whole family to sit down together for a meal. It just is not a priority for them to all be around the table with each other although they all eat in the open floor plan kitchen and family room at around the same time. Every day is a little different for this family because on any given day, Paula's home is comprised of different people. Both parents have children from other marriages and both share joint custody with their respective children's other parent, so the configuration of children in the house is different throughout the week and from week to week. Also, Brian is a picky eater and unless they planned to eat something he really likes, he eats something different from the rest of the family.

In reflecting on the dinner they shared during my observation, Paula mentions that eating together is not hard to do, so she does not know why they do not sit down together more often. She also talked about difficulty in having what she experiences as a non-traditional family life. I believe these two ideas are linked together. She was clear that she felt confident in her decision to divorce Brian's father and that they are all happier, but it was not without sacrifice. For Paula's family and others for whom having ideal moments have been elusive, experiencing ideal moments can feel threatening. Maybe Paula wonders why she was not able to create them before. So Paula's family does not use mealtimes as a place to create special meaning around who they are as a family. That happens on special trips and, for Paula and Brian, during car rides home from school; Paula picks Brian up every day (even when he is staying at his dad's house) so it is their special time. While she avoids traditional family meals, Paula has a hard time accepting that her family does not do them. It feels like sitting down all together is what she should be doing. She loves her son and she loves her family. She loves that he gets to have a

family that has a "family feeling" but a part of her regrets that it does not look the way she expected it too.

Through Paual's mealtime and the mealtimes that the other fifteen families who choose to share their time with me I was able to see salient features of family meals when children have autism; how logistical considerations, family-of-origin, and ideals shape decisions about what meals look like; how repetition of routine creates special meaning; and how parents express love through control and acceptance. Each of these ideas will be further explained throughout the results chapters.

Figure 3. Full model of shared family meals.
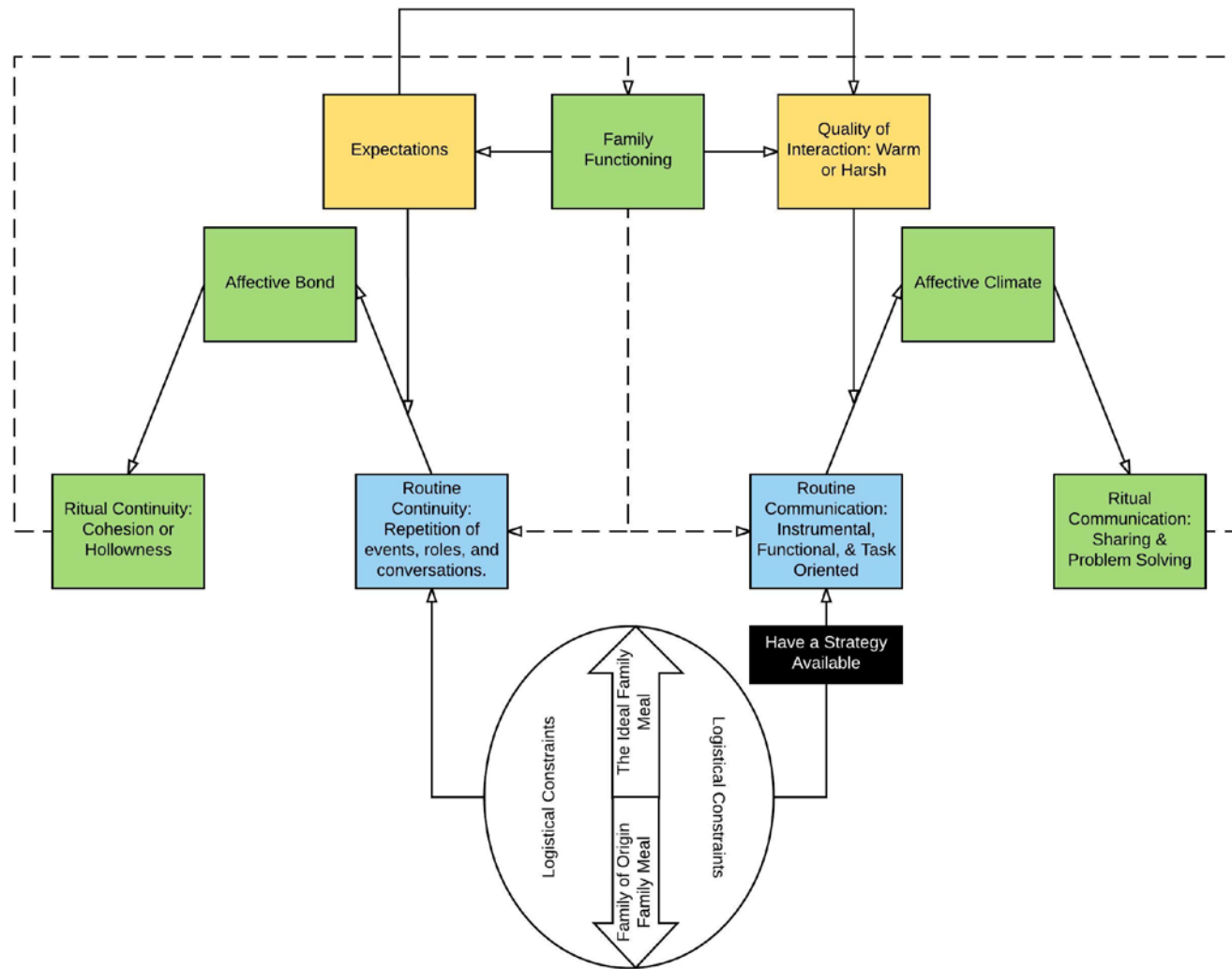
Chapter Five
The Nature of Family Meals: A New Vision

Hectic, *stressful*, *calming*, *chaos*, *miscellaneous*, *togetherness*, *debriefing*, *conversation*, *bonding*, *perspective*, *instilling manners and values*, *warmth*, *home-cooked*, *laid-back*, *fun*, and *care-free* are some of the words mothers used to describe their family meals. These words provide a short answer to research question one, *what is the nature of shared family meals when a child has autism*, which this chapter will go on to articulate more fully. Both the joy and the stress of family life can be heard; each mother had a balance to what she considered to be the nature of the meal which highlighted both the struggle and the rewards. For these families, mealtimes were a place to come together, but they could also be chaotic or just monotonous. The nature of family meals is hard to capture in a cohesive story as was often evident in the interviews. Having a meal takes intentionality but also feels like something that just happens. For example, when I asked one mother why sitting at the table is the best place for her family to eat dinner, she looked at me perplexed. I elaborated that some families eat in the kitchen or on the couch or in their bedrooms. Only then did she understand why I had asked the question. For that mother, the table is where you should eat and that is why you eat there, but for another mother, the table is where you put all the stuff that needs to put away and you eat on the couch.

In order to present the nuance and variation in the nature of family meals, in this chapter, I present a series of snapshots that provide a picture of family life. This album in words captures the candid, unexpected, mundane, and episodic nature of family meals. Sometimes the snapshots take the form of vignettes featuring a family in the study. The vignettes are based on a specific family, but they have been written to reflect an important part of the nature and significance of mealtimes and may capture elements of other family's stories. Sometimes the snapshots take the form of a description of a topic which was a prominent feature of family meals. I discuss features of the mealtimes I found interesting and unexpected: homework, medication, conversations, managing eating, and technology. These features of family meals may be specifically salient for families of children with autism. Through these pictures, it is possible to gain an understanding of the context in which the mealtime ritual is achieved. Despite the nuance in each family's story the overwhelming image that is left behind is how *normal,* in many ways, the family meals are despite having a child with unique sets of support needs.

Homework: Children's Work-life Balance

To understand the nature of something it is sometimes easiest to start at the beginning. For several families, the beginning of the mealtime routine actually started with something that is not typically associated with mealtimes: homework. Children sat and completed homework at the kitchen table while a parent (or parents) prepared the meal. During the meals parents often talked about homework assignments and quizzes. For families that did not start the mealtime routine with homework, it was the task that immediately followed dinner. In short, homework played a significant role in the course of the evening. Like the meal itself, homework was an activity that established roles, shaped relationships, and caused conflict.

Parents provided direct support for school work before and after the meal which reinforced an instructional component of their parenting role. For example, Samantha[5] helps her son Lionel with his homework as she is cooking. When he has a question about what a word means and how to look something up she gives him the answer or shows him how to do it. Sometimes she asks him questions to help him learn how to figure out the problem on his own. This is not just about getting homework done. It is also about their relationship. Lionel does not want his father to explain the meaning of the word, only his mother. At first I thought this could be because she explains things better, but throughout the meal and the interview, Lionel indicates in multiple ways a preference for his mother in the support person role. She is his teacher and the person he can go to for help and this seems to work for her. She goes to workshops and networks with other parents to enhance her abilities in that role. Homework and mealtimes are enmeshed activities for this family and are both tasks that reinforce Samantha's role as support person. Samantha uses the same strategies for helping Lionel figure out what to do with a brat that is too hot that she does to figure out a word that he does not understand. Her patience and her ability to break down problems so that he can manage them help create and maintain a special relationship.

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[5] Samantha is a 38-year-old European American woman with a bachelor's degree. A former educator, she now stays at home. Her husband is a 38-year-old European American man with an advanced degree who works in a STEM profession. They live in a single-family home with a semi-open floor plan in a small urban community with their two sons Lionel who is 9 years old and Eddy who is 8 years old. They have both been diagnosed on the autism spectrum. They almost always eat together although it is common for Lionel to leave the table.

For Ben[6] and Camden[7] discussing school work at home establishes the parents' role as the person who holds them accountable, supports them with success, and can see them for who they really are. For example, Janet and Rob had a lengthy discussion at dinner about Ben's homework. Ben had a big assignment coming up and he was struggling to pick a topic – it was on the holocaust and Ben was upset about the idea of researching people who had done something evil. Janet and Rob talked to Ben about different options and gave him advice such as writing about one of the heroes of the holocaust. In this specific conversation, Ben was able to share part of his personality: his ability to empathize and his tenderness. His parents were able to show acceptance not just for what he does at school but who he is as a person. More generally, families used conversations about homework to establish their relationships as one in which they can share and solve problems. Ben has few impairments related to functional communication, but Camden really struggles to express himself with words. His mom, Heather has found several strategies so their relationship can be based on sharing and problem solving. Like many parents, Heathers supports Camden with confirming or elaborating on written correspondence from teachers. At the end of dinner, before he is allowed to leave the table, she holds him in a tight embrace and whispers audibly in his ear, "I'm so proud of how hard you worked at school." Camden pulls away but Heather pulls him back, "Listen to me. I'm so proud of how hard you worked at school. I want to know your secret recipe right now. How do you do so good in school?" Camden often struggles at school, but Heather wants to use this good day as an opportunity for him to think about his positive behavior. After teasing his mom that he will not tell her and making Heather beg to hear it, Camden replies "I AM really good." Heather asks, "Your recipe is really good?" Camden says, "No – my recipe is that I am good. That's my

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[6] Ben is a European American 14-year-old boy who has been diagnosed with ASD who lives with his mother, Janet, a 53-year-old European American woman who is working on her bachelor's degree. Her husband, Rob, is a 47-year-old European American man, and has some college. Both parents are employed full time outside the home. They live in a single family closed floor plan home in a small urban community. Both Janet and Rob have other children who do not live with them. They almost always eat together.

[7] Camden is a 7-year-old European American boy who lives with his mother, Heather, a 40-year-old European American woman with a High School education in an open floor plan apartment in a rural community. Heather has recently remarried, but her husband works in a different state and only lives with them sporadically. Heather has an older son who does not live with them. Camden has been diagnoses with ASD. They almost always eat together.

secret recipe." This is another example of bringing school life home as a strategy for building relationship between the parent and the child.

For some families, discussions about school and support with homework were much more conflict laden, however they still shaped relationships and established roles. For example, many families spent hours doing homework. The work assigned rarely was expected to take hours but some children needed more intensive support that took a great deal of time. This could be the result of a lack of desire to participate but it could also be due to a need to check over each detail and make sure it was done perfectly. Sally's[8] daughter, Margaret, struggles to do homework. Sally describes her husband Jim helping Margaret with her homework:

> He has to sit next to her for two hours, and she'll say, 'I don't want to' or 'I've done it' [briefly her voice gets angry and unintelligible as she imitates Margaret]. She's ripped her homework up, she's done all that stuff. I mean you have to do two hours of patience of sitting next to her and being like I'll wait for you, and that's a lot.

Although it is fraught with tension, homework shapes the relationship between Margaret and her parents. Jim supports Margaret with the homework because Sally is too impatient to do so (patience and expertise were the two deciding factors of who helped with homework in two-parent families). Margaret gets to spend prolonged time with her father's attention focused on her while they are working together to achieve a task. He is her expert and her guide but because Sally is unable to do so creates distance between her and Margaret.

Francine[9] shares what burden homework can be, although her son, Tristen, is not assigned any. Francine said,

> He wouldn't be able to handle it- it would be a power struggle and we'll never get through the evening and we'll what- won't go to bed until you know ten or eleven o'clock at night... you're stuck there as their parent, you can't do anything else, you have other kids, you know?

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[8] Sally is a 42-year-old European American woman with an advanced degree who works as an educator. Her husband, Jim, is a 44-year-old European American with an advanced degree. A former professional, he now stays at home. They live with their two children, Margaret, 8, and Fred, 11 in a semi-open floor plan house in a small urban community. Margaret has been diagnosed with ASD. They almost always eat together.

[9] Francine is a 50-year-old European American woman with an advanced degree. A former medical professional, she now stays at home. Her husband, Scott is a 51-year-old European American with a Bachler's degree who works for a corporation. They live in a single-family home with a semi-open floor plan in a small urban community with two of their four children: Tristen, 9, and Clarissa who is in high school. Tristen has been diagnosed with ASD. They almost always eat together.

Although Francine has not experienced it, she knows families like Sally's who struggle with homework. Margaret and Tristen are different children and their parents have different goals and values. Margaret is in a gifted classroom and her parents are committed to supporting her with maximizing her academic potential. Tristen is in a self-contained classroom and his mother feels strongly that the key to his long-term success is his social ability. Academic skills go to the back burner. In either case, in a single conversation it is difficult to determine the degree to which the parents are able to accurately judge their child's capabilities. Are Margaret's parents strong advocates supporting her success in an advanced academic setting, or, are they expecting her to live into their idea of what they hope she should be able to do instead of what she is really capable of? Is Tristen's mother's vision of her son being clouded by her biases of children with disabilities, or, given that there is not an infinite amount of time and resources, is she simply focusing on what is most likely to bring him the most success? For these families, there is evidence that supports both sides of the argument. As difficult as it is to determine from the outside looking in, parents themselves struggled to understand their children's capabilities and limitations.

Sometimes they would express this difficult navigation as *is it the autism?* I believe *is it the autism* signifies a question as to whether or not the challenge they are facing is related to a physiological/neurological impairment or limitation. The alternative, the challenge *not being the autism* was more difficult to understand. At times this seemed to mean, a limitation or characteristic that is typical of child development. *Do all kids do [fill in the blank]?* Sometimes this would refer to something the child refused to do or would not do. *It's not that he can't do it, it's that he won't do it.* Another example from Margaret's family illustrates the difficulty that families have understanding the boundaries between typical childhood struggles, impairments associated with autism, and conflicting agendas. This intersects with another piece of the picture critical for understanding family meals: medication.

Medication: The Elephant in the Room

In the literature, there is an emphasis on picky eating and children with autism. To my knowledge, none of the studies control for children's medication. Children with autism are often prescribed medicine that can affect both appetite and metabolism. Mothers talked about struggling to get their children to eat, switching medication and then shortly thereafter, the child had a normal appetite. Sally describes how Margaret's eating changed:

Margaret when she was on Ritalin or Adderall, she was on Adderall, it was an appetite depressant. She was not hungry. And so there was a lot of, 'you need to eat four more bites.' So it was a lot more controlling cause you know she really wasn't hungry. Now she eats like a champ. And so I don't know if she's on something that stimulates her appetite or not but you know she's really changed. I'd say in the last four months.

Even if Sally understood beforehand that Adderall was an appetite suppressant, when they were at the table trying to get Margaret to eat, it felt like Margaret was being defiant. Eating behavior was not the only behavior that was effected which contributed to the feeling that it was not that she <u>could not</u> do it but rather that she <u>would not</u>. Sally's epiphany that some of Margaret's behavior was beyond what one would typically consider to be under Margaret's control happened around setting the table:

She's on a medication that supposed to help with self-control and I remember that the week that she went on it. I remember that I would go in there and be like Margaret it's time to do silverware and she would fall on the floor and cry. And the week she had medication, I was like it's time to do it and I remember holding my breath and she went okay. And I was like oh my God. I remember that feeling- it was really a monumental moment. We use to say come on. There used to be a lot of guidance physically put your hands on her, guide her over to the silverware. Open the drawer count down how many forks. Someone would stand over her and instruct her maybe one instruction at a time. Now we don't have to. Now we just say get the silverware and she knows.

Laura[10] has not had a revelation with Kevin. Kevin needs step by step support to set the table just like Margaret. Laura believes she has to increase control over Kevin to make him comply with an undesired task:

I'm reminding the boys get the placemat, put the placemats out, put the silverware out, Kevin you do this, Hayden you do that, so that way there's shared responsibility and contribution to what's going on in the household. Kevin just- even though we've been doing this for years, it's still the step-by-step for him because he doesn't like to do it. Now if it's something that he did enjoy or that he was even kind of okay with, he would

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[10] Laura is a 37-year-old European American woman with an associate's degree. Her husband, Tom, is a 40-year-old European American with a bachelor's degree. Both parents are employed full time outside the home. They have two sons: Kevin who is 11 and is diagnosed with ASD and Hayden who is 8. They live in a single family open floor plan home in a small community. They almost always eat together.

be able to do it on his own with his eyes closed but because there's that resistance there it's me having to step-by-step with him.

Laura does not recognize that some of Kevin's "resistance" could be due to physiological difficulties that impair the executive functioning abilities needed to perform that kind of task. Another mother, Christine[11], was aware that medication could cause real changes to behavior, especially eating behavior, but that her son should be able to "discipline himself" to overcome it.

Medication could also cause increased appetite and weight gain. When I was talking to Vanessa[12] there was a picture of a little boy on the wall behind her. He looked like a healthy, if not skinny little boy. I asked about it and she said it was Lincoln, but the Lincoln I met was unrecognizable even though the photo was only a year old: "lithium is a huge one for weight gain. And Lincoln was on Lithium and he gained like 80 pounds and they finally had to- even though the medicine was working- they had to take him off and put him on something else." Vanessa's other son had a similar problem. She was trying to get the whole family to eat healthier but it was a struggle to make so many changes at once- no more fries at McDonald's, no more soda, pre-bagging snack size portions, and only allowing healthy snacks between meals. At the same time that she must limit consumption, she wants Lincoln to learn to have a diverse diet so she is also pushing him to try at least a few bites of what is served at meals. To Lincoln it must seem very confusing that in some cases he is supposed to limit his intake and in others he is supposed to eat more than he would choose for himself. Vanessa takes the boys to a dietitian so they are hearing it from more than one source, but it is a difficult concept.

For each of these mothers the idea of what their child should be capable of doing and what their child is capable of doing is unclear. It seems reasonable to expect them to set the table

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[11] Christine is a 48-year-old Asian American woman with a Master's degree who works full time and identifies as having ASD. She has three children who are multi-racial. The oldest, Stewart, is a 17-year-old boy has been diagnosed with ASD. She identifies the youngest, Olivia, is a 10-year-old girl as also being on the spectrum. She has a 15-year-old son, Austin, which she does not identify as having any disability. They live together in a closed floor plan apartment in a small urban community. She shares custody with her ex-husband a 60-year-old European American with a bachelor's degree who works in the service industry. He was at their house for dinner during the observation. They sometimes eat together.

