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APPROACHING AUTISM: A QUALITATIVE REVIEW OF
MATERNAL AND FAMILIAL ADAPTATION
AMONG FAMILIES OF CHILDREN WITH AUTISM

by

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A thesis submitted to the faculty of

Brigham Young University

in partial fulfillment of the requirements for the degree of

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Department of Sociology

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BRIGHAM YOUNG UNIVERSITY

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ABSTRACT

APPROACHING AUTISM: A QUALITATIVE REVIEW OF MATERNAL AND FAMILIAL ADAPTATION AMONG FAMILIES OF CHILDREN WITH AUTISM

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Department of Sociology

Master of Science

The purpose of this study is to serve as an exploration of family experiences in relation to a child's autism diagnosis. Specifically, it focuses on family adaptation as explained by McCubbin, et al.'s Double ABCX Model (1983). Given that mothers play a crucial role in the family system and are often the primary caregivers for children with disabilities, maternal adaptation is also investigated.

This study employs qualitative methods, including in-depth personal and group interviews. Mothers shared their perceptions and experiences surrounding children's autism diagnoses, including initial recognition of atypical behavior and development, the formal diagnosis process, and subsequent transitions within the family system. Maternal reports of personal and family adaptation revealed notable similarities between the theoretical framework of family adaptation and actual family processes. Families of children with autism experienced multiple stressors, and through the mediating influence

of coping strategies, they discovered useful resources, redefined their circumstances, and progressed toward bonadaptation. Mothers followed similar patterns of adaptation personally, though some elements of maternal adaptation were predictably different from those of other family members, given the responsibilities of a parental role. Findings of this study yield insights into social and cultural influences and related adaptations among families of children with autism.

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I wish to thank the school and program administrators who helped me meet potential research subjects and allowed me access to their facilities to hold interviews. I would like to especially acknowledge Sondra Hurst, for her support from the beginning. She provided an open door for me into this field and has encouraged me in many learning opportunities and experiences since.

I also want to recognize the invaluable help of my committee, for their mentoring and guidance, as well as their enthusiasm and support throughout the research and writing processes. Their feedback and individual expertise have transformed my perhaps initially idealistic research interests into a feasible project that I find fascinating. Thank you for having confidence in me and for seeing the value in this research.

Finally, I wish to thank my family and friends for their never-ending love and support. I am especially grateful to my parents for teaching me not only to value education and pursue academic goals, but to use my opportunities to benefit others. I also appreciate my siblings, cousins, and friends who value the things that I care deeply about. Thank you for asking questions, taking interest in this project, and cheering me on for months.

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CHAPTER 1: INTRODUCTION

Children with disabilities and their families have been studied as special populations for several decades across cultures (Bigge, et al. 2001). Just as modern technology and advanced medicine provide innovative insights on the biomedical and physiological implications of disabilities, greater understanding of these special populations continues to emerge in the social sciences. Though ongoing research and its subsequent applications address a broad range of issues associated with various disabilities, some facets of this field would benefit from further investigation.

For example, evolving awareness of autism, a disabling disorder affecting neurological, biological, and social processes, illustrates the need for thorough research. Autism is the most common and fastest-growing of the Pervasive Developmental Disorders (i.e., Rett syndrome, Asperger Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, Childhood Disintegrative Disorder). It affects the normal functioning of the brain, most frequently inhibiting social and communication skills (Cooper 1999). In addition to language and communication difficulties and cognitive impairments, behavioral symptoms of autism may include reactivity to frustration and repetitive, self-stimulatory behavior (American Psychiatric Association 2000). Actual functioning abilities and related symptoms vary by individual though, as autism disorders are classified on a spectrum ranging from mild to severe (Brownell and Thomas 2001). Individuals with Autism Spectrum Disorders (ASDs) often learn in uncommon ways and may process sensory input atypically as well. Symptoms of autism are present before age three and may continue throughout life (Centers for Disease Control and Prevention 2008). Autism affects individuals from all races, ethnicities, and socioeconomic

backgrounds and is four times more likely to affect boys than girls. According to a 2007 study, approximately 1 in 150 8-year olds throughout the United States have an autism spectrum disorder (Centers for Disease Control and Prevention 2008).

Medical classification and comprehension of autism have progressed immensely in recent decades and investigative research continues (Centers for Disease Control and Prevention 2008). Awareness of sociological issues affected by autism has also improved, though perhaps more slowly than medical advances in the field. Sociological studies of autism commonly focus on the family unit as the social system primarily affected by individuals with autism. A child's autism may be considered a stressor on the family system, potentially altering patterns of family interaction, communication, or behavior. Each member of the family may be influenced to some extent by this stress, and his or her perceptions of it and associated responses may affect the functioning ability of the family as a whole. This study will maintain a concentrated investigation of the social impacts autism has on the family, with specific emphasis on mothers.

In family disability research, mothers are commonly the informants due to their significant position within the family. Mothers of children with disabilities generally play a critical role in the custody and care of their children (Nyland 2006; Hoffman et al. 2008), in addition to their influence otherwise within the family system. Therefore, this study focuses on maternal perceptions and responses to having a child with autism, including related effects on herself and her family. Concentration is placed primarily on the period of time surrounding a child's diagnosis, including the recognition of a child's atypical development or behavior before a diagnosis and initial reactions and transitions following a diagnosis. Existing theories of family adaptation and coping provide

perspective in considering experiences with autism in the family. Qualitative methods are employed to address the scope and objectives of this research. Specifically, the study is based on personal responses of mothers of children with autism as given in group and individual interview settings. Emerging thematic commonalities from these discussions contribute to a greater comprehension of family adaptation processes associated with families of children with autism. Findings from this study are designed to increase awareness of autism-related issues, and may prompt further research or actual assistance for these families. Sociological insights regarding families of children with autism are particularly significant due to the contemporary need for extensive research on this type of disability.

LITERATURE REVIEW

Effects of Autism on the Family

Medically-documented prevalence and growth of Autism Spectrum Disorders may imply sociological consequences as well. Since the family unit is generally accepted as the most appropriate place to raise a child with a disability, any economic burden of ongoing interventions, therapies, and diagnostic adjustments rests with them (Cooper 1999). Experts agree that early diagnosis and intervention is ideal, since young children with autism are more likely than their older counterparts to develop cognitive and social skills, whether typical or atypical. Familial responsibility for these educational interventions, along with daily care and acquisition of other resources and assistance, is unavoidably demanding. Lack of organized resources and education available for some families raising children with autism can make this responsibility even more difficult (Little 2003; Dyches et al. 2004; Nyland 2006).

Along with the material burdens inherent in parenting a child with disabilities, families deal with emotional and social implications as well. It is well-established that families raising a child with autism experience high levels of chronic stress (Tunali and Power 2002; Smith et al. 2007; Hoffman et al. 2008). Some families have described news of a diagnosis as a strike at the heart of their family's value system, throwing off the family equilibrium and its previous cycle of development (Foster and Berger 1985; Boyd 2002). Even before a family receives a formal diagnosis, recognition of atypical behaviors or patterns of development may act as a stressor in the family system. A stressor may be defined as a "life event or transition impacting upon the family unit which produces, or has the potential of producing, change in the family social system"

(McCubbin et al. 1983:8). Behaviors associated with autism may be taxing on the family, and have been associated with poor psychological functioning among parents and siblings (Sperry and Symons 2003; Hastings et al. 2005; Smith et al. 2007). The stresses and demands of caring for a child with autism are arguably most strenuous for the mother as she maintains primary parenting responsibilities for her child's special needs (Hoffman et al 2008).

Contextual factors associated with familial experiences and autism are significant and require consideration (Griswold 1994). Research on family stress and adaptation presents a theoretical framework when considering the effects of autism on the family collectively and as individuals. Early research on family stress began with a study on war-induced familial separation due to a captive or unaccounted for father (Hill 1949). Based on this research, Hill (1949) formulated what he termed the ABCX model, depicting interacting elements that ultimately result in varying degrees and forms of family stress. Briefly summarized, Hill (1949, 1958) stated that *A (the event), interacting with B (the family's crisis meeting resources), interacting with C (the definition the family makes of the event), produces X (the crisis)*. McCubbin et al. (1982) later expanded Hill's paradigm to include postcrisis variables, asserting that depictions of family stress require the consideration of factors related to adjustment following the stressor event as well. McCubbin et al. (1982) claim that conceptualizing *crisis* simply as a single event is not adequate in understanding familial responses to stressor events. Rather, including an analysis of ongoing family adjustment following a finite crisis event may more accurately depict stress in the family context. Given these assertions,

McCubbin et al. proposed the Double ABCX Model, which is commonly accepted in contemporary research.

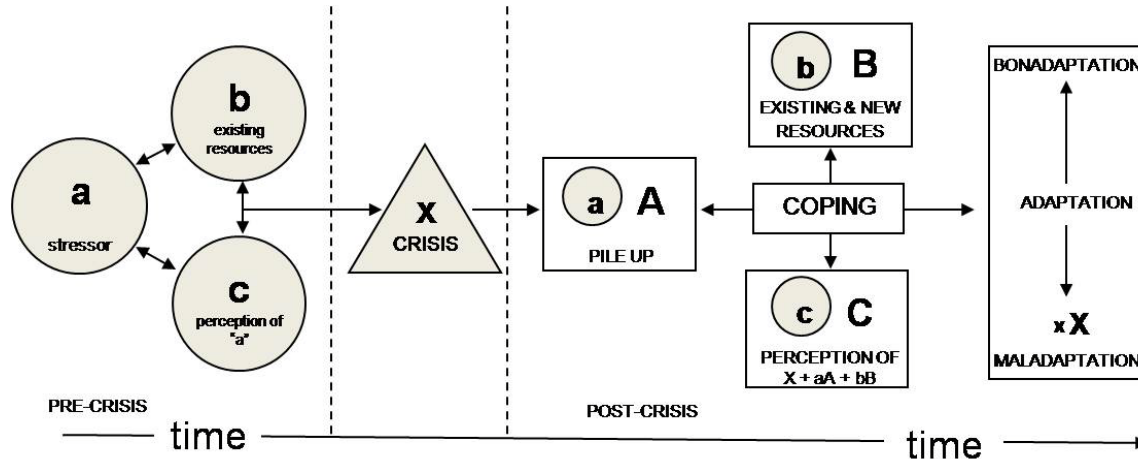


FIGURE 1. The Double ABCX Model (McCubbin, et al. 1983)

Family Demands

Initially, both models of family adaptation (Hill 1949, McCubbin et al. 1982) coincide, beginning the process with a stressor. The potential change that a stressor may produce in a family system may be evident in various aspects of family life, including alterations in boundaries, roles, patterns of interaction, goals, or values. Other hardships associated with family stressors may place additional demands on the family system (McCubbin et al. 1983). The initial stressor and its associated hardships move the family into a “crisis” state, but according to McCubbin et al. (1982, 1983), families commonly experience a pile-up of demands following the event of a major stressor as well.

A pile-up of demands may emerge on individual, family, or community levels, and is referred to as the “aA” factor in the Double ABCX Model. This pile-up may occur due to a combination of varying types of stressors affecting the family in crisis. These

stressors are generally events that occur at a relatively distinct time and demand change from the individual or family (McCubbin 1998). Stressors may potentially include normative transitions, prior strains, consequences of family efforts to cope, or social and intra-family ambiguity (McCubbin et al. 1983). Unresolved hardships of previous stressors or inherent tensions of an ongoing role, such as parenting a child with a disability for example, may also contribute to a pile-up of demands (McCubbin 1998).

Family Capabilities

Internal and external resources available to individual family members, the family system, and the community can be used to meet the pile-up of demands accompanying a crisis (McCubbin 1998). The Double ABCX Model identifies two types of family resources within this “bB” factor: existing and expanded resources. Existing resources, those already established within the family system, may minimize the initial stressor’s impact on the family and lessen the likelihood of the family entering into a crisis state (McCubbin et al. 1982, 1983). Other resources may change in response to the nature of demands or be realized through increased social networking, professional referral, or personal effort. For example, Smith et al. (2007) cite several studies finding that mothers of adolescents with autism demonstrate higher levels of psychological well-being than mothers of young children with autism. This could be attributed to expanded resources emerging or developing over time, on personal, family, or community levels.

Personal resources include characteristics of education, health, or knowledge available to individual family members in times of crisis. *Family system resources* may include family cohesion, adaptability, income, resiliency, mutual support, or understanding. These resources are a family’s internal abilities to protect it from the

impact of stressors and facilitate family adaptation during crisis (McCubbin et al. 1982; Connor 1998; Genero 1998; McCubbin 1998). Family systems theorists would argue that each member of the family, or element of the system, is interdependent and influences every other member of the family. The family system is viewed as greater than the sum of its parts and provides a context for understanding the behavior of individuals within the family (McCubbin 1998). In the case of family system resources as a component of family adaptation, each individual's personal resources would contribute to the overall ability of the family unit to cope with stressors. However, the family's resources as a whole, according to family systems theory, would be greater than the theoretical sum of personal resources provided by individual family members. Assets such as family cohesion and mutual relational support are crucial to the adaptation process during crisis but could not effectively exist without the context of the family unit.

Community resources are means available outside the family, including people and institutions, that help a family system meet the pile-up of demands associated with a crisis. In the case of families with autism, educational and therapeutic interventions are valuable resources. Accessing a combination of available and helpful resources becomes challenging for many of these families though, especially since children's needs commonly change over time (Little 2003). The acknowledgement of internal, though perhaps more abstract resources, in addition to more apparent, external assistance for families seems to be a crucial element to understanding family adaptation. For instance, though monetary or service-oriented community resources are undoubtedly beneficial for families in crisis, McCubbin et al. emphasize that social support is one of the most

important community resources families can develop or maintain when coping with a crisis (1982).

Social support, defined as belief that a family is cared for and loved, esteemed and valued, and belongs to a network of mutual obligation and understanding (Cobb 1976), enables families to be “more resistant to major crises and... better able to recover from crisis and restore stability to the family system” (McCubbin et al. 1983:15). Social support, both through the availability of social networks and ability of those networks to provide support, may vary but will likely enable families to better develop and maintain a process of bonadaptation and resiliency (McCubbin 1998). It may contribute to this familial bonadaptation specifically through alleviating parental stress. Social support is one identifiable factor that serves as an effective stress mediator for mothers especially (Boyd 2002). Consideration of social support, both as a relational influence and in terms of individualistic components, may provide significant insights into familial resiliency and adaptation to crisis (Genero 1998; McCubbin 1998).

Social support may encourage experiences of mutuality, or the bidirectional movement of feelings, thoughts and activity between individuals. This provides families with feelings of connectedness, facilitating and giving meaning to adaptive processes that accompany the crisis experience. Meanings that arise through mutual social relationships may become a critical source of validation and encourage a sense of empowerment to act in behalf of self or others (Genero 1998). Social support through extended family, friends, and perhaps religious or community structures may be key for families in the process of adaptation (Bagley and Carroll 1998; McCubbin 1998, Boyd 2002; Overton and Rausch 2002).

Family Definition

In the initial phases of the Double ABCX Model, a family faces stressors and accompanying hardships and then subjectively defines the situation and how they believe it will affect them. This definition expresses the perceived seriousness of the experienced stressor, and is based on the family's values and previous experiences in handling situations of change or crisis (McCubbin et al. 1983). The "cC" factor in the Double ABCX Model includes the meaning a family gives to the total crisis situation, including the initial stressor, the pile-up of additional demands, the family's available resources, and perceptions of needed changes to bring the family system back into balance. Families of children with autism may define the crisis of having a child diagnosed with autism differently than families of children with other developmental disabilities. Many children with autism are born without any indication of atypical development. Their parents later deal with the loss of "normal" expectations for a child they previously assumed had no disabling challenges. In contrast to parents who learn of their child's disability soon after birth, this transition may pose additionally stressful for families seeking to make meaning of their child's autism diagnosis (Dyches et al. 2004).

Attributed meaning or perception of the crisis may change as new information is discovered or as components of the problem are discussed (Bagley and Carroll 1998). When an individual faces a crisis event where a basic human need is under threat, he or she may "redefine what constitutes fulfillment of that need, and... develop alternative means of achieving it" (Tunali and Power 1993:950). Familial definitions or perceptions of crisis may involve religious beliefs or attributed meaning to the stressors experienced (McCubbin et al. 1982). Family definition, or redefinition, of a crisis situation serves as a

crucial component in facilitating coping and eventual adaptation in the family system (McCubbin et al. 1983).

Some mothers may follow this pattern of reconstituting how various human needs are satisfied and/or pursuing alternative ways to fulfilling them when faced with raising their children with autism. One study claimed that some mothers of children with autism did not differ greatly from mothers of children without autism in their actual lived experiences. Rather, they differed in what they valued, likely indicating previous redefinition in certain domains of their lives. Redefinition was also found to be an important factor in positive reports of life satisfaction among mothers of children with autism (Tunali and Power 2002). Redefinition may contribute to families identifying positive outcomes in relation to a crisis event, a trend increasingly acknowledged in disability research (Smith et al. 2007).

Crisis and Adaptation

According to Hill (1949), the combination of family demands, capabilities, and interpretations of stressors combine to produce crisis. Crisis has been conceptualized as a continuous variable referring to the amount of disruptiveness, disorganization, or incapacitation in the family system (Burr 1973). Crisis is distinct from stress, which is considered a demand-capability imbalance in the family, in that the family is unable to restore stability following stressor events. It is also characterized by consistent pressure to alter family structures and patterns of interaction (McCubbin et al. 1982). So if a family is able to encounter stressors without succumbing to systemic change and maintain stability over time, they may never enter a state of crisis.

