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Interacting Beliefs and Processes in Mothers of Children Diagnosed with Autism

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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

Interacting Beliefs and Processes in Mothers of Children Diagnosed with Autism

by

Lara L. South

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Clinical Psychology

June 2016

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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ABBREVIATIONS

ANOVA	Analysis of Variance
APE	Adaptive Physical Education
ASD	Autism Spectrum Disorder
AUT	Eligibility of Autism in School Settings
DSM	Diagnostic and Statistical Manual of Mental Disorders
LOC	Locus of Control
MCDAs	Mothers of Children Diagnosed with ASDs
MM	Mixed Methods
N	Number of participants
OT	Occupational Therapy
PT	Physical Therapy
QUAL	Qualitative
QUANT	Quantitative
SB/RI	Stereotyped Behaviors or Restricted Interests

ABSTRACT OF THE DISSERTATION

Interacting Beliefs and Processes in Mothers of Children Diagnosed with Autism

By

Lara L. South

Doctor of Philosophy, Graduate Program in Clinical Psychology
Loma Linda University, June 2016
Dr. Kimberly R. Freeman, Chairperson

The purpose of this study was to expand previous research regarding beliefs in mothers of children diagnosed with autism spectrum disorders (MCDAs). Specifically, the pilot to this dissertation showed that mothers believed that the disorder was more stable than any specific behavior, but this distinction was not found for beliefs about treatment being able to control the disorder versus behaviors. Consequently, the quantitative strand of this study aimed to determine whether the mothers' beliefs about locus of control interacted with beliefs about treatment control. It was hypothesized that mothers with a higher belief in personal locus of control (LOC) compared to beliefs about external loci of control (i.e., child, professional, divine influence, chance) would view treatment as being able to control behaviors more than the disorder. Furthermore, these beliefs were viewed within the framework of the Commonsense Self-Regulation Model, which includes beliefs, emotions, coping methods, and appraisals. Accordingly, qualitative methods were used to expand the exploration of interactions beyond just the domain of beliefs to the entire process. In other words, the qualitative strand of this study aimed to determine if the self-regulation process occurred in MCDAs, and if so, how?

Most of the results of the quantitative strand were not statistically significant, indicating that the distinction between the disorder and specific behaviors was not as pronounced for beliefs about treatment control as it was for stability beliefs, even when considering MCDAs' beliefs about LOC. However, the few results that were significant were in the opposite direction as hypothesized. For the qualitative strand, while the self-regulation process was supported, additional themes emerged related to different systemic levels (e.g., systems mothers directly interacted with, systems interacting with each other, indirect interactions, and culture). Specifically, MCDAs' processes were more completely represented by integrating the Commonsense Self-Regulation Model with Bronfenbrenner's Bioecological Model and looking at elements related to Process, Person, Context, and Time (PPCT). These results have clinical and research implications for considering internal and systemic interactions. In particular, it would be important to increase positive interactions between MCDAs and other systems that impact the mothers' processes of understanding and helping their children.

CHAPTER ONE

INTRODUCTION

This dissertation seeks to bring the stories of mothers of children diagnosed with autism spectrum disorders (MCDAs) to the forefront of medical and mental health communities. As observed by the student researcher who is leading this dissertation, MCDAs seem to have a hard time figuring out exactly what autism is and finding treatments that they think will help their children. As a result, they often turn to professionals for guidance and assistance. The primary goal of these professionals should be to ask themselves, “What is best for my client?” Facilitating the search for treatment that best fits their client’s needs (as opposed to thinking that one’s own treatment model will be best for all clients) is of utmost importance. An important step in doing this is to understand clients’ personal experiences and to get feedback on what *they* think can be done better in the future. Accordingly, this dissertation explores the connections between MCDAs’ beliefs, emotional reactions, treatment seeking practices, and treatment appraisals. The focus for this study was on *mothers* specifically (as opposed to *parents*) because they have oftentimes been more involved in treatment and research than fathers (Flippin & Crais, 2011; Johnson & Simpson, 2013; Tehee, Honan, & Hevey, 2009).

The importance of the findings in this dissertation rests in their potential application to connecting the MCDA community with health and mental health fields. The gathering of stories from MCDAs will provide rich information about how their beliefs evolve and interact with each other and what processes they navigate in seeking care. A careful analysis of this information will hopefully provide professionals with a valuable framework for understanding the issues MCDAs face. The hope is that professionals can use this information to better serve this growing population. For instance, professionals may be able to provide education about areas in which it is difficult to find clarity (e.g., what the diagnosis entails, how to navigate treatment systems, etc.) They may need to become advocates for their clients to receive the most appropriate treatments. They may need to facilitate positive cognitive and emotional processes. They may become allies that could be able to provide a supportive base for the families. The possibilities are many. The findings of this dissertation will help identify the current needs of the community of MCDAs so that professionals can improve upon the system of services, make the treatment processes more effective, and potentially enhance these families' quality of life. Before doing this, though, the scientific method necessitates operationally defining key concepts in this research.

Defining Autism

The most foundational question to ask when starting research on autism is, "What is autism?" A direct answer to this question, however, is complex and perhaps even elusive. Currently, one in 68 children are diagnosed on the autism spectrum (Centers for Disease Control and Prevention, 2014). However, each child presents with a different set of areas of difficulty, making it tough for MCDAs to know exactly what to expect or how to best help their children. There are some unifying factors that provide a basis for an autism diagnosis, but these change over time and across settings. For example, the Diagnostic and Statistical Manual, Fourth Edition, Text Revision (DSM-IV-TR) provided the criteria for an autism diagnosis for 13 years (American Psychiatric Association, 2000). It stipulated that a child must demonstrate difficulty with socialization, communication, and stereotyped behaviors or restricted interests (SB/RI) to qualify for a diagnosis of Autistic Disorder (American Psychiatric Association, 2000). Various combinations of these deficits and excesses were used for diagnosing other Autism Spectrum Disorders (ASDs): Asperger's Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Child Disintegrative Disorder, and Rett's Disorder (American Psychiatric Association, 2000).

Recently, though, the fifth edition of the DSM was released and combined all ASDs into one category (American Psychiatric Association, 2013). In other words, they are all now considered under the label "Autism Spectrum Disorder." Additionally, the criteria have been modified so that communication problems are subsumed under the first criterion of "social communication" problems (American Psychiatric Association, 2013). Severity level has also been added as a specifier (American Psychiatric Association, 2013). While only the test of time will tell whether or not this change will be more beneficial to the population, it may stir additional confusion as the change takes effect.

Further confusing matters, the way autism is defined in schools is different from how it is defined by the DSM. Specifically, an *eligibility* of "autism" (designated as "AUT") in schools does not necessarily equate to a *diagnosis* of autism. The California Code of Regulations, Title 5, Section 3030 defines an eligibility of autism as follows:

> (g) A pupil exhibits *any combination* [emphasis added] of the following autistic-like behaviors, to include but not limited to:
>
> (1) An inability to use oral language for appropriate communication.
>
> (2) A history of extreme withdrawal or relating to people inappropriately and continued impairment in social interaction from infancy through early childhood.

(3) An obsession to maintain sameness.

(4) Extreme preoccupation with objects or inappropriate use of objects or both.

(5) Extreme resistance to controls.

(6) Displays peculiar motoric mannerisms and motility patterns.

(7) Self-stimulating, ritualistic behavior.

("Eligibility criteria, 5 CCR § 3030," 2013)

In other words, a child may demonstrate some “autistic-like behaviors” but not necessarily meet full criteria for a diagnosis of an ASD and still have the “autism” label. These children are included in the one in 68 statistic.

With each of these different definitions, one must ask how an MCDA is to know what type of treatment to look for or where to find it? Does her child need behavioral modification, speech therapy, adaptive physical education (APE), occupational therapy (OT), physical therapy (PT), psychotherapy, medication, consultation with a dietician, or anything else? Can she get these services through insurance or does she need to seek assistance from school-based programs or a regional center? What happens when she does not like the services her child is receiving? Where else can she get assistance? Talking to MCDAs about their experiences is crucial in figuring out how professionals can better facilitate this search in the future. For that reason, this dissertation will look at these mothers’ beliefs and explore the processes they have gone through to try to understand what will be most helpful for them.

Defining the Theory

To begin to try to understand these mothers’ processes, the theoretical framework that provides a context from which to understand the current study is the Commonsense Model of Self-Regulation (hereafter referred to as the “Self-Regulation Model”). The model is process-oriented and includes domains of beliefs, emotions, coping methods, and appraisals (Leventhal, Leventhal, & Cameron, 2001).

Commonsense Model of Self-Regulation

The Self-Regulation Model is an important theory of the process people undergo when faced with an illness or disorder (Leventhal et al., 2001). The theory was founded on the following ideas:

1. People are self-regulating systems that try to make sense of and control illnesses/disorders.
2. Their ability to problem-solve is based on personal beliefs and appraisals.
3. The social environment (e.g., media, language, etc.) shapes the self-regulation process (Leventhal et al., 2001).

The three main components of the model are representations, coping procedures, and appraisals (Leventhal et al., 2001). These components occur both cognitively and emotionally (Leventhal et al., 2001). The model also includes feedback loops that indicate that each component of the model interacts with one another and may be modified with each new experience (Leventhal et al., 2001).

The Self-Regulation Model is being used as the framework for the current study because it represents experiences MCDAs have with their children’s disorder using a comprehensive process. First, they try to understand what the disorder is. They also have personal beliefs and experiences that shape their understanding. In addition, they are influenced by what they see in the media and information they gather from their environment. Furthermore, they try to cope with the disorder in any way they can and have appraisals of whether those coping methods are working. The details of the different components of this model in the context of autism research will be described further in the literature sections.

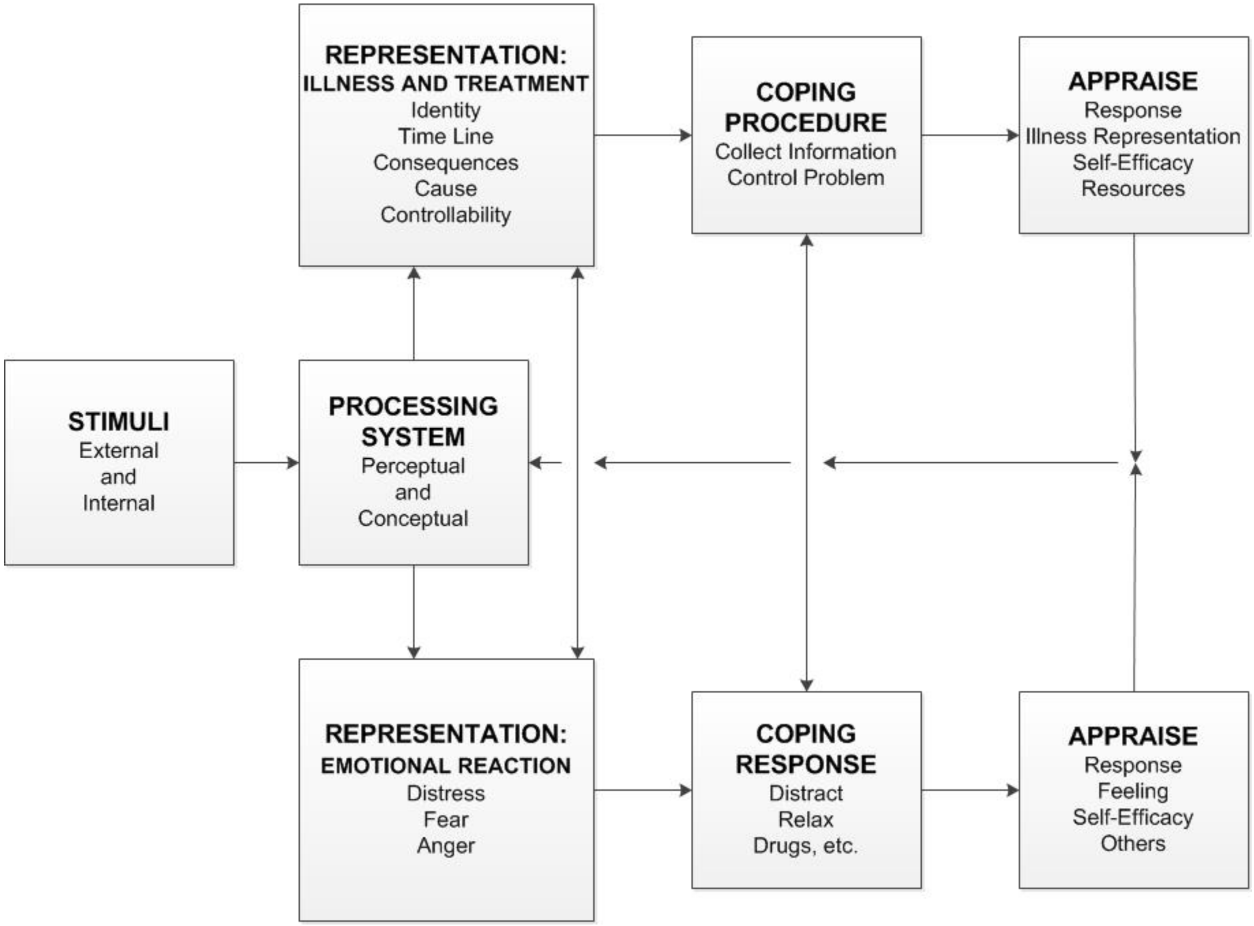

Figure 1. Commonsense model of self-regulation (Leventhal et al., 2001).

Defining the Variables

The pilot study to this dissertation used the Self-Regulation Model as a theoretical framework and examined two specific components of the model: *Timeline (Acute/Chronic)* and *Treatment Control*. The Timeline (Acute/Chronic) variable measures the belief about whether an illness or disorder will last a short time (acute) or a long time (chronic). In other words, it looks at the beliefs about the stability of the condition. The Treatment Control variable measures the belief about if treatment can actually help control the illness/disorder, or if improvement can be made through treatment.

In the pilot study, it was hypothesized that there would be differences in beliefs about ASD and beliefs about specific behaviors. The reason for researching whether this distinction existed was because the primary student researcher noticed a discrepancy in the neurodevelopmental scientific understanding of the disorder compared to the behavioral way it is defined. In other words, she conceptualized that autism could be viewed as a disorder that is deep-rooted in neurobiology that manifests through behaviors. This being the case, it was thought that there may be two separate beliefs when looking at the disorder. The first belief would be that the overall disorder would be stable because the underlying processes would remain different than neurotypically developing individuals due to the differences in brain form and function. The second belief would be that there is still the capacity to change behaviors that commonly occur with the disorder.

The most effective way to illustrate this difference between internal processes and outward behaviors is from a personal conversation the primary student researcher had at her undergraduate college with a high functioning male with autism. The person shared that although he could now identify emotions in others, such as sadness, the internal process was to break down specific features (e.g., the person's mouth is downturned which means they are frowning which means they are sad). Consequently, he was able to improve a social communication behavior (identifying an emotion), but he had a way of processing information that indicated that he still had differences related to autism.

The importance of determining whether MCDAs held this difference between beliefs about the disorder and beliefs about specific behaviors is best summed up by one of the mother's words from the current study. When talking about what health professionals could do to show mothers they cared about them and their children's needs, her response was, "Don't give them false hope, but don't make it feel like you're hopeless either." If MCDAs are able to balance the outlook of positive change with understanding the reality of possible limitations, it is thought that they would actively seek treatments for their children and not be as discouraged when they do not see immediate progress.

The results from the pilot study found that the timeline (acute/chronic) variable *should* be further divided into beliefs about the stability of the disorder and beliefs about the stability of specific behaviors when mothers are trying to make sense of their children's ASDs (South, 2013). Specifically, social interaction problems, communication problems, SB/RI, tantrums, and aggression were all seen as *less* stable than the disorder (South, 2013). However, this same division was *not* supported for beliefs about treatment control (South, 2013). Curiously, even with the difference in stability beliefs, there was no statistical difference between MCDAs' beliefs about treatment being able to improve the disorder and their beliefs about treatment being able to improve social interaction problems, communication problems, SB/RI, tantrums, or aggression (South, 2013). In other words, treatment was thought to improve both the disorder and behaviors (South, 2013). Consequently, one purpose of this dissertation was to determine whether another variable interacted with the treatment control variable, affecting the outcome: namely *Personal Control*.

The original version of the measure that assessed the treatment control variable did not include other measures of control; however, the current revision of the measure being used considers a second domain of control as important: personal control (Moss-Morris et al., 2002). The personal control variable looks at whether the person thinks he or she has the ability to control the illness/disorder. However, other research has shown that MCDAs believe in various loci of control. Specifically, that research supports five different loci that MCDAs think could help improve their children's autism: the child, the parent, a professional, chance, and divine influence (DeVellis, 1985). Additionally, a large amount of research shows that parental involvement in treatment is a major marker of success for children on the autism spectrum (Aldred, Green, & Adams, 2004; P. Benson, Karlof, & Siperstein, 2008; Frankel et al., 2010; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Lovaas, Koegel, Simmons, & Long, 1973; McConkey et al., 2010; Moes & Frea, 2002; Scahill et al., 2009). Given this, a mother's belief about if she can help control the disorder or behaviors may interact with her beliefs about whether treatment will be able to improve the disorder or behaviors. This interaction is evaluated in part of the current dissertation to extend the pilot study; however, this one interaction does not fully account for the fact that the Self-Regulation Model is a complex process model.

Although quantitative methods can illuminate a great deal about the relationship between variables, they only look at a snapshot in time. Qualitative methods, though, can address processes. Since the Self-Regulation Model is the primary sensitizing theory for this study, the processes of MCDAs could be explored more completely through qualitative methods. Specifically, a further extension of the pilot study in the current dissertation is to examine how the different domains and components of the model work with each other as a complex changeable process in MCDAs. In other words, it was considered that the qualitative methods could *validate* the Self-Regulation Model. Being that qualitative methods have traditionally been used for *creation* of theory, though, analyses were still open to *novel* concepts that emerged from the data. In other words, although the researchers used the Self-Regulation Model as a sensitizing guide, they were vigilant in seeking alternative explanations for the mothers' processes that could have contradicted this model.

Defining the Method

Due to the complexity of processes that MCDAs go through in trying to understand and help their children, it is imperative to use a method that can capture the intricacies. Specifically, this study used a mixed methods approach. Mixed methods (MM) research is a research orientation that has only truly emerged as distinct from quantitative and qualitative research within the past 20 years (Teddlie & Tashakkori, 2009). It struggles to bring together two schools of thought that oftentimes resist being integrated. Quantitative (QUANT) research is rooted in the scientific method, which focuses on repeatable tests that use numbers for reliable statistics. Qualitative (QUAL) research, on the other hand, takes a more fluid, or creative, approach that delves into the complex (sometimes unpredictable) realm of stories, visual media (e.g., pictures), field notes, and other types of real-world data. The dialectic between these two camps can occasionally seem insurmountable, but MM research values the unique benefits that each type of research brings.

Paradigm

Research has different paradigmatic views that lie along a QUANT-MM-QUAL continuum. QUANT researchers oftentimes do not attend to the research paradigm being used, but QUAL researchers consider it a major contributor to the research process. Therefore, QUAL research is usually at the center of epistemological research debates. With the rise of a QUAL paradigm called *constructivism* (which believes that reality and truth cannot truly be measured because it is relative), an *incompatibility thesis* was developed that asserted that QUANT and QUAL methods could not be combined due to the *positivist* nature of QUANT research (i.e., there are absolute truths that can be measured through observation and experimentation; Teddlie & Tashakkori, 2009).

MM research, on the other hand, countered with a point of view called *pragmatism*, a belief that research should include the method(s) that best address the question(s) being asked (Teddlie & Tashakkori, 2009). As a result, several MM paradigmatic stances arose from this shift in thinking. The approach being used for the current study is the *dialectical thesis*, which does not proclaim that any one paradigm is better than any other is, but stresses that multiple, diverse perspectives are important (Teddlie & Tashakkori, 2009). Thinking dialectically “involves considering opposing viewpoints and interacting with the tensions caused by their juxtaposition" (Teddlie & Tashakkori, 2009, p. 100). This standpoint assumes that all paradigms have something to offer and that discussing the research topic from multiple models helps one better understand the phenomenon under study and more fully explain its complexity (Teddlie & Tashakkori, 2009).

Overarching Research Question

Following from the concept that QUANT and QUAL methods can coexist in harmony by building on one another to form a more complete picture, it is important to note the overarching question that links the QUANT and QUAL pieces together in MM research (Teddlie & Tashakkori, 2009). The main question for the current study is, "How do the domains and components of the Self-Regulation Model interact and create a changeable process?" This links the two strands, as the QUANT method looks at interactions between specific components and the QUAL method looks at the overall process connecting the domains.

Mixed Methods Design

This study used a *parallel* MM design (Teddlie & Tashakkori, 2009). In other words, both QUANT and QUAL methods were gathered concurrently within the same study to address different aspects of the area under research. Specifically, QUANT methods were used to determine the *relationship between* MCDAs' control variables within the cognitive domain of the Self-Regulation Model. Complementarily, QUAL methods were used to examine *how* the self-regulation *process* occurred within MCDAs, if at all. The primary student researcher of this study viewed the QUANT and QUAL portions as equally important (i.e., one was not seen as more important than, or dominant over, the other). The specific procedures for each strand will be described in their respective methods sections.

Meta-Inference

In MM research, it is typically not enough to do separate QUANT and QUAL analyses and make separate inferences from each strand of the study. It is recommended that the inferences be integrated together to formulate a meta-inference, which provides implications for the study overall (Teddlie & Tashakkori, 2009). Otherwise, the strands may be considered two separate studies or only quasi-mixed. Therefore, after the analyses were complete for both the QUANT and QUAL strands of the current study, it was determined whether the inferences could be integrated into a meta-inference. Specifically, it was explored whether adding different loci of control to the Self-Regulation Model (the QUANT strand) added further information to the overall process (the QUAL strand). However, since the strands were being studied in parallel, it was deemed possible that the two strands might not be able to be integrated, so precautions were taken to not make connections where there were none. In other words, it was understood that the strands should not be forced together if the findings did not support meta-inference. The determination of whether or not a meta-inference could be made will be reasoned at the end of the QUAL discussion section as concluding thoughts for the study overall.

Defining the Researcher's Point of View

To better understand the approach that was taken in gathering, analyzing, interpreting, and writing up the data for this study, it is essential to understand the primary student researcher's point of view. This is because, although QUANT research has generally noted that researchers should minimize their bias in studies, QUAL research acknowledges that the researcher has an impact on the study no matter how much the researcher believes he or she has removed him or herself from it. In fact, by acknowledging that the researcher may affect the outcome, it only heightens the significance of examining the researcher's position so that any effect can be properly accounted for. Fundamentally, researcher factors are foundations for any research assumptions and guide research objectives.

The primary student researcher of the current study situates herself in a *moderate epistemological position* that is neither completely objectivist nor completely subjectivist. Specifically, she believes that the way people interpret information affects their view of reality and these interpretations can differ even within the same person based on who they are with and the context of the interaction. C. S. Lewis (1955) summarized this viewpoint most poignantly in a volume of *The Chronicles of Narnia*, *The Magician's Nephew*, when the narrator says, "For what you see and hear depends a good deal on where you are standing: it also depends on what sort of person you are" (p. 75). Correspondingly, the primary student researcher considers herself as coming from a *social constructionist* lens. This QUAL research paradigm is concerned with understanding how participants perceive and understand the world around them (i.e., make meaning), recognizes that realities change based on the relationship and context, and aims to present multiple viewpoints (Daly, 2007; Gergen, 2009).

Consequently, this researcher believes that while data can be observed, how that data is collected and who is collecting it may impact what is observed and how that information is interpreted. To begin with, the primary student researcher acknowledges that even the questions she is asking are influenced by her perspective on autism. Specifically, she believes that treatments can help improve the defining behaviors, but the neurodevelopmental foundation of the disorder implies that the mental processes will be different than neurotypical peers across the lifespan. The primary student researcher is also aware that the researcher-participant relationship can impact data collection and the researcher-data interaction can influence interpretation. For example, the participant may feel more open with one researcher over another, the researcher may direct follow-up questions based on his/her own understanding or focus, the researcher may interpret a phenomenon from a particular lens, etc. As a result, it was deemed necessary to include a team of researchers in collection, analysis, and interpretation of data. This was so that any possible differences in information or interpretation based on the participant-researcher social interaction could be more well-rounded through multiple perspectives.

It should also be noted that the primary student researcher's perspective on social construction, multiple truths, and dialectics impacted the decisions on study design and how the information is presented in this dissertation. With respect to study design, it was thought that multiple method types would assist with providing different angles to look at the data and that seemingly opposing views can be brought together into a cohesive whole. Regarding the presentation of information, the primary student researcher ascribes to Gergen's idea that scientific information does not have to be devoid of the researcher's voice or creativity. For example, Gergen (2009) purported that interpretation of data could be presented in even the most creative mediums such as poetry or art (p. 154). As a result, the primary student researcher felt that rather than a stringent objective report of findings, it was vital to include attempts at understanding the personal experiences of the mothers in the study and embody their voices at various points in this dissertation.

Aims

The primary aim of this study, accomplished in two parts, is to expand upon pilot research that looked at MCDAs' beliefs about whether treatment could control or improve the child's disorder or specific behaviors. The first part of doing thus is to analyze additional belief variables through QUANT methods. The second part is to explore a complex process that includes their beliefs through QUAL methods.

By examining how the different domains of MCDAs' experiences interact, a more complete picture can be analyzed. Therefore, to provide both a broad spectrum of data as well as opportunities for in-depth exploration into MCDAs' experiences, the current study used a MM approach. As a result, the first part of the aim of this dissertation research is to expand on the pilot thesis by using statistical evaluation of numeric data (QUANT methods) to see if MCDAs' beliefs about loci of control interact with their beliefs about treatment control. Complementarily, the second part of the aim is to analyze mothers' stories and explore their process-oriented responses (QUAL methods) so that the interactions between the different domains can be mapped out.

The following summarizes the primary aims of the current study:

1. *Overall* - Explore and expand the connections and interactions between the different domains of the *Commonsense Self-Regulation Model*.
2. *Quantitative* - Determine the *relationship between* MCDAs' beliefs about treatment control (children's ASD vs. behaviors) and their beliefs about LOC (personal vs. external) and evaluate whether there is an *interaction* between these variables.
3. *Qualitative* – Validate, expand, or generate an explanation of how the *process* of self-regulation occurs in MCDAs.

Outline

This dissertation is organized into three main sections: the QUANT strand, the QUAL strand, and a discussion. First, the literature review of the QUANT strand will describe the pilot study as well as autism literature related to two components of the Self-Regulation Model that may interact (treatment control and loci of control). Next, the QUANT methods section will describe the modifications made to the pilot study procedures for the current study. Then, the results of the analyses for the QUANT strand will be presented. Subsequently, the literature review for the QUAL strand will look at each domain of the Self-Regulation Model in the context of the current autism literature. After this review, the QUAL methods and analyses will be explained. Lastly, the discussion section will describe interpretations for both the QUANT and QUAL strands as well as a possible integration of the two (i.e., meta-inference).

PART I

QUANTITATIVE STRAND

CHAPTER TWO

QUANTITATIVE LITERATURE REVIEW

For the QUANT strand of any MM study, the aim is typically to determine a numerical relationship between at least two variables using statistics (Teddlie & Tashakkori, 2009). The Self-Regulation Model illustrates a complex process that has many moving parts that can be compared relationally. This includes many subcomponents of cognitive representations (i.e., personal views/beliefs/understanding), such as understanding of the illness or disorder, beliefs about causes, etc. In addition to the established cognitions, the primary student researcher hypothesized that more levels could be relevant for MCDAs. Specifically, as mentioned in the introduction, in the pilot study to this dissertation, it was found that when mothers are trying to make sense of their children's ASDs, the Timeline (Acute/Chronic) variable of the Self-Regulation Model should be divided further into beliefs about the stability of *disorder* and beliefs about the stability of *specific behaviors* (South, 2013). However, this same division was not supported for mothers' beliefs about Treatment Control (South, 2013). In other words, no difference was seen between beliefs about treatment controlling the disorder and beliefs about treatment controlling any specific behavior.

To emphasize, the division between the disorder and specific behaviors was deemed an important distinction to evaluate because of its implications for mothers to have a healthy understanding of autism. Specifically, the primary student researcher believed that a balanced view of autism would incorporate a hopeful attitude toward behavioral change while simultaneously demonstrating an understanding of the inherent challenges of having an ASD. One may liken this viewpoint to Koffka's statement, "The whole is other than the sum of its parts" (Dewey, 2007). The word "other" is often mistranslated as "greater" or "more" but Koffka did not feel that this accurately represented what was trying to be conveyed (Dewey, 2007). Specifically, the intention was to say that the gestalt was not additive but "the whole had an independent existence in the perceptual system" (Dewey, 2007). In this same way, MCDAs' cognitive representation of ASD may not simply be based on adding up a number of symptomatic behaviors but an understanding of the gestalt of autism as a whole, independent construct.

As mentioned previously, control in the Self-Regulation Model should not only consider treatment control, but personal control as well (Moss-Morris et al., 2002). In addition, it should be considered that MCDAs believe in other loci of control for improving their children's disorder or behaviors. Specifically, the literature supports five different loci that MCDAs think could help improve their children's autism: the mother, the child, a professional, divine influence, and chance (DeVellis, 1985). Furthermore, there is a plethora of research that shows that parental involvement in treatment impacts outcomes for children on the autism spectrum (Aldred et al., 2004; P. Benson et al., 2008; Frankel et al., 2010; Kasari et al., 2010; Lovaas et al., 1973; McConkey et al., 2010; Moes & Frea, 2002; Scahill et al., 2009). Therefore, MCDAs' beliefs about loci of control may interact with their beliefs about treatment control.

For example, if a mother does not believe in her own personal agency to help her child, she may not be as involved. If she is not involved, her child may not benefit as much from treatment. If her child does not show progress, she may think that the treatment is unable to improve her child's behaviors. In other words, this mother's low belief in her own ability to control her child’s disorder would lead to a low belief in the ability of treatment to help her child.

On the other hand, if a mother believes highly in her personal agency to help her child, she would likely be more involved. If she is more involved, treatment is more likely to be effective. If the treatment is more effective, this mother is more likely to see the treatment as “working.” In other words, a mother who has a high belief in personal control may be more likely to believe treatment can help improve her child’s behaviors.

Resultantly, the aim of the QUANT strand of this study was to evaluate the interaction between MCDAs’ beliefs about treatment control (disorder vs. specific behaviors) and their beliefs about loci of control (personal vs. external) as an extension of the pilot study that preceded this dissertation. To describe each of these components in more detail, this literature review will:

a. Provide an overview of the Self-Regulation Model,
b. Summarize the current autism literature as it relates to each of the controllability variables,
c. Describe the pilot study from which this dissertation developed, and
d. Explicitly state the QUANT research question and hypothesis.

Self-Regulation Model

As previously mentioned, the Self-Regulation Model is a process model that looks at beliefs, emotions, coping, and appraisals. It represents the self-regulation process in both cognitive and emotional dimensions. The cognitive dimension includes cognitive representations (or beliefs/understanding), cognitive coping strategies, and cognitive appraisals. Similarly, the emotional dimension includes emotions, emotional coping mechanisms, and emotional appraisals. For the QUANT portion of this study, only a couple variables will be examined in the cognitive representations (beliefs) domain due to addressing a direct question that arose out of the pilot study of whether the controllability variables (beliefs about treatment control and personal control) interact. While the other dimensions and domains will be addressed more completely in the QUAL portion of this dissertation, only the controllability variables will be expanded on in this section.

Controllability

As already stated, the controllability variables within the Self-Regulation Model are important for the current study because they expand the pilot research that preceded this dissertation. Consequently, this literature review will explore these particular variables in depth. Research on controllability using the Illness Perceptions Questionnaire-Revised (IPQ-R) has indicated that it should be divided into two components (Moss-Morris et al., 2002). The first component is whether the participants believe treatment can control or improve the illness/disorder (i.e., Treatment Control). The second component of controllability in the Self-Regulation Model is whether participants believe in a personal locus of control (i.e., Personal Control); however, the literature on MCDAs' beliefs about autism indicates that it is important to consider other loci of control. In the next section, the autism literature related to treatment control and personal control will be discussed.

Treatment Control

The Self-Regulation Model considers whether someone believes treatment can help control or improve an illness or disorder. In other words, it looks at outcome expectations, or begs the question, "Will treatment work?" (Moss-Morris et al., 2002). MCDAs may often wonder about what treatment(s) can help improve their children's ASDs or behaviors. Finding the most appropriate treatment is multidimensional. Specifically, one must ask, “Which is the best treatment for this particular child in this particular context with these particular resources at this particular time?”

Some treatments are evidence-based and have significant backing, such as early intensive behavioral interventions (EIBI); although, programs may range in effectiveness (Rogers & Vismara, 2008). Specifically, it is touted that these treatments can be so successful that children diagnosed with autism can make such drastic gains that they can "move off the spectrum" (Lovaas et al., 1973; Matson & Horovitz, 2010). However, there is a wide array of responses children can have to these treatments ranging from deterioration to considerable change (Howlin, 2008; Sherer & Schreibman, 2005). Additionally, gains made through treatment may slow down or be lost after the interventions have stopped (Matson & Horovitz, 2010; Taylor & Seltzer, 2010). Furthermore, changes may depend on cognitive ability and severity level (Beadle-Brown, Murphy, & Wing, 2006; Charman et al., 2005; Matson & Horovitz, 2010; Shattuck et al., 2007b).

There are a number of treatments that are frequently used with children with ASDs that have some research support. These include but are not limited to the following interventions: Applied Behavior Analysis (ABA), Pivotal Response Treatment

(PRT), Early Start Denver Model (ESDM), Developmental Individual Difference Relationship Model (DIR or Floortime), Relationship Development Intervention (RDI), Training and Education of Autistic and Related Communication Handicapped Children (TEACCH), Social Communication/Emotional Regulation/Transactional Support (SCERTS), Speech-Language Therapy (SLT), Occupational Therapy (OT), Sensory Integration (SI), Physical Therapy (PT), Social Skills Training (SST), and Picture Exchange Communication System (PECS; Adams et al., 2012; Autism Speaks, 2010; Callahan, Shukla-Mehta, Magee, & Wie, 2010; Case-Smith, Weaver, & Fristad, 2015; Gutstein, Burgess, & Montfort, 2007; Lerna, Esposito, Conson, & Massagli, 2014; Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014; Molteni, Guldberg, & Logan, 2013; Novak & Berry, 2014; Pajareya & Nopmaneejumruslers, 2011; Prizant, Wetherby, Rubin, & Laurent, 2010; Rao, Beidel, & Murray, 2008; Virués-Ortega, 2010; Vivanti et al., 2014).

There are many other treatments that MCDAs may have their children try, including ones that have minimal evidentiary support as well as some that may or may not be effective. Treatments with some supportive evidence include certain pharmacological treatments and dietary interventions, but the effects need to be reviewed on an individual basis (Autism Speaks, 2010; Palermo & Curatolo, 2004; Whiteley et al., 2010). Other complementary and alternative medicine (CAM) therapies (e.g., vitamins/minerals, food supplements, massage, etc.) are sometimes used, although their efficacy remains controversial (Şenel, 2010).

There are also some treatments that have no support and potentially can have hazardous effects such as the Miracle Mineral Solution and chelation therapy. The

Miracle Mineral Solution (MMS) is a treatment that essentially transforms into bleach if taken as directed and can cause life-threatening reactions (U. S. Food and Drug Administration, 2014). Another ardently contested treatment is chelation therapy ("Autism chelation trial scrapped," 2008; Bihari, 2006; Şenel, 2010). This treatment is based on the idea that mercury has a causal link with autism (Bihari, 2006). However, the original study that associated the Mumps/Measles/Rubella (MMR) vaccine with autism due to its mercury content had its findings retracted and many studies since then have discredited its claims (Immunization Action Coalition, 2008; Murch et al., 2004; Wakefield et al., 1998). More importantly, chelation therapy may be toxic or have harmful side effects such as liver or kidney damage (Bihari, 2006; Hoecker, 2010).

It was hypothesized in the pilot study that was a precursor to this dissertation that MCDAs would believe that treatment would help improve specific behaviors more than the ASD itself (South, 2013). As previously discussed, this distinction is important because mothers that do not distinguish between the disorder and behaviors may either have a negative outlook that treatment will not help anything or have false hope that everything will be “cured.” This can be problematic if these beliefs either lead the mothers to not try treatments that could have positive effects or try any treatment, including ones that could be dangerous. The pilot data did not support the hypothesized distinction between the disorder and behaviors for beliefs about treatment control; however, that study did not incorporate the other aspect of controllability, where the mothers placed their locus of control (LOC). Before investigating the importance of the relationship between these two types of control (treatment control vs. LOC), the literature on MCDAs’ LOC for their children’s disorder will be examined.

Personal Control

The second aspect of controllability in the Self-Regulation Model is whether a person believes he/she can control the illness/disorder (Leventhal et al., 2001). Namely, it looks at whether the person has an internal, or personal, LOC. However, MCDAs place their hope in various sources. Some take personal responsibility, some divide responsibility between themselves and other agencies, and some place responsibility solely on external/professional sources (Dale, Jahoda, & Knott, 2006). Specifically, five different loci of control MCDAs believe in have been identified in research: the mother, the child, a professional, divine influence, and chance (DeVellis, 1985).

It cannot be stressed enough that mothers being involved in their children’s care is extremely important. The research literature abounds with examples that parent involvement is one of the largest components responsible for positive behavioral outcomes in autism treatments (Aldred et al., 2004; P. Benson et al., 2008; Frankel et al., 2010; Kasari et al., 2010; Lovaas et al., 1973; McConkey et al., 2010; Moes & Frea, 2002; Scahill et al., 2009). That being the case, what happens if they do not believe that they can help their children? What happens if they leave everything up to others or hope their children can pull themselves up by their bootstraps? One may surmise that they would not get as involved and, therefore, their children would not make as much progress. If this happens, this may foster a further sense of helplessness and they may become disappointed or possibly even lose hope. As a result, an essential next step for research is to see whether where the mothers place their LOC interacts with their beliefs about treatment controlling/improving their children's ASDs or behaviors. This interaction was the basis for the QUANT strand of the current study.

Pilot Study Description

In order to fully understand the driving force behind this dissertation, it is important to understand it within its context using the backdrop of the pilot study that preceded it. The pilot study was a QUANT study that evaluated three main questions:

- Do MCDAs' beliefs about the stability of the disorder significantly differ from their beliefs about the stability of specific behaviors?
- Do MCDAs' beliefs about treatment controlling or improving the disorder significantly differ from their beliefs about treatment controlling or improving specific behaviors?
- Does time since diagnosis impact any of these beliefs?

It was hypothesized that MCDAs would see the disorder as more stable than any specific behavior, that they would see treatment as being able to control behaviors more than the disorder itself, and that as time since diagnosis increased their beliefs about stability and treatment control would increase.

During the pilot study, twenty MCDAs were recruited using flyers, posts in online forums, and word-of-mouth snowball sampling. These mothers completed an online survey that included an informed consent and three questionnaires. First, they completed a demographics questionnaire about variables conceptually related to beliefs about autism (see Appendix E). Second, they filled out a modified version of the Illness Perceptions Questionnaire-Revised that included questions specific to autism (see Appendix F). This questionnaire was modified to divide the Timeline (Acute/Chronic) and Treatment Control scales into questions about the disorder and questions about specific behaviors commonly seen in children with ASDs (i.e., social interaction problems, communication problems, SB/RI, tantrums, and aggression). The Personal Control scale was also divided into questions about perceived mother's control and perceived external loci of control found in the autism literature (i.e., child, professional, divine influence, and chance). The third part of the online survey used in the pilot study was a section of open-ended questions related to the Self-Regulation Model to provide exploratory data regarding MCDAs' personal experiences of their children's autism diagnosis and treatment (see Appendix G). Mothers who chose to provide contact information were entered into a randomized drawing for a $250 gift card to Target.

Results were analyzed via SPSS software using Repeated Measures Analyses of Variance (ANOVAs), paired t-tests, and correlations including demographic covariates that were significantly related to both test variables in an analysis. (The rationale for Repeated Measures ANOVA will be described further in the QUANT methods section of this paper). Analyses supported that MCDAs viewed the disorder as significantly more stable than any specific behavior; however, the other two hypotheses were not supported. In other words, mothers did not view treatment as being able to control the behaviors any differently than the disorder and time since diagnosis was not significantly related to any test variable.

Quantitative Research Question

The discrepancy between the division of the disorder and behaviors being supported for stability but not treatment control and the fact that mothers' personal agency may have significant implications for treatment led to the research question for the current QUANT strand. The research question is, "Do MCDAs' beliefs about treatment controlling/improving their children's disorder differ from their beliefs about treatment controlling/improving specific behaviors when they have a higher personal LOC rather than an external LOC?" In other words, this dissertation explored the interaction between Treatment Control (disorder vs. behaviors) and LOC (personal vs. external).

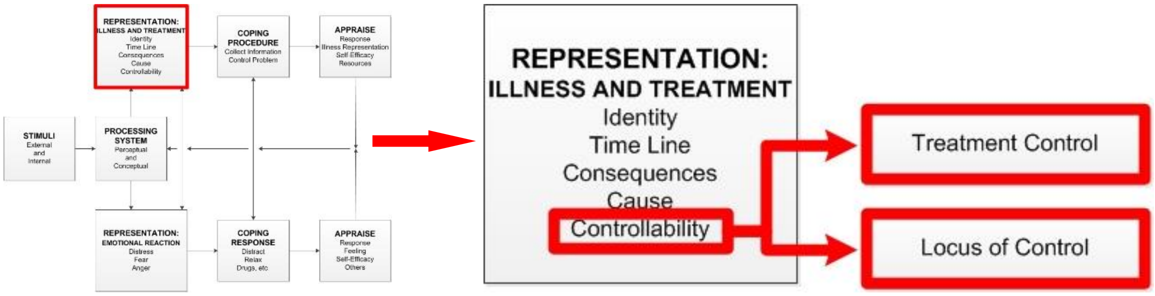

Figure 2.   The quantitative relationship between treatment control and locus of control.

Hypothesis

In QUANT strands of MM research, it is essential to explicitly state a measurable hypothesis that evaluates the relationship between at least two variables (Teddlie & Tashakkori, 2009). For the current study, the QUANT hypothesis was as follows: MCDAs who scored higher on the mother's personal control scale than other loci of control scales would score higher on the scales of treatment control for specific behaviors than the scale of treatment control of the disorder. That is to say, the difference in beliefs about treatment controlling the disorder and beliefs about treatment controlling specific behaviors would be moderated by the level of mother's LOC. Figure 3 illustrates this hypothesized interaction.

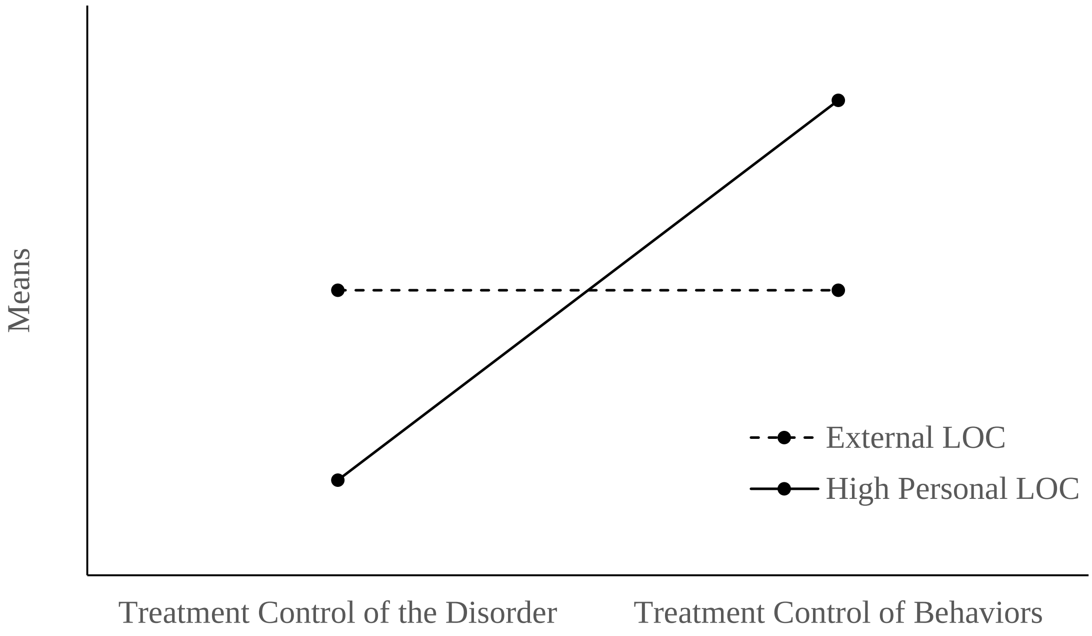

Figure 3. Hypothesized interaction between beliefs about locus of control and beliefs about treatment control of the disorder versus specific behaviors.

In other words, the following differences were expected *only* when the mother's personal LOC was higher than the external LOC being compared:

Treatment Control Scores for:				**Treatment Control Scores for:**
Social Interaction Problems				
Communication Problems				
SB/RI	→	Higher Than	→	Disorder
Tantrums				
Aggressive Behaviors				

CHAPTER THREE

QUANTITATIVE METHOD

This chapter includes sections on participants, instrumentation, procedures, and the QUANT analyses being used. The procedures sections contain a description of the original pilot procedures to provide context for the current study as well as a description of the current QUANT procedures. The section delineating the QUANT analyses will outline the data screening, assessment of internal consistency, examination of descriptive statistics, and statistical analyses employed to test the hypotheses with a rationale for their usage.

Participants

In order to determine the optimal number of participants needed for analyses in the current study, power analysis was performed. Preliminary analyses of the effect sizes from the pilot data ranged from very small to very large. Given this wide range, a power analysis was run using G*Power with optimistic values of a large effect size ($f = .40$) and high power ($1-\beta = .80$) for a significance value of $p < .05$, which resulted in a recommended number of participants (N) of 45. Some researchers, though, indicate that the minimum number of participants for QUANT analysis should be 50 because a sample of this size produces similar results to larger samples (R. Hill, 1998; Sawyer, 1984). Consequently, for the QUANT portion of the study, a sample size of 50 total participants (pilot plus new) was planned.

For the current study, participants were mothers of children diagnosed with autism. The mothers were required to be 18 years of age or older and the children needed to be 18 years of age or younger. If the mother had more than one child diagnosed with an ASD, she was asked to answer the questions regarding the oldest child. In addition, the mothers needed to read, write, and speak in English because there were no qualified translators on the research team. Participants were recruited through flyers, word-of-mouth snowball sampling, postings in online forums, and brief presentations at local establishments. Facilities included treatment centers as well as institutions where mothers may not have had adequate resources to access treatment (e.g., homeless shelters). Mothers were compensated $10 for each part of the study they completed, for a total of $10-$30.

Instrumentation

The two QUANT instruments used to gather data for the current study included a demographic questionnaire and the Illness Perceptions Questionnaire–Revised–Autism (IPQ-R-Autism). The rationale for the demographics questions will be presented followed by the background, scale descriptions, meanings of scores, and scoring procedures for the IPQ-R-Autism.

Demographics Questionnaire

During the initial pilot data collection, there were a number of different demographic variables that were thought to influence MCDAs' beliefs. The questionnaire outlining the variables that were considered can be found in Appendix E.

In exploratory analyses of the pilot study, several variables were found to be significantly related to certain treatment control variables. Specifically, the child's specific diagnosis was related to beliefs about treatment controlling the disorder, social interaction problems, communication problems, and SB/RI. The child's sex was related to beliefs about treatment controlling SB/RI. The number of siblings was related to beliefs about treatment controlling communication problems and SB/RI. Birth order was related to beliefs about treatment controlling the disorder, communication problems, SB/RI, and tantrums. Income was related to beliefs about treatment controlling social interaction problems. Comorbidity was related to beliefs about treatment controlling communication problems.

Given these previously determined relationships, only these demographic variables were evaluated in the current study and their relationships to the LOC variables were determined. Any demographic variable that was significantly related to both study variables in an analysis would be added as a covariate.

Illness Perceptions Questionnaire – Revised – Autism (IPQ-R-Autism)

The original Illness Perceptions Questionnaire (IPQ) was a theory-driven measure based on the commonsense model of Self-Regulation Model that was described previously (Weinman, Petrie, Moss-Morris, & Horne, 1996). The scales of the original measure assessed cognitive representations of identity, cause, timeline, consequences, and cure/control of the illness (Weinman et al., 1996). A revised version (IPQ-R) was created to address psychometric problems with the original scale and include additional scales relevant to the model: cyclical timeline perceptions, illness coherence, and emotional representations (Moss-Morris et al., 2002).

The subscales that are calculated for the IPQ-R include the following:

- Identity (sum of the “yes” responses in the second column of the first section)
- Timeline Acute/Chronic (sum of Illness Perception Question 1 [IP1] through IP5 plus IP18)
- Consequences (sum of items IP6 through IP11)
- Personal Control (sum of items IP12 through IP17)
- Treatment Control (sum of items IP19 through 23)
- Illness Coherence (sum of items IP24 through IP28)
- Timeline Cyclical (sum of items IP29 through IP32)
- Emotional Representations (sum of items IP33 through IP38), and
- Causes (items Cause 1 [C1] through C18, should not be summed and should not be viewed as a unitary measure; "Using and scoring the IPQ-R," *n.d.*).

The “yes” responses of the Identity subscale receive one point each ("Using and scoring the IPQ-R," *n.d.*). The other scales receive scores as follows: strongly disagree = 1, disagree = 2, neither agree or disagree = 3, agree = 4, strongly agree = 5 ("Using and scoring the IPQ-R," *n.d.*). Items that should be reverse scored are IP1, IP4, IP8, IP15, IP17, IP18, IP19, IP23, IP24, IP25, IP26, IP27, and IP36, which are designated with an “R” after the item number during scoring (e.g., IP1R; "Using and scoring the IPQ-R," *n.d.*).

High scores have different meanings for each scale. For the Identity scale, high scores represent strongly held beliefs about the number of symptoms attributed to the illness ("Using and scoring the IPQ-R," *n.d.*). On the Timeline (Acute/Chronic) scale, high scores represent strongly held beliefs about the chronicity, or stability, of the condition ("Using and scoring the IPQ-R," *n.d.*). For the Consequences scale, high scores represent strongly held beliefs about the negative consequences of the illness ("Using and scoring the IPQ-R," *n.d.*). On the Timeline (Cyclical) scale, high scores represent strongly held beliefs about the cyclical nature of the condition ("Using and scoring the IPQ-R," *n.d.*). For the Emotional Representations scale, high scores represent strongly felt negative emotions ("Using and scoring the IPQ-R," *n.d.*). In contrast, high scores on both the Personal Control scale and Treatment Control scale represent positive beliefs about the controllability of the illness and high scores on the Illness Coherence scale represent positive beliefs about personal understanding of the illness ("Using and scoring the IPQ-R," *n.d.*).

Multiple versions of the questionnaire have been developed to address specific concerns for different diagnoses. A version of the questionnaire (IPQ-RA) was developed specifically for autism (Anbar, Dardennes, & Kaye, 2005). Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) evaluated the structural and internal validity of the IPQ-RA in a study about MCDAs' treatment choices. Regarding the representations, they found the seven factors (illness coherence, treatment control, time line [acute/chronic], consequences, time line [cyclical], personal control, emotional representations) with 79% of the items being correctly classified and each subscale having respectable to very good internal reliability, ranging from Cronbach's alpha (α) of 0.69 to 0.89, with the exception of treatment control, which had minimal acceptability of Cronbach's α equal to 0.62 (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010). The causal portion of the questionnaire divided into three factors (personal attribution, environmental causes, and chance or bad luck) and the identity scale of the questionnaire showed respectable internal reliability of Cronbach's α equal to 0.70 (Al Anbar et al., 2010).

The questionnaire used for the pilot study as well as the current study was modified even further by dividing the Timeline (Acute/Chronic) and Treatment Control scales into two parts:

1. Questions about mothers' beliefs about the disorder, and
2. The same set of questions altered for the mothers' beliefs about specific behaviors observed in children diagnosed with ASDs.

Behaviors that were evaluated included symptoms that have been part of the diagnostic criteria for autism (problems with social interaction, communication, and SB/RI). Other behaviors that were also included were tantrums and aggressive behaviors because they have been shown to be significant stressors for MCDAs (Barry & Singer, 2001; McCracken et al., 2002; Scahill et al., 2009; Singh et al., 2006).

In addition, for the current study, the Personal Control scale was divided into the five different loci of control determined by Devellis (1985) to be relevant to MCDAs: the mother, the child, a professional, divine influence, and chance. This Revised Illness Perceptions Questionnaire for Autism (IPQ-R-Autism) consisted of 167 questions. Only the Treatment Control and Personal Control scales were used for the current study.

The unmodified scales from the original IPQ-R were calculated the same way as described above. However, the Treatment Control scale was divided into six categories:

- Treatment control of the disorder (Treatment Control Disorder; IP19R + IP20 + IP21 + IP22 + IP23R)
- Treatment control of social interaction problems (Treatment Control Social; IP19aR + IP20a + IP21a + IP22a + IP23aR)
- Treatment control of communication problems (Treatment Control Communication; IP19bR + IP20b + IP21b + IP22b + IP23bR)
- Treatment control of SB/RI (Treatment Control SB/RI; IP19cR + IP20c + IP21c + IP22c + IP23cR)
- Treatment control of tantrums (Treatment Control Tantrums; IP19dR +IP20d + IP21d + IP22d + IP23dR)
- and Treatment control of aggressive behaviors (Treatment Control Aggression; IP19eR + IP20e + IP21e + IP22e + IP23eR).

High scores on any of these scales indicate strong positive belief in the controllability of the disorder or behaviors through treatment (i.e., whether treatments can help control or improve the disorder or behaviors). Scores for the scale composites can range from five to 25. Table 1 summarizes the meanings of scores for each subscale.

Table 1. Meanings of high scores on the modified Treatment Control subscales.

Scale	Meaning of High Scores	Score Range
Treatment Control Disorder	Treatment can improve the disorder	5-25
Treatment Control Social	Treatment can improve social interaction problems	5-25
Treatment Control Communication	Treatment can improve communication problems	5-25
Treatment Control SB/RI	Treatment can improve SB/RI	5-25
Treatment Control Tantrums	Treatment can improve tantrums	5-25
Treatment Control Aggression	Treatment can improve aggressive behaviors	5-25

Additionally, the Personal Control scale was divided into five categories:

- Mother Control (IP12a +IP13a + IP14a + IP15Ra + IP16a + IP17aR)
- Child Control (IP12 + IP13 + IP14 + IP15R + IP16 + IP17R)
- Professional Control (IP12b + IP13b + IP14b + IP15Rb + IP16b + IP17bR)
- Divine Control (IP12c + IP13c + IP14c + IP15Rc + IP16c + IP17cR)
- and Chance Control (IP12d + IP13d + IP14d + IP15Rd + IP16d+ IP17dR).

High scores on any of these scales indicate a strong positive belief in that particular locus having control over the disorder. Scores for the scale composites can range from six to 30. Table 2 summarizes the meanings of scores for each subscale. See Appendix F for the modified questionnaire being used for the current study.

Table 2. Meanings of high scores on the modified Personal Control subscales.

Scale	Meaning of High Scores	Score Range
Mother Control	The mother can control the disorder	6-30
Child Control	The child can control the disorder	6-30
Professional Control	A professional can control the disorder	6-30
Divine Influence	A higher power can control the disorder	6-30
Chance	Chance can control the disorder	6-30

Pilot Procedures

Before describing the procedures for the current study, it is important that the procedures for the pilot study be explained, as this dissertation is an extension of that research and some of the data that was gathered was used for the current study. Using the foundation of the Self-Regulation Model, the pilot study evaluated three hypotheses: MCDAs would see an ASD as more stable than any specific behavior, they would see treatment as being able to control behaviors more than the disorder itself, and as time since diagnosis increased their beliefs about stability and treatment control would increase. The pilot methods for evaluating these hypotheses and those results will be explained in the next sections.

Pilot Quantitative Methods

The following information describes the methods used in the pilot study. As mentioned before, twenty MCDAs were recruited from local treatment facilities using flyers, posts in online forums, and word-of-mouth snowball sampling. The flyers briefly described the study and provided the survey link as well as the student researcher’s email address if a mother wished to receive more information. Participants could either enter the survey link into their browser or send an email to the student researcher to have the survey link sent directly to them.

Once recruited, the nature and purpose of the study, data collection procedures, as well as the risks and benefits of the study were explained in an informed consent form. The consent form was placed at the beginning of the survey and participants were asked to select boxes to acknowledge that they were a mother of a child diagnosed with an ASD, were at least 18 years of age, understood the informed consent form, and gave their consent to participate. Participants were informed that they must provide contact information on a separate website to receive the drawing prize, but that providing this information was completely optional and would not be linked to their survey responses in any way. They were also notified that their information would be kept confidential, that it would only be viewed by researchers directly involved in data collection, and that safeguards were applied to the information for privacy. Specifically, the survey used Secure Socket Layer (SSL) encryption, the identifying information remained separate from the survey responses at all times, and the de-identified information was assigned subject numbers. Additionally, any identifying information was stored on the Loma Linda University (LLU) closed network with password protection and no link to survey responses. Mothers who chose to provide contact information were entered into a randomized drawing for a $250 gift card to Target.