[12] Vanessa is a 30-year-old European American woman with a bachelor's degree who works in a health profession. Her husband, Pete, is a 39-year-old European American who is pursuing his associate's degree and working part time. She has two children from a previous marriage who are both European American and diagnosed with ASD: Lincoln, 6, and Aaron, 10. She identifies her ex-husband as having ASD. Lincoln primarily lives with his mother and Aaron primarily lives with his father, although the boys are always together on the weekends and alternate between homes. Pete has a teenage daughter from a previous marriage who lives with them sporadically. Vanessa's house has a semi-open floor plan and is in a small community. They sometimes eat together.

without step-by-step instruction. It seems reasonable that they should eat during dinner time. It seems reasonable that they should limit themselves to healthy snacks. The mothers are knowledgeable about autism and medication, but are struggling to integrate that knowledge with these specific mundane tasks.

Dinner as a Time for Intimate and Meaningful Conversations: Sylvia's Family

Whereas homework and medication are not intuitive features of family meals, conversations are; however, for families with children with autism, it is not assumed that mealtimes are a site for intimate and meaningful conversations. In contrast to popular conceptualizations, for almost all families the study, mealtimes were an important space for conversation. Sylvia[13] and Freddy's shared meal illustrated how this important function of mealtimes looks, feels, and sounds like for autistic families.

It has always been just Sylvia and Freddy and as such Freddy has had to be more flexible than other children with autism. When it is time to go to the grocery store or laundry mat, Freddy has to go too. Over the years, Sylvia has also learned to make things more predictable. When I came to observe, they were having a very calm, routine night. Sylvia helps Freddy with his homework as she cooks. They talk while they eat and then Sylvia cleans up while Freddy plays in his room. Sometimes they have crazy weeks. For the past couple, they have hardly been at home at all between Tae Kwon Do, visiting Sylvia's mom, and other things that just come up. When things get like that they eat out or relax in front of the television while they eat.

My observation was not one of those hectic days and they both seemed focused on one another. After Freddy prays he explains to his mom that he likes it when she asks him to pray with her pouty face. Freddy explains to his mom about "the other woman" which is when his mother asks him to do things sternly. If "the other women" [stern mom] she asks him to pray, he will not do it, but if she asks him just right, with her pouty face, he says yes. Freddy loves his mother. He asks her for a hug and tells her, "your mom is everything … if anyone takes me away than everyone is nothing … I will never leave you." They talk about this idea, the idea that someone might take Freddy away for a long time. Mom is worried about how difficult it is for Freddy to read the intentions of others. A man gave him money for a video game at the store and he accepted it, which made Sylvia uncomfortable. You could understand why during their

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[13] Sylvia is a 32 year old Hispanic American woman with some college who works part time in the service industry. Freddy is a multi-racial (Hispanic and African American) 10 year old boy who has been diagnosed with ASD. They live in a semi-open floor plan apartment in a small urban community. They sometimes eat together.

conversation. She tries to explain the dangers of strangers in a story. In the story, an old man tricks Freddy with skittles. As mom narrates the story and the old man says, "would you like skittles?" as if on que, the real-life Freddy's eyes light up and he says "YES!"

Sylvia's fear that Freddy has a vulnerable combination of naiveté, social desirability, and difficulty communicating is well founded even if the specific situation she is trying to prepare him for is unlikely. She uses dinner time as an opportunity to talk about her fears and try to explain them to Freddy. She missed that Freddy was trying to do the same thing, but Freddy was not worried about strangers. He was worried about his mom dating for the first time and that someone might come between them and their special bond. Freddy can have difficulty with pronouns and even though Sylvia is usually good at understanding him, she misses that when Freddy said, "if anyone takes me away" that he really meant you – "if anyone takes you away than everyone is nothing." In the end he enters her world and talks about stranger danger. He even tells his own version of the story to show that he understands.

All the children in the study had the ability to use short phrases and sentences, however they varied to the degree they could have independent verbal engagement. Despite impairments to reciprocal communication skills, families used mealtimes as a time to connect and share. The function of mealtimes as a time for engaging and connection is critical. I will return to this idea in more depth in subsequent chapters. Whereas conversation during mealtimes is largely ignored in the literature, the next picture in album provides a grounded description of what preoccupies the literature: picky eating and how to manage it.

Managing Eating

Sylvia was one of the few mothers in the study who did not worry about her child's eating. Freddy was heavier than what would be considered healthy for a child his age, and Sylvia had some awareness that she needed to start teaching Freddy to manage his eating, but it was just beginning to get on her radar. Many of the families in the study did have concerns about eating, but unlike Sylvia, for the most part, mothers were concerned about under consumption and picky eating so I have focused on how families manage children who are very selective in their eating. For all families who had children with very limited diets, it was a concern; however families had very different approaches in how they managed it. To better understand the different approaches, I first took a close look at the two pickiest eaters in the study and then expanded to exploring how eating was managed in less extreme cases.

Tristen was the pickiest eater in the study. He ate very few foods and was brand specific even after several months of eating therapy. Camden was a close runner up. Heather had to negotiate for every bite that he ate. Both boys prefer calorie dense, high fat, high salt, and/or sugary foods. These foods are highly rewarding and that reward comes almost immediately upon consumption. This seems to override their bodies' natural disgust towards food. Both boys showed signs of sensory sensitivity especially to smell.

Even though the boys looked similar in terms of their eating behavior, what it looked like during the meal and how each of their mothers talked about their eating, was very different. Tristen's mom, Francine, full heartily believes in ABA not just as an instructional strategy, but as a mindset for being able to understand and reach her son. He has a system of rewards throughout his day. His mother practices extinction during dinner. Extinction is an ABA technique in which reinforcement is withheld to eliminate occurrences of behavior. In the case of dinner, the behavior that she is trying to eliminate is non-standard forms of communication. The reinforcement that she is withholding is her own attention and conversation. This means that if Tristen says something unexpected or in a non-standard way, it is completely ignored by his mother, but Tristen has very few phrases that he can say in a standard way. She goes out of her way to set him up to be able to use them, but Tristen gets ignored a lot at dinner. Strategies like this, as well as reinforcing desired behavior, are a constant for Tristen. In many ways it seems to be successful, but it is a very extreme way of living and it can feel isolating- to have mom unwilling to engage with you on your terms. I say mom specifically, because dad does not use the same strategies. The only area where Tristen is in complete control of his behavior is what he eats. Francine assured me that I would see a lot of special dinners for children on the spectrum- parents making two separate meals, but in my study, their family was one of the only ones. Francine would use any reinforcement to get him to eat, but nothing worked. She would love for Tristen to eat the same thing as the rest of the family, but for now she will settle with him turning and facing forward at the table.

Francine has all but given up on expanding Tristen's diet, although in the week between the observation and interview, he added a new food: oatmeal with maple syrup. Heather works on food expansion regularly with Camden. She describes it as them being on the same team and needing to take turns picking out what to eat. She and Camden plan their meals together and she checks back in with Camden to make sure he still wants to eat what he said in advance. That

does not mean he actually eats what they plan, but she is trying. Like Francine, Heather uses intentional strategies to reach Camden, but they do not come as clearly from an accepted practice like ABA. She does not use the name, but what Heather does most closely resembles positive behavior support (PBS). Although PBS as a package of strategies has a different history and emphasis compared with ABA, they are consistent philosophically (e.g., behaviorally based, seek to identify the function of the behavior, and use reinforcement to change behavior; Johnston, Foxx, Kevinson, Green, & Mulick, 2006). Heather uses a lot of praise throughout the meal and during set up and clean up. Camden is engaged in all these tasks – he has cooking, social, eating, and cleaning responsibilities. Heather gives him direction, praise, and rewards and he completes tasks. What he eats is just one part many skills that Heather is working on. Whereas Francine is focused on Tristen having a normative mealtime experience, Heather is focused on setting Camden up to, one day, have an independent one.

This idea of normativism played out with families who had picky eaters in two different ways. Beside Tristen and Camden, all the other picky eaters looked like picky eaters who were typically developing. Typically developing children sometimes interrogate their parents about what is being prepared, get sad when food is not cooked just right, refuse to try new foods, hate it when their foods touch, avoids specific textures of foods, have difficulty with foods with mixed ingredients, or like to eat the same foods all the time (Boquin, Moskowitz, Donovan, & Lee, 2014). These are the exact same types of behavior in my observations and in parent descriptions of picky eating. In this way, children are participating in a highly normative aspect of childhood, but parents did not view it this way. Parents conceived of a "normal" food based interaction much more akin to what I would consider to be an "ideal" food based interaction. Essentially, parents wanted children to accept what was offered without complaining.

Parents struggled to understand if their child's reaction to food was related to their autism. Samantha has two sons on the spectrum who both have picky eating that is not dissimilar to typically developing children's picky eating. They have negative reactions to unfamiliar foods and difficulty with complex foods like lasagna (layers of different ingredients, different textures, and elements that cannot be seen). She has different appraisals for each of their reactions. Eddy, who is the youngest, simply does not like specific foods, however Lionel reacts to something in the food, "something offensive in the smell or how it looks." With Eddy, what is problematic is his preferences, but with Lionel what is problematic is the food. To

complicate this picture further, although the boys picky eating may be within the normative range, their reactions to food may not be. Eddy will run out of the room screaming. In the past he has run out of the house. Lionel gets anxious about food and will go sit in a different room by himself. Why do the boys have such a difficult time coping with exposure to an undesired food? In this family, and others for whom exposure to undesired food is perceived as a threat, it is because the presence of the food represents a threat to their very safety. Eddy and Lionel are dependent on Samantha to be able to anticipate their needs and help them to navigate the world. In general she is really good at it, but in this case she does not even realize that she is testing them.

In short, there is a subclass of children with autism who have extremely picky eating that seems related to heightened sensory sensitivity. This causes food to be revolting and can be difficult to manage. There is another group of children, who are also picky eaters, but their picky eating falls into the "normal" range of picky eating although their behavioral reactions may be extreme. In both cases, parents struggle with understanding *what is the autism?* In the case of the second group of children, they can pathologize normal childhood behavior. The difficulty in understanding the boundaries of impairment made it difficult for parents to provide appropriate support. Whereas managing eating is the focus of the literature on mealtimes and autism, the next feature of mealtimes, technology, is often a focus is discussions of mealtimes for typically developing families, yet essentially ignored for families of children with autism.

Technology: Facilitating or Distracting?

Most of the families intentionally limited the use of technology during the meal. They felt that it would make conversation more difficult, eliminate that family feeling, or distract the children from eating.   For example, Laura said,

> …when we do that [let the children watch TV during dinner] it takes them forever to eat because they're more focused with what's happening with the TV, whereas if we're at the table and we just have the music going through the TV and we're all sitting together, you know, there will still be distractions and there will still be the petty little arguments between the boys and us intervening when appropriate but it's not nearly as much…[Laura goes on to connect the decision to limit television more broadly to the past, the meaning of eating at the table, and why dinner is important]…it's just…when I

was growing up we always ate at the table, when my husband grew up they always ate at the table, the table is where the heart, for me, the heart of house is at.

It sounds like letting the children eat while watching television is linked to the idea of pulling them away from the table, however the television is within view of the table and they have enough space to move it closer if they wanted to, thus the table is taking on a symbolic meaning- one that she makes explicit. The table is the heart of the home because it is where they come together and focus on one another and the television is a distraction from that.

When families did have the television on, it could be intentional in order to help facilitate conversation or make the dinner time routine feel more relaxed. Tina[14] describes why she likes watching television during dinner, "it's just a big distraction and an ice breaker kind of a thing." She also connects watching television with her own and her children's communication difficulties, "For me and probably for them too, and you wouldn't believe it now because I'm talking to you but talking or communicating is very hard. It is for them." Unlike Laura, who felt like television escalated conflict between her sons, the parents who either regularly or occasionally watched television felt like it was important for reducing conflict and keeping the children calm. Vanessa said, "sometimes the TV is on because it's not worth it, like if he's watching a show, it's not worth the huge meltdown that's gonna happen if we turn it off."

In my observations, television itself did not seem to drastically limit conversation, however personal devices did. In a few families, the television would be on and each family member may be texting, playing a game, or watching something else on a tablet or phone. When a family was just watching traditional television, they would comment to each other about what was on, ask each other questions often triggered by something on television, and had conversations about other topics. This connection stopped as soon as the attention turned to the personal device. It also seemed like the traditional television was easier to ignore if the conversation became more engaged. Vanessa saw the difference: "we don't turn it [cell phones] off but we try to make it a habit not to you know be playing on it or I'm bad about reading books so I try not to sit down and read a book when I should be paying attention." Vanessa felt like she could not turn off the phone because she needed to be available to her job and her non-

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[14] Tina is a European American woman who works on her associate's degree online. Her husband, Mark is European American works in construction. She has three European American children from a previous marriage but the oldest one is no longer at home. Marissa, 12, and Conner, 11, are both diagnosed with ASD. They live in a closed floor plan town home in a small community. They almost always eat together.

cohabitating son, but she understood that she could escape into her device and lose touch with what is happening around her. This was especially problematic when they were at the table which is when they are setting aside time to connect with one another.

Although few families watched television or used personal digital devices during dinner, for all the families in the study, screen time was part of evening life often bookending the meal. Both parents and children used personal digital devices and/or television before and after the meal. Like during the meal, traditional television watching before or after dinner would be a much more shared experience than personal device use and usually involved multiple members of the family watching together. As it was during the meal, personal device use was less communal. Even for the family with no television in the home and whose children were allowed no screen time, when the father engaged with his personal device he stopped interacting with the children. Children were often watching television or playing games (either on game systems or tablets) before the meal, after the meal, or both. Usually this was described by the parent as the child having free time and that being the chosen activity. Because of concerns about this, some families had very specific rules about screen time such as limiting the amount of time or making it contingent, or at least partially contingent, upon desired behavior as decided by the parent.

The Nature of Mealtimes and Autism: Clarissa's Family

Each family mealtime had unique characteristics that made it idiosyncratic to that particular group of people; however, what was most striking was how recognizable mealtimes were to what you would expect in any household regardless of a child's disability status. Of all the families, I expected Clarissa's [15] family to be the most divergent. Clarissa was born in an Asian Country. She moved to the United States with her husband leaving behind her children who only recently joined them. Her youngest son, Luke, was diagnosed with autism once he came to the United States although his special needs were evident earlier. Her husband does not eat dinner with Clarissa and the children. Clarissa believes it is because he is uncomfortable with Luke. Clarissa's oldest daughter, Leanna, is the one who redirects and corrects Luke when he needs it. Clarissa is a little uncomfortable that Leanna is in that role but Luke responds well

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[15] Clarissa and her husband are Asian immigrants who work full time. They have three children living at home who were all born abroad: Leanna, 23, Linda, 17, and Luke 8 who was diagnosed with ASD. Everyone in the family speaks English and their native language. They attempted to speak English during their mealtime observation but occasionally spoke their native language. The observation and interview were coded by a research assistant who spoke the same language. Clarissa's family lives in a semi-open floor plan apartment in a small urban community. They sometime eat together excluding the father who does not join them for dinner.

to her. Clarissa works a lot so they eat fast food almost every night, but Luke loves it. In each of these ways their family is unique in this study, but the overall arc of the meal is essentially the same. At one point, Luke sits in his sister's lap and Leanna prompts Luke to thank their mom for dinner which he does. It reminds me of a moment in Sally's family where her husband Jim prompts Margaret to ask Sally about her day. In both cases a caregiver, steps-in to indirectly make sure that the other caregiver does not get taken for granted. Clarissa's family, like the other families in the study, comes together, and eats. There is laughter, singing, and joking. People share about their day, their feelings, and frustrations. There is a universality to the nature of family meals, despite the struggles and challenges families face and despite their children's impairments. The next chapter will look deeper into these pictures of family life to explain how functional routines and meaningful rituals are established and the barriers to achieving them.

Chapter Six

How Functional Routines and Meaningful Rituals Were Established and Barriers to Achieving Them

In this chapter, I answer research questions two and three: *how do families establish useful mealtime routines and meaningful mealtime rituals when a child has autism* and *what are the barriers to achieving the family meal.* Ritual and routine were enmeshed processes that cyclically co-created one another. The mealtime behavior patterns (routines) were rooted in memory, emotions, and ideals and these behavior patterns, in turn, created meaning within the family (rituals). Although routines and rituals were enmeshed processes, they were not identical ones. I conceptualized establishing the mealtime *routine* as setting the parameter of behaviors that were considered a "family meal" for any individual family. There were three elements that were critical to establishing the mealtime *routine*: the ideal family meal, family-of-origin-family-meals, and logistical considerations. I conceptualized the mealtime *ritual* as the symbolic meanings created through behaviors that were considered "family meal." In order to do this, I expanded previous research in terms of the communication, commitment, and continuity of the meal. Throughout this chapter, I have discussed barriers to achieving mealtime rituals and routines. Francesca's family story illustrates these enmeshed processes and how rituals and routines cyclically co-create one another.

Enmeshed Processes of Routine and Ritual: Francesca's Family

In many ways Francesca[16] had a very traditional upbringing, but her story challenges the common narrative of an idealistic traditional past. Her mother stayed at home and her father worked, but her mother could not really cook, clean, and organize the home and Francesca resented her for it. This "break in the contract" can clearly be seen in her memories of her family meals. Her mother cooked and they sat all together and ate at the same time, but their house was so cluttered and disorganized that no one was oriented toward each other. Even if they were, they probably would not be able to see each other over all the stuff. As resentful as Francesca was that her mother could not provide the ideal home life, she also resented that her mother expected her to enact traditional values in her own adulthood: marry, have children, and stay

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[16] Francesca is a 37-year-old European American woman with an advanced degree who stays at home with her children. Her husband, Jakub, is a 42-year-old European-American with an advanced degree who works in higher education. They have a son and daughter who are five (twins): Fritz and Frieda. Fritz has been diagnosed with ASD. Francesca suspects that Frieda may also have ASD. They live in a single-family home with a closed floor plan in a small urban community. They almost always eat dinner together.

home to raise them. She felt oppressed by the chaos of her home and oppressed by the idea that the most important thing for her to do was to become a wife and a mother. It left her feeling like she was not appreciated for who she was – she was not seen.

Although Francesca has several advanced degrees, she has decided to stay home with her children. In that way, she enacted her mother's expectations and her children have a similar up-bringing to her own, but she works very hard to make sure their home life is not chaotic. Francesca is exceptionally intentional about space. It is important for her that the space communicates the purpose of the task at hand so they always eat in the dining room and moved from home with an open floor plan specifically so they could have a dedicated room. There is no ornamentation or clutter in the dining room (or anywhere in the house). Each item serves a purpose. A table runner helps establish zones for appropriate passing. Francesca has been very successful in eliminating chaos, but her family mealtime does have an oppressive feeling that echoes her childhood home. Although she wants her children to feel free and appreciated for their individuality, this value is not reflected during mealtimes in which every behavior is tightly controlled. The frequency of corrections and directions creates a harsh climate that makes warm affective family bonding difficult. It also creates disconnect between her ideology as a parent and her practice of parenting.

Establishing Functional Mealtime Routines

Ideal family meals, family-of-origin-family-meals, and logistical considerations were critical for the establishment of the mealtime routine (Figure 4). The idea of how mealtimes *should* be acts as a forward force. It creates a vision of what the routine should look like; a goal of what families are trying to achieve. For Francesca, it was an idea that meals should be ordered, organized, predictable, and empowering. Pulling in the opposite direction, the family-of-origin-family-meal roots a person to the past and anchors the understanding of what mealtime is and how it feels. For Francesca, mealtimes were rooted in chaos and rejection. The logistic parameters of life constrain the behavioral possibilities. For Francesca's family, she and her children always eat dinner together. Usually her husband was also present although he could be out of town for work or have evening activities. They ate dinner in the dining room around the table. Francesca has access to information about nutrition and healthy foods. Each of these components is presented as a given but they have their own series of *how* questions associated with them: how is the ideal of the family meal formed; how did the family-of-origin-family-meal

get established; how were the logistical decisions made? For each dimension of how functional routines are formed, I will discussion the how questions associated with them, and the barriers to achieving them.