In McCubbin's Double ABCX Model, coping is the mediating factor between interacting post-crisis variables that leads eventually to adaptation. Coping is the process by which individuals respond to threats of stress, and strategies for coping are generally categorized as emotion-focused or problem-focused. Emotion-focused coping strategies concentrate on alleviating or managing feelings of distress, while problem-focused strategies center on solving the problem or changing the source of stress (Smith et al. 2007). Coping strategies can be applied consciously or unconsciously to meet the demands of situations both within and outside of an individual's control. For uncontrollable situations, cognitive rather than behavioral strategies are more effective and allow an individual to make sense of the situation or change the way it is viewed. Successful cognitive strategies may include finding meaning in a situation, reaching acceptance, gaining perspective, using humor, or reinterpreting situations positively (Tunali and Power 2002).

Adaptation, the conceptual outcome of this process, occurs when a family has reached a balance of demands and capabilities on individual, family system, and community levels. Families have accommodated, compromised, regulated, and given meaning to the crisis event (McCubbin et al. 1982). Adaptation exists as a continuum, from bonadaptation to maladaptation. Bonadaptation refers to positive adaptation and occurs when "a family has achieved a balance minimizing discrepancy between resources and demands" (LoBiondo-Wood 2008: 232). When a family reaches bonadaptation, they have used coping mechanisms to understand the meaning of the crisis, and to accept it. Maladaptation refers to the negative end of the adaptation continuum. It is typified by family imbalance. Maladaptive families may demonstrate psychological or physiological

ill health, along with a deterioration in family functioning abilities and integrity of the family system (LoBiondo-Wood 2008).

Social and Cultural Context

Though definitions of culture may vary, its connection to society is widely accepted, making culture an essential component to consider in any sociological investigation. In its most rudimentary form, culture is usually identified as one of four things: norms, values, beliefs, or expressive symbols, though it may be referenced on more complex levels as well (Peterson 1979). Wendy Griswold (1994) proposes one explanation of how cultural and social elements interact and how cultural meanings become increasingly apparent within a social context. Griswold's *cultural diamond* begins by identifying "cultural objects" as anything audible, visible, tangible, or able to be articulated that expresses socially shared significance. Cultural objects tell a story and may include anything from a poem or song, to a religious doctrine, habitually-used phrase, or even a hairstyle. Griswold identifies cultural objects separately from other aspects of culture since these smaller parts of a larger, interconnected system may facilitate analysis. Griswold asserts that these cultural objects are created by people, whether artists, inventors or merely members of society who first communicate an idea. However, cultural objects are not only experienced by these creators. Griswold points out that all cultural objects must be received by individuals as well: those who think about, participate in, hear, or read them. These receivers are more than just a willing audience though. According to Griswold, they are active meaning makers as well. Perhaps most important to this cultural diamond is the fact that "both cultural objects and the people who create and receive them are not floating freely, but are anchored in a

particular context” (Griswold 1994:14). The social world involves any economic, social, political, or cultural patterns occurring at any point in time. When depicted visually, the cultural diamond demonstrates the relationships that each of these four elements has with each other.

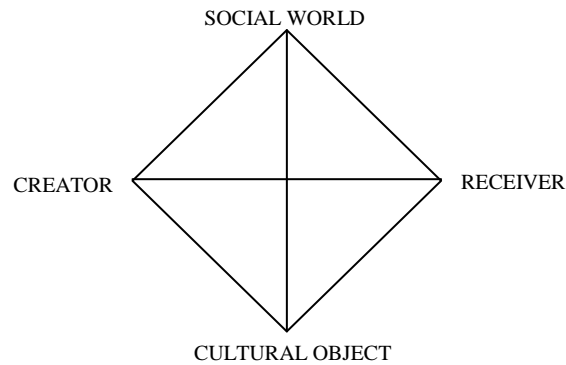


Fig 2. The Cultural Diamond
(Griswold 1994:15)

Griswold’s cultural diamond reinforces the importance of studying sociological aspects of families of children with autism. Though the actual autism diagnosis is singular to an individual, the experience cannot be separated from the social context of family, or even from a broader social context. Previous perceptions of autism, initial responses to diagnoses, emotional transitions and adaptation to daily functioning, as well as the discovery and utilization of resources are all family processes interconnected with the social world. Family members of children with autism are active creators and receivers of meaning both with each other and with those outside of the immediate family. As knowledge and experience shape personal perspectives over time, meanings created and received by family members of children with autism may change as well. Recognizing how individuals and families create and receive meaning may provide important insights into understanding how they interact with the social world.

Negotiating ongoing cultural nuances produces inherently continuous adaptation for families of children with autism. Social factors, including community resources, professional diagnosis, and social supports, strongly influence a family's initial adaptation process. As the family successfully adapts to these social influences, perhaps accepting some and rejecting others, they will continue to encounter a variety of social and cultural factors. These may include positive and negative perceptions of others, newly discovered resources, or changes in social support. The presence of the social world perpetuates ongoing adaptation in families of children with autism. The social world includes both those with and without autism who affect the experiences of a family with children with autism. The beliefs, norms, values, and even expressive symbols (or *culture*, according to multiple definitions) of some families of children with autism may vary from those of others, making their experiences unique and worthy of investigation.

Realistically, in order to gain a greater understanding of families of children with autism, their social and cultural experiences must be explored. Studies specifically addressing these families are contemporary and relevant, given the unique characteristics of autism and its relatively recent rise to the forefront of research and public concern. Autism differs from other disabilities in that it is often not recognizable to the untrained eye. In contrast to children with other physical and mental disabilities, such as Down Syndrome, children with autism often appear physically to be no different than their neurotypical peers. Because there may not be any visibly apparent distinction between children with autism and any other children, people may unfairly judge them based on typical expectations without any awareness of their special needs. For example, if an uninformed individual witnessed a young child with autism, who was unable to express

himself verbally, communicating emotion through socially-unacceptable means, the individual may incorrectly attribute the child's behaviors to poor parenting or as a reflection of the child's disposition, rather than to the special needs of the child. Gray (1993) reports that parents often feel socially stigmatized because of uninformed perceptions of their child with autism. He further notes that mothers report perceived stigma significantly more often than fathers. In most contemporary societies, women tend to be the designated caretakers in the family, primarily responsible for rearing the children (Genero 1998, Thornton 1998). Stigma experienced by women in a maternal role may then be perceived more frequently than among other family members due to ascribed caregiving responsibilities (Hoffman et al 2008). This type of social stressor provides one example of the pileup of stressors and hardships identified by McCubbin et al. (1983).

Focus on Mothers

The existing literature addressing mothers of children with disabilities provides some insight into their experiences and challenges (Craig and Scambler 2006; Nyland 2006). In addition to the material and physical challenges negotiated by mothers of children with disabilities, there are also social and emotional hurdles associated with their familial roles. For instance, mothering children with disabilities involves a gradual change in the mother's expectations and realizations of her child's general potential and social standing (Nyland 2006). These conjectures regarding disabilities in general apply to mothers of children with autism as well. However, some characteristics distinctive to children with autism (e.g., wide range of functioning abilities and behaviors, lack of physical indicators of disability) may indicate distinguishing characteristics of their

mothers, when compared to mothers of children with other disabilities (Joseph and Tager-Flusberg 1997; Boyd 2002; Sperry and Symons 2003; Dyches et al. 2004).

Mothers of children with autism have been identified in the literature relatively recently in terms of the unique challenges they face, and studies of this population are steadily increasing. Contemporary research of mothers of children with autism has investigated various facets of maternal stress and psychological well-being (Boyd 2002; Hastings et al. 2005; Smith et al. 2007; Hoffman et al. 2008). Maternal stress may come from a variety of sources that shift over time and are unique to individuals and families. For instance, sleep problems among children with autism are related to maternal reports of stress. According to one study (Hoffman et al. 2008), mothers' reports of their own sleep problems correlated with their reports of their children's sleep problems. The severity of a child's autism also correlated with maternal stress, though autism severity and child sleep problems were not correlated. Mothers react differently to stress and differ in their perceptions when compared with fathers of children with autism (Hastings et al. 2005). For example, mothers of children with autism report more depression than their partners, but also seem to hold more positive perceptions about their child with autism and his or her impact on the family. According to Hastings et al (2005), maternal stress is predicted specifically by children's behavior problems, not by personal adaptation or even children's symptoms of autism. Mothers who experience greater amounts of stress are more likely to seek social supports (Boyd 2002). Interestingly, mothers of children with autism benefit more from informal social support than from formal supports. Social supports serve as a stress-buffer and may be related to lower levels of depression and anxiety among these mothers as well (Boyd 2002).

Recent studies have also investigated the use of coping mechanisms for mothers of children with autism. A study by Smith et al. (2007) draws comparisons between mothers of toddlers with autism and mothers of adolescents with autism. Both groups of mothers showed signs of significant stress and elevated depressive symptoms. Both groups also demonstrated that higher levels of problem-focused coping and lower levels of emotion-focused coping were associated with better maternal well-being. While these coping strategies proved effective for mothers of toddlers with autism regardless of the child's level of autism, for mothers of adolescents with autism, coping acted as a buffer when autism symptoms were severe. Coping strategies vary for families of children with autism, but many families cope by redefining their circumstances and perceptions. Mothers who redefine their life situations positively demonstrate greater life satisfaction in comparison with those who do not. Tunali and Power (2002) claim that mothers of children with autism place less emphasis on career success and others' opinions of their child's behavior than mothers of neurotypical children. Mothers of children with autism also place more emphasis on spousal support and parental roles and spent more leisure time with extended family.

Maternal perceptions related to child autism have also been evaluated in recent literature. Mothers of children with autism who have developmentally regressed have relatively similar perceptions of their children's medical history and developmental milestones as mothers whose children with autism have not regressed (Davidovitch et al. 2000). However, mothers whose children with autism regress report associated feelings of guilt more frequently than mothers whose children do not regress. Maternal perceptions of their children's needs and available resources reinforce the importance of

early intervention for children with autism (Little 2003). Studies of other maternal perceptions related to having a child with autism are limited.

Contemporary research addresses some key sociological issues among mothers of children with autism. This field of research continues to expand and the need for ongoing research is great. Though current studies investigate mothers' psychological well-being, coping mechanisms, stress, and perceptions of their children's autism, among other subjects, these studies are generally conducted without regard to whether sociological factors differ for these mothers at various phases of their children's development or diagnosis process. Even studies comparing maternal effects among different age groups of children fail to account for when the children's symptoms of autism began or when an official diagnosis was reached. In these studies, mothers with children at a certain age are assumed to be experiencing similar social and emotional effects. However, this may not be accurate, as projected by the family adaptation model. Changes in appraisal of and adaptation to autism in the family, or changes in the availability or usage of resources may be associated with this crisis event (McCubbin et al. 1983). These changes would denote differences in social and emotional experiences and perspectives among mothers at varying points in the adaptation process. In order to more fully ascertain the experiences of mothers and families of children with autism overall, the time period surrounding a child's autism diagnosis and associated adaptations should be recognized as distinctive and important to study.

Research Questions

Based on this assertion, I approach this research with the purpose of exploring maternal and familial experiences associated with adaptation to autism prior to, during,

and just following the process of diagnosis. My research questions correlate with McCubbin et al.'s family adaptation model (1983) and are influenced by Griswold's cultural diamond (1994), though the methods selected permit flexibility and expansion beyond these theoretical conceptualizations as needed. My main research question is: How do families, specifically mothers, adapt to having a child with autism? Other related research questions include: What stressors accompany childhood autism diagnosis? How available and effective are resources for families of children with autism? How do maternal and familial perspectives of a child's autism change with a diagnosis and over time?

I propose to address these questions by evaluating mothers' reports of personal and family adaptation to having a child diagnosed with an Autism Spectrum Disorder. Based on the theoretical models reviewed, I expect to find both cultural and social influences on family adaptation, as described by Griswold (1994) and McCubbin, et al (1983) and depicted in Figure 3: A proposed application of the Double ABCX Model.

I anticipate that participants will report that recognition of their children's atypical behavior or development played a large part in motivating them to seek out an official diagnosis for their child. The mothers' previous perceptions and experiences with autism, along with social support and awareness of available resources, may also contribute to this step. After obtaining an official diagnosis of autism, families may experience a pileup of stressors and hardships, including family-related stress in terms of daily functioning, financial burdens, or social and cultural pressures such as stigma or unrealistic expectations. Some of these stressors may be attributed to received meanings from the social context of the family. Families may adapt by creating new meanings or

redefining their situations to receive meanings differently. Families may also redefine autism and how they perceive a family member with autism as they discover new information and apply that knowledge within their family context.

Redefinition may ensue as families discover and develop resources to cope with the challenges of autism. For instance, mothers may access community, professional, and educational resources that facilitate adaptation for themselves and their children. Social support, another strong influence from the family's surrounding social world, may also increase as extended family, friends, and others learn of the stressors facing families of children with autism. Coping strategies implemented by mothers of children with autism and their families will propel other interacting factors toward adaptation. Ideally, these various components will contribute positively and result in bonadaptation. Should a family experience maladaptation, they will enter a state of crisis and further adaptation or changes must take place. Though some elements of the adaptation process cannot likely be predicted for the mothers in this study particularly, I anticipate findings that correspond to some degree with this autism adaptation model.

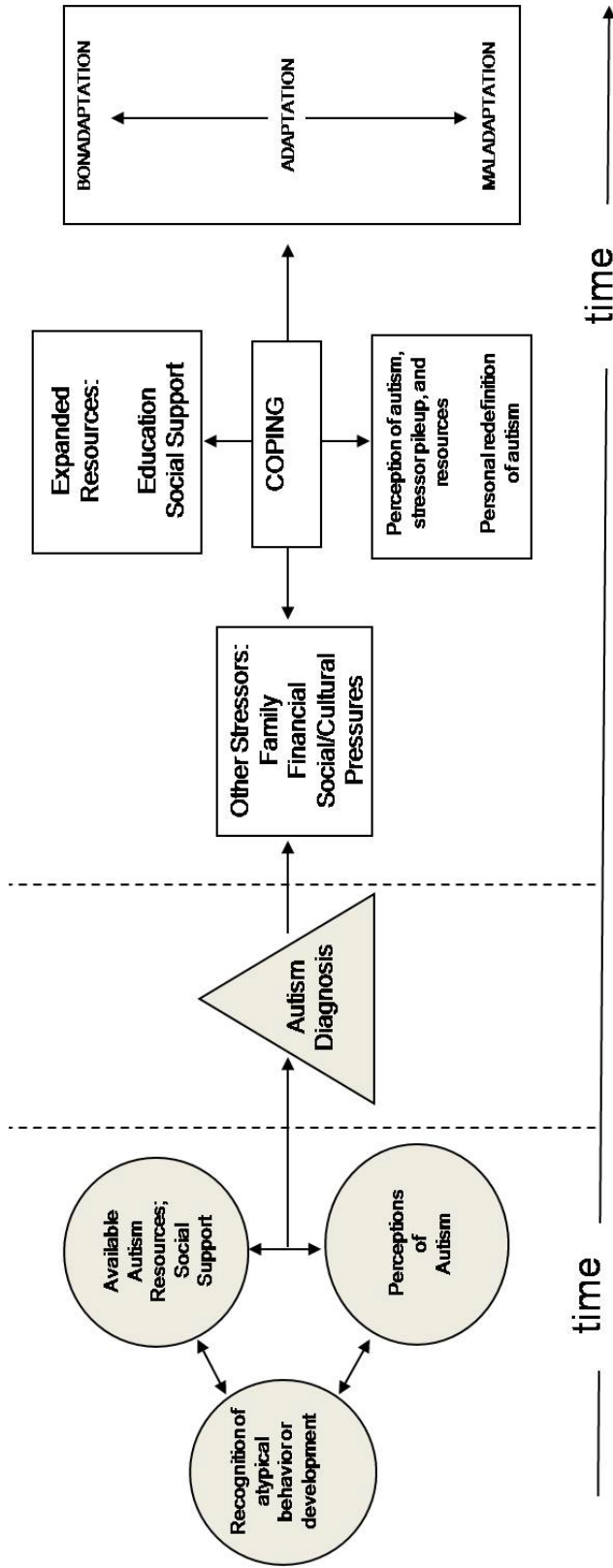


FIGURE 3. Applied Double ABCX Model:
Proposed Autism Adaptation.

CHAPTER 2: RESEARCH METHODS

Given the current need for family disability research, one purpose of this study is to explore the experiences of mothers of children with autism, in the context of their families. This study focuses on any challenges, benefits, and adaptations a family encounters in the initial phases of a family member's autism. Specifically, research participants report on the time period preceding official diagnosis, the diagnosis process, and a short time following the diagnosis. This includes the families' initial recognition of atypical development or behavior in a child, the process of discovering and diagnosing potential problems, and both formal and informal transitions to intervention and daily functioning. Using the framework of family adaptation described previously, I examine maternal reports of personal and family experiences in order to investigate whether some families of children with autism demonstrate commonalities in their experiences and in descriptions of the process of familial adaptation.

Sample

Twelve women participated in this study, all of whom have at least one child diagnosed with an Autism Spectrum Disorder (ASD). In determining the concentration of this research project, I chose to focus on adaptations surrounding the time period of autism diagnosis. Therefore, I primarily recruited mothers whose children had been diagnosed within the past three years. This approximate time frame was preferred so that participants would have a recent recollection of their experiences, emotions, and perceptions, but would not likely be in the midst of the initial adaptations immediately following a diagnosis. Ten of the twelve participants had obtained formal autism diagnoses within the past three years. The other two participants' children were

diagnosed more than three years before this study. (For demographic data questionnaire, see Appendix A.)