After the consent page, participants filled out the demographics questionnaire, the IPQ-R-Autism, and open-ended questions. The participants could skip any question that they did not wish to answer.

Hypotheses were tested via SPSS software using Repeated Measures ANOVAs (to be able to evaluate beliefs within subjects using covariates), paired t-tests, and correlations. Demographics were included as covariates when significantly related to both test variables in the analysis.

Pilot Quantitative Results

Results supported that MCDAs viewed the disorder as significantly more stable than any behavior. Specifically, there were statistically significant differences when comparing:

- Beliefs about stability of the disorder vs. beliefs about stability of social interaction problems when controlling for whether or not the child was on medication, $F(1, 17) = 17.616$, $p = .001$, $\eta_p^2 = .509$
- Beliefs about the stability of the disorder vs. beliefs about the stability of communication problems when controlling for whether or not the child was on medication, $F(1, 16) = 30.013$, $p = .000$, $\eta_p^2 = .652$
- Beliefs about the stability of the disorder vs. beliefs about the stability of SB/RI when controlling for whether or not the child was on medication, $F(1, 17) = 31.393$, $p = .000$, $\eta_p^2 = .649$
- Beliefs about the stability of the disorder vs. beliefs about the stability of tantrums when controlling for whether or not the child was on medication, $F(1, 17) = 19.124$, $p = .000$, $\eta_p^2 = .529$, and
- Beliefs about the stability of the disorder vs. beliefs about stability of aggressive behaviors, $t(19) = 5.154$, $p = .000$, Cohen's $d = 1.152$.

For each result, the disorder was seen as more stable than the behavior. Analyses did not support the other two hypotheses. Specifically, treatment was not seen as being able to control behaviors any differently than the disorder and time since diagnosis was not significantly related to any test variable.

Current Quantitative Data Collection Procedures

The procedures for the current study were similar to those of the pilot study; however, they were expanded to include face-to-face interactions. The following section will describe the procedures used for the current study, including recruitment, informed consent, and survey administration.

Recruitment

A new flyer was used for the current study to recruit new participants (see Appendix A). An email explaining the study was sent to mothers who expressed an interest in participating and a meeting time and place were arranged (see Appendix B). Additionally, student researchers gave short presentations at local facilities (see Appendix C for script) to allow mothers to speak with them in person to schedule a meeting time and place.

Informed Consent

When a mother came for her appointment, she first had the informed consent (see Appendix D) explained to her by a student researcher. The informed consent included:

- A brief explanation of the study
- A description of the data collection methods (i.e., survey, interview, and focus group)
- Information about recording of responses
- A statement of confidentiality
- An explanation of voluntary participation
- A notice of potential risks
- Contact information for questions or complaints, and
- Authorization for use of Protected Health Information (PHI)

The mother was able to indicate the parts of the study in which she wanted to participate (survey, interview, and/or focus group) and indicate permissions for recording, using anonymous quotes in research articles, and/or future contact. If the mother provided permission to contact her, she filled out her contact information on a separate form. No coercion tactics were used and each mother only provided her contact information if she agreed. The contact information was securely stored behind locked doors at Loma Linda University. Only the research team had access to the contact information.

Completing the Survey

After completing the consent form, if the mother chose to do the survey portion of the study, she filled out the demographics questionnaire and the IPQ-R-Autism. It should be noted that these questionnaires were updated to correct any administrative errors previously found in the pilot study. The pilot data could still be used, though, as the errors only occurred on scales that were not used for the analyses in the current study.

The participants completed the survey online or using paper and pen. This was to ensure that low-income participants who did not have access to a computer could fill out the survey and mothers could complete the survey in whatever format with which they felt most comfortable. Additionally, a student researcher was able to answer any questions directly or assist with filling out the form using any necessary accommodations.

Quantitative Analyses

As previously discussed, QUANT research is primarily concerned with the relationship between variables and analyzes numbers using statistics (Teddlie & Tashakkori, 2009). Before the main analyses could take place, the data was screened, internal consistency was assessed, and descriptive statistics were evaluated for any covariates. Each of these processes are described in this section as well as the main analyses that were planned for testing the QUANT hypothesis.

Data Screening

Before performing the main analyses, data were screened for missing data, outliers, and normality. When a score was missing from a main test variable, data was imputed using the mean of the other question scores within the same composite. This was done to maximize the power for each analysis. Only 12 responses were imputed for the variables used in this study, and there was never more than one response per question that required imputation (i.e., 0-2%). To check for outliers, *z*-scores were calculated for each of the dependent variables with a designated cut-off of three standard deviations (i.e., $z \geq 3.29$). No score fell outside this range, so no responses were excluded. The normality of the dependent variables was also assessed. None the of the main test variables had significant skew or kurtosis, indicating that they did not violate the assumption of a normal distribution.

Validity and Reliability

When doing QUANT research, it is important to consider whether the measures being used are valid and reliable (as opposed to QUAL research's focus on credibility and trustworthiness, which will be described later in the corresponding section). Validity in QUANT research is defined as whether a test measures what the investigator intends that it measure (Cohen, Cohen, West, & Alken, 2003, p. 55). This is essentially a philosophical question and can only be estimated by a convergence of evidence. The current study addressed validity by using an established measure (i.e., the IPQ-RA) as the foundation for the QUANT strand. In other words, it was based on established constructs and did not rely on the researcher's notions alone.

Reliability "means that a scale should consistently reflect the construct it is measuring" (Field, 2005, p. 666). Cronbach's α was used to measure the internal reliability of each scale being used from the IPQ-R-Autism for the current study. This was especially important for the scales related to loci of control, as Personal Control was the only scale on the IPQ-R-Autism that had been previously tested with this population. As mentioned earlier, additional scales were added due to previous literature suggesting that MCDAs may also believe in other loci of control for their children's improvement (i.e., the child, a professional, divine influence, and chance), so evaluating their internal reliability in the current study was essential. When looking at the Treatment Control scales, reliability fell within the undesirable (.60-.65), minimally acceptable (.65-.70), and respectable (.70-.80) ranges (DeVellis, 1991). When looking at the LOC scales, reliability fell within the respectable and very good (.80-90) ranges (DeVellis, 1991). None fell within the unacceptable range (below .60). Tables 3 and 4 show the reliability for each subscale.

Table 3. Reliability of Treatment Control subscales.

Scale	Cronbach's α
Treatment Control Disorder	.624
Treatment Control Social	.701
Treatment Control Communication	.661
Treatment Control SB/RI	.753
Treatment Control Tantrums	.739
Treatment Control Aggression	.723

Table 4. Reliability of Locus of Control subscales.

Scale	Cronbach's α
Mother Control	.805
Child Control	.766
Professional Control	.828
Divine Control	.945
Chance Control	.811

Descriptive Statistics

Descriptive statistics provide frequencies, means, and measures of variability that correspond to the characteristics of the participants in the study and their responses. In other words, they *describe* what the participants were like and how they responded. Descriptive statistics were analyzed from the demographic questionnaire to provide aggregate information about the participants. Means and standard deviations were also calculated for each scale being used for the primary analyses.

Testing the Hypothesis

There are three sections to discuss how the QUANT hypothesis was tested. First, the process of determining covariates is discussed. Then, the main analyses that were planned are defined more clearly. Lastly, the rationale for the type of analysis being used is explained.

Determining Covariates

Determining what covariates to include in an analysis was required before the main analyses were performed. This is because variables that are significantly related to both outcome variables in an analysis may explain a significant portion of the variance (i.e., they co-vary and are therefore defined as *covariates*). Thus, covariates need to be accounted for so that any differences found between the primary variables were not due to a confounding relationship. As previously mentioned, the demographic variables chosen to be analyzed to determine whether they should be covariates were selected because they had previously been shown to be significantly related to the Treatment

Control variables in the pilot study. Other demographic variables were not tested at this time because they had already been shown to not be significantly related to the Treatment Control variables, and thus, would not be related to both variables in the analyses.

Only two relationships were found to be significant when determining if any covariates should be included. There was a significant negative correlation between the number of the child's siblings and the mothers' belief that the children diagnosed with autism would be able to have some control over the disorder or behaviors. Additionally, there was a significant relationship between income and the mothers' belief that they had some personal control over the disorder or behaviors. Specifically, mothers that had household incomes over $60,000 had a significantly higher belief in Mother Control (*M* = 24.24, *SE* = 0.769) than mothers with household incomes below $60,000 (*M* = 21.21, *SE* = 0.858). However, since these two variables were not related to any of the Treatment Control variables as would have been predicted from the pilot results, they were not included as covariates. See tables 5 and 6 for these results.

Table 5. Demographic variable significance with Treatment Control DVs.

	Dx	Soc	Comm	Stereo	Tant	Agg
Child Diagnosis	t = 0.792	t = 1.546	t = 1.543	t = 1.462	t = 0.565	t = 0.201
Child's Sex	t = 0.695	t = 1.721	t = 1.037	t = 0.470	t = 0.816	t = 1.917
Number of Siblings	r = 0.126	r = 0.204	r = 0.187	r = 0.249	r = 0.093	r = 0.036
Birth Order	r = 0.176	r = 0.183	r = 0.183	r = 0.273	r = 0.156	r = 0.131
Income	t = -0.728	t = -1.534	t = -1.219	t = -1.329	t = -0.616	t = -1.127
Comorbidity	t = -0.703	t = -0.655	t = -0.511	t = -0.599	t = -0.543	t = 0.011

Note. DVs = Dependent variables. Dx = Disorder. Soc = social problems. Comm = communication problems. Stereo = stereotyped behaviors or restricted interests. Tant = Tantrums. Agg = Aggressive Behaviors. Child diagnosis was split into ASD vs other and income was split into above and below $60,000 due unevenly distributed frequencies.

Table 6. Demographic variable significance with Locus of Control DVs.

	Mother	Child	Professional	Divine	Chance
Child Diagnosis	t = -0.373	t = 0.312	t = 0.311	t = -0.800	t = -0.564
Child's Sex	t = -1.015	t = 0.117	t = -1.243	t = 0.100	t = -0.355
Number of Siblings	r = -0.220	r = -0.297*	r = -0.025	r = 0.187	r = -0.068
Birth Order	r = -0.173	r = -0.235	r = -0.009	r = 0.082	r = 0.042
Income	t = 2.637*	t = 1.855	t = 1.440	t = -0.136	t = -0.783
Comorbidity	t = 0.317	t = -0.476	t = -0.130	t = -0.651	t = -0.599

Note. * = p < .05. DVs = Dependent variables. Child diagnosis is split into ASD vs other and income is split into above and below $60,000 due unevenly distributed frequencies.

Planned Analyses

To review, the QUANT hypothesis for the current study was that MCDAs who scored higher on the Mother Control scale than other LOC scales would score *higher* on the scales of Treatment Control of *behaviors* than on the scale of Treatment Control of the *disorder*. To analyze this, the overall differences between the Treatment Control scales (disorder vs. behaviors) and the Personal Control scales (mother vs. external loci) were tested for significance using a type of Analysis of Variance (ANOVA). Specifically, since these scales were within subjects, which violated the assumption of independence, a Repeated Measures ANOVA was deemed most appropriate.

To determine whether there was an interaction between Treatment Control and LOC, different group comparisons were planned. To provide an overarching comparison for each analysis, first mothers were categorized into mothers with Mother Control composite scores that were higher than all other LOC composite scores (i.e., the highest Mother LOC group) and mothers with Mother Control composite scores that were equal to or less than at least one external LOC composite score (i.e., the External LOC group). However, this overall comparison would not show which specific external control composite differs. Consequently, it was thought necessary to make comparison groups for each LOC composite. The following table provides the definitions for the LOC groups.

Table 7. Locus of Control group definitions.

Group Name	Definition
Mother LOC	MCDAs whose belief in the mother's personal LOC was higher than the external control variable being compared
External LOC	MCDAs whose belief in the mother's personal LOC was not higher than the beliefs in all other external LOC variables
Child LOC	MCDAs whose belief in the child's LOC was higher than the belief in the mother's personal LOC
Professional LOC	MCDAs whose belief in professionals' LOC was higher than the belief in the mother's personal LOC
Divine LOC	MCDAs whose belief in divine LOC was higher than the belief in the mother's personal LOC
Chance LOC	MCDAs whose belief in chance as a LOC was higher than the belief in the mother's personal LOC

In other words, the members of the Mother LOC group varied depending on which external LOC composite was being compared. The following table shows the division of participants per LOC comparison.

Table 8. N for each group by each Locus of Control comparison.

Comparison	Group	N
Mother LOC vs. External LOC		
	Mother LOC	6
	External LOC	44
Mother LOC vs. Child LOC		
	Mother LOC	35
	Child LOC	15
Mother LOC vs. Professional LOC		
	Mother LOC	15
	Professional LOC	35
Mother LOC vs. Divine LOC		
	Mother LOC	26
	Divine LOC	24
Mother LOC vs. Chance LOC		
	Mother LOC	42
	Chance LOC	8

Each pairing of groups was then added as a between-subjects variable to each comparison of Treatment Control of the disorder versus Treatment Control of a specific behavior to determine whether an interaction existed.

Thus, the analyses run were as follows:

- Treatment Control Disorder vs. Treatment Control Social by Mother LOC group vs. each External LOC group (i.e., External, Child, Professional, Divine, Chance)
- Treatment Control Disorder vs. Treatment Control Communication by Mother LOC group vs. each External LOC group (i.e., External, Child, Professional, Divine, Chance)

- Treatment Control Disorder vs. Treatment Control SB/RI by Mother LOC group vs. each External LOC group (i.e., External, Child, Professional, Divine Influence, Chance)
- Treatment Control Disorder vs. Treatment Control Tantrums by Mother LOC group vs. each External LOC group (i.e., External, Child, Professional, Divine Influence, Chance)
- Treatment Control Disorder vs. Treatment Control Aggression by Mother LOC group vs. each External LOC group (i.e., External, Child, Professional, Divine Influence, Chance)

Rationale

A special note needs to be discussed regarding the use of Repeated Measures ANOVAs in this context. This type of test has traditionally been used for comparing the same test repeated over time, yet this is not what is being done for the current study. However, the core function of a Repeated Measures ANOVA is to compare one value with a second value being measured within the same person. The concept of these two numbers being over time is conceptual, and not objectively reflected in the statistical analysis. Specifically, a paired *t*-test results in the same *p*-value when comparing only two numbers with no covariates. This is because an *F*-value (the resultant statistic from an ANOVA) is the exact same as a *t*-value (the resultant statistic from a *t*-test) squared (i.e., $F=t^2$), which is simply an exponential transformation that does not affect the *p*-value. However, a paired t-test is not labeled a “Repeated Measures t-test” because other types of comparisons can be made. In this way, a Repeated Measures ANOVA could be thought of as a “paired ANOVA.” Consequently, the current study used Repeated Measures ANOVA as a test that functioned as a comparison between one belief and a second belief within the same mother. Furthermore, Repeated Measures ANOVAs were required rather than paired t-tests because both within- and between-subjects variables needed to be included.

CHAPTER FOUR

QUANTITATIVE RESULTS

There are three general sections for presenting the results of this study. First, the descriptive statistics will outline the characteristics of the study sample and composite scores. Second, the results of the overarching comparison will be presented. Lastly, the results for specific comparisons will be reported.

Descriptive Statistics

To begin the presentation of results, a summary of the descriptive statistics of the demographic variables will be described to illuminate the characteristics of this sample. Almost half of the children were reported to have ASD, while over half of the mothers reported diagnoses that still represent the shift from the DSM-IV-TR to the DSM-5 (i.e., Autistic Disorder, Asperger's Disorder, and PDD-NOS). This may be because the average time since diagnosis was near five years. The average severity level reported by mothers was within the moderate range. There were 88% male children represented and 12% female, which is consistent with what would be found in the general population (i.e., four to five times more males than females). The average age of the children was 9-years-old.

The mothers were generally well-educated and most mothers were employed for wages or homemakers. The majority of mothers were married to their first husband and parents were typically in their late 30s to early 40s. Most mothers reported being Christian or Catholic. The family make-up generally included four people in the home, frequently with siblings of which some also had a disability. The mothers reported receiving a few services for themselves personally and several services for their children. Mothers on average reported being highly involved in their children's treatments.

An important point that should be made is that purposeful effort was made during the recruitment process to find participants from groups that were not captured in the pilot study which are frequently underrepresented in research in general. One measure that demonstrates that this was partly successful was the percentages of the mothers' ethnicities. Specifically, Black/African-American, Hispanic/Latino, and Multiracial mothers were represented at percentages greater than the national averages for these groups (United States Census Bureau, 2014). Additionally, in the pilot sample, almost half the sample had household incomes above $100,00, but in the current sample, almost equal percentages for household income were above and below $60,000, which is near the median household income of California (United States Census Bureau, 2014).

The following tables (9 and 10) present the descriptive statistics of the demographic variables:

Table 9. Mean of participant characteristics.

	M	*SD*	Range	
			Minimum	Maximum
Mother's age	39.90	7.063	24	55
Father's age	43.13	8.898	28	68
Child's age	9.00	4.486	2	18
Time dx (mo)	56.07	41.946	1	156
# Siblings	1.58	1.126	0	5
# dx Siblings	0.45	0.775	0	4
# Ppl in hm	4.06	1.069	2	7
Mother's Ed	14.86	2.828	11	22
# Mom Services	1.72	1.938	0	10
# Child Services	4.76	2.918	0	11
Severity	3.02	0.861	.50	4.67
Involvement	8.64	1.925	1	10

Note. Time dx (mo) = time since the child was diagnosed with Autistic Disorder in months. # dx Siblings = number of siblings with a disability. # Ppl in hm = number of people in the home. Mother's Ed = mother's highest level of education in years. # Mom Services = number of services the mom has received. # Child Services = number of services the child has received. Severity = mean of the mother's perceived severity of the child's disorder/behaviors. Involvement = mother's perceived involvement in her child's services on a 10-point scale.

Table 10. Frequency of participant characteristics.

	N	%
Child's Diagnosis		
Autism Spectrum Disorder	23	46
Autistic Disorder	15	30
Asperger's Disorder	9	18
Pervasive Developmental Disorder NOS	3	6
Mom's Ethnicity		
Caucasian/White	24	48
African-American/Black	9	18
Hispanic/Latino	12	24
Asian	2	4
Multiracial	3	6
Child's Ethnicity		
Caucasian/White	18	36
African-American/Black	8	16
Hispanic/Latino	11	22
Asian	2	4
Multiracial	10	20
Child's Sex		
Male	44	88
Female	6	12
Religion		
Catholic	14	28
Christian	28	56
Buddhist	1	2
Atheist	1	2
Other	6	12

Table 10, cont.

	N	%
Marital Status		
Never married	3	6
Living with significant other	1	2
Married (1st husband)	32	64
Separated	3	6
Divorced	5	10
Re-married	5	10
Employment Status		
Employed for wages	22	44
Self-employed	5	10
Unemployed	7	14
Homemaker	12	24
Student	2	4
Unable to work due to disability	2	4
Household Income		
$0-$20,000	5	10
$20,001-$40,000	9	18
$40,001-$60,000	10	20
$60,001-$80,000	5	10
$80,001-$100,000	5	10
Greater than $100,000	9	18
$100,001-$150,000	4	8
$200,001-$250,000	1	2
$250,001-$300,000	1	2

Note. Both DSM-IV-TR and DSM-5 disorders were included due to the recent transition between the two manuals. Household income includes a "Greater than $100,00" category due to the higher brackets only having been added after the thesis data was collected to account for the high number of participants selecting this range. Categories that were included on the survey may not be included in this table if no participants fell within them. Percentages may not add to 100% due to missing values.

For the Treatment Control composites, mothers generally slightly agreed on average that treatment could control the disorder and behaviors (i.e., the means were above 15, which would have represented an average response of neither agreeing nor disagreeing). See Table 11 for descriptive statistics for each Treatment Control composite.

Table 11. Descriptive statistics for Treatment Control composites.

			Range	
	M	*SD*	Minimum	Maximum
Disorder	18.120	2.939	13	25
Social	18.440	2.956	13	25
Communication	18.520	2.991	13	25
SB/RI	17.640	3.527	10	25
Tantrums	18.485	3.142	12	25
Aggression	18.242	3.057	11	25

Note. Each variable is a composite score of items from the Treatment Control scale of the IPQ-R-Autism. Disorder = all ASDs. Social = social problems. Communication = communication problems. SB/RI = stereotyped behaviors or restricted interests. Aggression = aggressive behaviors.

For the LOC composites, mothers generally slightly agreed on average that the mother, the child, professionals, and a higher power had some control (i.e., the means were above 18, which would have represented an average response of neither agreeing nor disagreeing). However, they disagreed on average with chance as a LOC. See Table 12 for descriptive statistics for each LOC composite.

Table 12. Descriptive statistics for LOC composites.

			Range	
	M	*SD*	Minimum	Maximum
Mother Control	22.680	4.254	11	30
Child Control	19.700	4.413	8	28
Professional Control	22.540	4.141	13	30
Divine Influence	20.764	6.848	6	30
Chance	13.848	4.747	6	25

Note. Each variable is a composite score of items from the LOC scales of the IPQ-R-Autism.

Results of the Main Analyses

As previously mentioned, the results for the main analyses were divided into the results for the overarching comparison and then the results for specific comparisons. Each Repeated Measures ANOVA was evaluated for statistical significance at the .05 level. Partial eta-squared (η_p^2) was reported for each analysis to provide an estimate of effect size. Using the benchmarks set by Cohen (1988), a small effect size is above .01, a medium effect size is above .06, and a large effect size is above .14. However, it should be noted that modern statisticians caution that this measure may overestimate the effect, especially for small samples (Levine & Hullett, 2002). The observed power for each analysis was also reported for each analysis because underpowered analyses can also overestimate the effect size or can potentially cause a Type II error (i.e., not detect an effect when one does exist, M. K. Smith, 2013). No corrections for Type I error (i.e., detecting an effect that does not exist) were made at this time due to the fact that the current research was exploring whether interactions existed rather than confirming previously identified relationships.

Results Comparing Mother LOC to All External LOC

When comparing the overall highest Mother LOC group with the External LOC group, most comparisons were not statistically significant. However, the difference between Treatment Control Disorder and Treatment Control Social approached significance ($p = 0.052$). Additionally, there was a significant main effect when comparing Treatment Control Disorder versus Treatment Control Communication, $F(1,48) = 4.225$, $p = 0.045$, $\eta_p^2 = 0.081$. Specifically, both the Mother LOC group and the External LOC group believed treatment could control communication problems (Mother LOC by Treatment Control Communication $M = 18.333$, $SE = 1.234$; External LOC by Treatment Control Communication $M = 18.545$, $SE = 0.456$) *more* than the disorder (Mother LOC by Treatment Control Disorder $M = 17.500$, $SE = 1.209$; External LOC by Treatment Control Disorder $M = 18.205$, $SE = 0.446$). This result had a medium effect size.

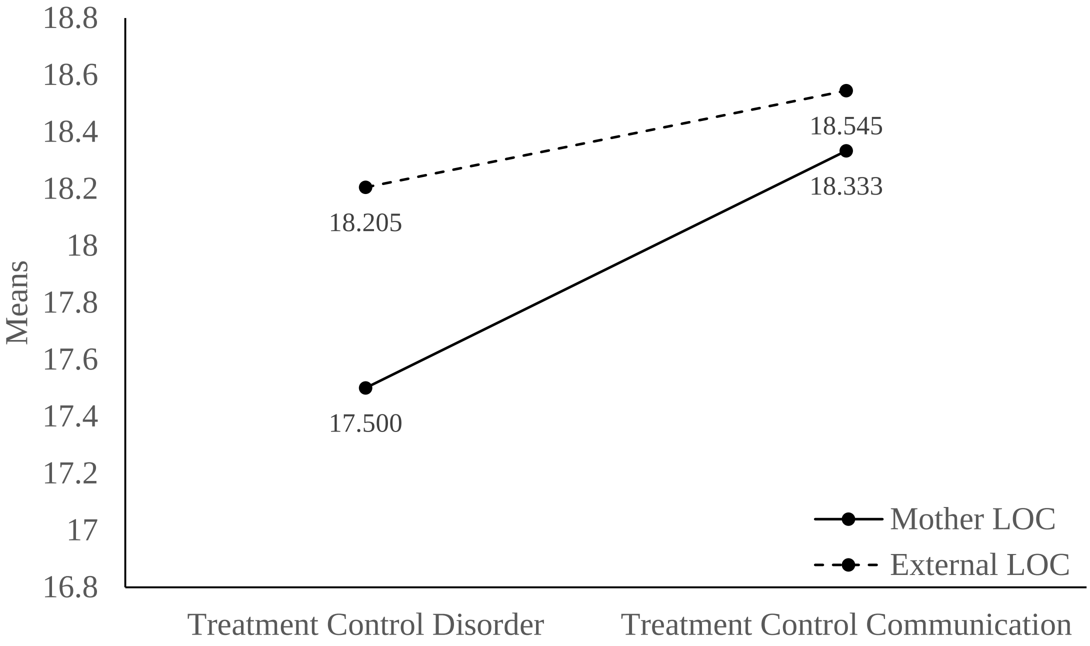

Figure 4. Main effect for Treatment Control Disorder vs. Treatment Control Communication by Mother LOC vs. External LOC.

It should be noted that the group Ns were uneven, so caution should be used with interpretation. However, both Box's and Levene's tests were not significant, indicating that there were no violations of equality of covariance or error variance, respectively. The following tables provide the results for the overarching comparison:

Table 13. Results of Treatment Control Disorder vs. Treatment Control Social by Mother LOC vs. External LOC.

	F	df	*p* value	η_p^2	Observed power
Main Effect	3.961	1, 48	.052	.076	.496
Within-Subject Interaction	1.149	1, 48	.289	.023	.183
Between-Subjects Effect	0.106	1, 48	.746	.002	.062

Table 14. Results of Treatment Control Disorder vs. Treatment Control Communication by Mother LOC vs. External LOC.

	F	df	*p* value	η_p^2	Observed power
Main Effect	4.225	1, 48	.045*	.081	.522
Within-Subject Interaction	0.743	1, 48	.393	.015	.135
Between-Subjects Effect	0.130	1, 48	.720	.003	.064

Note. * = p <.05.

Table 15. Results of Treatment Control Disorder vs. Treatment Control SB/RI by Mother LOC vs. External LOC.

	F	df	*p* value	η_p^2	Observed power
Main Effect	2.738	1, 48	.105	.054	.368
Within-Subject Interaction	0.691	1, 48	.410	.014	.129
Between-Subjects Effect	0.670	1, 48	.417	.014	.126

Table 16. Results of Treatment Control Disorder vs. Treatment Control Tantrums by Mother LOC vs. External LOC.

	F	df	*p* value	η_p^2	Observed power
Main Effect	0.111	1, 48	.740	.002	.062
Within-Subject Interaction	0.552	1, 48	.461	.011	.113
Between-Subjects Effect	0.633	1, 48	.430	.013	.122

Table 17. Results of Treatment Control Disorder vs. Treatment Control Aggression by Mother LOC vs. External LOC.

	F	df	*p* value	η_p^2	Observed power
Main Effect	0.031	1, 48	.860	.001	.053
Within-Subject Interaction	0.376	1, 48	.543	.008	.092
Between-Subjects Effect	0.602	1, 48	.441	.012	.118

Results Comparing Mother LOC to Each LOC Group

As mentioned for the planned analyses, it is important to look at how these mothers' personal LOC compares to each external LOC. This is so that any specific differences can be revealed. The tables on the subsequent pages show the results. A narrative highlighting the significant results follows.

Table 18. Main effects for Treatment Control Disorder vs. Treatment Control Social by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	2.149	1, 48	.149	.043	.301
Mother LOC vs. Professional LOC	3.455	1, 48	.069	.067	.445
Mother LOC vs. Divine LOC	3.844	1, 48	.056	.074	.485
Mother LOC vs. Chance LOC	1.429	1, 48	.238	.029	.216

Table 19. Within-subject interactions for Treatment Control Disorder vs. Treatment Control Social by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.193	1, 48	.662	.004	.072
Mother LOC vs. Professional LOC	0.290	1, 48	.593	.006	.082
Mother LOC vs. Divine LOC	4.778	1, 48	.034*	.091	.572
Mother LOC vs. Chance LOC	0.023	1, 48	.865	.001	.053

Note. * = $p < .05$.

Table 20. Between-subjects effects for Treatment Control Disorder vs. Treatment Control Social by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.006	1, 48	.941	.000	.051
Mother LOC vs. Professional LOC	1.590	1, 48	.213	.032	.235
Mother LOC vs. Divine LOC	0.030	1, 48	.863	.001	.053
Mother LOC vs. Chance LOC	1.548	1, 48	.219	.031	.230

Table 21. Main effects for Treatment Control Disorder vs. Treatment Control Communication by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	2.850	1, 48	.098	.056	.380
Mother LOC vs. Professional LOC	5.543	1, 48	.023*	.104	.636
Mother LOC vs. Divine LOC	5.522	1, 48	.023*	.103	.634
Mother LOC vs. Chance LOC	2.984	1, 48	.091	.059	.395

Note. * = $p < .05$.

Table 22. Within-subject interactions for Treatment Control Disorder vs. Treatment Control Communication by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.495	1, 48	.485	.010	.106
Mother LOC vs. Professional LOC	0.887	1, 48	.351	.018	.152
Mother LOC vs. Divine LOC	5.522	1,48	.023*	.103	.634
Mother LOC vs. Chance LOC	0.054	1, 48	.816	.001	.056

Note. * = $p < .05$.

Table 23. Between-subjects effects for Treatment Control Disorder vs. Treatment Control Communication by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.019	1, 48	.891	.000	.052
Mother LOC vs. Professional LOC	1.337	1, 48	.253	.027	.205
Mother LOC vs. Divine LOC	0.051	1, 48	.823	.001	.056
Mother LOC vs. Chance LOC	1.312	1, 48	.258	.027	.202

Table 24. Main effects for Treatment Control Disorder vs. Treatment Control SB/RI by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	2.540	1, 48	.118	.050	.346
Mother LOC vs. Professional LOC	6.066	1, 48	.022*	.105	.642
Mother LOC vs. Divine LOC	2.391	1, 48	.129	.047	.329
Mother LOC vs. Chance LOC	0.855	1, 48	.360	.017	.148

Note. * = $p < .05$.

Table 25. Within-subject interactions for Treatment Control Disorder vs. Treatment Control SB/RI by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.159	1, 48	.692	.003	.068
Mother LOC vs. Professional LOC	5.630	1, 48	.022*	.105	.642
Mother LOC vs. Divine LOC	0.211	1, 48	.648	.004	.074
Mother LOC vs. Chance LOC	0.107	1, 48	.745	.002	.062

Note. * = $p < .05$.

Table 26. Between-subjects effects for Treatment Control vs. Treatment Control SB/RI by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.014	1, 48	.905	.000	.052
Mother LOC vs. Professional LOC	4.675	1, 48	.036*	.089	.563
Mother LOC vs. Divine LOC	0.010	1, 48	.919	.000	.051
Mother LOC vs. Chance LOC	1.026	1, 48	.316	.021	.168

Note. * = $p < .05$.

Table 27. Main effects for Treatment Control Disorder vs. Treatment Control Tantrums by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	1.242	1, 48	.271	.025	.194
Mother LOC vs. Professional LOC	1.850	1, 48	.180	.037	.266
Mother LOC vs. Divine LOC	2.057	1, 48	.158	.041	.290
Mother LOC vs. Chance LOC	3.015	1, 48	.089	.059	.398

Table 28. Within-subject interactions for Treatment Control Disorder vs. Treatment Control Tantrums by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.134	1, 48	.716	.025	.194
Mother LOC vs. Professional LOC	0.063	1, 48	.803	.001	.057
Mother LOC vs. Divine LOC	1.220	1, 48	.275	.025	.191
Mother LOC vs. Chance LOC	1.113	1, 48	.297	.023	.179

Table 29. Between-subjects effects for Treatment Control Disorder vs. Treatment Control Tantrums by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.009	1, 48	.924	.000	.051
Mother LOC vs. Professional LOC	1.667	1, 48	.203	.034	.244
Mother LOC vs. Divine LOC	0.005	1, 48	.943	.000	.051
Mother LOC vs. Chance LOC	0.727	1, 48	.398	.015	.133

Table 30. Main effects for Treatment Control Disorder vs. Treatment Control Aggression by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.148	1, 48	.702	.003	.066
Mother LOC vs. Professional LOC	0.453	1, 48	.504	.009	.101
Mother LOC vs. Divine LOC	0.319	1, 48	.575	.007	.086
Mother LOC vs. Chance LOC	1.684	1, 48	.201	.034	.246

Table 31. Within-subject interactions for Treatment Control Disorder vs. Treatment Control Aggression by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	0.003	1, 48	.959	.000	.050
Mother LOC vs. Professional LOC	0.442	1, 48	.509	.009	.100
Mother LOC vs. Divine LOC	5.820	1, 48	.020*	.108	.657
Mother LOC vs. Chance LOC	2.020	1, 48	.162	.040	.286

Note. * = $p < .05$.

Table 32. Between-subjects effects for Treatment Control Disorder vs. Treatment Control Aggression by LOC group comparisons.

	F	df	*p* value	η_p^2	Observed power
Mother LOC vs. Child LOC	.000	1, 48	.997	.000	.050
Mother LOC vs. Professional LOC	1.366	1, 48	.248	.028	.209
Mother LOC vs. Divine LOC	0.240	1, 48	.626	.005	.077
Mother LOC vs. Chance LOC	0.542	1, 48	.465	.011	.111

The significant results will be described in more detail so that the particulars of each significant difference can be elucidated. It should be noted that Box's and Levene's tests were also reviewed for these results with no significant assumption violations.

There was a significant within-subject interaction when comparing Treatment Control Disorder versus Treatment Control Social by Mother LOC versus Divine LOC, $F(1,48) = 4.778$, $p = 0.034$, $\eta_p^2 = 0.091$. Specifically, there was *no difference* between beliefs about treatment being able to control social interaction problems ($M = 18.192$, $SE = 0.584$) and beliefs about treatment being able to control the disorder ($M = 18.231$, $SE = 0.582$) for the Mother LOC group, whereas the Divine LOC group believed treatment could control social interaction problems ($M = 18.708$, $SE = 0.607$) *more* than the disorder ($M = 18.000$, $SE = 0.606$). This result had a medium effect size.

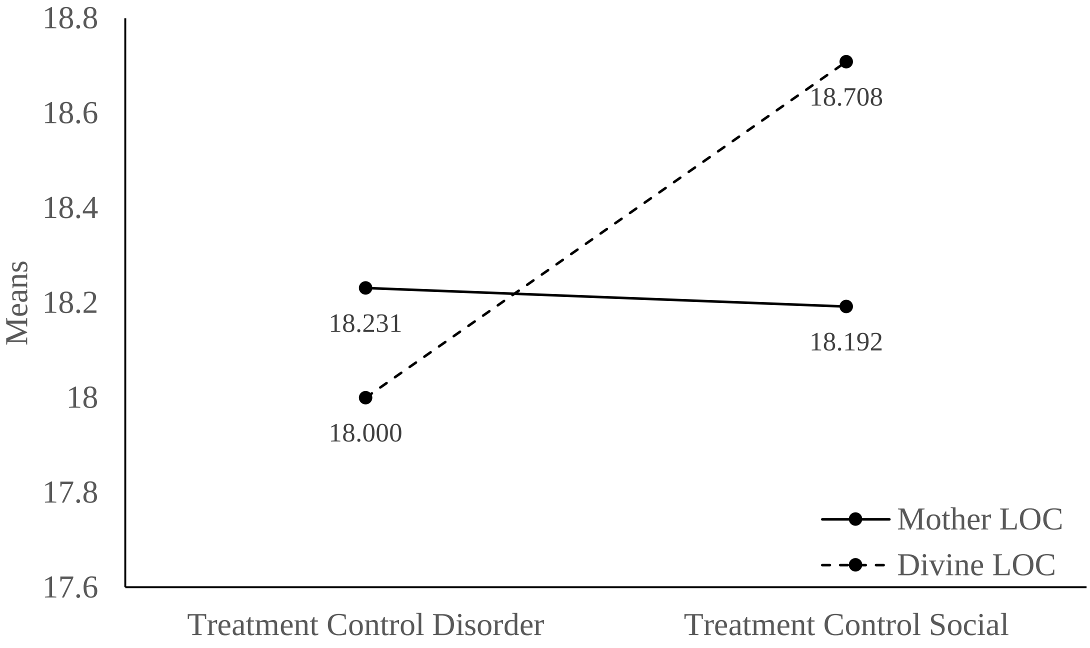

Figure 5. Within-subject interaction for Treatment Control Disorder vs. Treatment Control Social by Mother LOC vs. Divine LOC.

There was a significant main effect when comparing Treatment Control Disorder versus Treatment Control Communication by Mother LOC versus Professional LOC, $F(1,48) = 5.543$, $p = 0.023$, $\eta_p^2 = 0.104$. In other words, both the Mother LOC group as well as the Professional LOC group believed that treatment could control communication problems (Mother LOC by Treatment Control Communication $M = 17.933$, $SE = 0.774$; Professional Control by Treatment Control Communication $M = 18.771$, $SE = 0.507$) *more* than the disorder (Mother Control by Treatment Control Disorder $M = 17.267$, $SE = 0.752$; Professional Control by Treatment Control Disorder $M = 18.486$, $SE = 0.493$). This result had a medium effect size.

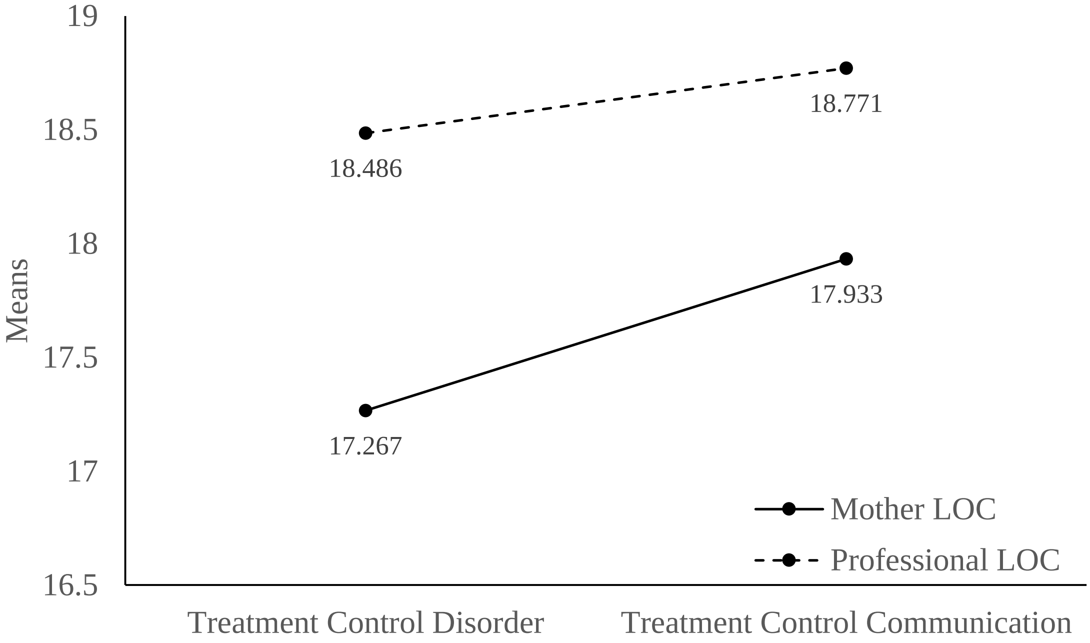

Figure 6. Main effect for Treatment Control Disorder vs. Treatment Control Communication by Mother LOC vs. Professional LOC.

There was a significant main effect when comparing Treatment Control Disorder versus Treatment Control Communication by Mother LOC versus Divine LOC, $F(1,48) = 5.522$, $p = 0.023$, $\eta_p^2 = 0.103$. There was also a significant interaction for this comparison, $F(1,48) = 5.522$, $p = 0.023$, $\eta_p^2 = 0.103$. Specifically, there was *no significant difference* between mothers' beliefs about treatment being able to control communication problems ($M = 18.231$, $SE = 0.590$) and treatment being able to control the disorder ($M = 18.231$, $SE = 0.582$) for the Mother LOC group, whereas the Divine LOC group believed treatment could control communication problems ($M = 18.833$, $SE = 0.614$) *more* than the disorder ($M = 18.000$, $SE = 0.606$). These results had medium effect sizes.

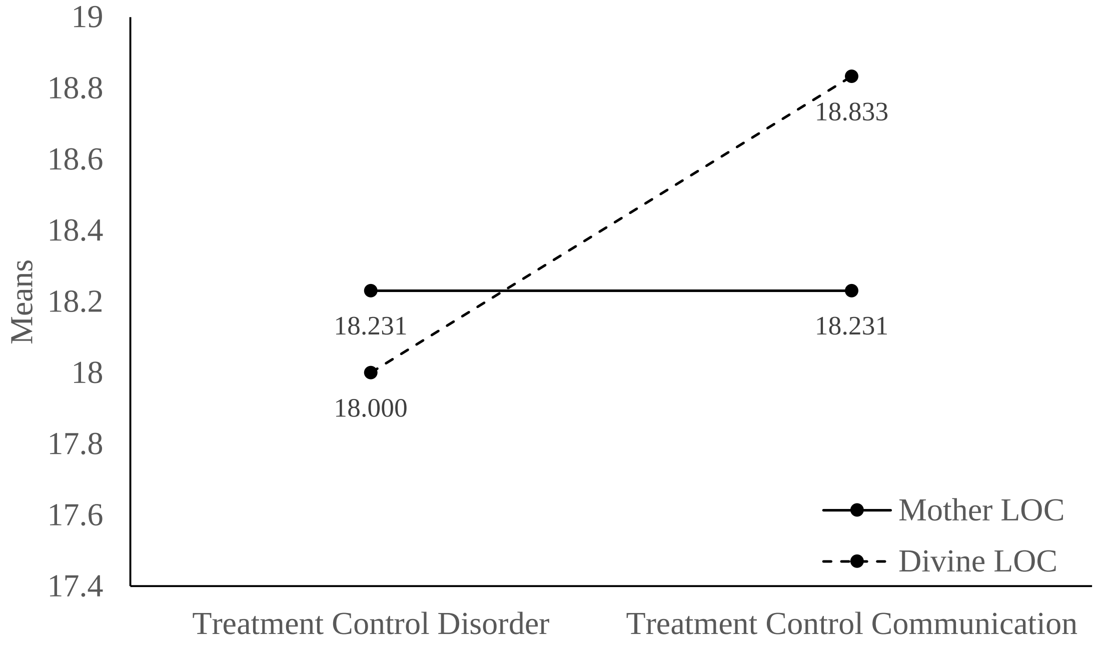

Figure 7. Main effect and within-subject interaction for Treatment Control Disorder vs. Treatment Control Communication by Mother LOC vs. Divine LOC.

There was a significant main effect when comparing Treatment Control Disorder versus Treatment Control SB/RI by Mother LOC versus Professional LOC, $F(1,48) = 6.066$, $p = 0.022$, $\eta_p^2 = 0.105$. There was also a significant within-subject interaction for this comparison, $F(1,48) = 5.630$, $p = 0.022$, $\eta_p^2 = 0.105$. Specifically, the Mother LOC group believed treatment could control SB/RI ($M = 15.733$, $SE = 0.859$) *less* than the disorder ($M = 17.267$, $SE = 0.752$), whereas there was *no difference* in beliefs about treatment being able to control SB/RI ($M = 18.457$, $SE = 0.563$) and beliefs about treatment being able to control the disorder ($M = 18.486$, $SE = 0.493$) for the Professional LOC group. Furthermore, there was a significant between-subjects effect for this comparison, $F(1,48) = 4.675$, $p = 0.036$, $\eta_p^2 = 0.089$. In other words, the Mother LOC group viewed treatment being able to control both the disorder and behaviors *less* overall than the Professional LOC group. These results had medium effect sizes.

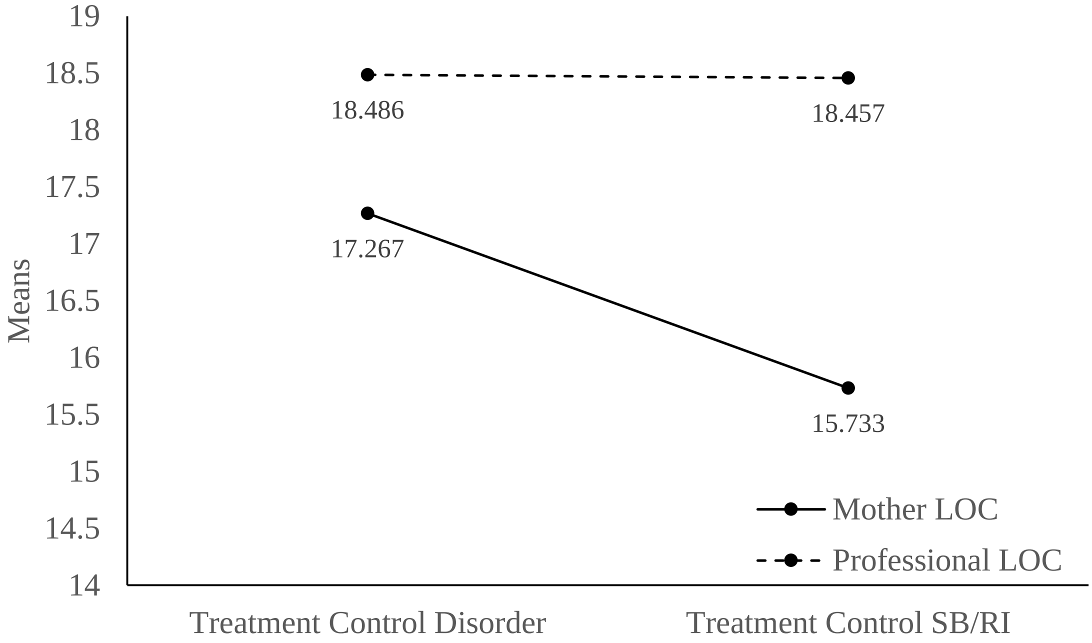

Figure 8. Main effect, within-subject interaction, and between-subjects effect for Treatment Control Disorder vs. Treatment Control SB/RI by Mother LOC vs. Divine LOC.

Lastly, there was a significant interaction when comparing Treatment Control Disorder to Treatment Control Aggression by Mother LOC versus Divine LOC, *F*(1,48) = 5.820, $p = 0.020$, $\eta_p^2 = 0.108$. Specifically, the Mother LOC group believed treatment could control aggressive behaviors ($M = 17.750$, $SE = 0.597$) *less* than the disorder ($M = 18.231$, $SE = 0.582$), whereas the Divine LOC group believed treatment could control aggressive behaviors ($M = 18.775$, $SE = 0.621$) *more* than the disorder ($M = 18.000$, $SE = 0.606$). This result had a medium effect size.

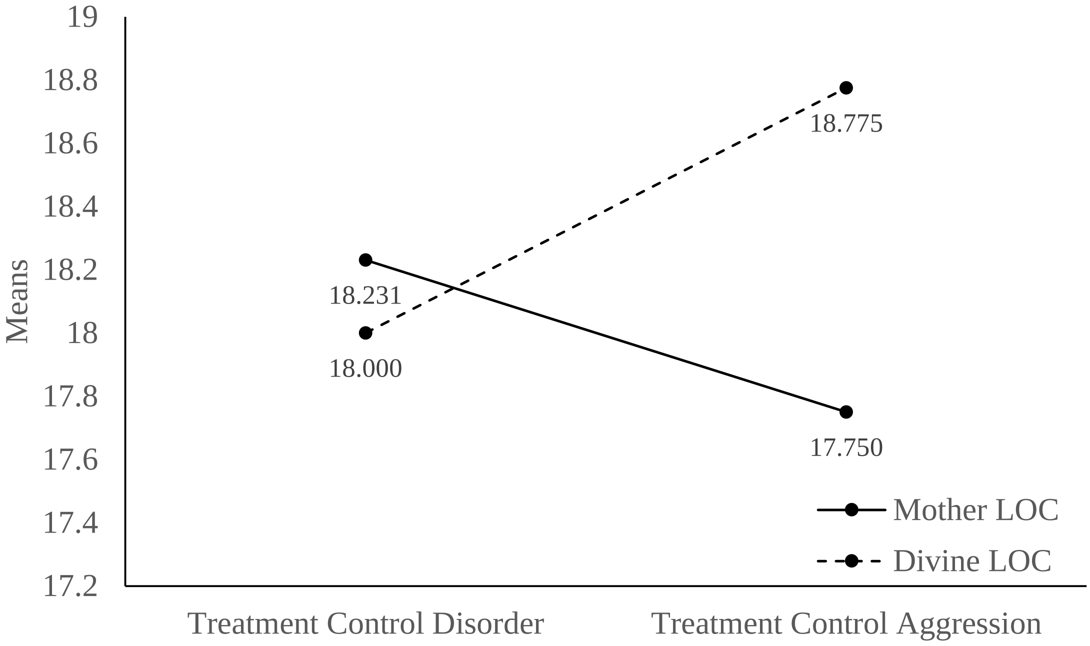

Figure 9. Within-subject interaction for Treatment Control Disorder vs. Treatment Control Aggression by Mother LOC vs. Divine LOC.

It should be noted that for all analyses the *observed power* was low. In other words, even though this study achieved the appropriate N determined during *power analysis* based on optimistic values of high power, a p-value less than .05, and a large effect size, the results were not strong (i.e., effect sizes were not very large and *p*-values were not very low), causing low *observed power*. As a result, although there were no *p*-value corrections (e.g., Bonferroni), there is a low likelihood that a Type I error occurred. Therefore, the significant differences were deemed interpretable. However, it is possible that, due to the analyses being underpowered, Type II errors may have occurred for the nonsignificant results or that the effect sizes were overestimated in the significant results.

PART II

QUALITATIVE STRAND

CHAPTER FIVE

QUALITATIVE LITERATURE REVIEW

In current QUAL research, it is acknowledged that researchers have background knowledge that influences how they view information and may impact how they interact with QUAL data. The Self-Regulation Model is one piece of the background information for the current study and is considered what is called a “sensitizing concept.” In other words, the researchers may be sensitized to viewing the QUAL data from this theoretical lens. However, Charmaz (2006) states that sensitizing concepts are not necessarily limiting, but can be used as jumping-off points. Consequently, the current QUAL research strand used the Self-Regulation Model as a place to begin looking at MCDAs’ processes, but the primary student researcher and her team did *not* limit themselves to this model if new concepts emerged from the mothers’ stories. Additionally, in order to provide a broader base of sensitizing concepts, the primary student researcher sought out research team members from other behavioral health disciplines (i.e., Marriage and Family Therapy and Social Work).

MCDAs’ personal experiences with autism are key to expanding autism research. They are the experts on their everyday experiences. The limitation of QUANT research is that these experiences are highly complex and contain a multitude of potential variables, which may differ for each person. Given this, it is extremely important to determine the processes that MCDAs go through when trying to understand, cope with, and appraise autism by understanding their personal autism stories.

As stated previously, one model that can be used to conceptualize MCDAs’ beliefs about their children’s ASDs is the Self-Regulation Model. Additionally, the components of this model interact with each another, creating a changeable process (Leventhal & Mora, 2005). Being that the strength of QUAL research is its ability to explore process, this QUAL literature review will describe all sections of the Self-Regulation Model in the context of the associated autism literature to provide a detailed background that addresses the model as a whole process.

Cognitive Representation

One major piece of the model that has been studied in MCDAs is the cognitive representation of the disorder. This includes how a person identifies the disorder, how long they think it will last, what they believe the consequences will be, what they suppose the cause is, and whether they presume that the disorder can be controlled. The current ASD literature relating to each of these components will be examined in depth in the following sections.

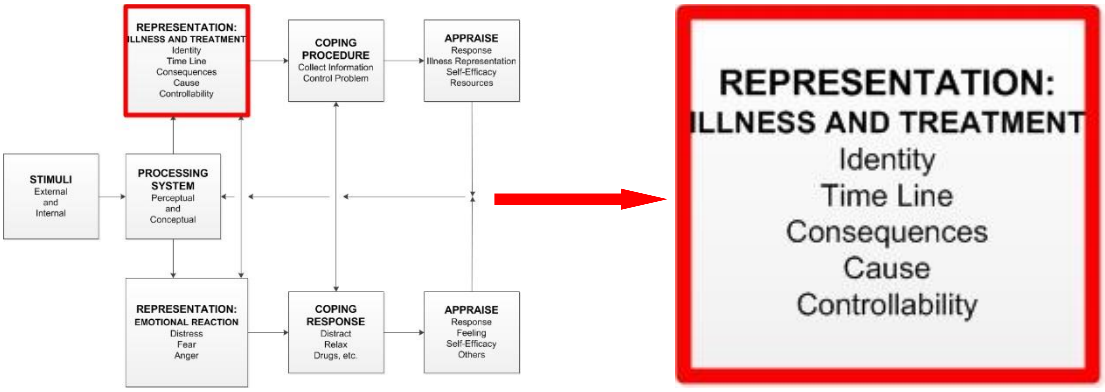

Figure 10. Cognitive representation.

Identity

The first part of the cognitive domain of the Self-Regulation Model is figuring out what symptoms are part of an illness/disorder. This can be extremely confusing for MCDAs. There are many different behaviors and symptoms that children diagnosed with ASDs can display, yet not everything is symptomatic of autism. Professional support would greatly benefit mothers, as psychoeducation could be provided about what possibilities might be expected. The criteria for the symptoms of Autistic Disorder used to come from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR): social interaction problems, communication problems, and SB/RI (American Psychiatric Association, 2000). However, the criteria for other ASDs showed different combinations of these symptoms. Additionally, understanding the criteria is even more confusing at this point in time because the revisions for the fifth edition of the DSM combined all ASDs into one diagnosis with criteria that may apply to all variations.

Other symptoms may occur comorbidly with autism that are not actually symptoms *of autism*. For example, the child may also have a disorder such as an intellectual disability. The prevalence of this particular comorbidity has been reported between 25% and 70% of children with autism (Dawson, Mottron, & Gernsbacher, 2008). These children have low cognitive ability, but this is not part of the criteria for autism. Having problems with tantrums and aggressive behaviors are also well-documented in children with ASDs; yet, these behaviors are not classified as symptoms (Barry & Singer, 2001; McCracken et al., 2002; Scahill et al., 2009; Singh et al., 2006).

There are other indicators of autism that are not as well known. These can include neuropsychological difficulties with visuospatial short-term memory, planning, social cognition, theory of mind, imitation, executive functioning, emotional functioning, sensory/arousal functioning, attention, memory, or language (Losh & Piven, 2007; Rogers, 1998; Tonn & Obrzut, 2005; Zinke et al., 2010). Other challenges may be present that we are not even aware of yet, and each child's particular needs should be considered as unique and specific to the individual.

Given the numerous combinations of symptoms and behaviors that are possible within the autism spectrum, it is important to determine how MCDAs define autism and what symptoms and behaviors they attribute to the disorder. This is especially relevant because it has been shown that mothers believe the disorder is more stable than any specific symptom or behavior (i.e., social interaction problems, communication problems, stereotyped behaviors/restricted interests, tantrums, and aggressive behaviors; South, 2013). Therefore, their understanding of what the disorder is as a whole may differ from specific diagnostic criteria.

Timeline

Research on a measure that was developed to test the cognitive representations of the Self-Regulation Model (Illness Perceptions Questionnaire-Revised; IPQ-R) determined that the timeline subcategory includes two components: acute/chronic and cyclical (Moss-Morris et al., 2002). In other words, there are thoughts about the length of time of the disorder as well as the possibility of recurring symptoms.

Timeline (Acute/Chronic)

MCDAs vary in what they believe about the timeline of autism. Some believe it is completely unstable, some think it is completely stable, and some have hope that some progress can be made but acknowledge limitations of the disorder (Bilgin & Kucuk, 2010; Dale et al., 2006). However, there are differences when thinking about the stability of the disorder compared to the stability of specific behaviors. Research shows that improvements in different symptom domains can occur at different rates over time, depending on the symptom severity; although, symptoms often persist over the lifetime and are sometimes compounded by low I.Q. (Beadle-Brown et al., 2006; Charman et al., 2005; Matson & Horovitz, 2010; Shattuck et al., 2007a; Starr, Szatmari, Bryson, & Zwaigenbaum, 2003). These improvements are often made through early treatment interventions (Matson & Horovitz, 2010; Rogers & Vismara, 2008).