Figure 4. How functional routines get established.
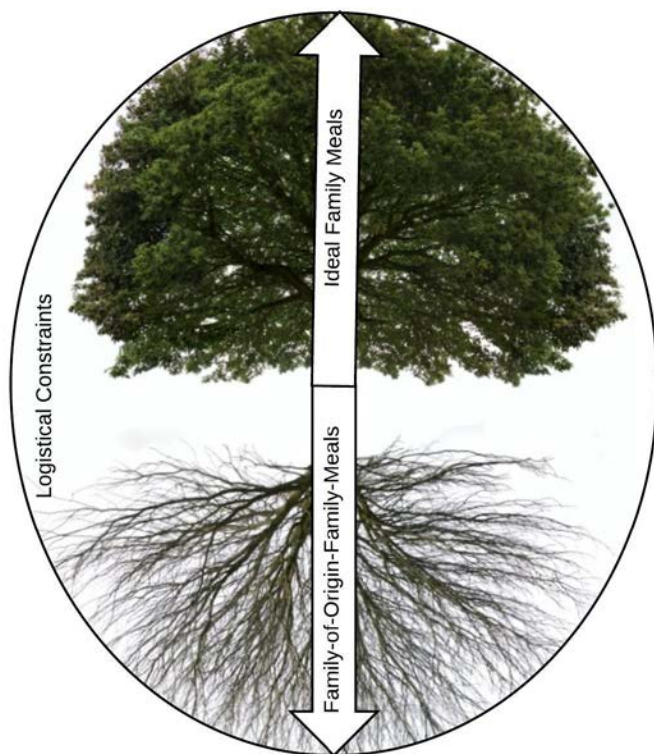
The ideal family meal. There was a great deal of consistency in how mothers described the ideal family meal. Ideally, families should sit around a table, almost every night, and communicate with each other throughout dinner. Family members should enjoy themselves and each other's company during the meal. They should laugh, but also share important parts of their day. This will bring them closer together. The meal should be nutritious (but also taste good), everyone should eat everything (and like it), and they should use good table manners (although it should still be fun). The children should help out and eventually become independent. Things should go smoothly without complaining or arguing. Mothers wanted their children to look back on their mealtimes and feel that it was positive and important. They wanted their mealtimes to have created a connection that will last even when they have moved out of the home.

Heather (whose son's secret recipe is being good), describes the ideal family meal by emphasizing themes of independence, sharing, and supporting her child with decision making.

[The ideal meal would look like] us individually serving ourselves with serving bowls at the table. Pouring our own drink. Sitting down, joining in, conversating back and forth with everybody on their day- like they say something happened, you know? Maybe ask a question that goes further into detail: "what happened there?" Or, "what did you and this person do?" Or, "why did this made you upset- what did you do about it?" "How did it make you feel?" You know, kind of ask questions and get further into the choice.

Sarah[17] emphasizes agreement, eating together, conversation, and the desire to be present. "An ideal family would be everybody agrees on one thing that we're gonna eat and everybody is able to sit and eat at the same time. [We] have conversation and all pretty much be there 'till everybody's done. Not just I'm done, bye see you later." Like Heather and Sarah, each mothers' depictions of the ideal meal emphasized different aspects of the picture, but the consistency is clear.

How is the ideal of the family meal formed? Although mothers did not articulate clearly where this image comes from, the consistency across families suggests the ideal of the family meal is heavily influenced by culture. Many mothers did report having a model for their ideal. This could be their family-of-origin-family-meal, their partner's family-of-origin-family-meal, or another family meal they experienced growing up. There is one element of this ideal that I believe is salient to their identity as parents of children with autism: independent children. Although mealtimes have been described as where children learn to be "competent and appropriate members of a society" (Ochs & Shohet, 2006) and facilitators of social, cognitive, emotional, and nutritional development (Larson, Branscomb, & Wiley, 2006), this is not quite what parents are referring to when the say *independent*. Parents were referring to the ability of the child to complete concrete tasks related to the meal without support (e.g. sit at the table oriented forward, wash dishes, carry a plate to the sink, or wipe off the table). This function of the meal is salient because the eventual independence of the child is not assumed.

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[17] Sarah is a 40-year-old Hispanic American woman with an associate's degree who left her work in the medical field to stay at home with her children her two children. She identifies as having autism. Her son, Oscar is a 13-year-old Hispanic American who has been diagnosed with ASD. She also has a younger daughter. Oscar has had father figures in his life through his mother's romantic partnerships, but she is not currently dating. Although they rarely eat dinner as a family when they do they often share their meals with a roommate who is an adult male.

Cindy[18] was told her son Frank would never be independent and never learn to write. She did not understand why they had put him in a non-verbal class when he started school because he knew how to speak. Now he is writing and very social – in her words "popular." She wants him to learn how to cook meals for himself from scratch (he can already make peanut butter and jelly and use the microwave).

> I'm teaching him how to make the French fries from scratch. I have a little thing that I bought off of HSN [Home Shopping Network], so when you put something in it you can chop it up or slice it up or whatever. So we clean off the potatoes really good and then put them in there, and you know you take your cut potatoes and put them in the oven and season them and you have French fries from scratch.

Every family was doing something to support their children with being independent with at least some tasks related to the meal and valued independence as a goal.

Barriers to the ideal family meal. For the most part, family meals largely resembled the ideal image. Some families did not have the most nutritious meals, or always eat together every night, or even sit at the table together, but they tended to be consistent with how families ideally wanted mealtimes to go. In Sarah's words "We're halfway there. We really are." They recognized the positive elements and were forgiving of themselves when they needed to make compromises for things outside of their control (such as some of the logistical considerations I will discuss shortly). As I discuss barriers throughout this chapter, it is in reference to achieving the ideal meal. As I shift in to discussing how meaningful rituals are established, I will also address how they can become hollow. This is the threshold that I used in terms of barriers to having a functional routine: when the ideal is comprised to the point that it causes distress as articulated by the parent, it is a barrier to having a functional routine. Family-of-origin-family-meals could be either a facilitator or a barrier. Logistical considerations could pose constraints. Because experiences functioned as either facilitators or barriers, I often discuss them as moderators.

Family-of-origin-family-meals. In order to be able to create a mealtime routine the mothers, often in collaboration with their partners, either learned or reacted directly from the

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[18] Cindy is a 34-year-old African American woman with a bachelor's degree who works in the service industry. Frank is an 11-year-old African American boy who has been diagnosed with ASD. Frank has contact with his biological father and half siblings but Cindy has full residential custody. They live in a semi-open floor plan apartment in a small urban community. They almost always eat dinner together.

past. Some women learned practical life skills that were useful for creating functional routines
from their family-of-origin-family-meals: cooking, cleaning, and meal planning. Although the
practical skills necessary to create a meal were important, the emotional landscape set by family-
of-origin-family-meals shaped how parents thought about those skills and how they should enact
them. For example, when Whitney[19] gives her son the option to eat something other than what
she prepared, it is not because she does not care what he eats or does not want him to get upset
about what is served. This choice is rooted in her experience with starvation as a child.

> Until I was three, I dunno, I was three. I don't remember shit. Mealtimes with my mother,
> we were excruciatingly poor and a lot of times we did not eat. Okay so I mean if we did
> eat, it was Ramen noodles. It was you know vegetables that we grew from our garden.
> Like summertime was great because we had more food kind of thing.

When Vanessa makes sure to put something in the crock pot so they can have a "sit down
dinner," that choice to provide stability and predictability is a direct reaction to all the times she
had to step into the parenting role when she was growing up.

> My mom drank a lot. She would cook or she would start to cook and we would have to
> finish because she would leave it. Me and my brother and sister kind of all- always had
> meals together. [Did somebody take a leadership role?]. Me…I was the oldest…I try not
> to do anything like my mother did.

Unlike Whitney and Vanessa, Laura desperately wanted to recreate her family mealtimes.
Not just the way it looked, but the way it felt (she and her parents are now best friends).

> Mom would come home from work, she would get home, I don't know, between 4:30
> and 5:00. She would change and then she would go into the kitchen and it was either
> something in the crockpot or a casserole that she was warming up and my dad would kind
> of be coming out of his sleep fog [he worked overnights], so he would be sitting at the
> table with his cup of coffee, just, you know, waking up. And my brother and I would be
> helping either set the table or whatever it was my mom needed us to do to help out. Then
> once we were all sitting at the table it was the best part of the day, worst part of the day,
> is there anything going on in the house within the house or the family that you know is

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[19] Whitney is a 39-year-old European American woman with a bachelor's degree who is self-employed. Her son,
Logan, is a 10-year-old multi-racial (African American and European American) boy who has been diagnosed with
ASD. Logan does not have contact with his biological father, but his is co-parented by his mother's partner Mary.
Mary is a 45-year-old Hispanic American woman with a high school education who works in the service industry.
They sometimes eat dinner together.

bothering you, or is there anything on your mind that you want to talk about. So nothing was really off limits about the topics that we approached or that we talked about. We laughed a lot. It was a very just kind of easy, informal, family style.

How did the family-of-origin-family-meal get established? Most of the mothers in the study were the second or the third generation for whom family meals as we know them today was the norm. This is based on the timeline of family meals becoming a standard practice in the post-world war II era (Cinotto, 2006). The mothers talked about how their parents work, divorce, "emotional drama", alcoholism, poverty, culture, mental health issues, ability to cook, relationships, and the size of the family influenced their childhood family meals. These are some of the same features that would affect their own routines. It was difficult to determine discrete patterns. For example, Heather and Sarah both had large families. Heather explained that all of her family ate together because she had a large family and they needed a place to touch base. Sarah explained that she always ate by herself because her family was too large for everyone to get together except on special occasions. Both the families had 10 children. One parenting practice that several mothers mentioned was having to eat everything on the plate or having to eat everything that was served. Janet describes having to eat liver:

> My dad would cook liver and onions and I just refused to eat it. I mean I would. I would give my best shot and refuse to eat it. But, yeah, we did have to eat it, so it was always covered in ketchup and it was disgusting.

Laura also talked about being forced to eat.

> My dad made us sit there, you know, supposedly 'till we ate it all. If it was something we didn't like he would, he never forced us, but I mean he would yell and guilt us into it to the point … I would get that upset … I would get sick. So it was always a horrible kind of experience.

In her testimony, it is evident how this shaped her experience with mealtimes generally, not isolated to the moments where she was forced to eat. Anyone who talked about being forced to eat remembered it very negatively and none of these parents attempted to force their children. Being flexible about what children eat was one of the common divergences from family-of-origin-family-meals even among participants who had positive memories of their meals growing up. This speaks to the cycle of recreation and reaction that is critical to how routines reflect yet also distort through the passage of time.

How family-of-origin-family-meal moderates achieving a functional routine: Laura and Whitney's families. Laura and Whitney could not have more different upbringings. Laura grew-up in a warm, supportive home and her parents continue to be her best friends. Whitney grew up in abject poverty until her mother lost custody and she was raised by her grandparents. With her grandparents, Whitney experienced love and care, but they were not warm. Growing up, Laura's family meals were filled with laughter and everyone shared about their day. For Whitney, they were just about eating, which was okay for her. It was difficult for her to engage during meals even at school due to her early childhood experiences with hunger. Based on that information alone, it would be reasonable to predict that traumatic childhood family meals such as Whitney's would be a barrier to achieving a functional routine and traditional sit down family meals such as Laura's would be a facilitator, but in reality, the pattern is not nearly so straightforward. Although I am sure that Whitney's childhood experience posed challenges for her, it was not a barrier in the sense that it prevented her from having a functional mealtime routine. In fact, Whitney had one of the most functional routines of anyone in the study despite her childhood, despite her son being a picky eater, despite having to regularly work evenings, despite having a partner who does not know how to cook, and despite having a son with ADHD in addition to autism which made sitting at the table particularly difficult. On the other hand, Laura struggles to facilitate meaningful connections during family meals. There are high levels of tension and much of the conversation revolves around power struggles. Although they usually sit together and eat as a family the meal feels more like just another thing that has to get done in the evening.

Although I do not believe Whitney would ever say her family-of-origin-family-meal was a facilitator of a functional routine, I believe it was not a barrier for several reasons. First, Whitney was self-aware of the emotional impact of her childhood in her daily life. She knew that she had experienced trauma and she knew that her experience influenced the lens in which she viewed the world. That gave her control over it. Second, Whitney had an alternative model. She moved in with her grandmother and although it was not particularly warm, she was able to see the act of caregiving as an act of love. Her grandmother also taught her how to cook which made creating her own routine easier. Finally, in the absence of having what she needed, Whitney formed her own values. She knew that it was important for her son to feel safe, loved, and accepted and so she planned ways to make him feel that way. In doing so, she was able to

use normalcy as a tool rather than a constraint. By looking at how Whitney achieved resilience, it possible to see how, regardless if the parent remembers mealtimes as an idyllic experience, family-of-origin-family-meals can be a barrier for achieving a functional routine.

Self-awareness. For Laura, despite having positive feelings about her family meals growing up, they seemed to be a barrier to her creating a functional routine because of a disconnect with how they affected her emotional landscape. Although Laura could be described as self-aware in general, she did not see the role that normalcy played in her childhood and how it affected her difficulty in accepting her son's difference. Specifically, she was not aware of how ardently her parents instilled in her the value of child complacency. This affects her view of herself as a good parent. She describes her parents as

> Honest to God parents, who, now they are my best friends. Because now I understand and I get it and you know all of the things that I listed off about growing up and having our experiences [using manners, becoming independent, following expectations], it's because they did their job the best they could as parents. And so it all- it just kind of comes full circle.

When her son has difficulty following social norms, doing things independently, and meeting her expectations, it threatens her sense of herself as a good parent. As she experiences that threat her instinct is to control the situation but her rigidity can make her mealtime routine dysfunctional. In Laura's family and in others, a lack of self-awareness would make the mealtime routine, or elements of the routine, problematic.

Role Model. Sarah had a difficult childhood and never had an alternative role model. She described trying "to do the exact opposite of what I was raised up as." Before she was able to do that, she enacted the same patterns and she "started seeing my son pretty much having the same patterns I did when I was a child." The combination of not having a childhood experience that she wanted to recreate and not having an alternative model was a barrier to achieving a functional routine although she is working hard to overcome it.

Understanding values. Samantha clearly understands how to communicate her value of education to her son in the everyday task of supporting him with homework. In doing so, she also communicates to him that he is capable and competent. Samantha has less clarity in understanding what she values regarding mealtimes and how to enact them. In this response, she

is trying to explain why she has the general feeling that she wants to eat dinner together more often.

> I don't know. I guess at the end of the day it seems like we've all have been doing our own thing and it's nice to kinda [pause]- I don't know? We all get along pretty well. It's not like we need more like family togetherness or something but I just like- I don't know? It is kind of stressful- I don't know why I want to (laughter). Now that I am thinking about it, "why do I want more?" (laughs) Yeah I don't know. I guess I like the idea of it maybe.

She alludes to how her routine is not quite functional right now. Both boys are having a hard time staying at the table, but especially Lionel. Part of the reason the routine is functional is because, without realizing it, she is testing their ability to try new foods. On any given day, she might cook something that Lionel does not know if he likes (or might actively dislike). He cannot predict it and I believe he may be confused and upset that Samantha is not anticipating his reaction – she does it so well so much of the time. She does not believe that mealtimes are critical for communicating the value of togetherness (and she might be right in her family situation).

Logistical considerations. Work, family structure, the layout of the home, extracurricular activities, and finances made a huge impact on who was at home for dinner, when families ate, what they ate, and where they ate. For example, work affected the timing of the meal (dinner happened after parents got home from work), the consistency of the routine (it was more difficult to eat together regularly if parents worked some evenings), who cooks (one parent may be the primary cook, but the other parent may cook if that parent is working), and who was home for dinner. Family structure often dictated who was at home throughout the week. The layout of the home could facilitate the family feeling like they were eating all together even if they were not all at the table. If a family had a dining room and an eat-in kitchen, the dining room was only used for formal occasions. Many of the children had extracurricular activities and this was usually a night where they would eat dinner out or have a quick, informal meal. Mothers did not discuss how finances affected their food choices directly, but there were sometime comments during the observations that suggested their impact. For example, a mother expressed apprehension about eating too much of something, not because of a dietary concern but because they wanted to make sure they had more later. Families often dealt with the

logistical considerations differently. For example, in some families where the mother did not like to cook, the father took on the responsibility, but another family ate take out every night. The child's age did not seem to play a role in logistical considerations. This is likely because, although there was a fairly broad age range, the children were all in a similar developmental stage.

How the logistical decisions were made. Many of the logistical considerations felt happenstance. For example, although Francesca's family was intentional about most aspects of their meal time routine, they were not intentional about what time it took place. For the observation, they picked 6:30 as the start of their mealtime observation fairly randomly. Francesca comments to her husband that she likes eating at this time and maybe they should try it in the future. He agrees but remembers that it would not work on days that they have choir. She says that they could try it on other days. When I interviewed her a week later they had not yet started implementing a specific time to eat, but Francesca does not work and the children are home schooled so she has a lot of flexibility regarding when they eat, sleep, and wake up. In contrast Laura does not get off from work until 5:30 and has until 8:00 to get two children dinner, baths, homework, and sometimes to sports events. Because of the time constraints they have to eat dinner right away when she gets home- it does not feel like someone decided that is the time they should eat. Most families had to negotiate these decisions, as well as other decisions related to the meal, but who did what was often attributed to being part of that person's personality. For example, Samantha's husband loads the dishwasher and when asked how they decided that was his responsibility, she said, "Um I think it's just because [clears throat] he likes things really clean (laughs)." Laura's husband likes to eat standing up, not at the table with the rest of the family, "Tom, for whatever reason, I don't know if he's not capable of eating while he's sitting [laughs], he prefers to stand up while he eats, plus that way if the kids ask for more milk, he's you know, he's still kind of milling about." Paula describes why her husband cooks, "I really say that I can't cook. I can follow a recipe, but you know he'll just throw stuff together and it's just wonderful- how do you even think of that?" The roles seem to fall into place and feel natural.

When logistical considerations pose barriers. Any logistical consideration could potentially be a barrier, but they were most problematic when they created inconsistency. For example, in Paula's family (who does not regularly eat dinner together), it was difficult to

maintain a functional routine given her family structure, that different children were in the house on different days; in her words, their "split lives". Although, there were other blended families in the study, Paula's family had the most intricate custody arrangement. Paula had other routines that were very functional but mealtimes (and bedtimes) suffered from the lack of consistency. In fact, the routines that were the most functional were also the most consistent (like his transition and school routines). This was true in other families such as Vanessa's. Her son only eats with his dad and brother every other weekend, but it causes problems each time he comes home because his father has different expectations about what is okay to eat. When both the boys are together at her house (which happens on the alternating weekends), they struggle to get along, which is part of the reason why the custody arrangement is such that the boys are only together on the weekends. For, that her children only eat together at the table when they are at her house undermines her value of sitting together and likely contributes to why her son pushes her so hard to be allowed to eat when and where he wants like he does at his father's house. The only family where the parents were divorced or separated in the study, whose routine was not affected by custody, was Laura's. Laura has a more relaxed routine than her ex-husband. She does not think that her children struggle when they are at their father's with increased formality, but they are able to fall into her laid back routine easily when they come home. In most cases, inconsistencies in routine were due to logistical considerations such as work and family structures.

**Establishing Meaningful Mealtime Rituals**

Previous research has theorized that routines and rituals are distinct constructs that vary in terms of the degree of symbolic meaning along the dimensions of communication, commitment, and continuity with routines having little symbolic meaning and rituals being rich in symbolic meaning (Fiese et. al., 2002; Fiese, Foley, & Spagnola, 2006). My analysis, departs slightly from previous work. Instead of focusing on the degree to which routines and rituals vary in their symbolic meaning, I have focused on the relation between routines and rituals. In my analysis the "how" of how meaningful rituals are established was that rituals were created through the routine enactment of activities. The behavior patterns take on a deeper meaning, not necessarily because of the subjective interpretation of experience, but rather because pattern and repetition are pathways to symbolic meaning. At times there was a disconnect between what the routine elements communicated and the desired subjective meaning. This was how rituals could

become hollow or empty. I will explain each of the enmeshed processes of co-creation for the dimensions of mealtimes.