Nine participants have one child diagnosed with autism, two participants have two children diagnosed, and one participant has three children diagnosed on the autism spectrum. (See Table 1.) Of these children, none were enrolled in general education classrooms without special assistance. Four children attended general education classes in public schools, with some special education support (“IEP services” in Table 1). Five children attended special education or autism classes in public schools (“SpEd class” in Table 1). Seven children attended private schools for children with autism.

Name~	Total Children	Children with ASD	Diagnosis Age Child1	Diagnosis Age Child2	Diagnosis Age Child3	School Child1	School Child2	School Child3
Ann	3	1	2	^	^	Private	^	^
Chris	4	1	5	^	^	IEP services*	^	^
Emily	9	1	3.5	^	^	Private	^	^
Eowyn	2	1	3	^	^	Private	^	^
Hannah	3	1	3	^	^	Private	^	^
Janet	2	1	2	^	^	SpEd class*	^	^
Kristi	4	2	6	4.5	^	IEP services*	Private	^
Leslie	5	3	3	1.75	2	IEP services*	Private	SpEd class*
Lynn	1	1	5	^	^	SpEd class*	^	^
Melissa	2	1	4	^	^	SpEd class*	^	^
Michelle	2	2	2	3	^	Private	SpEd class*	^
Rayne	10	1	6	^	^	IEP services*	^	^

~ Participant pseudonyms

^ Not applicable

*Public school

Table 1. Participant Demographics, Child Information

The twelve mothers who participated ranged in age from 26-41, with an average age of 34. These mothers had from one to ten children, with an average of 3.9 children

per family. Eleven participants were currently married and one was currently divorced and single. All research participants were high school graduates and seven had college degrees. All participants' spouses were also high school graduates and seven had college degrees. Though respondents answered questions of employment in various ways, ten participants identified themselves as currently unemployed or full-time mothers. None of the spouses' occupations were reported as full-time fathers; ten of them were identified as having other full-time employment. My interest in employment status was primarily related to whether one of the parents was fiscally unemployed for the purpose of parenting full time. Information regarding ethnic, religious and socioeconomic backgrounds was not obtained from research participants. Because the purpose of this research was to explore maternal experiences with children with autism and not to generalize findings, the sample of women was selected with the intent to minimize sources of diversity, other than age and number of children.

Other contextual factors should be considered in understanding the experiences of these participants. Research was conducted in a suburban county in Utah. According to a 2007 Centers for Disease Prevention and Control study, Utah has the third highest rate of autism among fourteen states studied throughout the nation. Community and private autism resources are available in this and surrounding counties, though organized and accessible resources in the area are arguably less available than current need dictates. However, all families interviewed had access to public schools and services mandated by the Individuals with Disabilities Education Act (IDEA) in relatively close proximity. According to the National Center for Education Statistics (2007), the state of Utah is ranked 35th of the 50 states in total expenditures for public elementary and secondary

education. Utah ranked lowest in the nation for total elementary and secondary education expenditures per pupil. Utah does offer a special needs scholarship to qualifying elementary- and secondary-level students. This allows parents to access public funds for private schools or programs that best meet students' special education needs (Utah State Office of Education, 2009).

A Latter-day Saint religious majority influences social and cultural norms in the region. Religious influences seemed to play an important role in adaptation for some participants. References to personal spirituality, LDS church organizations, and social factors associated with religion were mentioned in multiple interviews.

Study Design

Given the evolving and sometimes sensitive nature of parenting a child with disabilities, some participants had never previously discussed their experiences with autism with someone outside of their family or close friends, and others may rarely verbalize their perceptions even to family members. In-depth personal and group interviews provided an open environment for participation discussion and an especially effective method for exploring processes of family adaptation. I conducted one focus group in September 2008 and eight individual interviews in May 2009. The focus group interview was conducted with four participants. This interview took place in a school setting and was digitally recorded and transcribed. Though other group interviews were originally planned, participants were given the option of individual or group interviews. Most participants recruited for this study expressed preference for individual interviews. In order to accommodate research subjects and provide a convenient and comfortable environment for interviews, all remaining data collection consisted of individual

interviews. All of the interviews, which were digitally recorded and transcribed, took place in settings designated by the interviewees, including schools, a park, and participants' homes. Interviews ranged from thirty minutes to an hour and a half.

Some participants became involved in this study through my personal contacts, and others were recruited through local public and private schools and early intervention programs. Professional relationships from my previous work as a teacher for children with autism provided the initial group of participants. I also contacted administrators in a local private school and a few early intervention programs educating children with autism. Some administrators allowed me to send home introductory letters about my research. Several parents from these programs then contacted me personally to arrange interviews. Others returned their contact information through program administrators, and I subsequently initiated communication and arranged for interviews with them. In addition to these private programs, I contacted a public school district's autism specialist. She invited me to attend the district's support group for mothers of children with autism. I made contact with additional participants at that meeting. The group facilitator also emailed my introduction letter to everyone in the district autism network. Several additional participants contacted me after receiving this email.

Although both individual interviews and a group interview were conducted, the information shared by participants was consistent across the different research contexts. The primary difference in the data collection process was the role of the researcher. I provided less direction in the group interview than the individual interviews. Questions and topics that emerged from the focus group dialogue were beneficial in determining the focus and direction of individual interviews. However, both interview formats were

effective for their respective participants, allowing for individual reflection and response revealing the rich nuances of family life and autism.

Discussion topics were categorized to emphasize elements of the family adaptation framework, including *stressors*, *resources*, *appraisal*, and *adjustment* (See Appendix B). Participants' responses demonstrated a variety of possible events, reactions, perceptions, and adjustments families of children with autism experience. While responses were personal and reflected diversity of thought and experience, several ideas and occurrences were consistent among multiple participants.

Standard ethical considerations were utilized in conducting this research (Berg 2001; Lofland, et al. 2006). IRB approval was applied for and obtained initially. Informed consent was also obtained from all participants before proceeding with interviews (See Appendix C). To ensure privacy for the research subjects, identifying information was removed from all written research records. Though participants used their real names during the interviews, pseudonyms were subsequently applied for each participant and for family members and other individuals referred to by name during interview discussions. I have kept all identifying records strictly confidential during the research process and will not retain them longer than necessary for research purposes. Due to the potentially sensitive nature of topics discussed during these interviews, confidentiality was naturally a consideration. This was especially emphasized with focus group participants. Though not all of the focus group participants were familiar with each other, some of the women were previously acquainted through school or community networks. Because of these social connections with each other, confidentiality was especially critical. Each focus group participant signed a confidentiality statement, and

specifications of their confidentiality agreement were explained and consented to verbally before beginning the group interview as well.

Sensitivity to research subjects was another important ethical consideration for this study. In addition to protecting research participants from exploitation (through informed consent) and maintaining confidentiality, I responded to participants with respect and reciprocity. To encourage respectful, nonthreatening relationships with participants, I assumed the role of “learner” while the respondent was the “expert”, demonstrated basic competence on relevant subjects to elicit thorough explanations, and used language that did not stereotype or label participants or their families (Lofland, et al. 2006; Creswell 2007; Corbin and Strauss 2008). The women interviewed in this study disclosed details of their children’s medical histories, individual and familial repercussions both socially and emotionally, personal opinions and insights, and other potentially delicate information. Sharing this type of information prompted various responses from participants, including occasional manifestations of emotion. Despite the range of reservation or candor with which respondents divulged information, their comments are assumed to be authentic (Patton 2002). One of my roles as a researcher was to mediate between the diverse meanings expressed within varying degrees of participant response to identify the essence of their experiences (Creswell 2007).

Although this research was not undertaken specifically to inform any social practice or program, it is expected to generate information contributing to applied fields. The need for social science research in the field of autism is great, and this study will benefit the discipline by exploring some of the initial challenges and changes experienced among families of children with autism during the process of diagnosis. Conclusions

drawn from this study may prompt further investigatory research or practical intervention as well. Research findings are generally anticipated to promote greater awareness and appreciation of the unique experiences, challenges, and adaptations undergone by families of children with autism.

Research Process

At the outset of this project, I chose to conduct my research using focus groups because I felt that these women could benefit from sharing their experiences with others who would genuinely relate. I organized a focus group of women with whom I was previously acquainted. It was held on a weekday evening and free babysitting was offered to those mothers who attended. Even with the offer of child care, several mothers were unable to attend due to the needs of their children. In retrospect, scheduling group interviews during their children's school day would likely have been more effective. The focus group was held at a local school building, and all of the research subjects who participated in that interview had at least one child who attended the school. Though all of the women in the focus group recognized each other as parents associated with the school, few were personally acquainted.

The group interview was intended to be relatively unstructured, in hopes that topics discussed would yield more focus for future interviews. Participants were each given an interview guide with a few topics listed to prompt discussion. Though some of the participants were somewhat reserved initially, they grew increasingly comfortable and carried the evolving discussion with minimal moderation from myself. I attempted to end the interview after two hours of ongoing discussion, but it continued for another thirty minutes. All of the women appeared to leave the focus group having enjoyed their

experience. I planned to continue with my design to hold additional focus groups in hopes of having similarly positive experiences.

Several months later, I contacted public and private elementary schools, in addition to several public and private early intervention programs. I initiated contact through emails, phone calls, and in-person visits. Though most administrators and program directors were receptive, I was met with some mixed responses. Through the efforts of myself and others, I recruited several additional research subjects. The women I interviewed were articulate and expressive in describing the processes of acquiring and adapting to an autism diagnosis in their families. I was consistently impressed with the mothers who participated in this study. Though faced with unique challenges and life circumstances, they were invariably making concerted efforts to provide the best for their families as a whole and for their children with autism.

Most individual interviews took place during the day, when older children were at school. Interviews proceeded without any major problems and participants seemed to relate well with the questions and prompts presented. Several of the women interviewed expressed appreciation at being able to discuss their experiences with autism openly and frankly. Some mentioned that they did not often have that opportunity, and also that they welcomed the chance to potentially help other mothers facing similar circumstances through sharing their own experiences.

Overall, the data I collected from interviewing mothers of children with autism was rich, insightful, and authentic. In retrospect, individual interviews proved to be very effective in obtaining detail from a completely personal viewpoint. I still believe the group interviews could be very beneficial for participants and would stimulate insightful

discussion. I do not regret the form of data collection I used; however, future investigations with this population could be further developed by including additional group interviews. After collecting the data, interviews were transcribed and prepared for data analysis.

Data Analysis

Analysis of qualitative data commonly involves coding, the process of raising raw data to a conceptual level. Rather than simply summarizing, I applied tools of analysis to dissect and condense data into themes, differentiating meanings while maintaining contextual relevance (Creswell 2007; Corbin and Strauss 2008). After identifying relevant concepts represented in the data, I then developed those concepts in terms of their distinctive features to eventually determine a meaningful representation of the original data (Corbin and Strauss 2008).

Throughout this study, I adhered to typical analytic methods for qualitative data. Preparation for in-depth data analysis was initially integrated with standard data collection (Creswell 2007). For instance, during or following interview sessions, I documented additional observations that were not otherwise included in the interview transcription as needed. At times, I also wrote reflective passages, or memos, adding personal insights or impressions related to the context of the interview dialogue (Corbin and Strauss 2008). After organizing, transcribing, and reviewing the raw data gathered, I began the actual coding process.

Initially, I combined manual analysis with the use of NVivo software. Hand coding significant statements, especially at the outset of the data analysis process, reinforced my familiarity with the data and helped me to narrow expressed themes and

code them more accurately. The majority of the coding was carried out using NVivo data analysis software. As codes from the transcribed interviews evolved, I identified several salient patterns and themes (Creswell 2007).

Throughout the data analysis process, one analytic tool that was especially effective for me was simply to ask questions. The use of questioning was fundamental to every evolving stage of data analysis and was inherently specific to this research project. Theoretical, practical, guiding, and sensitizing questions served as catalysts propelling data analysis throughout this study (Lofland, et al 2006; Corbin and Strauss 2008). Some of these analytical questions included: How do participants' experiences with accessing resources vary and how do they relate to the Double ABCX Model? Why did some mothers delay testing their child for special needs classification? How did the role of siblings in the family adaptation process differ between families? Some questioning was deliberate while other questions emerged during reflection. Asking questions consistently shaped the direction of data analysis.

Making comparisons that often surfaced easily within the data gathered also facilitated data analysis (Corbin and Strauss 2008). Responses from some participants related to those from others and yielded natural comparisons. Comparing participant responses, both of similar and differing perspectives, frequently promoted clarity and guided the direction of data analysis. At other times, I drew on theoretical explanations to provide greater comprehension of the data (Corbin and Strauss 2008). Comparisons of family adaptation theory, family systems theory, and other sociological theories to the data collected from respondents were effective in grasping meanings expressed. Other strategies used to facilitate analysis included considering various meanings of words,

flipping concepts around to gain different perspectives, utilizing applicable personal experiences, recognizing personal biases, and looking at language or emotions expressed (Corbin and Strauss 2008).

CHAPTER 3: THE DIAGNOSIS PROCESS

Responses of mothers of children with autism support theoretical conjectures regarding the complexity of family adaptation. McCubbin's Double ABCX Model and the previously proposed application for family adaptation to autism provide helpful frameworks for initial consideration of research findings. Families of children with autism, and specifically mothers of children with autism, seem to have experienced many of the components outlined by these previous models. Based on the original Double ABCX Model and the related findings of this study, I propose a revised application indicating processes of adaptation to autism in the family (See Figure 4.) Families of children with autism used coping strategies in tandem with multiple factors to alleviate and transform the initially-occurring stressors. The changes in this application of the Double ABCX Model reflect the importance of social support in maternal and familial adaptation for families of children with autism, and the importance of cultural context as a shaping influence throughout processes of adaptation. In discussing the particular findings of this study, I reference this applied Double ABCX Model (Figure 4) and my original research questions.

Leading up to what might be termed the "crisis event", mothers in this study experienced several interacting factors that laid a foundation for the adaptation process. First, maternal recognition of their child's atypical behavior or development seemed to be a crucial component of how well or quickly mothers later adapted to a diagnosis. A few mothers in this study did not originally believe that their child's conduct was out of the ordinary. Later, when it was brought to their attention, or when a diagnosis was given

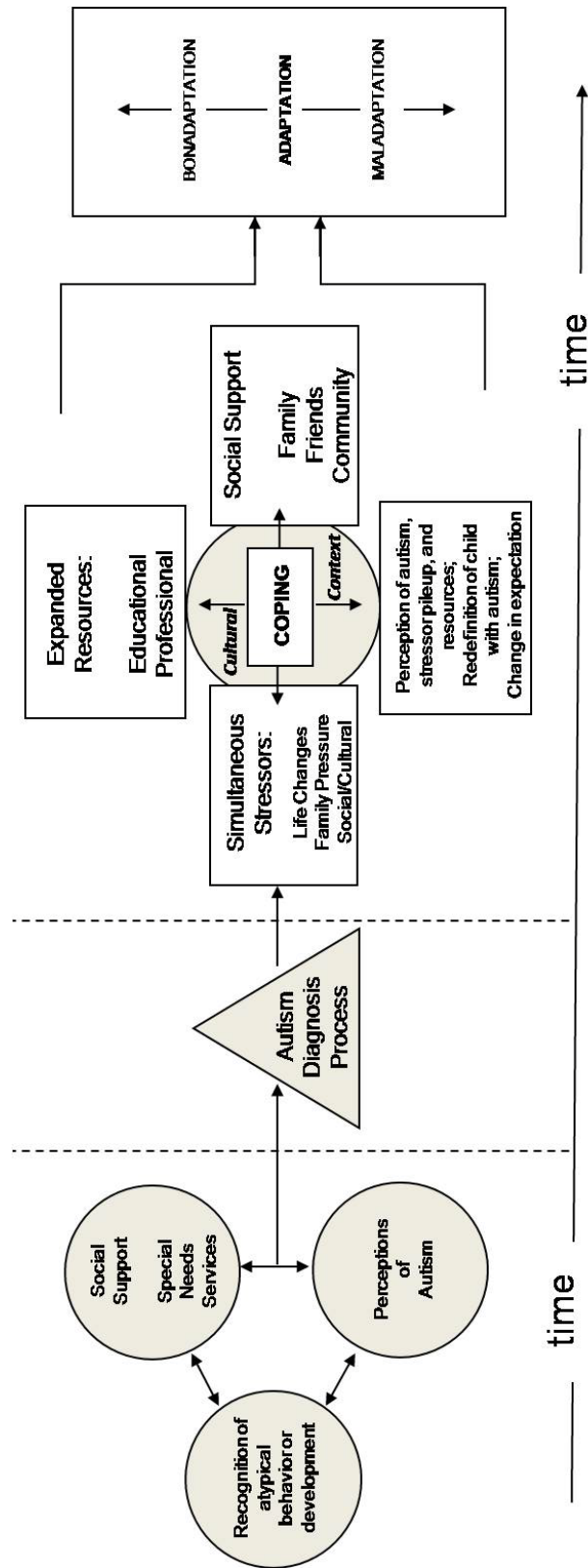


Figure 4. Applied Double ABCX Model: Autism Adaptation.

without preliminary maternal awareness of the symptoms, the impact seemed to be more profound than it otherwise may have been. Maternal awareness, or lack of awareness, of child behavior and development also interacted with maternal preconceptions of autism. Though none of the participants were very well-informed about autism, most had some basic perception of the disorder. The way they perceived autism apart from their child seemed to affect how they initially adjusted to the idea of autism as a part of their child. Again, maternal lack of awareness or misconceptions about autism seemed to foster more dramatic and difficult adjustments to their child's diagnosis.