Recently it was discovered that MCDAs' beliefs about the stability of the disorder were significantly higher than their beliefs about the stability of specific behaviors (South, 2013). Given the many different presentations of autism, there may be some currently undifferentiated subtypes of autism that are, in fact, more stable than others. If this is the case, certain manifestations of autism that appear to have a persistent, potentially lifelong, course of impaired functioning may need to be differentiated through alternative categorization or the addition of certain specifiers that do not yet exist. On the other hand, there may be subtypes of autism that are more apt to change, and perhaps require an "in remission" specifier that has not yet been included in the DSM.

Timeline (Cyclical)

A disorder and its related behaviors may not only be thought of as simply lasting a short or long time, but may potentially be considered as in remission or as recurrent. The core symptoms of ASD tend to persist across the lifespan (Matson & Horovitz, 2010).

Over the life course, autism may present differently or offer new challenges (Matson & Horovitz, 2010; Shattuck et al., 2007b). Although some declines in symptoms can occur over time and through treatment, sometimes gains may be limited or cannot be maintained (Bodfish, 2004; Shattuck et al., 2007b). Therefore, it is important to consider what MCDAs experience when they see a cyclical pattern of behaviors their children display.

Consequences

The next cognitive element is beliefs about consequences of the disorder. Given the variations in autism presentations, the consequences can widely differ in severity. For instance, some individuals can function well with minimal support, whereas others require very substantial support (American Psychiatric Association, 2013). This can include needing long-term care beyond postsecondary school, such as living at home or in a supervised setting (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014).

The impact of autism can reach beyond just the individual to other members of the family as well. Most notably, there is often a negative impact on parent and sibling psychosocial functioning (Lovell & Wetherell, 2016; Nealy, O'Hare, Powers, & Swick, 2012; Rao & Beidel, 2009). In addition, MCDAs disproportionately have adverse effects on employment and earnings (D. L. Baker & Drapela, 2010; Cidav, Marcus, & Mandell, 2012). There are also significant economic costs associated with taking care of a person with an ASD (Knapp, Romeo, & Beecham, 2009). Given these challenges, MCDAs may have a variety of beliefs regarding the consequences of their children having an ASD.

Causes

Another component of cognitive representations within the Self-Regulation Model is cause. Being that there is not a single identified cause of autism, the range of potential causes is vast. Possible causes of autism that have been discovered through scientific research generally fall into two major categories: *biological* and *environmental*. Although this section cannot list all possible causes due to the immenseness and rapidly growing nature of the autism literature, it provides a brief overview of some major categories that have been identified.

With regard to the potential *biological* causes of autism, genetic correlates approach the most foundational level. There has not been one specific chromosome or gene that has been shown to be related to autism as it has been with Down syndrome (Roubertoux & Kerdelhué, 2006). However, there have been numerous genetic contenders linked to possible causes of autism. These correlates include:

- Chromosomal abnormalities such as microdeletions and microduplications in specific loci (i.e., 15q11-q13, 22q11, and 16p11.2),
- Genetic syndromes such as Fragile X syndrome and 22q11.2 deletion syndrome,
- Dysregulation in protein production from the SEMA5A gene,

- Defective PCDH10 and DIA1 gene expression as a result of neuronal activity and synaptic changes,
- Polymorphisms in per1 and npas2 which are correlated with problems in sleep, memory, and timing, and
- Polymorphisms on genes that affect metal metabolism

  (Christian et al., 2008; Kelley et al., 2008; Kwasnicka-Crawford, Roberts, & Scherer, 2007; Melin et al., 2006; Morrow et al., 2008; Nicholas et al., 2007; Serajee, Nabi, Zhong, & Huq, 2004; Veenstra-VanderWeele & Cook, 2004; Vorstman et al., 2006).

Neurological differences are also posited as biological causes for autism. These include brain abnormalities with the cerebellum, medial temporal lobe, frontal lobe, corpus callosum, amygdala, hippocampus, limbic system, brain volume, and a widely distributed neural network (Akshoomoff, 2005; Penn, 2006; Stefanatos & Baron, 2011; Tonn & Obrzut, 2005). Other problems can occur with the neurotransmitter systems, neural growth, or the mirror neuron system (Oberman & Ramachandran, 2007; Penn, 2006).

The second domain of possible causes of autism is *environmental*. Some changes in the prenatal environment have been correlated with the development of autism. For example, prenatal stress has been shown to be a potential causal factor (Beversdorf et al., 2005; Kinney, Munir, Crowley, & Miller, 2008). Specifically, stressors that occur during the gestational period of 25 to 28 weeks are most highly correlated with the development of autism and the development of the cerebellum (Beversdorf et al., 2005). Obstetric variables such as hypertension, preeclampsia, generalized edema, and albuminuria have also been shown to be related to autistic symptomatology (Wallace, Anderson, & Dubrow, 2008). Another possible environmental cause is related to diet. Specifically, higher levels of peptides have been found in children with autism's urine which may be correlated to brain abnormalities, autistic-like behaviors, and/or a genetic predisposition (Reichelt & Knivsberg, 2009).

These examples are neither an exhaustive list nor definitive causes, thus adding to the complexity of causal attributions of autism. Beliefs about causes can be so varied that it is suggested that researchers not calculate a subscale score for causes on the IPQ-RA, the measure being used for the QUANT strand in the current study that is based on the Self-Regulation Model ("Using and scoring the IPQ-R," *n.d.*). In one study that used the IPQ-RA with MCDAs, factor analysis revealed three main beliefs about causes: personal attribution, environmental causes, and chance or bad luck (Al Anbar et al., 2010). Since there is significant variability in thoughts about causes and new information is being discovered all the time, it was important to see what the MCDAs in the current sample believed about causes.

Controllability

The two areas of controllability in the Self-Regulation Model have already been described in detail in the QUANT literature review, but it is important to include a summary about them in this section because they are important pieces of the model and are relevant to this QUAL strand as part of the sensitizing concepts. First, there is *treatment control*, which is the belief that a treatment can control or improve a disorder or illness. Second is *personal control*, which looks at the person's belief that they can control the disorder or illness. The literature indicates that MCDAs may place the LOC for their children's ASD in external loci as well, which is an essential tenet to the current study. It was hoped that the QUANT strand of this study would add information about the interaction between these two aspects of controllability within the Self-Regulation Model to expand the understanding of MCDAs' QUAL process.

Emotional Reaction

Trying to make sense of a disorder does not only include thoughts: it includes feelings as well. Moreover, our thoughts can influence our emotions. Finding out her child has a diagnosis on the autism spectrum can be an extremely emotional experience for a mother and there are many emotional reactions that can occur along the journey of trying to help her child. The following section will explore the current literature on MCDAs' emotional reactions.

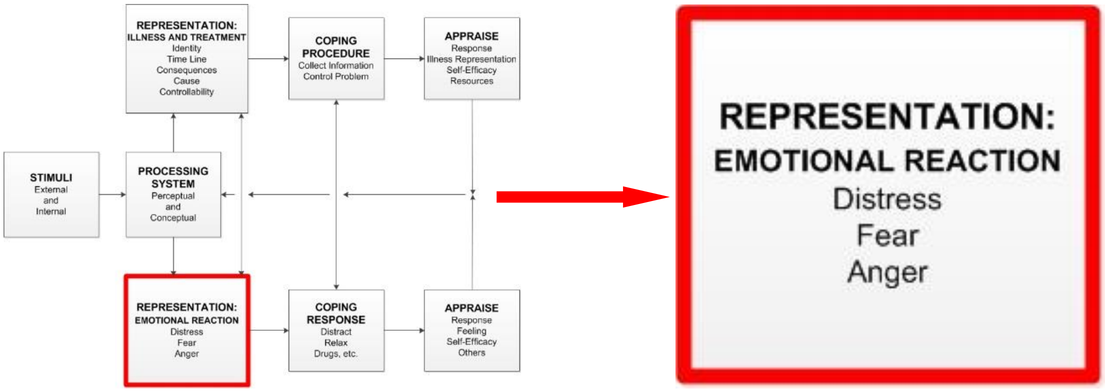

Figure 11. Emotional reaction.

MCDAs often experience emotional distress. One finding that has been shown over and over again is that MCDAs exhibit significantly more stress, even when compared to mothers of children with other developmental disabilities (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Duarte, Bordin, Yazigi, & Mooney, 2005; Eisenhower, Baker, & Blacher, 2005; Konstantareas & Homatidis, 1989; Konstantareas & Papageorgiou, 2006; Noh, Dumas, Wolf, & Fisman, 1989; Pisula, 2007; Pisula & Kossakowska, 2010; Schieve, Blumberg, Rice, Visser, & Boyle, 2007; Yamada et al., 2007). MCDAs have also been shown to experience more depression than mothers of normally developing children; however, the findings have been less consistent and may depend on context variables such as family level adaptability, the child's behavior problems during the study, support network size, and stressful life events (J. K. Baker, Seltzer, & Greenberg, 2011; Barker et al., 2011; P. R. Benson, 2006; Dale et al., 2006; Wallace et al., 2008). Furthermore, MCDAs may experience some anger, frustration, or aggravation at the behaviors their children exhibit, which makes it more likely for additional stressors to occur (P. Benson & Karlof, 2009; Schieve et al., 2007). Other literature on emotional experiences of MCDAs report grief, emotional breakdown, worry, hopelessness, shock, pessimism, denial, and regret (Bilgin & Kucuk, 2010).

Coping

Previous QUAL research on MCDAs' personal experiences has primarily focused on one area: coping (Bilgin & Kucuk, 2010; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Marshall & Long, 2010). One study by Marshall and Long (2010) evaluated the coping processes of MCDAs based on their narrative stories. They found two primary domains, cognitive and emotional, which are consistent with the Self-Regulation Model (Marshall & Long, 2010). Given the limited scope of previous research on mothers' experiences, the current study sought to provide a broad perspective by looking at how MCDAs' coping methods interacted with their cognitive understanding, emotional reactions, and appraisals. This included how this process changed over time. In this section, the current literature on cognitive and emotional coping in MCDAs will be explored.

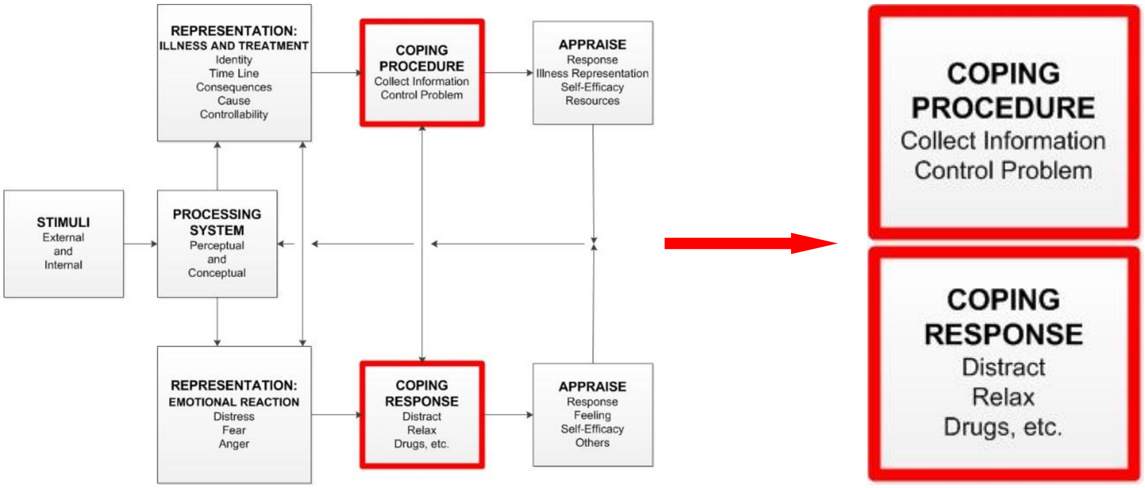

Figure 12. Coping procedures and responses.

Cognitive Coping

One dimension of coping is through cognitive methods. Planning and positive reinterpretation are cognitive coping methods that have been found to be beneficial for MCDAs' well-being (L. E. Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). However, these positive problem-solving coping strategies may take time to master. It is important to know how MCDAs' cognitive coping begins so that these positive skills can be promoted as early as possible in the self-regulation process. In a study by Marshall and Long (2010), although each mother's story was unique, one consistent theme found was that the mothers attempted to get information and find appropriate treatments for their children immediately after diagnosis. In other words, information and help-seeking was one of the first steps in coping with their children's disorder.

Help-seeking is a complex phenomenon that involves three primary stages: problem recognition, a decision to seek help, and support network and service utilization patterns (Cauce et al., 2002; Srebnik & Cauce, 1996). Problem recognition includes clinical assessment of need, perceived/subjective assessment of need, and structural and relational family characteristics (Cauce et al., 2002; Srebnik & Cauce, 1996). The decision to seek help can be influenced by demographic characteristics as well as sociocultural values/beliefs (Cauce et al., 2002; Srebnik & Cauce, 1996). Use of a support network and services may be determined by barriers or facilitators of utilization, such as community and social networks, economic factors, service characteristics, and policies (Cauce et al., 2002; Srebnik & Cauce, 1996).

The literature on help-seeking within MCDAs in America is essentially nonexistent. Specifically, when searching for help seeking, parent, and autism in a popular database (EBSCO), only seven entries were returned and none of them were from populations within the United States. Additionally, the literature indicates that there is often difficulty with accessing help (Pisula & Kossakowska, 2010; Shyu, Jia-Ling, & Wen-Che, 2010). With insufficient help, mothers often need to advocate for their children and make treatment decisions themselves (Pisula & Kossakowska, 2010; Ryan & Cole, 2009). It is even more difficult for families living in rural areas and for ethnic minorities to get diagnostic or treatment services (Cauce et al., 2002; Chuan-Yu, Chieh-Yu, Wen-Chuan, Su-Ling, & Keh-Ming, 2008). Again, this highlights the importance of professionals becoming advocates for their clients and linking access to resources. This study seeks to get MCDAs' perspectives on their help-seeking behaviors and how professionals can take an active role in helping better meet their needs.

Emotional Coping

Coping is not only a cognitive process, but an emotional one as well. As previously mentioned, stress is one of the primary emotions felt by MCDAs. These mothers use both positive and negative coping strategies for dealing with stress (Bilgin & Kucuk, 2010). Sometimes they use healthy ways of coping such as seeking mutual support from family or talking about concerns with family and friends (Bilgin & Kucuk, 2010). Other times, they may use unhealthy ways of coping such as smoking or using alcohol (Bilgin & Kucuk, 2010). Certain emotion-focused strategies such as venting, denial, and behavioral disengagement can actually increase MCDAs' depressive symptoms (L. E. Smith et al., 2008). It is necessary to acknowledge that emotions are not static, though. Marshall and Long (2010) noted, "the life stories told by the mothers reveal meaning-making processes that evolved over time, as mothers came to terms with their children's autism" (p. 114).

Appraisals

After MCDAs have attempted to cope both cognitively and emotionally, they then make various appraisals. These appraisals may feed back into the self-regulation process and modify other domains over time, which then create reappraisals. Using a hypothetical example, if a mother on a cognitive level believed the cause of her child's autism was the MMR vaccine, she may choose to have her child engage in chelation therapy. When she sees this therapy is unhelpful or even harmful to her child, she may appraise the treatment as ineffective or even re-think the possible cause. On an emotional level, the mother may initially experience stress and choose to drink alcohol. During her emotional appraisal, she may realize that this method only decreases her overall well-being and choose to engage in healthier coping behaviors such as seeking treatment through a mindfulness based stress reduction (MBSR) program.

Whether a mother views her cognitive and/or emotional beliefs, reactions, and coping methods as right or wrong, helpful or unhelpful, working or not working, et cetera, is central to how the self-regulation process transforms over time. It is also important to know what MCDAs like and do not like about the current status of treatments available for them and their children. The current study would take this a step further and determine what MCDAs think professionals can do better to help them. The current literature on MCDAs' appraisals will be expanded upon in the next sections.

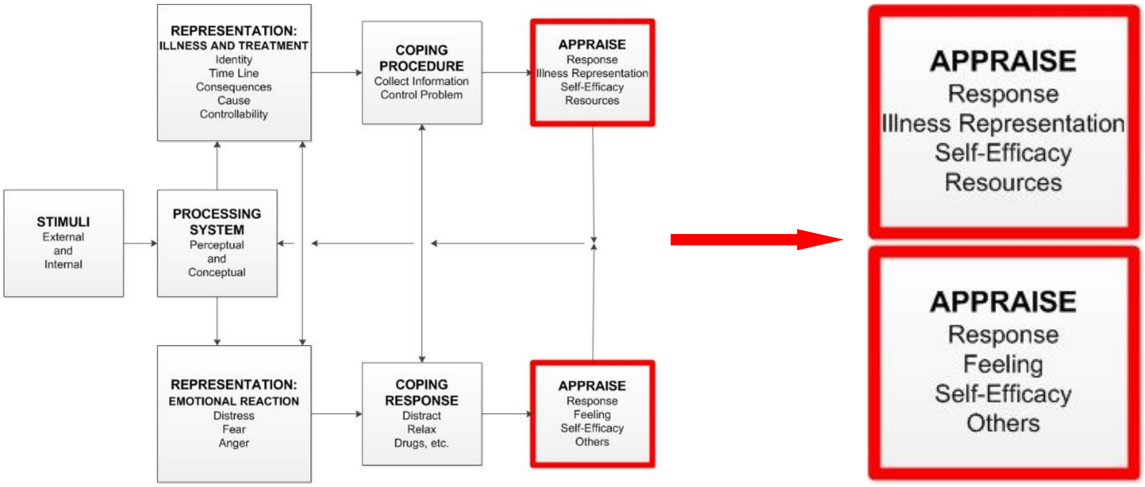

Figure 13. Cognitive and emotional appraisals.

Cognitive Appraisals

One part of appraisals is that of the cognitive representations and coping procedures. These include appraisals of the response to the coping procedure attempted, what to believe about the disorder, one's self-efficacy in managing the disorder, and the available resources. One study that focused on parents' appraisals of autism treatments found six themes: "effectiveness of treatments, relationships with professionals, access to desired treatments, costs, concerns about using medications, and stress" (Mackintosh, Goin-Kochel, & Myers, 2012). Mackintosh et al. (2012) were particularly struck by how often negative interactions with professionals were reported. The current study hopes to discover how professionals can be better facilitators of positive understanding, emotional reaction, and coping processes rather than be part of the stressors or barriers. Knowing MCDAs' appraisals by studying the self-regulation process and getting their input on how to move forward in a positive direction was thought to be an important step to providing benefits to this population and combating injustices they may have faced thus far.

Emotional Appraisals

Professionals need to join MCDAs as a team and support them not only functionally but emotionally as well. As previously mentioned, these mothers experience a plethora of negative emotions, such as stress and hopelessness. Struggling with trying to help their children creates new stressors and challenges that sometimes negatively affect their well-being. As MCDAs look at their experiences, they appraise how they feel, the effectiveness of their coping responses, their own self-efficacy to manage their emotions, and what they think of others who might be part of their support system. One study found that MCDAs felt isolated and highlighted the need for professionals to provide support to the families of children diagnosed with autism (Woodgate, Ateah, & Secco, 2008). By understanding MCDAs' perspectives and appraisals of their emotional journeys through the self-regulation process, it is hoped that this research provides professionals with insights on how to better offer a supportive and compassionate foundation.

Examining Process

The Self-Regulation Model is not simply a stagnant assortment of domains, but a set of moving parts that each interact and influence one another in a dynamic process. While QUANT research can address relationships between variables, it does not adequately address the process gestalt of the model. Consequently, including a QUAL strand is a necessary accompaniment to the QUANT strand. By using MM, this study provides a more complete picture of MCDAs' experiences.

One way to address the process of the Self-Regulation Model is by looking at changes. For example, after assessing what an MCDA believes about causes, it would also be important to ask if those beliefs have changed over time and if so, how? Using an imaginary potential sequence may clarify this idea: If a mother believes that her child's autism was caused by genetics, she may feel a sense of hopelessness about her child making any improvements. She may settle on trying Applied Behavior Analysis (ABA), as it is a leading treatment at this time, but feel skeptical about its efficiency. With her negative feelings, she may seek social support from other mothers who have similar experiences. If she starts seeing her child improve through the ABA treatment, she may appraise the treatment as "working" which may give her a glimmer of hope that things can get better. If her support network is able to lift her spirits and model emotional strength, she may begin to feel a sense of self-agency with her child and become more involved in her child's treatment through parent training. Her involvement would only strengthen the possible improvements for her child, and create a resilient cycle of healing for both her and her child. Actual experiences of MCDAs were likely to differ from this hypothetical example, so it was important to determine if and how self-regulation processes occurred for them through this QUAL strand of the study.

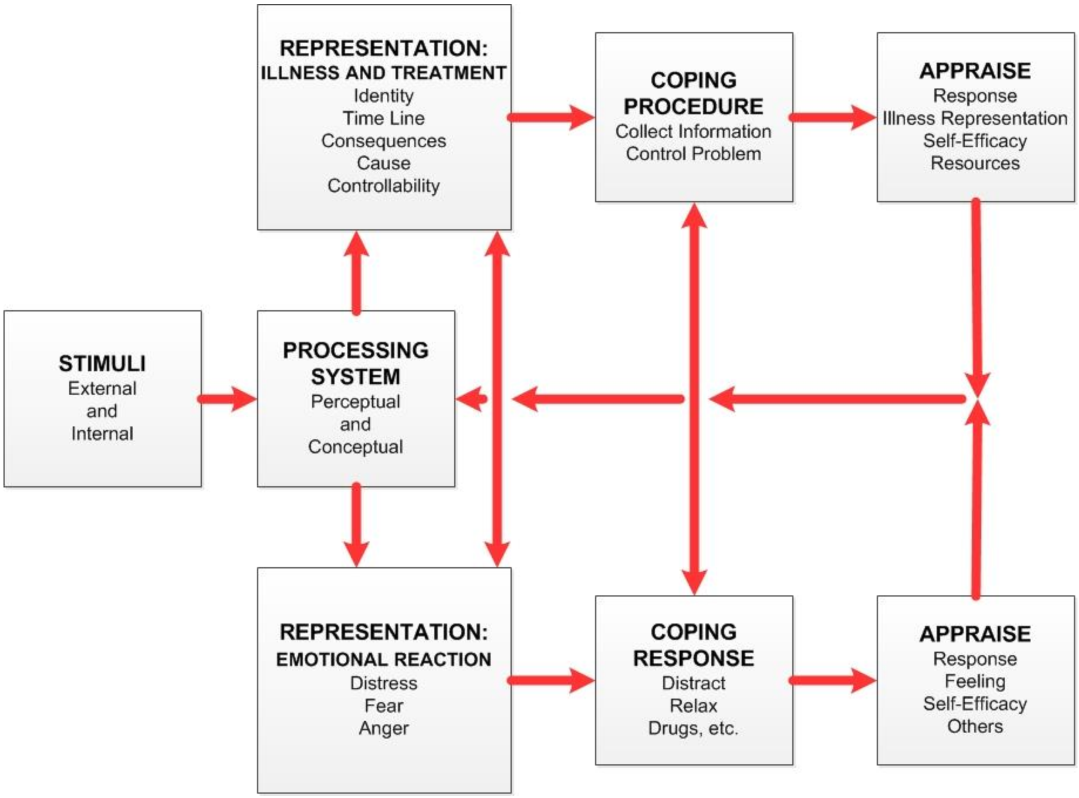

Figure 14. Qualitative self-regulation process in MCDAs.

Qualitative Research Question

In QUAL research, there is not a measurable hypothesis, but a guiding research question. QUAL methods generally focus on process-oriented questions. Therefore, the guiding QUAL research question for the current study is as follows: “Does the self-regulation process occur in MCDAs, and if so, how?”

CHAPTER SIX

QUALITATIVE METHOD

There are several major methodologies within QUAL methods, but one of the most well-known is *Grounded Theory*. This methodology was originally developed by Glaser and Strauss (1967) on the premise that theories that are created should be grounded in QUAL data (i.e., not simply made up from researchers' biased ideas). It provided clear and practical methods of how to interpret QUAL data, which are used in much of contemporary QUAL research. The components of grounded theory practice were defined as:

- "Simultaneous involvement in data collection and analysis
- Constructing analytic codes and categories from data, not from preconceived logically deduced hypotheses
- Using the constant comparative method, which involves making comparisons during each stage of the analysis
- Advancing theory development during each step of data collection and analysis
- Memo-writing to elaborate categories, specify their properties, define relationships between categories, and identify gaps
- Sampling aimed toward theory construction, not for population representativeness
- Conducting the literature review *after* developing an independent analysis." (Charmaz, 2006, pp. 5-6)

Glaser and Strauss eventually split in their approaches to grounded theory and Strauss developed his ideas further with Corbin.

Corbin and Strauss noted that grounded theory was initially influenced by interactionism and pragmatism. Interactionism believed that people do not merely react to others' actions but they interact with the meaning they attach to those actions. Pragmatism has several assumptions, which are important for understanding the paradigmatic stance from which grounded theory arose. It assumed that:

- Knowledge results from action and interaction
- Reflective thought has an antecedent in reality and does not spontaneously generate
- We live in a world of contingencies and process
- There is an accumulation of collective knowledge
- "The experiences of whoever is engaged in an inquiry are vital to the inquiry and its implicated thought processes"
- "…what is discovered about 'reality' cannot be divorced from the operative perspective of the knower," and
- "…knowledge can be useful for practice or practical affairs" (Corbin & Strauss, 2008, p. 4)

In the most recent edition of their book describing their methods, though, Corbin noted a shift in her perspective to more postmodern and postconstructivist ideas. She noted a particular appreciation for Charmaz and her approach to grounded theory using a constructivist paradigm. Given the primary student researcher's alignment with the ideas of social constructionism, the current study used Charmaz's Constructivist Grounded Theory methodology. Charmaz's constructivist approach diverged from both Glaser and Strauss and assumed the following:

> "…neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices…any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it…Research participants' implicit meanings, experiential view-and researchers' finished grounded theories-are constructions of reality" (Charmaz, 2006, p. 10).

Charmaz also looked at grounded theory as a set of flexible guidelines rather than a prescriptive set of rules.

Congruent with this methodology, the method section that follows will describe how the number of participants was determined, give a brief background of the QUAL methods used in the pilot study that preceded this dissertation, outline the current data collection method, and then describe each phase of the QUAL analyses, including coding and methods for establishing credibility and trustworthiness.

Participants

In QUAL research, the number of participants is not pre-determined, but the data collection is determined to be complete once *theoretical saturation* has been achieved. Theoretical saturation is defined as "the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory" (Charmaz, 2006, p. 189). Although QUAL data collection was completed when *theoretical saturation* had been determined, 20 participants were expected to complete individual interviews. This estimate was based on Daly's (2007) suggestion that 20 to 25 participants have generally proven "enough" for theoretical saturation in QUAL research (p. 179). Of those 20 participants, it was expected that between six to ten of them would participate in a focus group, as this was the optimal number of focus group participants recommended by some researchers (Daly, 2007; Ebrahim, 1995). The actual number of participants for the QUAL strand ended up remaining at 20. Two focus groups ended up being planned after interviews were completed due to participants being almost equally distributed across two distant areas. Most mothers who participated in the study expressed interest in the focus group and nine mothers indicated that they would be able to join one of them once dates and times were established; however, the only four focus group members attended.

The participant characteristics are displayed here to show descriptive information about the subsample of mothers who completed both the survey and the interview. This is because the participant characteristics reported in the QUANT strand represented the overall demographics of the MCDAs that completed the surveys, while this section focuses on describing the subset of mothers who were involved in the QUAL strand. It should be noted, though, that two mothers who did interviews did not complete surveys, so these descriptive statistics are based on a maximum 18 of the 20 mothers who completed interviews.

When looking at this subsample, most demographics were similar to what was seen in the overall sample; however, there were some differences. For example, the age groups were slightly older while the mean severity was slightly less severe. Additionally, the percentage of African-American/Black mothers was higher, whereas the percentage of Hispanic/Latino mothers was lower, and there were no Asian mothers. Regarding religion, there were no Buddhists or Atheists in this subsample. There were also no mothers whose marital status was listed as Living with Significant Other.

Table 33. Mean of interview participant characteristics.

	M	*SD*	Range Minimum	 Maximum
Mother's age	41.56	6.56	32	55
Father's age	46.71	9.81	33	68
Child's age	10.11	4.34	3	17
Time dx (mo)	56.89	42.18	4	144
# Siblings	1.67	1.33	0	5
# dx Siblings	0.37	0.50	0	1
# Ppl in hm	3.89	1.32	2	7
Mother's Ed	14.72	2.99	11	22
# Mom Services	1.83	1.43	0	4
# Child Services	5.67	2.81	2	11
Severity	2.86	0.92	.5	4.5
Involvement	8.11	2.56	1	10

Note. Time dx (mo) = time since the child was diagnosed with Autistic Disorder in months. # dx Siblings = number of siblings with a disability. # Ppl in hm = number of people in the home. Mother's Ed = mother's highest level of education in years. # Mom Services = number of services the mom has received. # Child Services = number of services the child has received. Severity = mean of the mother's perceived severity of the child's disorder/behaviors. Involvement = mother's perceived involvement in her child's services on a 10-point scale.

Table 34. Frequency of interview participant characteristics.

	N	%
Child's Diagnosis		
Autism Spectrum Disorder	7	40
Autistic Disorder	6	33
Asperger's Disorder	4	22
Pervasive Developmental Disorder NOS	1	5
Mom's Ethnicity		
Caucasian/White	8	44
African-American/Black	7	39
Hispanic/Latino	1	6
Multiracial	2	11
Child's Ethnicity		
Caucasian/White	6	33
African-American/Black	5	28
Hispanic/Latino	1	6
Multiracial	5	28
Child's Sex		
Male	16	89
Female	2	11
Religion		
Catholic	3	17
Christian	11	61
Other	4	22

Table 34, cont.

	N	%
Marital Status		
Never married	2	11
Married (1st husband)	11	61
Separated	1	6
Divorced	3	17
Re-married	1	6
Employment Status		
Employed for wages	8	44
Self-employed	1	6
Unemployed	3	17
Homemaker	4	22
Student	1	6
Unable to work due to disability	1	6
Household Income		
\$0-\$20,000	3	17
\$20,001-\$40,000	1	6
\$40,001-\$60,000	5	28
\$60,001-\$80,000	3	17
\$80,001-\$100,000	2	11
\$100,001-\$150,000	2	11
\$200,001-\$250,000	1	6
\$250,001-\$300,000	1	6

Note. Both DSM-IV-TR and DSM-5 disorders were included due to the recent transition between the two manuals. Household income includes a "Greater than \$100,00" category due to the higher brackets only having been added after the thesis data was collected to account for the high number of participants selecting this range. Categories that were included on the survey may not be included in this table if no participants fell within them. Percentages may not add to 100% due to missing values.

Pilot Open-Ended Questions

As the Self-Regulation Model proposes, beliefs, emotions, coping methods, and appraisals create a cycle that is continually adapting to new information and experiences (Leventhal et al., 2001). Consequently, open-ended questions were included at the end of the pilot survey based on the different domains of the model to better understand mothers' unique dynamic processes rather than just static content (see Appendix G for the questions and Figure 15 for the association between the model's domains and the questions). Specifically, the mothers' beliefs, feelings, coping procedures, and appraisals as well as how these factors have changed over time were asked about in the pilot study. Some additional questions were asked above and beyond the domains as well.

While questions were not asked of all subcategories of the "Cognitive Representation" domain, a question about cause was asked because the literature on the IPQ-RA indicated that causes should not be quantified and should be explored within the context of each study. Additionally, a question about expectations was asked because the QUANT research for the pilot study was related to mothers' expectations regarding the timeline. Furthermore, as an extension of the mothers' appraisals, and to make the survey a useful tool for professional development, the mothers were also asked what professionals did that was helpful and what could have been done better.

The responses to the open-ended questions in the pilot study served as a tool to refine the final questions to ask the mothers who participated in the QUAL strand of the current study. This analysis is described further in the following section.

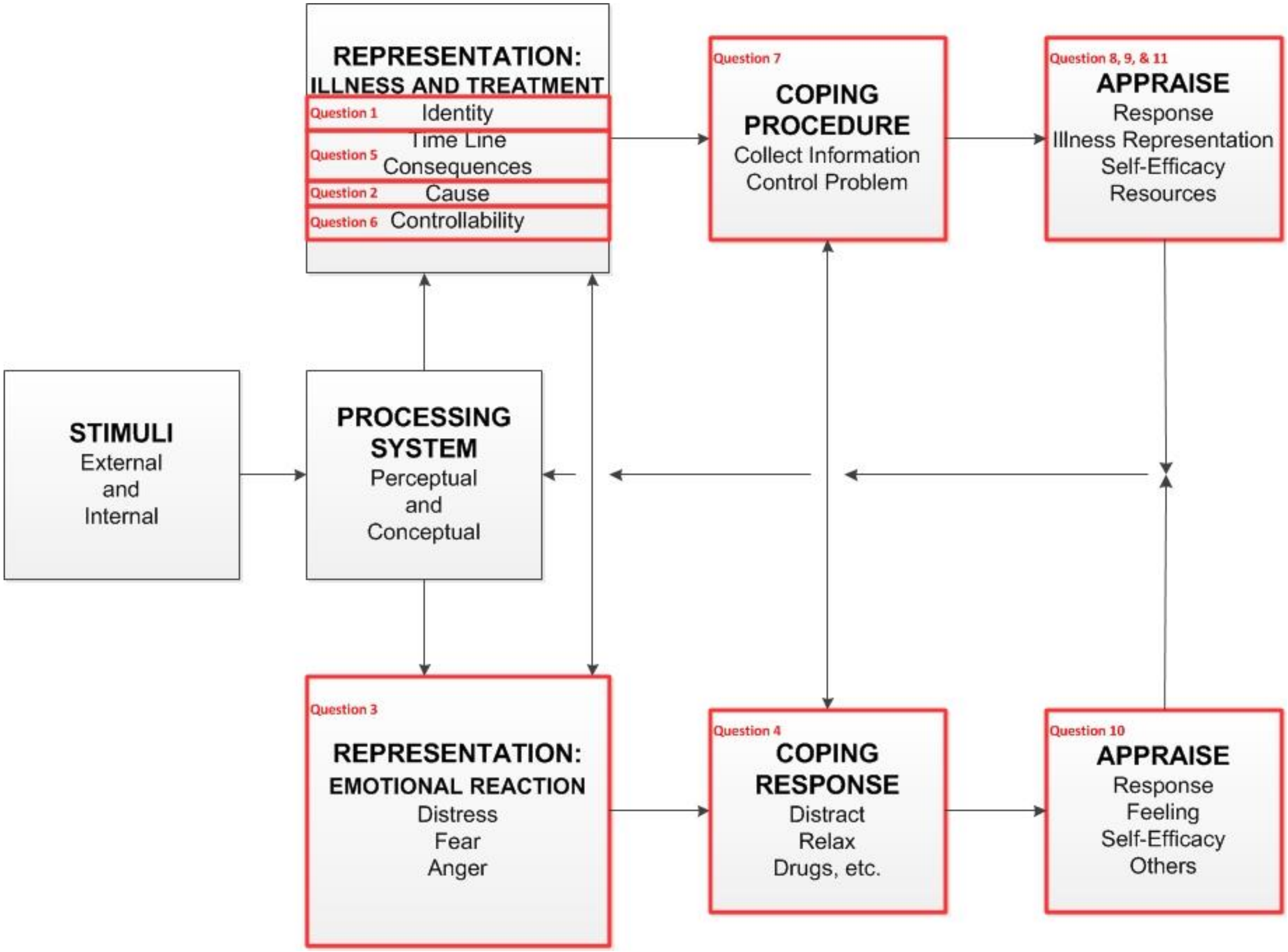

Figure 15. The association between open-ended pilot questions and the Self-Regulation Model domains.

Analysis of Pilot Responses

To begin the analysis, each member of the core research team individually completed word-by-word coding of the pilot responses of a single subject (i.e., cross-coded) and then came together to discuss the resultant codes. This was done to look at inter-rater consistency of coding and explore when team members' codes diverged. Research team members separately coded the remainder of the pilot subject responses. The primary student researcher compiled common codes and sought feedback on them from the other team members to facilitate category development. Analytic memos were written to start recording emerging themes and possible theoretical processes. Specifically, themes that arose were trauma and grief, confusion and research, the search for treatment, fighting to get what is wanted, and "the new normal" (see Appendix I for memos in the reflexive journal). These emerging themes touched on most of the domains in the Self-Regulation Model (i.e., cognitive representations, emotional reactions, coping strategies, and shifting processes as a result of appraisals).

Analysis of the pilot responses by the research team revealed that although the original pilot questions did encourage the mothers to talk about multiple domains, they did not promote process-oriented responses. Therefore, the questions were reworded to include more process language (e.g., "describe the way," "tell me how," etc.) Additionally, to prime for more process description, a general question was included at the beginning of the interview asking the mothers to describe their journey. Furthermore, questions were added to evaluate the connection between processes (e.g., how thoughts impact feelings). Moreover, some questions and possible probes were added to help saturate emerging themes (e.g., mothers fighting for what they want). The primary student researcher assembled all the questions together to form a semi-structured interview. The interview was then sent to the entire research team for review, the questions were revised according to feedback, and the interview was finalized once all members agreed on the questions. (See Appendix H for the finalized semi-structured interview guide and Figure 16 for the final breakdown of associations between questions and domains.)

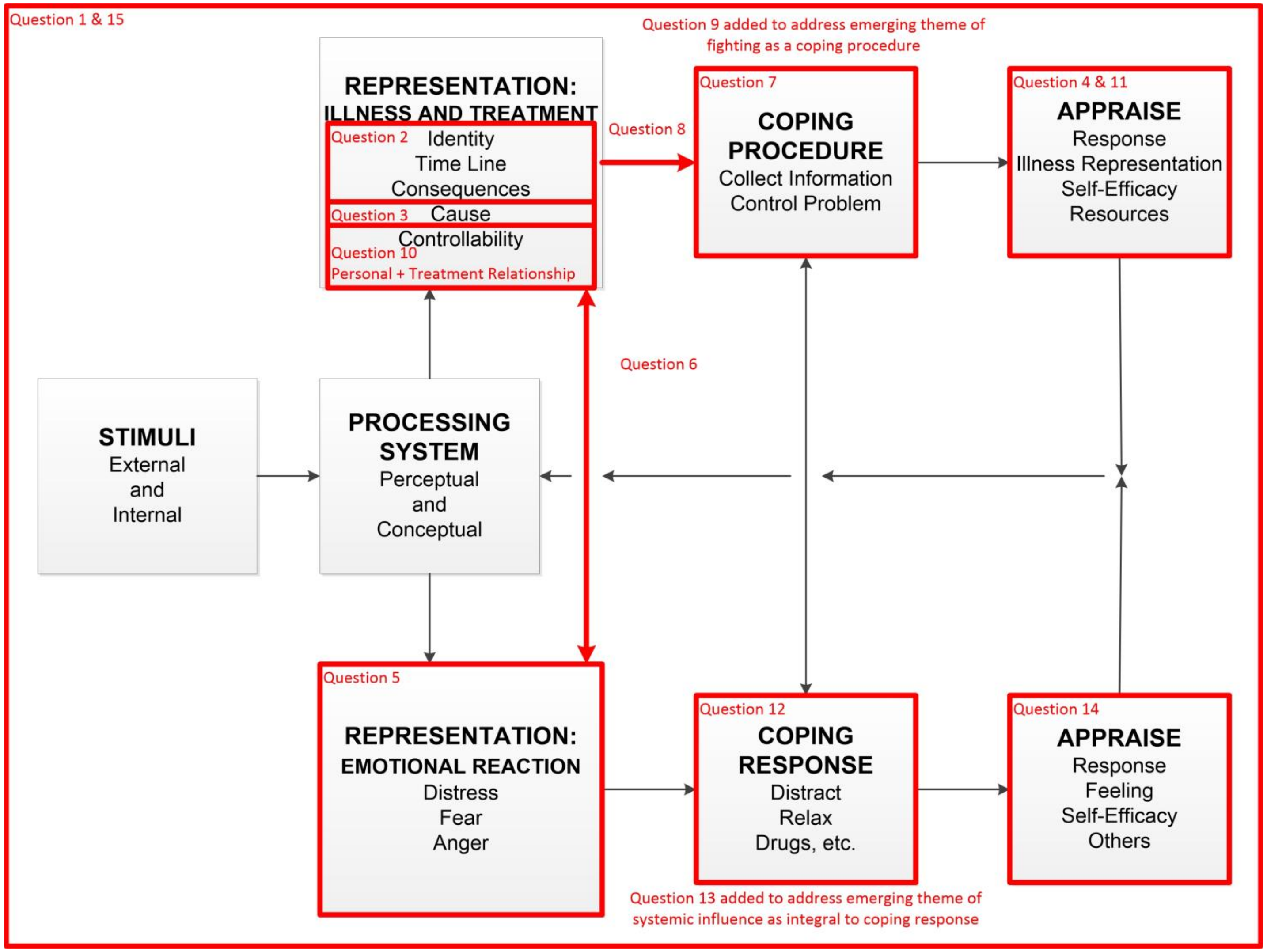

Figure 16. The association between the final semi-structured interview questions and the Self-Regulation Model domains.

Current Qualitative Data Collection Procedures

The semi-structured interview developed from the pilot data was used for the QUAL strand of the current study. This section describes the QUAL data collection procedures used, including how the interviews were conducted as well as the procedures used for the follow-up focus group.

Individual Interviews

Participants who chose to participate in the QUAL strand of the study were asked open-ended process questions that relate to each domain of the Self-Regulation Model (i.e., beliefs, emotions, coping strategies, and appraisals) in a semi-structured interview. Specifically, the open-ended questions from the pilot study were modified to help achieve theoretical saturation and expand on areas that required more depth of information as described earlier in the "Analysis of Pilot Responses" section. Additionally, the interviews were flexible so that additional probing questions could be asked of mothers to clarify responses. These interviews occurred face-to-face between a student researcher and each mother individually at an agreed upon venue based on each mother's preference. The interviews were audio-recorded so that each interview could be transcribed verbatim. The recordings were erased immediately following transcription to protect confidentiality.

Focus Group

Once all the individual interviews were completed, transcribed, and coded, participants were asked to return for a focus group. Due to disparate location clusters, two focus groups were planned at two different locations; however, participants only showed for one of the groups. This group was facilitated by two members of the research team. It acted as a "member check," which is described in more detail in the analyses section. The participants were asked in an open discussion to provide feedback on the researchers' interpretations of the data.

Qualitative Analyses

Although the QUANT analyses were performed by the primary student researcher once all data for the study had been collected, QUAL analysis was performed in an iterative manner with data collection (after approximately every five interviews) in correspondence with the emergent nature of this type of research. In other words, a few interviews were conducted, transcribed, and coded followed by another few interviews and so on until all interviews were completed. After both strands of analyses had been finished, it was determined whether a meta-inference could be formulated to integrate the findings for the overall study.

As mentioned before, grounded theory was used as the primary methodology to test the QUAL research question of the current study: "Does the self-regulation process occur in MCDAs, and if so, how?" Specifically, the constructivist grounded theory methods for QUAL analysis delineated by Charmaz (2006) were used as a guide when analyzing the interviews and focus group data. This section describes this method, including word-by-word, line-by-line, focused, and thematic coding. When doing QUAL analysis, researchers much also be conscientious about the trustworthiness and credibility of their findings. Therefore, this section also includes descriptions of how these standards were tracked.

Coding

Using a collaborative approach for coding is one way of establishing rigor in QUAL research by ensuring that multiple perspectives are heard and decisions are made through consensus (C. E. Hill, Thompson, & Williams, 1997). In other words, the interpretations were not constrained by any potential biases of the primary student researcher because differences of opinion could be debated. Hence, three research team members conducted the interviews and coded the interview data. These members each coded individually and then met together to discuss the codes until consensus could be reached regarding common codes. Furthermore, five transcripts were cross-coded (i.e., two research team members would code the same interview) to assist with consensus and incorporate different perspectives. The coding stages included word-by-word, line-by-line, focused, and thematic coding. Each of these coding types will be described in detail in the following sections.

Word-by-Word Coding

As previously mentioned, the pilot study to this dissertation gathered responses to open-ended questions that addressed each domain of the Self-Regulation Model. As an online survey, the responses provided by participants were typically brief. It has been advocated that word-by-word analysis can be particularly useful for internet data (Charmaz, 2006). Consequently, word-by-word analysis was done on these responses to obtain the largest amount of information from the limited pilot data. QUAL research uses an emergent process, so after this analysis, the pilot questions were revised and a semi-structured interview guide was formulated for the current study (see Appendix H). Using the pilot data to inform the questions to be asked aided with *theoretical saturation* by allowing the questions and population sampling to be targeted in areas that required more development. For example, wording was altered to facilitate process responses better and questions were added to increase discussion about interactions between domains. Additionally, mothers with lower incomes (e.g., those at a homeless shelter) were sought out to provide a more representative sample due to the pilot study disproportionately capturing mothers with higher incomes. This was thought to be particularly relevant because SES is an indirect measure of other challenges that may impact mothers' experiences.

Line-by-Line Coding

Once individual interviews were collected, line-by-line coding (aka "open coding") was done by determining main concepts and interpretations from the data. This was so that the interpretations were sure to come from the data rather than be restricted by the researchers' pre-conceived expectations. In other words, while the study aimed to determine if the Self-Regulation Model was validated, the researchers had to be open to unexpected findings and expand the model, as appropriate, to include concepts that were important to MCDAs.

Focused Coding

Once main concepts were established, they were organized into common categories (i.e., “focused coding”). This represented the beginning of theme formation. Again, while the expected themes were from the domains of the Self-Regulation Model, emergent themes were not discounted.

Theoretical Coding

After the categories were established, the connections between the various categories were explored. This is because Charmaz (2006) indicates that simply labeling themes remains at a descriptive, rather than process, level and that action-oriented coding needs to be used to move to a theoretical level. The interactions between categories had not been fully explained in previous research with MCDAs, so the current study aimed to expand the knowledge of MCDAs’ experiences through examination *how* of their *processes* occurred.

Credibility and Trustworthiness

In response to QUANT research’s emphasis on validity and reliability and the potential for subjective interpretation in QUAL research, QUAL methods have established ways of analyzing the credibility and trustworthiness of the findings. One way of doing this is to examine the self of the researcher and use reflexive journaling to provide a trail that follows the interpretive process. Additionally, an audit by an outside researcher offers an external lens that scrutinizes any missed concepts. Lastly, a member check makes sure that the findings “ring true” for the participants themselves. How each of these checks and balances were implemented as part of the analyses will be described next.

Journaling and Analytic Memos

A *reflexive journal* is part of what is called an “audit trail” in QUAL research (Charmaz, 2006; Daly, 2007; Teddlie & Tashakkori, 2009). In other words, since the theoretical connections that are made in QUAL research are made directly by the researcher(s), one must document how these ideas developed. Therefore, the researchers’ viewpoints were tracked through journal writing throughout the study. This included personal thoughts and reactions, introspective reflections, inferences made as part of data analysis, and any other information that would be important to document. Part of the introspection included examination of the *self of the researcher*, or in other words, how qualities of the researcher may have influenced data collection and interpretation. The journal also included *analytic memos*; namely, initial write-ups of potential interpretations of themes and their connections (Charmaz, 2006). This journal was attached as an appendix to this dissertation so that the interpretive process could be critically reviewed as desired (see Appendix I).

Audit

Although there was a team doing the coding to include multiple viewpoints, it was also important to include a fresh view from someone outside of the research team (C. E. Hill et al., 1997). This helped get a new perspective to make sure the team had not missed anything important and assisted with prevention of groupthink. Therefore, once coding was completed, the codes were *audited* by someone who was *not* part of the core research team. Specifically, someone familiar with grounded theory read a random sampling of five transcripts and went over the common codes to determine whether any major concepts were missed. The auditor reported that after reviewing the information, there were no obvious omissions.

Member Check

Using a *member check* is an important part of determining the trustworthiness of the researchers' interpretations of the data. Once the analyses were completed, the findings were presented to a focus group of participants who provided feedback. Participants should be actively involved in the research process since the interpretations should represent *them*. This focus group gave an opportunity for the participants to have a voice in the analysis and how the findings would be presented to the scientific community. Specifically, they were asked if the interpretations fit for them and what, if anything, should be added that might have been missing.

CHAPTER SEVEN

QUALITATIVE RESULTS

The QUAL data was analyzed to answer the question, “Does the self-regulation process occur in MCDAs, and if so, how?” All of the major domains of the Self-Regulation Model were supported within the mothers’ responses and this QUAL results chapter will outline how. However, as previously mentioned, the research team was vigilant to consider alternative explanations for the data so that the responses were not forced to fit the model, and the team was open to new interpretations. What became evident through the analysis was that the Self-Regulation Model was insufficient to account for all the elements described in the mothers’ journeys. Specifically, it became clear early in the iterative analytic process that systemic influences played a big part in MCDAs’ efforts to understand and help their children.

To report these results, this chapter will be divided into four sections. First, findings will be presented that were relevant to the Self-Regulation Model. Second, findings regarding the emergent *systemic themes* will be described. Furthermore, since processes involve elements changing over time, results related to the dimension of *time* will be outlined. Lastly, the themes related to *processes* mothers recounted will be delineated (i.e., the “how” findings).

Findings Supporting the Self-Regulation Model

The results that were congruent with the Self-Regulation Model will be presented in this section. Specifically, the findings will be described in relation to how MCDAs’ responses fell within each pre-existing theoretical domain from the model: *the perceptual* *and conceptual processing system, cognitive representations, cognitive coping, cognitive appraisals, emotional representations, emotional coping*, and *emotional appraisals*. The categories of responses that make up each theoretical domain (i.e., common elements discovered during focused coding) will be explained to help provide a rich description. (Note that common codes are italicized for emphasis.) In addition, to be sure that the researchers were staying grounded to the data, examples are provided to show the nuances within the categories and to stay true to the mothers' voices.

Perceptual and Conceptual Filter

At the start of the Self-Regulation Model is the mothers' perceptual and conceptual processing system. In other words, the mothers' experiences are filtered through how the mothers perceive what is happening. The mothers in this study described some of the elements that contributed to this theoretical component such as her own *contextual factors* (i.e., background), *additional stressors* (e.g., health), personal *characteristics*, and self-*identity*.

As far as background, some examples mothers talked about that influenced how they viewed the experiences were having her own developmental delays as a child, relating to her own upbringing (e.g., her mother was hard on her, her father was strict), having a family history of autism, or being in an occupation that gave her previous exposure to autism (e.g., social work, teaching, medical profession). Mothers also noted that they sometimes have their own health or mental health issues that color the lens with which they view their experiences (e.g., previous miscarriages or ectopic pregnancies, developing cancer, having mood disorders). They also sometimes reported dealing with additional stressors that may be unrelated to autism such as needing to take care of ill parents, grieving the death of a parent, moving frequently, or going through a divorce.

Furthermore, the mothers noted characteristics that might impact their perceptions such as age, race/cultural background, language (e.g., bilingual household), religion, education level, socio-economic status, job status (e.g., working vs. stay-at-home mom), military status (e.g., active vs. retired), advantaged/disadvantaged status, or level of acculturation. With respect to the characteristic of sex, some mothers also indicated that fathers may deal with the process differently than they do. They also identified qualities of self that might impact how they perceive the process, such as being introverted, conservative, religious/spiritual, calm, laidback, resourceful, intellectual, patient, emotional, empathic, or not easily trusting/guarded.

Cognitive Representations

The first part of the cognitive dimension of the Self-Regulation Model is cognitive representations. There were many cognitive beliefs that the mothers expressed when talking about their journeys. Most of these fell within the areas previously discussed as part of the Self-Regulation Model (i.e., identity, timeline [acute/chronic], timeline [cyclical], consequences, causes, treatment control, and personal control). In addition, a theme that emerged from the data that related to cognitive representations that MCDAs discussed but was not previously delineated in the Self-Regulation Model was a sense of *not knowing*. Each of these types of beliefs will be discussed in this section.

Identity

MCDAs had many different beliefs about what they identified as being part of their children's ASDs. These included *beliefs about autism, beliefs about symptoms,* and *beliefs about the child*. Examples of these beliefs follow.

The mothers' beliefs about autism included how they *defined* autism as well as general ideas about it. For example, many mothers identified autism as a neurological disorder or difference in brain function. They were also aware that it affects certain areas, such as socialization and communication and has corresponding developmental delays. However, some mothers indicated that it may be undefinable or defined it as just a difference. In particular, mothers sometimes *normalized the child* by having beliefs such as that autism is not an identity, the autism behaviors should be separated from the child, the child just learns a different way, autism is not a deficit, autism is just another factor about the child, or that autism is just a variation of human experience. Mothers also had general or idiosyncratic thoughts about autism. A few examples of these thoughts are that it affects multiple systems in the body, the expression is different for each child/each child is unique, it is poorly understood, the spectrum is very wide, it is similar to personality, it may be adaptive, there are no physically distinguishing features, children with autism seem to have special talents, etc.

Beliefs about symptoms included those about symptoms in general as well as ones their children specifically demonstrated. For example, mothers identified common symptoms associated with ASDs such as problems with social interaction, communication problems (e.g., not talking, articulation issues), repetitive words or movements (e.g., hand-flapping or other "stims"), or restricted interests. Mothers also identified specific problems or behaviors such as developmental delays in specific areas (e.g., basic adaptive functions like potty training), regression, poor eye contact, lining up toys, difficulty with imaginary play, preference to play alone, sensory issues, environmental sensitivities, heightened reactivity, difficulty switching tasks, saying things bluntly, sensitivity to change, needing to follow a schedule, black-and-white thinking, and needing to follow rules exactly. However, they also included beliefs about other features that can be associated with ASDs such as problems with attention, impulsivity, organization, tantrumming, self-injury, aggression, destructive behavior, feeding, digestion, coordination, gross motor issues, spatial awareness, issues related to obsessions or compulsions, and sleeping.

The beliefs about the child that mothers reported included ones related to autism as well as ones related to the characteristics of the child. For example, mothers sometimes had beliefs about how high- or low-functioning the child was, what level of services the child needed, what the child could learn or do, what motivated the child, or how the child learned best (e.g., with structure, with the right environment, by being active, using kinesthetic activities). They also had ideas about characteristics of the child (e.g., good, intelligent, loving even if the emotions do not show, head-strong, high maintenance, sensitive, aware, impatient, healthy, has a sense of humor, has a younger frame of mind, etc.)

Timeline

Mothers also had ideas about the timeline of the disorder or behaviors. They were commensurate with the acute/chronic and cyclical timeline dimensions outlined in the

Self-Regulation Model.

Specifically, many mothers believed that the disorder is something that is lifelong, but they also believed some behaviors would improve over time. This is consistent with what was found in the pilot study to this dissertation. Additionally, the belief about behaviors being able to change was often related to personal experience with already seeing the child learn or make improvements or seeing the child "grow out" of certain behaviors.

The mothers also had cyclical timeline beliefs, such as that the experiences they go through can re-occur at different life stages (e.g., childhood, adolescence, adulthood) or after significant life events (e.g., changing schools). Furthermore, they believed that symptoms may become more evident over time, they may evolve, or different problems arise (e.g., trouble making friends shifting to trouble developing romantic relationships).

Consequences

MCDAs had various beliefs about the consequences of the disorder. On one side, they sometimes had *negative expectations* and *concerns about the future*. On the other side, they had *positive expectations*.

Some mothers had negative expectations of how autism will impact their children's lives. In particular, many mothers indicated that they had highly negative expectations more toward the beginning of their journey. Specifically, they noted that they were initially pessimistic and hopeless about the future, had low expectations, and had ideas that were worse that what ended up happening in reality. Other negative expectations included thoughts that their children may not get married or may need long-term assistance.

The mothers also described positive expectations. For example, they believe that progress was possible, the child may be able to do a job that matches his or her ability level, and in some cases may be able to lead a normal life. Many mothers described that their expectations became *less negative over time*.

Causes

Most mothers indicated that they were *not sure* of the cause of autism, but there were several different types of causes that mothers believed were possibilities. For example, they talked about *genetic causes* or differences in genes. Sometimes this was verified with genetic testing for children with particular genetic abnormalities (e.g., 1p36 deletion syndrome).

MCDAs also discussed that autism may be *hereditary*, runs in the family, or is a family trait. This was especially thought to be the case when the mother *recognized autistic tendencies in family members* and thought those people might be on the autism spectrum. This could either be within the nuclear family (e.g., the husband or the mother herself) or with extended family members (e.g., an uncle, a cousin, etc.)

Mothers also reported various possible *environmental causes* such as mercury in fish, exposure to chemicals, poor nutrition, or insufficient prenatal care. There were also beliefs in various *medical causes* such as stress in the womb, elevated heart rate during Cesarean-section, the umbilical cord being wrapped around the child's neck, having an accident during pregnancy, labor needing to be induced, gestational diabetes, meconium in the amniotic fluid, and being born breech.

Many of the mothers indicated that the disorder may be due to *multiple causes* such as an interaction between genes and environment, having a predisposition to develop these behaviors which is amplified by reactions environmental factors, or epigenetics. There were also causes that they *ruled out* such as the mother not showing enough affection or a punishment by God.