    Communication: instrumental becomes symbolic. *Routine* communication is instrumental, functional, and task oriented whereas *ritualistic* communication is symbolic, emotional, and deep (Fiese, Foley, & Spagnola, 2006). *Routine* communication was extremely visible during family meals: "May I please have the grapes," "I'm going to check on the meat when the timer goes," and "You don't have to stir it constantly if you don't want." These comments are instrumental to the meal. They are how the family achieves the tasks related to the meal, but they communicate more than simply passing or cooking. Instrumental utterances communicate who the family is: the degree of formality among family members, roles, lovingness, and kindness. Imagine the tone if the comments above were phrased differently: "give me the grapes," "why didn't anybody check the meat," or "stop stirring- you're stirring too much." Although these phrases have the same instrumental function, they have dramatically different symbolic ones. In this way the instrumental becomes the symbolic; the routine takes on ritualistic purpose. Previous research has specifically looked at the degree to which routine communication is direct (as opposed to indirect) as being related to positive family functioning (Fiese, Foley, & Spagnola, 2006). Perhaps because the children in my study have autism, almost all the routine communication was direct like the examples listed above. The tone, expression, wording, and frequency of directions and corrections created the climate of the meal. It was the way in which the routine was communicated that created a climate hospitable to communication that is consistent with the ritualistic purposes of the meal: sharing and problem solving. Figure 5 visualizes these relations. To further explicate this model, I will go through each element conceptually and then use the model to explain the communication processes of two families in the study.

Figure 5. The relation between routine and ritual communication
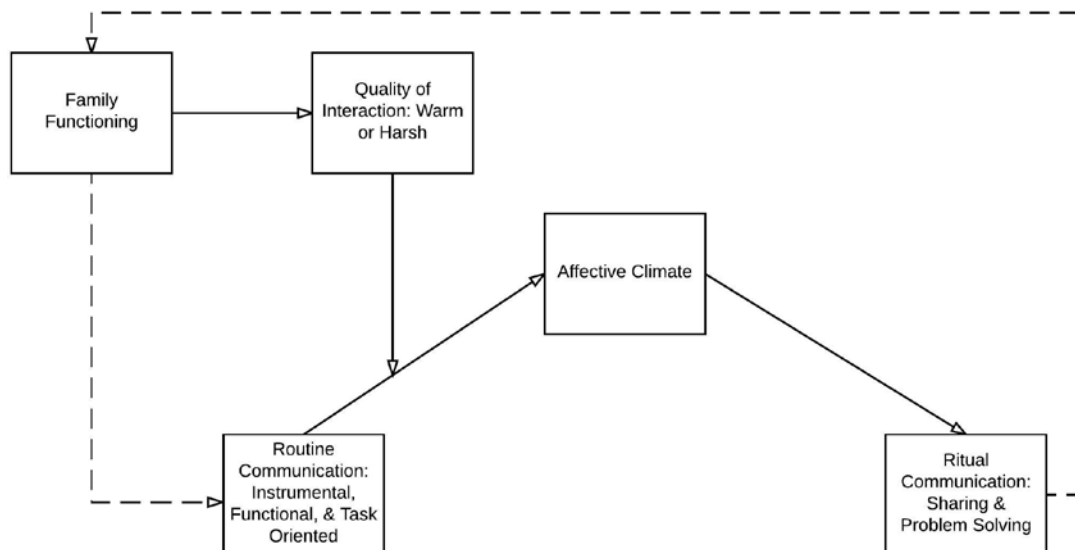
I defined the quality of the interaction in terms of harshness or warmth as the observable affective indicator of family functioning (which will be discussed in more depth in the next chapter). All families had to use instrumental, functional, and task oriented communication in order to achieve a family meal but the degree to which this communication was harsh or warm created the affective climate for the meal. The quality of the interactions was determined by the tone (loving, neutral, or angry/critical), facial expression (smiling, neutral, or stern), wording (open, polite, rude, short), and frequency of directions and corrections. When the tone was loving, family members smiled, diction was polite, and directions were limited, - it created a positive affective climate. When the tone of communication was angry or critical, when facial expressions were stern or angry, when the wording was harsh, and when the frequency of directions was great, then it created a negative affective climate. The affective climate of the meal affects ritualistic communication in terms of time spent in sharing and problem solving and quality of sharing and problem solving interactions. Families with a positive climate spend more time sharing and problem solving. Additionally, the sharing is at a greater depth and the problem solving has less conflict. When sharing is deep and problem solving happens without conflict, the family's overall adaptive functioning is reinforced.

I will discuss two families to illustrate this model in action. Cindy and Frank did not have much sharing and problem solving (*ritual communication*) in the family meal I observed.

Frank did talk to Cindy about his day and the things on his mind, but there was little reciprocation from Cindy[20]. When Frank did not want to do his homework, they could not resolve the problem without Frank crying, yelling, and leaving the table. This was consistent with how Cindy talked about her feelings about conflict during the meal. She said that if Frank had difficulties then "he can go to his room. He's dismissed…If it's a problem, then I'll see you later." There was tension during the meal (*affective climate*). Cindy often sounded angry (raised her voice) and was critical of Frank. The climate was a reflection of the *quality of interactions* in Cindy's *routine communication*: she matched directives with criticisms; Cindy rarely smiled at Frank; her directives were often phrased in ways that were short and bordered on rude; and there were many corrections and directions throughout the meal. This is not to say there were no warm comments during the meal. Frank made sure to tell Cindy how much he liked the food. Cindy called Frank "sweet heart." Although these types of comments were present the relative ratio was in the direction of harsh interactions dominating the meal. Also, the warm interactions seemed to carry less weight in affecting the overall tone of the meal.

In contrast, Paula's family did a great deal of sharing and problem solving during the meal (*ritual communication*). They worked out logistical considerations like how they would use the leftovers and shared events that had happened outside the home (*routine communication*). The *quality of interaction* was overwhelmingly warm: there were few directions given, but when they were, it was in a loving or neutral tone; Paula would smile and use pet names as she asked Brian simple questions about the meal; when Paula tried to correct Brian about singing, she did so playfully and her request was open to his challenge (he told her that he was just singing and that it was normal, then proceeded to sing even louder); there were few instances of corrective behavior. The warm interactions created an open and caring *affective climate*, which opened the door to sharing and problem solving.

Commitment: tasks carry emotional weight. *Routine* commitment refers to how the task is accomplished whereas *ritual* commitment refers to emotional investment to others as opposed to tasks (Fiese, Foley, & Spagnola, 2006). This has been examined in terms of the rigidness of achieving a task in a specific way compared to genuine concern for others. When rigidity is discussed for families with autistic children, it is almost exclusively discussed as the

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[20] Overall, parents shared much less than their children during the meal. Several mothers said that they did not feel it was appropriate for them to share too much.

difficulties caused by the child's rigidity. The language of rigidity being the opposite of concern for others is paralleled in the autism discourse beyond the topic of mealtimes- that children with autism lack the empathy or perspective taking skills necessary to be flexible. Perhaps because I was observing in the family context and because of the age of the children, I believe that the rigidity of the parent, not the child, carried the most emotional weight. When parents were able to dis-invest in their idea of how things should go in order to make things function more smoothly for their child, they gave up control and adjusted their role, but it had the effect of communicating acceptance. Francine, Janet, Whitney, and Heather all talked about having these moments- moments where they gave up their preconceived notions about their parenting role. Francine (who practices ABA) talked about her revelation regarding Tristen's need to have a particular plate.

> It drove me crazy. It's like I'm going to reward him for something that I asked him to do. This is crazy. I'm not doing that. And then I'm like, the plates, he would scream because he wanted *this* plate. Or if the schedule changed he would be off the hook. I have to do something. He's going to drive us all nuts. ABA is like, okay, if you do this, even the schedule change, this is what you're going to get if you do it. And it really sucked for me. But it worked. I was like, okay, we're going to do this. It's not that hard.

Francine, like the other mothers who had these types of epiphanies, talked about it in terms of figuring out what works instead of acceptance, but it was an act of acceptance to make the accommodation. They did not talk about what they gained in giving up their sense of how things should be, but you could hear the pride in their voices. In shifting their understanding of their role, they gained a sense of competence. The meaning was made not in the moment but in the new pattern of behavior. In this way, commitment is critical to ritual continuity which will be discussed in greater detail in the next section.

 When tasks carry emotional weight: Samantha's family. Samantha is an "autism mom." She goes to workshops, is a resource for other parents, and is a great advocate for her son, Lionel. It seems like this may be part of her process of understanding what it means to have a son with autism. At first, she had a hard time accepting the diagnosis. She would not tell people that he had autism, but as her understanding of autism grew, it gave her a sense of control and opened the door to acceptance of the label. They have a close relationship and his attachment to her is strong. He writes a comic book about a boy and a queen who are super heroes and go on

adventures. He says his comics are where he shares his feelings. The close bond is mutual, but she may have some guilt about how long it took for her to feel comfortable with the idea of her son being autistic. The close bond coupled with the sense of guilt seemed to create tensions with other members of the family, but the tensions were under the surface and not at the forefront of their self-awareness. As such, the tensions would come out through mundane tasks. When Lionel refused his father's help and insisted on his mother's support, this served to keep the bond between them special. When Lionel's younger brother, Eddy, sensed the closeness between his mother and brother he would do small things to provoke them (such as refuse directions from his mother or intentionally ignore his brother) which reaffirm to him that he was not part of their inner circle.

  Symbolic acts. Pervious conceptualizations of commitment did not examine how some tasks carry emotional weight as symbolic acts. There were several features of the meal that seemed to hold special meaning. In most of the families the parents served the children instead of the children serving themselves. This was true even if the family brought all the food out to the table. The child may be allowed to carry their full plate to the table, but not scoop the food. There were older children and children without cognitive impairments who were served by their parents (usually whoever had done the cooking). To the parents who served the children, it felt like a practical choice rather than symbolic one, but it is a nurturing act to provide food. When Janet serves Ben (the oldest child in the study), you can see the love in the act of her providing for him, but it also reinforced his dependence on Janet and Janet's control. Francesca's five-year-olds serve themselves (the youngest children in the study). For Francesca this is a very value laden choice, "For me it's all about establishing independence early because when I grew up my dad was in the air force. He was just a private before he got discharged but he taught us to be very independent very self-reliant so that I guess I wanted too definitely pass that down."

  Another task that carried symbolic meaning was food selection. There were many logistical considerations that went into food selection such as cooking ability, food preferences, time, money, nutritional considerations, and environmental implications. Upon deeper reflection, each of these logistical considerations is laden with values. Some mothers reported experimenting with cooking techniques outside of their comfort zone to make meals with their romantic partners more special. One family never ate out as part of their effort to be able to afford one parent not working outside the home. Beyond the broader confounding of food

selection and the values that it represented there was a specific aspect of food selection with special meaning: whether parents accommodated their child's food preferences. Similarly, to the discussion of rigidity above, when parents choose to accept their children's food preferences it carried a deeper meaning of acceptance. Children felt safe, loved, and understood. Mothers would report feeling conflicted. Instead of feeling affirmed that they were accepting their child's unique needs, they could feel that they were "giving-in." This could mediate the act of accepting food preferences deeper communication of acceptance.

Continuity: repetition creates tradition. Continuity of the mealtime *routine* has been referred to as the frequency of shared family meals, the repetition of conversational themes, and the repetition of roles whereas the continuity of the *ritual* has been referred to as the cohesion of the family unit and carryover across generations (Fiese, Foley, & Spagnola, 2006). Again, in previous conceptualizations the repetition of behavior is conceptualized as being on one end of a continuum with symbolic meaning being on the other. I would argue that the repetition of behavior is an important pathway to the construction of symbolic meaning. The degree to which the mealtime routine can be carried out and repeated creates cohesion in the family and traditions which can be passed down, however, it can also create hollowness in the ritual – going through the motions but not having that "family feeling." Meaning is always being made, but families have a specific type of meaning they are trying to achieve and if they are unable to achieve that meaning, it can have a harmful effect on family functioning. Again, the affective bond is critical to the repetition of the mealtime behavioral pattern creating cohesion. This is how very similar looking behaviors can have different outcomes (Figure 6).

Figure 6. The relation between *routine* continuity and *ritual* continuity.
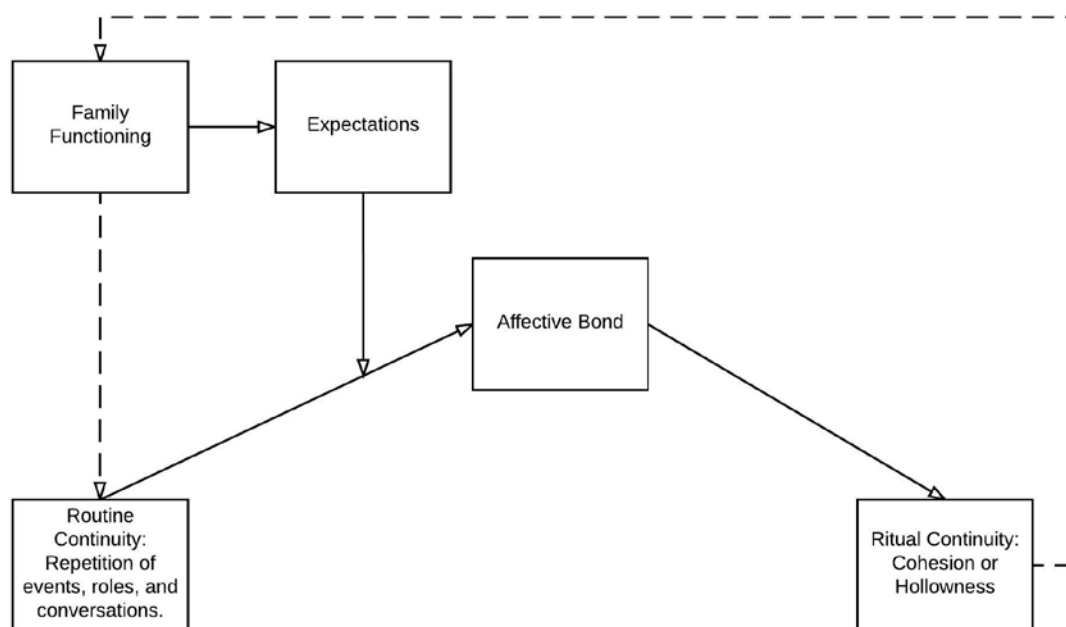
Family functioning has a moderating effect on routine continuity: the degree to which families can carry out the repetition events, roles, and conversations that are functional for the family. Heather described the importance of the affective bond with her son Camden.

> Growing up, I had a little bit rougher childhood than Camden and my mom didn't say that [she loved me] all the time. It was more of a question whether or not I was loved and wanted, so that's very important to me to make sure that my children don't ever ever question that, so that's why I feel that I have more patience with Camden and you'll find me saying it probably 75 times a day. Camden I love you. I said Camden I love you, he's like I love you too mommy! That was one of his first actual full sentences, I love you too. So you know- I mean he hears that a lot.

The affective bond mediates the relation between routine continuity and ritual continuity: constructing the meaning from the mundane.

The relation between routine continuity and ritual continuity is most easily seen in when the ritual is at risk for not creating cohesion. This happens when expectations for the child are misaligned with the child's capabilities or needs. Two families in the study were at risk of having hollow rituals. In both families, on the surface, everything looked near ideal. In Laura's family her husband Tom always did the cooking. Her children helped set the table and then

waited patiently until everything was ready. They sat down and ate together and talked during dinner. On the night of my observation, there was a minor conflict between Kevin and his parents over the acquisition of Gogurt, but this does not seem to affect the overall feeling of the meal as calm and organized. Sally's family meal seemed equally ideal. Her husband, Jim, is also responsible for the cooking and their son helped cook while Margaret helped set the table. They talked amiably before, during, and after dinner. Everyone helped clean up but Sally was mostly responsible. At the end of the meal, Sally and Margaret got into a heated argument about whether or not Margaret washed her hands after she used the restroom and Sally asked Jim to help moderate. The conflict has a harsher tone than I expected given the general amicability of the family members, but took up a very small amount of time given the course of the meal.

   I went into the interview with Laura thinking that there might be some tension between Kevin and the rest of the family. During the meal he almost never initiated conversation despite seemingly having the skills to do so. When I came into the house for the interview, Kevin fell down the stairs. Laura tried to comfort him, but he did not seem soothed by her presence. During the interview, I showed Laura a clip from her family's mealtime that included the Gogurt conflict. I asked her what she was thinking during that time, and was surprised by the intensity of her response:

> Please stop arguing. Please stop arguing. Please stop arguing. I'm also thinking, Tom don't make such a big deal out of it- it's fricking Gogurt and applesauce. And Kevin just sit down and eat it because those are two things that he likes. Just sit down and eat it. I think, for me, that's where the stressful part comes in because I'm thinking to myself please don't let things blow up or escalate to the point of people being irritated with each other.

   Laura went on to talk about what a difficult time her family had and how out of control Kevin's behavior was for a significant period of time. She was afraid of going back to that place. Margaret also went through a difficult time where her behavior was really out of control and Sally is also afraid of going back to that place:

> She would trash her room, and she would scream and scream and scream, and she would pull everything off her hangers, she threw dinner plates. I mean she was breaking chairs. You have an out of control child and you felt like as parents "What if I don't want my child anymore?" I mean that's really pretty significant.

In both cases, Laura and Sally needed to build back the trust in the relationship, have faith in themselves that they can be successful in the parenting role, and trust in their love for their child. Trust that their child was someone they could love. And Kevin and Margaret need to learn to trust that their parents can keep them safe – safe from themselves. Small conflicts bring this all into question; it was not about Gogurt or washing hands. In Laura and Sally's families, you can clearly see the role of the affective bond in mediating the relation between routine continuity and ritual continuity and how this process reflects and reinforces family functioning. The reflection and reinforcement of family function are two of the critical roles of family meals, which is the focus of the next chapter.

Chapter Seven

The Role of Mealtime Rituals and Routines: Negotiating the Tension between Expressions of Love through Control and Acceptance

In the previous chapter I outlined (1) the parameter of behaviors parents have access to in order to establish useful mealtime routines, (2) how routine communication becomes ritualistic communication, and (3) how routine continuity becomes ritualistic continuity. Figure 7 shows how each of these pieces fit together in order to answer research question four: *what roles do mealtime rituals and routines play in family life when a child has autism.* The full model illustrates the role of family meals: mealtimes reflect and reinforce family functioning. Family functioning has been outlined previously in multiple literatures; however, in this chapter I articulate a grounded understanding of family functioning. The affective components, in terms of climate and bond, were critical for mealtimes to achieve their desired meaning and be a place where sharing and problem solving could happen. Affective climate and bond were achieved through a dialectic of acceptance and control. Parents used controlling behavior during the meal as an expression of love to support their children with being successful with the tasks related to the meal (the routine components are blue in the model to indicate that routine communication and continuity are expressions of love though control). Parents also expressed love through acceptance in terms of how they created expectations and communicated those expectations (expectations and the quality of interactions are yellow in the model to indicate that they are expressions of love through acceptance). Navigating the dialectic of control and acceptance, being at peace with the tension, and having some degree of balance were necessary to achieve the affective and symbolic elements of the meal and also reinforced family functioning (these components are represented by green- the integration of control and acceptance). Family functioning was also reflected in routine communication, routine continuity, expectations, and the quality of interactions, however there could be a wrench in the system. There were times when families simply did not have access to the resources necessary to support their children and, in those cases, adaptive family functioning was difficult to achieve. To further introduce this theory, I will share Heather's family meal as an illustration of how families navigate expressions of love through control and acceptance before moving on to define each concept and how they interact.