Recognition of Atypical Development

For each woman who participated in this study, her child's diagnosis process began with the initial recognition of atypical development or behavior. This recognition was made by a parent in some cases, but in other cases, a medical or educational professional, family member, or friend initially noted differences in the child. Several mothers whose oldest child was later diagnosed with autism noted their initial lack of awareness of potential warning signs, since they had no other children to serve as a standard of comparison for typical development. When people other than the child's parents noticed atypical development, they generally suggested that parents be cognizant of potential tendencies associated with autism. Some referred children for testing with an autism or pediatric mental health specialist as well.

For some children, early signs of autism involved regression or changes in their developmental trajectory. Some mothers observed that their children were losing previously-acquired language skills or demonstrated decreased social interaction and eye

contact. Others noticed a change in behavior, including increased tantruming, dramatic transformations in disposition, or the onset of self-stimulatory behaviors.

Some children seemed to display delayed development from birth, rather than experiencing a regression in later months or years. These mothers often recognized atypical development, but were not alarmed since it seemed consistent with that child since birth, or was not considerably different from developmental variation that naturally occurs among young children. Several of these children experienced communication delays and some demonstrated irregular sleep habits, anti-social behavior, or sensory processing sensitivities.

Previous Maternal Perceptions of Autism

Participants' motivation to seek out a diagnosis of their child's atypical behavior and special needs, as well as their later reactions to an autism diagnosis, seemed related to their previous perceptions of autism. Many of these women claimed they knew essentially nothing about autism before hearing it referred to during their child's diagnosis process. Though some recognized the term, they had never met anyone with autism and had no preconceived ideas of the disorder. Other participants' primary association with autism was Dustin Hoffman in *Rainman*, where he portrayed a man with autism who also had savant abilities.

Before encountering it with their own child, some mothers perceived autism as a set of stereotypical behaviors related to severe, or low-functioning autism. As one mother summarized, "The child who sat in the corner and banged his head and didn't speak at all... house was destroyed, bedding torn up, the child who can't leave his room, can't function. I mean, that was pretty much... what I accepted as autism." Not

surprisingly, mothers who perceived autism this way often dismissed the possibility of their higher-functioning child having autism, since he or she did not seem to fit into this particular depiction. Even some mothers whose children demonstrated severe behaviors did not initially make connections to autism. These mothers saw their children as individuals and loved family members, and perhaps viewed autism as a disorder cognitively separated from any individuals they had encountered. One mother expressed,

Most of the time... you saw anything on the news or any kind of promotional thing or educational thing... they usually showed a child in fit mode, in a meltdown. And so you think that's what they do, that's who they are all the time. And so to me, it made it seem less like they were actual children and more like... out of control and you know, hardly capable of... controlling responses and stuff.

Some participants had distant social connections or cursory acquaintances with someone with autism, but none of the participants considered themselves well-informed or aware of the disorder before discovering it with their child. One participant had worked extensively with individuals who had physical disabilities. A few others were familiar with general developmental disorders or learning disabilities due to higher education or work experiences.

Professional Diagnosis

The manner and timing of the diagnosis itself seemed to be a key variable in the adaptation process. Some mothers described feeling emotionally or mentally unprepared for the reality of this lifelong stressor entering their families. A few mothers seemed to feel that real adaptation could not begin until they had a conclusive diagnosis to adapt to. For those children who did not obtain a diagnosis of autism for several months, or even years, their family's ability to fully adapt may have been inhibited.

Participants' experiences with obtaining a formal autism diagnosis for their children varied. A few parents reported having their children referred for autism testing, undergoing the evaluations, obtaining an autism diagnosis initially, and then proceeding to access needed resources, with no notable difficulties in the process. Most of the mothers interviewed, however, did not have such a smooth experience in reaching their child's autism diagnosis. Some mothers first went to public school districts to identify their child as having autism, while others went to medical or mental health professionals. Mothers who received a preliminary educational classification reported having to get an official medical diagnosis later. This caused frustration, since these mothers were not informed prior to the educational classification that further measures would be required. Kristi's experience was typical in this regard.

So I went to the school autism [specialist] to get him tested, I thought... to get a diagnosis. So they do this like, hour long test and at the end they tell me 'Oh, he has autism, but we can't give you that diagnosis'... And I think, 'Why did I just waste all my time coming here?'

Melissa expressed frustration as well that educational professionals did not provide concrete recommendations, including testing referrals, for her son. She, and a few others, arranged for their children to receive intervention services to address special needs, though the official diagnosis of these needs was still uncertain. For a couple of these families, children did not fully meet diagnostic criteria when they were tested. For instance, one boy demonstrated four of five red flags for autism used for educational classification and another child did not accumulate enough points on a diagnostic test to actually be diagnosed with autism. In these cases, parents were encouraged to wait before seeking a further classification or diagnosis to track the child's development.

One of these parents, Michelle, explained that though the process of reaching an autism diagnosis was long and complicated, she was not upset by it since her son had participated in early intervention services throughout that time. However, the diagnosis process was still frustrating to her because of the uncertainty that accompanied varying potential diagnoses.

I think that was the toughest part... we had so many people kind of giving us... almost false hope that it was something else. That we were gonna be able to put the tubes in and he was gonna be great. Or get the throwing up to stop and he was gonna be great. I think that was the hardest thing is that, you know, we had this small fraction that was like, 'It is autism.' And then all these professionals that were telling us, 'No... it's not.'

Michelle, like several other mothers, was given multiple diagnoses over time before professionals finally determined her son had autism. Prior to reaching an autism diagnosis, participants' children had been diagnosed with developmental delays, communication disorders, auditory processing disorders, gastrointestinal disorders, Asperger Syndrome, and Pervasive Developmental Disorder. Though mothers had received these incomplete or inaccurate diagnoses previously, only one seemed to question whether her son's autism diagnosis was accurate. The others seemed to accept the autism diagnosis as a correct fit for their child's disability.

Some mothers reported rather negative experiences in obtaining their children's diagnoses. Most of the negative experiences shared related to medical and educational professionals having limited knowledge of autism and its symptoms, or not recognizing the mother as a resource in achieving an accurate diagnosis. In one relatively extreme case, one mother stated, "I was also told that I was spoiling him, smothering him... just giving in to... his every demand. That's why he wasn't talking." Another mother, Hannah, described her experience:

He went to... the first evaluation and I was so frustrated at the end of it, just 'cause I felt like he was a kid on a conveyer belt. They didn't even... really look at him as this individual kid with likes and dislikes. And they kept trying things out that were like, 'Oh yeah, he does that. He can do that at home, but he doesn't perform on demand.' And they would totally ignore me and anything I had to say, they'd just brush me off... They were like, 'Well this is what we're seeing right now.' And I'm like, 'Yeah, but I know him. He's my kid.' And so, that whole thing left a really bad taste in my mouth.

A few mothers were caught off guard by the diagnosis, since no previous mention of autism had been made by their pediatrician or educational professionals. In Ann's case, a new pediatrician's assessment of her son's symptoms struck her as abrupt and unexpected.

We went in, sat in the office, hadn't even met the guy. He comes in, talks to Michael a little bit, looks at him, leaves the room, comes back in, and hands me a paper that says 'Signs of Autism.' I mean, that was it... And I just... I lost it after that... But I think so much of it was how it was presented to me.

Though some of the women interviewed had negative experiences related to their child's diagnosis, others were very satisfied with the professional measures taken to determine their child's needs. When Chris approached her pediatrician about her concerns for her son, for example, he asked her to keep a log of behaviors that she observed at home since he was unable to identify any problems during short office visits. Later, they discussed these observations and he identified how her son's behavior related to criteria for autism diagnosis. Some participants' children had multiple factors contributing to their atypical development. In these cases, medical and educational professionals worked with the children and their parents over time to eliminate inaccurate diagnoses and find the correct combination of challenges affecting the child in order to provide the best intervention. Reaching a correct diagnosis may have seemed arduous at times, but these mothers generally spoke of the process in positive terms.

Other Simultaneous Stressors

Elements of family adaptation after a crisis event, as described by McCubbin, et al. (1983), seem to directly relate to those experienced by families of children with autism following a diagnosis. Most of these families experienced a pileup of stressors surrounding the time of their children's diagnoses. Additional stressors included major life changes, financial hardships, and other strains placed on relationships within immediate and extended families. Specific examples of simultaneous stressors answer the research question regarding stressors that accompany an autism diagnosis for these families.

Though the process of diagnosing a child's autism alone is arguably stressful for the mother and the entire family, other stressors occurring simultaneously compound the crisis. Most of the women interviewed identified some type of external stressor occurring around the same time that they were recognizing the need for and obtaining a diagnosis. For example, six of these families relocated to a different state or city immediately prior to or following their child's diagnosis. Some of these moves caused a change in the amount or type of extended family and other social support available to these families as well. Though none of the families moved because of a child's diagnosis, the stress associated with moving arguably impacted both the child with autism and the rest of the family during this time period.

Four of the mothers interviewed stated that they were pregnant or had just given birth to another child at the time they received a diagnosis. Again, the stress of this change in the family system and the mother's increased responsibility likely contributed to the effect of stressors during that time. Participants also noted the stress of having

other children to care for, in addition to the child receiving an autism diagnosis. Some of these children deal with other special needs as well, which further contributes to the pileup of stressors experienced by the families in this study. Two of the women interviewed went through divorces relatively soon after their children's diagnoses. One woman who has three children on the autism spectrum recalled,

At that time, I was under extreme pressure. I had to show there was progression. It was a hard divorce and any sign of them regressing or not showing progression, it was severe consequences. And I'd get taken back to court again.

A few women also referred to personal health challenges that inhibited their ability to care for their children and fully investigate their child's diagnosis and potential resources. Rayne, who clearly experienced multiple stressors surrounding her son's diagnosis, described her experience.

We moved from Las Vegas to Utah, and I'm not sure if it was the transition or just the crazy time of our life that made him regress back, but... first it was accidents... and then it was urinating on everything all the time. Then it turned into feces smearing everywhere... We were kind of in a stressful time in our lives anyway with moving and trying to find a house to live in... I was having baby number ten and I was also experiencing a lot of health issues... I had been having these attacks where I would throw up for six hours straight, every five minutes. And three months into my last pregnancy, I finally went in and... my gall bladder was full of all sorts of stuff... So anyway, as soon as I had that baby, I had to go in and have my gall bladder removed, and then there was complications. So that year happened the exact same time as all of his stuff.

Simultaneous stressors occurring in the family system surrounding a child's diagnosis affect the way a mother, and the rest of the family, reacts to the autism diagnosis.

Maternal Reactions to a Child's Autism Diagnosis

Though adaptation to a child's autism diagnosis undoubtedly requires time, initial reactions to a diagnosis may provide a context for how individuals and families begin the process of adaptation. As discussed, previous maternal perceptions of autism, the process

of diagnosis, and other simultaneously experienced stressors likely impact mothers' reactions to their children's official autism diagnosis. Mothers interviewed in this study described feeling a variety of emotions following their child's diagnosis. Several mothers expressed feeling relief at news of the diagnosis. It provided validation of their child's special needs and their own efforts. As Chris described, "It was a relief to have a name... just to have a handle to hold on to. To know that I could find more information."

Despite the relief of identifying their child's special needs, mothers also felt overwhelmed by what now lay ahead for them and their families. The daunting task of finding resources for their child, while balancing other family demands and responsibilities, developed contrasting sentiments to the relief initially felt by some of these mothers. Eowyn described the overwhelming implications of a diagnosis: "The weight of the future is too much. There's too much in the now that you have to deal with, and the weight of the future is more than you can bear." For Leslie, having two previously diagnosed children made her third child's diagnosis even more overwhelming.

I didn't cry when Ashton and Lily were diagnosed.... But with Robbie it's just like...It's busy... it's very busy. It's time consuming. There's not a lot of sleep involved and when you have kids that close... and there was a lot of other things going on and...I just, my eyes filled with tears. And it's not like I started sobbing. It's more like, 'How? How am I gonna have one more?'

A couple of mothers mentioned the difficult decision of whether or not to share news of the diagnosis with others. Though immediate family was usually aware of the child's special needs, telling other people about the child's diagnosis held certain implications. Publicly acknowledging their child's autism made it seem more of a reality to some mothers. Also, some participants feared that the diagnosis would cause others to label their child negatively. As Rayne described,

I didn't really go back out into the world with it yet. I was really trying to keep it kind of more personal, more private... when I had the diagnosis it kind of validated it a little bit more so I was able to say, 'Yes, he's been diagnosed with autism.' But part of me kept thinking; I kept struggling... I don't want people to label him.

Emily's comments add to this idea.

When my husband and I first found out...he said, 'I don't think we should tell anybody... I don't want him labeled, because back when we went to school, you had the resource kids and they were labeled...' I said, 'You know what, I think we do need to tell people, because we need to not be ashamed that he is different. He needs to know that he's okay, and the kids need to know that it's okay if he's different'... It is a fear.

The diagnosis process, including any efforts and setbacks before actually obtaining a formal diagnosis, is a foundational component for maternal and family adaptation to a child's autism. The following chapters will specifically discuss adaptation for mothers and for families of children with autism. Some inherent overlap in their courses of adaptation will occur since the mother is part of the family system. However, looking at elements of their transitions separately facilitates greater clarity and depth in understanding the adaptations associated with autism in the family.

CHAPTER 4: MATERNAL ADAPTATION

Though the formal diagnosis largely marks the beginning stages of adaptation to a child's autism, mothers may begin this process in their own individual timing. Some may have a realization of their child's disability and initiate adaptation long before receiving a formal validation of it, while others may not emotionally accept the diagnosis until long after it has been professionally given. In addition to the initial reactions to the diagnosis already discussed, mothers in this study mentioned several examples of coming to personal realizations of their children's diagnoses. The types of responses these mothers described did not seem to vary based on the child's functioning abilities or the severity of their autism.

Personal Realizations of Diagnosis

Regardless of the timing or manner of her child's diagnosis, a mother must accept the reality of this diagnosis before she can personally adapt to it. Several mothers in this study reported being in denial about their child's autism for varying periods of time following the diagnosis. For Ann, whom the pediatrician first told about autism by handing her a paper listing its signs, it took about one year to accept the diagnosis. For another mother, doctors expressed concern about her son months before she would concede to testing because she believed he would grow out of it, and then "he tested so far below the line, it shocked [her]." Emily had acknowledged that her son was different in many ways, but waited several months to begin testing as well. She said, "You go through the process of denial... I kind of go by feelings of things and it wasn't time to take him to the doctor yet. You know, I just, I didn't feel it was the time." Another

mother received her son's diagnosis but said, "It took me like six months to realize, okay, now we have a diagnosis. Now we need to do something about it."

Some mothers whose children displayed delays from birth admitted that they were relatively unaware of the significance of their children's needs because they were so accustomed to everyday life and did not view their child's behavior as notably atypical. Leslie described when she first realized the accuracy of her children's diagnosis.

It wasn't until I went home and started studying and really what they said sank in. And I was sitting there looking at the kids and they were watching TV. And they were sitting right next to each other, but never once did they look at each other, interact with each other, say a word to each other. And that is when I realized...

Personal realizations of their child's diagnosis seemed to be a turning point for some mothers. It launched them on a path towards adaptation, though the initial steps were often difficult to navigate. Most of the mothers interviewed discussed some degree of negative emotion experienced during the weeks and months following their child's diagnosis.

Negative Emotion

As mothers referred to their early experiences in adapting to an autism diagnosis, they usually described at least one incidence of extreme emotion. One mother described being in depression for almost a year after her son's diagnosis before coming to terms with it. Some became defensive in behalf of their child, especially when encountering others who did not interact with them sensitively. As Hannah described:

I don't take Ian out, just because I'm worried... I'm not worried about being embarrassed about what he does. I couldn't really care less... people who have a problem or whatever, deal with it. I'm more worried actually about myself than anything, because I already had... massive mother bear tendencies before any of this, and this has made it like a hundred times worse. I'm always ready to be on the defense for my kid if I have to... I'm more worried about me saying

something or doing something that I shouldn't because I'm like, 'Listen... Don't look at my kid like that!'

Mothers described not wanting to feel pity from others. One mother described a pang of emotions when she observed typically-developing children of her child's age, yet not allowing herself to dwell on those feelings. Some mothers also described emotions of guilt or self-blame associated with their child's diagnosis. Chris expressed ongoing feelings in this regard.

You feel immense guilt anyways that you're not doing exactly what he needs, because you don't really know what he needs, because the needs change all the time. And even if you know what he needs, being able to access somebody or something that can help him, it's all a guessing game.

Eowyn articulated another aspect of self-blame that she and a couple of other mothers felt related to their child's diagnosis.

So when I found out that he had autism... and found out some things about his brain structure and... there's the child-rearing aspect and then there's the physical aspects of bearing and nursing children, and I'm like, 'I'm a failure. I can't even get them into this world right... much less from there!' ...With that kind of burden, with that kind of mark against you to begin with, how can you ever possibly be a good mom? You know, you spend the rest of your life making up for that.

Eowyn's comment leads into another commonly stated emotion: mothers who feared their parenting was inadequate for their children's needs. Mothers frequently expressed the sentiment that they should have known about their child's autism beforehand. As Kristi verbalized about her daughter's diagnosis, "Why didn't I see this? I'm her mother! ...What kind of mother am I?" Several mothers felt that they should have been able to see the signs of autism or known how to teach their child needed skills. These mothers also struggled with knowing how to appropriately discipline their child with autism and maintain balance with other children in the family. Ann described

questioning herself and wondering if her son's behavior and special needs were related somehow to something she was doing wrong. Leslie expressed a similar thought. "I wonder all the time, are we missing something? Are we not doing enough? Are we not giving enough time? Are we not trying?" Participants also felt at times that what they offered as a mother was not adequate. One mother expressed this feeling.