Due to the current controversy surrounding *vaccines*, this possible cause warrants specific attention. This is especially salient since almost all mothers felt compelled to mention their position on it when talking about possible causes even without direct prompting from any of the research team members. Some mothers were adamant about vaccines not causing the disorder because of the lack of scientific evidence and the risks that not having vaccines pose (e.g., resurgence of those diseases and possible death). Other mothers did not believe that their child's disorder was caused by vaccines because it did not match their experience, but they did not want to discount the experiences of other mothers who believed that vaccines did cause their children's ASDs. Some mothers were undecided about whether vaccines had an impact or not. There also were mothers who had strong convictions that vaccines did cause their children to develop autism because of their children having negative reactions the same day as receiving their shots.

Treatment Control

Just as mothers had negative and positive expectations for the consequences of the disorder, they also had *negative and positive expectations* for whether treatments could help improve or control the disorder. In other words, sometimes they believed a treatment would help and sometimes they believed a treatment would not be helpful. These beliefs were specific to the treatment the mother was discussing. Thus, a mother may have had a negative expectation for one treatment being able to help but a positive expectation for a different treatment.

Personal Control

Some MCDAs also had various beliefs about their personal control within the process of helping their children. For example, mothers talked about believing in their own *personal agency* such as being a big influence on their children, having an active/leading role, and being able to help their children between the treatments. Some also talked about how they believe they were the *advocates* or the voice for their children.

Not Knowing

A large piece of cognitive representations that does not fall within any of the categories above is simply the element of *not knowing*. Many of the mothers described that at the beginning of their journey, they frequently did not know what to believe. For example, they did not know what behaviors were part of the disorder, what to expect, what treatments were available, what information was valid, et cetera, until later in the process of understanding. The most succinct way to represent this phenomenon is the colloquial phrase, “You don’t know what you don’t know.” In other words, there were areas of knowledge that were outside of their awareness prior to beginning their journeys.

For example, if a mother did not know that music therapy existed, she would not have been able to have any beliefs about it or be able to pursue it as a treatment option. Making things even more *confusing*, mothers reported that there is a lot of conflicting ideas and misinformation available to the public alongside reliable information, making it extremely difficult to know what to believe. Thus, mothers often found that they became aware over time of the things that they did not know at the beginning of their journeys. Additionally, they still had trouble knowing what to believe even when they did become aware.

Cognitive Coping

The next section of the cognitive dimension of the Self-Regulation Model includes the coping procedures mothers used. There were several common coping methods present in MCDAs' stories that fell into this category. Specifically, mothers reported *gathering information*, *finding treatments*, *seeking help and resources*, and *taking action*.

A huge step in the coping procedures that mothers described was the process of gathering information. In particular, they attempted to get more information on autism, the available treatments, and what they personally could do to help their children. Some of the ways that mothers did this was searching online, researching information, asking professionals questions, educating themselves, reading books or articles, taking classes, going to fairs or conferences, seeking information from other mothers, and looking at different autism organizations (e.g., Autism Speaks, International Autism Network). As mentioned in the previous section, the mothers described how there was so much information available that it oftentimes became confusing and overwhelming.

Another significant coping strategy the mothers used was to try to find treatments for their children. Part of this occurred while gathering information to see what treatments would help, but there was also a decision-making process that went along with it as well as specific actions. Particularly, mothers had to sift through the information and decide what treatments they wanted to try. Most mothers *tried multiple treatments* to address different issues and tried to obtain treatments that were a good fit for the child's ability level. Sometimes, though, they were unable to find a good match or determined that they needed to be open to trying different things than what they originally thought would be helpful. Some were selective with what they wanted to try due to being cautious or not trusting certain treatments, but some wanted to pursue all options and *try alternatives*. This process was difficult for many mothers, as they described it as looking "blindly" or being confused by conflicting information. Some mothers were *given treatments* for their children or received guidance in finding treatments, but this was less common. More about the interactions with other systems will be expanded upon in the systems section later in this chapter.

Mothers also tried to cope by seeking help and resources. For example, they would ask for help or advice, reach out, seek opinions, seek out support, network with people, find things online, write letters to people, call different places, go to conferences, etc. A common place where mothers looked for help was at their local Regional Centers; however, not all mothers were able to receive assistance there. They also tried to find out what resources were available through word-of-mouth from other mothers who have already been through the process. It should be noted that in terms of help and resources, while recommendations were often provided by professionals, some mothers indicated that this was often not enough for them to truly know where to look or what next step to take.

Mothers also took specific actions to try to help their children. For example, they talked about needing to be proactive and take initiative to make contact, becoming involved, networking, and doing things on their own with the children at home by teaching themselves or following “homework” given to them by professionals. They also noted specific logistical actions that they needed to do to help make things work like change insurance companies, make appointments, etc.

Cognitive Appraisals

Once MCDAs make their efforts to cope with helping their children, the Self-Regulation Model indicates that they would appraise the outcomes of what happened. These appraisals were evident in the mothers’ stories. Specifically, they had *self-appraisals* as well as *appraisals of treatments*. Additionally, going through the process helped them *decide what to believe*. That is to say, there is a feedback loop leading to how beliefs change over time.

One part of the appraisal process was mother’ self-appraisals, or appraisals of their own self-efficacy in the process. These appraisals were positive, moderate, or negative. Positive self-appraisals included thinking they did well or “not half-bad” and seeing themselves as active, involved, or “on top of things.” The moderate self-appraisals essentially indicated that the mother was doing the best she could. An example of a moderate self-appraisal was best voiced by one of the mothers who said, “Do I think myself as being an expert in autism? No. But living with it and seeing it, I can say this is what I see and this is what I understand about autism.”

Unfortunately, there were a number of mothers who had negative self-appraisals. For example, they believed they were ineffective or not doing well and that they needed to do things better. They also sometimes blamed themselves or thought that things were their fault. Some of the MCDAs’ self-appraisals also included evaluating themselves as being negative through the process. For example, mothers said things like, “You build up kind of a thick skin.” However, it should be noted that much of the negativity the mothers saw in themselves was related to the systemic interactions that will be described later.

In addition to appraising themselves, they also *appraised treatment* outcomes. These appraisals were either that treatment was *helpful, not helpful, or negative*. Some of the positive treatment appraisals that MCDAs discussed in their stories were that the treatment was working/effective (i.e., the child was making progress in it), that it was good or the best available, or that it was a “cornerstone” treatment/necessary. They also appraised certain characteristics of treatment as positive such as flexibility, consistency, specialization, individualization, and being evidence-based. Regarding appraisals of treatments as unhelpful, mothers talked about how a treatment did not work, there was no difference, or it was not a good match for the particular child.

There were a variety of appraisals of treatment as negative. Some of the mothers stated that certain treatments were “terrible,” “bad,” “a joke,” “dumb,” or “crazy medicine.” They also discussed how some treatments were hard to do, not worth the time, intrusive, or unpleasant. Some of the outcomes appraised by the mothers as most negative were that the child regressed or got worse, the child had a bad reaction to the treatment, it created more problems, or that there were problematic side effects.

In the Self-Regulation Model, beliefs are not static, but can shift and change through the interactive process between the various domains. Consequently, although mothers may have had certain beliefs at the beginning of their journeys, they went through a process of deciding what to believe. Some mothers talked about listening to others' opinions, looking at the source of information, seeing if the treatment is backed by research, etc. However, mothers particularly noted the impact of coming to decisions based on their own *personal experiences*. Initially, MCDAs' thoughts were based on past experiences and they determined what to believe based on if it matched their previously existing cognitive framework (i.e., the perceptual and contextual filter previously discussed). For example, the mother may have had previous exposure to children with disabilities in her work, so her beliefs about the disorder and treatments might be impacted by those previous experiences at the start.

However, once mothers began gathering information and getting treatments, they would start to decide what to believe based on those new experiences which influenced them to grow and evolve in their understanding. Specifically, many mothers indicated that they chose what to believe based on what they saw with their own children. A huge component of this was the idea that the process involved a lot of "trial-and-error" and that it was difficult to know what to believe about something until a mother experienced it herself. In other words, the mothers would appraise their own cognitive representations after going through different experiences and decide if they needed to modify their beliefs.

For example, if a mother initially believed that the medical route would be best but then her experience was that medical treatments (e.g., medication) were ineffective, she then had to challenge her own beliefs and consider alternatives. Additionally, as previously mentioned, many mothers started from a place of not knowing. Consequently, mothers often tried whatever treatments they could get access to and then decided what to believe about it after seeing the outcome. Other systemic beliefs and appraisals developed through the processes mothers went through, which will be addressed in the context section.

Emotional Representations

In addition to the cognitive elements of the Self-Regulation Model, there were substantial emotional elements present in MCDAs' journeys. The emotions represented could be categorized as either positive or negative. Additionally, there were several different facets of these emotions. Each of these emotional representations will be presented here.

Positive Emotions

MCDAs talked about several different *positive emotions*. For example, they reported feeling emotions related to happiness (e.g., happy, glad, joy) and gratitude (e.g., grateful, lucky, fortunate). They also described positive emotions about their own self-efficacy (e.g., empowered, confident, secure, in control, prepared). Additionally, they spoke of positive emotions relating to the journey with their children (e.g., relief, excitement, hope, pride). However, MCDAs' stories were also filled with many negative emotions.

Negative Emotions

Most often MCDAs described their experience as an "emotional rollercoaster" that is filled with "all the emotions at once." Mothers described experiencing "a lot of negative and painful emotions." Some of the major categories of *negative emotions* that were discussed were *anger*, *fear*, *anxiety or stress*, *sadness*, *grief/loss*, and *guilt/shame*.

Anger

Some of the emotions that were reported relating to anger included being angry, frustrated, mad, bitter, agitated, furious, "pissed off," aggravated, irritated, and irate. They described having resentment, lashing out, misplacing their anger, screaming, and feeling like "I was gonna snap again."

Fear

Examples of fearful emotions included feeling scared, terrified, worried, and "freaked out." One of the common fears involved *having concern for the future*. Specifically, MCDAs reported concerns such as wondering what the child will be able to do; being concerned that the child will encounter obstacles, challenges, or negative experiences; not knowing what will happen when she (the mother) dies; worrying about the possibilities of college, a job, or leaving home; and being terrified of the child transitioning to adulthood. Additionally, these fears often interacted with mothers' beliefs and coping behaviors. For example, she may have fear if she believes something is wrong. Regarding interactions with coping processes, one mother noted that that when trying to gather information, "the internet will scare you half to death."

Anxiety and Stress

Emotional reactions related to anxiety and stress included feeling the stress of being an MCDA, being anxious about the future, and feeling "crazy," exhausted, overwhelmed, tired, worried, nervous, or even traumatized. MCDAs also noted that they would have breakdowns, "anxiety attacks," or panic. There were also reports of stress causing them to develop an anxiety disorder, become more vigilant, or have physiological effects (e.g., breaking out, getting sick more often).

Sadness

Mothers also discussed emotions related to sadness such as feeling depressed, hopeless, helpless, down, like a victim, raw, lonely, devastated, sad, defeated, and hurt. It was described by one mother that "autism is devastating to every dynamic of your life." Feelings of sadness can also be related to appraisals such as the mother blaming herself. These feelings can also arise due to negative experiences that happen such as no one showing up to the child's birthday party or the child being bullied.

Grief or Loss

Beyond just sadness, the large majority of mothers described feeling a sense of grief or loss. This emotion has a direct connection with cognitions. Specifically, a frequent sentiment MCDAs reported was “I grieved for the child I thought I would have.” In other words, they noted they had expectations of what the child would be able to do or an idea of the ideal child and they experienced a sense of loss when they realized their child would not live up to that expectation. Some mothers even compared the sense of loss to the death of a child. One mother noted that she had even seen recommendations to have a funeral for the child “because the normal kid or the kid that I anticipated I was going to have is not that child.”

Guilt or Shame

Some mothers also reported feelings of guilt or shame. Reasons for feeling guilty included vaccinating the child, not being as involved, waiting so long to get the child help, not recognizing problems in the system earlier, and feeling like it was her fault or wondering if she did something to cause it. Sometimes mothers also felt shame regarding the diagnosis or had the experience of others shaming her.

Emotional Coping

There were a number of coping mechanisms mothers used. Some were directly *emotion-focused*, such as crying, writing in a journal, or seeing a therapist. They also used *relaxation and recreation* strategies such as mindfulness, taking a break, getting a massage, having a hobby, going to a movie, etc. Some mothers used *active* coping strategies such as *changing her own behavior* (e.g., becoming more flexible), *seeking support*, or trying to keep a sense of *humor*. However, sometimes mothers used defense mechanisms of *avoidance* and denial. The connection between emotions and cognitions was also apparent in their coping mechanisms. For example, in order to deal with negative emotions, some mothers noted that they made conscious efforts to *change their thinking* (e.g., have a different mindset, reframing their thoughts from being resentful to seeing it as a blessing, changing negative thoughts to positive ones, etc.) In particular, MCDAs often tried to *focus on the positive*. For example, mothers would see positive qualities in the child (e.g., affectionate, smart), view the child as a blessing, look at strengths, notice what is functional and the capabilities of the child, count "small victories," etc. One mother indicated that "it's all perspective."

Emotional Appraisals

Just as there are cognitive appraisals, MCDAs also had emotional *appraisals* as outlined in the Self-Regulation Model. Many mothers indicated that they were not doing well with taking care of their own needs or what they were doing was not working. They also often indicated that their strategies were not the best/ideal or not positive and that they needed to find new/better ways of coping. Again, the emotional elements experienced by the mothers were not static, but frequently changing. Some mothers described that after realizing that they were not handling their emotions well, they were able to change what they were doing to deal with them. For example, they may initially have used negative coping strategies and once appraising them as such, made efforts to use more positive strategies that helped things become a little *easier over time*.

Findings Regarding Systemic Themes

As previously mentioned, when analyzing whether the Self-Regulation Model represented MCDAs' experiences, systemic issues became highly evident in their experiences. While Leventhal et al. (2001) acknowledged that the social environment influences the self-regulation process, the systems were not represented in the Self-Regulation Model. The themes that emerged from the data related to systemic issues included MCDAs' interactions with various *systems*, *interactions between systems*, *indirect systemic influences*, and *cultural issues*. Each of these themes comprises various categories, which will be discussed in the same way as was done for the domains of the Self-Regulation Model. In other words, the common categories will be described and examples provided to elaborate on these themes.

Systems

Mothers described several different systems that impacted their experiences. These included family, school, peers, church, and health services. The findings related to each of these systems will be described as they relate to MCDAs' journeys.

Family

The *family* is one of the most influential systems. As such, it is not surprising that MCDAs described many elements related to family. These include the *family structure*, *support within the family*, as well as various types of interactions. Types of *family interactions* include those with a *spouse, siblings*, and the *mother-child* dyad. Mothers also discussed how the child's *autism changed family interactions*. Furthermore, beyond the immediate family, mothers also discussed interactions with *extended family*. Each of these types of interactions that were reported within the family system will be discussed in this section.

Family Structure

The family structure has an impact on how interactions occur in the family system. For example, there were different family structures such as the father working and the mother staying at home, the mother working and the father staying at home, both parents working (sometimes on opposite shifts), and single mothers. Furthermore, mothers sometimes took on multiple jobs to help support the family or pursued further education.

Spouse Interactions

In addition to the work-home balance, the family structure also included MCDAs' relationships with the children's fathers. For example, mothers were never married, married to their first husband, divorced, or remarried. For single mothers, some got along with the biological fathers, some had negative interactions (e.g., fighting over child support), and sometimes the father was not involved. For mothers who were married, some described the fathers sharing responsibility for caring for the child and some indicated that the roles were separate. Additionally, some described having marital conflict, differing parenting styles, or lack of father involvement, while others noted that their husbands were extremely emotionally supportive.

Sibling Interactions

Not only was the family structure described in terms of the parents, but with respect to other children in the home as well. While sometimes the child with autism was the only child, sometimes there were siblings, and sometimes the siblings also had autism or other disabilities. If a sibling also had autism, many mothers described the contrast in going through the process of understanding and helping their children with a second child. If the sibling(s) did not have a disability, the mothers also spoke about the impact of birth order. For example, older siblings sometimes helped take care of the child. However, mothers indicated that they felt like this was a burden on the sibling.

Frequently MCDAs noted how their relationship with the child diagnosed with autism impacted the relationships they had with their other children. For instance, mothers often felt guilty about not spending as much time with their other children and noted that they needed to make sure to set aside special time with them. Some mothers indicated that the differences in interactions had caused strained relationships with the siblings that they needed to repair. Additionally, mothers indicated that they simply had different interactions with the siblings due to the differences in ability level (e.g., different discipline styles for each child, feeling a sense of pride in the achievements of the neurotypical child). Some MCDAs also noted that they wanted the sibling to have his or her own life.

MCDAs also often recognized the impact on the siblings of having a brother or sister diagnosed with autism. For example, siblings could have conflict with the child diagnosed with autism, be embarrassed by what the child diagnosed with autism did, or feel like what they did was dictated by what happens with the child diagnosed with autism. Mothers sometimes felt like the sibling's "childhood [had] been taken" and did everything they could to provide a normal, healthy life for the sibling. This sometimes included finding other support for the sibling such as a sibling support group. On the other hand, some mothers indicated that a sibling was very resilient and had learned to be inclusive with others they met.

Mother-Child Interactions

The interactions between mother and child are the most fundamental within the family system. As previously mentioned, many mothers believed in their own personal agency in helping their children, and thus were very involved in helping their children. As a result, mothers had a variety of interactions with their children.

Some interactions were positive, such as loving and guiding the child, playing games, doing enrichment activities with the child, spending time together, knowing the child better than anyone else, or being "best friends." Some interactions described were negative, such as the child being angry or aggressive with the parent, feeling rejected by the child, having difficult experiences, having trouble communicating, getting frustrated with the child, etc. Some interactions were not necessarily negative between the mother and child, but hurtful to the mother nonetheless. For example, one mother in the focus group shared that her child asked her if she would want to "fix" him and was passionate about the fact that she should never have to apologize for her child being the way he is.

Most frequently, though, interactions described by MCDAs had to do with gaining an understanding of how to help the child. Specifically, many mothers talked about their own learning and growth in the process such as learning how to be patient, do things at home, implement skills from providers, teach things in a different way, etc. Mothers also talked about specific ways they learned how to work with their children such as needing to be consistent, playing to the child's strengths, working with the child constantly, setting boundaries, needing to explain and teach everything to the child, providing structure, needing to do a lot of prep work to do simple things, and needing to constantly monitor the child. For higher functioning children, mothers also described a process of learning to "let go of the reins" and *foster the child's independence* (e.g., standing back, letting the child speak for himself, etc.)

Due to the mother's frequent interactions with the child, many mothers also shared their perspectives on their *children's experiences*. For example, mothers would often talk about the child's emotions (e.g., feeling ashamed, mad, frustrated, depressed, anxious, "low," excited, happy, etc.) They also described child's relational interactions outside the family such as the child being bullied, not meshing well with certain providers, being shamed, and other types of interactions with other children or adults. They also described various events that occurred in the child's life and how the child reacted to it (e.g., shutting down, getting through tough times by his faith in Jesus, having a meltdown, seeking out his own treatment options, etc.)

Impact of Autism on Family Interactions

Having a child with an autism diagnosis impacts everyone involved. This is especially true for the family interactions. One mother noted "every aspect of your life changes: what you eat, what you drive, where you go, how you sleep. Every, every component of your life completely changes." Other MCDAs also described *having a* *hard time* dealing with everything like never feeling "done," "Your whole life is turned upside down," and "It's been a hell of a road." Many MCDAs indicated the impact of autism on the family and how it is challenging for everyone. Specifically, they noted that the family needed to adjust what they do and how they interact. For example, mothers talked about how they might need to lower their voices not to disturb the child, they may change everyone in the family's diet to match the child's, a sibling might not be able to do certain activities because of resources going to the child, the mother may forego self-care because "they wear you down," or the family might make sacrifices for the benefit of the child.

Barriers within the family system. It should also be noted that not only does the child's autism impact the family, but elements of the family can also impact what can be done for the child. For example, *barriers within the family system* that can impact the processes they go through include financial limitations, not having enough time, having too much on their schedule already, not having resources or information, the mother having too many obligations, needing to take care of everyday things as well (e.g., laundry, dishes, cleaning), having other children in the family with special needs, the mother not being able to take time off, or the mother having mental barriers (e.g., worrying what would happen). The child can have barriers as well, though, such as symptoms getting in the way of participating in certain activities, the child refusing to participate, the child not feeling comfortable, or certain child characteristics (e.g., age).

Extended Family Interactions

Beyond the immediate family, MCDAs had varying degrees of closeness with extended family. Some mothers were able to connect with extended family and have some additional family support. For these mothers, they described their extended family members as educating themselves, providing emotional or functional support (e.g., respite), and respecting how the mother takes care of the child. Other mothers perceived a lack of support with extended family and said things like, “It’s crazy how people will scatter when things get tough.” In other words, they felt like their families were not supportive and as if they were on their own. Sometimes, though, the perceived lack of support was more due family simply not living close. In the worst cases, mothers described negative interactions with extended family. For example, they talked about how extended family did not agree with her parenting style, would blame her for problems and judge her, not understand the child’s challenges, etc. Sometimes interactions became so aversive that mothers had to cut certain people out of their lives because of the negative influence.

School

Another system that had a significant presence in the experiences that MCDAs described was the child’s school. Specifically, the mothers described a number of interactions that they had with school personnel. Some mothers *appraised* some teachers as very *helpful* in providing appropriate care for the child, such as by spending extra time with the child or tailoring treatment to the child’s level.

Unfortunately, oftentimes mothers *appraised* school staff as *not helpful* or *negative*. For example, the school sometimes did not provide appropriate services. This was due to not setting up an individualized education plan (IEP), not including the best provisions on the IEP, or not implementing the accommodations that were spelled out in the IEP. In addition, problems occurred when schools did not place the child in the most appropriate setting (e.g., general education, special education class, Non-Public School, or home school). This was in either direction of either wanting a more or less restrictive setting. Furthermore, some mothers described actions, or non-actions, by staff that were a safety issue and could have been dangerous to the child. For example, one mother described an event where her child had run out of the classroom and no staff followed him.

It is also unfortunate that many mothers had *negative appraisals* of school staff such as "their heart's not in it," the IEP teams are adversarial, or the staff take a position of power over the mother (i.e., a "one up" position). They also felt like school staff were too afraid to say their concerns or did not believe the mother's intuition about her child. It was sometimes described as feeling like it is the mother against a whole team of professionals. In other words, many MCDAs did not feel supported by the school. One mother stated it as, "Your child is just another piece of paper to come across the desk."

Peers

The system of peers in the context of MCDAs can relate to the child's peers or the mother's peers. With respect to the child, MCDAs sometimes referred to interactions between the child and his or her peers as an element of their journey of trying to help their children. Specifically, mothers described having difficulty when having to deal with their child being bullied or when other negative interactions occurred (e.g., not getting invited to a friend's birthday party).

Additionally, mothers frequently *compared their children to the children's peers*, which impacted their own experience. For example, if the mother noticed that the child acted differently than his or her peers, it sometimes helped initiate the process of finding out the diagnosis. The mother comparing the child's ability to that of his or her peers also caused either positive or negative emotions. For example, when comparing to neurotypical peers, sometimes mothers felt sad that their child could not do things that a typical child would. However, MCDAs also often compared their children to other children on the autism spectrum. On one hand, mothers sometimes felt positively if they felt like things "could be worse." On the other hand, they were frustrated if they thought their children were not getting the same services as other children. This frustration was seen in mothers of low-functioning children who thought higher functioning children received more services, and vice versa. Often, MCDAs noticed the uniqueness of each child when comparing their children to other children on the spectrum.

When looking at the mothers' peer interactions, mothers found some peers *helpful* and some *negative* or *unhelpful*. Mothers also *compared themselves with other mothers* just as they compared their children to other children. The mothers' peer interactions related to friends, support systems, or interactions with other mothers.

With respect to positive peer interactions, mothers describe support systems that were helpful. For example, mothers described making friends with other MCDAs, creating their own networks, getting help from support groups, having others to talk to, having mentorship, and finding friends who become like family. Some of the actions that mothers identified as being positive from their helpful peers were: listening, giving helpful advice, being nonjudgmental, being easily accessible, and providing resources or functional support.

Regarding negative peer interactions, mothers described former friends as well as other MCDAs. In either case, mothers talked about others judging or criticizing her, not being supportive, being disconnected, interfering or making things more difficult, and not being understanding or accepting. Mothers also sometimes disagreed with what others were telling them to do or others' views about their children. In addition, mothers noted that they sometimes lost friends because of the lack of connection.

Mothers also compared themselves to their peers. For example, some mothers made comparisons to mothers of neurotypical children, noting that they had trouble relating to those mothers and sometimes felt like they could not enjoy themselves as much as those mothers. They also compared themselves to other MCDAs. Most often, mothers acknowledged that everyone's experience of dealing with autism is different. Sometimes they had negative evaluations of other MCDAs, such as that other MCDAs were more desperate than they were, fought more, were more negative, did not give treatment enough time to work, etc. Sometimes mothers compared themselves in terms of resources, such as other MCDAs having money for things they could not afford. Frequently, these comparisons led to negative feelings. On the other hand, sometimes mothers compared themselves to other MCDAs in terms of feeling a connection with them and feeling like others understand their experiences better.

The mothers' peer interactions were not only one way with the peers influencing them, but MCDAs sometimes felt compelled to *help and inform others*. For example, some mothers indicated that they were the ones giving advice, help, support, and information to others. They also talked about becoming an *advocate* for others, becoming a mentor, volunteering, or creating a community.

Church

In addition to family and peer support, MCDAs also often brought up topics related to *spiritual support* as key elements in their journeys; although, this was not present for all mothers since some did not consider themselves religious or spiritual. On the negative side, some mothers talked about how they initially had negative feelings about autism because they felt like it was a punishment from God. However, they indicated that they shifted to more positive beliefs like, "God trusted me with this special child…and He knew we would love him and care for him as best we could." Other positive *spiritual beliefs* included that God guided her, the child was part of God's plan, her experiences were divine lessons, or that her religion was a protective factor. Some mothers also talked about believing in the power of prayer and how religion transformed them.

Many of the mothers who considered themselves religious indicated feeling supported by God and some noted having support in their religious community, such as from a pastor. However, some mothers also noted a conflict in wanting to be involved with a religious community but feeling like the accommodations were not adequate for the child. In addition, sometimes there were people in the religious community that a mother already knew from other contexts (e.g., school) with whom they already experienced negative interactions. These problems created barriers to accessing spiritual support that they desired.

Health Services

Health services are other systems that play a huge role in the experiences of MCDAs. Interactions with these systems could involve primary care physicians as well as other health professionals like speech therapists, occupational therapists, behavioral therapists, psychologists, psychiatrists, etc. Some of the types of interactions included *assessments or evaluations*, *getting a diagnosis*, or provision of *treatment*. Mothers described some positive interactions as well as a plethora of *negative interactions*. Throughout the frequent interactions that mothers had with health services, they formulated *positive and negative appraisals* of these systems and the professionals therein.

Sometimes MCDAs described positive interactions and appraisals of health services. For example, some MCDAs noted that actions they found helpful were when a professional put forth effort, was actively involved, explained things, provided education, took extra time, went above and beyond what was expected, provided a convenient service (e.g., in home, at convenient hours), offered guidance, followed up/checked in, was proactive/preventative, connected the mother with resources or services, was willing to answer questions, provided emotional support, gave information on what to expect, was willing to support the mother’s treatment decisions, or even gave a hug. They also noted that positive qualities of some professionals included when the professional was helpful, supportive, encouraging, kind, nice, compassionate, knowledgeable, experienced, a specialist, receptive, communicative, responsive, collaborative, open, understanding, nonjudgmental, and caring toward both mother and child.

On the other hand, MCDAs frequently described negative interactions with health professionals. These interactions caused MCDAs to appraise a large percentage of professionals as unhelpful or incompetent. Some of the negative actions that MCDAs described that professionals did were related to assessment. For example, mothers described professionals saying the child did not have any problems when he/she did, making excuses for symptoms, not doing an evaluation when one was needed, not doing comprehensive testing, only addressing what the mother brought up, and not listening to the mother's experiences. When the assessments were completed, professionals also sometimes did not explain the diagnosis, tell the mother what she was supposed to do, provide recommendations/information, or connect the mother to resources. In addition, sometimes when professionals did provide information, it was outdated or misinformation. MCDAs also had negative interactions where professionals were not prepared, did not take time with them, or were misleading. They also felt like professionals sometimes put all the burden on them or made them feel like they were a burden or hassle. Regarding service provision, MCDAs sometimes felt like professionals did not provide basic services that should have been available to all children with ASDs, include them in the treatment, help, or do their job. Furthermore, MCDAs sometimes perceived professionals as putting in mediocre effort and not caring.

MCDAs also described characteristics of professionals that were negative such as being rude, insensitive, not educated or knowledgeable about issues related to autism, uncertain, incompetent, antagonistic, shaming, judgmental, distant, unavailable, having no sense of compassion, having no bedside manner, ignorant, competitive, flippant, mean, or “brutal” (i.e., overly blunt). That is to say, a large majority of mothers perceived a lack of support from their health professionals.

One interaction that illustrates many of these points is when one mother described asking the pediatrician about whether the child had autism and the doctor just said “obviously.” The mother said, “And for her to just say, ‘Obviously.’ Just to sum it up with one word, just to disregard my pain and the impact of the diagnosis on my life, on my marriage, on my child, on his life. Uh, I cannot understand how…I don’t know how anybody could be that, um, hollow.”

Barriers in Health Services

There were several *barriers* that mothers described when talking about the system of health services. The most prevalent barrier described was having a service be denied, “shot down,” or rejected. These barriers were due to the child not qualifying based on symptom presentation (e.g., too high functioning), a service not accepting the evaluation from a different place, not being able to get a service without an official diagnosis, not being able to get into the program (i.e., put on a waiting list), or the program not being a good fit for the child.

Interactions Between Systems

Another common theme that arose within mothers’ stories was that there were interactions (or non-interactions) between systems. These included interactions between family and school, family and a health service, school and health services, one health service with another health service, etc. For example, the family interacts with the school through IEP meetings and works with health services when involved in the child's treatment(s). Participation in treatments included if an MCDA was hands-on in treatments, attended meetings, learned how to model skills for their children, took classes, etc.

One thing that can be either helpful or detrimental to MCDAs' processes of understanding and helping their children is whether there were *interactions between other systems* outside the family. For instance, it can be helpful when health services collaborate with school services or vice versa, but it can add to confusion or be very frustrating for mothers if those different systems are not on the same page. Lack of collaboration can occur either when there is no communication between the two systems or if providers from different systems disagree with one another.

In addition, there are certain services that act as "gatekeepers" to other services, thus requiring interactions between systems. The most prevalent example of this phenomenon is that services often require a referral from the local Regional Center. Another way that there were barriers for MCDAs was if the Regional Center did not provide a referral or did not inform the mother about all the options available to her. Moreover, sometimes the Regional Center refused to provide certain referrals because the service provider was out of their service area, the Regional Center in that area did not have enough resources to provide all services to all clients, or that Regional Center did not support a particular service. This was particularly problematic when the service that was not supported was a basic autism service, such as one-on-one ABA.

Due to the frequent negative experiences that mothers encountered, another type of systemic interaction that was seen was when the mother needed to *advocate* for the child. This occurred when the mother advocated for the child to receive certain accommodations at the school, advocated for the child to receive certain health services, advocated for the child during interactions with peers, etc. This was oftentimes between the mother-child dyad and other systems, but the mother could also enter into new systems that helped her advocate (e.g., getting an advocate or legal help).

Indirect Systemic Influences

Beyond systems with which MCDAs had direct interactions, there were also systems beyond the mothers' immediate environment that had impacts indirectly. Specifically, the school districts and insurance companies had indirect influences. Unfortunately, these influences were most often *barriers*. For example, certain school districts sometimes did not have enough resources or had policies that instituted "red tape" resulting in denial of certain services through the school. Similarly, insurance companies oftentimes denied coverage of certain services or had service caps. Additionally, sometimes mothers needed certain benefits and had to change insurance companies.

There were also a few other indirect systemic influences that mother discussed. For example, some mothers talked about frequent staff turnover within a treatment agency causing problems because of different staff being better than others as well as lack of consistency. In other words, changes at the agency level caused problems within the system of the treatment team. Additionally, many mothers talked about how many agencies did not provide their services in certain locations. Consequently, MCDAs either had to seek services outside their area or go without that service. Moreover, certain agencies only offered services at certain days or times that the family could not attend (e.g., weekdays only, no evening hours). Even more broadly, state boards sometimes had blanket laws that did not make sense for every situation. In addition, redistricting sometimes created problems for mothers who were on the border between two districts because of needing to find different services approved for that area.

Cultural Issues

On a broader level, MCDAs discussed certain themes within their stories that relate to various cultural issues. These included *beliefs about systems* regarding western medicine, *barriers* related to discrimination, and experiences that point to an *autism subculture*.

Regarding western medicine, MCDAs discussed that this culture tends to resort to offering medication as the first option. Some mothers did not like that medicine was often the first treatment route, especially due to side effects of the medicine and the fact that there is no one medication that is effective for treating autism specifically; however, some mothers saw the value of medicine and believed that it was helpful. One mother in particular saw the differences in western and eastern approaches because she was living in Japan on a military base at the time. She saw the western approach within the base compared to the eastern approach in the surrounding area.

The second cultural issue that was reported by MCDAs was discrimination. This occurred in a couple different ways. One common experience of mothers was discrimination due the child’s disability status. Many mothers talked about how their child was not accepted or understood and how they themselves frequently felt judged or blamed. The judgmental attitudes could either be related to the mother’s parenting (e.g., thinking she just needed to discipline the child more) or simply awkward looks from people not knowing what to do or say when the child was having a problem. Some mothers also recognized multi-level discrimination for their families. For example, discrimination happened on a functional and institutionalized level as well, such as school districts or Regional Centers in poorer areas not providing needed services to the children there. Some African-American MCDAs also saw discrimination based on race. In particular, one mother pointed out how African-American children are often misdiagnosed as having an intellectual disability as opposed to an autism diagnosis.

Cultural issues do not only have to do with culture as a whole, but subcultures as well. Many MCDAs described elements within their stories that indicate that there is an autism subculture. Elements of this culture are that there is a certain sense of “kinship” and connection with other MCDAs when they become aware that their children are on the autism spectrum. Oftentimes there is a sense of sharing in the same sorts of odd challenges that are part of a whole different lifestyle (e.g., celebrating when the child eats something new, putting bells on doors to alert the mother that the child has run off, etc.) One mother described it as, “It’s like being in this very weird club.”

However, there is also a sense that each mother’s experience is unique. This dialectic was shared by one mother as, “We’re all in this together…but at the end of the day…it’s just this…deeply personal journey.” As a result, sometimes mothers felt like it was hard to connect with other MCDAs because they felt like their experience was so different from other MCDAs that they met. In addition, it sometimes felt isolating because they could not find other MCDAs since not all mothers are open about the fact that their children have autism. As one mother put it, “We’re our own little community…We just don’t know each other.” Furthermore, some mothers *felt judged or blamed* even by other MCDAs and felt like they were outcast even within the autism community. MCDAs who felt like “outcasts” were most often mothers of children who were higher functioning.

Findings Related to Time

While the passage of time was most often implicit in MCDAs’ stories, processes necessarily involve the dimension of time. Furthermore, sometimes MCDAs described particular experiences that related to time. These could either be in relation to the mother’s personal life course or to the historical context of this time period.

Regarding the mother’s lifetime, the most direct link to this level of time was when mothers referred to their age. Sometimes this was discussed in terms of the mother having children later in life. Mothers also talked about how the process of understanding and helping her child became *easier over time*. In other words, the consistent interactions within and between systems allowed the *mother to learn and grow* over time, thus giving her knowledge of how to handle situations better.

There were also a few ways MCDAs discussed this time in history as it related to their experiences. In some cases, mothers talked about the transition from the DSM-IV-TR to the DSM-5. This is a historical event relevant to autism diagnosis and, therefore, treatment options. For example, some MCDAs discussed how their children had been diagnosed with a different pervasive developmental disorder under the DSM-IV-TR (e.g., Asperger's Disorder, PDD-NOS), and oftentimes insurance or certain service agencies would not pay for the child to receive services because they did not have the specific label of Autistic Disorder. A few mothers particularly noted how they were aware that the DSM-5 had shifted to where everything is considered under the umbrella of Autism Spectrum Disorder, but certain agencies had not caught up to the transition, causing further *delays in treatment*. On a related note, some mothers were also aware of the historical change of insurances now being required to pay for autism treatments, and their insurances not having yet shifted to this requirement. Lastly, some mothers noted that the process of obtaining help for their children may be different now than it was, say, 10 years ago because of increased prevalence and awareness in this time period.

Findings Related to Process

Beyond simple descriptive themes, theoretical coding required an analysis of action to help uncover process. Processes that emerged from the data were *noticing a difference*; *getting an evaluation*; *feeling grief, stress, and/or relief*; *gathering information*; *searching for treatment*; *fighting or being persistent*; and an experience that mothers described as *"This is the new normal."* Each of these processes will be described in detail in this section. Specifically, the examples of what mothers reported as part of each process will be described as well as categories connected to each process that were barriers or facilitators.

Noticing a Difference

To begin the journey of understanding and helping their children, MCDAs needed to start by noticing that there was some sort of difference. This occurred either because the mother noticed certain symptoms in the child, the mother noticed that the child was different compared to other children, the mother saw changes in development (e.g., stopped talking), or someone else pointed out a difference or suggested the possibility of autism (e.g., someone in their support system or a provider). Most mothers indicated that they noticed some signs even from an early age.

Frequently, though, mothers noted that even when they noticed a difference or someone pointed it out, they oftentimes got stuck at this point because of *denial*. For example, MCDAs often would state that their initial understanding of autism was based on a classical presentation or media portrayals, so they would initially reject the idea that their children had autism if they did not fit that stereotype. Additionally, MCDAs would sometimes reject other people's opinions, misattribute symptoms to other possible reasons, normalize the behaviors, or defend against their own emotional reactions to the possibility of the diagnosis.

For mothers to be able to move forward in the process, they needed to have some level of *acceptance* that their children were different. Even if they were not sure what the problem was, they still needed to acknowledge that they needed to seek help with figuring out what was the issue.

Getting an Evaluation

The next common step that mothers reported in their journeys was getting an evaluation or assessment. Sometimes the mothers sought out the assessment, sometimes they received a referral, and sometimes it was provided by a school or health professional. In some situations, this was a complex process requiring evaluations from multiple specialists.

A significant barrier to an MCDA's process continuing on was when there was *misdiagnosis* or a *lack of diagnosis*. Some mothers felt like this was because the evaluation that they got was not comprehensive or their child did not demonstrate behaviors or abilities during the assessment period that they did at home. Consequently, some mothers indicated that they needed to seek a second opinion or pay out of pocket for an outside assessment. Mothers also noted resultant diagnostic problems included the diagnosis being inaccurate, different assessments conflicting one another, or being told that nothing was wrong. Making things even more difficult to parse out, many children had *comorbid issues* including medical problems (e.g., epilepsy, seizures, ear infections, asthma), other mental health issues (e.g., anxiety, depression, Oppositional Defiant Disorder, Attention-Deficit/Hyperactivity Disorder), or even other disabilities (e.g., a learning disability). Consequently, misdiagnosis could be more likely when symptoms overlapped with other issues. If there were problems with assessment or diagnosis, mothers would get stuck at this stage.

What helped mothers to move forward was when they got the correct (autism) diagnosis. *Getting a diagnosis* was a significant hurdle for mothers to cross because of the implications. Namely, early diagnosis helped get early interventions. On the other hand, when there are *delays* in assessment or diagnosis, this *caused problems* for the child. For example, some MCDAs indicated that they may have missed a window of opportunity and the child could have been farther advanced.

Feeling Grief, Stress, and/or Relief

After getting the diagnosis, mothers had significant emotional responses. As mentioned before with respect to the person, a highly prevalent experience reported by MCDAs was a grieving process. Once receiving the diagnosis, the mother has to come to terms with the fact that her suspicions of something being different are confirmed. This experience can be incredibly overwhelming with a flood of emotions similar to the grief of a traumatic loss.

In addition to the emotional responses of grief, the majority of mothers reported a significant amount of *stress*. This stress was related not only to the process of trying to find help for their children, but everyday challenges of dealing with autism as well. For example, many mothers described having a lot to handle and struggling through it to where they felt tired or drained.

Grief and stress were not the only types of responses to receiving the autism diagnosis, though. Some mothers felt *relief* instead. For instance, some MCDAs were expecting the diagnosis once they understood the symptoms were associated with autism but had trouble getting the diagnosis. As a result, these mothers were relieved at getting the diagnosis because it meant that they could move forward to getting services for their children.

There are a couple of reasons that may make it difficult for mothers to move forward in this emotional process. One difficulty that several mothers talked about was how they could not address their own emotions because they just had to "*deal with it*." Mothers talked about this response as "sucking it up," "not wallowing in it," "you gotta do what you gotta do," "making do," or just doing it. In other words, some mothers repressed their own feelings so that they could take action. Another reason for having trouble moving forward with the emotional process was that stressors constantly arise, so even if a mother has dealt with feelings of grief before, she may re-experience those feelings as new challenges emerge. As previously mentioned, the process was described as an "emotional rollercoaster." One mother in the focus group even noted that it was like a rollercoaster that you can never get off and is constantly changing from one day to the next.

There are also some things that help mothers move on to a new stage in the process, though. One element that helps with moving forward in the emotional process is learning to *accept* what is. In other words, MCDAs who were further along in the process of understanding and helping their children noted that the they needed to accept that child that they have (as opposed to the child that could have been) and accept the reality of the present and future. Sometimes the mother's own personal therapy helped her to come to this place of acceptance. On a related note, another piece that helped mothers to continue on their journey was to *gain a balanced perspective*. For example, mothers described accepting the stability of the autism diagnosis and being "at peace" with the child's autism-related challenges, while still expecting that the child can make some gains in treatment respective to his or her ability level.

The balanced perspective also included being able to separate the mother's identity from her child. Early in the process, MCDAs frequently reported that their *focus was completely on their children*. For example, they noted that they viewed their children as their whole life and were constantly focusing on the child's needs. More specifically, mothers made statements like, "everything in my life's my child," "it's not about me anymore," and "your life *is* having a child with autism." This was often at the expense of *not focusing on themselves* at all and neglecting their own needs. For example, a common sentiment was, "I had to put my own self second." On the other hand, MCDAs who had a balanced perspective realized that they had to also *focus on themselves* and have their own identity in order to function better for their children. In one mother's words, "I have to help myself before I can help her." For example, these mothers noted that they forced themselves to do things for themselves, addressed their own feelings, did things to take care of themselves, etc.

Gathering Information

On the cognitive front, as previously mentioned, an almost ubiquitous approach by MCDAs was to gather information. There was almost always a sense of urgency to try to understand everything they could about the disorder: what it is, what problems are associated with it, what to do about it, what treatments are most effective, what causes it, etc.

There were several elements that MCDAs discussed that made it difficult to move through this part of the process. First and foremost, there was so much information that it made it *confusing* and difficult to figure out what was accurate. Many MCDAs reported that they got much of their information from the internet and that it was very scary, confusing, and overwhelming to search through everything. This was because a lot of the information on the internet was negative and different perspectives conflicted with one another. The difficulty was not only with internet information, though. Many mothers reported having a *lack of information* from the professionals who gave them the diagnosis (thus why they were searching for information elsewhere). Alternatively, the information given to them was “dim-and-grim.” For example, several mothers reported that their pediatricians gave them extremely *negative expectations* of what their children would be able to do.

What helped mothers move along in their processes from a cognitive standpoint was *gaining an understanding*. This did not mean that mothers had everything figured out, but that they were able to come to a general personal understanding that they found helpful. This understanding could be due to an understanding of autism and its defining behaviors, associated features (e.g., trouble with sleeping or gastrointestinal problems), strategies for helping their children, etc.

Searching for Treatment

Regarding the behavioral aspect at this stage of the process, MCDAs searched for treatments for their children. They sought evidence-based practices (e.g., ABA, social skills, SLP, OT, etc.) and/or *tried alternatives* (e.g., dietary interventions, naturopathy, alternative school placements, massage, reflexology, hypnosis, acupuncture, music therapy, drama therapy, etc.) Additionally, MCDAs frequently had their children try *multiple types of treatments* either to address different symptoms or as “trial-and-error.”

Furthermore, they sometimes would *change treatments* if they did not think the one they had was effective, they wanted/needed to change providers, they moved, etc. The step of searching for treatments was aided if the mother was guided by a professional through this part of the process or if a service was provided without the mother needing to ask for it.

However, mothers frequently had difficulty finding and accessing the treatments that they wanted for numerous reasons. To begin with, most MCDAs indicated that they received *poor functional support* from the providers who gave the diagnosis. In particular, MCDAs indicated that they were not given specific steps or instructions on where to look for treatments or how to do it. Also, if the mother did receive recommendations, she was mostly left to do things on her own with no follow-up.

Once mothers did find out where to request services, services were often *denied*. This was sometimes due to a lack of resources on the part of the provider, which led the mothers to need to pay out of pocket. However, they sometimes lacked the personal resources to be able to fund all the services that had been denied. Additionally, oftentimes mothers had difficulty finding treatments that were a good fit for their children. This was because of ability level (e.g., the service was for lower functioning children), age (e.g., the service was only offered up to a certain age), the child not responding well to that type of intervention, etc. As a result, they oftentimes *wished their children had better treatment*.

What helped mothers move forward was when they *received appropriate services*. However, this frequently did not happen initially, leading to an extra step in the process that most mothers felt should not have been needed: *fighting or being persistent*.

Fighting or Being Persistent

While not always necessary, the large majority of MCDAs reported needing to fight for what they wanted for their children. One mother stated it this way: “You have to fight for all your services. It’s just part of getting up.” It should be noted that while most mothers described this part of the process as “fighting,” some mothers did not agree with that term and preferred the description of “being persistent” instead.

Mothers fought for or were persistent in pursuing services for their children in a plethora of ways. Examples of what MCDAs described that fit the “fighting” description included “pushing,” threatening, saying no, refusing to accept what is given if they did not agree, demanding, being aggressive, and battling. This could go beyond the mother alone and include legal processes as well, such as appealing, getting legal help, getting an advocate, going through a lawsuit, being in litigation, having fair hearings, or going to a state agency. Examples mothers shared that were more line with “being persistent” were bargaining, re-applying, never giving up, voicing their opinions, and getting a second opinion. Some mothers also described a sense of needing to manipulate the system (e.g., use a friend’s address to be eligible for services in a particular area) or be kind to the providers in order to get what they want.

Some things caused mothers to have trouble getting out of a fighting cycle. For example, many mothers *appraised the professionals as being incompetent or negative* toward them, which created *barriers* to moving forward. One mother in the focus group described that experience as the professionals “stonewalling,” which resonated strongly for some of the other mothers in the group. As previously discussed regarding microsystem barriers, MCDAs also reported having difficulty with “red tape” that was in place from various systems that forced them to wait. One mother described the interactions with professionals as needing to “hurry up and wait.” Getting stuck in this cycle frequently caused *delays in treatment*.

What helped MCDAs to move out of a fighting cycle was *collaboration* or partnership with providers or coming to a compromise (e.g., 30 minutes of speech services instead of the 60 minutes that the mother requested). These facilitative responses helped mothers move back on track with receiving appropriate services.

This Is the New Normal

If a mother was able to learn to accept things as they were, have a balanced perspective, gain an understanding, and receive appropriate services for her child, several mothers described coming to a stage where “this is the new normal.” In fact, five different mothers used the phrase “new normal” independent of each other and three of those exactly stated it as “this is the new normal.” Other ways this was voiced was “learning to live with it,” “this is my life,” autism is “part of our family,” “autism is a whole lifestyle,” “just walk step-by-step with a kid with autism,” “things could not be the way they were before,” “you just have to learn how to make it work,” and “this journey on being parents of autistic kids.” This stage of the process involved a mental shift to adjust to autism-related changes, taking things one step at a time, juggling the child’s needs with the family dynamic, integrating treatment into home life, predicting child’s challenges to be able to prepare for them, and making changes to fit the needs of the child. If a mother was able to learn to accept things as they were, have a balanced perspective, gain an understanding, and receive appropriate services for her child, several mothers described coming to a stage where “this is the new normal.”

Although coming to a space where “this is the new normal” was a commonly reported theme, it should be noted that it does not indicate that everything is “perfect” or that everything has been figured out. In fact, it is more a sense of being able to work through the challenges that come up on a day-to-day basis. Mothers often described that they went through a process of *learning and growing* through their journeys. For example, some mothers said things like, “You learn a lot about yourself,” and, “You got to learn in order to make your family work.” Additionally, it does not mean that this is a final stage where a mother arrives and never goes through any of the other stages of the process again. In one mother’s words, “I think it’s still a learning process…an ongoing education.”

PART III

DISCUSSION

CHAPTER EIGHT

DISCUSSION OF QUANTITATIVE RESULTS

This chapter will be limited to discussion of the QUANT results, as the QUAL results and meta-inference will be discussed in the following chapter. This chapter will include interpretation of the QUANT results, limitations of the QUANT strand of this study, future directions for QUANT research, and the conclusion for the QUANT results.

Interpretation of Quantitative Results

To summarize the QUANT results, the analyses were either not statistically significant or in the opposite direction from what was hypothesized. In general, for the results that were significant, the Mother LOC group viewed treatment as being able to control the behavior the same as or less than the disorder, whereas the Divine LOC and Professional LOC groups believed treatment as being able to control the behavior the same as or more than the disorder. In other words, there was *not* an association between mothers with a personal sense of control and a high sense of treatment control for behaviors more so than the disorder. The exception to this generalization is that both groups overall believed treatment as being able to control communication problems more than the disorder. See Table 35 for a summary of the specific significant results.

Table 35. Summary of significant quantitative Treatment Control results.

Analysis			Disorder	>/</=	Behavior
Disorder vs. Social Interaction Problems by Mother LOC vs. Divine LOC					
	Main:	Mother LOC vs. Divine LOC			
*	W/In:	Mother LOC	Disorder	=	Social
		Divine LOC	Disorder	<	Social
Disorder vs. Communication Problems by Mother LOC vs. All External LOCs					
*	Main:	Mother LOC vs. All External LOCs	Disorder	<	Communication
Disorder vs. Communication Problems by Mother LOC vs. Professional LOC					
*	Main:	Mother LOC vs. Professional LOC	Disorder	<	Communication
Disorder vs. Communication Problems by Mother LOC vs. Divine LOC					
*	Main:	Mother LOC vs. Divine LOC			
*	W/In:	Mother LOC	Disorder	=	Communication
		Divine LOC	Disorder	<	Communication
Disorder vs. SB/RI by Mother LOC vs. Professional LOC					
*	Main:	Mother LOC vs. Professional LOC			
*	W/In:	Mother LOC	Disorder	>	SB/RI
		Professional LOC	Disorder	=	SB/RI
*	Btwn:	Mother LOC	Disorder *and* SB/RI Lower Overall		
		Professional LOC			
Disorder vs. Aggression by Mother LOC vs. Divine LOC					
	Main:	Mother LOC vs. Divine LOC			
*	W/In:	Mother LOC	Disorder	=	Aggression
		Divine LOC	Disorder	<	Aggression

Note. * = p < .05. Main = main Effect. W/In = within-subject effect. Btwn = between-subjects effect. LOC = locus of control. Social = social interaction problems. Communication = communication problems. SB/RI = stereotyped behaviors and restricted interests. Aggression = aggressive behaviors.

One thing that is evident from the significant results is that mothers did, in fact, have different loci of control. Most notably, almost equal numbers of mothers were in the Mother LOC group and the Divine LOC group. Additionally, the Divine LOC group tended to show the hypothesized pattern of beliefs (treatment control of behavior higher than treatment control of the disorder) as opposed to the Mother LOC group. This was an unexpected finding. In order to help understand this result, the mothers of the focus group were asked about why this may be the case since all results were presented to them. The mothers indicated that their spirituality or religion was a significant coping mechanism for them that helped them accept what was happening and have hope. Furthermore, one focus group members indicated that mothers who have a sense of personal control may feel more responsible if things do not go well.

The impact of religion and spirituality on coping has been established in previous research. Specifically, spirituality is associated with positive maternal socioemotional functioning and stress-related growth (Ekas, Whitman, & Shivers, 2009). Additionally, the challenges that families face can be interpreted through the lens of certain cultural and spiritual beliefs (Jegatheesan, Miller, & Fowler, 2010). Furthermore, the meaning-making processes in religious parents of children who have developmental disabilities creates a higher sense of coherence than for secular parents who find meaning in non-religious dimensions (Manor-Binyamini, 2012). However, there can also be negative religious coping that can be associated with higher depressed affect (Tarakeshwar & Pargament, 2001).

Beyond the Divine LOC group, there were also differences between the Mother LOC group and Professional LOC group. Retrospectively, it makes sense that mothers who place an equal or higher sense of control in professionals would have higher belief in treatment control, especially for specific behaviors (e.g., communication problems), since professionals are integral to treatment. Additionally, it is possible that even mothers who are actively involved in treatment do not recognize that their actions *are* part of treatment. In other words, even if they believed the things that they did (e.g., implement behavioral strategies at home) would help their children improve, they would not have a high belief in treatment control even if they did not believe what they were doing was *treatment* per se.

The fact that MCDAs did not consistently view treatment as being able to help behaviors more than the disorder has a couple implications. Mainly, it shows the division between behaviors and the disorder is not as distinct when considering treatment control as compared to the significant difference that was found in the pilot study between beliefs about the stability of the disorder versus beliefs about stability of behaviors. Additionally, although mothers do see the disorder as more stable than any specific behavior, they still generally believe treatment should help improve things overall. Furthermore, while treatment control and the mothers' locus of control were divided into separate constructs, it is possible that mothers viewed both concepts within the same general framework of controllability.

The fact that there were some significant results, though, implies that different types of beliefs *do* interact. Specific to this study, beliefs about treatment control do, in some cases, interact with beliefs about LOC. This suggests that beliefs do not exist independently, but within interactive contexts, just as the concept of process within the Self-Regulation Model would indicate. In other words, beliefs are not static, but dependent on certain interactions. This could be internal reactions, such as between different beliefs in the cognitive representation domain of the Self-Regulation Model. However, this also likely includes interactions across domains. For example, the Self-Regulation Model would assume that beliefs also interact with coping procedures, emotions, etc. This is particularly evident in these results with the fact that religion or spirituality can be both a belief and a cognitive or emotional coping mechanism.

Limitations of the Quantitative Strand

There are a couple limitations in the current study that need to be considered. Namely, low reliability and multiple analyses could have had an impact on the results.

The first limitation to consider is that although none of the Treatment Control scales fell in the unacceptable range of reliability (below .60), a couple of the Treatment Control scales did not have the generally accepted range of internal reliability of .70. This seems to indicate that the Treatment Control scale does not measure as cohesive a construct as would be preferred. This is likely due to varied wording in the questions (e.g., control vs. improve). This is especially noteworthy due to one question using the word “cure,” which is a highly controversial word within the autism community (Robison, 2009). Additionally, one mother noted that she did not agree with the term “control” as she was filling out the survey. Consequently, the inconsistent results may have been due to not having a scale that cohesively represented the mothers’ beliefs about treatment.

In addition to scale reliability, another limitation was the fact that multiple analyses were performed at the same time. This was done due to the exploratory nature of these analyses. In other words, the purpose was to determine *if* relationships existed rather than *confirm* them. Nonetheless, running multiple analyses at the same time increases the risk for Type I error (i.e., rejecting the null hypothesis when the null hypothesis is true, or in other words, saying there is a difference when one does not exist). These limitations lead to ideas for future directions for research as related to the QUANT results.

Future Directions for Quantitative Research

There are a few possible future directions for research based on QUANT results of this study. These possibilities relate to further scale development, replication, and additional relationships between beliefs.

One future direction for QUANT research could be further development of the treatment control scale on the IPQ-R-Autism. For example, factor analysis of the questions would help determine if certain questions should be removed. Additionally, other methods for increasing internal reliability could be implemented, such as adding more questions or rewording questions to be more cohesive.

Another direction for future research could be replication. Specifically, the analyses with significant results could be replicated or proven false with a replication study. In addition, this type of confirmatory analysis could control for Type I error and require corrections for *p*-values for a more conservative examination of results.

A third possible direction for future research is to look for other types of interactions. For example, research could test interactions within the domain of cognitive representations with other types of beliefs (e.g., timeline and consequences). Researchers could also use future research to make comparisons across domains (e.g., cognitive representations with coping procedures).