Figure 7. Full model of shared family meals.
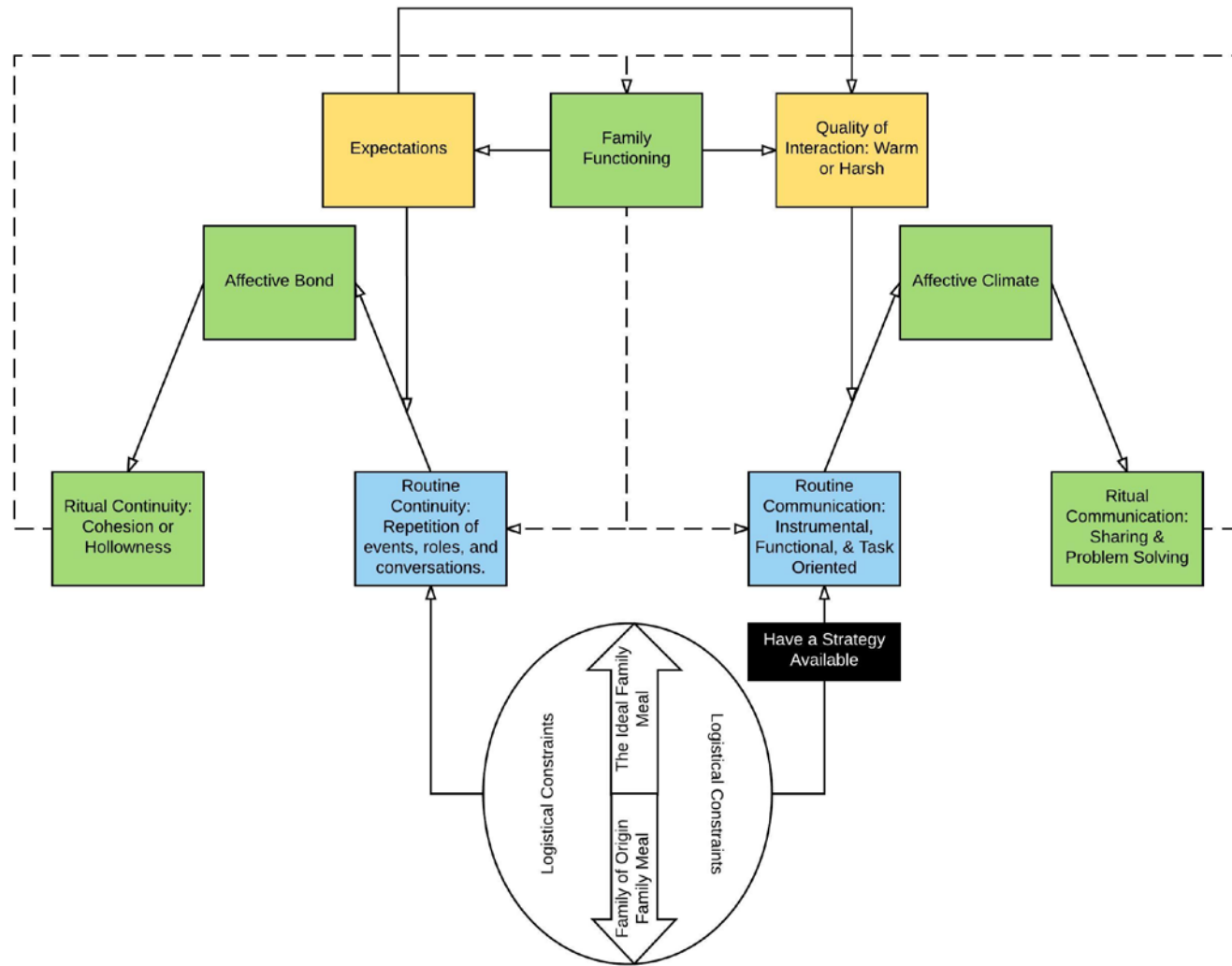
The Dialectic of Control and Acceptance: Heather's Family

In the beginning of many interventions for children with autism, before the instructor starts working on specific skills, they establish something called "instructional control." Essentially it means the child is able to follow simple directions, stay still, sit in chair, and attend to an instructor. Camden's teacher was not able to establish instructional control, at least, not for very long periods. Additionally Camden struggled with emotional regulation. When he was sad, embarrassed, frustrated, angry, or even excited he could act out verbally or physically. Heather started tightly restricting what he could watch so that Camden would not use, or threaten to use, the things he saw on television at school. His teacher struggled to teach self-regulation skills and provide emotional support. Camden tested boundaries. He wanted to please, but he also wanted to understand his realm of control. These struggles are not uncommon for children with autism, but the combination of lack of instructional control, emotional support, and clear boundaries had been making school difficult for Camden. His school was suspending him every day before lunch[21].

Heather was doing everything in her power to support Camden with being successful at school. She wished she could go to school with Camden and show his teacher how to better work with him. He struggled with all the same things at home, but Heather had figured out strategies for helping Camden be successful. When I am working with parents, I often try to teach strategies that Heather had learned (e.g. being consistent, giving responsibilities, and using praise). But there was more than the effective use of strategies contributing to Camden's success at home. Heather and Camden had a strong and healthy affective bond. Her expectations of him and what their life should look like affirmed and accepted him for who he is; she saw, anticipated, and strategized around his struggles, but also had hopes for him and was constantly pushing him to develop his skills. This reinforced their bond and created cohesion between the two of them. Heather's expectations also shaped the quality of her interactions with Camden and kept their mealtime pleasant even though she was demanding a lot from him. Camden worked

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[21] Two other families in the study were being denied access to a full day of school. Vanessa's son Lincoln was being suspended every day after just one hour of school. Vanessa realized that it was a violation of her son's rights and was in the process of transitioning him to an alternative school which promised to serve him for a full day. Tina's daughter Marissa's school was using a combination of late start, maximum bus time, and taking her from the alternative school to general education school in the middle of the day which limited her actual instructional hours to four or less each day. Tina did not seem concerned, but also may not have pieced together the problematic nature of the situation.

hard to meet his mother's expectations. He loved that she understood him, that she was proud of him, and that she believed in him.

As Heather is figuratively negotiating expressions of love and control, she literally negotiates with Camden. Here she is commenting on an excerpt from their mealtime:

I didn't realize how much I negotiate with him. When I say, "Three." He's like, "No, two. I'm like, "Okay." I guess I just do it without even, you know, realizing that I do. Instead of saying, "No. I said three" And then, I didn't realize how much he sweet talks me. He'll come up and hug up on me and say "please." He uses his manners quite a bit.

She is willing to yield some of her control over to him, because she expects that he may need to express his power (or even only be hungry for two bites of pizza). This expression of love through acceptance is met by Camden with warmth and love of his own.

Expressions of Love through Control: I'm Doing This Because I Love You

When I use the word control I define it broadly as the efforts of one person to set parameters on the behavior of another. For routine continuity or communication to be achieved, parents had to exert control. This could look like giving a clear direction, verbally acknowledging a perceived error, giving a verbal correction, stating a rule, expressing an expectation, giving a consequence, giving a choice, or praising a desired behavior. There were less direct ways in which parents exerted control. For example, parents decided what families ate, what food was even in the house, when eating happened, where it happened, the rules for mealtimes, and when exceptions to the rules would be made. All of these are examples of control. Control could happen through emotional manipulation: giving or withholding warmth or connection in response to behavior (or to illicit behavior). Not all expressions of control were expressions of love. When children exerted control, it was rarely an expression of love. For example, after dinner Margaret did not wash her hands after using the restroom. Her mother reminded her to wash them and Margaret lied to her mother and told her that she already had. Sally yelled, accused Margaret of lying, and demanded that she wash her hands. Margaret refused. In this exchange Margaret was exerting control, but she was not expressing love for her mother. It could be that she wanted to feel powerful; throughout the meal she was given many directions and she complied with them, but it could have made her feel like it was her turn to be the boss. Alternatively, she may have been motivated by security and wanted to see if her

mother was capable of controlling her anger so Margaret tested her. Another motivation may have been wanting to feel safe in the way that anything that is predictable feels safe even if it is being yelled out. Parents were sometimes motivated to exert control by similar impulses, but they had another layer of motivation. Laura explains it:

> I just want [my children] to be happy and to know [long pause, she is emotional] that they are loved, and that [long pause] they're important, but also what they say and what they do hold weight with me, and that they're valued, and that they're not, you know, this isn't a dictatorship. We work a lot and, I don't know maybe any other family in our situation might say the exact same thing, but probably we work exceptionally harder than other families in our situation to make it as normal as possible, and to make it so his quality of life will be the best it can be given the circumstances. [It's] like having kids is like having your heart walking right outside of your body…You want to keep 'em safe, and you want to have them grow as individuals but at the same time you don't want them to get hurt. You don't want them to experience pain. You want the best of everything for them. You don't want them to have to experience the negative aspects of life, but then there comes the difficulty of letting them do that… And the earlier you learn it the better off you're going to be, and so even though he has a disability it's not your crutch to lean on your entire life. And society is not going to change for you so unfortunately you're the one who's going to have to adapt into what the mainstream is. And it's extremely hard to watch. It's extremely hard to watch [Laura is crying], and know that there are things that you can make better and there are things that will never change and will never stop being hard for your kids. But in order for them to grow up and live on their own and be productive and live, you know, a happy life, that's what has to happen... *I'm doing this because I love you*. It also makes me think of -I'm not you're friend I'm your mom, first and foremost. Now if we could be- if we can be friends after the mom part that's just the icing on top of the cake, but first and foremost I'm your mom and I'm not here to be your best friend because there are things that I'm going to say that you are going to hate. Does that mean that I am kind to say it? No. But it means that I have to because I'm your mom and it's what's best for you.

As can be heard in Laura's statements, for parents, intimately tied to their decisions about control were sentiments of love (*having kids is like having your heart walking right outside of your body*), responsibility (*I'm doing this because I love you*), and hope (*I want them to be happy, loved, productive*). The need for control was also connected to their children's disability. In Laura's case, this was reflected in her desire for Kevin to meet her understanding of success and her fear that it may not happen if she fails (*society is not going to change for you so unfortunately you're the one who's going to have to adapt into what the mainstream is*). Other parents used control as a way to accommodate for impairments associated with autism. Although, this may ultimately be connected larger goal of independence and success, it is expressed in the moment and the task. For example, Francine used a reward system to support Tristen with sitting at the table:

> He's not allowed. I mean he knows the rules are if I want the reward I have to sit at the table. You may have heard- we were rewarding him for sitting there, reminding him he was going to play a game or whatever it was, if he sat at the table. His motivators have to be big for some of that stuff because he won't sit there because he can't stand it. And I get it, it's about taking him out of his comfort zone and saying okay, you do this for me and this is the end result- you get to play the game or whatever it was that night.

> Even though Francine does not explicitly tie her strategy of rewarding Tristen to an act of love, the energy it takes to dedicate time, planning, and consistency is motivated by her love for Tristen. Having said that, a lack of control should not be conflated with a lack of love. The choice of when to exert control, the strategies parents selected to exert control, and the effectiveness of the strategies was determined by expressions of love through acceptance.

Expressions of Love through Acceptance: He Can be Himself Here and All of his Odd Little Glories

When I use the word acceptance I mean to see a person for who he or she is rather than a stereotype or an idealized version of self. To accept is to affirm another's existence not because they are perfect but because they are human. Janet describes acceptance as creating a haven for Ben so he does not have to fake normal.

> There's a huge range of normal and he's getting closer to that. He does a good job of faking normal and that's, sadly, the goal to pretend to be normal, so that you can be

accepted. He can be himself here. We try to not make him fit into molds, like he has to at school and out in public. *He can be himself here and all of his odd little glories.* He can be himself here.

Janet goes on to describe some of Ben's interests that may make it difficult for him to find acceptance outside of the home. But in providing a safe space to be himself, Ben experienced a profound acceptance that he could take into the world. This expression of love was communicated through Janet's expectations of Ben. Janet did not expect Ben to fit into a particular mold.

It may not seem radical that love is expressed through acceptance and that parents affirm their children as human, but read how Heather's thinking about her son shifted:

[Camden] kept being kicked out of daycare after daycare. I couldn't work. I couldn't get anybody to watch him and he was just too much to handle…I just thought my child was braindead. You know he's just, like he's just really out there as far as having a disability. He's going to be labeled and pointed at and looked at differently, and you know made fun of and not treated right. And then I learned that autistic children are very smart and know a lot more than you think that they know, and they just want to be treated like everybody else, and they don't want you to make excuses saying they're autistic…So now we know that Camden can't help this. He can't be punished for things he can't control and there's resources out there to help you, and these people are going to be held accountable to make sure that Camden is being treated right. So that was a big relief… I'm his advocate, I'm his voice, you know I-I know what triggers him and it's my job to make sure that his voice is being heard at school and he's just as comfortable at school and other places than he is at home.

Heather shifted from not being able to see Camden because she was so overwhelmed by her inability to support him, to believe her role is be Camden's voice and advocate. This is a profound act of acceptance and challenging one because, as Heather says, these children are labeled, made fun of, not treated well by others, and looked at differently than those around them. There are things people expect children to be able to do that these children sometimes cannot and sometimes this makes people see them as less, even their own parents. Whitney (who never makes her son go to bed hungry) had a similar shift as Heather.

It came sort of as a whole Epiphany. He was probably five. Yeah that's when he first went to the pavilion. He was about five and I realized nothing that I was doing was working. I kind of have this entire life awakening moment where I was like, hmm I don't think we're doing anything right, which of course is not completely true. But, the first time he was psychiatrically hospitalized, I had a whole month to sit back and reflect on how crappy of a parent I was and you know where I can go better and [she laughs] not do so much wrong. In all retrospect, I mean he didn't go to the pavilion because I'm a crappy parent; he went to the pavilion because he's mentally ill. But your first thinking is I'm a crappy parent. So from there I made a very conscientious effort throughout the day whether it was mealtime or whether it was getting dressed or whether it was taking a shower to try to figure out what worked best for him. I'll be honest; I've been in therapy for a long time. I did not anticipate that when I had a child. That was not what I signed up for. It was not what people told me it was gonna be. People said this will be hard. Nobody said it was gonna be that. I think there's a lot of autistic parents that don't have the ability to admit that. But boy I can admit that this is not what I signed up for, so going to therapy really helped me to be okay. And my therapist would say, "Well did it work?" "Well, no." She'd look at me and go, "Well then try it again." But that made sense to me right. I came to a point where I realized he was unhappy. Like him as a person, like as a little kid person. He was not happy as a rule in his life and I didn't like that. I experienced that as a kid, granted I experienced it for very different reasons, radically different reasons. But I experienced it and I thought to myself well that's not fair to him, I'm gonna give him something better than what I had.

When Whitney was able to accept that her son had serious challenges that she could not control or remedy and accept that this was not what she wanted for her life, she started to see her son as the *little kid person* that he was. She could see his unhappiness. Through that acceptance her expectations started to shift and then so did everything else. It was when she could not see her son beyond his extreme behavior when she could not find strategies to support him. Her expectations were misaligned with his needs. In the chaos, Whitney tried to exert more and more control, but that was not what he needed. Logan needed just the right amount of control. It was Whitney's expression love through acceptance that achieved the balance. Although Whitney

describes her epiphany, acceptance is not something that happens once (I either accept you or I do not). Acceptance is process that happens over, and over, and over again. Acceptance (and sometimes a lack of acceptance) happens throughout the meal and across mealtimes.

Expressions of love where enacted during family meals through parental expectations and this happened in two ways. First, acceptance shaped the expectations of parents in terms of what a child could and should do. When these expectations were closely aligned with the child's actual ability, it strengthened the affective bond. For example, Whiney knows that Logan can sit at the table, but he might need to bounce around. She knows what he will eat and struggles to eat, so she systematically exposes him. Her expectations are within the zone of behavior he can do on his own and do with support. Second, acceptance created the expectation that children should have their own thoughts, wants, opinions, and agendas. When parents had the expectation that children should have agency in this way, it influenced the quality of their interactions: they were more likely to be warm, overtly caring, polite, open to dissent, and limit their directions. For example, Janet expected Ben to be his own person and so she asks him to help her with setting the table instead of telling him what to do. In both cases, the opposite could be true. Parents' expectations could be misaligned with their children's capabilities. Furthermore, parents could expect children to be compliant which would lead to an over dominance of control.

Struggling to Balance Control and Acceptance

Cindy, Christine, and Tina had expectations that were misaligned with their children's capabilities. Cindy underestimated Frank's support needs. Christine overestimated Julia's impairments. Tina was more accepting of one child over the other. The tense nature of Cindy and Frank's mealtime was previously described. Because she expected Frank to be able to independently complete the tasks associated with the meal, she got angry when he could not or did not, this in turn, affected the quality of her interactions. It also affected their bond. That their bond feels threatened to Frank is expressed in his multiple attempts to get verbal affirmation of Cindy's love and affection throughout the meal. Christine and her oldest son have autism. When she noticed some of the same traits in Julia, she came to believe that Julia had autism too, but Julia does not see herself as autistic. There is a child in her class who has autism and she does not see herself struggling in the same way. Whether or not Julia has autism is less

important than Christine's ability to really see Julia: to accept Julia's strengths and weaknesses. It is affecting their bond. Instead of trying to connect during dinner, Julia is constantly trying to prove her competence by cooking things without help and being contrary. In Tina's family, Tina expresses her love through acceptance with her son Conner but sometimes struggled to do so with Marissa. Tina believed Marissa would never move out of the house or have any independence, but there was no reason why this would be the case (although Marissa may have needed support to be out on her own). Not accepting Marissa's capabilities affected the bond between Tina and Marissa, but also with Conner. Conner would cling to his mother and try to match her expectations of him. He was capable of completely different things at school than at home. I believe that Conner, at some level, was afraid of losing his mothers' acceptance so he was limiting his own ability to grow.

Francesca, Francine, and Laura expected their children to be compliant and had difficulty accepting their unique wants and needs. In each case, this lead to a critical tone, stern facial expressions, short commands, that happened with an intense frequency. For Francesca's family, the lack of smiling was noticeable. In viewing the recorded mealtime observation, she actually commented on how surprised she was that there was so little smiling during her family meals. Francesca stated that she wanted her children feel accepted, but was not aware that she also held the expectation that her children should express their individuality in a narrow range. In Francine's family, expecting compliance at the expense of recognizing needs looked like ignoring comments about her son's day because she could only hear them as inappropriate expressions. Because Francine was not expecting Tristen to share about his day and because she is rigid about appropriate forms of communication, Francine misses that Tristen needs to process being hit by a classmate. In Laura's family, she was aware that her son would have preferences, but she did not appreciate these preferences as valid which lead to an argument over Gogurt.

Parents could identify when something that was not quite working, when they were not getting that family feeling from the meal, when they were having difficulty sharing and communicating, and when they were feeling disconnected. Mothers' would blame it on themselves, their ability to plan, and their cooking. Although Christine could recognize that there was a lot going right with her family meals, she had so much self-blame and self-doubt.

I'm not very good at traditions, but the fact that we sing the Doxology and we hold hands and we know that when we are together, even if it's not all of us. That's something that's continued since from before the divorce. Um, I don't know. It's, a least a little connection that this is what we do, this is who we are kind of thing.

Christine does have a routine, rituals, and healthy meals. She sees it but she also negates it (*I'm not good at routines despite making family dinner happen at least four times a week with two active teenagers; I'm not good at traditions despite starting every meal with prayer; I'm not good at cooking despite making nutritious meals throughout the week*). It was more natural for her to blame herself for not meeting an idealized version of the family meal than it was for her to express her love through acceptance of herself and her children. The irony was that it was her lack of acceptance, not the lack of idealism, which sometimes caused her family meals to be tense and not have that family feeling.