I just think that's the hardest when you realize that you're not enough; that your love is not enough. Not that you don't love them, but it's not enough. It's not gonna reach it this time. There's something more... It's almost feels like... I've failed him. I've completely failed him. Dave held me in his arms and I just sobbed and sobbed. I don't know what else to do. We're trying and we're trying... We go on four or five hours sleep a night and I don't know if people realize that...

Personal doubt of parenting abilities was often aggravated by participants' perceptions that others viewed them as bad parents as well. Though these apparent judgments from others were often communicated through nonverbal behavior, mothers perceived that meaning frequently in public situations. One mother described her experience with being judged as a poor parent.

We get the look sometimes too, because with Ian... it takes my entire strength sometimes to try and like, pin him down so he doesn't hurt anybody. And it probably looks to other people like I'm being too rough. And I'm not. I'm just trying to not get a busted face or let him hurt somebody else. But yeah... they don't know looking at him. They just think I'm... being unnecessarily rough or something. I'm just trying to protect him and myself.

Several other participants described similar circumstances where others may have perceived them as bad parents because their child's appearance did not indicate any special needs.

Mothers described a variety of other negative emotions experienced following their child's diagnosis. Several mothers identified going through a type of grieving process after learning of their child's autism. Most common was a sense of denial,

preceding the personal realizations of their child's diagnosis. Several mothers discussed going through a period of mourning subsequently as well. Rayne stated:

You have a normal son; you can't give that up. You can't admit that, because that means he's no longer normal and you're gonna have to face all of the things that you've been trying to avoid. So after I got his diagnosis, you know, I kind of floundered for a while... To me, it was like this disease of autism took my child.

Leslie expressed how her feelings of mourning were not specifically for her children, but rather for her expectations.

You almost mourn a little bit... Not my kids. I didn't mourn the diagnosis... You're born having expectations for your kids that you didn't realize you had. You're just so sure they're going to go to school, do sports, date, you know, everything. And all of a sudden, I had to change. I mourned my expectations, but definitely not my children.

Changes in expectations seemed to be an important component of the emotional transition that occurred for mothers as they began to adapt to their children's autism.

Changing Expectations

As discussed previously, part of the adaptation process involves redefining the circumstances presented. Less tension between expectations and actual happenings will promote adaptation for individuals and families. In the case of these mothers, changing their expectations for their children with autism was a crucial step in overcoming negative emotions and progressing toward personal adaptation. As Leslie stated, some parents do not realize they even have expectations for their children, until they realize those expectations may not be met. The loss of former expectations may be difficult, but is necessary for mothers to replace those expectations with new hopes and goals for their children and families.

Ann and Chris both stated their initial expectation that since their sons were born "normal", they wouldn't have any major challenges with them. As Chris described:

You know, they come out and you look, ten fingers, ten toes, yay! And you just go, okay! But as they grow... you'd never expect to have one... and it does change your life.

Ann's experience was similar:

When I had Michael, the first thing when he came out and they say, 'Oh, you have a healthy baby boy! ...Everything checked out great... This just shows how stupid I was, but I just immediately thought, 'Okay, okay, I won't have to deal with anything probably til he's a teenager.' So when he was diagnosed, that's what hit me hardest... I was not prepared... 'He's healthy! I don't understand!'

One challenge of shifting personal expectations involved uncertainty about the child's future progression. During the focus group interview, several mothers conversed about adults with autism and what expectations were realistic for their children. Kristi shared her experience of getting to know a local grocery bagger with autism, and wondering if her son would achieve a similar level of independence as an adult. When she mentioned this to her son's teacher, the teacher responded that she hoped for much more for that child. Kristi was left wondering what an appropriate level of future expectations should be for her son. Eowyn verbalized a similar quandary:

On the one hand, Sam requires a lot of heart and you throw your whole self into it, but it kinda hurts to think about all the dreams that you had, that you've lost. And now, you still feel kind of an obligation to help him achieve all that he can, but you don't know what that is. You never know when you get there or not... You know, do I start a savings account for college? ...Do I do that? These are things you have to face.

Another difficulty of determining appropriate expectations, as expressed by a few mothers, was determining their child's perspective and interests in relation to their expectations. For example, Leslie shared an experience of realizing that her son's interests did not match her goals for him.

I used to worry, 'Oh, he's so lonely. He's unhappy.' So finally, when he's able to talk, I ask him, 'Are you unhappy at school, just sitting in the field collecting

rocks?’ He says, ‘Are you crazy? No, I love it.’ Alright. I was so afraid that he was unhappy, that he just sat there wishing he could be with everybody else, but I was wrong. He loved what he was doing... If he didn’t, why would he be doing it? He would come home with just pockets full of them... ‘Oh, he’s so lonely.’ No, he wasn’t at all.

In the process of the interviews, some mothers exhibited a noticeable change in tone and facial affect as they shifted from talking about their negative emotions and disappointed expectations to talking about their child now. Cultivating new goals and expectations seemed to accompany positive adaptation for the mothers in this study. One prominent concept that seemed to help these mothers in developing new expectations was changing their focus to the near future rather than being preoccupied with uncertainties in the years ahead. As Janet described:

We’re not sure what her life will be like as she grows up. So we want her to have the best possible life that she can have, and do everything that other kids do, but we know there’s going to be limitations. So it’s... kind of a day by day, year by year, way of thinking.

Mothers also described changes in expectations for themselves, their families, and others. Modifications in expectations seemed to liberate these women, in a sense, from the concern, anxiety, and disappointment associated with unmet and unrealistic previous expectations. Some participants expressed current expectations for themselves that demonstrated a shift from the negative, overwhelmed feelings experienced previously. One mother said:

We’re doing what we can, and you can only do so much. I think some of these families out there... they’re trying to cure their child... but we just take it for what it is, do what we can, and you just keep going with life.

A few women also described having higher expectations for their other children, in terms of the amount of responsibility given them in the family. Several participants expressed having more flexible expectations for others they encountered in contexts

outside of their own family as well. Having a child with autism became an eye-opening experience for them in regards to the challenges faced by other children and families.

Some participants mentioned specific goals they had for their children or for themselves. For their children, these goals usually focused on achieving certain social skills or functioning abilities. The goals they had set were generally related to present functioning levels. For instance, one mother's goal was for her child to interact with her, while another mother's goal was for her son to go to school without an aide and maybe participate on sports teams. Goals that participants expressed for themselves often related to ways they wanted to help their children, such as learning how to teach them needed skills. One mother also shared her current goal of educating others about autism, in hopes of reducing uninformed judgments of her child.

Social Support

Stressors experienced following a child's diagnosis seemed to be counterbalanced by available resources. In response to an original research question, discussions of the availability and usefulness of resources demonstrate some variation among families. Though the Double ABCX Model considers all expanded resources within one variable, the impact of social support on families of children with autism begs separate consideration. Social support offered to these families encompassed a range of utility and value. Though this social support came in many forms and its effectiveness varied by family, it was inevitably an influential factor in maternal and familial adaptation. Social support is discussed here as an aspect of maternal adaptation because of its important role for the women in this study, though it undoubtedly influenced the family system as a

whole as well. What mothers reported as both helpful and unhelpful support was provided by extended family, friends, members of the autism community, and others.

Family Support

In several cases, extended family members were the first to suggest tendencies of autism based on their observations of the child. These family members consistently had good intentions and cared about the child's needs. Though mothers acknowledged this, they were not always open to initial suggestions of autism, sometimes because they were not ready to accept the possibility of their child's special needs. Family members continued to offer support, usually in terms of advice or information about autism they had gathered. For Melissa:

My mom has been a huge support. She goes and reads all the stuff and emails it to me. She's like me. We're both novices. But she has the time to get on the computer and look, and she actually reads autism books and then will... send me...highlighted pages of things that she's found that might be helpful.

A few other mothers mentioned particularly supportive siblings, who often related well because they also had a child with special needs or had experience working with children with special needs. Participants identified the relief that it was to talk candidly with a family member about the challenges, humor, and successes that occurred in daily life with autism, and to feel understood and validated. When family members had this type of positive relationship, they often shared suggestions or information they had discovered, related to autism. In addition to providing emotional support, some extended families help in daily care of the child with autism. In these cases, mothers expressed great appreciation and reliance on the invaluable support of family. For example, Lynn described supportive efforts from her family.

Every day, if I didn't have them, there's no way I could do it. They pick him up from day care and keep him until I can get home... There are nights when I can't get Cole to calm down, and he's just completely out of control, and I'm able to call someone and they have to come over to settle him down. Because at that point, mom isn't gonna be able to do it, you know, someone else needs to try. So family has been a huge support.

Unfortunately, not all support offered by extended families was viewed so positively by the mothers in this study. In the cases where offered support was not received well, mothers were often overwhelmed with the frequency, amount, or presentation of advice or support. Unwelcome support from family members, according to the descriptions of these mothers, often came immediately following a child's autism diagnosis. One mother said:

With my mom, it was kind of a two-edged sword because she was so adamant... She would call every day and just say, you know, 'Have you gotten him into this program yet? Did you take him off of the milk? Did you stop feeding him this? Are you giving him his cod liver oil? Are you giving him this vitamin and this vitamin and this vitamin?' We just couldn't possibly do the 600 things that she called every day about. And it got to the point where that was kind of a strain... She really wanted him to get better and she believed that that was possible, but she didn't understand that it wasn't physically possible or mentally advantageous for Aaron to be put through all of that at one time.

One mother in the focus group described a situation when her mother-in-law brought her a large stack of papers that she printed off with information about autism. The mother was already overwhelmed with the needs of her children, so this well-intended support only added to the stress she was already experiencing. Another mother in the group responded to the story, "Or would you like to take the kids for the weekend so I can read all of it? That would be a little more helpful... Think about what really helps those parents who are about to lose their minds." Some other reports of unhelpful

support involved extended family members interacting with the child with autism in a way that escalated behaviors or disrupted norms in their household.

Support from Friends

Offers of support from friends and acquaintances were received with similar responses by mothers in this study. Some support was viewed as extremely helpful and appreciated. Other help actually resulted in more stress for the mother. Chris summarized what several other mothers also expressed:

People standing on the outside saying, ‘Well, why aren’t you doing this and why aren’t you doing that?’ It isn’t helpful at all... ‘Well now this mother, Jenny McCarthy, she cured her son, and she did this and that.’ And, ‘Have you done the diet? And have you done this and that and the other?’ Well I’m not going to, because there’s no reason. He doesn’t have the symptoms. Why would I try something else on him? The poor kid gets tested enough as it is. I’m not gonna mess around with him. So that is not helpful... What is helpful is people who are willing to switch with me, let me help them and they help me... So I’ll watch your kids while you do something, if you watch my kids while I take him to therapy... That is immensely helpful.

Several mothers reiterated the point that they considered friends and neighbors who are willing to help with daily activities and engage in a relationship with the family as more supportive than those who may offer unsolicited advice. Several mothers mentioned how meaningful it was when friends offered to babysit on occasion, or when neighbors invited their child with autism to participate in birthday parties or to play with their own children. Hannah described how friends who are supportive to both her and her child have become important to her.

People that are good with my kids... particularly Ian, people I can see that he likes, that he knows that it’s a good place to be, and they like him and they treat him normal and all that... Those people have my undying friendship for life. ...There’s nothing like those people in his life and I value them... so much more than I thought I could anybody outside of my family, just because, how they are toward Ian tells me so much about them, their character. And those are people that I want to be around, because they get it.

Some mothers, while acknowledging how much they appreciated sincere offers of help and support, also conceded that they did not feel comfortable accepting these offers at times, because of the demands accompanying their child's special needs. A few mothers shared examples of entrusting their child with a family member or friend who had offered to babysit, only to find the child in a precarious situation later, of which the adult was unaware. These mothers did not think the adults were being neglectful necessarily, but stated that few people understood the attention required to watch after their children with autism. As Lynn described:

I don't take everyone up on their offers because I'm always nervous... 'cause it's not like you're just dropping your kid off and saying, 'Have a great time.' You have to drop him off and explain to them, 'Well he doesn't always use the bathroom on the toilet, so take him in and have him try. Then if he poops his pants, you can throw his underwear away and put this on him. And don't let him get by your stove, and lock all your doors.' So you can't just take him to someone that doesn't have experience... Because when you say to them, 'You have to keep your eye on him the entire time,' they think that means that they can go get on the computer. And that's not what that means! So you can't take everyone up on their offer.

Keeping this in mind, it seemed to be almost as important to these women just to know that others were willing to support them if needed, even if their offers of support were refused. For example, Janet had a commitment that would have required her to leave town during the same time that her husband was out of the country.

And my next door neighbor, she actually volunteered to take her [Janet's daughter] for three days so I could go. I'm like, 'I love you to death for doing that, but you're not ready for that!' As we were talking, she goes, 'You know what, I think you're right. I don't think I could have handled it for three days.' And I said, 'I love you for volunteering, 'cause two years ago that wouldn't have even crossed your mind.'

Some mothers noted changes in their friendships following their child's diagnosis, including which friends they spent time with and how often they spent time with these

friends. Overall, participants reported spending less time with friends than they did before having a child with special needs.

Community Support

In addition to supportive friendships previously established by these women, several of them noted the importance of new friends met through the autism community. Participants valued advice and guidance from other mothers who had children with autism. Not only did they appreciate having a mentor to negotiate the challenges of having a child with autism, these mothers welcomed the emotional support, both formally and informally, provided by these other women. Several women mentioned the influence of local support groups in their own coping and adaptation processes. These mothers indicated that support groups also helped with their overall family functioning because they could vent about frustrations they faced in a separate setting with others who related, and not bring those stressors back home. Janet described:

I have people I can call and say, ‘Okay, this is what’s happening. Okay, just get me through this’... It’s nice to know that I have friends that are going through the same thing. You know, their kids are different, but it’s still the autism spectrum... ‘Been there, done that’. So it’s just nice to have that support of other people... ‘cause, you know, you’re just not alone.

Other community organizations, including church organizations, proved to be an important resource for these women as well. Some mothers mentioned large community events, such as “Walk Now for Autism” sponsored by the national organization *Autism Speaks*, as a beneficial resource connecting them to helpful social, educational, and professional networks throughout the community. Online communities also linked mothers to needed resources and provided a forum for more social support between mothers of children with autism.

As time and various elements of adaptation, such as coping, social support, and shifting expectations influence mothers, their maternal perspectives of autism also transform. Mothers were asked to identify their current perceptions of autism and their child with autism. Their comments, especially in contrast to reports of maternal perceptions prior to their child's diagnosis, provide interesting evidence of how redefinition of a stressor contributes to overall adaptation.

Autism and My Child

As families accessed more resources, including increased knowledge about autism, and learned to cope with the pile-up of stressors associated with having a child with autism, they also came to redefine autism and their child. In an intriguing transformation of perspectives, mothers of children with autism came to not only view their circumstances as a regular part of life, but at times, a beneficial component of their family system. Participants' perspectives of their children were loving and optimistic, and their views of life were positive. As posed in an original research question, mothers of children with autism and their families demonstrated perspective changes through redefinition, providing them with a realistic, yet accepting view of their child and autism. Redefinition of expectations and of other life influences propelled these families further towards a state of bonadaptation.

Mothers who participated in this study consistently stated that they had become more educated about autism throughout their child's diagnosis process and in subsequent years. As Rayne stated, "Autism became people to me. They weren't just a set of behaviors." These women affirmed having an increased awareness of autism and an increased interest in studying and learning about the disorder. They also asserted their

recognition that autism affects their child, but is not the definition of their child. Through the process of learning about autism, these mothers came to realize the complex relationship between autism and their child's personality, abilities, and character. Chris described her view of autism's effect on her son and others.

It's almost like they wear this mask of autism. And you have to get behind that, you have to release them from it, to find out who they really are. And there's always bits of the autism in their personality, but the more you learn about autism and the more you get to know them, you can pick them out.... People... who don't know autistic children... they only see the autism and they don't recognize the person, the child behind it who's trapped. And the more you work with children who are autistic, the more you can be patient... I don't know, it's like you can distinguish between autism and them, so you don't get frustrated as easily... You can recognize it... When you can understand what they're dealing with, that they're not dealing with what you have to deal with. They're dealing with way more... I see them more as individuals than as a lump.

Lynn added to this view:

I view autism as something that no one will ever be able to figure out. It's so different in every kid that you come across. It's very interesting to me because it's like this completely separate world. And I sometimes wish I could see into that world to find out what they're thinking, how they're feeling.

Several mothers described their child in relation to other children on the autism spectrum, commenting that every child with autism was indeed unique. Some mothers remarked that they were glad their child had certain challenges, and not others that they had observed among other children with autism. These comments demonstrated another way that mothers had redefined their child's autism. Some referred to themselves as "lucky" or "blessed" because their child did not deal with challenges that they viewed as more difficult than those they currently faced.

In making meaning of their child's autism, while incorporating newly-found knowledge about the disorder, several mothers offered metaphors or analogies to describe the autism spectrum, children with autism, or related subjects. Their descriptions

demonstrated ways that they currently frame their child's disability to make sense of the circumstances they encounter. Eowyn provided one example of creating a metaphor to enable better understanding of her son's autism for herself and others.

My explanation is, I have a Peter Pan. He never grows up. That's the way I put it. Because if you say he has autism, sometimes people look at you and... are like, 'Yeah, right.' Or some people are like, 'You're just using this as a crutch.' But somehow I thought of that a while back... Peter Pan's a hero. There aren't very many autistic heroes and... when I do find some, I kinda latch onto them. So that's my thing, I have a Peter Pan who doesn't grow up. And if they give me a weird look, I say 'autism' and they're like, 'Ohhh.' But it's... not holding up a sign saying, 'I'm hiding behind this label', it's 'I'm accepting him for who he is.'