Conclusion of the Quantitative Results

Most interactions between treatment control beliefs and beliefs in LOC were not statistically significant, but there were a few significant comparisons when looking at the Mother LOC group versus the Divine LOC or Professional LOC groups. In particular, results were in the opposite direction than was hypothesized, with the Mother LOC group viewing treatment as being able to control behaviors equal to or less than the disorder. These results indicate that a mother's sense of personal control is not linked to higher belief in treatment controlling behaviors. In other words, the difference between the disorder and behaviors is not highly distinct when looking at treatment control. Additionally, the fact that mothers with a Divine LOC did sometimes have higher belief in treatments control of behaviors highlights the importance of spirituality as a coping mechanism in MCDAs. Furthermore, the significant interactions between beliefs in treatment control and beliefs in LOC stress the importance of considering how different beliefs interact with each other and how beliefs may interact with coping procedures.

CHAPTER NINE

DISCUSSION OF QUALITATIVE RESULTS

The discussion in this chapter will focus on the QUAL results since the QUANT results were discussed in the previous chapter. This chapter will be outlined in the following way: interpretation of the QUAL results, limitations of the QUAL strand, future directions as they relate to research and clinical application, conclusions for the QUAL results, and concluding thoughts for the study including ideas for meta-inference.

Interpretation of Qualitative Results

Interpretation in QUAL research is not necessarily a linear process. *Induction* is typically used for the generation of theory, whereas theory is usually the starting point in *deduction* (Daly, 2007). *Abduction*, however, is a more creative process that "is concerned with finding the 'best explanation,' is shaped by both the presence and inadequacies of existing theory and the need to generate new theoretical explanation" (Daly, 2007, p. 43). Additionally, sometimes theory is not the intention at all, such as in phenomenological and narrative approaches that are "more interested in upholding the integrity of the description of the lived experience" (Daly, 2007, p. 43). In many qualitative approaches, though, induction, deduction, and abduction all occur in the recursive patterns of exploration, analysis, interpretation, and search for explanation (Daly, 2007).

At the outset of this study, the less traditional QUAL approach of deduction was used to gather evidence to determine if MCDAs' processes supported the Self-Regulation Model. However, as previously mentioned, the research team was also open to using induction if the model did not fit the data. The push-and-pull between much of the evidence supporting the Self-Regulation Model *and* the discovery of other concepts emerging in the mothers' stories led to the team trying to find the best explanation.

The research team associated the systems that emerged in the mothers' stories with an existing theory, Bronfenbrenner's Bioecological Theory. Bronfenbrenner's theory was not evaluated during the initial literature review process because it was not anticipated as part of the QUAL research question and the literature was only reviewed under the framework of the Self-Regulation Model as a sensitizing theory. However, Bronfenbrenner's theory became evident as an integral piece of the experiences described by the mothers. This is the reason why Bronfenbrenner's model has not been addressed until this discussion. As a reminder, one of the founders of grounded theory, Glaser, even warned against doing literature reviews prior to collecting the data due to the emergent nature of QUAL research (Daly, 2007). Accordingly, the research team returned to the literature to hone their understanding of Bronfenbrenner's model only after systemic elements became prevailing themes.

Bronfenbrenner's theory purports that interactions at different systemic levels impact individual development across the life course (Bronfenbrenner & Morris, 1998). Consensus of the research team doing the analysis was that although the Self-Regulation Model accounted for much of the internal processes, Bronfenbrenner's model accounted for additional systemic variables that the mothers described. In other words, it was deemed that there should be an integration of self-regulation and systemic processes to more accurately represent the mothers' experiences. This integration is also consistent with the primary student researcher's dialectical paradigm that suggests that multiple perspectives can coexist at the same time with both being correct and that considering more than one viewpoint can create a fuller picture. Therefore, this discussion will illustrate both how the mothers' responses fell into the domains of the Self-Regulation Model as well as how they fell into Bronfenbrenner's Bioecological Model. The elements of Bronfenbrenner's model will be defined as they are presented since they were not outlined previously.

It should also be noted that after further reviewing the literature on Bronfenbrenner's concepts, it was discovered that his model has evolved over time, and his current research acknowledged that the role of the person was underrepresented in his earlier model (Bronfenbrenner, 2005). As a result, the most recent perspective on his model is that there are four defining characteristics that are dynamically interrelated: process, person, context, and time (Bronfenbrenner, 2005). Accordingly, the Process-Person-Context-Time (PPCT) model analyzes processes and outcomes "as a joint function of the characteristics of the environment and of the person" (Bronfenbrenner, 2005, p. 115).

Given this new understanding, the team determined that an integration of Bronfenbrenner's Bioecological Model with the Self-Regulation Model would present a fuller picture of the process experiences MCDAs described. Specifically, the Self-Regulation Model represented themes related to the *person*, while Bronfenbrenner's Bioecological Model represented themes related to the *context*. Furthermore, the *processes* MCDAs described showed the importance of integrating the two since interactions occurred within the mother, within and between various systems, and between the mother and various systems. Consequently, the information presented in this discussion will be organized in the following way:

- Discussion of the results relevant to the *person* using the framework of the Self-Regulation Model.
- Discussion of the results relevant to *context* using the different systemic levels outlined by Bronfenbrenner.
- Discussion of the results relevant to dimension of *time*.
- And lastly, a discussion of the overall *processes* described by MCDAs.

It should be noted that the processes are presented last so the characteristics of the person and context that are integral to the interactions can be delineated beforehand.

Person

Bronfenbrenner and Morris (1998) noted that it was important to consider the biopsychosocial characteristics of the person when doing research, especially since this key feature was less pronounced in earlier versions of the Bioecological Model. The *person* component includes “his or her individual repertoire of biological, cognitive, emotional, and behavioral characteristics” (Bronfenbrenner, 2005, p. xv). The Self-Regulation Model addresses many of these elements by looking at cognitive and emotional domains as well as coping behaviors. The results related to the person within the framework of the Self-Regulation Model will be summarized next.

Summary of Results Regarding the Person

MCDAs described elements relevant to each domain of the Self-Regulation Model. To start with, mother's viewed their experiences through a perceptual and conceptual filter based on their own background, health, additional stressors, personal characteristics, and self-identity.

They also expressed various cognitive representations (i.e., beliefs). These included beliefs about identity, such as beliefs about autism, symptoms, and the child. They also involved acute/chronic and cyclical timeline beliefs. In addition, MCDAs had beliefs about consequences, including negative expectations, concerns about the future, and positive expectations. Beliefs about causes were also present in MCDAs' stories, including those regarding genes, environment, multiple causes, or vaccines as well as being unsure about cause. There were also different aspects of control beliefs including whether they thought treatment would be helpful or not helpful and whether they would personally have an influence. Something that was not in the Self-Regulation Model, but was described by MCDAs with respect to beliefs was simply not knowing.

Mothers also expressed processes related to cognitive coping and cognitive appraisals. Specifically, for cognitive coping, MCDAs indicated that they gathered information, tried to find treatments, sought help and resources, and took action. It should be noted that, as discussed in the literature review, help-seeking had not truly been explored in previous research with regards to MCDAs. However, much of what MCDAs described match the general help-seeking model: problem recognition (i.e., the noticing a difference stage described in the process section of the results), a decision to seek help, and service selection that includes informal supports (e.g., family, peers, church), collateral services (e.g., school), and formal health services. Beyond coping procedures, with regards to cognitive appraisals, MCDAs described self-appraisals, appraisals of treatment, and deciding what to believe.

In addition to the cognitive elements, MCDAs expressed a number of emotional representations. Sometimes there were positive emotions. There were also a lot of negative emotions, including anger, fear, anxiety and stress, sadness, grief/loss, and guilt/shame. These emotional reactions are consistent with what was found in previous studies on emotions that were discussed in the literature review.

Elements related to emotional coping and emotional appraisals were evident as well. Regarding emotional coping, MCDAs described avoidance, emotion-focused coping, relaxation and recreation, active coping, changing behavior, seeking support, humor, changing thinking, and focusing on the positive. They also appraised themselves regarding their coping strategies (e.g., not doing well, needing to change strategies, etc.)

Context

Beyond just the person, Bronfenbrenner's Bioecological Model provides a framework for understanding the systemic influences as an interacting context. Context within the PPCT Model is conceptualized as nested levels, or systems, as depicted in Figure 17. Each systemic level will be described in this section since each emerged as part of the MCDAs' stories during analysis. The different systemic levels are referred to as the microsystem, mesosystem, exosystem, and macrosystem. This context section will be organized by each of these systems so that each level can be defined and results can be summarized as they relate to each level.

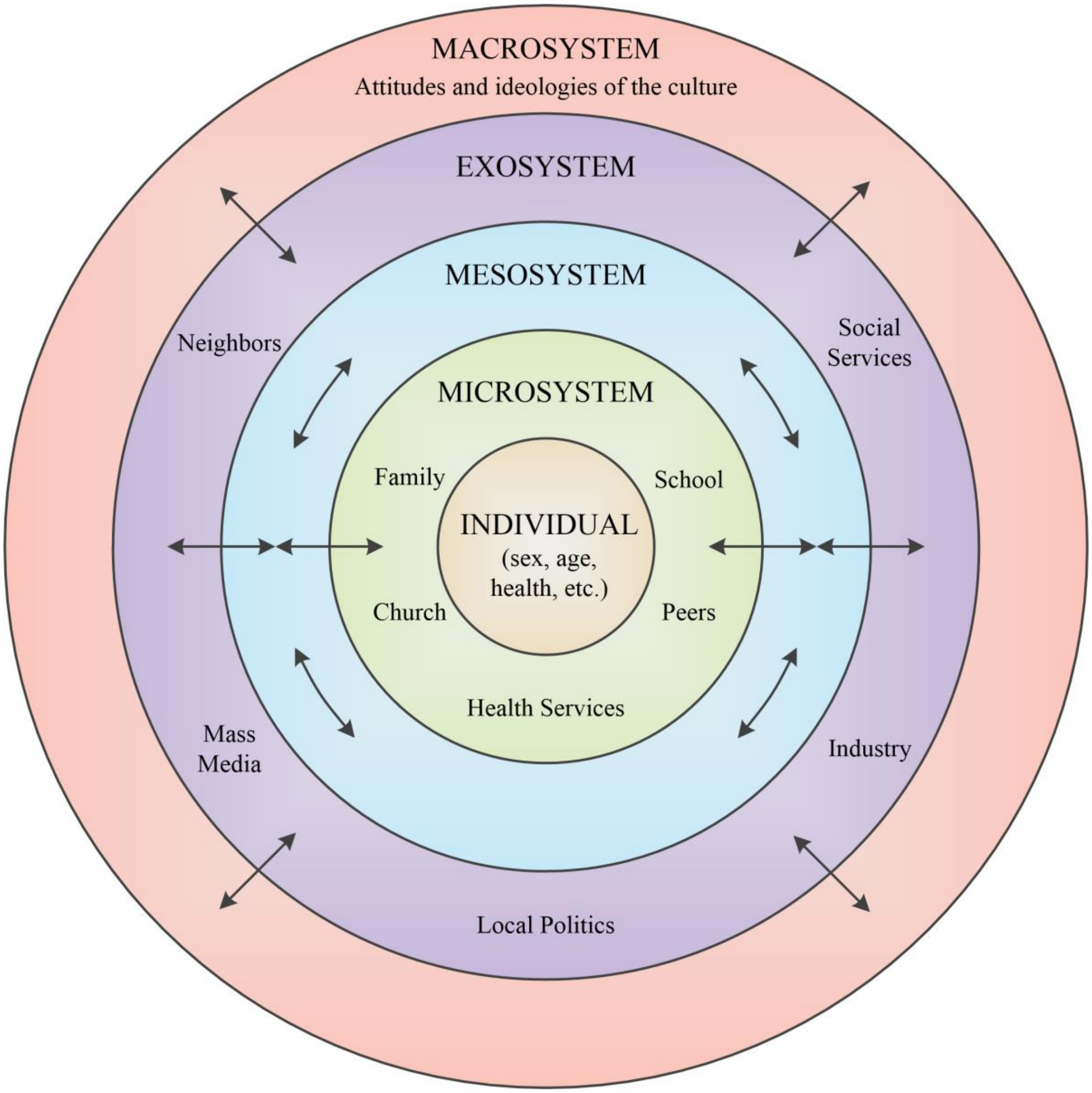

Figure 17. Bronfenbrenner’s Bioecological Model (figure derived fromMcLaren & Hawe, 2005).

Microsystem

Bronfenbrenner (1994) defined a microsystem as “a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical, social, and symbolic features that invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in, the immediate environment" (p. 1645). Microsystems contain the most influential interactions that directly impact the individual. Consequently, to fully understand the concept of the microsystem, each component of its definition needs to be explored in depth. Each segment of this definition will be explained subsequently.

The first part of this definition that needs attention is the concept that a microsystem is "a pattern of activities, roles, and interpersonal relations." Activities and interpersonal relations were initially introduced to this definition of a microsystem because of original concepts Bronfenbrenner used from Lewin that there were two critical features in immediate situations: *activity* and *the existence of connections between people in the setting* (Bronfenbrenner, 2005). Specifically, an activity is defined as "an ongoing process characterized by intention and possessing a momentum of its own…a dominant feature of an activity is the perception of a goal and movement toward the goal" (Bronfenbrenner, 2005, p. 45). Interconnections between people are viewed "in terms not so much of interpersonal feelings as of the relations of the various parties toward each other as members of a group engaged in common, complementary, or relatively independent tasks" (Bronfenbrenner, 2005, pp. 45-46). These interconnections can be specific relations, or social roles, such as mother, teacher, friend, etc.; but they can also include any type of interpersonal relationship or interconnection. For example, Bronfenbrenner noted that every member within a microsystem influences every other member, but also added that relationships can influence other relationships (e.g., the influence of the wife-husband relationship on the parent-child relationship).

The next piece of this definition to examine is that these patterns of activities, roles, or interpersonal relations are “experienced by the developing person.” An important piece of a microsystem is that it always includes the individual. According to Bronfenbrenner, the individual is seen as an active agent that plays some part in the process. He admitted that he did not put particular emphasis on this aspect in his earlier writings, but acknowledged that it was a fault and encouraged further examination of the individual’s impact on systems. While the systems that surround the individual play an active role in the individual’s development, the individual has an impact on the systems as well. In other words, the relationship between the individual and surrounding systems is bidirectional. Consequentially, Bronfenbrenner stated that proper modeling of a microsystem would include assessment of the individual’s “cognitive competence, socioemotional attributes, and context-relevant belief systems…with particular emphasis on those qualities that meet criteria for being characterized as developmentally instigative” (Bronfenbrenner, 2005, p. 160). Furthermore, these characteristics are not only relevant to the individual at the center of the systemic levels, but the other people with whom the person interacts.

The next portion of the definition that should be explored is that the microsystem involves “a given face-to-face setting with particular physical, social, and symbolic features.” That is to say, the interactions that occur at the microsystem level involve proximal, or firsthand, exchanges. These can include person-to-person relationships as well as the individual’s dealings with “the world of symbols and language” (the semiotic system, Bronfenbrenner, 2005, p. xvii).

In addition, these elements of a microsystem “invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in, the immediate environment.” In other words, these mechanisms can help facilitate or be barriers to interaction. Additionally, the interactions should be sustained and become more complex to be part of the person’s development. Finally, they should be in the “immediate environment” because microsystems involve direct (as opposed to indirect) interactions.

Summary of Microsystem Themes

There were a number of themes found related to various microsystems. Most notable were elements related to the family system. Mothers described the impact of the family as it related to family structure, spouse interactions, sibling interactions (sibling with sibling or mother with sibling), mother-child interactions, the impact of autism on family interactions, barriers within the family microsystem, and interactions with extended family. There were also microsystem interactions regarding the child’s school, which the mothers appraised as either helpful, not helpful, or negative. The peer microsystem was discussed in relation to both the child’s peers as well as the mother’s peers. Specifically, mothers noticed child-peer interactions and compared the child to the child’s peers while also having their own positive or negative peer interactions that included comparing themselves against other mothers. Church was also another level of support that could be positive or negative which included spiritual beliefs about support from God. Last but certainly not least, MCDAs described numerous interactions with health service microsystems which led them to have positive and negative appraisals of treatments and professionals. This included many barriers they encountered with receiving services.

Mesosystem

A mesosystem "comprises the linkages and processes taking place between two or more settings containing the developing person" (Bronfenbrenner, 1994, p. 1646). In other words, a mesosystem is an interaction between one or more microsystems. Although Bronfenbrenner describes the various systemic levels as nested, as represented in Figure 17, they can also be represented as networked (See Figure 18; Neal & Neal, 2013). This is because the Bioecological Model describes each system in the framework of interactions.

There were a few different *mesosystem interactions* that MCDAs brought up when talking through their experiences. Specifically, mothers described various interactions between different microsystems (e.g., family with school, family with health services, one service with another service, etc.) Oftentimes, due to negative interactions and barriers, MCDAs frequently needed to advocate for their children and sometimes entered into new microsystems to do so (e.g., legal services).

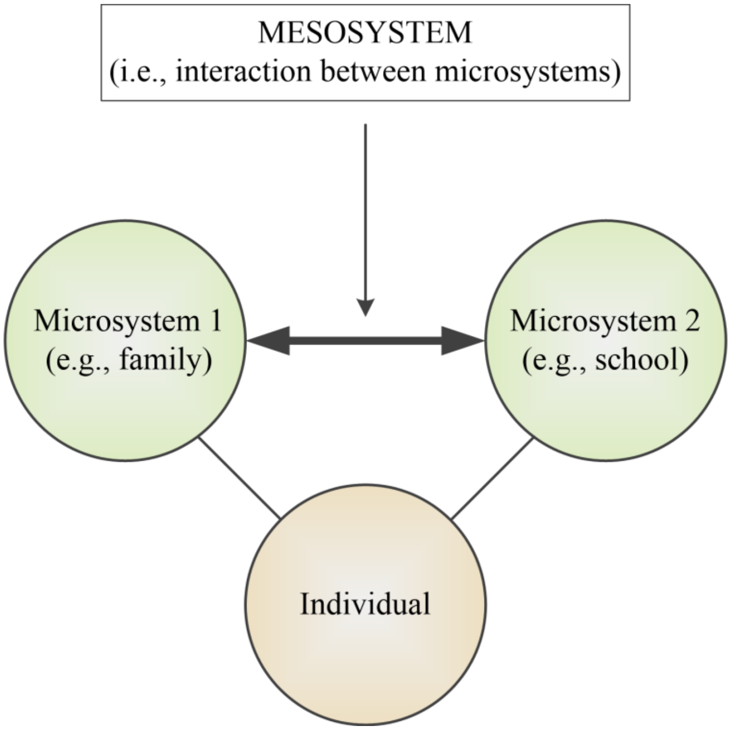

Figure 18. Representation of a mesosystem as networked.

Exosystem

Bronfenbrenner (1994) defined an exosystem as “the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes within the immediate setting” (p. 1646). In other words, exosystems are indirect interactions (See Figure 19). It should also be noted that the type of system depends on the reference point. For example, if the mother works, her workplace is an exosystem for the child because the child is not part of that system yet that system affects the child; however, it is a microsystem for the mother because she is directly involved in that system.

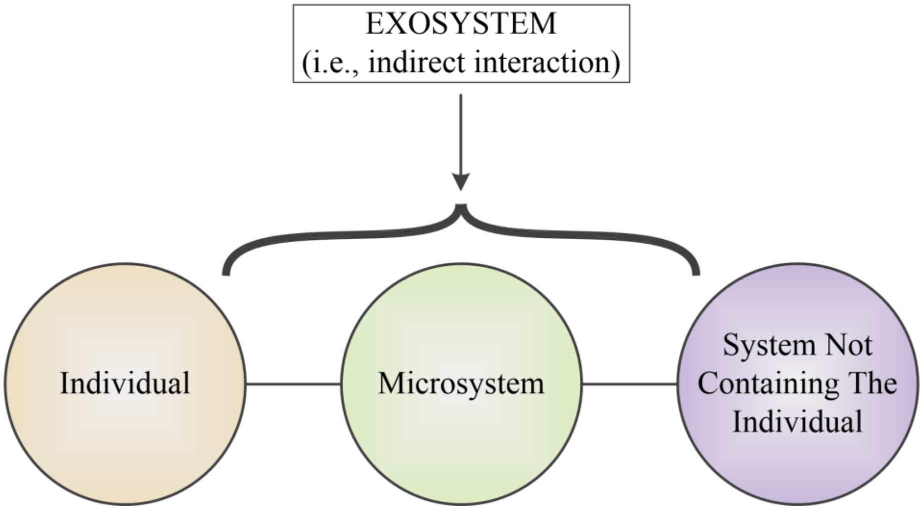

Figure 19. Representation of an exosystem as networked.

There were a few exosystems interactions that affected the processes of most MCDAs trying to help their children. Specifically, mothers described certain difficulties they encountered, such as insurance or school districts restricting what they could receive for health services or school accommodations, respectively. Furthermore, policies and changes at an agency, district, or even state level had indirect influences on what occurred within various microsystems.

Macrosystem

A macrosystem "consists of the overarching pattern of micro-, meso-, and exosystems characteristic of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunity structures, hazards, and life course options that are embedded in each of these broader systems. The macrosystem may be thought of as a societal blueprint for a particular culture or subculture" (Bronfenbrenner, 1994, p. 1646). The key concept of the macrosystem is that it represents cultural influences that impact the other systems. The mothers in this study described a few different macrosystem interactions, such as being located where western medicine is the prevailing approach, experiencing various levels of discrimination, and being part of an autism subculture. A special interpretive note needs to be expanded upon with regards to some MCDAs' cultural identity within the autism subculture.

MCDAs' Cultural Identity

For MCDAs of higher functioning children, it appeared as if they sometimes felt like they were "outcasts." The researchers likened the experiences they described to the cultural conflict and marginalization that sometimes occurs in individuals with a bicultural or multicultural identity (Benet-Martínez & Haritatos, 2005). In other words, these mothers did not feel accepted by mothers of typically developing children because their children were different, yet they also did not feel accepted by other MCDAs because their children were not severe enough and sometimes other MCDAs discounted that their children even had autism.

Integration of Person and Context

Due to the findings supporting elements representing domains within the person as well as systemic components, the research team believed that it would be important to find a way to show an integrated model to better represent what was found in the QUAL results. Using the Self-Regulation Model depicted in Figure 1 and Bronfenbrenner's Bioecological Model as depicted in Figure 17, a new 3-dimensional rendering was created to show the integration of the two. This integrated model is represented in Figure 20. This integrated model shows the self-regulation process in the center of the individual and how it occurs within the context of the various systemic levels. Furthermore, it should be noted that the first few domains of self-regulation in this integrated model are positioned such that they align roughly with how they interact with the various systemic levels. For instance, the perceptual processing system is centered on the individual and is represented as mesh to symbolize how information is filtered through an MCDA’s perception. Furthermore, the cognitive and emotional representations are more aligned with the individual, but are somewhat related to the microsystems (e.g., mother-child dyad, various support systems). Furthermore, the cognitive and emotional coping responses are elongated along the micro-, meso-, and exosystem levels because MCDAs’ responses occur within the context of interactions with others.

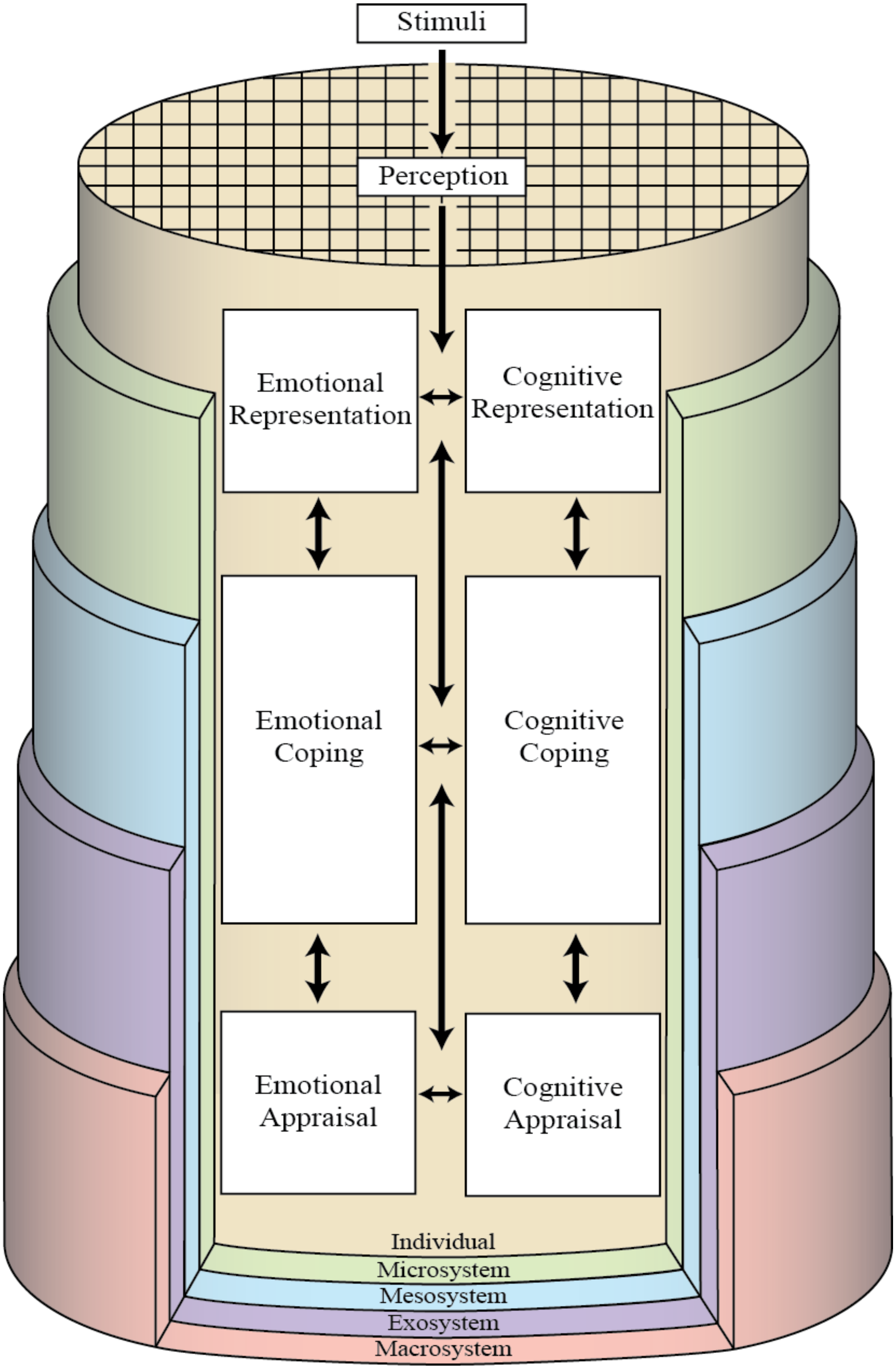

Figure 20. Integrated model.

Time

Bronfenbrenner acknowledged that another defining property that should be included in his model is the dimension of *time*. While it is intuitive that processes occur over time, it should be noted that there are also different levels of time that apply to the life course (Bronfenbrenner, 2005; Elder & Shanahan, 2006). Two specific levels that MCDAs referred to when describing their experiences were regarding the mother's personal timeline (i.e., "ontogenetic time" or "life time"/ "lifetime") and time within historical context (i.e., "historical time"). Specific elements related to the mother's life time include her age, her learning and growing over time, and the process getting easier over time. With respect to historical time, sometime mothers talked about the transition from the DSM-IV-TR to the DSM-5, the shift to insurances now being required to pay for autism treatments, and the process being different now than it used to be.

Process

To reiterate, the processes that emerged from the data were *noticing a difference*; *getting an evaluation*; *feeling grief, stress, and/or relief*; *gathering information*; *searching for treatment*; *fighting or being persistent*; and an experience that mothers described as *"This is the new normal"* (See Figure 21). The components relevant to each stage will be summarized in this section. Elements related to the person and context will also be delineated for each step to show their relationship within the processes. Additional sections will follow that describe how some processes may be re-experienced, process steps may occur in alternative orders, and the personal journeys of MCDAs are experientially unique.

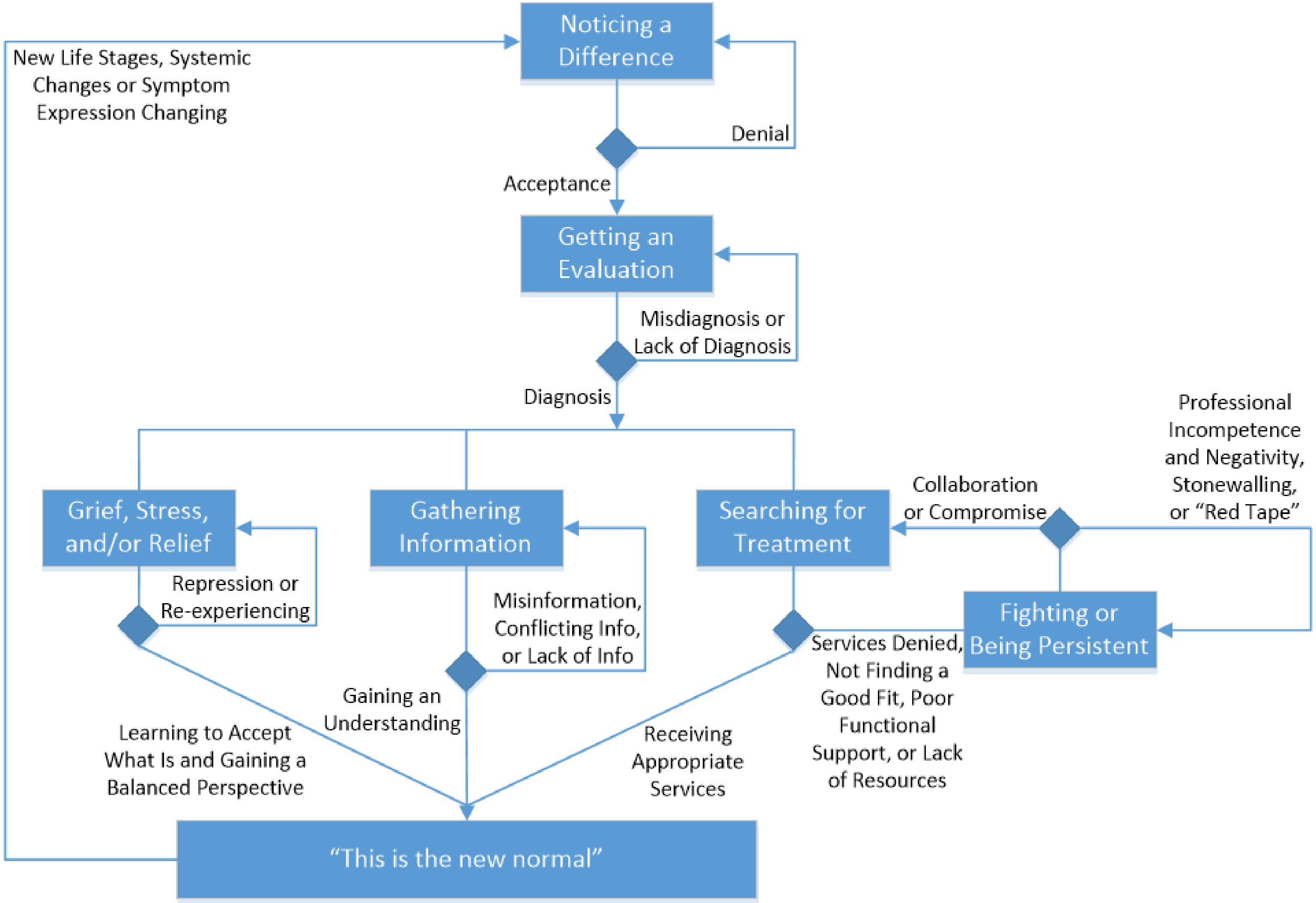

Figure 21. Flowchart of the processes described by MCDAs.

Noticing a Difference

As discussed in the QUAL results section, MCDAs start their journey by noticing a difference. This could either be by the mother seeing certain symptoms or others pointing out differences. Mothers tended to get stuck at this point if they were in denial, but continued on once they accepted that something was different about the child.

Person and Context Elements in Noticing a Difference

There were several elements related to both the person and the context that were part of this stage. Regarding the person, identity beliefs were a large part of what contributed to this stage. In other words, MCDAs' beliefs about autism, associated symptoms, and behaviors were key in whether they chose to accept or deny any differences they saw. Additionally, a number of microsystem interactions helped support or deny the existence of symptoms such as interactions with the family, the mother's peers, school staff, or health providers. These microsystems could also initiate the process if they pointed out differences they noticed, which helped set the process in motion.

Getting an Evaluation

The next step in the mothers' journeys was getting an evaluation. This could be done either through the school or by health professionals. Barriers at this stage included misdiagnosis or having a lack of diagnosis. What helped mothers continue on was receiving the diagnosis.

Person and Context Elements in Getting an Evaluation

In the stage of getting an evaluation, there are cognitive elements active in the person and different systemic levels interacting. For the person, getting an evaluation is something that is done as part of the cognitive coping procedures. Additionally, the mother uses cognitive appraisals to determine if she thinks the evaluation is accurate. Microsystems that are part of this process can be either health services, schools, or both. Furthermore, mesosystem interactions between health services and schools were, on one hand, detrimental if they did not collaborate or agree, or, on the other hand, helpful if they created a unified team.

The next stage included a few processes that occurred simultaneously. These processes could be seen as corresponding to emotions, beliefs, and behavior.

Feeling Grief, Stress, and/or Relief

The emotional process that stemmed from getting a diagnosis most often involved grief and stress; although, some mothers reported feeling relief. Mothers tended to get stuck in a negative emotional state when they repressed how they felt and just "dealt with it." Mothers were better able to address this emotional process if they came to have a balanced perspective of the child's capabilities and limitations as well as a balance between focusing on the child and focusing on self. However, it was also noted that negative emotions could be re-experienced as new challenges arose.

When interpreting the data, the research team noticed that many of the emotional responses map onto the stages of *grief* outlined by well-known psychiatrist Kübler-Ross: denial, anger, bargaining, depression, and acceptance (Penzo & Harvey, 2008). Not only do mothers experience denial when first noticing a difference, but they sometimes experience *denial* once receiving the diagnosis as well. Some mothers also noted that they felt significant *anger* after receiving the diagnosis. Bargaining was reported in the sense of the mothers trying everything they could to seek professional help for their children's problems. Other bargaining responses were stated, but less frequently so (e.g., wishing she could run away); however, the focus group members indicated that sometimes they had thoughts that they just did not say out loud because of how "bad" they sounded. Consequently, these types of bargaining responses may be more prevalent than were reported by the mothers in this study. *Depression* was also a common experience in MCDAs; sometimes even to the extent of suicidal ideation. However, MCDAs frequently did report coming to a place of *acceptance*.

Person and Context Elements in Feeling Grief, Stress, and/or Relief

The most evident domain related to the stage of grief, stress, and/or relief is the domain of emotions. However, how the mother responded to those emotions, or in other words her emotional coping strategy, was also part of this process. Moreover, these emotions interacted with many different types of beliefs. For example, negative beliefs about the timeline, consequences, cause, treatment control, or personal control could all contribute to fostering negative emotions.

In addition to the person, there are also influences from people in essentially all microsystems that could impact how the mother feels. For example, the mother's significant other, her friends, the church group, health providers (child's or mother's), and child's school staff all play a role in providing either positive or negative support.

Gathering Information

Almost all MCDAs talked about trying to gather information once receiving a diagnosis. Sometimes this process was very confusing, and a lot of the information that was given to them caused them to have negative expectations. In addition, there was frequently a lack of information given by providers to help them get through this process. To continue on in this cognitive process, MCDAs described gaining a personal understanding of the disorder and of how to help their children.

Person and Context Elements in Gathering Information

There are components relevant to the individual, microsystem, and mesosystem levels active within the process of gathering information. With respect to the person, all cognitive domains are pertinent. First, gathering information was a key step in cognitive coping procedures. Additionally, the mother made decisions about what she wanted to believe, or in other words, engaged in cognitive appraisals. These components fed back into all types of beliefs.

There are different ways that systems interacted within this stage that had either a positive or negative influence. For example, health providers have a positive impact if they proactively explain things and a negative impact if they do not provide information. Mothers who were given information without having to ask for it seemed to have fewer problems. The mother’s peers telling her information was also either helpful or unhelpful depending on if the information was correct and supportive or not. Family also had an impact because they sometimes gathered information as well and shared it with the mother. Mesosystem interactions were important when gathering information because they added to confusion if one system (e.g., school) said one thing and another system (e.g., health services) said something else. On the other hand, if those systems were all on the same page, it helped facilitate the process.

Searching for Treatment

In order to help their children, MCDAs also needed to try to find treatments for their children after receiving a diagnosis; although sometimes they were given treatments without needing to seek them out. They often tried multiple treatments and alternative approaches and would often decide to change treatments for various reasons. Receiving appropriate services helped the mothers move forward in their journeys, but the majority of mothers encountered a number of barriers and were frequently denied services that they wanted. MCDAs often had poor functional support during this process and wished they had better treatments for their children. Due to these difficulties they encountered, they frequently engaged in a process that they felt should not have been needed: fighting or being persistent.

Fighting or Being Persistent

MCDAs reported numerous negative interactions with professionals, which led them to need to fight or be persistent to get what they wanted. This included not only advocating for their children themselves, but sometimes seeking outside help with legal services or advocates. As part of what kept the fighting process cycling, MCDAs appraised many professionals as unhelpful or incompetent and had barriers put in their way that caused delays in treatment. What helped MCDAs get back on path to receiving appropriate services was when there was collaboration with the professionals.

Person and Context Elements in Searching for Treatment

There are a few different elements of the person that interact during the process of searching for treatment. First of all, searching for treatment is a cognitive coping procedure. If a fighting cycle is activated, this can also trigger many different emotions as well, such as anger. There can also be either cognitive or emotional appraisals as a result. One example of a cognitive appraisal at this stage is whether the mother thinks the treatment is going to be effective for her child. An example of an emotional appraisal could be how well she feels like she handled a fighting process. Specifically, some mothers reported not liking who they became when fighting for their children’s services.

There are a few systems relevant to the search for treatments as well. Most evident are the school and health service systems since they are the ones providing help most often. Specifically, the providers in these systems provided functional supports, such as the services themselves, academic supports, financial assistance, resources, referrals, etc. However, more often MCDAs described having poor functional support from school and health providers. For example, the services provided by insurance could be inadequate, the choices were limited, there was inconsistency between service providers, there was poor contact by professionals, the school frequently had too much demand for the resources they had, sometimes even the advocates that provided were perceived as not being on the mother’s side, etc. The family could also be involved in treatments or provide other types of functional support (e.g., help taking care of the child). Additionally, the mother's peers could inform her of what services she should be getting. They could also tell her about other treatments of which she may not have been aware.

"This Is the New Normal"

If an MCDA has come to some sort of acceptance, gained a personal understanding, and received appropriate services, there is a stage that many mothers described as "this is the new normal." Although they may not have everything working perfectly, there is a sense of having a lifestyle that works for them where they are able to handle everyday challenges. This does not mean, though, that MCDAs who reach this stage are completely at peace or that they never re-experience any of the other processes again.

Person and Context Elements in "This is the New Normal"

Most elements of the person contribute to the stages where "this is the new normal." For example, an MCDAs' beliefs and emotions play a significant role in whether she can accept a new way of living. Her cognitive and emotional coping methods impact how well she is able to handle everyday challenges. Most significantly, deciding that "this is the new normal" is in and of itself an appraisal of how things are. All systemic levels also impact how easily a mother can come to this stage because they can all be either obstructive or supportive.

Re-Experiencing

Even if a mother is able to move through all the processes and come to the experience of “this is the new normal,” there are things that may cause her to go through some of the processes again. For example, if a mother noticed that the child’s *symptom expression changed* over time, this fed back to the concept of noticing a difference. Similarly, over the life course of the child, there are different life stages (e.g., childhood, adolescence, adulthood) where new challenges become more salient. For example, for adolescents that are moving into adulthood, transitional services become a need. MCDAs who were at this point with their children described new emotions coming up (e.g., feeling “terrified”) and searching for different services that would help at this life stage. Similar transitions were noted by mothers with starting school, going from elementary to middle school, and middle school to high school. The re-experiencing can also occur when other changes occur (e.g., changing schools, switching treatment providers, etc.)

However, it should be noted that MCDAs often indicated that the *process gets easier over time*. This was largely because they were more familiar with the steps that they needed to go through. Additionally, they did not always need to repeat all the steps in the process. For example, they may not have always needed to get another evaluation. However, sometimes they did because some providers only accepted evaluations from certain places (e.g., medical providers did not accept school evaluations much of the time).

Alternative Ordering

While the flow of processes has been presented as one step leading to another, this is a generalization based on a common progression of events. However, some of the steps occurred at different points in the process for different mothers. For example, sometimes mothers described that they experienced more stress or emotions related to grief prior to getting the diagnosis. Additionally, many mothers started gathering information as soon as they noticed a difference because they were trying to figure out what the problem was. Moreover, the extra step of fighting or being persistent was sometimes connected to other stages as well, such as getting the evaluation.

Experiential Journey

An extremely important point that was emphasized by the focus group when providing feedback on the process results was that while these steps represent common experiences for MCDAs, they do not accurately portray what it is like to actually go through the experience. In other words, while the steps do illustrate shared experiences that MCDAs go through, each journey is unique and can never fully be understood by anyone but the person going through it.

Limitations of the Qualitative Strand

There were a few limitations that should be discussed regarding the QUAL strand of this study. First, although there was a research team, there were only three core team members. This limited the number of perspectives that were involved in interpretation. As discussed in the introduction to this study, from a social constructionist standpoint, the researcher-data relationship is inseparable from the interpretive process. Consequently, there may be other theories or alternative explanations that were not included in the current study because they were not how the research team related with the data. However, it should also be noted that having too many perspectives could have created a lack of clarity in coming to consensus. Similarly, another limitation was that there were only four focus group members in the member check stage, instead of the desired six to ten, which limited the amount of perspectives on the feedback provided to the researchers.

Another possible limitation for the current study is that there was a lot of data to interpret within the mothers’ stories. As a result, there were many different themes and the interpretive focus was on connecting the themes to theory. Consequently, it is possible that the explanations for each individual theme may not have been expanded as much as would have been done in other qualitative interpretive approaches (e.g., phenomenological or narrative).

Future Directions

There are a number of research and clinical directions that could follow from the results of the QUAL strand of this study. These directions would be most impactful when considering the recommendations MCDAs had for professionals.

Recommendations for Professionals

Included in the interview, mothers were asked what professionals could do to help them through the process of understanding and helping their children. This is because just knowing the process is ineffectual unless something can be done to help MCDAs through it. Mothers had a plethora of recommendations for professionals, including what not to do as well as what to do.

To begin with, there were some suggestions from MCDAs of what not to do. One of these suggestions had to do with the approach to intervention, which was to not just push medicine. However, most of the suggestions of what not to do were relational in nature. Specifically, MCDAs indicated that professionals should *not* be nonchalant or overly blunt when giving the diagnosis, not send the mother home to deal with the diagnosis by herself, not be antagonistic, not rush the mother, not have a negative perspective, not give “dim-and-grim” expectations/make if feel hopeless, not give false hope, and not have a harsh tone. More of the suggestions mothers had, though, were of what to do.

Some of the recommendations of what to do involve providing information. Specifically, mothers suggested that professionals should provide information about the diagnosis when it is given, explain the assessment decision, explain all treatment options, be available to answer questions, provide education, explain things “in layman’s terms, and not doctor terms,” guide parents where to look if they want to do some research, and talk about what insurance covers at the time of diagnosis. They also suggested for professionals to be more educated regarding autism (e.g., be familiar with associated features), know what is available in their area, recognize the mental health needs of MCDAs, have knowledgeable staff in charge, and be comfortable expressing concerns. MCDAs thought that things that would help with providing information included having things like a resource fair, pamphlets, a resource list with descriptions (i.e., a directory), or a handbook/kit. One mother indicated, “What to expect when you’re expecting, there needs to be a book like that for autism.”

Other recommendations are regarding collaboration such as including everyone in the evaluation process, co-create plans, providing guidance, following up/checking in, interviewing the parent to get an idea about them and developing a plan, working together in treatment, inviting the mother to participate in the treatment, addressing the whole family system (e.g., the parents and siblings rather than just the child diagnosed with autism), actively seeing if there are any questions, and asking about what the mother’s fears are. Elements that mothers indicated would help with this relationship were having open communication, listening, taking time with the mothers, and learning from the mothers. One mother stated, “You can’t discount a parent’s experience on a day to day basis…the parent knows just as much, if not more.”

In order to have a good partnership, professionals also need to know how to have a collaborative attitude. For example, some MCDAs suggested that professionals should humble themselves, put themselves in the mother’s shoes, and train in how to deal with angry/emotional mothers (e.g., take a class on sensitivity). One mother noted, “I think it’s really working with them [professionals] to overcome, um, their negative, whatever they call it now. Their negative countertransference or whatever…Or their negative responses to the parents. And it’s going to be negative. I mean, you’re dealing with people who are in the middle of the worst part of their lives.” Relational actions that were thought to help with this alliance were to connect on an emotional level, be able to separate the behaviors from the child, be open, have empathy and understanding, show compassion, provide emotional support, show (and not just say) that they understand/care, say something nice or uplifting, or even possibly give a hug.

Additional recommendations MCDAs had related to things that they thought should be offered like referrals, service recommendations, preventative services, resources, and classes. They also had suggestions for different things that could help with establishing support such as offering support groups, having more support for siblings, creating a support network, hosting an autism hotline that parents can call when they are having a hard moment, providing a list of organizations that can help mother connect with other parents, or even post a bulletin board.

In addition to things that could be offered, there were also suggestions for what should be part of standard practices. For example, MCDAs suggested professionals should create a standard approach to assessment, provide earlier screening, have a comprehensive protocol, refer for all possible associated symptoms (i.e., preventative assessment rather than only assessing the problems that are evident), set up appointments immediately (instead of sending mother away to do it on her own), have an office environment that is friendly/comfortable for the children, and have services spread to more areas/make them accessible. They also believed that there should be certain personnel that professionals connect mothers with immediately such as a care coordinator, a case manager, a grief counselor, specialists, or an MCDA mentor.

Some mothers also thought that professionals should do things to address parents' efficacy as well. For example, some mothers believed that professionals should hold the parents accountable, test the parents' knowledge, or visit the home to see what environmental changes need to be made. They also suggested proactive actions to help the parents such as having a screener or standardized questionnaire for the parents' issues, encouraging parents to get their own therapy, or having mothers be in a service at the same time as the child rather than just sitting in the waiting room.

Finally, some mothers had suggestions that go above and beyond the family to other systems as well. For example, it was suggested that professionals should find common ground between school and medical systems. Additionally, they believed that professionals need to become advocates such as by standing up for mothers who have a disparity in services.

Research Directions

Regarding future research directions, participant action research would be extremely valuable. At just described, many mothers noted how they would have found it helpful when going through their processes to have had a handbook or guide. As a result, researchers could work with mothers to create the guide and then conduct surveys on how well it increased mothers' knowledge or how effective it was in helping new mothers navigate the process. This involvement of participants in research could be used for small informational pamphlets as well.

Clinical Directions

There are also numerous clinical applications that could proceed from the feedback MCDAs gave. What immediately stood out to the primary student researcher was that a "Wraparound" process should be more widely used for families of children diagnosed with autism. The Wraparound process "refers to a family-determined, individualized, team-based care and planning and coordination process" (Miles, Brown, & The National Wraparound Initiative Implementation Work Group, 2011). Most often, this Wraparound approach has been used for children with emotional and behavioral disabilities and those in foster care; although, there have been some programs developed for children diagnosed with developmental disabilities that have shown some initial success (EMQ FamiliesFirst, 2012; Los Angeles County Department of Children and Family Services, 2009). The Wraparound process has ten principles that considerably overlap with MCDAs' recommendations: 1) family voice and choice, 2) team based, 3) natural supports, 4) collaboration, 5) community-based, 6) culturally competent, 7) individualized, 8) strengths based, 9) persistence, and 10) outcome based (Bruns, Walker, Adams, VanDenBerg, & National Wraparound Initiative Advisory Group, 2004). Although Wraparound has traditionally been used for the purposes of returning or maintaining children in a home placement, this process would be helpful if implemented with MCDAs with respect to finding and implementing services.

Related to service provision, other clinical applications of the feedback given by mothers would be to implement certain practices with the professionals with whom they interact. For example, it may be necessary to develop programs for sensitivity of school and health professionals as a proactive step to have less negative and more positive interactions occur. On the oppose end, systems should be put in place for MCDAs to be able to regularly evaluate the professionals so that the professionals can alter their interactions to best meet the needs of the families. This is particularly important, since receiving frequent feedback helps professionals build alliance with their clients and leads to better outcomes (Shaw & Murray, 2014).

Conclusion of the Qualitative Results

MCDAs described complex journeys of trying to understand and help their children that involved many interacting components. These components included interconnected internal domains that were commensurate with the Self-Regulation Model (i.e., the person) as well as a systemic network consistent with Bronfenbrenner's Bioecological Model (i.e., the context). Furthermore, the person and context components worked together within a series of shared processes that MCDAs experienced leading to a "new normal." Even with these shared processes, though, each mothers' journey was and is uniquely experiential and unequivocally personal.

Concluding Thoughts

To conclude this MM study, it is important to determine whether a meta-inference can be made to unite the QUANT and QUAL strands. Although the strands of this study were done in parallel, as noted in the introduction, it was explored whether adding different loci of control to the Self-Regulation Model (the QUANT strand) added further information to the overall process (the QUAL strand). Although not all interactions tested in the QUANT strand were significant, different loci of control were supported in MCDAs' survey responses, and sometimes external loci were higher than the mother's personal LOC. These different loci were also evident in QUAL strand, as various external systems emerged as important elements in MCDAs' stories. Therefore, a meta-inference for both strands is that both internal and external elements are important in mother's beliefs and processes.

Another important conclusion for this study is that interaction is central to both the QUANT and QUAL strands. Specifically, the QUANT results showed that sometimes specific beliefs about controllability interact and the QUAL results showed that interactions between the person and context were crucial to MCDAs' processes. In other words, interactions occurred both internally and systemically.

There is one final conclusion that needs to be emphasized as a crucial note from the feedback given by mothers about the findings from this study. Just as MCDAs' understanding of autism is more than just adding up a variety of behaviors, so too are mothers' experiences more than just moving from one process to the next. It is possible that other qualitative methods (e.g., narrative or phenomenological) would capture these experiences more directly by staying true to reporting the lived experiences of each mother as opposed to finding commonalities of process. An important concluding point, though, is that for both beliefs and experiences, "The whole is other than the sum of its parts."

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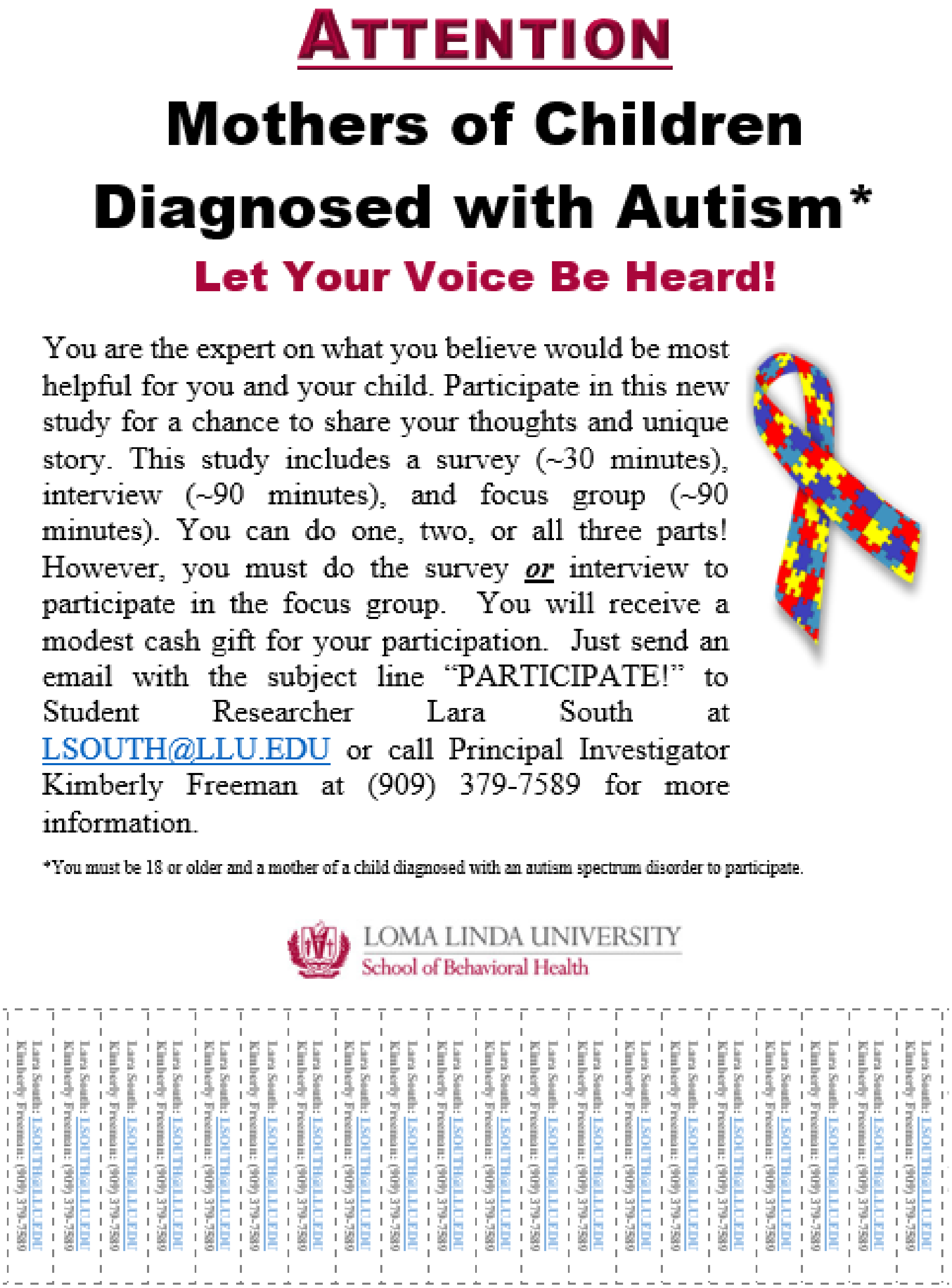
APPENDIX A

RECRUITMENT FLYER



ATTENTION

Mothers of Children Diagnosed with Autism*

Let Your Voice Be Heard!

You are the expert on what you believe would be most helpful for you and your child. Participate in this new study for a chance to share your thoughts and unique story. This study includes a survey (~30 minutes), interview (~90 minutes), and focus group (~90 minutes). You can do one, two, or all three parts! However, you must do the survey ***or*** interview to participate in the focus group. You will receive a modest cash gift for your participation. Just send an email with the subject line "PARTICIPATE!" to Student Researcher Lara South at LSOUTH@LLU.EDU or call Principal Investigator Kimberly Freeman at (909) 379-7589 for more information.

*You must be 18 or older and a mother of a child diagnosed with an autism spectrum disorder to participate.

LOMA LINDA UNIVERSITY
School of Behavioral Health

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Kimberly Freeman: (909) 379-7589

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APPENDIX B

RECRUITMENT EMAIL SCRIPT

Dear Mother of a Child Diagnosed with an Autism Spectrum Disorder,

Thank you for your interest in autism research! We at Loma Linda University are extremely interested to hear your input. There are three parts to this study and your participation in any part is completely up to you. First, Student Researcher Lara South and the research team for this study would like to invite you to take a survey. In the survey, you will answer some demographic questions and some questions about your beliefs and personal experiences with autism. This will take approximately 30 minutes. We also welcome you to participate in a one-on-one interview at a location convenient for you. In the interview, you will be asked questions about your own autism story. You will also be asked about ways you think professionals could help you better. The interview will last approximately 90 minutes. It may take a shorter or longer time depending on your answers. To make sure your responses are written down accurately, you will be audio- or video-recorded. We will never use your information without your permission. After the survey or interview, you will have the option to return for a focus group. The focus group will talk about the results of the study and ask for your input along with five to nine other mothers in the group. It will last approximately 90 minutes.

You may participate in one, two, or all three parts of this study. You can do the survey and interview by themselves or with other parts, but you must do either the survey *or* interview to do the focus group. You will receive $10 for each part you complete. If you would like to be a participant in this study, please reply to this email to schedule a meeting. Please, include your best available days and times. Again, thank you so much for your interest in this study. We look forward to seeing you!

Sincerely,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate
Loma Linda University
School of Behavioral Health
Department of Psychology

APPENDIX C

RECRUITMENT PRESENTATION SCRIPT

Hi, my name is (name) and I am a student researcher in the School of Behavioral Health at Loma Linda University. A research team is doing a study on the beliefs and experiences of mothers who have children with an autism spectrum disorder. We truly believe that you are the experts and that the people who are considered professionals need to hear your voices. There are three parts to the study: a survey that will take about 30 minutes, an interview that will take about 90 minutes, and a focus group that will take about 90 minutes. You may do one, two, or all three parts. You can choose to do the survey or interview by themselves, but you must do the survey or interview to do the focus group. Participation is completely voluntary and you can stop at any time. You will receive $10 for each part of the study you complete for a total of up to $30. If are interested, please come up to see me to ask any questions or to sign up. Thanks!