Balancing control and acceptance can be difficult for all families but it was particularly difficult for families with children with autism because of within child inconsistencies in terms of their capacities and limitations. Children were often unable to self-regulate and therefore could tolerate different demands on different occasions. For example, some of the children faced challenges during the day that caused them extreme distress. The children would struggle to reset from this distress which disrupted the routine. For Whitney's son it was storms. He had an extreme fear response to storms that he could not regulate. On stormy days, he could not participate in his normal routine. Paula's son got distressed if he made a mistake or broke a rule at school. He would get so upset with himself that it took hours for his mother to calm him down. For Cynthia's son it was haircuts; he could not have any additional demands placed on him on those days. These are all stressors the parents had come to accept and change expectations in the presence of, but they were speaking in hindsight of identifying the trigger. For Vanessa's son there were no clear, triggers that she could plan for or avoid and Lincoln's reactions could be extremely emotional and even violent. The emotional responses that these children experienced created unpredictability that posed a barrier to having a functional routine on a specific day, and for some families, caused enough inconsistency that it created a barrier to having a functional routine over time. When this happened, family functioning was disrupted by a factor not related to the dialectic of expressions of love through control or acceptance.

Sometimes mothers had expectations that were consistent with their child's capabilities and affirmed their child's personhood, but could not adequately meet their needs. Many families had passed through a period of time when this had happened and needed outside support to learn new skills, provide additional support, and restore a base level of family functioning. Without support, some families were able to hold on to a routine but could not maintain a balance of control and acceptance. Other families lost the routine all together. Vanessa's family was still holding a routine together, but it was a struggle. Lincoln's school was fighting Vanessa on every accommodation, she was overwhelmed by his appointments, and struggling with her insurance company to get counseling covered under her plan. Lincoln had a complex diagnosis of autism and mental health concerns and Vanessa felt like no one could help her. She was keeping things together through sheer willpower. Vanessa was seeking support for herself and hopefully it will provide her with an outlet like therapy did for Whitney, but without Lincoln also getting additional support, it seems unlikely that she could preserve her family functioning on her own. This potential wrench in the system is represented by the black box in the model. Parents had to have access to a solution (or set of solutions) that could work for their child.

Understanding What Works for Family Mealtimes

Parents struggled to see the interworking of the family system and influence change. It is difficult to see the meaning in the mundane and easy to get bogged down by the tasks associated with the meal. Having said that, many family meals were successful; created a place where sharing, problem solving, and cohesion happened. Now that I have examined the negotiation of control and acceptance in the theoretical, I will return to the concrete and give five examples of things families did that made mealtimes work.

1. Within reason, when parents let go of what their child ate (or did not eat), they were more able to focus on the affective components of the meal.
2. When parents taught skills related to cooking both parents and children felt competent and it nurtured their relationship.
3. When parents enjoyed their children because of their oddities not only in spite of them, children felt accepted.
4. When parents had access to support outside the family, they were better able to negotiate power and control and maintain routines.

5. When parents showed over signs of love (e.g. saying "I love you", giving hugs, giving praise), the meal felt warmer.

Each of these strategies was reflected in mealtimes in the study and reflects the theoretical model I propose. When parents allow a child to express food preferences it is an expression of love through acceptance, a reflection of the parent's expectations, it strengthens the affective bond and enhances the quality of interactions. When parents enact the role of teacher, it shows children that their parents believe in them which in turn strengthens the affective bond and creates cohesion. Compared with cooking, other tasks related to the meal felt like chores whereas cooking felt like a privilege. When children feel that they have a safe space where they are accepted, the overall climate of the meal is positive and they feel like they can share. When mothers indicated she had some type of support (either from a spouse, close friend, or therapist), they could manage the challenges of family life, but these challenges could not be managed on their own. When parents recognized the need for their child to feel loved, and strategized specifically around that, the meal felt warmer and the affective bond was strengthened. These are just five examples dialectic of control and acceptance was negotiated to make mealtimes work for families.

I would like to end this chapter with an example of how Whitney balanced control and acceptance to teach Logan how to cook but also strengthen their connection. Whitney recognizes the delicate balance, but also recognizes that her high (but reasonable) expectations bring them closer together.

> He only helps me until his patience runs out and then he's gone. So he's, he's never actually helped me cook start to finish, but I take whatever help I can get. Just because the more I can expose him, the more comfortable he'll be. I try to make it as positive an experience as possible so that he wants to come back and help… I get it, I get you don't wanna stick your hands in the dirty water. I get you don't wanna touch a greasy plate. That makes him crazy. To do a dirty dish makes him insane. It is not worth the fight… But once the dishes are done, once they're clean, it's his responsibility to put them away mostly because (A) you eat off of them and (B) it's a chore that teaches you responsibility and it teaches you that you are part of this unit. You live here as part of

this family… Having expectations that you can do this but also accommodating for the things that you actually can't do. That's the - I mean that's, it's a really fine to balance.

Chapter Eight

Discussion

Through this grounded theory exploration of family meals when a child has autism, I created new understanding about the nature of family meals, how mealtimes are achieved, the barriers to achieving them, and the role mealtimes play in family life.

The Nature of Family Meals

The nature of family meals when a child has autism generally looks like the "typical" American mealtime experience. Families come together to eat a meal, sometimes at a table or sometimes around the television, to eat, talk, joke, and share about their days. It could be a struggle for children to eat; family members could get distracted by their digital devices; members could get up from the table before everyone was done, but for the most part, the meal generally looked like what families wanted them to look like and what most people expect family meals to resemble.

There were a few characteristics that seemed salient to their identities as autistic families. For example, families struggled to understand "what is autism." In other words, they struggled to understand their child's capacities and limitations related to the tasks of the meal and thus set appropriate expectations. This was evident in what a struggle managing eating could be for families. There are two primary strategies for supporting children with autism with expanding their diet: sensory and behavioral approaches. Sensory approaches, such as the sequential oral sensory approach are when a therapist introduces food along a hierarchy designed to scaffold tolerance for the anxiety that the food produces (Benson, Parke, Gannon, & Muñoz, 2013). These practices are commonly recommended for children with autism (two families in the study had tried this approach); however, it has little empirical support (Peterson, Piazza, & Volkert, 2016). The other common approach is behavioral which includes the use of differential reinforcement, escape extinction, textural manipulation, physical guidance, and non-removal of the spoon (Laud, Girolami, Boscoe, & Gulotta, 2009). One of the families in this study had used this approach. Although there is more evidence for behavioral interventions, these strategies do not yet meet the criteria for an evidence-based practice (Silbaugh et al., 2016). The best practice from the literature on typically developing children to manage eating is called responsive feeding. Responsive feeding is an application of responsive parenting that suggests parents

should 1) create a pleasant, healthy, and predicable routine; 2) encourage children to pay attention to their own cues; and 3) respond supportively and contingently (Black & Aboud, 2011). Some of the children in the study could not recognize their own cues for hunger and satiety either because of medication, general difficulties with regulation, or because food could be revolting to them. Having said that, parents' efforts to control intake were rarely effective. Creating a pleasant, social, and predictable routine with access to foods the child was willing to consume was the most conducive to having a successful eating experience.

Another feature of the meal that seemed to be salient to their identities as autistic families was the ways in which sharing a problem solving occurred. Put simply, the conversations often sounded different than one might expect from other families. Families solved problems in greater detail, giving more step by step instructions. There were more disconnects between conversational partners and discontinuity in the flow of the conversation. Conversations relied more heavily on scripts and special insider language. Previous research has rarely recognized the work of problem solving and sharing that is conducted at family meals. It may be that, in previous research, the differences in how families with children with autism communicated were confused with a lack communication during the meal.

How Routines and Rituals are Created (and Barriers to Doing So)

Mealtime routines and rituals cyclically co-created one another. Mealtime routines were rooted in the past and sought to be as close to the ideal as possible. There were three elements that were critical to establishing the mealtime routine: the ideal family meal, family-of-origin-family-meals, and logistical considerations. Of these, the role of family-of-origin-family-meals is in line with Belsky's (1984) process model of the determinants of parenting. Although Belsky theorized about parenting generally - where I have examined parenting specific to the mealtime domain - we have both recognized the importance of developmental history in determining parenting practices. Several mothers in the study experienced child abuse or neglect. As Belsky and Jaffee (2015) suggested, those who had come to grips with their childhoods, had access to supportive relationship experiences, and reflected on breaking-the-cycle were able to stop the international transmission of maltreatment. I would expand this to say that they were able to stop the transmission of maltreatment because this self-awareness allowed these mothers to be intentional about using behavior to communicate acceptance and control.

Belsky and Jaffee (2015) also theorized about how developmental history determined parenting practices within the normal range by focusing on an adult attachment model. Adult parents could be *secure-autonomous* (self-reliant, objective, and non-defensive), *insecure-dismissing* (deny negative experiences and emotions), or *insecure-preoccupied* (continuing involvement of preoccupation with their parents). Although my interview protocol would not allow a full classification of parents, elements of these themes were present in the interviews. Moreover, as Belsky's (1984) process model would suggest, these attachment styles did not unilaterally affect parenting, but also interacted with child characteristics. Belsky focused on temperament in terms of child characteristics, but for the families in this study, the child's autism may be more salient. For example, it would be reasonable to assume that a parent with a secure-autonomous adult attachment style maybe better able to adjust to differences in their child's capacities, understand those differences to be based on the child's challenges with self-regulation, and refrain from self-blame. Although a goodness-of-fit (Lerner, & Lerner, 1983) affected the parenting relationship, for some families the presence of an identified and defined disability transcended the parents' inclinations toward parenting and pushed parents to adopt parenting practices that best met the needs of their child.

In addition to examining how useful routines are established, I also examined the creation of meaningful rituals. The routine enactment of mealtimes took on deeper meaning through repetition. Previous research has examined rituals as distinct from routines in terms of the degree of symbolic meaning (Fiese et. al., 2002; Fiese, Foley, & Spagnola, 2006). My grounded exploration led to a different analysis of the relation between ritual and routine. Routines are not void of symbolic meaning; they are inherently symbolic due to the role that past and ideal play in their creation. Rather, routines are a gateway to new meaning through their repeated enactment. This subtle shift may be especially important for families of children with autism. Children with autism, even children with some language, may not use language as the primary symbolic mediator of the mind. Patterned behavior may be more useful for creating cohesion, understanding, and a sense of "who we are" than the language of the meal.

Another area where this study expands previous understandings of family rituals is in terms of *hollowness*. Previously, hollowness has been defined as the mealtime lacking meaning (Wolin & Bennet, 1984). I would argue that behavior is communication, and that meaning is

always being made. Based on the lived experience of the families in my study, and because my perspective integrates family ritual and socio-cultural theory, I suggest that a more precise definition of hollowness would be when the meaning the mealtime makes is inconsistent with the desired meaning of the meal. For example, parents may have the goal that mealtimes are a space where everyone comes together and are affirmed. However, if the negotiation of control and acceptance is in too great of a tension, parents expectations could be misguided which could affect the bonding within the family. Instead of children feeling affirmed, they feel they are disappointing. The meaning that is being made is incongruent with the intended meaning and thus, instead of the mealtime reinforcing cohesion, despite going through the motions, it is hollow and perpetuates the difficult tensions between control and acceptance.

The Role of Mealtimes in Family Life

The role of the meal in family life was to manage the dialectic between expressions of love through control and acceptance. Overall, I have stressed the importance of both affective and instrumental processes, as other parenting scholars have, and argued that affective and instrumental processes are both reinforced and created during mealtimes. Affective components, in terms of climate and bond, were critical for mealtimes to be a place where sharing and problem solving could happen. Parents also needed to use controlling behavior during the meal to support children with completing the routine tasks of the meal. My assertion that control and acceptance must be balanced is consistent with Baumrind's conceptualization of an authoritarian parenting style: "a constellation of parent attributes that includes emotional support, high standards, appropriate autonomy granting, and clear bidirectional communication" (Darling & Steinberg, 1993, p. 487). Having said that, parenting styles are conceptualized as relatively static whereas I have outlined a dynamic process in which the tension between control and acceptance are constantly being negotiated in the tasks of daily living. Thus, I explore how parents come to enact (or do not enact) a more authoritarian parenting style as well as unpacking the underlying meaning being communicated to the child through behavior.

I see the model I propose for the role of mealtimes in family life being conversation with Darling and Steinberg's (1993) contextual model of parenting style. They argue that both parenting style and parenting practices are influenced by parent goals which, in my model, are consistent with family routines being rooted in past experiences and the ideal family meal. Like

Darling and Steinberg (1993), I differentiate between a parent's general attitudes about their child (parenting style) and the content of parenting behavior (parenting practices) yet also how parenting style influences parenting practices. Because my study is both domain (mealtimes) and context (autism) specific I can more closely analyze this process. Unlike Darling and Steinberg, I focus on outcomes in terms of the family rather than the child. Ultimately, understanding how control and acceptance is negotiated is critical for understanding what works for family meals. Without ignoring families' real challenges and struggles, I believe the model I have articulated explains how mealtimes can foster resilience.

Limitations and Areas for Future Research

In the qualitative tradition, limitations are discussed in terms of the studies' trustworthiness (as opposed to reliability and validity). I choose three benchmarks of trustworthiness to determine my sampling procedures: *variation*, *fairness*, and *grounded in examples*. I will discuss limitations among these dimensions. The variation dimension of trustworthiness means I provided sufficient examples to determine the boundaries and dimensions of concepts. This is often termed as the data yielding no new examples. Although, I felt comfortable ending the study, I was unable to observe family meals where there was not some coordination in the arc of activities among family members. Future research may need to examine evening routines and not specify mealtimes to capture these experiences. Additionally, I may have had insufficient variation to identify nuances in family processes based on child's age, ethnicity, family structure, and family income. Thus, as I identified dimensions, there may be areas of specificity that I left unexamined, for example, in my study factors such as age and family structure largely were accounted for in the logistical considerations that constrain mealtime routines. Future research could examine more intentionally within group differences to identify micro-processes in how decisions about logistical considerations are made.

The fairness dimension of trustworthiness means providing a balanced view which both includes and understands different value systems. This study was limited in terms of the ability to capture the experiences of some of the most vulnerable individuals with autism; this study only included families with children who had some reciprocal verbal language skills. Future research needs to examine mealtimes with children who use augmentative communication and who have more significant impairments to reciprocal communication. Additionally, future

research should examine the role of medication in children with autism's eating behaviors and parent's abilities to manage eating. Although this is not a limitation of fairness in my study, this is a failure of understanding of an important aspect of eating in the literature. Studies on autism and eating rarely, if ever, control or account for medication when examining eating patterns. Medication should be considered in future mealtime and eating research especially since parents rarely attributed selective eating and loss of appetite to medication and instead attributed it to children's willingness to eat which caused conflict in the family.

The final dimension of trustworthiness I identified was the work being grounded in examples: sufficient data to illustrate concepts and how they were defined. Although I believe my work is sufficiently grounded in examples, it maybe that readers less familiar with autism or family theory may find my use of examples insufficient for finding my work to be trustworthy. Beyond establishing trustworthiness from qualitative paradigm, future research could establish evidence for the model proposed in this study from alternative paradigms. There are elements of the model that would be difficult to capture given the internal processes that I suggest, having said that, there are aspects of the model that are observable and quantifiable. Future research can examine the relation between routine communication, the quality of interactions, and ritual communication from a different research tradition. Finally, future research should examine the dialectic of control and acceptance in other aspects of family life to determine the unique contributions of family mealtimes.

Implications for Practice: Moving from Managing Eating to Managing Mealtimes

Two children in the study had very selective diets and difficulty consuming enough food to sustain growth. These extreme cases warrant intense consideration of how to manage eating which may include professionally implemented feeding therapies and nutritional supplements. For all the other children in the study who were picky, the motivation to expose them to new foods was based on general feelings that parents have the right to decide what food children should eat. The children more or less acquiesced; however, the pressure to eat non-preferred food could cause conflict (e.g. yelling or arguing) and acting out behavior (e.g. refusing to eat or refusing to come to the table). Some parents sought support through occupational therapy but with limited success. Several of the parents who had experienced picky eating but saw it alleviate over time, found that medication changes or an approach that resembled responsive

feeding was able to slowly expand diet. In those cases, neither medication changes nor responsive feeding was recommended by professionals, but rather stumbled upon through accident or necessity.

What is missing from the literature on managing eating with children with autism is a recognition that addressing eating is more than increasing calories. How eating is managed affects relationships. Practitioners and therapists need to think about how to support families of children with autism to have mealtimes that foster a positive affective climate and deep affective bonds first and then consider the role of what the child eats as part of that larger goal. This may look like relinquishing control of what children eat and instead focusing on how to increase child participation in the supplementary aspects of the routine such as cooking, setting the table, sitting at the table, and cleaning using positive behavioral strategies. When children cooked and cleaned with non-punitive support they felt pride and responsibility. Parents who were successful at supporting children with these tasks also felt more efficacious. Programs for parents should focus on these skills while simultaneously trying to reframe picky eating as a normative developmental process whereby children experiment with power and control.

Supporting children with the tasks related to meal is just one way that parents can create functional routines that overtime can open the door to sharing, problem solving, and cohesion. Parents can also directly scaffold connection during the meal. Parents can teach children to complement, share, show concern, praise, and be affectionate. They can give children scripts, as Heather did, for sharing about their day. They can prompt meaningful exchanges as Jim did when he had Margaret ask Sally questions. When Fritz spontaneously says, "Wow! What a nice dinner" he can be praised and it can be explained how good that can make other people feel. Parents were already doing this naturally, but it could be intentionally supported and fostered especially for families who are experiencing difficulty with their mealtime routines. Practitioners and therapists can help parents process how to do this, model it in the home, and give parents strategies of how to do so effectively. For example, challenging parents to make at least five praise statements during the meal or that they look at their child and smile during the meal. In families that used these kinds of strategies, that made efforts to intentionally teach their children how to connect as part of the routine, there was a very different feeling from those who did not. These family meals felt warm, loving, and accepting.

Because family functioning was constantly being reflected and reinforced it could be difficult to initiate change without some sort of precipitating crisis. Many of the families that were using the strategies I have suggested only started doing so after things had gotten out of control. There were some families who may have been on the precipice of crisis (or perhaps just less adaptive functioning), but at this point they were just talking about their frustration with how mealtimes were going or an aspect of their routine. Practitioners and therapists should be aware that when parents report difficulty with managing mealtimes, this may be indicative of challenges with forming appropriate expectations or even beginning to feel like there is an emotional discontent. Therapists can intervene early to focus on mealtimes as place to facilitate relationship to keep larger problems at bay.

 One reason families had difficulty with expressions of love through acceptance was because they had an immense amount of pressure to support their children with developing skills and they are doing so under scrutiny. All the mothers had stories of being excluded or stigmatized because of having a child with autism. They could easily articulate harmful stereotypes that they felt people had about their families. This had real effects on parents' willingness to participate in social life and feel confident about their personal life. Families would benefit from public acknowledgement that the way they do mealtimes is appropriate for *their* family and expands ideas about family meals in productive ways. Throughout the interviews, mothers responded to validation of their parenting practices. The more the way mealtimes look for families of children with autism can be visible the more they can feel confident they are doing family the "right" way.

Finally, parents need support. Mealtimes were not a place that parents could share about their days, and although children frequently expressed love and concern for their parents, they were ill-equipped to be reciprocating social partners. When expressions of control were not expressions of love, it was often because the parent was not getting the social support that they needed to manage the challenges of family life. Additionally, the unique processes of identity development when parenting a child with impairments is difficult to manage without support. Mothers sought out formal support from therapists and informal support from other mothers of children with disabilities, but without that support, they struggled. As orchestrators of the family rituals, and chief scaffolders parents need to feel a sense of security so family meals can be

rooted in love, warmth, and acceptance. As early as initial diagnosis, when parents are receiving education on the types of therapies their children may need, they should also be given information on the support they may need both to cope with challenging emotions and learn the skills necessary to parent an exceptional child.