Every mother expressed in some way unfailing love and acceptance for her child with autism. Not only did they recognize and understand their child's characteristics and needs, several mothers expressed how much they enjoyed their child. These mothers found humor in daily interactions and even in high-stress situations. They celebrated their children's accomplishments, strengths, and personal qualities. As Leslie described, "How often do you have a child that doesn't lie... that has never hurt somebody? It's just... pure love. I mean, to us, we're lucky. We're really lucky." Though some of the sentiments shared by other mothers are similar, I include several quotes of mothers sharing personal views of their child with autism. These statements illustrate not only the deep love these mothers have for their children, regardless of their diagnosis, but the adaptation processes that have taken place for them personally.

Lynn:

Autistic children are wonderful children. My son is very, very loving. He will hug anyone he comes in contact with. A stranger in the grocery store, he tells them he loves them, he kisses their legs. He understands things that normal kids don't. He understands how to read, he understands computers, he understands video games. But he doesn't understand how to use the bathroom on the toilet, or run, or watch for cars when he's crossing the street, or stay away from fast-moving

water or hot stoves... My perception is that all these kids have a chance no matter what level they're at. High-functioning, low-functioning, middle of the road, they all have a shot to be wonderful adults and members of the community. And they have so much potential. We just have to figure out how to unlock that... If I had a choice, you know, between my son with autism or a perfectly normal child, I'd choose Cole with autism any day.

Michelle:

I think that the best thing is that we just really appreciate the things about Aaron that wouldn't be there without the autism. I think that he's so innocent even in a way that my three-year old isn't. My daughter, who I love, is just so fiery and she gets influenced by TV and kids and everything possible. And Aaron is just, you know, sweet and wants to make you happy and wants everybody to be happy and content. And he's just always been that way. Really isn't affected by anything else going on around him.... It's been nice to see him stay so pure and unaffected, untainted in a way.

Ann:

Focus on the good, because there is so much good in there with these kids... You know, I love Michael! ...If somebody came to me and said, 'We've got a cure. We're gonna cure Michael.' I'd be like, 'Woah. I don't know about this.... Does that mean he won't be creative anymore? And crack me up all the time?'

Leslie:

Yeah, we're happy... We [she and her husband] were talking the other day and even asked, would we change it? And no, we wouldn't change it.... Once I started to look through their perspective, they are the happiest kids. They don't know to expect what I have in life. They don't know to expect all the things that I had planned for them. All they have is what they know. All they have is to them what is as normal as you and I sitting here talking.

Melissa:

I look at Lincoln and say, there's nothing wrong with him... he thinks differently and you've got to treat him differently. He has to look at life a little differently than I do, which means that I need to look at his life differently. And I don't think of him as a child with a disability so much as... I've got to learn how to work with him and learn how to be his mom... I don't look at children with disabilities the same way anymore. He's his own personality, he's got his own opinions about things, he's happy, he gets sad, he has emotions just like anybody else. He just looks at life differently.

Other Personal Adaptations

In addition to those discussed, mothers mentioned a few additional adaptations they had experienced during their child's diagnosis. At times, mothers had to compromise their own preferences when considering the needs of their child or family. For instance, Chris described herself as a "fly by the seat of my pants kind of girl", yet her home now runs as a "routine machine." Though she still maintains some flexibility, she has had to adapt her own lifestyle to fulfill her son's need for structure. A few mothers mentioned how their parenting perspectives had shifted because of having a child with autism. Some admitted to previously observing other children or parents and thinking, "I would never let my child do that" or "I would never do that." These mothers openly laughed at themselves for having these assumptions and recognized that they had each adapted their parenting to their children's needs, rather than basing it on their own previous principles. As Emily said, mothers must "choose their battles" with their children with autism, perhaps even more frequently than they would with their other children.

During early discussions of the time surrounding diagnosis, several mothers brought up social and emotional difficulties they faced. Interestingly, some mothers later discussed resolutions they had reached in regards to some of these same problems. For example, several mothers doubted themselves as parents initially and felt inadequate to handle the challenges of their child's special needs. Hannah remarked later in the group interview:

Somebody at one point when I was feeling that way said, 'You have to remember that Ian also has you as a mom because there's something there for him. Like, whether you can do A, B, or C, he'll get what he needs. But what he needs is to be in your family, with you as his mom, with Jake as his dad... That's the experience

he needs to have. That's what he's here for. And all this other stuff, whatever you can do is great. You know, you're doing everything you can. But... they need what you give them more than they need all that other stuff'... I think it's the truth.

Though transitions to accepting this type of resolve likely took some time, it was interesting to see such direct examples of changing perspectives.

Emotional Transitions

Throughout these interviews, mothers discussed the emotional transitions involved in personal adaptation. In the process of accepting the diagnosis, changing expectations, accessing support, and redefining their circumstances, mothers came to the realization that they could thrive again. Even their ability to verbalize emotional transitions that they previously experienced seemed to signify a certain level of comfort with their current circumstances. Eowyn reflected:

The first two years are the hardest. Those first couple years, when you first lose hope and then you try... to find hope again. And you're starting to figure out what works and what doesn't. And you have to... wade through all the different therapies and... find out what you can't afford and what sacrifices you can live with. And that takes a couple years. And then you suddenly realize, life *does* go on! You know, because for a long time, for those first couple years, it feels like it won't.

Ann found comfort in the idea that humans are very adaptable beings. She said, "When I heard Michael had autism, I just thought, that's it. I can't do it.... Now see, it's life... It's devastating, but then we become better for it." This adaptation and realization seemed to happen unconsciously for most mothers. One of Leslie's concluding remarks exemplified the emotional transitions that have taken place for many of these mothers.

It's interesting to talk. I very rarely talk about it. For years I didn't. I don't know why. It's like I thought, 'They won't understand' and I was too busy with, 'I can't feel.' I can't feel. I can't let anybody know what I'm feeling and I can't let anybody know that I'm crumbling inside. And now it's like, 'Oh, what do you want to know?'

Though the adaptation process will likely be ongoing for these mothers, given that their children's needs will change over time, they seemed to have reached a state of bonadaptation in terms of the stressors associated with autism.

CHAPTER 5: FAMILY ADAPTATION

Discussions of a child's autism diagnosis and related maternal adaptation cannot be adequately viewed without also considering the context of family adaptation. Because the child and the mother are both parts of a family system, any stressors, resources, or transitions that affect one family member will influence the whole family as well.

Autism is undoubtedly a stressor on the family, but mothers in this study provided greater insight into what kinds of effects having a child with autism has had on their families.

Family Effects

One common theme that mothers discussed was difficulty in balancing their children's needs, including their child with autism and other children in the family. Because a child with autism may have demanding needs in terms of time, interventions, or attention required, a few mothers expressed concern that their other children feel equally nurtured. Kristi described one experience where the needs of her whole family were brought into perspective.

So I called up the doctor that diagnosed Max and was talking to him about it. I'm like, 'I think we're gonna move... so we can have him go to school.' And he was like, 'For your information, it is \$20,000 a year.' ... He put it in perspective for me. He was like, 'You have three other children that you need to think about. Yeah, he has special needs, but your other children need you too.'

Several mothers acknowledged a sort of "team" approach toward working with their child with autism, where siblings were active participants in providing for that child's needs. Some mothers described relying on their children to let them know when their child with autism had run off or was in need of help. Parents also depended on their children to help the sibling with autism negotiate social situations and, to some extent, to report to the parents when the child with autism was unable to express themselves about

situations the parents needed to be aware of. One participant even referred to an older daughter in the family as a “second mother” to her child with autism. Extra responsibility or parental expectations for siblings of children with autism did seem to be more commonly associated with older siblings, but depending on the child with autism’s functioning abilities, younger siblings also shared increased responsibility in some cases. Rayne described the effects her son’s autism had on her other children.

They’ve taken responsibility of Caleb on themselves, because again, I’ve had health issues. So who’s been dealing with Caleb while I’m in bed and can’t move is my kids. The other thing that I really I think affects them is that... because I homeschool, I have a lot of time and energy that I have to dedicate to the children. But with Caleb I couldn’t dedicate any time to the rest of my children. It all went to Caleb. And they never resented him and they never got angry about it. They just know that’s the way it is. And they have been... exceptionally amazing that way... they were just partners in Calebville.

Though Rayne’s children may not have become upset by her son’s needs, a few other mothers noticed different reactions with their children. Especially siblings who were relatively young were sometimes upset or aggravated by their sibling with autism’s special needs or behavior. According to these mothers, their children perceived certain disciplinary differences or compromises (such as sharing or altering activity plans) as unfair and difficult to understand. In contrast, several mothers noted that their children had never been raised with anything different and just accepted special needs as part of family life. As Leslie described:

It’s our normal, we don’t know any different. Our first three were this way. It’s just how we’ve always run our house, scheduled. There’s movie times. There’s play times. There’s school times. There’s adventures every day. There’s things that you just do to keep things running and... make sure they keep progressing...

Other families, especially with siblings who were significantly older, seemed to require conscious adaptation to the child’s needs. Emily mentioned that her older

children actually received training through available resources on how to handle her younger son's special needs.

In addition to the adaptations that must be made within the family, siblings of children with autism often deal with implications in social situations outside of the family context. Especially for children who are relatively close in age to the child with autism, interactions with peers in relation to their sibling seemed to be complex. For example, Janet described how her older daughter was faced with challenges because of her other child's autism.

It's been hardest on our ten-year old because they call her sister 'weird.' They don't want her around, whereas she's craving that socialization with her sister and she wants to be with her and the friends. So that's been a challenge with her, is getting her strong enough, I guess, to be able to handle it... She is now sticking up for her sister. There are times where, 'Okay, we have to have this talk again.' But she does really well.

One mother also described how her children felt isolated, in a sense, because they thought they were the only kids that dealt with the challenges unique to having a sibling with autism. This mother recounted a conversation after one of her older sons had met some other children with autism and their families through a community project, when he said:

I am a sibling. You know, I have an autistic brother. And I felt isolated, like I was the only one who had to deal with cleaning poop off the floor every day. That I was the only one that had to dodge him when he decided to throw his cup of orange juice in the morning. You know, I thought this is it, this is my life, and I'm the only one like this.

Though siblings may experience stressors in different ways than parents, as part of the family system, they are directly affected by autism. Based on maternal descriptions, these stressors affected other children in the family to different extents. Some reported their child's behavior having minimal impact on their siblings in daily

activities, in terms of stress. Others had a different experience, as one mother depicted. “The kids are defensive every day of their life. They’re worried about how and what they’re gonna do that’s gonna trigger him.”

Another challenge that a few mothers recognized, usually associated with younger siblings, was learned behavior from the child with autism. These mothers described how some younger siblings would engage in self-stimulating or other atypical behaviors because they had observed it from their sibling with autism. In these cases, the learned behaviors caused increased stress for these mothers since they did not initially know what the behaviors were indicative of for their younger children.

In addition to stressors facing children in the family, effects of having a child with autism are also acutely felt by the parents. Maternal adaptation has already been discussed at length, but stressors, responses, and adaptation of fathers requires further investigation. A few mothers mentioned ways they had observed their husbands adapting to their child’s needs. For one father, this involved changing the way he interacted with his family because his loud voice triggered negative reactions for his son with autism. Another father, who designs homes professionally, provided drains throughout the house in the floors and bathrooms in response to his son’s love for water and tendency to flood things. A few other fathers made efforts to stay involved with the progressing diagnosis process, asking questions and discussing intervention options and child behaviors with their wives. Though not many examples of paternal adaptation were discussed, fathers likely followed somewhat similar patterns of personal adaptation to those of the mothers in these families.

Some participants discussed the additional stress that having a child with autism has put on their marriages. Financial burdens related to therapies and interventions were discussed by multiple participants. Though parents acknowledged that many resources were available to them, they also noted that there was no way they could financially afford providing all these services for their children. Varying insurance coverage, preferences for interventions, and child needs all seemed to factor into the amount of financial stress felt by parents in this situation. Parents also acknowledged feeling additional responsibility, given that they now had a child with special needs. Eowyn described fiscal responsibility that she and her husband felt for their son following his diagnosis.

When we got the diagnosis, we realized we needed to go make wills, we needed to get life insurance... you know, all of a sudden, we realized that all of our responsibilities with Sam in particular would outlive us. It wasn't enough to die. I can't die! I've gotta set all this stuff up for Sam. Because otherwise, who's gonna take care of him? If I don't say, the sister-in-law who I know all of her kids love my kids and she is good with Sam... of everybody I know, she has the best chance of doing a good job with him. I can't let the court decide that! ... And if she's gonna inherit him... how fair is that to her. If I'm gonna ask her to take on this responsibility, I need to get a life insurance policy, so if something happens to me, she can cover his expenses for therapy. You know, I have to think about paying for therapy after I'm dead!

Other stressors inherent in family life seemed to increase for families of children with autism and a few participants noted making conscious efforts to strengthen their marriages because of this. Having a child with autism seemed to influence every aspect of family life in some way. Even basic decisions, such as daily activities, traditions, or family trips, were coordinated with the child's needs in mind. For example, Janet's family takes a big summer trip every year. She and her husband have had to shift away from activities and destinations that may have previously chosen, because of their

daughter's special needs. In her words, "Yes, it would be great to go see that place, but you know it's gonna be miserable for us. So we go do something else instead. We still see what we want to see, but we do it in different ways now." Melissa also noted changes in their family trips. Because of the disruption it causes with her son, they rarely visit extended family that live long distances away. This has affected some family relations, and prompted adaptation among extended family members as well.

Stressors that manifested themselves primarily in marital relationships varied in different families. One mother expressed an initial sentiment about her husband,

For a while, I kinda thought he didn't care. I was like, 'Do you not care at all?' 'cause I'm like researching all the books and talking about it all the time, and Scott was just kinda like... But ya know, I just realized we just take things in... totally different ways. For me it's like... so much you just want to talk and share, and hear and know.

Differences in coping strategies and adaptation processes between husbands and wives seemed to cause strain for some of the families in this study. The difficulties and demanding schedules associated with having a child with autism were significant for several couples. For a few mothers, the demands and stresses of having a child with autism became overwhelming, and ultimately devastating, to their marriages. One of these mothers shared the experience of her family and the effects of tremendous stress associated with her son's autism.

When my husband...first found out... he didn't want to believe it.... But he came around, and absolutely loved his son. But our son went through about two years of extreme tantrums... he couldn't communicate. He'd lay on the ground all night long screaming, kicking, hitting, biting, throwing things... My husband worked as a teacher also and coached at nights, and he'd come home and my son would still be screaming. And I was done. I'd taught all day, special needs students, and then you know dealt with Cole all night. And it's ten o'clock at night and... he's just... completely out of control. We're up five times a night, and he just couldn't take any more. He said, 'I just, I can't handle it.' And he left...

But, you know, there was no fight for custody... He knew. He said, you know, 'You're the one that's done it all along and you can continue to do it' basically. So, it affected our family hugely, because... he no longer has a father figure in his life... I had a stepdaughter who is Cole's sister, and they don't get to see each other anymore because of that, which is hard, but she was absolutely wonderful with him. His grandparents are now in another state, and I'm here with the other grandparents, and that's been really hard on Cole.

But you know, autism is a hard thing on a family, a single mom, because... with any child, your job is never done. But when they have autism, things don't go normal. You don't go home and fix dinner and have a bath and go to bed and sleep through the night. You do a lot... It's just a difficult job. I wouldn't give it up for anything. I love it. I definitely wouldn't trade him, but I wish people understood how much it takes to raise a child like this.

Several mothers echoed this final sentiment, that raising a child with autism presents unique and intense difficulties at times, of which others are generally unaware. Stressors facing families of children with autism, including siblings and parents, following a diagnosis are decidedly strenuous. The effects of autism on these families instigate processes of adaptation, including the implementation of various coping strategies.

Coping Strategies

Coping mechanisms were an integral part of the adaptation process for participants and their families. Participants reported incorporating both emotion-focused and problem-focused coping strategies in their family processes. These coping strategies mediated the effects of stressors confronting families, as depicted in the Double ABCX Model. Coping was a daily occurrence for most of these families and was an underlying current of both maternal and family adaptation.

Families incorporated various coping strategies specific to their family contexts and evolving needs. Though some participants identified conscious coping strategies implemented in their families, many seemed relatively unaware of steps they had taken to

cope with family stressors. Some realized these strategies during the discussion and others identified them while answering other questions. One common trend I noticed in participant responses was coping through avoidance of stressors. Sometimes this involved avoiding interactions with people who provoked stressful responses, including extended family members in some cases. Some participants also felt that too much information was overwhelming, and therefore, avoided it. They wanted to be aware of basic information about their child's needs and abilities, and applicable interventions, but they chose to ignore other available information as a way of coping with their current situation. Melissa also expressed how she avoids certain activities with her son because of the inevitable stress that would accompany these activities.

I don't bring in the stress element. Like, I don't take him to the store. I don't even try it... I don't bring him to parks because if I do, he takes off from me... I don't do things that put me into a stressful situation if I can help it.

In contrast to coping strategies utilized to avoid stress, other strategies involved coping through proactive, alternative activities. For example, some participants spoke of going on walks or drives as a family to alleviate stress among individual family members. Other diversions, such as summer vacations or outdoor activities, helped families cope with the stress of having a child with autism. One mother mentioned the importance of frequent dates with her husband, giving them both a chance to get out of the house for a brief time, as a coping strategy in their family. For most families, having regular, structured time, including set schedules for daily activities, was an imperative coping strategy. Predictability for their children with autism seemed to be one of the greatest methods of relieving stress throughout the family. As Chris described,

Just to reduce the stress on him is how we reduce the stress on us... Most of the things that families typically do to reduce stress, it's a whole different story for us. You know, 'cause you're breaking the routine. And if you're gonna break the routine, you gotta prepare in advance. And it's a huge thing...