APPENDIX D

INFORMED CONSENT FORM

LOMA LINDA UNIVERSITY

School of Behavioral Health

INFORMED CONSENT

TITLE: The Process of Self-Regulation in Mothers of Children on the Autism Spectrum
SPONSOR: Department of Psychology
PRINCIPAL INVESTIGATOR: Kimberly Freeman, MSW, Ph.D.

Purpose

You are being invited to participate in this study because you are a mother who is 18 years or older and has a child diagnosed with an autism spectrum disorder who is under the age of 18. The purpose of this study is to explore the processes and experiences that mothers of children diagnosed with autism spectrum disorders go through when trying to help their children. Specifically, we want to know how you came to understand autism, how your emotions have changed over time, the process you went through trying to find treatments, and what you think health professionals can do better. The rationale for this study is to expand on the results of previous research that looked at the beliefs mothers had about the stability and improvement of their children's autism spectrum disorder and specific behaviors.

Procedures

You have a unique perspective on autism and your child. This study includes three parts: a survey, a one-on-one interview, and a focus group. You may choose to participate in one, two, or all three parts. However, to take part in the focus group, you must complete either the survey or the interview or both. In addition, you must consent to audio- or video-recording to participate in the interview or focus group. The survey and interview may take place on the same day or on different days, depending on your preference. The location of the study session(s) will also be based on what is most convenient for you (such as the Loma Linda University [LLU] Psychology Department, LLU Social Work & Social Ecology Department, the LLU Behavioral Health Institute [BHI], your home, or your work). It is recommended that the child ***not*** be present for the study sessions, but the child will be allowed if no other childcare arrangements can be made. Childcare will *not* be provided by the research team. There is no cost to you for participating in this study. Your answers for any part of this study will be used for research within the School of Behavioral Health at LLU. The minimum number of mothers that will participate in this study is 50 and the maximum is 100. They will be recruited from various treatment facilities, online communities, and organizations where mothers may have limited access to resources (e.g., homeless shelters). If you would like to see a list of these sites, please ask the researcher.

- **Survey:** If you decide to participate in the survey, you will respond to questions either on a computer or using a paper and black pen. The survey will be given to you by a student researcher from the School of Behavioral Health at LLU. If you need assistance, please let him/her know, and he/she will make any accommodations needed. You may also ask questions if you are unsure how to answer a question or need clarification. You may take the survey by itself or with the interview and/or focus group. However, to do the focus group, you must do either the survey *or* interview. The survey is estimated to take about 30 minutes. Approximately 50 total participants will complete the survey portion of this study.

- **Interview:** If you decide to participate in the one-on-one interview, a student researcher will ask you questions directly and you may answer with as much information as you feel comfortable providing. The interview will be audio- or video-recorded for research purposes only. You may do the interview by itself or with the survey and/or focus group. However, to do the focus group, you must do either the survey *or* interview. It is estimated to last about 90 minutes, but the time may vary depending on your responses. Approximately 20 participants will take part in the interview portion of this study.

- **Focus Group:** If you do the survey and/or the interview, you will have the option to take part in a focus group discussion with five to nine other mothers of children diagnosed with autism spectrum disorders. You cannot do the focus group if you have not done either the survey or interview. This group will be guided by a student researcher from the School of Behavioral Health at LLU's BHI. The student researcher will start the focus group by making sure everyone is comfortable and answering any questions you may have. The focus group is estimated to last approximately 90 minutes, but the time may vary depending on the group discussion. It will be video-recorded for research purposes only.

Recording Information

As previously mentioned, both the interview and the focus group will be audio- or video-recorded so that the responses can be written down word-for-word. The recordings will be transferred from the location of the interview or focus group to a LLU office in a locked vehicle and stored under lock and key. Additionally, the recordings will be destroyed immediately after they are written down. Furthermore, your responses will be given a code so that any personal information you provide can be stored separately. Since your responses will be recorded word-for-word, you will be asked under the permissions section at the end of this form whether your answers can be quoted anonymously in publications. You will not be identified by name in any publications describing the results of this study. We will never use your information without your permission.

Confidentiality and Risk

Efforts will be made to keep your information confidential. Specifically, any personal information will be stored separately from your responses. If you provide contact information (optional), it will not be shared with anyone besides the researchers directly involved in this study. Your contact information, answers to the study questions, and recordings will be kept private under lock and key or using secure encryption. In addition, any personal information will be destroyed within one year of the completion of this study. However, we cannot guarantee absolute confidentiality. For example, your personal information may be disclosed if required by law.

If you decide to take part in the focus group, everyone in the group will be asked not to talk to people outside the group about what was said in the group. In other words, everyone will be asked to keep what was said in the group confidential. However, we cannot guarantee absolute confidentiality in this setting because we cannot stop or prevent other participants who are in the group from sharing things that should be confidential.

The risks of doing this study are thought to be low. However, difficult emotions may rise when thinking about autism, your child's behaviors, and the struggles you have gone through trying to help your child. Some of the questions the researcher asks you may be upsetting or make you uncomfortable. If you do not wish to answer a question, you do not have to answer it. If your emotions become too difficult to handle, please let the student researcher know immediately. Although therapy or treatment advice cannot be offered, the student researcher will give you a list of treatment providers in your area.

You are free to withdraw from this study at any time. If you decide to withdraw from this study, you should notify the research team immediately. Likewise, your participation in the study may be stopped by the study staff/investigator for any reason without your agreement. The only alternative to participation in this study is not to participate.

Voluntary Participation

Participation in this study is completely up to you. Your decision whether or not to participate or withdraw at any time from the study will not affect any services that you may be receiving and will not involve any penalty or loss of benefits to which you are otherwise entitled.

Benefits and Compensation

To thank you for your participation, you will receive $10 after each study visit. There are between one to three sessions, depending on the part(s) of the study you complete. The total possible amount you can receive for participation in this study is $10-$30. If you decide to withdraw from the study or are withdrawn by the research team, you will receive compensation for the visits that you have completed. In addition to this personal benefit, the hope is that by understanding the experiences of mothers like you, health/mental health professionals can help other mothers of children diagnosed with autism spectrum disorders better in the future.

Questions or Complaints

If you wish to contact an impartial third party not associated with this study regarding any questions about your rights or to report a complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647, e-mail patientrelations@llu.edu for information and assistance.

Permissions (Please initial all that apply.)

You must ***at least*** consent to participate in either the survey ***or*** the one-on-one interview. You must participate in the survey, interview, or both to participate in the focus group. You may consent to one, two, or all three parts of the study (survey, interview, and focus group). Consent to record is ***required*** if you consent to the one-on-one interview and/or focus group. Consents to be quoted or provide contact information are ***optional***.

_____ I consent to participate in the survey.
_____ I consent to participate in the one-on-one interview (consent to record required).
_____ I consent to participate in the focus group (consent to record required).
_____ I consent to have my responses audio- or video-recorded.
_____ I consent to have my words quoted anonymously in research publications.
_____ I will provide my consent to contact and contact information on a separate page.

Consent

I have been invited to participate in a survey, interview, and focus group about the experiences of mothers of children diagnosed with autism spectrum disorders. I have read the contents of the consent form and have listened to the verbal explanation given by the researcher. I have had the opportunity to ask questions about this study and my questions have been answered to my satisfaction. Signing this consent document does not waive my rights nor does it release the investigators, institution, or sponsor from their responsibilities. I may email Student Researcher Lara South at lsouth@llu.edu or call Principal Investigator Kimberly Freeman at (909) 379-7589 if I have additional questions or concerns. I voluntarily consent to participate in this study. I understand I will be given a copy of this consent form after signing it.

______________________________	______________________________
Signature of Participant	Printed Name of Participant

____
Date

I have reviewed the contents of this consent form with the person signing above. I have explained potential risks and benefits of the study.

______________________________	______________________________
Signature of Investigator	Printed Name of Investigator

____
Date

Loma Linda University
School of Behavioral Health
Department of Psychology
11130 Anderson Street
Loma Linda, CA 92350
Phone: (909)558-8577
Fax: (909)558-0971

LOMA LINDA UNIVERSITY

School of Behavioral Health
Department of Psychology

CONTACT FORM

Subject # _____
(For Research Team Use Only)

Since this study includes multiple steps, we may want to contact you in the future to schedule appointments, clarify your answers, ask additional questions, or invite you to participate in the focus group.

May we contact you? You may choose one or more reasons why we may contact you. Giving permission to contact you is *optional*.

YES

___ I may be contacted to schedule appointments.
___ I may be contacted to clarify my answers.
___ I may be contacted to ask follow-up questions.
___ I may be contacted to participate in the focus group.

NO

___ I *do not* wish to be contacted.

If yes, please fill out the following information:

Name	
Address	
Phone #	
Email	

I consent to be contacted under the circumstances checked above.

____
Signature of Participant

____
Date

INSTITUTIONAL REVIEW BOARD

Authorization for Use of Protected Health Information (PHI)

Per 45 CFR §164.508(b)

RESEARCH PROTECTION PROGRAMS
LOMA LINDA UNIVERSITY | Office of the Vice President of Research Affairs
24887 Taylor Street, Suite 202 Loma Linda, CA 92350
(909) 558-4531 (voice) / (909) 558-0131 (fax)/e-mail: irb@llu.edu

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TITLE OF STUDY: The Process of Self-Regulation in Mothers of Children on the Autism Spectrum

PRINCIPAL INVESTIGATOR: Kimberly Freeman, MSW, Ph.D.

Others who will use, collect, or share PHI: Lara South, Amber Hearn, Taggart Kountz

The study named above may be performed only by using personal information relating to your health. National and international data protection regulations give you the right to control the use of your medical information. Therefore, by signing this form, you specifically authorize your medical information to be used or shared as described below.

The following personal information, considered "Protected Health Information" (PHI) is needed to conduct this study and may include, but is not limited to: your child's autism diagnosis.

Results of any diagnostic and laboratory tests collected for this study will become part of your permanent medical record.

The individual(s) listed above will use or share this PHI in the course of this study with the Institutional Review Board (IRB) and the Office of Research Affairs of Loma Linda University.

The main reason for sharing this information is to be able to conduct the study as described earlier in the consent form. In addition, it is shared to ensure that the study meets legal, institutional, and accreditation standards. Information may also be shared to report adverse events or situations that may help prevent placing other individuals at risk.

All reasonable efforts will be used to protect the confidentiality of your PHI, which may be shared with others to support this study, to carry out their responsibilities, to conduct public health reporting and to comply with the law as applicable. Those who receive the PHI may share with others if they are required by law, and they may share it with others who may not be required to follow national and international "protected health information" (PHI) regulations such as the federal privacy rule.

Subject to any legal limitations, you have the right to access any protected health information created during this study. You may request this information from the Principal Investigator named above but it will only become available after the study analyses are complete.

The authorization expires upon the conclusion of this research study.

You may change your mind about this authorization at any time. If this happens, you must withdraw your permission in writing. Beginning on the date you withdraw your permission, no new personal health information will be used for this study. However, study personnel may continue to use the health information that was provided before you withdrew your permission. If you sign this form and enter the study, but later change your mind and withdraw your permission, you will be removed from the study at that time. To withdraw your permission, please contact the Principal Investigator or study personnel at (909)379-7570.

You may refuse to sign this authorization. Refusing to sign will not affect the present or future care you receive at this institution and will not cause any penalty or loss of benefits to which you are entitled. However, if you do not sign this authorization form, you will not be able to take part in the study for which you are being considered. You will receive a copy of this signed and dated authorization prior to your participation in this study.

I agree that my personal health information may be used for the study purposes described in this form.

Signature of Patient *or* Patient’s Legal Representative	Date
Printed Name of Legal Representative (if any)	Representative’s Authority to Act for Patient
Signature of Investigator Obtaining Authorization	Date

APPENDIX E

DEMOGRAPHICS QUESTIONNAIRE

General Information

In this section we will be asking you general information about you and your family.

1	Are you the child’s:	☐Biological/Birth Mother ☐Stepmother ☐Adoptive Mother ☐Foster Mother ☐Guardian
2	Your age	
3	Child’s biological father’s age	
4	Your child’s age? (Reminder: If you have more than one child diagnosed with an autism spectrum disorder, please answer the questions about the OLDEST child that is 18 or younger.)	
5	Your ethnicity	
6	Child’s father’s ethnicity	
7	Your child’s ethnicity	
8	Child’s sex	☐Male ☐Female
9	Date your child was diagnosed (at least the year)	
10	Number of years and/or months since your child was diagnosed	
11	Number of child’s siblings	
12	Number of child’s siblings with a disability	
13	Ages of the child’s siblings	
14	Number of people living in the home	

General Information, cont.

1	Household Income	☐$0-$20,000 ☐$20,001 - $40,000 ☐$40,001-$60,000 ☐$60,001 - $80,000 ☐$80,001-$100,000 ☐$100,001-$150,000 ☐$150,001-$200,000 ☐$200,001-$250,000 ☐$250,001-$300,000 ☐Greater than $300K
2	Your highest level of education completed	☐Less than high school (Grade: _____) ☐High school/GED ☐Some college ☐2-year college degree (e.g., Associates) ☐4-year college degree (e.g., BA, BS) ☐Master’s degree ☐Doctoral degree ☐Professional degree (e.g., MD, JD)
3	Your religion	☐Catholic ☐Christian ☐Mormon ☐Jewish ☐Muslim ☐Hindu ☐Buddhist ☐Atheist ☐Other: ____________________
4	Your current marital status	☐Never married ☐Married (1st husband) ☐Separated ☐Divorced ☐Re-married ☐Widowed ☐Living with significant other
5	Your current employment status	☐Employed for wages ☐Self-employed ☐Unemployed ☐Homemaker ☐Student ☐Retired ☐Unable to work due to disability
6	Your occupation	Primary: ______________________________ Secondary (if applicable): ____________________
7	Child’s father’s occupation	Primary: ______________________________ Secondary (if applicable): ____________________

Mother's Services

In this section we will be asking you some personal questions about yourself. This is so we can get an idea of your own physical and mental health. Remember that you can skip any question you do not wish to answer.

1	Your medical and/or psychological diagnoses	________________ ________________ ________________ ________________
2	Services you have received? (Please check all that apply.)	☐Parent training ☐Government financial assistance ☐Traditional individual psychotherapy (i.e., talk therapy) ☐Couples therapy ☐Group therapy ☐Family therapy ☐Psychiatric hospitalization ☐Art therapy ☐Music therapy ☐Dance/movement therapy ☐Drama therapy ☐Equine/animal-assisted therapy ☐Others: ________________
3	Services you would like to receive for yourself and why you have not been able to get them (e.g., have not looked, currently looking, request denied, unavailable in my area, etc.)	________________ ________________ ________________ ________________
4	Medications you are taking	________________ ________________ ________________ ________________

Child's Services

In this section we will be asking you some questions about your child. This is so that we can get a better idea of your child's physical and mental health. Remember that you can skip any question you do not wish to answer.

1	What is your child's official diagnosis?	☐Autistic Disorder ☐Asperger's Disorder ☐Pervasive Developmental Disorder NOS ☐Childhood Disintegrative Disorder ☐Rett's Disorder ☐Autism Spectrum Disorder

2 How severe do you consider your child's…

	Very Low	Mild	Moderate	High	Severe	N/A
Autism Spectrum Disorder?	☐	☐	☐	☐	☐	☐
Social interaction problems?	☐	☐	☐	☐	☐	☐
Communication problems?	☐	☐	☐	☐	☐	☐
Stereotyped behaviors (e.g., hand flapping) or restricted interests?	☐	☐	☐	☐	☐	☐
Tantrums?	☐	☐	☐	☐	☐	☐
Aggressive behaviors?	☐	☐	☐	☐	☐	☐

3	Who first diagnosed your child?	☐Medical doctor ☐Psychiatrist ☐Psychologist ☐Neuropsychologist ☐School psychologist ☐Social worker☐Marriage and family therapist
4	Other medical and/or psychological diagnoses	______________________________ ______________________________ ______________________________
5	Medications your child is taking	______________________________ ______________________________ ______________________________

6	Services your child has received and alternative practices your child has tried? (Please check all that apply.)	☐ Placement in a special education classroom ☐ Speech therapy ☐ Occupational therapy ☐ Adaptive PE ☐ Applied behavioral analysis (ABA) intervention ☐ Social skills training ☐ Traditional individual psychotherapy (i.e., talk therapy) ☐ Family therapy ☐ Group therapy ☐ Psychiatric hospitalization ☐ Play therapy ☐ Neurofeedback ☐ Gluten-free diet ☐ Casein-free diet ☐ Art therapy ☐ Music therapy ☐ Dance/movement therapy ☐ Drama therapy ☐ Equine/animal-assisted therapy ☐ Others: ____
7	Services or alternative practices you would like your child to receive and why you have not been able to get them (e.g., have not looked, currently looking, request denied, unavailable in my area, etc.)	____ ____ ____ ____ ____
8	On a scale from 1 to 10, how involved in your child’s treatment are you? (Circle a number.)	1 2 3 4 5 6 7 8 9 10

↑ Not involved in any treatment

↑ Involved in all treatment all the time

9 How satisfied were/are you with your child's services?

	Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Satisfied	N/A
Placement in a special education classroom	☐	☐	☐	☐	☐
Speech therapy	☐	☐	☐	☐	☐
Occupational therapy	☐	☐	☐	☐	☐
Adaptive PE	☐	☐	☐	☐	☐
Applied behavioral analysis (ABA) intervention	☐	☐	☐	☐	☐
Social skills training	☐	☐	☐	☐	☐
Traditional individual psychotherapy (i.e., talk therapy)	☐	☐	☐	☐	☐
Family therapy	☐	☐	☐	☐	☐
Group therapy	☐	☐	☐	☐	☐
Psychiatric hospitalization	☐	☐	☐	☐	☐
Play therapy	☐	☐	☐	☐	☐
Neurofeedback	☐	☐	☐	☐	☐
Gluten-free diet	☐	☐	☐	☐	☐
Casein-free diet	☐	☐	☐	☐	☐
Art therapy	☐	☐	☐	☐	☐
Music therapy	☐	☐	☐	☐	☐
Dance/movement therapy	☐	☐	☐	☐	☐
Drama therapy/Psychodrama	☐	☐	☐	☐	☐
Equine/animal-assisted therapy	☐	☐	☐	☐	☐
Other:___________________	☐	☐	☐	☐	☐

APPENDIX F

ILLNESS PERCEPTIONS QUESTIONNAIRE – REVISED – AUTISM

IPQ-R-Autism

Identity

Listed below are a number of symptoms and behaviors that you may or may not have observed since your child was diagnosed with an Autism Spectrum Disorder. Please indicate by circling Yes or No whether you have observed these symptoms or behaviors since your child was diagnosed and whether you believe these symptoms or behaviors are related you your child's disorder. (Please choose yes or no for each column.)

	I have observed this symptom or behavior since my child was diagnosed.		This symptom or behavior is related to my child's disorder.	
Prefers to be alone	Yes	No	Yes	No
Rejects caressing and hugs	Yes	No	Yes	No
Gets agitated	Yes	No	Yes	No
Constant rituals and habits	Yes	No	Yes	No
Avoids eye contact	Yes	No	Yes	No
Fixed attention to details	Yes	No	Yes	No
Says little for his/her age or nothing at all	Yes	No	Yes	No
Repeats irrelevant words or phrases	Yes	No	Yes	No
Repetitive movements (e.g., rocking, wringing hands, etc.)	Yes	No	Yes	No
Cannot tolerate even small changes	Yes	No	Yes	No
Does not play pretend	Yes	No	Yes	No
Does not acknowledge others	Yes	No	Yes	No
Does not point to what he/she wants	Yes	No	Yes	No

Cries easily	Yes	No	Yes	No
Whines	Yes	No	Yes	No
Has temper tantrums	Yes	No	Yes	No
Yells or screams	Yes	No	Yes	No
Gets mad easily	Yes	No	Yes	No
Is aggressive toward others	Yes	No	Yes	No
Is aggressive toward him/herself	Yes	No	Yes	No
Has difficulty paying attention	Yes	No	Yes	No
Has trouble concentrating	Yes	No	Yes	No
Seems anxious	Yes	No	Yes	No
Seems sad or depressed	Yes	No	Yes	No
Breaks rules	Yes	No	Yes	No
Refuses to do things I ask him/her to do	Yes	No	Yes	No
Shows no guilt	Yes	No	Yes	No
Complains of headaches	Yes	No	Yes	No
Vomits often	Yes	No	Yes	No
Complains of stomach pain	Yes	No	Yes	No
Sees things that are not really there	Yes	No	Yes	No
Has strange ideas	Yes	No	Yes	No

We will be asking you some questions about your own personal beliefs about your child's autism spectrum disorder and his/her behaviors (i.e., social interaction problems, communication problems, stereotyped behaviors [e.g., hand flapping] or restricted interests, tantrums, and aggressive behaviors.) Please indicate how much you agree or disagree with the following statements about your child's disorder or behaviors by checking the appropriate box.

Timeline (acute/chronic)

1. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child's disorder will last a short time.	☐	☐	☐	☐	☐
My child's social interaction problems will last a short time.	☐	☐	☐	☐	☐
My child's communication problems will last a short time.	☐	☐	☐	☐	☐
My child's stereotyped behaviors (e.g., hand flapping) or restricted interests will last a short time.	☐	☐	☐	☐	☐
My child's tantrums will last a short time.	☐	☐	☐	☐	☐
My child's aggressive behaviors will last a short time.	☐	☐	☐	☐	☐

2. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child's disorder is likely to be permanent rather than temporary.	☐	☐	☐	☐	☐
My child's social interaction problems are likely to be permanent rather than temporary.	☐	☐	☐	☐	☐
My child's communication problems are likely to be permanent rather than temporary.	☐	☐	☐	☐	☐
My child's stereotyped behaviors (e.g., hand flapping) or restricted interests are likely to be permanent rather than temporary.	☐	☐	☐	☐	☐
My child's tantrums are likely to be permanent rather than temporary.	☐	☐	☐	☐	☐
My child's aggressive behaviors are likely to be permanent rather than temporary.	☐	☐	☐	☐	☐

3. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child's disorder will last for a long time.	☐	☐	☐	☐	☐
My child's social interaction problems will last for a long time.	☐	☐	☐	☐	☐
My child's communication problems will last for a long time.	☐	☐	☐	☐	☐
My child's stereotyped behaviors (e.g., hand flapping) or restricted interests will last for a long time.	☐	☐	☐	☐	☐
My child's tantrums will last for a long time.	☐	☐	☐	☐	☐
My child's aggressive behaviors will last for a long time.	☐	☐	☐	☐	☐

4. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child's disorder will pass quickly.	☐	☐	☐	☐	☐
My child's social interaction problems will pass quickly.	☐	☐	☐	☐	☐
My child's communication problems will pass quickly.	☐	☐	☐	☐	☐
My child's stereotyped behaviors (e.g., hand flapping) or restricted interests will pass quickly.	☐	☐	☐	☐	☐
My child's tantrums will pass quickly.	☐	☐	☐	☐	☐
My child's aggressive behaviors will pass quickly.	☐	☐	☐	☐	☐

5. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
I expect my child to have this disorder for the rest of his/her life.	☐	☐	☐	☐	☐
I expect my child to have social interaction problems for the rest of his/her life.	☐	☐	☐	☐	☐
I expect my child to have communication problems for the rest of his/her life.	☐	☐	☐	☐	☐
I expect my child to have stereotyped behaviors (e.g., hand flapping) or restricted interests for the rest of his/her life.	☐	☐	☐	☐	☐
I expect my child to have tantrums for the rest of his/her life.	☐	☐	☐	☐	☐
I expect my child to have aggressive behaviors for the rest of his/her life.	☐	☐	☐	☐	☐
6. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child’s disorder will improve in time.	☐	☐	☐	☐	☐
My child’s social interaction problems will improve in time.	☐	☐	☐	☐	☐
My child’s communication problems will improve in time.	☐	☐	☐	☐	☐
My child’s stereotyped behaviors (e.g., hand flapping) or restricted interests will improve in time.	☐	☐	☐	☐	☐
My child’s tantrums will improve in time.	☐	☐	☐	☐	☐
My child’s aggressive behaviors will improve in time.	☐	☐	☐	☐	☐

Consequences

1. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child's disorder is a serious condition.	☐	☐	☐	☐	☐
My child's disorder has major consequences on his/her life.	☐	☐	☐	☐	☐
My child's disorder does not have much effect on his/her life.	☐	☐	☐	☐	☐
My child's disorder strongly affects the way others see him/her.	☐	☐	☐	☐	☐
My child's disorder has serious financial consequences.	☐	☐	☐	☐	☐
My child's disorder causes difficulties for those who are close to him/her.	☐	☐	☐	☐	☐

Personal Control

1. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
There is a lot which my child can do to control his/her symptoms.	☐	☐	☐	☐	☐
There is a lot which I can do to control my child's symptoms.	☐	☐	☐	☐	☐
There is a lot which professionals can do to control my child's symptoms.	☐	☐	☐	☐	☐
There is a lot which a higher power can do to control my child's symptoms.	☐	☐	☐	☐	☐
It is up to chance whether my child's symptoms can be controlled.	☐	☐	☐	☐	☐
2. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
What my child does can determine whether his/her disorder gets better or worse.	☐	☐	☐	☐	☐
What I do can determine whether my child's disorder gets better or worse.	☐	☐	☐	☐	☐
What professionals do can determine whether my child's disorder gets better or worse.	☐	☐	☐	☐	☐
What a higher power does can determine whether my child's disorder gets better or worse.	☐	☐	☐	☐	☐
Chance can determine whether my child's disorder gets better or worse.	☐	☐	☐	☐	☐

3. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The course of my child’s disorder depends on my child.	☐	☐	☐	☐	☐
The course of my child’s disorder depends on me.	☐	☐	☐	☐	☐
The course of my child’s disorder depends on professionals.	☐	☐	☐	☐	☐
The course of my child’s disorder depends on a higher power.	☐	☐	☐	☐	☐
The course of my child’s disorder depends on chance.	☐	☐	☐	☐	☐

4. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
Nothing my child does will affect his/her disorder.	☐	☐	☐	☐	☐
Nothing I do will affect my child’s disorder.	☐	☐	☐	☐	☐
Nothing professionals do will affect my child’s disorder.	☐	☐	☐	☐	☐
Nothing a higher power does will affect my child’s disorder.	☐	☐	☐	☐	☐
Nothing chance does will affect my child’s disorder.	☐	☐	☐	☐	☐

5. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child has the power to influence his/her disorder.	☐	☐	☐	☐	☐
I have the power to influence my child’s disorder.	☐	☐	☐	☐	☐
Professionals have the power to influence my child’s disorder.	☐	☐	☐	☐	☐
A higher power has the power to influence my child’s disorder.	☐	☐	☐	☐	☐
Chance has the power to influence my child’s disorder.	☐	☐	☐	☐	☐

6. Please select your answers.	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My child's actions will have no effect on the outcome of his/her disorder.	☐	☐	☐	☐	☐
My actions will have no effect on the outcome of my child's disorder.	☐	☐	☐	☐	☐
Professionals' actions will have no effect on the outcome of my child's disorder.	☐	☐	☐	☐	☐
A higher power's actions will have no effect on the outcome of my child's disorder.	☐	☐	☐	☐	☐
The actions of chance will have no effect on the outcome of my child's disorder.	☐	☐	☐	☐	☐

Treatment Control

1. Please select your answers.	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
There is very little that can be done to improve my child's disorder.	☐	☐	☐	☐	☐
There is very little that can be done to improve my child's social interaction problems.	☐	☐	☐	☐	☐
There is very little that can be done to improve my child's communication problems.	☐	☐	☐	☐	☐
There is very little that can be done to improve my child's stereotyped behaviors (e.g., hand flapping) or restricted interests.	☐	☐	☐	☐	☐
There is very little that can be done to improve my child's tantrums.	☐	☐	☐	☐	☐
There is very little that can be done to improve my child's aggressive behaviors.	☐	☐	☐	☐	☐

2. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child’s treatment will be effective in curing his/her disorder.	☐	☐	☐	☐	☐
My child’s treatment will be effective in curing his/her social interaction problems.	☐	☐	☐	☐	☐
My child’s treatment will be effective in curing his/her communication problems.	☐	☐	☐	☐	☐
My child’s treatment will be effective in curing his/her stereotyped behaviors (e.g., hand flapping) or restricted interests.	☐	☐	☐	☐	☐
My child’s treatment will be effective in curing his/her tantrums.	☐	☐	☐	☐	☐
My child’s treatment will be effective in curing his/her aggressive behaviors.	☐	☐	☐	☐	☐

3. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The negative effects of my child’s disorder can be prevented (avoided) by my child’s treatment.	☐	☐	☐	☐	☐
The negative effects of my child’s social interaction problems can be prevented (avoided) by my child’s treatment.	☐	☐	☐	☐	☐
The negative effects of my child’s communication problems can be prevented (avoided) by my child’s treatment.	☐	☐	☐	☐	☐
The negative effects of my child’s stereotyped behaviors (e.g., hand flapping) or restricted interests can be prevented (avoided) by my child’s treatment.	☐	☐	☐	☐	☐
The negative effects of my child’s tantrums can be prevented (avoided) by my child’s treatment.	☐	☐	☐	☐	☐
The negative effects of my child’s aggressive behaviors can be prevented (avoided) by my child’s treatment.	☐	☐	☐	☐	☐

4. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My child’s treatment can control his/her disorder.	☐	☐	☐	☐	☐
My child’s treatment can control his/her social interaction problems.	☐	☐	☐	☐	☐
My child’s treatment can control his/her communication problems.	☐	☐	☐	☐	☐
My child’s treatment can control his/her stereotyped behaviors (e.g., hand flapping) or restricted interests.	☐	☐	☐	☐	☐
My child’s treatment can control his/her tantrums.	☐	☐	☐	☐	☐
My child’s treatment can control his/her aggressive behaviors.	☐	☐	☐	☐	☐

5. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
There is nothing which can help my child’s disorder.	☐	☐	☐	☐	☐
There is nothing which can help my child’s social interaction problems.	☐	☐	☐	☐	☐
There is nothing which can help my child’s communication problems.	☐	☐	☐	☐	☐
There is nothing which can help my child’s stereotyped behaviors (e.g., hand flapping) or restricted interests.	☐	☐	☐	☐	☐
There is nothing which can help my child’s tantrums.	☐	☐	☐	☐	☐
There is nothing which can help my child’s aggressive behaviors.	☐	☐	☐	☐	☐

Illness Coherence

1. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The symptoms of my child’s disorder are puzzling to me.	☐	☐	☐	☐	☐
My child’s disorder is a mystery to me.	☐	☐	☐	☐	☐
I don’t understand my child’s disorder.	☐	☐	☐	☐	☐
My child’s disorder doesn’t make any sense to me.	☐	☐	☐	☐	☐
I have a clear picture or understanding of my child's disorder.	☐	☐	☐	☐	☐

Timeline (cyclical)

1. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
The symptoms of my child's disorder change a great deal from day to day.	☐	☐	☐	☐	☐
My child's symptoms come and go in cycles.	☐	☐	☐	☐	☐
My child's disorder is very unpredictable.	☐	☐	☐	☐	☐
My child goes through cycles in which his/her disorder gets better and worse.	☐	☐	☐	☐	☐

Emotional Representations

1. Please select your answers.	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
I get depressed when I think about my child's disorder.	☐	☐	☐	☐	☐
When I think about my child's disorder, I get upset.	☐	☐	☐	☐	☐
My child's disorder makes me feel angry.	☐	☐	☐	☐	☐
My child's disorder does not worry me.	☐	☐	☐	☐	☐
My child having this disorder makes me feel anxious.	☐	☐	☐	☐	☐
My child's disorder makes me feel afraid.	☐	☐	☐	☐	☐

Causes

We are interested in what you consider may have been the cause of your child’s disorder. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your child’s disorder rather than what others, including doctors or family, may have suggested to you. Below is a list of possible causes for your child’s disorder. Please indicate how much you agree or disagree that they were causes for your child by checking the appropriate box.

Possible Causes	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
My stress or worry	☐	☐	☐	☐	☐
Hereditary – it runs in my family	☐	☐	☐	☐	☐
A germ or virus	☐	☐	☐	☐	☐
Diet or eating habits	☐	☐	☐	☐	☐
Chance or bad luck	☐	☐	☐	☐	☐
Poor medical care in my child’s past	☐	☐	☐	☐	☐
Pollution in the environment	☐	☐	☐	☐	☐
My child’s own behavior	☐	☐	☐	☐	☐
My child’s mental attitude (e.g., thinking about life negatively)	☐	☐	☐	☐	☐
Family problems or worries caused my child’s disorder	☐	☐	☐	☐	☐
My overworking	☐	☐	☐	☐	☐
My emotional state (e.g., feeling down, lonely, anxious, empty)	☐	☐	☐	☐	☐
My ageing	☐	☐	☐	☐	☐
My alcohol use	☐	☐	☐	☐	☐
My smoking	☐	☐	☐	☐	☐
Accident or injury	☐	☐	☐	☐	☐
My child’s personality	☐	☐	☐	☐	☐
Altered immunity	☐	☐	☐	☐	☐

On the lines below, please list in rank-order the three most important factors that you now believe caused **YOUR CHILD’S disorder**. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. ______________________________________
2. ______________________________________
3. ______________________________________

APPENDIX G

OPEN-ENDED QUESTIONS FROM THE PILOT STUDY

1. How do you DEFINE autism? What behaviors or symptoms do you think are part of autism? If your beliefs about what autism is have changed over time, how and why?
2. Please, describe what you first thought the CAUSE of autism was. What factors influenced that belief (e.g., media, books, other parents, your own experience, etc.)? If your beliefs have changed, how and why?
3. What did you FEEL when you first heard about autism? If your emotions have changed, how and why?
4. How did you try to COPE with having a child diagnosed with autism when your child was first diagnosed? If you have changed how you cope, describe how and why.
5. When you first heard your child was diagnosed with autism, what did you EXPECT? Did you think it would get better, worse, stay the same, etc.? If your expectations have changed, describe how and why.
6. How INVOLVED were you in your child’s treatment when your child was first diagnosed with autism? If you have become more or less involved, describe how and why.
7. Please, describe the process you have gone through trying to GET TREATMENT(s) for your child diagnosed with autism.
8. Do you believe your child is currently getting the BEST treatment? If not, what do you believe the best treatment would be? What factors are preventing you from getting the best treatment for your child (e.g., money, time, availability, ability, etc.)?
9. What do you think health professionals (e.g., doctors, psychologists, psychiatrists, etc.) could do to help parents of children diagnosed with autism FIND the treatments they need? In other words, what are they not doing now that they should be doing?
10. How can health professionals (e.g., doctors, psychologists, psychiatrists, etc.) better HELP parents of children diagnosed with autism cope?
11. How can health professionals (e.g., doctors, psychologists, psychiatrists, etc.) better help parents UNDERSTAND what autism is and what to EXPECT when their child is first diagnosed?

APPENDIX H

SEMI-STRUCTURED INTERVIEW GUIDE

Overall Process

1. Describe your personal journey of finding treatments for your child and yourself. Include your thoughts and feelings, how you coped, and what you found helpful or not helpful.
    a. Possible Prompts:
        i. What barriers did you encounter?
        ii. What facilitated the process/helped the process along?

Cognitions and Information Seeking

2. How has your understanding of autism developed over time?
    a. Possible Prompts:
        i. How do you define autism?
        ii. What behaviors or symptoms do you think are part of autism?
        iii. What were your expectations about your child diagnosis of autism (e.g., get better/worse, stay the same)? If these expectations have changed, how?
        iv. how do you think autism develops over time?
        v. Where did you find the information that influenced how your thoughts developed?
        vi. How did you decide to accept or reject what other people believed or told you about autism?
        vii. What do you think has been the biggest influence on your child?
        viii. How have your thoughts about autism changed from the beginning to now?

Cognition – Cause

3. Tell me how you think your child came to have autism and how you came to believe that.
    a. Possible Prompts:
        i. Do you think the cause of autism is the same for every child? If not, how do you think autism is caused in other kids?
        ii. How did you find information about possible causes?
        iii. Did you believe in a different cause before now, and if so, how did you change your mind?
        iv. Have you ever felt like someone blamed you for your child developing autism, and if so, how did you deal with that?

Cognitive Appraisal of Cognitions

4. When your child was first diagnosed, how could health professionals (e.g., doctors, psychologists, psychiatrists, etc.) have better helped you understand what autism was and what to expect??
    a. Possible Prompts:
        i. How could they help other parents with this in the future?
        ii. What information should they provide and how?
        iii. What can they do to be more informed themselves?

Emotional Reactions

5. Describe how you felt when your child was first diagnosed with autism and how those feelings may or may not have changed until now.
    a. Possible Prompts:
        i. What is the biggest factor that influenced why you felt this way?
        ii. Have you ever felt emotions like grief or traumatic stress regarding your child? If so, how did you deal with them?
        iii. Did anyone help you cope with your feelings, and if so, how?
        iv. Did anyone make you feel worse, and if so, how?

Connection between Cognitions and Emotions

6. Have your thoughts about autism and your child influenced how you feel or vice versa? If so, how?
    a. Possible Prompts:
        i. What thoughts were most influenced by your feelings?
        ii. What feelings were most influenced by your thoughts?

Cognitive Coping – Treatment Seeking

7. Describe the process you have gone through trying to get treatment(s) for your child.
    a. Possible Prompts:
        i. What are all the types of treatments you have tried?
        ii. Have you tried multiple providers for a particular type of treatment?
        iii. What barriers have you encountered, and how did you deal with them?
        iv. Tell me about anything, anyone, or any organization that helped you get the treatments you wanted.
        v. Do you believe your child is currently getting the best treatment? If not, what do you believe the best treatment would be? What factors are preventing you from getting the best treatment for your child (e.g., money, time, availability, ability, etc.)?

Connection between Cognitions and Emotions to Cognitive Coping

8. Tell me how your thoughts, beliefs, or emotions about your child's autism may or may not have influenced your choice of treatments. Include ones you have tried and ones you have not tried.
    a. Possible Prompts:
        i. Did a treatment ever not work out how you thought it would, and if so, how did that influence what you believed or felt about autism and your child?
        ii. Why did you decide not to try certain treatments?

Process Theme of "Fighting"

9. Have you ever felt like you have had to fight to get what you wanted for you and your child, and if so, tell me about how this has happened and what the result was?
    a. Possible Prompts:
        i. Have you ever had to seek legal help or hire an advocate? If so, describe what happened.
        ii. Have you learned any advocacy skills, and if so, how?

Importance of Personal Agency in Treatment Improvement

10. Describe how you have been involved in your child's treatment(s).
    a. Possible Prompts:
        i. How have professionals included you in the treatment?
        ii. Have you learned certain skills to work with your child, if so, what and how?

Cognitive Appraisal of Cognitive Coping

11. How would you like health professionals (doctors, psychologists, psychiatrists, etc.) to help parents of children diagnosed with autism find the treatments they need.
    a. Possible Prompts:
        i. What actions can they take?
        ii. What services can they offer?
        iii. What would show you that they cared about you and your child's needs?

Cognitive and Emotional Coping

12. <u>Describe the way you have coped mentally and emotionally with the process of understanding and taking care of your child.</u>
    a. Possible Prompts:
        i. How do you take care of your own needs?
        ii. Do you ever feel like your child has become your whole life? If so, how do you deal with that?
        iii. How has your life changed now in response to your child's autism-related needs?
        iv. Have you come to a point where you have accepted a new way of living that is structured around taking care of your child's needs (some mothers have described this as "learning to live with it" or "the new normal")? If so, how did you come to this point?

Process Theme of Systemic Influence

13. <u>Tell me how your family and other people have supported or not supported you through the process of understanding and helping your child as well as dealing with your emotions.</u>
    a. Possible Prompts:
        i. Have you been involved with any autism support groups, and if so, how have they helped?
        ii. Have you felt supported by health professionals? How or how not?

Emotional Appraisal of Emotional Coping

14. <u>How do you think health professionals should help parents emotionally cope?</u>
    a. Possible Prompts:
        i. What actions can they take?
        ii. What services can they offer?
        iii. What would show you that they personally cared about you and your child?

Open End

<u>Is there anything else you would like to add to your personal story?</u>

APPENDIX I

REFLEXIVE JOURNAL

Entry 1: From Dissertation Proposal

The following two sections were originally included in my dissertation proposal qualitative methods section, but my committee believed that these would fit better in my reflexive journal. Consequently, I am putting them here so I can document my idea process without over-encumbering my dissertation write-up.

Methodology. Before outlining the specific qualitative data collection methods, it is important for a qualitative researcher to first identify her epistemological position, paradigmatic stance, theoretical framework, and methodology. This is because each of these factors is a foundation for the research assumptions and guides the research objectives. The researcher of the current study situates herself in a *moderate epistemological position* that is neither completely objectivist nor completely subjectivist. Specifically, she believes that the way people interpret information affects their view of reality and these interpretations can differ even within the same person based on who they are with and the context of the interaction.

She considers herself as coming from a *social constructionist* lens. This qualitative research paradigm is concerned with understanding how participants perceive and understand the world around them (i.e., make meaning), recognizes that realities change based on the relationship and context, and aims to present multiple viewpoints (Daly, 2007; Gergen, 2009). Additionally, there are different paradigms associated with mixed methods research in particular. The researcher of this study ascribes to the *dialectical thesis* that "all paradigms have something to offer and the use of multiple paradigms contributes to greater understanding of the phenomenon under study…This involves considering opposing viewpoints and interacting with the tensions caused by their juxtaposition" (Teddlie & Tashakkori, 2009, pp. 99-100).

As previously mentioned, the theoretical framework of the current study is the *commonsense self-regulation model*. This theory proposes that people are meaning-making systems that use a process of understanding, emotionally reacting to, coping with, and appraising illnesses or disorders (Leventhal et al., 2001).

The methodology for the current study is primarily rooted in *grounded theory*, which takes a structured approach to bring together themes from the data that are traditionally used to develop theory. However, elements from other methodologies will be integrated into the current study's conceptualization to provide a more complete picture. This is congruent with the researcher's social constructionist and dialectical paradigmatic views. Although this study is essentially validating a preexisting theory, the primary methodology to be used is grounded theory because it is believed that any themes that are developed should stay close to the respondents' viewpoints and be grounded in the data they create (Charmaz, 2006; Corbin & Strauss, 2008). Additionally, this methodology's specific guidelines for how to analyze qualitative data have been shown to be effective and have a large evidence base.

The current study's methodology will also be informed by *phenomenological analysis* in that it will consider that respondents, as well as researchers, are meaning-making systems that are constantly interpreting reality (Daly, 2007; J. A. Smith, Flowers, & Larkin, 2009). Consequently, although the researcher aims to find major themes in

MCDAs' self-regulation process, she will also honor the individuality of each participant and the unique meanings that they make.

It is also hoped that this study will help provide insights into how mental health professionals can best assist MCDAs' understand autism spectrum disorders and find treatments. Therefore, some principles of *participatory action research* will also be incorporated into the methods. Specifically, the mothers will be viewed as active participants in the research process and the researcher will facilitate development of solutions to any societal injustices they have faced (McIntyre, 2008).

Lastly, the researcher thinks that qualitative research is best done when multiple viewpoints are heard through team discussion, which is a tenet of *consensual qualitative research* (C. E. Hill et al., 2005; C. E. Hill et al., 1997). As a result, qualitative coding will be performed by a minimum of two researchers who will collaborate and come to a consensus on final coding decisions. The first researcher will be the student researcher leading this dissertation. The additional researcher(s) will be recruited by mass email to the Psychology department, individual emails to other students at Loma Linda University that have expressed interest, and/or word-of-mouth referrals. The information that will be coded by these researchers will come from individual interviews and a focus group.

Self of the Researcher. In qualitative research, there are varying views on how the researcher influences the research. On the objectivist side of the spectrum, it is thought that what is researched is completely unbiased and the researcher does not influence what is studied (Daly, 2007). On the subjectivist side, researchers are thought of as inseparable from what is being researched because they help co-construct the data through their interactions and interpretations (Charmaz, 2006; Daly, 2007). A middle stance believes that any biases the researcher may have can be separated, or "bracketed", out to minimize the effect on the research (Daly, 2007; J. A. Smith et al., 2009). As someone who believes one does have at least some effect on data creation and interpretation, the student researcher of this study considers it important to be transparent about the characteristics and views one has.

The primary student researcher of this study is a middle class Caucasian female in her late twenties. She is a graduate student near the end of her PhD training in Clinical Psychology at Loma Linda University. Her concentration is "Clinical Child" and she has worked in a variety of settings with children who have disabilities as well as their families. This area of psychology is her passion. She has done many activities with the community of children on the autism spectrum including behavioral intervention, case management, parent training, play therapy, neuropsychological assessment, psychoeducational assessment, and talk therapy.

As a therapist, the primary student researcher considers her theoretical orientation integrative. That is to say that she does not believe there is any one therapeutic approach that will help every client. Therefore, she tailors treatment to the needs of the client and conceptualizes cases from multiple viewpoints to help provide a more complete picture. This stance influences her research orientation in that she believes it is important to look at the phenomenon under study from different lenses to provide a more well-rounded description. As a result, the researcher believes in the importance of mixed methods research and uses a dialectical research orientation, which was described earlier.

As previously mentioned, the researcher's worldview stems from the social constructionist ideas that reality is co-constructed in relationships and that people make individual meaning based on their interactions (Gergen, 2009). That being the case, the researcher will monitor her own actions, reactions, thoughts, and interpretations throughout the research process to be transparent about how she is interacting with the participants and the data. This will be done through a reflexive journal that will also serve as a workspace for writing out possible theme developments and theoretical connections.

Entry 2: Analysis of Pilot Data

Research Team Recruitment. Dr. Freeman recommended someone, Stacey, and I reached out to one person that I had partnered with previously in my qualitative research class, Amber, and they both agreed to be part of the team. I also sent an email to the psychology department asking for students who were interested in assisting with qualitative coding and received four replies of interest. Unfortunately, three of the students had other obligations and were unable to commit to the project. Taggart was the student who remained to help.

Coding Pilot Responses. Stacey, Amber, and I, all reviewed the most detailed response from the pilot responses that came from the open-ended questions I had at the end of the survey I used for my thesis. (Taggart reviewed qualitative research procedures at this time so that he would be competent to code future data.) For the pilot codes, we used comments in a Word document because we did not have access to NVivo yet. I discussed the codes with each team member (separately due to the completion of coding occurring at different times for each person) to explore inter-rater consistency, to discuss divergence in coding, and to brainstorm potential categories that were arising. Stacey, Amber, and I also divided up the remainder of the pilot responses and coded our assigned subjects separately.

Entry 3: Determining Common Codes

After the team completed the pilot codes, I printed the open codes and stacked common codes together. Each stack then became a common code, which I listed in a word document and sent to the team members for feedback. These codes are listed here:

Common Pilot Codes

- Stimuli
    - Many Stressors Present at the Same Time
    - Family History of Mental, Behavioral, or Substance Abuse Issues
    - Medical Diagnoses
    - Child’s Learned Skills
    - Slow Progress
    - See Other Children with Autism
    - Change in Functioning after Particular Events (e.g., vaccination)
    - Sleep Disturbance
    - Child’s Behaviors
    - Interaction between Disorder and Behaviors

- Perception
    - Interprets Child’s Behaviors as Fear/Stress Response
    - Not Alone
    - Difficulty
- Understanding/Thoughts/Cognitions
    - Religious Beliefs
    - Personal Values
    - Finding Value/Beauty/Good in the Child
    - Developmental Course
    - Understanding of Autism
        - As a Disorder/Disease
        - Neurological/Brain Dysfunction
        - Mentally Debilitating
        - Help Needed Across the Lifespan
        - Stable/Unstable
        - Not Knowing/Understanding
        - Variability/Individual Presentation or Course
        - Other Disorders Included
        - Something Wrong/Not Normal
        - Works Differently
        - Complex
        - A Personal Definition
        - Misperception
        - Developmental Dysfunction
        - As Different than Just the Behaviors
        - A Mystery
    - Behaviors/Symptoms
        - Different than Other Children’s
        - Social Problems/Deficit
        - Communication/Speech/Language Problems
        - Obsessive Interests/Fixation (e.g., lining up objects)
        - Self-Stimulatory Behaviors
        - Repetitive Behaviors (e.g., flapping)
        - Lack of Focus/Attention
        - Trouble with Non-Verbal Communication
        - Autism is a Set of Symptoms
        - Represent Multiple Diagnoses/Disabilities
        - Sleep Problems
        - Self-Injurious Behaviors
        - Some Children Behave Normally
        - Sensory Problems
        - Poor Fine Motor Skills
        - Difficulty with Eye Contact
        - Rude, Abrupt, Outspoken, Selfish
        - Loneliness/Alone
    - Cause

        - Beliefs about what it is not (e.g., alcohol)
        - Not Clear/Unknowable
        - Medicine
        - Heredity/Genetics
        - Mother's Stress
        - Environmental Toxins (e.g., Aspartame)
        - Immunizations/Vaccines
        - Biological/Medical
        - Problems with Development in the Womb
        - Combination of Genetics and Environment
        - The Mother Herself
    - Cure/Recovery/No Cure
    - Beliefs about Self of Mother
        - Expert on Her Child
    - Severity
    - Individuality of Each Child
    - Expectations
        - Of Professionals/Others
            - Referrals
            - Practical Guidance
            - Help
            - Support
        - Of Child
            - Low/Limited
            - Anticipated Challenged
            - Success
            - Getting Better
            - Very Low/Doomed
            - Normalcy/Activities of Daily Living
            - Isolated
    - Rejecting Beliefs of Others
        - Media (e.g., Jenny McArthy)
        - Negative Family Perceptions
    - Diagnosis
        - Should Be Done Early
        - Should Use Best Measures (e.g., ADOS)
        - Belief that Current Categorization is too Broad
    - Consequences
- Cognitive Coping
    - Help/Treatment Seeking
        - Parent-Initiated
        - Provider-Shopping
        - Change Treatment
        - Getting What They Want No Matter What
        - Finding Ways to Work within the System (e.g., apply for grants)
        - Needing Multiple Services for Different Areas of Need

        - Being Denied Services
        - Seeking Help Through Multiple Systems/Collaborate with Community Agencies
            - Schools
            - Regional Centers
            - Medical Settings
    - Gather Information from Books, Media, and Scholarly Articles
    - Fight
        - Asking or Demanding
        - Fighting for Services
        - Advocacy
        - Taking Initiative
        - Persistency
        - Standing Your Ground
        - Try to Influence Other's Thinking
    - Seek Legal Help
    - Helping Others in a Similar Situation
    - Trusting the School System and Attending IEPs
    - Changing Focus to Healing and Everyday Functioning
    - Question
    - Wait
    - Teach Skills to Others
    - Try to Fix It
    - Plan
    - Take Parenting Classes
    - Follow Directions
    - Hide
    - Ignore
    - Step Back When Things are Working
    - Separate from Unhealthy Lifestyle
    - Take One Day at a Time
    - High Involvement
        - Involved with Child
        - Taking Proactive Action
        - Parent as Primary Professional
        - Making and Taking to Appointments
        - Making Decisions for Child
        - Participation in Studies
- Cognitive Appraisal
    - Professionals Don't Know/Don't Understand/Are Ignorant
    - Lack of Functional Support
    - View of Own Coping Method as Pestering
    - Treatment is Not the Best
    - Treatment is the Best They Can Get
    - Seen as Not Helpful
        - Dietary Treatments

        - Certain “professionals”
        - Organizations that are “opportunists”
    - Seen as Helpful
        - ABA
        - MAPS
        - Private Sessions
        - Private School
        - Practical Suggestions to Take Home
    - Some Ineffective Treatments are Just as Expensive as Effective Ones
    - Child is Making Improvements
    - Child Needs More Treatments
    - Agencies that Work with the Families are Seen as More Positive
- Emotions/Feeling
    - Reactions
        - Crying
        - Blame Others
    - Hope
    - Confusion
    - Grief
        - Denial
        - Depression
        - Anger
        - Bargaining
        - Acceptance
    - Emotional Distress
        - Fear/Scared
        - Terrified
        - Devastated
        - Shock
        - Sadness
        - Brokenness
    - Positive Emotions
        - Pride
        - Happiness/gladness
        - Relief
        - Feeling Fortunate or Lucky
        - Empowered
        - Content
        - Confident (In Own Decisions)
    - Feeling Alone
    - Regret
    - Overwhelmed
    - Frustration
    - Doubt
    - Guilt
    - Exhausted

    - Offended
    - Anger at Others
    - Resentful
    - Disappointment
    - Helplessness
    - Hopelessness
    - Self-Blame
    - Concern for Child
    - Numb
    - Stress
        - Hypervigilence
        - Anticipatory Stress
        - Trauma
        - Fight or Flight Response
- Emotional Coping
    - Communication
    - Prayer
    - Meditation
    - Avoidance/Distraction/Disengagement
    - Face It
    - "Coming Back to Reality"
    - Contain Them
    - Don't Give Up
    - Resilience
    - Looking Forward
    - Getting Help with Own Mental Health Issues
    - Negative Strategies
        - Drinking
    - Blame Others
    - Seeking/Getting Support
        - From Religious Community
        - From Other Parents
        - From Mentors
        - From Family
- Emotional Appraisal
    - Seen as a Difficulty Process/A Struggle
    - Overcoming/Coming Out Stronger
    - Professionals Cannot Help Parents Cope
    - Seek Lack of Emotional Support
    - Viewed as Good Coping Strategies
        - Support Group Run by Other Parents
        - Patience
- Recommendations
    - For Professionals
        - Educate Professional Self on Issues Specific to Autism/Be Knowledgeable/Be Informed

        - Only Comment if You Understand and Be Honest When You Don’t Know
        - Offer Grace
        - Be Comforting
        - Display Warmth/Be Personable
        - Give Support
        - Show Empathy
        - Build a Relationship with the Parent
        - Treat with Greater Hope
        - Take Time/Don’t Rush
            - To LISTEN
            - To Answer Questions
            - To Address Parents’ Worries
        - Confront the Fakes
        - Be Nonjudgmental
        - Collaborate
        - Take an Active Role in Advocating for Appropriate Treatments
        - Make No Assumptions
        - Be Patient/Give Parents Time to Work Through Their Process in the Room with You
        - Be Careful with Your Words
        - Put the Client First
        - Don’t Be Afraid of Giving News
        - Have Consensus on Diagnosis
        - Connect with the Autism Community
        - Take a Course on How to Work with Parents of Autism
        - Get Involved/Advocate
        - Be Flexible in Hearing Other Viewpoints
        - Be Aware of What Insurance Covers
        - Be Accessible
    - For What to Offer Parents
        - Education
        - Guide to the Next Step
        - Offer Accessible Informative Evidence-Based Materials
        - Provide a Place Where Parents Can Get Immediate Help (e.g., 24 support line, email support?)
        - Consultation with Autism Specialists
        - Specific Recommendations
        - Help Navigating the System
        - Practical Suggestions to Take Home and Use Right Away
        - Teach Skills
        - Be Specific about Autism is and What to Expect
        - Facilitate Access to Resources
        - Financial Assistance
        - Provide Specific Referrals
        - Discuss All Different Types of Treatment Options

        - Help Connect Parents to a Network of Support
        - Home Visits
        - Information about Treatment Efficacy
        - Ways to Experience Self-Care
        - Encourage Parents to Get Advocates/Attorneys etc.
        - Enroll in Newsletter
        - Develop a National Plan for Consistency and Strength
- Process/Change
    - Change in Beliefs
    - Change in Emotions
    - Thoughts Impact Feelings
    - Observations Impact Beliefs (e.g., about cause)
    - Cognitive Coping Methods Linked to Emotional Coping
    - Emotional Reaction linked to Incoming Stimuli from System with Impacts Beliefs about Child
    - Beliefs Influenced by Cognitive Coping Method of Information Gathering
    - Lack of Knowledge Linked to Feeling of Confusion
    - Appraisals Impact the Process of Trying to Find the "Right" Treatment
    - Social System Impacts Beliefs because of the Experience of Others
    - Perception of Behaviors Related to Beliefs about Cause
    - Cyclical
    - A Journey
    - Making Healthy Choices
    - Expectations Change
        - By Seeing the Child's Progress/Improvement or Lack Thereof
- Other
    - Family Influence/Dynamics
        - Criticism from Family Members
        - Uniting with Spouse
        - Child's Disorder Impacts Family Relationships
        - Lack of Family Support
        - Accept/Deny Their Input
        - Shared Experiences
        - A Sixth Sense of Connection with Child
    - Wants
    - Time
    - Professional Involvement/Lack Thereof
    - Child's Life Becomes Mother's Life
    - No Rest or Break/Always on Call
    - Mother's Guilt of Self-Care
    - Mother's New Roles/Identity
        - Expert/Educator
        - Advocate
        - Helper
        - Protector
    - Change of Life

        - Job
        - Sleep
    - Systemic Issues
        - Problems with the System
            - Children Slip through the Cracks
            - Dismissal
            - Lack of Resources
            - Political or Financial Agendas Cause Children to Suffer
            - Lack of Support
            - People Have Lost Trust
            - Only the Lowest Required Services Offered
            - The System Progresses Slowly
        - Lack of Caring or Empathy
        - Professionals Lack Effort
        - Judgment and Negativity from Others
        - Professionals are Not Knowledgeable
        - Barriers
            - Financial
            - Insurance
            - Availability
            - Time
            - People in Management Positions Making Decisions
            - Evidence-based practices not offered
            - Only Offered the Bare Minimum
            - Limited Access/Lack of Coverage
            - Differential Provision of Services
            - Services Denied/Not Approved
            - Proper Treatments Were Delayed/Waitlisted/Need to Jump through Hoops
    - Learning to Live with It: "The New Normal"/Building a Family Routine
    - Process of How the Mother Answered the Question

Entry 4: Emerging of Themes

I wrote an analytic memo of a possible process based on some themes that I thought might be emerging from the data. I sent this memo to all team members and solicited their feedback.