Conclusion

I have attempted to understand autistic ritual within a larger cultural conceptualization of the form and function of rituals, provide insights into family life, identify strategies parents naturally employ, and theorize based on social and cultural understandings of autism rather than taking a deficit oriented approach. Doing so allowed me to contribute to the emergent literature of family meals and autism and identify a model of family processes, whereas the current discourse is dominated by a discussion of identifying, and to some extent addressing, problematic eating behavior.

The role of mealtimes in family life was to negotiate a dialectic of acceptance and control that was critical to family functioning. Routine communication (which reflected logistical constraints, the ideal family meal, the family-of-origin-family-meal and predicated upon having strategies available) could either be harsh or warm. The quality of the interaction was a reflection of family functioning. Families with warm interactions had positive affective climates that promoted ritualistic communication such as sharing and problem solving which, in turn, reinforced an adaptive balance of control and acceptance. In a parallel process, routine continuity (which was also a reflection of logistical constraints, the ideal family meal, the family-of-origin-family-meal) could enhance the effective bond if the parents had appropriate expectations of child behavior, which reflected the dialectic of acceptance and control. Appropriate expectations also lead to warm interactions. When the affective bond was strengthened it led to ritual continuity in the form of cohesion which also contributed to an adaptive balance of acceptance and control.

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Appendix A

Reflexive Statement

I started working at the Developmental Services Center (DSC) in Champaign immediately after finishing my undergraduate degree in 2004. It had never occurred to me to work with individuals with developmental disabilities and when I had applied to DSC, I thought the organization helped children. My initial professional impulse was to work with at-risk adolescents as a clinical psychologist and was only planning on taking a year off from school. DSC changed that plan. I will never forget my job interview there. As my career at DSC progressed, I would go on to conduct dozens and dozens of these interviews as the manager of one of our sheltered workshops. Often, when doing this, I would once again see DSC as I saw it the very first time: a bustling and institutional space filled with people I could not immediately relate to. In the activity and work spaces, there are lots of people. None of these people look or sound or move the way you expect. I had interned at Cook County Detention Center and volunteered in shelters with homeless teens during my undergrad program so I had seen intens, institutional environments, but individuals with developmental disabilities are the most isolated and most marginalized in our society and my naïve and privileged perspective initially kept me from seeing adults with developmental disabilities as being a group I could relate to, much less their community as being one that I could belong to. I was grateful for my experience waitressing as I had gained some ability to hide my emotions, but at DSC I think what I mostly felt was a sense of shock. I took the job even though I had been offered a position at Cunningham Children's Home, an adolescent residential facility that would have been a better fit with my original career trajectory. When I reflect back on this on this turning point in my life, I attribute my choice to the influence of the women who interviewed me: Laura Bennett and Mia Lewallen[22]. Both had been doing this work for a long time and they were, and continue to be, passionate, compassionate, dedicated, and engaging. They are the kind of people I wanted to work for and work like.

My initial job at DSC was to write and coordinate instructional programs for the 12 individuals on my caseload and supervise day program activity areas (art, computer, exercise,

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[22] As where I worked and who I worked for is public information, I used full real names to refer to these individuals. As the people with developmental disabilities that I worked with were receiving confidential services and naming them would indicate their disability status, I used pseudonyms.

work, theater, and leisure) as needed. Running an activity area meant facilitating activities, running instructional programs, providing personal care assistance, and supporting with transitions to the next activity. I had no idea how to do my job. I felt like I worked in different country (a different planet) where all the rules, customs, and values were all different. I had culture shock. I am a naturally social awkward and socially obtuse individual but, I am not particularly shy. I learned to manage and overcome the anxiety and difficulties this causes by being quiet and reserved in new situations. In most arenas, this disposition is seen as a weakness, but when I first started out at DSC, it was ultimately a strength as it led me to sit back and observe. I began to understand what people were saying. I started to learn how to tell jokes. I started to learn what kind of complements people liked to get. What they liked to talk about. I found I could really be myself and I felt a profound sense of acceptance. I became an insider.

The insider-outsider relationship at DSC is complex. You have a developmental disability or you do not. You are a direct service provider or a service coordinator. You make decisions or you follow plans. Each one of these distinctions indicates a different relationship, insider status, and roll: consumer[23], staff, boss. These rolls dictate what you can and cannot do, your responsibilities, and your power. The roles were perfectly clear to almost everybody; perfectly clear to individuals with very limited cognitive and communicative abilities. It was communicated in a million different ways through the structure and symbols of the institution: who has keys, who works in the carpeted area (half of DSC's building is carpeted- the half with offices), who sits in a special chair, who can initiate touch.

There were also ritualized behaviors that delineated in-group boundaries, clarified roles, and communicated a deeper meaning. Unlike many of the structures of the institution, the rituals were often insisted upon by an individual with a disability to regain a sense of control and autonomy. Jane's ritual is a good example. When I worked with her, Jane was in her 40s. She was blind, had autism, and intense echolalia so she could only speak things she had heard recently like pieces of conversations or songs from the radio. Jane could easily have been shuffled around from place to place without knowing where she was going, who was taking her there, and with no ability to communicate to others if someone had done something to harm her,

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[23] The state of Illinois gives the option of three terms for referring to the people with disabilities by an agency: consumer, client, and individual served. DSC selected consumer based on the belief that it connotes a sense of empowerment, that the individuals actively choosing to select the services offered to them.

but not Jane. Jane was powerful. If you wanted Jane to walk you had to perform her ritual. If I wanted Jane to go to art after lunch which was her scheduled activity, I would say quietly in her ear, "Jane, this is Sarah. Lunch is over. It's time to go to art. Please stand up." Jane would stand and I would say, "It's time to brush you." Jane would take a small plastic brush that looks kind of like a white sponge with soft bristles all over it from a belly bag she always wore. I would say, "Thank you Jane. I'm going to brush you now." Jane would give me her hand and I would slowly and firmly rub the brush in a "W" pattern around her arm from her wrist to her forearm before moving up to her back, then down the other arm, then repeat the brushing on each of her legs from the ankle to the calf. Then I would say as I handed her back the brush, "Here you go, Jane. Now I'm going to do your joint compressions."   Jane would put the brush back in her belly bag and then I would, starting with her right hand, push each of her fingers into her hand, her hand into her wrist, her wrist into her arm, her arm into her elbow, and then her upper arm into her shoulder before repeating the process on the other side. Then I would say, "Okay Jane, it's time to walk to art." And she would take my arm and we would walk.

The process that Jane and I engaged in was initiated long before I came to DSC by an occupational therapist, but the techniques have no empirical validity for aiding with transitions in the way we were implementing them. As such, I am sure the people working with Jane would have given up on this process given how time consuming it was, but they had not. Jane insisted on it, though she was not rigid. She would accept slight variations in wording, sequence, and technique. Jane was not compulsive. Her staff at home did not perform the ritual and neither did her mother, but she choose to accept their support. If the fire alarm was going off, I would say, "Jane, we need to go outside" and she would stand and walk with me immediately. But under normal circumstances, at DSC, if you did not perform the ritual correctly, Jane would not move. She either would not stand up or would not walk. If you assumed that she was going to walk and took her arm and began moving she would yell, "No. No. No. No. No. No. No." Only people who did not really know Jane would try to do that. People who knew Jane respected her and communicated that to her by performing the ritual. The ritual ensured that whoever was supporting Jane was one of her people. It also made her feel powerful, in control, and cared about. It is an intimate ritual performed quietly, in close proximity, and with physical contact. It

was important for my staff to perform the ritual as through the ritual they enacted respecting autonomy and negotiating control.

My understanding is that a reflective statement has two purposes. (1) It is a mechanism for explaining your training in qualitative inquiry and (2) It is a mechanism for coming to understand your own biases. My training in grounded theory happened during my graduate studies at the University of Illinois, but DSC is where I learned how to see. Jane is one of the people who helped me see, to value the DD[24] community on its own terms. DSC is where I came to understand systems, look for patterns, and interpret meaning from behavior. The act of writing forces you to think and process. Writing is also a way to express these biases to your reader so they can better understand the context through which your work should be interpreted. I introduced the story about Jane with a brief account of my own experience to help define my perspective, to expose my gaze. My time as an insider, where I felt trust and acceptance, is the reason why I am passionate about doing research to better understand the lives of people with disabilities. Participating and perpetuating a system that maintains their isolation and marginalization is why I feel compelled to do research that helps individuals with disabilities to live more freely in their communities of choice. Early on in my professional life, I was responsible for people's lives and livelihoods. Whereas the work I do now can be intensely intellectual, the work I did before was intensely emotional. That affects my memories of that time and place and the conclusions that I draw which can create biases. The experience of working at DSC continues to inform my practice and push my thinking, even now, as an academic removed from a direct service environment.

My graduate training in grounded theory was largely based on the work of Cathy Charmez although I was exposed to the variations in thinking about grounded theory through formal coursework. In addition to grounded theory methods with Jennifer Hargasty, I took mixed methods with Jennifer Greene. Through the study of mixed methods, I grew in my understanding of paradigm and the implications of paradigm for methodology. In the Spring of 2016 I went on a qualitative data analysis retreat facilitated by Research Talk. There I was

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[24] The community of individuals with developmental disabilities and the non-disabled professionals who support them (broadly defined) is often referred to as the DD community. Parents are also part this community. DD is upon first glance an acronym for developmental disability but when applied to the community has a broader meaning.

exposed to new tools for analyzing qualitative data in the grounded theory tradition. Each of these training experiences can be seen in my work.

I have another series of biases related to my own experience with mealtimes. Personally, I value family mealtimes. I grew up having them. For the most part we had a pretty traditional shared family meal, however, there were times when our family meals where chaotic and this corresponded to times when our lives were chaotic. When I was first married, eating dinner together was important to my understanding of how to do family. Although we are much more flexible in how mealtimes happen now, my husband and I almost always eat together. Now that we have a son, it is sometimes easier to eat after he has gone to bed, but more and more we eat all together. I draw upon my understanding of cultural, social, and historical conventions in my expectations of how mealtimes should be carried out. Having expressed this, I do not believe that my personal values are why I am interested in studying mealtimes. I think there are many ways to do family well and I do not maintain nostalgia for family meals. I do not believe mealtimes are really under threat as is occasionally suggested in our culture at large, but rather that changes in family meals reflect changes in the resources and challenges that families face. I am interested in family meals when a child has autism because there appears to be a *need* to understand mealtimes better as families report it as a stressful event. Also, there appears to be an *opportunity* for resilience and enrichment in family life in sharing a meal for some families.

Finally, I would like to situate myself in cultural space. I am a white, cis female, heterosexual, Midwestern, Lutheran, relatively affluent American. I have never been divorced and my white, cis gender, heterosexual, affluent parents have never been divorced. I was raised in Champaign-Urbana; I am a fourth generation graduate of the University of Illinois and the first to get a Doctorate of Philosophy. No one in my immediate or extended family has autism. My mother had a brother with intellectual disability and a brother with cystic fibrosis. My husband and I both have learning disabilities, received special education, and had individualized education plans, however, these disabilities rarely interfere with our daily living.

Appendix B

Recruitment and Registration Materials

View of www.mealtimes.illinois.edu

We'd like to learn more about your family's mealtimes and to do this we'd like to actually see what happens and then talk to you about it. Fill out this form to register for the study. After you register, we'll be in touch to confirm with you.

This study is only being conducted in Central Illinois at this time. If you are interested but outside this area, feel free to register and we'll let you know if our focus area opens up.

Your name?

Are you an adult (over the age of 18)?

○ Yes
○ No

Are you the parent or guardian of a elementary or middle school aged child with autism spectrum disorder (ASD)?

○ Yes
○ No

This study has two parts. First, we will record dinnertime in your home. Then we will interview you and your child (separately) about mealtimes. The interviews will also be recorded. You'll receive $25 after the dinnertime observation and $50 after the interviews.

Filling out the information below means you will be registered for the study and contacted to schedule the observation and interviews but there is no commitment on your part.

Phone

Email

Address

Which contact method
do you prefer?

We have a few questions to better understand who is signing up for this study.

What do you call the evening meal in your family?

- ⚪ Dinner
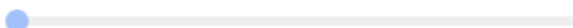- ⚪ Supper
- ⚪ Other

During a typical evening meal, what room(s) do your family members typically eat dinner in? Check all that apply.

- ☐ Kitchen
- ☐ Living room
- ☐ Dinning room
- ☐ Outdoors
- ☐ Family room
- ☐ Other

In a typical week, how often does everyone in your family sit down for an evening meal together?

	0	1	2	3	4	5	6	7

Number of evenings
on average

Who do you consider to be "everyone"?

Number of adults

Number of children

Which is most true for your family?

In some families, a typical evening meal is about getting food.			In other families, a typical evening meal has special meaning.	
Very True	Somewhat True		Somewhat True	Very True
☐	☐	BUT	☐	☐

Thank for your registering for Exploring Mealtimes on the Spectrum. We'll be in touch soon to confirm with you. If you have any questions contact Sarah Curtiss at curtiss5@illinois.edu or 217-840-8288.

Know anyone else you think maybe interested? Please share.

Understanding Mealtimes
on the Spectrum

We'd like to learn more about your family's mealtimes and to do this we'd like to actually see what happens and then talk to you about it.
-A study from the University of Illinois-

A study for families of a child with *autism*

This study has two parts. First, we would record dinnertime in your home. Then we would interview you and your child (separately) about mealtimes. The interviews would also be recorded. You'll receive a $25 gift card after the dinnertime observation and a $50 gift card after the interviews.

To register go to mealtimes.illinois.edu
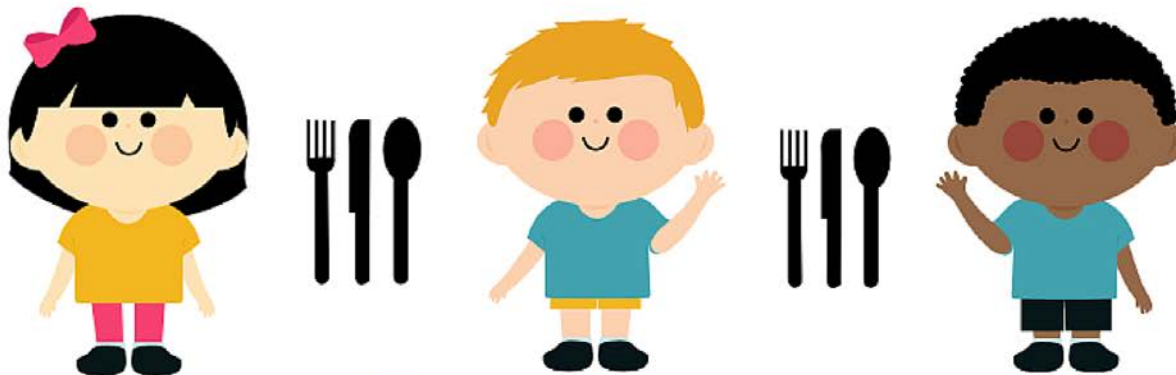
I ILLINOIS

Email: Direct Solicitation

Understanding Mealtimes on the Spectrum

Parents of elementary and middle school aged children with autism are invited to participate in a research study on family mealtimes. This study has two parts. First, we would record a dinnertime in your home. Second, we would interview you and your child (separately) about family mealtimes. The interview would also be recorded. You'd receive a $25 gift card after the dinnertime observation and a $50 gift card after the interviews. To register or for more information go to mealtimes.illinois.edu or contact Sarah Curtiss at curtiss5@illinois.edu or 217-300-5994.

Email: To Service Providers

Please Share this Research Opportunity

Please consider posting the attached flyer or sharing the email below with families who may be interested.

Parents of elementary and middle school aged children with autism are invited to participate in a research study on family mealtimes. This study has two parts. First, we would record a dinnertime in your home. Second, we would interview you and your child (separately) about family mealtimes. The interview would also be recorded. You'd receive a $25 gift card after the dinnertime observation and a $50 gift card after the interviews. To register or for more information go to mealtimes.illinois.edu or contact Sarah Curtiss at curtiss5@illinois.edu or 217-300-5994.

Appendix C

Participant List

Paula and Brian

Paula is a 51-year-old European American woman with a bachelor's degree. Her husband, Travis, is a 50-year-old European American with a bachelor's degree. They both work full time outside the home. He has three children from a previous marriage who are European American. He shares joint custody for the two younger sons Mark, 12, and Chris, 13. Paula also has joint custody of her son, Brian who is a 10-year-old European American who has been diagnosed with ASD. Paula identifies her ex-husband as having ASD. Paula's house has an open floor plan and is in a small community. They rarely all eat together.

Samantha and Lionel

Samantha is a 38-year-old European American woman with a bachelor's degree. A former educator, she now stays at home. Her husband is a 38-year-old European American man with an advanced degree who works in a STEM profession. They live in a single-family home with a semi-open floor plan in a small urban community with their two sons Lionel who is 9 years old and Eddy who is 8 years old. They have both been diagnosed on the autism spectrum. They almost always eat together although it is common for Lionel to leave the table.

Janet and Ben

Janet is a 53-year-old European American woman who is working on her bachelor's degree. Her son, Ben, is a European American 14-year-old boy who has been diagnosed with ASD. Her husband, Rob, is a 47-year-old European American man, and has some college. Both parents are employed full time outside the home. They live in a single family closed floor plan home in a small urban community. Both Janet and Rob have other children who do not live with them. They almost always eat together.

Heather and Camden

Camden is a 7-year-old European American boy who lives with his mother, Heather, a 40-year-old European American woman with a High School education in an open floor plan apartment in a rural community. Heather has recently remarried, but her husband works in a different state and only lives with them sporadically. Heather has an older son who does not live with them. Camden has been diagnoses with ASD. They almost always eat together.

Sally and Margaret

Sally is a 42-year-old European American woman with an advanced degree who works as an educator. Her husband, Jim, is a 44-year-old European American with an advanced degree. A former professional, he now stays at home. They live with their two children, Margaret, 8, and Fred, 11 in a semi-open floor plan house in a small urban community. Margaret has been diagnosed with ASD. They almost always eat together.

Francine and Tristen

Francine is a 50-year-old European American woman with an advanced degree. A former medical professional, she now stays at home. Her husband, Scott is a 51-year-old European American with a Bachler's degree who works for a corporation. They live in a single-family home with a semi-open floor plan in a small urban community with two of their four children: Tristen, 9, and Clarissa who is in high school. Tristen has been diagnosed with ASD. They almost always eat together.

Laura and Kevin

Laura is a 37-year-old European American woman with an associate's degree. Her husband, Tom, is a 40-year-old European American with a bachelor's degree. Both parents are employed full time outside the home. They have two sons: Kevin who is 11 and is diagnosed with ASD and Hayden who is 8. They live in a single family open floor plan home in a small community. they almost always eat together.

Christine and Olivia

Christine is a 48-year-old Asian American woman with a Master's degree who works full time and identifies as having ASD. She has three children who are multi-racial. The oldest, Stewart, is a 17-year-old boy has been diagnosed with ASD. She identifies the youngest, Olivia, is a 10-year-old girl as also being on the spectrum. She has a 15-year-old son, Austin, which she does not identify as having any disability. They live together in a closed floor plan apartment in a small urban community. She shares custody with her ex-husband a 60-year-old European American with a bachelor's degree who works in the service industry. He was at their house for dinner during the observation. They sometimes eat together.

Vanessa and Lincoln

Vanessa is a 30-year-old European American woman with a bachelor's degree who works in a health profession. Her husband, Pete, is a 39-year-old European American who is pursuing his associate's degree and working part time. She has two children from a previous marriage who are both European American and diagnosed with ASD: Lincoln, 6, and Aaron, 10. She identifies her ex-husband as having ASD. Lincoln primarily lives with his mother and Aaron primarily

lives with his father, although the boys are always together on the weekends and alternate between homes. Pete has a teenage daughter from a previous marriage who lives with them sporadically. Vanessa's house has a semi-open floor plan and is in a small community. They sometimes eat together.