A few mothers discussed the importance of prioritizing as a coping strategy.

Because of the variety of options available to facilitate their children's progress, and the range of shifting needs for their children themselves, mothers spoke of having to focus their attention on more minute aspects of the challenges facing them. Michelle verbalized these efforts to cope with stressors.

I think that we've really tried to cope by picking the one thing that was most important to us... and then kind of letting everything else go. Because at first, we were just doing so many things and so many schedules and so many picture programs... that we just drove ourselves insane. And medicines too, like diets and pills and supplements and it was just crazy. So... just kind of stepping back and deciding what one thing is the most important to us right now, and then we fix that and move on to something else.

Several women mentioned religious or spiritual beliefs and actions, such as prayer, that helped them cope personally and as a family with the stressors of raising a child with autism. Leslie described having feelings prompt her to try things with her children when she was at a loss as to what to do. She said, "For us, I've needed to have something higher to hold on to... it has always been what has needed to be done."

Hannah described her belief in an after-life where her son's disability would no longer affect him as a comfort to her.

I'm just so glad that I don't have my grandma's view that... this life is it, because that would be the hard part. Like for me, my daydreams are not of a giant house and a great car. It's... when I can sit down and have a massive conversation with Ian. I'd be like, now what were you thinking when this was going on? What was this about? ...I can't have a real conversation with him right now and I'm... living for that day. I can't wait for that. That's gonna be... the best conversation.

Though the coping strategies discussed here are primarily from the mothers' viewpoint, they are likely similar to those employed throughout the family system. Spouses and children may also cope through avoidance of stressors, engaging in alternate activities, prioritization, or religious belief, among other strategies. According to McCubbin, et al. (1982), these coping strategies become a mediating factor, and type of driving force for adaptation. Coping facilitates the influence of other factors, including available resources, to promote family adaptation.

Resources

According to the Double ABCX Model, resources existing prior to the crisis event play an important role for individuals and families encountering preliminary stressors. In the case of these mothers and families of children with autism, certain existing resources seemed to be more influential than others. External community resources, such as professional or educational services available for these children with special needs, played a relatively minor role for most families. For the few parents who were taking advantage of services before receiving their child's diagnosis though, these resources did seem to minimize the distress of an autism diagnosis to some extent. Most families in this study were generally unaware of what external resources were even available for children with autism before their own child's diagnosis. Other community resources seemed to be more influential for these families, including social support. Personal and family resources, including capabilities related to health or family cohesion for example, were important in confronting subsequent stressors.

Following diagnosis, resources for child educational and social interventions were especially helpful to these families. Social support resources also benefited families,

though mothers likely profited most from family, friend, or community support. Social support resources specifically for siblings of children with autism are available in this region, but no participants mentioned taking advantage of these resources. Other resources on personal, family, and community levels proved to have a substantial impact on adaptation in the family system. One interesting component of adaptation among families of children with autism was *how* these expanded resources emerged. For some, the process of obtaining resources was complex, demanding, and uncertain. Because of the taxing, and often changing, needs of children with autism, discovering appropriate resources may have become a stressor in and of itself at times. When adequate resources were acquired, however, they greatly facilitated adaptation among these families.

Both before and after children's diagnoses, parents were referred to resources that others thought could benefit their child and address his or her special needs. Referrals to resources came from many different sources. Some pediatricians or specialists gave parents information about available resources with their child's diagnosis, or as part of medical evaluations. Educators also connected several families with needed resources, including services available through the schools themselves. A surprising number of referrals to helpful resources came from people not affiliated professionally with the autism community. Extended family members, friends, and sometimes new acquaintances informed many parents of resources that could benefit their children with autism. In some cases, these resources were merely mentioned in passing, while at other times, people researched information to help these families. Whatever the situation, parents tended to sift through the recommendations they were given in order to find services and supports that best meet the needs of their families and children.

Resource Availability

Since several of these families relocated to Utah within a short time before or after their child's diagnosis with autism, some of them had different resources available previously in other locations. Basic types of resources used to help children with autism are similar in any location though. For example, many children with autism benefit from speech therapy and occupational therapy, which may be accessed through public or private institutions. Participants mentioned a variety of resources they knew of, or had used with their child. Some of their children were in special education preschools or classes in the public schools. Others were enrolled in general education classes, but received additional academic, social, or other support based on their needs. Some children attended early intervention programs and a few had participated in home programs or therapy previously. Several participants' children were enrolled in private schools specifically designed to educate children with autism. In addition to services provided throughout the school year, some parents enrolled their children in summer school programs, usually to help the children retain developed skills. A few parents mentioned taking advantage of services provided by child psychologists and developmental pediatricians as well.

Several parents chose to involve their children in private services instead of, or in addition to, those offered publicly. While the reasoning behind which resources they chose was not explicitly discussed, some parents seemed to prefer public schools and services, while others favored private schools and services. One mother, whose son takes advantage of both public and private services, expressed her opinion.

I will say there is a huge difference in doing speech through school and doing speech privately... The school is wonderful, but it's different going privately...

The focus is different. I feel like at the school, they're held back by what they can and can't say, whereas privately, there's no bounds. So it's just different in the way they can approach your child and work with your child and the things they can talk to you about... And then also, I'm the one that takes him to speech privately, so I talk to the speech therapist every time I go. At school, they rely on him to bring home anything. And bless his heart, he's just not very reliable. It may or may not make it into his backpack. And if it makes it into his backpack, it may or may not make it home. And if it does make it home, it may or may not be in a form I can read.

In some cases, parents delayed taking advantage of resources, though they were aware of potential supports for themselves and their children. For one family, the child did not qualify for needed services because she was too young. Later, when she was old enough, she qualified and was able to use available resources. In a few other cases, mothers delayed accessing resources in part because of other simultaneous stressors. When participants felt that family life was already overwhelming and somewhat unsteady, they chose to postpone use of resources temporarily.

Most of the resources available to families directly benefit their child with autism, by providing assistance with certain activities, or providing therapy or intervention. Though these resources are designed for the child, the entire family usually profits from them. When daily functioning becomes easier, or more enjoyable, for the child with autism, the whole family's ability to cope and eventually thrive in their circumstances seems to increase.

Accessing Resources

Though participants theoretically have equal access to public resources in their current locations, their experiences with finding and implementing needed services were varied. A few parents had enrolled their children in schools or programs (sometimes before their child's special needs had been diagnosed), which led them into other

resources with little complication. Others received helpful recommendations in the initial stages of diagnosis, eliminating much of the personal effort otherwise required to seek out resources. Of those who lived in other states when first accessing resources, some reported having organized resource options made available to them along with their child's diagnosis. Others reported having few viable options available to them and being more satisfied with the resources discovered after moving to Utah. One mother specifically commented on how much she preferred the hands-on, in-home therapies that her daughter received in the Utah area to the previous program which she participated in somewhere else.

Several mothers told of qualified and helpful medical professionals, educators, and autism specialists who assisted them, not only in acquiring needed services for their child, but in discovering additional resources that could be made available. Chris described her appreciation of one special educator who took notice of her son in a typical classroom and proactively addressed his needs.

She walked by the room one day and witnessed what was going on... and she said, 'That's not okay. We can help him. He's struggling and we're not doing for him what we could be doing.' And so they called a meeting... and said, 'We are going to do this and this for him,' which I had never heard of another family that happening to. So I'm very grateful to Brookstone and everybody there for saying, 'We're not meeting his needs. We're going to change things, and this is what we're going to provide him.' And now he has a tech that goes with him. He goes to special ed social classes once a week. He meets with the school psychologist once a week. I mean they're just really bending over backward... And it's doing wonders for him.

A few families also discovered resources in public and private venues that assisted with their child's special needs, facilitating smoother family adaptation by allowing family members to continue in their typical activities. For example, one mother described her experience at Disneyland with her daughter.

They have what's called a guest assistance pass. And basically you go to the guest services and say, 'I have a child with a disability' and tell them what's happening... So I said, you know, 'I've got a daughter with autism. She will not be still. She will not wait in lines...She has no patience, and she'll run off.' And like on cue, she ran off. And the guy says, 'Safety issues?' And I said, 'Yeah, basically. But we need to have a fun time here.' So basically what it does is it puts you to the front of the line. You don't have to wait. Best thing around. So it's an amazing service. And you don't even have to show proof of the diagnosis. You just go in and say, 'This is what's going on.' And it's wonderful... If we were to stand in line for an hour and a half, it would be the most miserable thing in the world. But this way, we get to go on all the rides and we get to keep her active and it's great.

A few families in the study enrolled their children in therapeutic horseback riding programs, which their children loved and looked forward to. Two families in this study benefited from having a service dog to assist their sons with autism. Rayne noted her reliance on the dog as a resource benefiting the family and keeping her son safe.

Whenever Caleb escapes, he'll usually take the dog with him. And then if I can't find Caleb, I can find the dog. Like Caleb will hide under cars so I won't find him, but the dog will sit. And if I go run, if I'm around the neighborhood, my kids are calling for Brownie and Caleb, Brownie will start barking... If he's missing, I give my kids a half an hour to find him. If they can't find him in half an hour, then I get in the car and we drive and look for Brownie. If that doesn't work then we broaden the net... And we've never had a problem where we haven't been able to find him.

Though several of the mothers interviewed reported having generally positive experiences finding and using local resources for their families, several mothers also expressed frustration at the sometimes discouraging searches they had undertaken. One mother said after her son's diagnosis, she did not know who to call, or how to arrange for speech or occupational therapy for her son. Her school district has since organized an autism network which, though she only recently became aware of it, has proved helpful in suggesting potential resources. Kristi shared the experience of having her daughter enrolled at school with faculty who was arguably underqualified to meet her special

needs. A relatively new charter school, their special education teacher left for a better teaching position within the first couple months of the school year, and school did not replace him. Though Kristi was dissatisfied with the services provided after only a short time in the school, she did not want to remove her daughter because of the anxiety that would accompany such a change. Lynn also expressed disillusionment at the availability of resources that she actively sought out after relocating to a relatively rural area of Utah. In another state, her son had a speech therapist, occupational therapist, music therapist, and was in an early intervention preschool.

Now moving to Utah has been a different story... We left just absolutely remarkable services. And I moved here and I make phone calls and I never get return calls. I've looked online, I've done my research. I'm trying all my avenues and I just feel like it's dead end after dead end after dead end, which is really sad for all the children that live in Utah that need this support.

For parents beginning to pursue resources, significant personal effort was often required. Some participants also noted family members who contributed to these efforts of finding appropriate resources. Emily described having "no idea of anything", but seeking out information and resources through the internet and books. Several participants also noted that their husbands had spent time researching and reading to learn more about autism and their child's needs. Eowyn described how her personal exploration for autism resources and information benefited her son in a school setting too.

His teacher had twenty years experience, had a child with cerebral palsy, never had had an autistic child before, didn't have a clue what to do with him... I kind of threw myself into this... I dove into *The Child with Special Needs* and my mom with her psychology background was able to help me kind of understand what the basics were... and how to implement it. So I actually did an inservice for the teacher and the TAs and, you know, I have a degree in English! I don't know anything about autism! But I had to go in and do an inservice so that they know what to do.

In contrast to those who were not easily able to find available resources, a couple of mothers grew frustrated with having too many options, but not being able to use them. Janet and Kristi both described being aware of many types of therapies and interventions available, but because of the financial expense, they were limited in what they could actually access for their children. Other mothers noted difficulty in determining which of the available therapies was best suited to their child's needs. These parents sometimes consulted teachers or others who worked with their children, but often they determined effective treatments through trial and error.

Impact on the Family

While experiences with discovering and accessing resources were varied, all of the families in this study eventually found services that seem to address their child's needs for the time being. Professional and educational resources available to children with autism, as well as social supports and other resources that benefit their families seemed to have a great impact on families as they experienced processes of adaptation. Rayne discussed her hesitation to put her son in a public school classroom, since she was "just being self-reliant and... was just gonna make it better [herself]." After realizing how much attention her son demanded of her and the rest of her family, she finally conceded.

After the diagnosis and when he was started going to school and started doing resources, it seems like there's been kind of a collective sigh of relief. 'Okay, maybe we're not alone in this.' If he really has a disorder then we can go, 'Alright.'

Fulfilling children's needs with available resources is a crucial step in facilitating family adaptation. Several mothers expressed having a "sigh of relief" experience when they finally settled on appropriate resources for their children. Hannah articulated how

educational resources made her immense responsibilities suddenly become more manageable.

I remember saying to my mom after he started, after he'd been in a couple weeks and I knew he was in the right place. She said, 'Do you feel like a burden's been lifted?' And I said, 'Honestly no, I don't feel like it's been lifted, but I feel like I've got people sharing it with me now... I've got this line of people that are right there in the trenches with me. It's not gone, 'cause he's my kid and it's lifelong... But just knowing there's this team now, that these people that really do care, and they have his best interest at heart. Just being able to spread that around and share it a little bit was just like, 'Okay, this feels like we can put one foot in front of the other again now.'

In addition to feeling a reprieve from stressors, resources actually provide an opportunity for siblings to learn new skills and develop potential interests. As one mother described, "I see my kids really gravitating towards special needs kids... They have a connection... now I think which is very powerful." A few mothers described how some of their older children had become involved in volunteer activities related to individuals with disabilities, and had considered studying special education or therapeutic fields in the future.

Family Perceptions of Autism

Families encountered stressors associated with autism, developed coping strategies, and accessed resources to facilitate adaptation, which prompted a transformation in their perceptions of autism as well. Redefinition, discussed as a component of maternal adaptation, also occurred for other family members. As siblings and parents changed their interpretations of autism, its accompanying hardships, and their family member with autism, they progressed toward bonadaptation as a family system. Mothers described their perceptions of autism prior to having a child with the disorder, and other family members likely held similar perceptions.

In terms of extended family members, it seemed that no matter where they began in terms of their relationship with the child with autism, or their correct or incorrect views of autism generally, they moved in a positive, more informed, direction over time. Some family members developed meaningful relationships with the children and accepted them regardless of ability or disability. Others overcame misconceptions, realized how they could be more helpful to families, and settled into acceptable relationships with the family and child. Overall, extended family perceptions seemed to show a pattern of adaptation to a child's autism, just as immediate families and individual family members, though perhaps on a less dramatic scale.

Immediate family perceptions of autism also alluded to personal transformations and adaptation. Several participants acknowledged changes in expectations throughout the family, and greater flexibility in accepting individuals without judgment. Although actual daily events and challenges may not have transformed family life into a perfectly adjusted existence, alterations in family perspectives greatly improve potential for adaptation. Chris summarized her family's current views by saying,

You know, you're a little more understanding, a little more real. You don't try to hide behind the façade of 'Everything is fine. We're just a perfect family.' Not that you tell your troubles to everybody, but you just try to be more real and more understanding.

As mothers described family's perceptions of their child with autism, several described what could be considered essentially stereotypical family relationships, with only small variations demonstrating adaptation. For example, one mother described the relationship between her children:

He's just a normal older brother who teases them relentlessly and is the coolest thing ever and they would do anything for him. And then they yell and scream because he trips them or pulls their hair. You know, he's an older brother.

Patrick and Kinsie are best friends, but Buddy and Kinsie definitely have the big brother- little sister thing going on. Which is annoying, but it's part of a family.

Just before this description of sibling relationships in their home, she explained how their relationships have adapted to meet the special needs of her oldest son.

Speaking of her second child, Patrick:

I do rely on him. More than a mom would normally rely on a 6 year old I think. I've explained a little bit... He's had to be more accountable, because Buddy's receptive language is more along the lines of a four- or five- year old... So Patrick's had to be the 'watchman on the tower' kind of a thing. Like when Buddy takes off, then Patrick comes and tells me. And it's Patrick's responsibility to tell me. Even though I keep an eye on him, that kid is fast. And I'll check on him and two minutes later he's gone... So Patrick has definitely had to become more responsible, more accountable, even than is fair.

This account of family relationships seemed very typical among the families in this study. Siblings resumed normal, daily activities, progressing in their relationships and family interactions, but including the modifications necessary to accommodate their sibling with autism. Rayne shared an experience when she was under stress and one of her sons brought her the situation into perspective.

But I had gotten the house all cleaned up and I was ready to leave. And Caleb had gotten an orange juice or milk or something and threw it everywhere. So there I am, you know, time schedule, had to get [there] by a certain time, and I have to remop the kitchen and wipe down all the cabinets and... I was ready to lose it. And my son walked up to me and he put his arm around me, and he goes, 'Mom just remember, it's just Caleb.'

Instances like this, where siblings spontaneously show acceptance of their sibling with autism's special needs and diffuse potentially stressful situations in a family context, demonstrate bonadaptation in the family. Several participants shared experiences when children and parents collaborated to overcome challenges or make adjustments in family interactions related to their child with autism. Though a few parents mentioned particular

children who were still struggling with their sibling's autism and associated challenges, most participants described relatively well-adapted family systems.

Both maternal and familial redefinition of autism and associated perceptions of children with autism were closely related to cultural and social contexts of the family and community. Cultural perspectives, including how families viewed disability diagnosis overall, how a child's atypical behavior was accepted in social settings, and dynamics of family relationships affected how families adapted over time. As discussed previously with Griswold's cultural diamond, social and cultural context anchor family interactions and processes. Families in this study experienced cultural influences from their socioeconomic, religious, and racial/ethnic groups, which simultaneously impacted their adaptation and coping processes. Recognizing cultural context provides an essential framework for understanding family adaptation.