Memo 1: Possible Process

I. Trauma and Grief
    a. When a mother first hears that her child is diagnosed with an autism spectrum disorder, the first stage of the process is akin to experiencing a traumatic loss. Shock, devastation, and stress are frequent emotional reactions as well as various stages of grief (e.g., denial, anger, depression). The mother may feel as if she has lost the child she was expecting to have,

which may be especially true for children with severe symptomatology. The emotional impact can often be exacerbated when doctors or other professionals do not take the time to listen or show empathy toward the mother. Family influence is also a big factor that affects how well the mother is able to cope emotionally with hearing the diagnosis. For instance, some mothers report having a supportive spouse who they can join with as a unit to take care of their child. On the other hand, some mothers report having family members who blame them for their child developing autism and actively contribute to their stress.

II. Confusion and Research
    a. After first hearing the autism diagnosis, mothers are often confused because they are not adequately informed by professionals. Many mothers perceive those that are supposed to be "professionals" as being unknowledgeable and unhelpful. Consequently, mothers frequently do their own research through books, articles, seeking assistance through local schools or regional centers, etc. Unfortunately, sometimes mothers look at information from nonscientific media and are misinformed. It takes significant discernment for mothers to determine what to believe and what to discount or reject.

III. The Search
    a. Just as with knowing what autism is, mothers struggling with knowing where to find help for their children and what treatments are available. While professionals may give recommendations, they are oftentimes not specific, are not collaborative with the desires of the family, do not include all options, and do not include follow-up to make sure that the family actually were connected to resources. Consequently, these mothers struggle to search for what treatments are best and where to get them. Sometimes they receive help from local organizations such as regional centers, but there are frequently many barriers for these mothers to getting proper treatments for their children. For example, health insurance and school districts often offer the minimum services required and sometimes even those services are not what work best for that family. Many families turn to their own personal finances to try to provide what they think would be helpful for their children, but they are constrained by their financial means and they oftentimes accrue significant debt, adding to their stressors. Additionally, the organizations that are supposed to help are sometimes the ones who deny services or put families on waiting lists for a very long time.

IV. The Fight
    a. Since these mothers do not get what they want initially, they have to fight for it. They do this through hiring and firing multiple companies to find the one that is the best fit, demanding services in Individualized Education Plans (IEPs) such as speech or occupational therapy, and/or turning to legal help. In addition to professional help, mothers connect within the autism community to mentor and support each other. Many mothers learn how to become advocates themselves along the way.

V. The New Normal
    a. After constantly fighting for what they want, the mothers eventually come to an acceptance of a particular treatment or set of treatments. Even when they do not believe it is the best treatment, they settle for what they think is the "best we can get". They also "learn to live with it". In other words, they learn how to take care of their children and create a life that works for them. One mother described this stage as "the new normal".

Entry 5: Discussion about Memo 1

Stacey provided feedback about the Memo:

Email from Stacey to Lara

Hi, Laura!

Hope you had a happy Easter, too! Please remind me, you're working on the process for a new grounded theory, correct? After reading over the memo, I can tell you've put a lot of work into this endeavor. Good for you! I agree that most families go through the stages of grief when their child is first diagnosed. And if you were to run a focus group and present your info, I believe many of the mothers who responded would agree to the process you listed.

My perspective in looking over the process is a little different, just because I've worked with families who have children with Autism for some time as a provider. I think in soliciting online responses, we're probably getting one type of parent. So, if you're just interested in that population, saturation will be easier to achieve. However, if you're interested in mothers in general, I think you'll find greater response differentiation by reaching out to a variety of mothers through multiple avenues.

What I mean is, I've found that parents usually fall into three categories (of course this is not based off of any official research, just my informal observations/experiences):
1) The Well Informed Parent: Though still devastated by their child's early diagnosis, this parent is well informed about the diagnosis and implications to help their child succeed prior to their child being diagnosed. This may be due to their education, work/life experience, etc. Of course, the situation makes them a prime candidate to become an expert after the diagnosis.
2) The Unsure Before, but Jumps in to Learn Parent: Then, there is the parent who didn't initially know much (if anything) about the diagnosis. However, they're willing to do whatever it takes to help their child, and seek resources and information until they are extremely competent/a good resource for themselves and others (most likely the crowd that's responding to the online surveys).
3) The Lackadaisical Parent: The parent who didn't know much before and may not care to know all that much after the diagnosis. They're content to let others (teachers, professionals, other family members, etc.) take the lead in their child's care.

I think the process will look different for each type of parent. Also, even though I just listed 3 categories, I'm still hesitant to ever put people in a box. So, I think there is naturally individual variation aside from the 3 parental types I tried to describe, too. Hope that makes sense! If not, just disregard it. :)

Anyway, those are my (slightly random) thoughts for now . . . Best wishes as you continue toward your dissertation!
-Stacey

Reply from Lara to Stacey

Hi Stacey,

Thank you for your thoughts about that. I was just building the memo based on what I saw emerging from the data, so I appreciate that you are looking outside the box. I definitely agree with you that my pilot data may have targeted one particular type of mother. In fact, when I was analyzing my demographic data of these mothers for my thesis, over half of the study sample was highly educated mothers with high household incomes (i.e., greater than $100,000). That is actually one reason why I invited Amber to the team because she has a special interest in homeless populations (and also that she is an amazingly kind person who always puts forth her best effort and takes her time putting together a quality product), so she is going to help me with recruiting participants who have less access to resources. If you have other ideas of populations to target, I would love to hear them.

I remembered that you said you had some experience working with families of children with autism, but I don't know if you every told me in what capacities. Can you describe a little more about your background with autism? I have also worked extensively with these families (which is part of why this is my research), so I wanted to let you know my background as it relates specifically to autism:

- 6 years part time doing parent training and Applied Behavior Analysis with children who had severe autistic symptomatology at the Lovaas Institute
- 1 year of play therapy with a child diagnosed with PDD under Dr. Freeman's supervision at LLU's internal psychology clinic (now at the BHI, but it was actually in the psych department when I was there)
- 1 year of neuropsychological testing at Casa Colina Centers for Rehabilitation (I believe about 5 of my patients were brought in for testing related to autism)
- 1 year of psychoeducational testing at Non-Public Schools through the San Bernardino City Unified School District (although I only remember 2 students having autism)
- 1 school year (i.e., 9 months) of individual therapy (60 min/wk per client) with 5 students on the autism spectrum at a Non-Public School through The Help Group

Now in response to your categories of parents, I had a lot of ideas that came up, so I am just going to write them down to "think out loud" and create a log that I can add to my reflexive journal to track our group process of interpretation:

I definitely have seen a lot of the "Unsure Before, but Jumps in to Learn" parent, both in the pilot sample and in my previous contact with parents. However, a lot of the parents I worked with previously also fit the demographic of highly educated and relatively high household income, so I don't know if maybe that is the process for a specific demographic. In my experience, though, even the "Well Informed" parents still search for what is best for their *individual* child and know enough to know that there is always new research coming out so they are still on the quest for more information. Also, even if they know what is best for their child doesn't mean that they can actually access it due to financial or systemic restrictions (e.g., insurance won't cover it, the schools won't approve it, etc.) I am wondering, then, if the process is still similar with both of these types of parents and that both are likely to become experts and advocates.

I have only met one set of parents who I thought fit the "Lackadaisical" type. One of the things I learned when working with them, though, is that they did not really know how to "work the system". For example, they were unaware of their rights to request additional testing through the school system. On the other hand, when I did give them suggestions, they did not follow through either, so it was a little bit of both (i.e., not knowing and not putting in the effort). Pilot Subject 26 is another mother who I think sort of fits in this category, but rather than "Lackadaisical", she seemed more like a "Trusts the System to Work" Parent. Something else that might be part of this category of parent is "Doesn't Trust the System", so it may not be that they are "Lackadaisical" but actively avoiding dealing with a system they don't believe they can trust (e.g., African American parents may be skeptical to work with psychologists because of the history of African American children being mislabeled as Intellectually Disabled when their performance on testing may have had to do with cultural bias or institutionalized disadvantages). Given the diversity in this potential category, I don't know if his means that it should be divided or if it should be given a broader title like "The Parent Who Steps Back". OR maybe this is part of a decision tree that can be added to the potential process (e.g., everyone starts with the shock and then there is a decision to either jump in or to step back).

Sorry about the length of this email, but please let me know:

1. your experience with children diagnosed with autism
2. if you have any suggestions of other populations to target, and
3. if you have any response to these thoughts about your categories.

Thanks,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate

Loma Linda University
School of Behavioral Health
Department of Psychology

Stacey's reply to Lara:

Hi, Lara!

Thank you for sharing your thoughts and wading through my random brainstorming. :) Yes, Amber is awesome! I just realized that we're both taking Quantitative Methods this quarter. Small world! :)

Here's your requested info:
1. your experience with children diagnosed with autism
I've been an occupational therapist since 2008. It's been such a wonderful life lesson to work with children who have Autism and their families. It's an honor to share in their stories. (Just in case you need practice settings = outpatient pediatrics/neurology, the school system, hippotherapy, and academia)

2. if you have any suggestions of other populations to target, and
I think you're doing really well! Perhaps checking with school districts or your previous ABA center (if you haven't already?), or any high end clinics for the other extreme? Recruiting always sounds a little daunting to me, so great job!!!

3. if you have any response to these thoughts about your categories.
Oh, I probably wouldn't claim them as my categories, just brainstorming. hehe! :) I appreciate the additional brainstorming you provided. I feel like that's a part of qualitative research that I really enjoy --- the ideas and what if questioning. :) In looking over the info, I think that lackadaisical is a poor word choice on my part. I like your version of the parent who steps back better. Of course, just like with Autism Spectrum Disorder, likewise there is always a continuum of parents as I'm sure you well know. :) And yes, I do think that even a well informed parent continues to dive into research/resources with new motivation after their child's diagnosis. As far as a decision to step forward or back, I think that parents almost innately move to the next step without consciously deciding. It's almost like they just know this is something they must do (for those working to increase resources). I'd be interested to find out the thought process of parents who step back. (Does personality play into it? Other life factors that require their energy? Lack of understanding? Trust vs. distrust like you mentioned? A combination?)

Anyway, thank you for brainstorming and best wishes as you continue.
-Stacey

Entry 6: Updating the Interview Questions

As an attempt to foster theoretical saturation, the preliminary coding was used to update the interview questions from the ones that were originally used for the pilot questions. The following is the email chain the research team used to finalize the questions:

From Taggart to Lara:

Some notes, personal opinions mostly, on the Semi-Structured Interview Questions that you e-mailed:

Overall, the interview seems rather comprehensive, but still manageable. Some of the ‘items’ involve multiple questions (e.g. “Have your thoughts about autism and your child influenced how you feel or vice versa? If so, how?”). I’m supposing that if the interviewee chooses to only focus on part of the question, there’s assumed flexibility to allow restating other parts of the question(s) as ‘prompts’ as well.

By Item:

1.
For Item 1, I had an idea for a third (iii) prompt, but after reading the rest of the items, I thought perhaps it’s better included elsewhere. This item seems to be an ‘overall’ sort of item anyhow.

> ([suggestion for possible prompt] “iii. How have your thoughts ~~and feelings~~ changed from the beginning [first looking for treatment] to now?”)

2. [suggestion for rewording] How has your understanding of autism changed (developed) over time?

3. [suggestion for rewording] Tell me how you think autism develops, and how you came to believe that?

4. ii. “What can [professionals] do to be more informed themselves?”

> [this possible prompt surprised me a little – I have trouble imagining answers for it I think?]

5. (nothing) (this item partly addresses the ‘1. iii’ that I considered above)

6. iii. [suggestion for possible prompt] “How have your thoughts changed from the beginning to now?” [again, from ‘1.iii’ considered above]

> [I realize this prompt doesn’t quite fit the theme of the rest of the prompt, but I’m uncertain where else you can check for changes in thoughts/beliefs over time…]

7. (nothing) 8. (nothing)

9. iii. [suggestion for possible prompt] “How do you behave/act differently, to address your child’s (Autism-related) needs, than you otherwise would?” (OR) “How has your life changed now, in response to your child’s Autism-related needs”

10. [comment: this seems quite related to #7 – may possibly combine?] [possible rewording] “How have your thoughts, beliefs, or emotions about your child’s autism influenced your choice of treatments – the ones you’ve tried and not tried?”

11. ----- 15. (nothing)

Common Pilot Codes – here are some thoughts on these…

- Understanding/Thoughts/Cognitions
    - Behaviors/Symptoms
        - Different from Other AUTISTIC children's (special; set apart)

- Recommendations
    - For professionals
      [a lot of these seem quite similar – empathy, grace, support, comfort…these are all bedside manners…is it useful to not collapse them?]

- Process/Change
    - Cyclical
      [what would this look like? is this addressing cycles of emotions or of behaviors?]

- Problems with the System

  [possibly add:] Fear of repercussions (e.g. CPS) …or maybe add this under feelings? (fear/scared) *shrug*

- Process of How the Mother Answered the Question

  [how/when do I use this code?]

Note sure if these are addressed and/or where it's best to address them, but I thought it curious to (pro'lly redundantly) mention that you may want to include these?:

- Debt
- Child will/won't improve over time
- Child will/won't get better (cured) over time

From Lara to Team:

Hey Everyone!

Here are the interview questions revised based on Taggart's fantastic suggestions. I also put headers above each question to describe the main domain or theme and changed the order slightly (10 is now 8). If anyone has additional feedback, please let me know asap. I plan on submitting my proposal to Dr. Freeman by tomorrow.

Thanks,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate

Loma Linda University
School of Behavioral Health
Department of Psychology

From Stacey:

Looks good! Guess we already talked about other aspects on the phone (verifying that the interviews will be semi-structured and face-to-face . . . or whatever ends up working best :)). Have a good rest of your day! :)
-Stacey

From Taggart:

Hi Lara,

Just two thoughts:

ONE. You probably don't need lower grade-level language on the official questions since interviewers can just modify their language when appropriate (right? that would make sense for qualitative interview questions). But some of the language is borderline. Especially...

#3, "originates": <u>"how...autism originates, or develops..."</u>
...I bring this up because it's the first word that really seemed like it might throw the respondents. "develops" kinda has a more ambiguous meaning, which may be what you were going for. If you needed a lower-level alternative: "how do you think your child came to have autism?" might work.

TWO.

#8: <u>Tell me how your thoughts, beliefs, or emotions about your child's autism may *or may not* have influenced your choice of treatments...</u>

I have trouble envisioning how a respondent would answer the "may not have" portion of the question. It may be confusing? I remember thinking this when I read through the original version too but I don't think I made a comment about it then. I might be missing something though.

That's it! Looks good - hope it goes well!

best,
Taggart

From Amber:

Hello Lara,
Overall your questions are very clear. I do agree with Taggart.
The only question that I read that needed to be worded a little different in addition to Taggart's suggestions is question #4.
#4.How can health professionals (e.g.....) better help parents understand what autism is and what to expect when their child is first diagnosed?
To keep this question more directed to each participant I think it would be best to use the word **You instead of Parents** in this question.
The more personable or directed question will be:
#4.How can health professionals**(**e.g**....)** better help you understand what autism is and what to expect when **your** child was first diagnosed?
You are doing a great job!
If you have any questions about my feedback, please let me know.
Have a good night!
Amber

From Lara:

Hey Everyone,

Thanks for all the feedback! I have some thoughts in response to some of the suggestions, so please respond to them as soon as you can (sorry for the length of this email).

First, to respond to Taggart's feedback:

1. I absolutely agree with the "originates" comment. I had a really hard time figuring out how to reword that question and didn't really like how it came out, honestly. It originally read, "Tell me what you think is the cause of autism and how you came to believe that," which I thought was pretty clear, but you recommended, "Tell me how you think autism develops, and how you came to believe that," which I understood that you were trying to get at a more process-oriented wording but it did not quite capture the idea of cause (I didn't want the mother to confuse it with developmental progress or something like that). However, I did like the idea of tapping in to developmental course, as some mothers did talk about that in the pilot responses. I really like the wording of "how do you think your child came to have autism?", but I know mothers have ideas about cause in general as it relates to the autism community as a whole in addition to their personal beliefs about their own child. Maybe it could read, "Tell me how you think your child came to have autism and how you came to believe that," and then add a prompt, "Do you think the cause of autism is the same for every child? If not, how do you think autism is caused in other kids?"...However, now I'm stuck on the idea of putting a developmental question in somewhere and I'm not sure how we should do that. Maybe a prompt under question 2 that says, "how do you think autism develops over time?"

2. I can see what you are saying about conceptualizing "may not have". My original thought was that some mothers may think that their thoughts and emotions had no bearing on their treatment decisions, and I didn't want to assume that they did. Also, I could imagine a mother saying something like, "Well, I didn't have a choice, it was the only thing available." If you have an idea for rewording it to capture this essence of non-assumption, I would really like your help figuring that out. Your ideas for rewording have been fantastic!

In response to Amber's feedback:

My only hesitation about rewording it that way is that the child has to have already been diagnosed with an autism spectrum disorder (this is part of the inclusion criteria for the study), so the interaction with the professional would have already happened in the past. My thought process about wording it that way was that this could be their advice to better help mothers like them in the future. I do like the idea of making it personal, though, so maybe it could read something like, "When your child was first diagnosed, how could health professionals (e.g.,...) better helped you understand what autism was and what to expect?" and then include a prompt of "How could they help other parents with this in the future?"

I hope to hear from you guys soon! :-)

Thanks,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate

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School of Behavioral Health
Department of Psychology

From Taggart:

So...yup on all accounts - I agree! :)
Alright, obviously not that simple. I was thinking the same thing you were in response to Amber's suggestion it looks like. I didn't think a rewording of the question was needed, but your solution seems to work (and it gives a more personal feel, which is good I think).
And I can see now how the "may not have" part of #8 could be useful - I don't really know a better way to tap that info.
Lastly, I wasn't sure if you were looking for how autism developed specific to the respondent's child, what causes it to develop in general, or both - so I THINK your suggestion here takes care of that...but original question did too to an extent...we're just nit-picking.

From Amber:

Hello Lara,
Thank you for your thorough explanation.
That does make sense to rewrite your question as you did below. Now it sounds more personal and it also includes your intent of getting their advice/suggestions for parents in the future.
"When your child was first diagnosed, how could health professionals (e.g.,...) better helped you understand what autism was and what to expect?" and then include a prompt of "How could they help other parents with this in the future?"
Great work!
Thank you.
Amber

From Stacey:

Hi, all!

Thank you for the good discussion. I talked to Lara on the phone last week, but just wanted to share with the rest of the team as well. I was happy to help out with the preliminary data last quarter. (My advisor had recruited me/allowed research assisting time to be utilized then.) However, looking forward, with work, current research assisting time needs, grad school, conference, and studying for comps this summer, unfortunately I won't be able to truly devote the time needed to help out with the up and coming phase. Please know that if you aren't hearing from me amongst the email threads, it's not because I don't care, it's simply because I'm sadly not available to assist with the new phase. □ However, I'm so excited for the progress that has been and will continue to be made. Great work, everyone! I'll be cheering for your research endeavors!

Well, I don't have much else to add to the interview discussion, except Lara and I had talked about the value of specifying that the interview format will be semi-structured. Thus, greater flexibility will be possible during the actual interview process, and wording can serve as a guideline instead of a requirement. □

Hope you're all having a good weekend!

Take care,
Stacey

Entry 7: Logistics

- We have been taking care of logistics such as compiling a list of facilities to recruit from, having research team members sign conflict of interest disclosures, and getting IRB approval.
- Due to me moving to Illinois, the research team has agreed to meet over an online video conferencing site (Webex) weekly for at least one hour.
- Amber put together a data collection flow chart so that we could all be on the same page. I created a document to clarify misconceptions and created a more detailed explanation of each step.

Entry 8: Recruitment

Amber and Taggart have started recruitment by contacting or visiting facilities from our list. Amber and I have also worked on a follow-up letter to send to places once we have visited them if they stated they needed to wait for approval or if we needed to maintain contact for doing presentations.

Entry 9: Starting Interviews

We have been able to recruit a few mothers for participation and have started interviews. In our meetings, we have been reviewing procedures and making sure that everything is HIPAA compliant. The following email shows highlights of what we discussed:

Hi Amber,

Here are some notes about what Taggart and I talked about in our meeting tonight (hopefully I remember everything).

1. Remember to have the mother sign the HIPAA authorization in addition to the informed consent.
2. The focus group is only going to happen after we have collected all the data because the purpose of the group is to present the findings to them and get their feedback on our interpretation.
3. Make sure you keep the recording on a password protected device (e.g., locked phone, password protected USB, password protected computer, etc.) The recording should end up on a password protected USB in a locked location at LLU as soon as possible.
4. Let me know if you need me to buy you a password protected USB to use.
5. Taggart is going to ask if he can use a locked file area in the psychology department to store a USB, informed consents, and other hard copy data. Let me know if you have a locked location in the MFT department that you can use to store these documents or if you need to collaborate with Taggart in getting documents to him to store.
6. Once you transcribe the recording, password protect the transcription (I can tell you the password over the phone or through a web chat) and then delete the recording from all devices.

7. Remember to use NVIVO for coding. There are computers in the social work department with it on them, but there may be some in Griggs or the psych department. Taggart is going to ask about whether there are any in the psych department. Can you please ask about if there are any in Griggs?
8. As far as a receipt, just track what you spent and when using the format of the document that Taggart sent.
9. Regarding whether we can give help to the mothers if they ask, you can refer them to me or use your own judgement about if there are places that you know would be helpful (e.g., possibly the Inland Regional Center). Be cautious, though, because we need to make sure we are clear that we are a research team and not a treatment team.

Let me know if you have any questions about any of that.

Thanks,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate

Loma Linda University
School of Behavioral Health
Department of Psychology

Entry 10: Some Key Points

We have been able to get a lot more mothers recruited, especially from Leaps ‘n Boundz. Now that we have been interviewing and starting to transcribe and code, here are some notes that were made regarding some key points that came up as we thought back over the interviews:

- For the stages that were formed in the original memo, perhaps it is more like decision points (e.g., getting the diagnosis, fighting/getting treatment/being persistent, getting stressed out/accept this is what is)
- Systems have become extremely apparent and mothers don’t only talk about her thoughts about the child, but her relationship with the child, school and child, school and other services, etc.
- Another significant thing that keeps occurring is comparing the child to other kids (e.g., at least my child does not have this much of the disability, comparing their autistic child to children with a visible disability)
- The regional center is a major focus for getting resources

We also discussed the wording of the interviews since sometimes Amber and Taggart’s follow up prompts were not consistent with the intention of how it was worded. For example, there needed to be much more of a focus on how have things developed over time. Furthermore, coaching was needed for the prompts to facilitate expanding answers rather than cut off what was being said.

Entry 11: More Key Points

Over our past few meetings, we have been discussing some additional points that have been coming up as we have been coding the first five interviews:

- Causes – Personal experiences are important
- Information – the internet is a common place to get info
- Contextual factors are important in mother's personal experiences
- Possible decision point processes (crisis moment?): change moment, changing understanding, changing access to services, validating something is "different with my kid"
- Mothers bring up vaccination almost universally

Entry 12: Review of Procedures

Since we are about to resume interviews and I just had to update my human subjects certification, this prompted me to review the procedures with the team to make sure any questions could be answered and inconsistencies resolved. One issue that occurred was that Amber had not provided a copy of the informed consent form to the participants, which she resolved by sending copies via email.

Entry 13: More Key Points 2

The following email segments show additional key points that we discussed regarding what we found after the second 5 interviews. Especially of note was that we related the emerging systems themes with Bronfenbrenner's model and I was wondering if there was a way to combine the Bronfenbrenner (ecological/systems) and Leventhal (self-regulation) models together.

Taggart's emailed notes:

CODE NOTES: READ UP ON...
-Bronfenbrenner's Ecological Model - to look at a more systemic/community interaction
-Levenson's Common Sense self-regulation model - to look at coping, cognitive appraisals, behaviors, etc.
(e.g.)individual, direct family unit, community, social, chrono-system
-Lara's question: how can i combine these two models in a way that makes sense?
-is the 'community' level encompassed by the 'society' level?
-Or perhaps instead 'society' level factors are separate and bidirectionally interacting with the 'community' level?

-Examples of factors related to the chrono-system (the broadest level of Bronfenbrenner's model
-dsm-iv/dsm-5
-region/system - on whether they've adopted more recent beliefs, systems, etc., like the DSM-5 (vs. still using DSM-IV)

-whereas Lara's own workplace uses DSM-5, Medicaid still uses DSM-IV...which limits them for clients that use medicaid
-the Inland Regional Center (anecdotally) seems more prepared than one of the LA ones - the LA center is limited in part by their reliance on DSM-IV
-The Year - particularly as it relates to how common autism seems to be (one mother noted that if she were trying to seek help five years before, the rarity would have made it more scary, etc.)
-related to how old their child is and where along the 'process' the mother is - i.e. the mother's own history

-Question for Amber: low-income families - how does this interact with our system (either model, and our own understanding of the Mothers of Children Diagnosed with Autism process)?
e.g. do people with low-income tend to have fewer resources, and thus are less prepared/likely to 'fight' for services?
e.g. Does low income somehow highlight a child's needs for resources (because parents are less capable trying to compensate for child's needs than a higher-income parent would be able to)?
How does low-income influence that self-regulation system? (e.g. cognitive appraisal, emotional feeling)

-Possible decision point - decide to be that 'mom' that fights for their child, versus accepting what's given?
-we discussed whether/how this was a 'decision point,' and compared notes on how we envisioned these decision points within the process...
-is it more of a 'knotted rope'? or more of a 'branch'? (the 'knots' in the rope would either stall the process or cycle the process to the same point continually.
[these next few lines were NOT in the meeting, but kinda me trying to translate for myself...and perhaps you]
-In other words, the 'decision' is equivalent to "go forward" in the process or "stay here"
-the 'branch' version would be more like, the decision is equivalent to "go left" or "go right"...and one could later come to that decision-point again.
-This suggests that if they choose left OR right, later along the 'process' they may come to that decision again.
-For each proposed decision point (decide if my child has a problem; decide to have my child assessed for autism; decide my child is not broken compared to other children - just not neurotypical), determine whether either choice 'stalls' the mother in their 'process,' or if they can move on.

-Although we are trying to consider how these factors relate, etc., it's not really our priority yet. As Lara reminded me, "abduction" is kinda like "induction" and "deduction" simultaneously - and that's our job in coding right now. We are casting a wide net, which we will 'narrow' when we collapse our codes together.

Entry 14: Stages Memo

In order to start building the concept of the stages and decision points, I created the following memo:

Stages

I. **Noticing a Difference**. The first step is noticing that there is something different. This can entail the mother noticing something that she sees as different from other children, others pointing out to the mother that she may want to get her child evaluated, or professionals (e.g., healthcare providers, school personnel) initiating discussion about the possibility of an autism diagnosis.

II. **Getting an Evaluation**. After a difference is noticed, the child needs an evaluation to determine whether the difference meets criteria for a diagnosis. This step can be facilitated when professionals offer help connecting the mother to resources or referrals. This can be done through a neuropsychologist, school psychologist, a Regional Center, etc.

III. **Getting a Diagnosis**. After obtaining an assessment, there is the process of actually getting the diagnosis. This can be problematic when there is misdiagnosis or being told the child does not meet criteria for autism.

IV. **Learning How to Accept It**. Mothers often described a grieving process. The final stage of this is acceptance. However, some mothers described being relieved at getting the diagnosis because it gave them some direction.

V. **Gathering Information**. Most mother's described an intense search for information after getting the autism diagnosis.

VI. **Getting Treatment**. Mothers typically try to find what they think will be the best treatment for their child. There are MANY barriers that they need to break through in order to find the treatments that they think will be best. This frequently leads to mothers needing to ***<u>fight</u>*** for what they want.

VII. **"The New Normal"**. Many mothers described a phase after finding treatments of "learning to live with it," "dealing with it," or shifting their lives to what one mother termed as "the new normal."

These stages can occur in order, but may be re-experienced as changes occur. For example, if the child hits new life stages or if the symptom expression changes.

For each of the stages, it may be important to include the following:

a. **Barriers**
b. **Facilitators**
c. **Self-Regulation Model**
    i. **Cognitive**
        1. **Beliefs**.
        2. **Coping**.
        3. **Appraisal**.
    ii. **Emotion**

            1. **Feelings**.
            2. **Coping**.
            3. **Appraisal**.
    d. **Ecological Model**
        i. **Microsystem**.
        ii. **Mesosystem**.
        iii. **Exosystem**.
        iv. **Macrosystem**.
    e. **Chronosystem**.

When I presented this to Amber and Taggart, Taggart felt like the "getting a diagnosis" stage may not be separate from the "getting an evaluation" stage. Additionally, Amber felt like "learning to accept it" may be in the wrong order because mothers described acceptance at different points in their stories.

I also drew a possible integrated self-regulation/systems model, which I shared with Taggart and Amber. They did not have any suggested alterations at this time.

Entry 15: Analogy of Multicultural Identity

Both Taggart and I independently came up with the analogy of some mothers seeming to have a similar process to multicultural identity development. Mothers of children who are high functioning seem to have a sense of being between two worlds of motherhood. Specifically, they don't feel accepted by mothers of typical children because their child is not typical but they also don't feel accepted by other MCDAs who have children that are lower functioning because their children do not fit the classic autism stereotype.

Entry 16: Coding Consensus/ Noticing of Team Member Perspectives

We have spent an incredibly long time over a number of months attempting to come to a consensus about the common codes we have thus far. We each took turns at dividing codes into possible common codes. After that, each of us came up with a list of codes that we *disagreed* with going in a particular common code so that we could discuss why it was put there or why we thought it might go somewhere else. Sometimes the debates became a little heated, but we eventually came to a consensus on each of the coding decisions for the first half of the interviews. We indicated that for the remainder of coding, we would use the common codes unless we came across something we did not feel was captured in what we already found.

Some notes came up as we went through this consensus process that need to be highlighted. First, Taggart and I sometimes needed to encourage Amber to make her voice heard rather than just agree with what we were saying. We wanted to be sure that her perspective was not ignored or silenced when her thoughts differed. Second, this dynamic could have occurred because both Taggart and I are in the psychology department, so we may have a particular way of looking at things that diverges from her view that is based in marriage and family therapy. One particular thing that we noticed was that Taggart is more likely to lean on explanations related to the person, Amber is more likely to lean on explanations related to systems, and I (Lara) am somewhere in the middle and try to see things from both perspectives.

Entry 17: Bronfenbrenner Definition Review

During the consensus process, we had many discussions around Bronfenbrenner's model as well since we all felt that systems became evident in the mothers' stories and we used this model to help organize some of our common codes. Consequently, I dug deeper into understanding the model and came up with the following summary of how Bronfenbrenner's definitions have developed over time.

Bronfenbrenner's Ecological Systems Theory

In Making Human Beings Human: Bioecological Perspectives on Human Development

Microsystem

- Pp. 45-46 1977 Microsystem as related to Lewin: two critical features of the immediate situation
    - Activity: an ongoing process characterized by intention and possessing a momentum of its own, so that person is captured by a demand for closure. Consistent with this element of intention, a dominant feature of a activity is the perception of a goal and movement toward the goal.
    - The existence of connections between people in the setting. These interconnections are formulated in terms not so much of interpersonal feelings as of the relations of the various parties toward each other as members of a group engaged in common, complementary, or relatively independent tasks
- Pg. xiii. The setting within which the individual is behaving at a given moment in his or her life. It is "*the complex of relations between the developing person and environment in an immediate setting containing the person*". 1977/79
- Pg. 54 The ecological environment is conceived as extending far beyond the immediate situation directly affecting the developing person-the objects to which he or she responds or the people with whom he or she interacts on a face-to-face basis. Of equal importance are connections between others present in the setting, the nature of these links, and their indirect influence on the developing person through their effect on those who deal with him or her firsthand. This *complex of interrelations within the immediate setting* is referred to as the microsystem. 1979
- Pg. 56 Within this proximal domain, the focus of attention and of developing activity tends initially to be limited even more narrowly to events, persons, and objects that directly impinge on the [individual] 1979
- Pg. 80 involves the structures and processes taking place in an immediate setting containing the developing person (e.g., home, classroom, playground) 1988
- Pg. 100 definition expanded to include reference to social, physical, and symbolic aspects of the immediate setting that invite, permit, or inhibit engagement in

sustained progressively more complex interaction with and activity in the immediate environment 1989

- Pp. 147-148 In order to address the fact that other people in the system are not only defined by their social roles and relationships by have distinctive characteristics of temperament, personality, or systems of beliefs, the definition of microsystem was expanded:
    - A microsystem is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical and material features and containing other persons with distinctive characteristics of temperament, personality, and systems of beliefs 1992
- Pp. 156-157 Recognizes the developmental importance of the characteristics of significant others in one's life. In other words, consider not only the background characteristics of the person but background characteristics of the other persons living in the same environment as well (e.g., neighbors, friends, associates at work)
- Pg. 160 In a microsystem paradigm, the developing person is viewed as an active agent who inevitably plays some part in any developmental process taking place in the microsystem. Any research design for a microsystem must therefore take this active role into account. In addition, the scientific power of a microsystem model is enhanced to the extent that it provides for each of the following:
    - The assessment of cognitive competence, socioemotional attributes, and context-relevant belief systems of the developing person, with particular emphasis on those qualities that meet criteria for being characterized as developmentally instigative
    - The assessment and interpretation of personal characteristics from the different viewpoints of the person him- or herself, familiar significant others in the setting, and a trained observer, as well as from the perspective of the culture(s) and subculture(s) in which the developing person has been raised and has lived 1992
- Pg. 161 Each member of a microsystem influences every other member. In terms of research design, it is therefore important to take into consideration the influence of each relationship on other relationships: for example, within the family the effect of the husband-wife relationship o the parent-child relationship, the effect of the mother-child relationship on the father-child relationship, and vice-versa. The appropriate design for this purpose is a process-person-context model in which each relationship is treated as a context for processes taking place in others. 1992
- Pg. xvi-xvii. 1994 expansion: Incorporates activities, relationships, and roles of the developing person into the system: *a pattern of activities, social roles, and interpersonal relations experienced by the developing person in a given face-to-face setting* with particular physical social, and symbolic features that invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in, the immediate environment

- Pg. xvii. 1998 expansion: Inclusion of the *person's interaction* not only with other people in this level of the ecology but also *with the world of symbols and language* (the semiotic system)

Mesosystem

- Pg. 46 Mesosystem as related to Lewin: Comprises the relations among two or more settings in which the developing person becomes an active participant…a mesosystem is a system of microsystems.
    - Possible interactions of several types:
        - Ecological transition: the move by the developing person into a new and different ecological context (e.g., going from preschool to school, changing jobs, etc.)
        - Note: the book doesn't explain the other types but in looking up the original article, it seems that he notes:
            - "transcontenxtual dyad": a two-person system involving the developing person that reappears in more than one setting
            - Other forms of interconnection other than face-to-face: various forms of communication (e.g., telephone conversations, letters, etc.) and indirect connections via the "grapevine" or social network
- Pg. xiii. The set of microsystems constituting the individual's developmental niche within a given period of development: it is "the interrelations among major settings containing the developing person at a particular point in his or her life". 1977/79
- Pg. 54 The principle of interconnectedness…within settings, with equal force and consequence to linkages between settings…those in which the developing person actually participates 1979
- Pg. 56 the recognition of the possibility of relations between settings, coupled with the capacity to understand spoken and written language, enables the [individual] to comprehend the occurrence and nature of events in settings that he or she has not yet entered 1979
- Pg. 80 comprises the linkages and processes taking place between two or more settings containing the developing person (e.g., the relations between home and school, school and workplace). In other words, a mesosystem is a system of microsystems 1988
- Pg. 148 1992 Definition does not change from 1988 version
- Pg. 159-160 1992 Note: There is commonality with exosystem in that both deal with relations between two or more settings. Linkages can take a number of forms, among them the participation of the same persons in more than one setting, communications between settings, and the availability of information in one setting about the other. Thus there is the following principle:
    - The nature and power of developmental processes at the level for the meso- or the exosystem are influenced to a substantial degree by belief systems and expectations existing in each setting about the other. Provision for assessing such bidirectional orientations should therefore be

incorporated as a key element in research designs involving the relation between two settings

Exosystem

- Pp. 46-47 Exosystem in relation to Lewin: a setting that does not itself contain a developing person but in which events occur that affect the setting containing the person…may involve “significant others” in that person’s life…but active involvement of people from the [individual]’s own world in other settings is not the only source of exosystem influence. Any social institution that makes decisions that ultimately affect conditions of the family life can function as an exosystem. 1977
- Pp. xiii-xiv. Composed of contexts that, while not directly involving the developing person, have an influence on the person’s behavior and development. “An extension of the mesosystem embracing…specific social structures, both formal and informal, that do no themselves contain the developing person but impinge upon or encompass the immediate settings in which the person is found, and thereby delimit, influence or even determine what goes on there”. 1977/79
- Pg. 54 The principle of interconnectedness…within settings, with equal force and consequence to linkages between settings…those he or she (the developing person) may never enter but in which events occur that affect what happens in the person’s immediate environment 1979
- Pg. 80 Encompasses the linkages and processes taking place between two or more settings, at least one of which does not ordinarily contain the developing person, but in which events occur that influence the processes within the immediate setting that does contain that person (e.g., for a child, the relation between the home and the parent’s workplace; for a parent, the relation between the school and the neighborhood peer group) 1988
- Pg. 148 1992 Definition does not change from 1988 version

Macrosystem

- Pg. 47 Macrosystem in relation to Lewin: encompasses the overarching patterns of stability, at the level of the subculture or the culture as a whole, in forms of social organization and associated belief systems and lifestyles.
- Pg. xiv. Superordinate level involving culture, macroinstitutions (such as the federal government), and public policy. Influences the nature of interaction within all other levels of the ecology of human development. 1977/79
- Pg. 54 The complex of nested, interconnected systems is viewed as a manifestation of overarching patterns of ideology and organization of the social institutions common to a particular culture or subculture. Such generalized patterns are referred to as macrosystems. Thus, within a given society or social group, the structure and substance of micro-, meso-, and exosystems tend to be similar, as if they were constructed from the same master model, and the systems function in similar ways. Conversely, between different social groups, the constituent systems may vary markedly. Hence by analyzing and comparing the micro-, meso-, and exosystems characterizing different social classes, ethnic and religious groups, or entire societies, it becomes possible to describe systematically

and to distinguish the ecological properties of these larger social contexts as environments for human development. 1979

- Pg. 81 An overarching pattern of ideology and organization of the social institution common to a particular culture or subculture. In other words, the macrosystem comprises the pattern of micro-, meso-, and exosystems characteristic of a given society or segment thereof. If may be thought of as a social blueprint for a particular culture or subculture. 1988
- Pg. 101 Definition was expanded: The macrosystem consists of the overarching pattern of micro-, meso-, and exosystems characteristic of a give culture, subculture, or other extended social structure, *with particular reference to the developmentally instigative belief systems, resources, hazards, lifestyles, opportunity structures, life course options, and patterns of social interchange that are embedded in such overarching systems* 1989
- Pg. 148 The macrosystem consists of the overarching pattern of micro-, meso-, and exosystems characteristic of a give culture, subculture, or other broader social structure, with particular reference to the developmentally instigative belief systems, resources, hazards, lifestyles, opportunity structures, life course options, and patterns of social interchange that are embedded in each of these systems. The macrosystem may be thought of as a societal blueprint for a particular culture, subculture, or other broader social context. 1992

Chronosystem

- Pg. 82-83: 1988 Time is employed not only for ordering individuals according to age but also for ordering events in their historical sequence and context
- Pg. 119-120: 1992 Taking into account constancy and change not only in the person but also in the environment. Attention has focused on developmental changes triggered by life events or experiences – may have origins in the external environment or within the organism. Can be short term (life transition) or long term (life course).
- Pg. 165 Note 13: The term chronosystem, which characterizes a particular type of research design, is not to be confused, through
  clang association," with a series of concepts employed in the 1979 monograph, as well as later in this chapter, to differentiate various types of environmental systems (micro-, meso-, exo-, and macro-) that serve as context of development. The chronosystem is a methodological construct; the remaining four are theoretical but can also become substantive when put to empirical use.
- Pg. xv. Time, conceptualized as involving the multiple dimensions of temporality- for example, ontogenic time, family time, and historical time-constituting the chronosystem that moderates change across the life course 1998
- Pg. xvii. 1998 – micro-, meso-, and macro- levels of time:
  - Microtime: continuity versus discontinuity within ongoing episodes of proximal processes
  - Mesotime: periodicity of these episodes across broader time intervals, such as days and weeks

  - Macrotime: changing expectations and events in the larger society, both within and across generations as they affect, and are affected by, processes and outcomes of human development over the life course

Process-Person-Context-Time (PPCT) Model

- Process: pg xv. the developmental process, involving the fused and dynamic relation of the ***individual* and *the context***
  - Pg. xv. Encompasses particular forms of interaction between organism and environment, called proximal processes, that operate over time and are posited as the primary mechanisms producing human development. However, the power of such processes to influence development is presumed, and shown, to vary substantially as a function of the characteristic of the developing *Person*, of the immediate and more remote environment *Contexts*, and the *Time* periods, in which the proximal processes take place 1998
- Person: pg xv. the person, with his or her individual repertoire of biological, cognitive, emotional, and behavioral characteristics
  - Pg. xvi. Starting in 1989, Bronfenbrenner acknowledged a gap regarding the Person feature of the theory and defines it this way in 1998: Three types of Person characteristics are distinguished as most influential in shaping the course of future development through their capacity *to affect the direction and power* of proximal processes *through the life course*. The first are dispositions that can set proximal processes in motion in a particular developmental domain and continue to sustain their operation. Next are bioecological resources of ability, experience, knowledge, and skill required for the effective functioning of proximal processes at a given stage of development. Finally, there are demand characteristics that invite or discourage reactions from the social environment of a kind that can foster or disrupt the operation of proximal processes. The differentiation of these three forms leads to their combination in patterns of Person structure that can further account for differences in the direction and power of resultant proximal processes and their developmental effects.
  - Pg. xvi. The three types of Person characteristics are also incorporated into the definition of microsystem as characteristics of parents, relatives, close friends, teachers, mentors, coworkers, spouses, or others who participate in the lofe of the developing person on a fairly regular basis over extended periods of time
  - Pg. xviii. Within the bioecological system, *the individual*, in dynamic relation to his or her temporally embedded, multilevel ecology, *is an active agent in his or her own development*
  - Pg. xviii-xix. Characteristics of the person actually appear twice in the bioecological model (part of the influencing elements and then again as an outcome): “The characteristics of the person function both as an indirect producer and as a product of development”

        - Pg xix. The individual’s contribution to the process of development is made by a synthesis, an integration, between te active person and his or her active context
- Context: the context of human development, conceptualized as the nested levels, or systems, of the ecology of human development he has depicted (i.e., the systemic levels defined originally in the 1977/79 version of the model)
- Time: pg. xv. time, conceptualized as involving the multiple dimensions of temporality-for example, ontogenic time, family time, and historical time-constituting the chronosystem that moderates change across the life course

Based on these definitions, Amber, Taggart, and I had several discussions to come up with a shared understanding of what the definitions meant. This included picking out the key concepts, diagramming our understandings both nested and networked and sometimes both, and settling on the 1998 definition versions that were outlined in the preface of “Making Human Beings Human.” I should also note that we have been going over the integrated self-regulation + Bronfenbrenner model that I drew up and we have not found a good way to improve it.

Entry 18: Bronfenbrenner Memo

Given the Bronfenbrenner discussions, I put together a memo of my understanding of Bronfenbrenner’s model that could be used in the dissertation:

Bronfenbrenner’s Ecological Systems Theory

Microsystem

Bronfenbrenner defines a microsystem as “a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical and material features and containing other persons with distinctive characteristics of temperament, personality, and systems of beliefs” (Bronfenbrenner citation). To fully understand the concept of the microsystem, each component of this definition needs to be explored in depth. Each segment of this definition will be explained in the following section.

The first part of this definition that needs attention is the concept that a microsystem is “a pattern of activities, roles, and interpersonal relations”. Activities and interpersonal relations were initially introduced to this definition of a microsystem because of original concepts Bronfenbrenner used from Lewin that there were two critical features in immediate situations: *activity* and *the existence of connections between people in the setting* (citation). Specifically, an activity is defined as “an ongoing process characterized by intention and possessing a momentum of its own…a dominant feature of an activity is the perception of a goal and movement toward the goal” (citation). Interconnections between people are viewed “in terms not so much of interpersonal feelings as of the relations of the various parties toward each other as members of a group engaged in common, complementary, or relatively independent tasks” (citation). These interconnections can be specific relations, or social roles, such as mother, teacher, friend, etc., but can also include any type of interpersonal relationship or interconnection. For example, Bronfenbrenner noted that every member within a microsystem influences every other member, but also added that relationships can influence other relationships (e.g., the influence of the wife-husband relationship on the parent-child relationships).

The next piece of this definition to examine is that these patterns of activities, roles, or interpersonal relations are “experienced by the developing person.” An important piece of a microsystem is that it always includes the individual. According to Bronfenbrenner, the individual is seen as an active agent that plays some part in the process. He admitted that he did not put particular emphasis on this aspect in his earlier writings, but acknowledged that it was a fault and encouraged further examination of the individual’s impact on systems. While the systems that surround the individual play an active role in the individual’s development, the individual has an impact on the systems as well. In other words, the relationship between the individual and surrounding systems is bidirectional. Consequentially, Bronfenbrenner has stated that proper modeling of a microsystem will include assessment of the individual’s “cognitive competence, socioemotional attributes, and context-relevant belief systems…with particular emphasis on those qualities that meet criteria for being characterized as developmentally instigative” (citation).

The next portion of the definition that should be explored is that the microsystem involves “a given face-to-face setting with particular physical, social, and symbolic features.” That is to say, the interactions that occur at the microsystem level involve proximal, or firsthand, exchanges. These can include person-to-person relationships as well as the individual’s dealings with “the world of symbols and language” (i.e., the semiotic systems; citation)

In addition, these elements of a microsystem “invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in, the immediate environment.” In other words, these mechanisms can help facilitate or be barriers to interaction. Additionally, the interactions should be sustained and become more complex to be part of the person’s development. Finally, they should be in the “immediate environment” because microsystems involve direct (as opposed to indirect) interactions.

Mesosystem

A mesosystem “comprises the linkages and processes taking place between two or more settings containing the developing person” (citation). In other words, a mesosystem is an interaction between one or more microsystems.

Exosystem

Bronfenbrenner defined an exosystem as “the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes within the immediate setting.” In other words, exosystems are indirect interactions. It should also be noted that the type of system depends on the reference point. For example, if the mother works, her workplace is an exosystem for the child because the child is not part of that system yet that system affects the child; however, it is a microsystem for the mother because she is directly involved in that system.

Macrosystem

A macrosystem "consists of the overarching pattern of micro-, meso-, and exosystems characteristic of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunity structures, hazards, and life course options that are embedded in each of these broader systems. The macrosystem may be thought of as a societal blueprint for a particular culture or subculture."

Entry 19: Coding Definitions

Having finished the coding consensus and interviewed 5 more participants, the following is a list of code definitions that I provided to the team based on our numerous discussions so that they could refer to it during coding for the third wave of participants:

Code Definitions

- Additional Stressors: Life stressors that occurred in the mother's story that are unrelated to autism.
- Advocating: Taking a proactive role in standing up for her child either individually or on a more community level (e.g., lobbying)
    - Appraising Advocating: Reflection on if the advocating strategies were successful or not.
    - Beliefs about Advocating: General beliefs about the process of advocating.
    - Fighting or Being Persistent: Needing to fight for what is wanted. Some mothers hedged the wording to say that it was not as strong as fighting but just being persistent. This step seems like it may be an earlier step in the advocating process.
- Appraising Professionals as Helpful: Appraising the outcome of interactions with professionals as helpful.
- Appraising Professionals as Unhelpful or Incompetent: Appraising the outcome of interactions with professionals as unhelpful (i.e., it didn't really do anything) or incompetent (i.e., it created more barriers, was harmful in some way, or demonstrated a lack of expertise on the part of the professional)
- Appraising Social Support as Negative: Appraising the outcome of interactions with the social support system (part of emotional coping) negatively (i.e., as bad).
    - Appraising Support Groups as Unhelpful: Appraising the outcome of interactions with support groups (part of emotional coping) as unhelpful.
- Appraising Social Support as Positive: Appraising the outcome of interactions with the social support system as positive (e.g., helpful, supportive, etc.)
- Appraising Treatment as Negative: Appraising the outcome of treatment negatively (i.e., bad, harmful, etc.)
    - Appraising Treatment as Unhelpful: Appraising the outcome of treatment as not helpful, but not necessarily negative. This category is for those who felt the treatment just didn't work for their children, not necessarily that it was bad.

- Appraising Treatment as Positive: Appraising the outcome of treatment positively (i.e., it worked, the process went well, etc.)
- Assessment or Evaluation: Processes related to assessment or evaluation. This could be trying to get the evaluation or the process of the evaluation itself.
- Barriers and Systemic Issues: Barriers in the process of trying to understand or help the child. The majority of the barriers were related to systemic issues. There may also be systemic issues that are not necessarily barriers specifically within the mother's story, but issues that she felt were important to note.
    - Being Denied: The process of being denied creating a barrier within the mother's journey.
    - Chronosystem Barriers: Barriers related to the point in time (e.g., DSM 5 not being fully integrated at all places)
    - Exosystem Barriers: Barriers that occur in systems that are outside of systems that the mother has direct involvement in.
    - Macrosystem Barriers: Barriers that occur on a cultural or belief system level.
    - Mesosystem Barriers: Barriers that occur between two microsystems.
    - Microsystem Barriers: Barriers that occur within the systems the mother has direct involvement in.
- Being Given Information or Treatment: A receptive process of an external person or entity providing information or treatment to the child and/or mother.
- Beliefs about Autism: General ideas regarding autism that are not about its definition.
- Beliefs about Causes
    - Environmental Causes: Beliefs about environmental causes of autism.
    - Genetic Causes: Beliefs about genetic causes of autism.
    - Medical Causes: Beliefs about medical causes of autism.
    - Multiple Causes: Beliefs that there are multiple causes of autism.
    - Ruling Out Causes: When a mother says, "I don't think X is the cause."
    - Unsure of Causes: Not being sure what the cause of autism is.
    - Vaccine Beliefs: Beliefs about whether or not vaccines cause autism.
- Beliefs about Child: Beliefs about the child as an individual.
- Beliefs about Symptoms: Beliefs about symptoms that may or may not be related to autism.
- Beliefs about Systems: General beliefs about certain systems (e.g., the medical system)
- Changing Treatment: Mother changing the child's treatment for any reason.
- Child's Experience: Mother describing her perception of the child's experience.
- Child's Symptoms: Symptoms the mother lists that the child has.
    - Noticing Symptoms in the Child: The early process of noticing differences in the child before a diagnosis was even made.
    - Symptom Expression Changing: A late process in the journey where symptoms change in some way. This could be the child's symptoms improving or getting worse as well as the symptoms shifting based on stage of life.
- Comparing Child

  - Comparing Child to Children with Other Problems: The mother comparing the child to children with non-ASD issues (e.g., other diagnoses such as Down Syndrome or other issues all together such as cancer)
  - Comparing to Neurotypical Children: The mother comparing the child to what they see in “normal” children.
  - Comparing to Other Children on the Spectrum: The mother comparing the child to other children that have ASDs (e.g., not as severe as some others, etc.)
- Comparing to Other Mothers
  - Comparing to Mothers of Children with Other Problems: The mother comparing herself or her experiences to mothers who have children with problems that are not ASD-related.
  - Comparing to Mothers of Neurotypical Children: The mother comparing herself or her experiences to mothers of “normal” children.
  - Comparing to Other MCDAs: The mother comparing herself or her experiences to other mothers with children on the spectrum.
- Contextual Factors – Filter: These are factors that are part of the mother’s background or previous experiences that create a context from which she may be perceiving her child and these new experiences.
- Coping
  - Active Coping: Active strategies for coping.
  - Appraising Coping: The mother appraising her coping method(s).
  - Avoiding: Using avoidance as part of a coping strategy/defense mechanism.
  - Changing Behavior: The mother changing her own behaviors as way to cope.
  - Changing Thinking: The mother changing the way she thinks about something as a way to cope.
  - Emotion-Focused: Coping strategies that are focused on emotional coping.
  - Humor: The use of humor as a method of coping.
  - Problem-Solving: Coping with the situation by using problem-solving strategies.
  - Relaxation and Recreation: Using relaxation or recreation as a coping method.
  - Seeking Support: Coping via seeking support.
- Crying or Cried: The mother talking about crying as a part of her emotional reaction during her journey.
- Dealing with It: Just pushing through and dealing with whatever comes up. This is a more preliminary version of acceptance or coming to “the new normal”.
- Deciding What to Believe: Making a decision of what she wants to believe
  - Changing Beliefs: Changing a belief from what was originally believed
  - Deciding What to Believe Based on Personal Experience: Having personal experiences within the autism journey that influence what the mother believes (e.g., “well this happened to my child so that’s why I believe that”)

- Defining Autism: How a mother defines what autism is
- Delays
    - Assessment Delays: Delays in receiving an assessment.
    - Diagnosis Delays: Diagnosis being delayed.
        - Late Diagnosis Causing Problems: Not getting an official diagnosis until later in childhood causing problems for the child (e.g., not being as advanced as could have been)
    - Treatment Delays: Delays in receiving treatment
- Denial: Denying the autism diagnosis or rejecting help
- Differential Diagnosis
    - Differential Diagnosis Outside the Spectrum: Needing to differentiate from other disorders (e.g., ADHD)
    - Differential Diagnosis Within the Spectrum: Having a diagnosis other than autistic disorder or being high functioning
    - Experiencing Difficulties due to Differential Diagnosis: Difficulties arising because the child does not have a classic autism disorder (e.g., not getting treatment because the child was considered to be too high functionoing)
- Experiences Increasing Awareness: Previous personal experiences of the mother that allowed her to have a better understanding of autism (e.g., family history of autism) or having experiences that increased her awareness of own needs or experiences of others
- Experiencing Grief or Loss: Feeling a sense of grief or loss of the child that could have been (i.e., the ideal)
- Family System: Interactions and elements relating to the family.
    - Autism Changing Family Interaction: Mother describing changes in how the family relates to each other because of the child's autism.
    - Family Structure: Elements of the family structure (e.g., mother working)
    - Finding Support Within Family: Doing things with family members to feel supported.
    - Interacting with Extended Family: Interactions with members of the family that are not part of the nuclear system within the household. It must be clear in the mother's voice that the family she is talking about is considered external and not just extended based on traditional definitions of the term (e.g., if a grandmother is in the home and part of the everyday interactions, then she would not be considered extended family)
    - Interaction between Mother and Child: Interactions between the mother and the child with autism that is the focus in the study.
        - Fostering Child's Independence: A specific type of interaction between mother and child where she tries to step back and foster the child's independence
    - Recognizing Symptoms in Other Family Members: Noticing that other members in the family display symptoms of autism or talking about how other members in the family actually have autism.
    - Sibling Interactions: Interactions that involve a sibling.