Sylvia and Freddy

Sylvia is a 32 year old Hispanic American woman with some college who works part time in the service industry. Freddy is a multi-racial (Hispanic and African American) 10 year old boy who has been diagnosed with ASD. They live in a semi-open floor plan apartment in a small urban community. They sometimes eat together.

Tina and Conner

Tina is a European American woman who works on her associate's degree online. Her husband, Mark is European American works in construction. She has three European American children from a previous marriage but the oldest one is no longer at home. Marissa, 12, and Conner, 11, are both diagnosed with ASD. They live in a closed floor plan town home in a small community. They almost always eat together.

Clarissa and Luke

Clarissa and her husband are Asian immigrants who work full time. They have three children living at home who were all born abroad: Leanna, 23, Linda, 17, and Luke 8 who was diagnosed with ASD. Everyone in the family speaks English and their native language. They attempted to speak English during their mealtime observation but occasionally spoke their native language. The observation and interview were coded by a research assistant who spoke the same language. Clarissa's family lives in a semi-open floor plan apartment in a small urban community. They sometime eat together excluding the father who does not join them for dinner.

Francesca and Fritz

Francesca is a 37-year-old European American woman with an advanced degree who stays at home with her children. Her husband, Jakub, is a 42-year-old European-American with an advanced degree who works in higher education. They have a son and daughter who are five (twins): Fritz and Frieda. Fritz has been diagnosed with ASD. Francesca suspects that Frieda may also have ASD. They live in a single-family home with a closed floor plan in a small urban community. They almost always eat dinner together.

Sarah and Oscar

Sarah is a 40-year-old Hispanic American woman with an associate's degree who left her work in the medical field to stay at home with her children her two children. She identifies as having

autism. Her son, Oscar is a 13-year-old Hispanic American who has been diagnosed with ASD. She also has a younger daughter. Oscar has had father figures in his life through his mother's romantic partnerships, but she is not currently dating. Although they rarely eat dinner as a family when they do they often share their meals with a roommate who is an adult male.

Cindy and Frank

Cindy is a 34-year-old African American woman with a bachelor's degree who works in the service industry. Frank is an 11-year-old African American boy who has been diagnosed with ASD. Frank has contact with his biological father and half siblings but Cindy has full residential custody. They live in a semi-open floor plan apartment in a small urban community. They almost always eat dinner together.

Whitney and Logan

Whitney is a 39-year-old European American woman with a bachelor's degree who is self-employed. Her son, Logan, is a 10-year-old multi-racial (African American and European American) boy who has been diagnosed with ASD. Logan does not have contact with his biological father, but his is co-parented by his mother's partner Mary. Mary is a 45-year-old Hispanic American woman with a high school education who works in the service industry. They sometime eat dinner together.

Appendix D

Consent and Assent Forms

Please note that the consent and assent forms include a child interview that will not be included in the dissertation project.

Informed Consent Form for Parent and Child Participation of the Mealtime Observation & Interviews

Dear Parent,

We are Dr. Aaron Ebata and Sarah Curtiss from the Department of Human and Community Development at the University of Illinois at Urbana-Champaign. We would like to invite you and your child to participate in a research project that focuses on understanding family mealtimes of children with autism spectrum disorders (ASD). We can compensate parents who work with us on this project with a $75 for completion of the entire project ($25 will be given at the end of the first part of the project and additional $50 will be given at the end of the second part of the project). We hope the information gained from this project will assist in developing an effective supports for having successful family mealtimes. If you are willing to participate in this project, we will ask you to do the following:

First, we will ask you to **come to your home and set up recording equipment so that we can observe a normal dinner time.** We will set up the equipment, leave, and then return to remove the equipment once you notify us your meal is over. We anticipate it will take 20 minutes to set up and 10 minutes to take things down.

We will show you how the recording equipment works. If you or a member of your family becomes uncomfortable being recorded you can turn off the recording device. You can ask us to return and remove the equipment at any time.

Then, we will **meet with you and your child for an interview about family mealtimes**. We will ask to **video or audio tape these interviews**. As part of the interviews we will ask you and your child to watch part of the video we took of your family's dinner time. We will interview you and your child at the same time, but separately. We anticipate that these interviews will take up to 2 hours. If your child finishes before you we will play with your child until you are finished.

If your child refuses to be interviewed or in any way indicates fatigue, discomfort, or the desire to end the session, we will stop the interview immediately and play. If your child seems at all upset or requests to return to you, we will interrupt your interview.

When you have granted permission for your child to participate in this study with you, we will ask your child(ren) for his/her/their assent to participate. We will do this before the mealtime observation and before the interview. We will do this in your presence, using the attached

script, and we will rely on your understanding of your child's communication behaviors, signs of comfort or discomfort, energy level, etc. Please be assured that your child(ren) and your participation in this study is absolutely voluntary. If your child(ren) or you prefer not to participate or wish to withdraw at any time from the study and turn off the recording devices. You can also request to withdraw any of the collected data (including videotapes). There will be no penalties beyond the loss of the final $50 payment at the end of the project if you choose not to participate in the interview.

We do not foresee any risks to you or your child(ren) as you participate in this study, beyond those that exist in your daily lives. In the event that you or your child(ren) show signs of discomfort, stress, fatigue, frustration during observations or interviews, we will immediately address these signs and take steps to ease the condition (e.g., take a break, turn off the video recorder, stop the session, or postpone the session for another time or day).

We will analyze the data from the observation and interviews and will publish the results in conference proceedings and journals. We will also show the results in presentations but will not include any identifying information (videos, audio recordings, or photographs) without your written permission.

We hope that the benefits of learning more about mealtimes with families of children with ASD will outweigh any potential risks such as inconvenience in having someone in your home. We will take all necessary precautions to ensure protection of your family's complete confidentiality. We will use no real names on any written or verbal reports of our project. We'll assign your family code names and we will be the only ones who will have access to the master list containing your real names and corresponding code names. Dr. Ebata will store all the interview and assessment information under lock and key. Written documents will be shredded and audio/video tapes will be manually destroyed 5 years after we publish or present the findings.

There is one exception to confidentiality we need to make you aware of. In certain research studies, it is our ethical responsibility to report situations of child abuse, child neglect, or any life-threatening situation to appropriate authorities. However, we are not seeking this type of information in our study nor will you be asked questions about these issues.

If you have any questions about this study, please feel free to contact Aaron Ebata at ebata@illinois.edu. If you have any questions about your rights as a participant in this study or any concerns or complaints, please contact the University of Illinois Institutional Review Board at 217-333-2670 (collect calls will be accepted if you identify yourself as a research participant) or via email at irb@illinois.edu.
Please keep the attached copy of this letter for your records.

I, _____ (printed name) will participate in this study and also give permission for my child, _____, to participate in the study.

I select the following option for showing recordings from my sessions that can identify me and my child:

_____ Yes, you may show video recordings and still pictures of my child and me in presentations and publications for research and educational purposes.

_____ No, you may NOT show video recordings and still pictures of my child and me in presentations and publications for research and educational purposes.

Signature of Participant _____   Date_____

Child's Name:_____ Child's Age: _____

Date:_____

Signature of Parent/Guardian:_____

Signature of Researcher_____

Informed Consent Form for Parent and Child Participation of the Mealtime Observation Only

Dear Parent,

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We will ask you to **come to your home and set up recording equipment so that we can observe a normal dinner time.** We will set up the equipment, leave, and then return to remove the equipment once you notify us your meal is over. We anticipate it will take 20 minutes to set up and 10 minutes to take things down.

We will show you how the recording equipment works. If you or a member of your family becomes uncomfortable being recorded you can turn off the recording device. You can ask us to return and remove the equipment at any time.

When you have granted permission for your child to participate in this study with you, we will ask your child(ren) for his/her/their assent to participate. We will do this before the mealtime observation and before the interview. We will do this in your presence, using the attached script, and we will rely on your understanding of your child's communication behaviors, signs of comfort or discomfort, energy level, etc. Please be assured that your child(ren) and your participation in this study is absolutely voluntary. If your child(ren) or you prefer not to participate or wish to withdraw at any time from the study and turn off the recording devices. You can also request to withdraw any of the collected data (including videotapes). There will be no penalties.

We do not foresee any risks to you or your child(ren) as you participate in this study, beyond those that exist in your daily lives. In the event that you or your child(ren) show signs of discomfort, stress, fatigue, frustration during observations, you can ask us to return and remove the equipment at any time.

We will analyze the data from the observation and will publish the results in conference proceedings and journals. We will also show the results in presentations but will not include any identifying information (videos, audio recordings, or photographs) without your written permission.

We hope that the benefits of learning more about mealtimes with families of children with ASD will outweigh any potential risks such as inconvenience in having someone in your home. We

will take all necessary precautions to ensure protection of your family's complete confidentiality. We will use no real names on any written or verbal reports of our project. We'll assign your family code names and we will be the only ones who will have access to the master list containing your real names and corresponding code names. Dr. Ebata will store all the interview and assessment information under lock and key. Written documents will be shredded and audio/video tapes will be manually destroyed 5 years after we publish or present the findings.

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_____ No, you may NOT show video recordings and still pictures of my child and me in presentations and publications for research and educational purposes.

Signature of Participant _____   Date_____

Child's Name:_____ Child's Age: _____

Date:_____

Signature of Parent/Guardian:_____

Signature of Researcher_____

Child Assent Form for Mealtime Observations

Hi, _____! My name is _____. I would like to use my video camera and

make a movie of you eating dinner with your family. Is that OK with you?

If you want the camera turned off, you can let your parents know. (Pause. Watch for refusal behavior.)

Even though your mom or dad has already said that it is OK for you to do this, you don't have to.

If you want to stop at any time, you can, and that would be perfectly OK with me. Are we ready?

Name:_____

 [Assume child assent (verified by parent who is present) if child indicates no refusal behaviors.]

Child Assent Form for Interview

Hi, _____! My name is _____. I would like to show you a movie, play with you, and ask you some questions. Is that OK with you? (Pause. Watch for refusal behavior.)

I'm going to record our conversation. Is that OK with you? (Pause. Watch for refusal behavior.)

If you want to stop playing and talking, you can let me know. (Pause. Watch for refusal behavior.)

Even though your mom or dad has already said that it is OK for you to do this, you don't have to.

If you want to stop at any time, you can, and that would be perfectly OK with me. Are we ready?

Name: _____

 [Assume child assent (verified by parent who is present) if child indicates no refusal behaviors.]

Appendix E

Parent Interview Protocol

Family ### on #### . First, I'm going to ask you a little bit about your daily routines and then get into dinnertimes specifically.

1. *Daily routines*

   Could you tell me about a typical day in your life?

2. *The general nature of mealtimes and how they came to be that way*

   Follow up on the mealtime aspect of the "typical day" (e.g. So you mentioned [whatever they mentioned about mealtimes] could you tell me more about that?)

   a. **What does dinnertime look like in your home?**

   b. **Are there any times that it is different from this routine?**

   c. **Has it changed over the years?**

   d. **Do you usually eat at the ####?**

   e. **Does dinner usually happen around the same time?**

3. *Intentionality regarding the mealtime routine*

   In some families there is little planning around dinner time but in other families dinner time is planned in advance? How do you plan for meals?

4. *Frequency and importance of mealtimes*

   How often does your family eat dinner together?

   a. **Are you happy with how often you eat dinner together?**

   b. **It doesn't seem like eating together is a priority. What are the priorities in your family?** OR

   c. **It seems like you make eating dinner together a priority. Why is that?**

   d. **What are the barriers to eating together?**

      i. **Try to probe for individual, structural, and family level barriers.**

5. Continuity of the mealtime ritual

What was mealtime like for you growing up?

    a. Do you do things similarly or differently than your parents?

    b. As an adult, how do you hope #### feels about your family dinners when he looks back?

6. The meaning of the meal

What do family meals mean to you?

7. How meals feel

If you had to describe your family mealtimes with three words, what words would they be?

    a. **Why did you choose those words?**

       If a positive word…

    b. **Is it ever difficult to make that happen?**

8. Goals for the meal

What are your goals for the meal?

    a. **What are the barriers for achieving these goals?**

9. *Roles or lack thereof for each person in the household related to mealtimes and co-parenting*

It seemed like you were responsible for ####. Is that pretty usual? What would you consider to be your responsibilities?

If they have a partner…

    a. **Does your partner have specific responsibilities during the meal?**

       i. **Why do you do it that way?**

       ii. **How did you establish this way of doing things?**

       iii. **Has it changed over time?**

        iv. ***Are you happy with the current arrangement?***

    b. ***What expectations do you have for the children regarding mealtimes?***

        i. ***How do you work with your husband to get these expectations met?***

        ii. ***Sometimes dinnertime can be a struggle for kids. How do you handle it when your kids are having difficulties meeting these expectations?***

        iii. ***Do the children have any jobs/chores related to dinnertime?***

10. *Idealized version of mealtime rituals*

What would an ideal family meal look like for you?

    a. ***How close do you feel you family meal is to this?***

    b. ***What makes this difficult to achieve?***

11. *Special meals*

Are there ever any times where you might have a special meal that is really different from your normal routine?

12. *Eating out*

Does your family go out to eat? What is that like?

13. *Support from others*

When someone who is important to you, like your mother, is over for dinner, what is that like?

14. *Challenges related to mealtimes*

Does your family have any challenges related to dinnertime?

    a. ***Are any of the kids in the family picky eaters?***

        i. ***How has that affected dinnertime?***

        ii. ***How do you manage that?***

    b. ***Does anyone in your family follow a special diet?***

        i. ***How has that affected your dinnertime?***

    c. ***Do and of the children have difficulty completing homework?***

     i. How has that affected your dinnertime?

15. *Accommodations related to autism*

  Do you feel you make accommodations for #### because of his autism? How so?

The next few questions may or may not relate to dinnertime depending on how you do things in your family.

16. *Adaptive functions of family meals: sharing*

  In your family, when do you share about your day?

   a. When do you tell stories about things you've done together in the past?

   b. Some children with autism have a favorite story or a favorite topic that they want to discuss more than anything else. Does this sound like your child?

     i. What is that topic or story?

     ii. How does your family react to this topic/story?

       1. Do you have particular "rules" about special topics/stories?

17. *Adaptive functions of family meals: problem solving*

  Some families use dinnertime as a time to solve problems that they might be having either with each other or from outside the home. In your family, how do you help each other solve problems that you may be dealing with?

   a. *If they answer about interpersonal relationships, broaden to include problems outside the family system or vice versa. May want to ask for a specific example.*

18. *Adaptive functions of family meals: enacting and communicating values*

  What are some things that are important to your family?

   a. ***What are some things that your family values?***

   b. ***How do you feel that these are communicated during dinnertime?***

19. *The influence of autism on the family*

  When do you first start to realize that #### had autism?

   a. ***What does having a child with autism mean to you?***

b. *What was the diagnosis process like?*

c. *How was your initial reaction similar or different to how you feel now?*

If there are siblings…

d. *How has #### having autism affected the way you parent ####?*

Next, I'm going to show you a clip from your family dinner time and ask you a few questions.

20. *Would you say this captures a typical meal?*

21. *How did you feel watching the clip?*

22. *What were you thinking?*

23. *What do you think your partner and children were thinking?*

24. *What did you notice or stand to you?*

25. *Is there anything that surprised you or was unexpected?*

26. *Other communicative functions*

Are there any other things you talk about during meals that I haven't covered?

27. *Adaptive functions of family meals: family identity*

Is there anything else I need to know to really understand your family?

Thank you for sharing. This has been very helpful. The last thing I would like to do is fill out a quick survey with demographic information and information about your child's autism.

Appendix F

Excerpt from Episode Profile

Quotation Inventory

1. So then we have um we just are like well you can make yourself a quesadilla and then if TC doesn't if there is something offensive in the smell or how it looks like.

2. "How did you figure out how to do that or how did you come to do it that way?"…"I don't know."I guess I like the idea of it [family meal]

3. I would say at this point in our lives it's easier so there is somebody there to make our food for us and clean it up.

4. just the all the up and down up and down

5. I think when we're sitting together [at a restaurant] then Dad and I get to talk more.

6. that's fine you can eat over there" So we're separated which I don't like but I mean he's we're able to eat

7. if it's stressful for me I guess cuz its usually pretty stressful for Dad because if I'm stressed out uh then he kind of gets that and then if usually I'm worried about the kids behaving themselves and not you know upsetting anyone

8. that's when it sort of all fell apart

9. Well funny you should say that (clears throat). So typically I guess I don't I don't talk to the kids too much about my day.

10. It's fine…Yeah yeah yeah. It's kind of. I wish that I could (laughs) I had a better way um I wish I could find a way for him to share it like in a positive way

11. thinking for themselves, treating other people kindly, um being respectful to um each other and um family

12. gosh I seem stressed out

Powerful Quotations

Quote:

*M: Yeah we get our own, we serve ourselves yeah um and if the kids want something different then we have like LITTLE BROTHER does not like rice if but I try to have something at least one thing that they both like so if TC likes rice I might also have like chicken or something that is kind of like something that I know LITTLE BROTHER will like or leftovers is an option for him um and if nothing else he knows he can make himself a quesadilla in the microwave so then he is good with that and um there is a lot of usually if there is something LITTLE BROTHER does not like he will just scream his head off and complain and um he will run out of the room and so then we will just be like okay well and then as soon as he has called himself down he comes back and is **like "I don't like that"***

I: [laughs] okay..

M: So then we have um we just are like well you can make yourself a quesadilla and then if TC dosent if there is something offensive in the smell or how it looks like *we will sign like lasagna is a hard one for him or um yesterday we had like teriyaki beef with rice and I was not sure about that but he did not like the smell but he still stayed at the table which was big kind of a breakthrough for him. Usually he would just take himself and go to the other room with his food and like into this dining room. So um that was good he sat at the table last night with us um that is kind of how it goes and then with certain things like he eats a lot of rice and he (laughs) and he kind of makes a mess with it and so he knows and he is very responsible about cleaning up his mess so um yep he carries his dishes to the sink and he cleans up his mess when we remind him sometimes but yeah.*

I: Okay. Now how is I mean has dinnertime changed over the years? Over the last few years?

M: Oh yeah, definitely. Um because we I mean LITTLE BROTHER has always been pretty emotional he is just a whatever charged and um- TC late as um I'd say the last year even he has gotten more anxious with food so he has gotten um he didn't used to like get up and leave the room all the time like that was that has probably been the last couple years um but now everything is sort of heightened like it's been more it has been he's been a lot more sensitive to smell and um um just like how things look visually.

Memo:

I think the contrast of BOTH the boys behavior as reported by mom AND how she characterizes each boys behavior is interesting. Both boys are having difficulties with eating or really trouble being served food they don't like. LITTLE BROTHER has a pretty extreme reaction with running out of the room compared to TC who removes himself to another room but it's not

depicted as being an outburst more as anxiety. Also mom thinks about TC in terms of the food being offensive and with LITTLE BROTHER as having food he doesn't like. So the locus of the aversion is different. Also, mom seems to think that LITTLE BROTHER has a solution to his trouble, but with TC she doesn't understand what is going on. This may be why she sees his outburst as more problematic.

Quote:

just the all the up and down up and down *um- well first of all I mean like if he's got stuff on him then he runs around and gets touches everything and gets sticky or whatever but also it just seems like I just want us to be together [laughs] so it's nice when we are sitting down if he needs something then get up and get it but otherwise it's just nice to have it I guess like a start and a finish and like were not doing this all up and down all night long kind of thing*

Memo:

Sitting down all together seems like it's about togetherness, but it's also about reducing chaos. When the kids are up and down it's hard to process what's going on. It's harder to control their behavior.

Quote:

Well funny you should say that (clears throat). So typically I guess I don't I don't talk to the kids too much about my day.

Memo:

This has come up in other interviews. I wonder why mom has a hard time sharing. Does she not think what she does is important? That they aren't interested? Is it boundary setting? She doesn't elaborate.