Ongoing Adaptation

An interesting component of family adaptation among families of children with autism is that, to some extent, adaptation will be ongoing throughout the life course. Unlike other crises in family life, this stressor is not something that requires just one period of adjustment. Even after families reach a point where they have initially adapted to the needs and conduct of their family member with autism, the child will not remain a constant from that point on. Like any typical child, children with autism grow, develop, and demonstrate new interests and abilities. However, because of the atypical aspects of their development, children with autism may also encounter new challenges, exhibit new behaviors, experience new delays, or regress from previous developmental advancements. Lynn described her family's adaptation:

It's always a process. New things always come up. The behaviors don't always stay the same. He could go through a really good time, where good we just have our normal life, then he goes through... a bad time... When we go through one of those, we have to change what we're doing. We have to find new therapists, we have to look at medications, we have to visit different doctors... So I've adapted to it, but... I think it'll always be an ongoing process... We'll have to be flexible for the rest of our lives. But I guess I've adapted to being flexible... I'm a work in progress. He's teaching me lots of things.

As Lynn expressed, family adaptation is an ongoing process, a “work in progress.” Though families in this study seemed to show characteristics of bonadaptation, the process adjusting and coping does not completely end at this point. As described in McCubbin's model of family adaptation, families may spend significant time cycling through post-crisis variables before reaching bonadaptation. Then, after feeling they have adapted well to the stressors of having a child with autism, their circumstances associated with that child may change abruptly or subtly, placing them again at the start of a new adaptation process. New stressors may arise, changes in the family system may alter dynamics, a child's needs and behaviors may shift, and adaptation must continue. Cycles of family adaptation will recur differently for different families, since they relate to unique circumstances for individual children on the autism spectrum. However, as families progress through the adaptation process initially, they learn and discover important strategies for successful future adaptations.

Positive Effects of Autism

Mothers in this study were asked to reflect on the positive effects they had observed in relation to their child's autism. Some participants seemed caught off guard by this question, but after brief consideration, appeared to enjoy discussing the topic. Their answers usually centered on characteristics, experiences, or opportunities presented to them personally or to their families as a result of their child's autism. Melissa summarized some of the positive effects she had observed in her family.

My patience level has really grown a ton because... he needs extra patience. And my husband's patience level has really, really grown a ton.... I think just our knowledge has grown a whole ton, where we didn't know anything about special needs. Now all of a sudden, we're meeting new people through this disability. People we would never have been friends with, we're friends with. And opportunities that we never would have had, come up...

Many of the women interviewed made some reference to increased patience and understanding. Several also mentioned their increased appreciation for and celebration of small steps of progression. Lynn expounded on the benefits her son's autism has brought to herself and those close to the family.

I can't think of the right words other than just, pure love. The people that knew Cole in Arizona, friends, colleagues, had a true, just, love for him. I move here, my family...can't wait to see him. They can't wait to pick him up. I feel like... he's brought people together. It's brought an awareness of autism to my family and people around me...

It's made me appreciate everything that my child has done. Who else appreciates that their son learned to sleep through the night? Not many. I mean they might at first, but when you go through... five years of your child not sleeping through the night and they finally sleep through the night, that's wonderful.... He didn't say 'Mom' until the age of three... I mean, I still know the date... So I think we just appreciate the little things a little more. Not that regular parents don't, but that's just the norm, right? They can say it, and then they say a sentence... A year ago my son couldn't say a sentence, and he can now and that's awesome! That's remarkable.

A few parents described specific characteristics that their other children had developed in response to their adaptations and experiences with autism. Some of these included patience, understanding, generosity, unselfishness, willingness to forgive, kindness, maturity, less inclination to judge, and love. Participants recognized some of these traits developing in themselves as they adapted to life with autism as well. One mother also described how she had become more assertive and a better advocate for her son's needs. In reflecting on the challenges and adaptations they experienced associated with autism in their families, these mothers readily recognized positive effects.

Advice for Others

All of the mothers interviewed gave suggestions for other families who may suspect that their child has autism. The advice given seemed to reflect personal discoveries, challenges overcome, or lessons learned by research participants. Some of the comments made reiterate points discussed in other areas of the interview, but when asked to provide advice to other families, these were the subjects that participants chose to emphasize.

Several mothers asserted the importance of getting a formal diagnosis that correctly identified their children's special needs. They felt that the diagnosis was a key turning point in helping their children make needed progression. A few participants emphasized persistence and assertion in obtaining the diagnosis, regardless of perceived setbacks, inattention of professionals, or personal uncertainty. As Janet stated, "Get the diagnosis. Do whatever you have to do to fight it... Because once you have that, the doors open... the diagnosis I think has helped us the most." Leslie asserted the need for parents to serve as advocates in their children's diagnosis process as well.

Trust your instincts. Even if a doctor's telling you one way, even if all this research is telling you one way, if you feel this is what's best for your child because you know your child better than anybody, go with it and run and whatever falls behind you will fall. Whatever happens around you, just trust your instinct more than anything.

Multiple participants mentioned the need for mothers to make efforts in behalf of their children, not only in obtaining a diagnosis, but in securing appropriate services and other resources. Lynn believes that without the early intervention services she found for her son initially, he would not be functioning at his present level. Ann also discussed the importance of early intervention and the hope it can foster for parents of children with autism. Several mothers suggested the importance of mothers educating themselves about their children's needs and about autism in general. Chris cautioned against focusing on anecdotal reports of autism available in books or online though, since children may be affected so differently as individuals. She said, "Be careful what you read and don't just assume your child doesn't have autism because they're not like the story of the other child you read." Rayne also recommended being proactive, yet selective while researching autism.

Be open... there's a lot of different ideas about everything out there. And if you have already predispositioned to close your mind about one side or the other, you really kind of miss out. It doesn't mean just because you read about a different theory that you're gonna accept it... The more education you can give yourself, the more confidence you have that any decision you make will be the best that you can make, because you won't have closed your mind off...

Several mothers recommended sharing this education with others, including family members, friends, and even professionals who may benefit from information gathered. In addition to working independently for resources, some recommended finding helpful social supports. Michelle articulated what several mothers expressed.

I think that really the best thing that we ever found was... a solid support group, people who had been through it before... The most frustrating thing about autism right now is that there's so many avenues to take and you can't possibly do all of them. And I think it's invaluable to have people who have done it before and can help you kind of navigate that.

Two mothers specifically advised others to examine their perspectives and perhaps change their viewpoint in order to adapt more easily to the circumstances in which they find themselves. Leslie gave the following poignant advice to other families of children with autism.

Find joy in the moments... Remember it's just a moment and that moment passes, and what you do in that moment defines who you are and how your child will be... When there are bad moments, remember it ends. That a tantrum, whether it's fifteen minutes or three hours, it will end. Don't regret a moment in that time... Find the joys in the moments when you do have joy... It's not something to mourn.

Your child is still your child before the diagnosis, just without your expectations. Your child hasn't changed. Your expectations have to change. Your child is not unhappy. Your child doesn't know any different. It's you who are unhappy maybe, and it's you who realized that something is changing. But they are who they are... It is hard. It is heartbreaking. But learn to look at the world through their eyes. Once we do that, it changes... It totally changes perspectives. Nobody's every insolvable.

Other participants' advice given for families of children with autism included taking time for introspection before sharing news of the diagnosis with others, anticipating grieving emotions following diagnosis, and pursuing a diagnosis and resources as soon as possible after recognizing a need. One mother also recommended obtaining a 100-day kit from *Autism Speaks*.

CHAPTER 6: DISCUSSION

Implications

There are several implications of this study's findings that families of children with autism follow similar patterns of adaptation to those delineated in the Double ABCX Model. For instance, accessing expanded resources following diagnosis was valuable in moving mothers and families toward bonadaptation. This finding should encourage educational and medical professionals to refer families to potentially helpful resources soon after diagnosis in order to facilitate adaptation. These professionals should also take measures to ensure clear communication with families and accurate diagnosis of autism in order to avoid potentially negative experiences during the diagnosis process. Service providers and community programs should also recognize the importance of offering resources in an organized and accessible form to families who may benefit from them.

One particular resource, social support, was especially influential in promoting maternal and familial adaptation. Public and private programs associated with the autism community may greatly benefit families by providing organized forms of social support, including support groups or social networking opportunities. The need for social support among these families pertains to the community as a whole as well. Especially due to the prevalence of autism in the Utah area, community members have a responsibility to become educated about autism and related hardships for families, and to lend support to families of children with autism whenever possible.

Another important implication of this study is for the families of children with autism themselves. For families who have successfully navigated repeated adaptation processes, the accounts given in this study may provide encouragement and validation of

their efforts. For families with recently diagnosed children who may find themselves thrown into the early stages of adaptation to autism, this study provides perspective and hope. As these families access appropriate resources, acquire helpful social support, and redefine their circumstances and expectations, they will likely reach bonadaptation over time. Families of children with autism face unique and acute stressors, but many family systems respond to these challenges with resilience and eventually make successful adjustments.

Limitations

A few limitations of this study should be taken into account when considering its findings. Primarily, although adaptation has been discussed as an ongoing process that occurs over time, this study took place at only one point in time. Although maternal reflections were likely accurate, they may have been biased by the mothers' current state of bonadaptation. Therefore, this study was limited in that it evaluated longitudinal processes based on a single point of data collection.

Another limitation of this study was the demographic homogeneity of the research sample. Although specific data on race/ethnicity and socioeconomic status was not collected, most participants were evidently white, middle-class women. With a more ethnically, culturally, or socioeconomically diverse sample, results may have varied. Women in this study were also strongly influenced by Latter-day Saint religious norms and culture. Part of this cultural influence includes a strong social support network through church organizational structures. Also, these families demonstrate higher fertility than would commonly be seen in other places or cultures. These unique

demographic characteristics limited the study's scope and findings to a very specific sample.

Future Research

Initial exploration of family adaptation among families of children with autism yielded several additional research questions prompting future investigation. Given that this study focused on responses from mothers of children with autism, a natural expansion would be to evaluate responses from fathers of children with autism. Personal adaptation may progress differently for these fathers than for the mothers in this study.

Other variations of this basic research design would allow for more complete understanding of adaptation for families of children with autism across varying demographics. For instance, studying families embedded in diverse cultures would provide a different context for adaptation. Contextual factors associated with families from a broad range of socioeconomic backgrounds would also influence adaptation. Even including other participants from a middle-class, predominantly white background, but *without* strong religious influences may provide interesting comparisons to this study. Essentially, any expansion of the original demographic used in this research would enable greater understanding of the population and possibly lead to generalizable results.

As mentioned, conducting this study at only one point in time limited its potential findings. Future research could rectify this shortcoming. For example, a longitudinal study following a few families throughout the diagnosis process and subsequent adjustments would provide valuable data on family adaptations. Another approach could be to investigate the experiences of different families at multiple points of the adaptation

process and compare their responses. Including multiple points in time would allow for a more comprehensive and accurate view of family adaptation processes.

Several participants referred to stigma they felt from others in relation to their child with autism. As Griswold described in her cultural diamond, both creators and receivers of social and cultural interactions actively make meaning of their interrelations. Given this theoretical foundation, another future research question would deal with whether stigma perceived by mothers of children with autism is actually intended by others with whom they interact. Discerning between perceived and intended stigma may provide insight into maternal processes of adaptation and others' perceptions of autism.

As discussed, adaptation for families of children with autism is dynamic and continuous. One component of this ongoing adaptation which requires further investigation is the decision of a family member to exit the family system. In the case of divorce or separation specifically, individuals may choose to leave the stressors of caring for a child with autism behind rather than remaining at a state of maladaptation or continuing in attempts at bonadaptation. Studies of how, why, or in what timing these family members exit the family system due to autism-related stressors would provide interesting insights on family adaptation. Another component of ongoing adaptation worth investigating is whether families who subsequently return to adaptation processes after reaching bonadaptation adapt differently than they did when faced with stressors and adaptation initially.

This study served as a preliminary exploration of family adaptation processes among families who had children diagnosed with autism. Findings of this study prompt

several additional questions. The field of social science research on autism would benefit greatly from any future research related to autism and family processes.

Conclusion

Adaptation processes among mothers and families of children with autism closely mirror patterns of adaptation proposed in the theoretical model by McCubbin, et al. (1983). Families presented with the stressors of having children with autism adapt by implementing coping strategies, overcoming any potential pileup of stressors, finding and utilizing helpful resources, and redefining their circumstances. As they successfully navigate these components through various family processes, families of children with autism achieve a state of bonadaptation, which is essentially a balance of family demands and abilities.

This study serves as an exploration of adaptation processes and experiences associated with autism diagnosis in the family system. Findings of this study demonstrate the value of investigating unique family processes associated with having a child diagnosed with autism. Further sociological studies in this field would benefit families, service providers, educators, medical professionals, and communities by increasing awareness of relevant issues associated with autism in our society.

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APPENDIX A: PARTICIPANT INFORMATION

Any information provided will be kept strictly confidential and will not be used for any purposes unrelated to this research.

Name: _____ Age: _____

Marital Status: *Married* *Single, divorced* *Single, never married* *Widowed*

What level of education did you complete?

High school *Some college* *Bachelors Degree* *Graduate Studies*

What level of education did your spouse complete? (if applicable)

High school *Some college* *Bachelors Degree* *Graduate Studies*

What is your current employment status? *FT* *PT* *Currently unemployed*

Occupation: _____

What is your spouse’s employment status? (if applicable) *FT* *PT* *Currently unemployed*

Occupation: _____

How many children do you have? _____

How many of your children have been diagnosed with Autism Spectrum Disorders? _____

At what age was your child(ren) diagnosed with autism? *Child 1* _____ *Child 2* _____ *Child 3* _____

What age is your child(ren) with autism now? *Child 1* _____ *Child 2* _____ *Child 3* _____

Where does your child(ren) attend school? (*circle one for each child with ASD, where applicable*)

- Child 1:** a) Public school, typical class
- b) Typical class, some IEP services
- c) Public school, special education class
- d) Private School
- e) Other _____

- Child 2:** a) Public school, typical class
- b) Typical class, some IEP services
- c) Public school, special education class
- d) Private School
- e) Other _____

- Child 3:** a) Public school, typical class
- b) Typical class, some IEP services
- c) Public school, special education class
- d) Private School
- e) Other _____

To ensure confidentiality, real names will *never* be used to identify participants or family members in reports or transcriptions. If you would like to choose a pseudonym for yourself and/or your child(ren), please do!

If you are interested in the findings of this study, please include your contact information below.

Phone Number (*optional*) _____

Email Address (*optional*) _____

Thank you for your support and participation!

APPENDIX B: INTERVIEW GUIDE

Families of children with autism experience a unique set of circumstances, both privately and publicly. One purpose of this study is to explore how situations associated with your child's autism have influenced you and your family, especially in the *initial stages* leading up to your child's diagnosis. Please feel free to discuss any experiences, thoughts, or feelings you have had in relation to this topic. As a reminder, anything mentioned by you or others will be kept confidential and will be used for research purposes only.

Here are some ideas that may be helpful for you to consider for this group interview. We will probably not cover every question listed and we may discuss additional topics not outlined here. This is meant to prompt discussion on *positive*, *negative*, and *neutral* experiences prior to your child's diagnosis.

Stressors

- Describe the process of obtaining your child's autism diagnosis.
- What are the hardships associated with your child's autism?

Resources

- What resources were you aware of initially? What did you discover over time?
- How did you find out about resources available to your family or your child?
- How have available resources affected your family coping with your child's autism?
- What type of support have you received from others?
- How has support from others been helpful or not helpful?

Appraisal

- What were your previous perceptions of autism (prior to having child with autism)?
- What were the responses of your immediate and extended family to your child's autism?
- Do you or your family view your child's autism differently now than you did initially? If so, how?

Adjustment

- What has your family done to cope with stressors associated with your child's autism? What factors have influenced your own adjustment or lack thereof?
- How well do you think your family has adapted to having a child with autism?
- What positive effects have you seen for yourself or your family related to your child's autism?
- What advice would you give other families who suspect their child may have autism?

APPENDIX C: CONSENT TO BE AN INTERVIEW PARTICIPANT

This research project is an exploratory study regarding the personal and familial changes that a mother experiences when her child is diagnosed with autism. It is being conducted by Stephanie Williamson, a sociology graduate student at Brigham Young University.

As an interview participant, you will be asked to spend some time talking about your experiences in a small group of women or individually. This study has potential to benefit the autism community in the future by increasing awareness of social issues associated with autism. Results from this study may be presented in reports available to the public. You may benefit from the opportunity to share your experiences, thoughts, and feelings with other women or the researcher. This study involves some minimal risks. Due to the personal nature of the topic to be discussed, some people may feel uncomfortable or highly emotional in talking about their experiences. There is also a risk of violated confidentiality of what is shared in a group setting. To minimize this risk, we ask that you sign this form indicating that you agree to comply with standards of confidentiality. Also, any information from interviews in future reports will not identify individuals. It will be used in general terms to demonstrate the types of experiences had by mothers of children with autism. Any specific examples used from interviews will have all identifying information removed.

If you have any questions about this research, please contact Christopher Dromey, IRB Committee Chair, A-285 ASB, Provo, Utah 84602 or at 422-3841.

If you wish to speak to someone regarding your rights as a research subject, you may contact: Chair of the Institutional Review Board of Human Subjects, Brigham Young University, Provo, Utah 84602.

I hereby affirm that I will not disclose any information discussed during the course of this interview. I agree not to talk about material relating to this interview with anyone except other focus group members and the researchers.

My signature below indicates that I have received a copy, read, and understood the above consent; that I agree to comply with standards of confidentiality which it describes; and that I desire of my own free will to participate in this study.

Print Name: _____

Signature: _____