    - Mother with Sibling: Interactions that occur between the mother and her other children that or not the child of focus in the study.
    - Sibling with Sibling: Interactions that occur between the child with autism and other siblings.
  - Spouse Interactions: Mother and husband interactions.
- Feeling Negative Emotions
  - Anger: Feeling anger (e.g., at child, at others, at the process, at bureaucracy, etc.)
  - Anxiety or Stress: Feeling anxiety (i.e., emotional concern) or stress (e.g., physical reaction, active internal state). These have been combined since mothers use these terms interchangeably.
  - Confusion: A mental state of confusion.
  - Fear: Having fear (e.g., of the future) or being scared.
  - Guilt and Shame: Feeling guilty or having shame experiences (e.g., feeling self-conscious or uncomfortable)
  - Sadness: Feelings of sadness that differ from the sadness related to grief and loss.
- Feeling Positive Emotions: Feeling positive emotions (e.g., happy, grateful, lucky, etc.)
- Finding Treatment: The process of looking for treatments.
- Focusing on Self: Being able to focus on self (i.e., not completely focusing everything all on the child)
- Focusing on the Positive: Focusing attention on positive things.
- Functional Support: Getting practical help.
  - Getting Resources: The receiving of resources.
- Gaining Understanding of How to Help Child: Gaining knowledge that helps her actually know how to work with the child to help him or her.
- Gathering Information: Researching information.
- Getting a Diagnosis: The process of seeking a diagnosis in addition to actually receiving the diagnosis.
- Having a Hard Time: The mother describing the process as being hard.
- Having Comorbid Issues: The child having issues alongside autism. The comorbid issues can include other diagnoses (e.g., ADHD, anxiety) or other medical problems (e.g., GI problems, sleep problems)
- Having Negative Expectations: Worrying about negative outcomes.
- Having Positive Expectations: Expecting that things will get better.
- Having Process Get Easier Over Time: The process of helping the child not being as difficult as it was in the beginning.
  - Feeling Less Negative: Negative feelings decreasing.
- Helping and Informing Others: Taking an active role to help and inform others that are in the same situation or to inform others who may not understand the situation.
- Interacting Systems: Different systems interacting (e.g., medical with school).

    - Within Level Interactions: Interactions that occur between two systems that are on the same level of a Bronfenbrenner systemic level (e.g., a microsystem with another microsystem)
        - Interacting Levels of Support: Interactions that occur between two different support systems
    - Non-Interactions: Interactions that do not occur between systems (e.g., medical system not communicating with a different treatment system to coordinate care)
    - Between Level Interactions: Interactions that occur between two systems that are on different Bronfenbrenner systemic levels (e.g., a microsystem with an external system)
- Misdiagnosis: Getting a wrong, inaccurate, or incomplete diagnosis.
- Mother Interacting with Other Systems: Mother's individual interaction with other outside systems.
- Mother Taking Action: Mother taking some sort of action (e.g., changing insurance, getting an appointment, creating a network, etc.) This differs from personal agency or participating because these actions may not be directly involved in treatment.
- Mother's Characteristics: Descriptive of the mother (e.g., smart, strong, a teacher, etc.)
- Mother's Identity: A mother's sense of identity/who she is
- Mother's Personal Agency: A mother's belief/behavior/feeling that she can personally and directly make a difference for the child.
- Mother's Self-Appraisal: A mother's view of whether she is doing well or not.
- Needing to Pay for What is Wanted: Needing to pay out of pocket because a service is not covered by insurance or IEP.
- Normalizing the Child: Describing the child in a way that highlights the child's personhood rather than the difference.
- Not Focusing on Self: The mother not taking time for self-care or doing anything for herself.
- Not Knowing: Having a lack of knowledge about something.
- Participating: Taking an active role in treatment as a primary agent.
- Perceiving a Lack of Support: Feeling like there is no one there to help or provide emotional support.
- Poor Functional Support: Functional support (e.g., practical guidance, money, etc.) that is poor
- Receiving Services: A receptive process of getting services.
- Recommendations for Professionals: Responses to what the mothers would like from professionals.
    - Having Ideas about What Professionals 'Should' Do: These are ideas that mothers have about what they should be doing as a rule. These thoughts generally have a sense of judgment in them that professionals are not doing something that should be obvious.
- Seeking Help and Resources: Looking for help and resources for the child
- Spiritual Beliefs: Beliefs related to God or other spiritual phenomenon.

    - Spiritual Support: Support that is felt related to God or religious community.
- ‘This is the New Normal’: Coming to a point of reordering life around the child to where it has become accepted and normal
    - Acceptance: Accepting the child’s diagnosis and symptoms
    - Focusing on the Child: Doing everything centered around the child to a point where nothing else can be focused on. This seems to be an earlier step in the process of coming to “the new normal” because there is not a balance of taking care the child while still being able to take care of other parts of life.
- Trying Alternatives: Trying treatments that may be considered alternative to traditional treatments.
- Trying Multiple Treatments: The mother may try multiple types of treatment or multiple providers of the same treatment.
- Wanting (Better) Diagnosis or Treatment: Wishing the diagnostic process to be better or wanting a treatment that is better than what is had.
- Wanting More for Child: Wanting more in life for the child.

Entry 20: “Meta-Codes”

It should also be noted that Taggart created what he referred to as a “meta-codes” list that he felt helped him to see relationships between the variables and code more accurately. These tables will be added once the coding list is finalized.

Entry 21: Transcription Delays

With my chair’s permission, I am paying for transcription of the remaining interviews because it was taking too long for me to rely on Amber and Taggart (e.g., they have not finished any of the third set of interviews within the months that we have gone over the coding consensus). This is amplified further because of Amber backing out on transcribing a few of the interviews she did.

Entry 22: Last Set of Recruitment and Interviews

I underestimated the number of participants we had on our Leaps ‘n Boundz list and a couple of the mothers who did the interviews and said they would fill out surveys did not complete the online survey. Consequently, I needed to recruit more mothers. I created a new set of places to recruit from, which I went to personally. With this last push, I was able to get the final participants. I conducted these interviews and surveys myself as well because Taggart and Amber have become too busy with their own obligations.

Entry 23: Last Codes and Cross-Coding

Taggart has become difficult to get a hold of and Amber has indicated that she cannot do too much at this time because of her own research. As a result, I have had to do much of the final coding. However, each of them committed to cross-coding at least one interview so that we can maintain the credibility of the study. I am somewhat concerned about the fact that the others have not coded as much as I have, but all members have had at least some input at each step. The final tally is as follows:

Name	Interviewed	Initial Coded	Cross-Coded
Lara	6	14.5	3
Taggart	7	4	1
Amber	7	1.5	1

Entry 24: Added Codes from Final Round of Coding

Autism Culture: Ideas related to the idea of there being an autism community or culture
Beliefs about Professionals: General beliefs about professionals. These aren't different than appraisals, but are more general thoughts.
Beliefs about Treatment: General beliefs about treatment. These aren't necessarily appraisals because they may not have tried it but still have a thought about it.
Feeling Judged or Blamed: Feeling judged or blamed by others
Having Concern for the Future: Worries or concerns about the child's future
Mother Learning or Growing: Mothering learning, evolving, or growing through the process/journey

Entry 25: Taggart's Final "Meta-Codes" List

Here are the finalized "meta-code" tables that Taggart had worked on to help him code:

Key: Name of Code (Code 2-letter abbreviations, alphabetical, divided by slashes) (thought/feeling/behavior if multiple, with slashes)

Key Example 1: Code Name (Ex/La) Key Example 2: Code Example (Ex)(Th/Bx)

Key: (negative, negative/positive/ positive)
negative negative/positive positive

List of Meta-Codes: Change, Coping, Comparing, Diagnosis, Defining, Personal Experiences, Learning, Support, Systems, Treatment, Wanting

List of Meta-Code 2-Letter Abbreviations: Ch/Co/Cm/Di/Df/Ex/Le/Su/St/Sy/Tx/Wa

APPRAISING (AP)

Thoughts	**Feelings**	**Behaviors**	**Other**
Appraising Advocating (Ap/Co)	*(none)*	Problem-Solving (Ap?/Co)	*(none)*
Appraising Professionals as Helpful (Ap/Pr)		Mother's Personal Agency (Ap)(Th/Bx)	
Appraising Professionals as Unhelpful or Incompetent (Ap/Pr)			
Appraising Social Support as Negative (Ap/Su)			
Appraising Support Groups as Unhelpful (Ap/Su)			
Appraising Social Support as Positive (Ap/Su)			
Appraising Treatment as Negative (Ap/Tx)			
Appraising Treatment as Unhelpful (Ap/Tx)			
Appraising Treatment as Positive (Ap/Tx)			
Beliefs About Autism: Vaccine Beliefs (Ap?/Au)			
Coping: Appraising Coping (Ap/Co)			
Mother's Characteristics (Ap)			
Mother's Identity (Ap?)			
Mother's Personal Agency (Ap)(Th/Bx)			
Recommendations for Professionals (Ap?/Pr)			
Recommendations for Professionals: Having Ideas about what Professionals 'Should' Do (Ap?/Pr)			

AUTISM (AU) - any code directly relating with ASD concepts, including definitions and symptoms

Thoughts	**Feelings**	**Behaviors**	**Other**
Beliefs about Autism (Au)	Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)	*(none)*	*Child's Symptoms (Au/Chi)*
Beliefs about Causes (Au)	Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)		Noticing Symptoms in the Child (Au/Chi/Ex)
Beliefs about Causes: Environmental Causes (Au)			Symptom Expression Changing (Au/Ch/Chi)
Beliefs about Causes: Genetic Causes (Au)			
Beliefs about Causes: Medical Causes (Au)			
Beliefs about Causes: Multiple Causes (Au)			
Beliefs about Causes: Ruling Out Causes (Au)			
Beliefs about Causes: Unsure of Causes (Au)			
Beliefs about Causes: Vaccine Beliefs (Ap?/Au)			
Beliefs about Symptoms (Au/Chi?)			
Deciding What to Believe (Au?)			
Deciding What to Believe: Changing Beliefs (Au?/Ch)			
Deciding What to Believe: Deciding What to Believe Based on Personal Experience (Au?/Ex)			
Defining Autism (Au)			
Recognizing Symptoms in Other Family Members (Au/Ex?/Sy)			
Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)			
Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)			

CHANGING/LEARNING (CH)

Thoughts	**Feelings**	**Behaviors**	**Other**
Coping: Changing Thinking (Ch/Co)	*Having Process Get Easier Over Time (Ch) (Fe?)*	Changing Treatment (Ch/Tx)	Child's Symptoms: Symptom Expression Changing (Au/Ch/Chi)
Deciding what to believe: Deciding What to Believe Based On Personal experience (Au?/Ch?/Ex)	Having Process Get Easier Over Time: Feeling Less Negative (Ch) (Fe)	Coping: Changing Behavior (Ch/Co)	Family System: Autism Changing Family Interaction (Ch/Sy)
Deciding What to Believe: Changing Beliefs (Au?/Ch)		Trying Alternatives (Ch?/Tx)	
Experiences Increasing Awareness (Ch/Ex)		Trying Multiple Treatments (Ch?/Tx)	
Gaining Understanding of How to Help the Child (Ch/Chi)			

CHILD (CHI) - codes where the child is the primary subject

Thoughts	**Feelings**	**Behaviors**	**Other**
Beliefs about Child (Chi)	Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)	Family System: Interaction Between Mother and Child (Chi/Sy)	Child's Experiences (Chi/Ex)
Beliefs about Symptoms (Au?/Chi)	Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)	Focusing on the Child Chi/Co)	*Child's Symptoms (Au/Chi)*
Comparing Child (Chi/Cm)	Wanting More for Child (Chi/Ex) (Th/Fe)		Child's Symptoms: Noticing Symptoms in the Child (Au/Chi/Ex)
Comparing Child to Children with Other Problems (Chi/Cm)			Child's Symptoms: Symptom Expression Changing (Au/Ch/Chi)
Comparing to Neurotypical Children (Chi/Cm)			Family System: Sibling Interaction (Chi/Sy)
Comparing to other children on the spectrum (Au/Chi/Cm)			Family System: Sibling Interaction, Sibling with Sibling (Chi/Sy)
Gaining Understanding of How to Help the Child (Ch/Chi)			Having Comorbid Issues (Chi/St)
Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)			
Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)			
Normalizing the Child (Ap?/Chi/Co?)			
This is the 'New Normal': Focusing on the Child (Chi/Co)			
Wanting More for Child (Chi/Ex) (Th/Fe)			

COMPARING (Cm)

Thoughts	**Feelings**	**Behaviors**	**Other**
Comparing Child (Chi/Cm)	*(none)*	*(none)*	*(none)*
Comparing Child to Children with Other Problems (Chi/Cm)			
Comparing to Neurotypical Children (Chi/Cm)			
Comparing to other children on the spectrum (Au/Chi/Cm)			
Comparing to Other Mothers (Cm/Ex/Sy)			
Comparing to Mothers of Neurotypical Children (Cm/Ex/Sy)			
Comparing to Other MCDAs (Au/Cm/Ex/Sy)			

COPING/ADVOCATING (Co) - codes reflecting possible strategies for coping, advocating, or similar

Thoughts	**Feelings**	**Behaviors**	**Other**
Advocating: Appraising Advocating (Ap/Co)	Coping: Emotion-Focused (Co) (Fe/Bx)	*Advocating (Co/Sy?)*	*(none)*
		Advocating: Fighting or Being Persistent (Co/St)	
Advocating: Beliefs about Advocating (Co)	Coping: Humor (Co) (Th/Fe?)		
Appraising Social Support as Negative (Ap/Co?/Re?/Su)	Crying or Cried (Co) (Fe/Bx)	*Coping (Co)(Th/Bx)*	
Appraising Support Groups as Unhelpful (Ap/Co?/Re/Su/Sy)	This is the 'New Normal': Acceptance (Co) (Th/Fe)	Coping: Active Coping (Co)	
Appraising Social Support as Positive (Ap/Co?/Re?/Su)		Coping: Avoiding (Co)	
Coping (Co)(Th/Bx)		Coping: Changing Behavior (Ch/Co)	
Coping: Appraising Coping (Ap/Co)		Coping: Emotion-Focused (Co) (Fe/Bx)	
Coping: Changing Thinking (Ch/Co)		Coping: Problem-Solving (Ap?/Co)	
Coping: Humor (Co) (Th/Fe?)		Coping: Relaxation and Recreation (Co)	
Denial (Co/Di?/Re?)		Coping: Seeking Support (Co/Re/Su)	
Focusing on Self (Co)(Th/Bx)		Crying or Cried (Co) (Fe/Bx)	
Focusing on the Positive (Co)		Dealing with It (Co)	
Normalizing the Child (Ap?/Chi/Co?)		Focusing on Self (Co)(Th/Bx)	
Spiritual Beliefs (Co/Su/Sy)		Gathering Information (Co?/Re)	
This is the 'New Normal' (Co)		Helping and Informing Others (Co/Su/Sy)	
This is the 'New Normal': Acceptance (Co) (Th/Fe)		Mother Taking Action (Co/Sy?)	
This is the 'New Normal': Focusing on the Child (Chi/Co)		Mother's Personal Agency (Ap/Co?)(Th/Bx)	
		Not Focusing on Self (Co/St?)	
		Participating (Co?/Sy/Tx)	
		Focusing on the Child (Chi/Co)	

DIAGNOSIS/ASSESSMENT (Di) - reflecting processes related to seeking or receiving diagnosis or assessment for ASD, comorbid disorders, and medical issues

Thoughts	**Feelings**	**Behaviors**	**Other**
Assessment or Evaluation (Di)(Th?/Bx?)	Wanting (Better) Diagnosis or Treatment (Di/Tx) (Th/Fe)	Assessment or Evaluation (Di)	*Delays (Di/St)*
Delays: Late Diagnosis Causing Problems (Di/St)		Getting a Diagnosis (Di)	Delays: Diagnosis Delays (Di/St)
Denial (Co/Di?/Re?)			*Differential Diagnosis (Di)*
Differential Diagnosis: Experiencing Difficulties Due to Differential Diagnosis (Di/St)			Differential Diagnosis Outside the Spectrum (Di)
Wanting (Better) Diagnosis or Treatment (Di/Tx) (Th/Fe)			Differential Diagnosis Within the Spectrum (Di)
			Misdiagnosis (Di/St)

EXPERIENCES (Ex) - as in "personal experiences" - codes that reflect the MCDA's direct experience or experience of their child

Thoughts	**Feelings**	**Behaviors**	**Other**
Beliefs about Child (Chi/Ex)	*(none)*	*(none)*	Child's Experiences (Chi/Ex)
Comparing to Other Mothers (Cm/Ex/Sy)			Child's Symptoms: Noticing Symptoms in the Child (Au/Chi/Ex)
Comparing to Mothers of Neurotypical Children (Cm/Ex/Sy)			Child's Symptoms: Symptom Expression Changing (Au/Ch/Chi/Ex?)
Comparing to Other MCDAs (Au/Cm/Ex/Sy)			Contextual Factors (Ex)
Deciding what to believe: Deciding What to Believe Based on personal experience (Au?/Ch/Ex)			
Experiences Increasing Awareness (Ch/Ex)			
Family System: Recognizing Symptoms in Other Family Members (Au/Ex?/Sy)			
Mother's Characteristics (Ap/Ex?)			
Wanting More for Child (Chi/Ex/Fe)			

FEELINGS (Fe) - emotions, sensations, 'stress'...internal but not thoughts; including "wanting"

Thoughts	Feelings	Behaviors	Other
Coping: Humor (Co) (Th/Fe?)	*(n/a)*	Coping: Emotion-Focused (Co) (Fe/Bx)	Experiencing Grief or Loss (Fe)
Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)		Crying or Cried (Co) (Fe/Bx)	*Feeling Negative Emotions (Fe)*
Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)		Needing to Pay for What is Wanted (Re/Tx) (Fe?/Bx)	Feeling Negative Emotions: Anger (Fe)
This is the 'New Normal': Acceptance (Co) (Th/Fe)			Feeling Negative Emotions: Anxiety or Stress (St) (Fe)
Wanting (Better) Diagnosis or Treatment (Di/Tx) (Th/Fe)			Feeling Negative Emotions: Confusion (Fe)
Wanting More for Child (Chi) (Th/Fe)			Feeling Negative Emotions: Fear (Fe)
			Feeling Negative Emotions: Guilt and Shame (Fe)
			Feeling Negative Emotions: Sadness (Fe)
			Feeling Positive Emotions (Fe)
			Having a Hard Time (St) (Fe)
			Having Process Get Easier Over Time (Ch) (Fe?)

PROFESSIONALS (Pr) - including specific institutions, "teams," etc.

Thoughts	Feelings	Behaviors	Other
Appraising Professionals as Helpful (Ap/Pr)	*(none)*	(none)	(none)
Appraising Professionals as Unhelpful or Incompetent (Ap/Pr)			
Recommendations for Professionals (Ap?/Pr)			
Recommendations for Professionals: Having Ideas about what Professionals 'Should' Do (Ap?/Pr)			

RESOURCES (Re) - such as money, information, services, etc.; also see the "Support" category

Thoughts	Feelings	Behaviors	Other
Appraising Social Support as Negative (Ap/Co?/Re?/Su)	Needing to Pay for What is Wanted (Re/Tx) (Fe?/Bx)	Coping: Seeking Support (Co/Re/Su)	Additional Stressors (Re?/St)
Appraising Support Groups as Unhelpful (Ap/Co?/Re/Su/Sy)		Gathering Information (Co?/Re)	Being Given Information or Treatment (Re/Tx)
Appraising Social Support as Positive (Ap/Co?/Re?/Su)		Needing to Pay for What is Wanted (Fe?/Re/Tx)	*Functional Support (Re/Su)*
Denial (Co/Di?/Re?)		Seeking Help and Resources (Re/Tx)	Functional Support: Getting Resources (Re/Su)
Not Knowing (Re/St)			Poor Functional Support (Re/St?/Su)
			Receiving Services (Re/Tx?)

SUPPORT (Su)

Thoughts	Feelings	Behaviors	Other
Appraising Social Support as Negative (Ap/Co?/Re?/Su)	*(none)*	Coping: Seeking Support (Co/Re/Su)	*Functional Support (Re/Su)*
Appraising Support Groups as Unhelpful (Ap/Co?/Re/Su/Sy)		Family System: Finding Support within the Family (Su/Sy)	Functional Support: Getting Resources (Re/Su)
Appraising Social Support as Positive (Ap/Co?/Re?/Su)		Helping and Informing Others (Co/Su/Sy)	Perceiving a Lack of Support (St?/Su)
Spiritual Beliefs (Co/Su/Sy)			Poor Functional Support (Re/St?/Su)
Spiritual Support (Su/Sy)			

STRESSORS/BARRIERS (St)

Thoughts	**Feelings**	**Behaviors**	**Other**
Delays: Late Diagnosis Causing Problems (Di/St)	Feeling Negative Emotions: Anxiety or Stress (St) (Fe)	Advocating: Fighting or Being Persistent (Co/St)	Additional Stressors (Re?/St)
Differential Diagnosis: Experiencing Difficulties Due to Differential Diagnosis (Di/St)	Having a Hard Time (St) (Fe)		*Barriers and Systemic Issues (St/Sy)*
Not Knowing (Re/St)			Barriers and Systemic Issues: Being Denied (St)
			Barriers and Systemic Issues: Chronosystem Barriers (St/Sy)
			Barriers and Systemic Issues: Exosystem Barriers (St/Sy)
			Barriers and Systemic Issues: Macrosystem Barriers (St/Sy)
			Barriers and Systemic Issues: Mesosystem Barriers (St/Sy)
			Barriers and Systemic Issues: Microsystem Barriers (St/Sy)
			Delays (Di/St)
			Delays: Diagnosis Delays (Di/St)
			Delays: Treatment Delays (St/Tx)
			Having a Hard Time (Fe/St)
			Having Comorbid Issues (Chi/St)
			Misdiagnosis (Di/St)
			Perceiving a Lack of Support (St?/Su)
			Poor Functional Support (Re/St?/Su)

SYSTEMS (Sy)

Thoughts	**Feelings**	**Behaviors**	**Other**
Appraising Support Groups as Unhelpful (Ap/Co?/Re/Su/Sy)	Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)	*Advocating (Co/Sy?)*	*Barriers and Systemic Issues (St/Sy)*
Belief about Systems (Sy)	Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)	Family System: Finding Support within the Family (Su/Sy)	Barriers and Systemic Issues: Chronosystem Barriers (St/Sy)
Comparing to other mothers (Cm/Ex/Sy)		Family System: Interacting with Extended Family (Sy)	Barriers and Systemic Issues: Exosystem Barriers (St/Sy)
Comparing to Other MCDAs (Au/Cm/Ex/Sy)		Family System: Interaction between Mother and Child (Chi/Sy)	Barriers and Systemic Issues: Macrosystem Barriers (St/Sy)
Family System: Recognizing Symptoms in Other Family Members (Au/Ex?/Sy)		Family System: Sibling Interaction, Mother with Sibling (Sy)	Barriers and Systemic Issues: Mesosystem Barriers (St/Sy)
Having Negative Expectations (Au?/Chi?/Sy?) (Th/Fe?)		Family System: Spouse Interaction (Sy)	Barriers and Systemic Issues: Microsystem Barriers (St/Sy)
Having Positive Expectations (Au?/Chi?/Sy?) (Th/Fe?)		Helping and Informing Others (Co/Su/Sy)	*Family System (Sy)*
Spiritual Beliefs (Co/Su/Sy)		Mother Taking Action (Co/Sy?)	Family System: Autism Changing Family Interaction (Ch/Sy)
Spiritual Support (Su/Sy)		Participating (Co?/Sy/Tx)	Family Structure (Sy)
			Family System: Sibling Interaction (Chi/Sy)
			Family System: Sibling Interaction, Sibling with Sibling (Chi/Sy)
			Interacting Systems (Sy)
			Interacting Systems: Within-Level Interactions (Sy)
			Interacting Systems: Non-Interactions (Sy)
			Interacting Systems: Between-Level Interactions (Sy)
			Mother Interacting with Other Systems (Sy)

TREATMENT (Tx)

Thoughts	Feelings	Behaviors	Other
Appraising Treatment as Negative (Ap/Tx)	Needing to Pay for What is Wanted (Re/Tx) (Fe?/Bx)	Changing Treatment (Ch/Tx)	Being Given Information or Treatment (Re/Tx)
Appraising Treatment as Unhelpful (Ap/Tx)	Wanting (Better) Diagnosis or Treatment (Di/Tx) (Th/Fe)	Finding Treatment (Tx)	Delays: Treatment Delays (St/Tx)
Appraising Treatment as Positive (Ap/Tx)		Needing to Pay for What is Wanted (Re/Tx) (Fe?/Bx)	Receiving Services (Re/Tx?)
Wanting (Better) Diagnosis or Treatment (Di/Tx) (Th/Fe)		Participating (Co?/Sy/Tx)	
		Seeking Help and Resources (Re/Tx)	
		Trying Alternatives (Ch/Tx)	
		Trying Multiple Treatments (Ch/Tx)	

Entry 26: Process

I drew up a possible process model based on the process-oriented codes and the stages/decision points the team had previously discussed. I sent this model to Amber and Taggart and they each provided feedback. Here is the email chain that occurred:

From Taggart:

Hi!

I like it. Here are my thoughts...I was going to say "so far," but I'm not thinking they will change too much (though if I do have any additiional thoughts I'll let you know).

1. Box 1: Seems to be the initial appraisal.
2. Box 2: The two branches from this box feel like examples of feelings supported or not supported by the assessment/evaluation process/system.
3. Box 3, 4, and 5 (left to right): I noticed these seem to be emotion-focused, cognitive, and behavioral in theme. Cool!
4. Box 5 also seems to be very similar to Box 2. In fact...I suspect there's gathering info and emotion-coping at Box 2 as well...
5. Overall: I of course see most if not all of these decision-points to represent false dichotomies...which isn't bad, but merely something that I'd caveat in presenting the decision tree. (For example, there may be small or large amounts of denial at Box 1, but it's if one is generally denying noticed symptoms that they'd follow the denial path)
6. And lastly, I very much appreciate the note of how symptom expression changing and/or new life stages would have mothers go through the tree again. It'd be interesting to note what common life-stages or changing-symptoms were reported. ALSO, perhaps you'd note that subsequent decision-cycles may be less extreme than the initial cycle? I'm thinking off the top of my head, wondering if that feels true.

Hope this helps! The only real suggestion I think I have is #4 above (the others are just additional observations really). If you have any questions, please let me know. As you can see, I can use LLU's e-mail now (though I need to find a more permanent solution).

best,
Taggart

Lara's Reply to Taggart:

Hi Taggart,

Just as a follow-up to some of your comments:

Yes, I was going to mention how the process gets easier as mothers go through it again and how sometimes they may be able to skip steps, too. (e.g., don't necessarily need another assessment if the place will take the previous diagnosis)

Examples of life stages prompting needing to go through things again are moving from toddler to school-age or high school to adulthood, etc. Symptom expression changing might be the initial focus was on communication but now that the child is in school, the social problems are becoming more apparent.

Thanks,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate

Loma Linda University
School of Behavioral Health
Department of Psychology

From Amber:

Hello Lara,

I think that this a great decision tree!

I do wonder though, if you think it is important to include how the mothers think about themselves in this process leading them to obtaining services for their child?

If so, wouldn't the decision tree focus on the mother's perception of who they are or were when gaining support and services for their child? Can we include the Codes that represented the mother's perception of themselves, possibly placing those codes between the "grief and loss" to "fighting being persistent" processes?

I can't remember all the codes that focus on the negative and positive perceptions the mother's had of themselves based on this process, but I suggest that we include those codes to highlight how they also involved along with the evolvement of the services they received for their children.

I hope this was helpful!

I will be at work again this afternoon if you have any questions about my feedback please call me before 2PM.

Thank you.
Ms. Amber N. Hearn, M.FT
Loma Linda University
School of Behavioral Health
Department of Counseling and Family Sciences
Doctoral of Marital and Family Therapy Program (DMFT)
DMFT Candidate

Lara's Reply to Amber:

Hi Amber,

Those are some good points. I don't necessarily think any boxes need to be added to the flowchart for those things, but I do think those will be important notes that I will need to make as elements that influence the process. Other things that are going to be like that are stress, support systems, etc. They weren't necessarily steps in the process, but definitely pieces that influenced it. I especially had already thought of talking about the evolution of the mothers through the process so I'm glad we're on the same page! :-) The way I am going to write it up is person (i.e., beliefs, emotions, coping behaviors, appraisals), context (i.e., micro, meso, exo, macro systems), time (i.e., the different chronosystem elements of ontogenic, family, and historical time), and then the process (i.e., flowchart) including facilitators, barriers, influential elements, and different ways the boxes may align. That way the interaction between mother and context can be elaborated on and highlighted in their own sections to show how important they are. I have attached the other figure that is going in the dissertation to show the integrated self-regulation and ecological systems models (i.e, the cake). Let me know if you have any other thoughts about that.

Thanks,

Lara South, M.A.
Clinical Psychology Ph.D. Candidate

Loma Linda University
School of Behavioral Health
Department of Psychology

Entry 27: PPCT Outline

Given that the PPCT model would help with organizing the self-regulation and systemic factors as well as the process, the following is a possible outline of how to organize the information for the results:

PPCT

Person
- Stimuli
- Perception
- Cognitive Representations
- Cognitive Coping
- Cognitive Appraisals
- Emotions
- Emotional Coping
- Emotional Appraisals

Context
- Microsystem
- Mesosystem
- Exosystem
- Macrosystem

Time
- Microtime
- Mesotime
- Macrotime

(or ontogenic, family, and historical time?)

Process
- Noticing a difference
  - Acceptance vs Denial
- Getting an evaluation
  - Diagnosis vs Misdiagnosis
- Grief/Stress/Relief
  - Acceptance and balance vs Repression or Re-experiencing
- Gathering information
  - Gaining an understanding vs Misinformation or Lack of info
- Getting treatment
  - Receiving appropriate treatment vs Denied
    - Fighting
      - Collaborating vs Red Tape
- The new normal
- Re-experiencing, different ordering, other elements influencing it

Entry 28: Focus Group

Due to having a split of participants between LA and the Inland Empire, two focus groups were planned. Amber was unable to attend either day. Taggart was able to attend both. Only four members attended the Inland group even though 6-7 said they would. No mothers attended the second group even though 3 confirmed. Some of the notes that were provided by the focus group that took place include the following:
- It looks simple on paper, but does not accurately represent what it’s like to actually go through it (my note: the process does not represent the gestalt of the experience)
- “It’s right but not complete”
- It’s an emotional rollercoaster – “a rollercoaster you never get off”
- This process may indicate the first year, but they are constantly dealing with it/it’s a persistent lifestyle
- Every day is different
- The trail is unique
- Every day is a new unknown
- I need to highlight the confusion and not knowing with conflicting info
- “The new normal” is still a struggle

- Gaining a balanced perspective – I need to highlight how there are two ways this occurs: mom separate from child AND change with limitations
- The issue of acculturating to an autism culture came up

Entry 29: Completing the Abductive Process

Remembering that qualitative research uses abductive reasoning which is not only inductive but deductive as well, Taggart and I returned to the data to look for specific examples of different ways each code was expressed. These examples are as follows:

Code Examples

- Additional Stressors: E.g., family member dying, personal health problems, a negative event occurring at school, marital conflict or divorce, moving, needing to take care of someone else at the same time
- Advocating: E.g., pursuing what the child needs, being a voice for the child, being a mediator between the child and others, getting training in advocacy, informing others)
    - Appraising Advocating: E.g., viewing that her advocating was what helped the child
    - Beliefs about Advocating: E.g., advocating is more than just persistence
    - Fighting or Being Persistent: E.g., appealing, pushing, bargaining, saying no, being kind to get what you want, being persistent, going above and beyond what should have to be done, getting legal help, demanding, fighting for different things, meeting opposition, picking your battles, manipulating the system, refusing to accept what is given, re-applying, threatening, never giving up, voicing an opinion, getting an advocate, being aggressive, going through a lawsuit, getting a second opinion, battling, being in litigation, having fair hearings, going to a state agency
        - "You have to fight for all your services. It's just part of getting up."
- Appraising Professionals as Helpful: E.g., good, great, going beyond what is expected, helping provide a convenient service, supportive, putting forth effort and having compassion, being encouraging, helpful, knowledgeable, following up, providing guidance, caring about mother as well as child, actively involving the family, being understanding, being receptive, explaining things, checking in with the mother, responding, collaborating, having experience, taking extra time, providing emotional support, connecting to treatments or resources, partnering, providing education, providing a guide, not judging the mother, being kind, creating a comfortable environment, being accessible and communicative, being proactive/preventative, being open, willing to answer questions, doing the best they can, wonderful, competent, providing information on what to expect, being a specialist, nice, willing to support the mother's choice to try a different treatment avenue and help monitor it, giving a hug
- Appraising Professionals as Unhelpful or Incompetent: E.g., saying the child is normal when he/she is having difficulties, providing outdated information, being

too busy, not explaining the diagnosis or what to do, not providing recommendations, being rude or insensitive, don't provide information, not doing comprehensive testing, not providing basic services that should be available to all children with ASDs, the professional not being educated/knowledgeable about autism, putting in mediocre effort, being incompetent, don't care, being too afraid to say their concerns, not prepared, not keeping track of what is needed, not taking time, the quality of the service providers vary, not doing an evaluation, mother disagreeing with the how the assessment was done or the results, not helping, not being credentialed, only addressing what the mother brings up, not listening to the symptoms the mother says that were not observed during the limited assessment period, making excuses for symptoms, not being reachable, providing misinformation, not taking time, not including the mother, overgeneralizing, not connecting to resources, being uncertain, only wanting to do med management, being antagonistic, horrible, shaming, putting the burden on the mother, not doing anything, judging the mother, being distant, "their heart's not in it", "your child is just another piece of paper to come across the desk", not watching for child's safety, not providing services that were agreed on, actions don't match the caring words, mother feeling pressure of being against all the different providers at the IEP meeting, turning child away, no sense of compassion, no bedside manner, being "invisible", being misleading, not knowing what they were doing, "terrible", "nightmare", being "inappropriate" ("mean"), "should've known better", not caring about the child as a person, mismanagement, not caring, ignorance, misconduct, being competitive, being negative, not doing their job, making the mother feel like a burden or hassle, not paying attention to the child, being "brutal", "It's all grim and dim", being flippant, not helping the child, being unwilling to work with the mother, "And for her to just say, 'Obviously.' Just to sum it up with one word, just to disregard my pain and the impact of the diagnosis on my life, on my marriage, on my child, on his life. Uh, I cannot understand how…I don't know how anybody could be that, um, hollow."

- Appraising Social Support as Negative: E.g., being blamed, being pressured, being/feeling judged or criticized, being told negative things (e.g., she is a bad mom/can't take care of her child), not supportive, others being too demanding of the child, needing to cut out people who are unhelpful, mother disagreeing with advice given to her, feeling discounted, having conflict with family, needing to get out of a negative environment, mother disagreeing with other's views about the child, losing support, others interfering or making things more difficult, others not being understanding, saying they will support but then not being willing to do what is asked, others judging the child, others yelling, others being emotionally draining, people not stepping up, losing relationships with friends, people not knowing how to help take care of the child, not being accepting, others being disconnected
    - Appraising Support Groups as Unhelpful
- Appraising Social Support as Positive: E.g., good, getting close with the people that can help, being grateful for help, making friends with other MCDAs, getting support from groups, counseling as supportive, creating a network, receiving

support from husband, having emotional support, feeling connected, others being supportive, getting positive feedback, people listening, having someone to talk to, others being curious about autism, others understanding the child, getting advice or information, relating to others, having a large support system, feeling free to talk openly, having mentorship, others being encouraging, others being sweet, others being helpful, providing accommodations for the child, finding people who become like family, friends being active in supporting, others being sympathetic, not being judgmental, being easily accessible, others providing resources, family informing themselves, being close, "awesome", "incredible"

- Appraising Treatment as Negative: E.g., not working, a "joke", horrible, doesn't meet the child's needs, not worth time, child regressed, "crazy medicine", "dumb", distrust the treatment, not what is wanted, limited, created more problems, unpleasant, disagree with it, intrusive, hard to do, isolating, made things worse, mixed results, no results, not helpful, side effects, inconsistent, terrible, bad, providers not showing up, not established, treatment depends on the person providing it, high turnover, no one available to provide it, not a good fit, other children involved do not match characteristics of the child, don't like the dynamics of the group, providers not giving appropriate tasks, the service provision did not care for the child's safety, providers skewing things in their favor, child having a bad reaction, not specialized
    - Appraising Treatment as Unhelpful: E.g., not a good match for the child, overhyped, no difference, don't help, doesn't work
- Appraising Treatment as Positive: E.g., working, a cornerstone treatment, good, helpful, flexible, child showed improvement, positive, best available, small class size, effective, necessary, specialized, better than other treatments, evidence-based, consistent, important, satisfied, individualized attention, mother learning
- Assessment or Evaluation: E.g., assessment provided, thorough evaluation more effective, concerns about not getting an assessment or not a good one, assessment didn't pick up on all the symptoms, getting a referral for assessment, needing to pay for assessment that is outside the system, seeking assessment, needing multiple assessments, needing to go to different specialists, child not showing full capabilities during the assessment, assessment highlighting areas of difficulty, needing a second opinion
- Autism Culture: E.g., "We're our own little community…We just don't know each other.", everybody has strong opinions and wants you to agree with them, "we're all in this together…but at the end of the day…it's just this…deeply personal journey", autism is a whole lifestyle, being outcast by other mothers in the autism community (e.g., "I don't see that. I don't think he is.", a lot of people emotionally invested in a particular parenting style, "It's like being in this very weird club.", feeling an automatic connection with others who have kids on the spectrum
- Barriers and Systemic Issues: E.g., feeling defeated with all the roadblocks, other problems existing within that system (e.g., crime ridden area), not trusting the system
    - Being Denied: E.g., denied services, child doesn't qualify based on symptom presentation or being in the "gray area" (e.g., too high

functioning), professionals say the child doesn't need it, rejected, don't accept the evaluation from somewhere else, can't get something without the diagnosis, district not wanting to pay for a service, insurance denies it, child not being a good fit for the program, disparity between regional centers, shot down, can't get in

  - Chronosystem Barriers: E.g., DSM-IV vs DSM-5, not having good treatments available at the time of diagnosis, insurance wasn't required to pay at that time, being in the "second wave of autism coming through"
  - Exosystem Barriers: E.g., changing insurance, service cap, staff turnover in an agency, needing benefits, not having services locally, the service provider being overwhelmed and needing help, a different school not knowing what is going on, having more resources in a certain location, teachers can only do so much and beyond that it's the district, redistricting causing changes in where services can be obtained, no one available in area, state boards making blanket laws
  - Macrosystem Barriers: E.g., disparity in services based on location/SES/racism, feeling discounted by the government, black children more frequently getting misdiagnosed
  - Mesosystem Barriers: E.g., regional center as gatekeepers, ability to provide funding is limited, family schedule doesn't match provider schedule, needing to get a provider elsewhere because not provided where it's supposed to be, moving locations, can't move to the area that has better resources ("it's segregated"), regional center only paying for what is in that area, provider not offering convenient hours, provider being full, provider being inconsistent, the place that should help is actually part of the problem for the child, provider needing to prioritize services to children with more severe needs, "It's like knowing you can get something, but it's locked up. But everyone else can go get it. But you don't have your key.", provider stopping services in a location, needing proper documentation, the school treating all disabilities the same, not getting things if you don't know to ask for it, provider not willing to do treatment the way the mother things would be most helpful
  - Microsystem Barriers: E.g., child's symptoms getting in the way of participation, finances, time, too much on schedule already, not having resources or information, mother has other obligations (e.g., work or school), stress, needing to take care of everyday things as well (e.g., laundry, dishes, cleaning), having other children with different needs, child refusal, child age, can't take time off, mother having mental barriers (e.g., worrying about what would happen), child's discomfort
- Being Given Information or Treatment: E.g., word of mouth, given advice, being provided with something without having to ask/fight (e.g., case worker, social worker, coordinator, resources, advocate, evaluation, treatments through Regional Center or School, IEP), being given recommendations, being told information (e.g., symptoms, info about delays, no "cure", info about other services or resources), parent training, guidance, steps, tips from other MCDAs, education,

reports, someone informing that child's symptoms may be related to ASD, suggestions, someone setting things up for the mother, seminars

- Beliefs about Autism: E.g., autistic children should be given a chance, stigma is decreasing due to increased prevalence, autism diagnosis is outdated, autism related to anxiety and ADHD, expression is different for every child, lifelong/permanent, manageable, not curable, poorly understood, there is a reason for the child having autism, treatment for typical kids not indicated for autism kids, autism like personality, autism may be adaptive, believes metabolic processes have link to autism, initially having a stereotypical/classic view of autism, thinking of autism as a "birth defect", higher level of care needed for higher severity, each autistic child is unique, treatment addresses symptoms but not the disorder, seeing increase in autism prevalence, better equipped to deal with technology, a wide spectrum, initially thought it was the worst thing imaginable, not one-size-fits-all, brain processes things differently, "in order to have a cure, you have to have a cause…if it's something that's un-curable, then how would you find the cause?", has to do with behavior, comparing the loss of abilities to Alzheimer's, "devastating to every dynamic of your life", changing all the time, have special talents, feels things deeply, children with autism want to be respected, uses brain/processes differently, an unseen disability/look normal, smart, a terrible thing to have, something in the brain, "like a Rubik's cube", does not believe it is a gut disorder, neurodiversity, having a name helps you be able to address it, different skill sets, "…you don't cure brain wiring. You just learn how to live with it."
- Beliefs about Causes – note: most said were unsure, but had ideas of possibilities
    - Environmental Causes: E.g., mercury in fish, exposed to chemicals, DHA, grandmother smoking creating an epigenetic effect, how you grew up impacts development, bad nutrition, bad prenatal
    - Genetic & Hereditary Causes: E.g., genes, hereditary, runs in the family, family trait,
    - Medical Causes: E.g., stress in womb, elevated heart rate during C-section, umbilical cord around neck, mother had a car accident during pregnancy, labor induced, gestational diabetes, emergency C-section, meconium in the amniotic fluid, very blue when born, born breech
    - Multiple Causes: E.g., interaction between genes and environment, genetics create a predisposition to be sensitive to pollutants or vaccines, neurologically having a propensity toward these behaviors but then the "chemical soup" amplifying the problems, epigenetics, combination of things
    - Ruling Out Causes: E.g., not that the mother did not show enough affection, not shots, not a punishment by God
    - Unsure of Causes: E.g., I don't know, not really sure
    - Vaccine Beliefs: E.g., immunizations across generations building things up in the blood, mercury in vaccines, wishing could wait for vaccines until a little later
- Beliefs about Child: E.g., a good child, thought he would be a "dead bed", can advocate for himself, more intelligent that he can communicate, understands

what's wrong, has self-sufficiency skills, balanced view of child's ability, gaining understanding of the child, need to make child fit into society, outside looks normal, high maintenance, sensitive to issues of control, recognizing child's fragility, more sensitive, behaviors are motivated by emotions, child's preference for mom alienates others, child is going to progress/mature pretty much how they will, genuinely loving but the emotion not there, is super aware, learns best while being active, brain doesn't work like a typical child, is misunderstood, doesn't want to listen, had a long way to go, isn't retarded, doesn't know how to be patient, can be sneaky or spiteful, not stupid, catching on, head-strong, thought the kid was a brat, don't have to worry about some of the other pressures of childhood because protected, likes music, needs structure, is active, figures out different ways to do things, is brilliant, is confusing to others because looks older than his social development, people don't understand him, needs a specific environment to thrive, a good boy, not living up to his potential because of lack of support, has a younger frame of mind, can come across as rude to others, gets along better with older people, strange that delayed in some areas but not others, not the child's fault, has a sense of humor, need to trust the child will make decisions for himself once on his own, healthy, has to walk his own path, worth the fight

- Beliefs about Professionals: E.g., Supposed to keep their distance, believed her psychiatrist was crazy, doesn't think professionals have to be so mean, some people should not be in the positions they are in ("they replaced her with this woman that has no business even being around children"),
- Beliefs about Symptoms: E.g., not listening, short attention span, tantrums, hitting head against walls, stimming, poor eye contact, may not be able to communicate verbally, lining up toys, no imaginary play, sensitivity to things (e.g., sounds, fabrics, etc.), switching tasks is hard, reacts more extremely to everything, environmental sensitivities, everything is black and white, need to follow the rules, delayed in some areas but not others, have more trouble with things that people would see as "basic", developmental delays, not a bad thing, unpredictable, spatial awareness problems, each child is unique, social skill difficulties, interacts with diet, speech delay may relate to bilingual home, communication barrier, symptoms fluctuate in relation to mother's state of being, misbehavior, doesn't connect, repetitive movements, isolated, rejected the idea of autism because didn't match the classical symptoms, symptoms will change at different life stages (e.g., teenager, adult), picky eaters, digestive issues, communication problems, autistic children seem larger than other children, sensory issues, "uncomfortable in their own skin", get very fixated, safety issues, deficits, trouble eating, symptoms may have been impacted by only being at home with mother, can be pushy if can't fully express themselves, not huggers
- Beliefs about Systems: E.g., medical system pushes medicine, larger systems discount the parent's experience, a sense of antagonism when should be on the same team, schools don't emphasize the social stuff, everything is limited everywhere, need to find a way to advocate for the world to fit them too and not just them have to fit into the world, getting more prevalent and more informed, stigma/shaming/shunning still exists, people don't know how to separate the

behavior from the person, competitiveness is part of life, school staff are "frazzled", people have opinions about what the expectations should be for their children that are uninformed or "unintelligent", most info out there is negative, those in charge don't know how to deal with it (autism), the system is segregated by neighborhood, the parents need to educate everybody else, the resources don't last, need a mentor that understands, money shouldn't have to be the issue, health providers don't know what to tell you, parents shouldn't have to fight, the earlier one gets services the better, ridiculous that America treats disabled children this way, the system receives funding and then don't provide the services they should, it's frustrating especially when you were trying to be cooperative, better for the child to be in a more protected system, things that the system did should never have happened, people don't care, incompetence and ignorance from key players in the system, violate the child's rights, nobody wants to help, people don't take time and effort to get to know the child, that neighborhood system pays the lowest funding for the kids, the providers have low expectations, people have an image of what autism is based on a severe presentation, mothers in the US have certain stances because they don't know what it's like to struggle with non-1st world problems, people feel uncomfortable with the social disconnection on an evolutionary level because of our species being social creatures, autism will grow to be accepted over time, the shifting of social rules based on situation is confusing for people with autism, there is pressure to have the perfect child, being understanding of the limitations of the system, providers need to have better info available, system needs to be more positive, need to have more positive examples of autism in the media, there needs to be a culture shift to help promote understanding of autism, hard to explain to people outside the family system or to those who don't know much about autism, people don't want to listen to things outside their worldview, other cultures are more willing to incorporate non-Western medicine philosophy

- Beliefs about Treatment: E.g., ABA overrated, medication can help, needed to re-evaluate beliefs against a treatment, treatment depends on the person doing it, being against medication, "people are always looking for that new thing", don't force anything on the child if they don't want to do it, for every kid it's different, believing kinesthetic approach is best for her child, believing a treatment will help, thinking something wouldn't help, thinking a treatment doesn't sound right because of common sense, thinking something would have been a simple fix if the professionals were willing to implement it, thinking a treatment would help with a specific issue, thinking treatment is hard, believing there is no standard treatment, "I just don't think there's no right or wrong way"
- Changing Treatment: E.g., SpecEd to mainstream, public school to NPS, services changing on IEP, stopping a service, changing from one company to another, going from one district to another, changing providers, changing treatment approach, needing to change the service because of age restrictions, changing to a more autism specialized service, stopping meds, losing a service, changing due to negative results or negative experiences, changing due to trial-and-error
- Child's Experience: E.g., shamed, feeling ashamed, child being bullied, people interacting with the child, child relating with other children with disabilities, child

trying to understand his difference, child frustrated, has bad moods, needs space, will tell the people he wants to tell about his autism, needing to develop new friendships when changing schools, relationship with certain providers not meshing well, likes animals, liked something, mad, excited, academically successful, crying, isolated, reacted badly to vaccinations, shutting down, not necessarily wanting to be with a group of kids with autism even though on spectrum, feeling low, getting through tough times by faith in Jesus, having depression and anxiety, nervous, couldn't do work at school, terrified for his future, having a stressful time, uncomfortable in his own skin, "twitter pated but without all the lovey-dovey stuff", having anger issues, scared, comes up with "all kinds of clever work arounds", happy, "felt like he found his people", freaking out, able to rein himself back in, didn't freak out, took the steps to do what he wanted to do, thinking something is absurd, not liking something, having a meltdown, wanting to try treatments he learned about, wanting to do things he never did before

- Child's Symptoms: E.g., sensory issues, unaware of social environment, tantrums, dangerous behaviors, difficulty communicating, sleep problems, everything revolves around restricted interest, regression, slow to develop, sensitive to change, emotional limitations, social impairment, eating problems, repetitive words, anger, aggression, picky eater, auditory dyslexia, tantrums, doesn't listen, lies, short attention span, articulation problems, doesn't initiate play, hand flapping, preferred to play by herself, social skills problems, not talking, not potty trained, breaking things, taking things apart, impulsive behaviors, stimming, avoiding people, stopped speaking, slow developing gross motor skills, poor eye contact, lack of emotion in speech, black-and-white, over the top mad, less strength on one side, banging head, ocd-like issues, feeding issues, meltdowns, direct/no filter, not organized, obsessions/fixations, needs to follow a schedule, can't wait to say something that is important to him,
  - Noticing Symptoms in the Child: E.g., noticing delays, someone pointing out a difference, someone suggesting the possibility of autism, noticing signs early, realizing something is different, receiving a referral because a provider noticed the signs, seeing a change in development (e.g., stopped talking), having a suspicion
  - Symptom Expression Changing: E.g., seeing progress/improvement, symptoms shifting to different ones at different points in time, symptoms fluctuating, symptoms getting more obvious the older the child gets, developing/evolving, regression, different things pop up, growing out of something, learning, "a gradual process with setbacks"
- Comparing Child: E.g., to a sibling
  - Comparing Child to Children with Other Problems: E.g., cavities, cancer, emotionally disturbed, asthma, gangs, deaf, in a wheel chair, Down Syndrome, blind, missing arms or legs, schizophrenia, drug addict, getting someone pregnant
    - comparing to these things because of – not as severe as, more severe than, can't be seen like, don't have to deal with, don't qualify for services as easily like, not as understandable as, don't

    have a set treatment protocol like, worried about other possible issues like, could've been worse, kids with more debilitating things are able to still have a life, not going to die

  - Comparing to Neurotypical Children: E.g., not able to do things the same, doesn't develop the same, wishing child could be normal, learns differently, wants child to be treated the same, seeing typical kids can be painful, "everybody else has this kid that's like perfect, and mine is broken", some of the "attitude" of the child could just be a typical teenager thing, seeing accomplishments of other children and grieving that it may not be a possibility for the child, difference between shy and can't communicate, needing to find equivalent experiences for kids with special needs (e.g., little league baseball), child can't do some of the things typical boys can, perceiving that can't feel the same sense of pride, acts differently, isn't interested in the same things (e.g., prom), comparing to own experience at that age, some of the worries are typical worries for mom's in general
  - Comparing to Other Children on the Spectrum: E.g., could be worse on the spectrum/not as severe, comparing to extended family's children that also have autism, comparing to media portrayals, symptoms vary in different children on the spectrum, comparing to other children who had bad reactions to vaccines, presentation varies, symptoms look unique to each child, to another child who had a stomach obstruction and died, much easier than other children she has seen, sibling with autism also that has different presentation/needs, seeing other kids with autism getting better services (note: mothers with high-functioning kids think the low-functioning kids get more and vice versa), worrying about kids whose parents aren't on top of things, wishing child would be more severe so the disability could be more evident and would get more services, relating a story about a couple of adults who were able to make a marriage work, noticing child not getting as many services as another child even though severity was worse, comparing to children who were going through the diagnostic process years ago
- Comparing to Other Mothers:
  - Comparing to Mothers of Children with Other Problems: E.g., cerebral palsy
  - Comparing to Mothers of Neurotypical Children: E.g., mothers complaining about their kids not being able to do things and the mother wishing the kid could just do normal things, feels like can't enjoy self like other mothers, having trouble relating to these mothers, having awkward interactions with friends that were close, feeling more tolerant of families with other stressors
  - Comparing to Other MCDAs: E.g., others being more negative, others being desperate, thinks others have "bought into…that's going to cure the child", not fighting the same as other mothers, others have money to do things they can't afford, everyone's experience is different, comparing to stay-at-home moms, comparing to families that have the ability to stay in

    one location (her job required frequent moving), other mothers who think they could do a better job, believes some mothers don’t give a treatment enough time to have an effect, believes other mothers think something is working for their kids when it’s not, believes mothers can be on extremes of only going with what the school provides or paying for everything, don’t feel judged by MCDAs that get together and understand each other’s experiences, believes other mothers have their own autistic tendencies

- Contextual Factors – Filter: E.g., seven miscarriages and an ectopic pregnancy before this child, mother and father work in genetics, had a hard life, culture of origin views motherhood and challenging already, acculturating, culture of origin doesn’t blame the mother for problems, lived overseas, military life
- Coping: E.g., what can be done to cope is unique to each person, focusing on the present, resisting negative coping strategies, using negative coping mechanisms, seeing certain strategies as negative (e.g., overeating)
    - Active Coping: E.g., educating self, researching, serving others, figuring things out, working to make money, exercise, deep breathing class, switching to new strategies when something doesn’t work, focus on self before interacting with child, finding solutions, planning, working on self
    - Appraising Coping: E.g., haven’t been doing what she wanted to do, learning the best way, not working, not easy, wasn’t the best way, the ideal way, not coping well, wishes was more on top of it, some coping mechanisms are not positive, needed to find new ways of coping,
    - Avoiding: E.g., avoiding info, thoughts, grief, distraction, not letting self feel sense of loss, avoiding conflict, avoiding as coping mechanism, appraising avoidance as bad, using work to avoid
    - Changing Behavior: E.g., taking a self time-out, changing how used to react (e.g., take a breath instead of spank), becoming more sociable, get over shyness, evolve to make sure everyone is comfortable at home, becoming active, becoming flexible, changing to not be so indulgent
    - Changing Thinking: E.g., getting a different mindset, changing from feeling like a victim, make conscious decisions not to think negatively, changing from seeing kid as damaged to unique, changing to view self as a vessel of service, changing from being resentful to seeing it as a blessing, not getting hung up on things, getting a better understanding helped emotions, getting rid of certain types of thoughts, no longer viewing it as a punishment, instead of viewing autism as a label-a description, changing negative thoughts with positive ones
    - Emotion-Focused: E.g., writing feelings in a journal, getting the grief out, crying, get over mixed emotions, seeing a therapist to not be bogged down with guilt
    - Humor: E.g., joking, laughing, using humor
    - Problem-Solving: E.g., thinking through possible solutions to a problem, planning, take notes on how others deal with it, being a problem solver, figuring out how to deal with it
    - Relaxation and Recreation: E.g., sightseeing, deep breathing class, drink tea, count backwards, relaxation techniques, mindfulness, taking time out,

    taking a break, massage, do things non-autism related, take up a hobby (e.g., collecting figurines), swimming, going to a movie
  - Seeking Support: E.g., reach out to religious community, create an informal support group, going to conventions, reconnecting with family, reaching out to other MCDAs, joining a sorority, joining an autism society, seeking advice from own parents, seeking support from God, connecting with friends, joining a parent group, finding groups on social media
- Crying or Cried: E.g., crying, breaking down
- Dealing with It: E.g., dealing with it, sucking it up, not wallowing in it, "you gotta do what you gotta do", learning to deal, better to deal with it, making do, keep pushing, just getting through it, making it work, taking it one day at a time, just do it, doing our best, dealing with issues as they come
- Deciding What to Believe: E.g., filtering through what seems like conspiracy theory, being conflicted about what to believe because hearing different things, deciding based on if it's therapeutic and is backed with research, by listening to others' experiences, won't believe in it if don't understand it, looking at the source of the info, background education influences what to believe, balancing media messages with other evidence, deciding what theory applies personally, considering others' opinions
  - Changing Beliefs: E.g., changing expectations, changing what to believe based on seeing things not working, changing negative beliefs to more positive ones, changing beliefs based on having more information, gaining a more positive perspective, needing to have an open mind about a treatment that didn't think would work, expectations change based on what child shows capability of doing
  - Deciding What to Believe Based on Personal Experience: E.g., facts supported by personal experience, basing belief on personal experience, having previous experience with children with disabilities, making choices based on personal observations, mother's medical background, having a family history, learning through trial and error, occupation influencing understanding, learning through the journey, needing to try things for herself, having prior exposure to autism, following through what was going to be best for her rather than basing what was best for others, denying own thoughts if it was going to be helpful, listening to everyone but being selective of what to take in, based on child's ability level, seeing what works for the child, finding peace in knowing she didn't cause it because did pregnancy by the book, not seeing changes at the time of vaccines, having experience with people dying who didn't get vaccines and not understanding why people would want that returning, based on culture
- Defining Autism: E.g., affects the way a child socially engages with others, neurological problems that affects communication and social interaction, neurological disorder, undefineable, agreeing with technical definition, developmental delays, a difference, a difference in brain function, a disorder, a lifestyle, a whole-body issue, affect multiple systems in the body

- Delays: E.g., they should provide things without having to wait for you to ask for it
    - Assessment Delays: E.g., assessment results took a long time to get
    - Diagnosis Delays: E.g., took a long time, happened years after symptoms first noticed, waiting for dsm turnover to 5, asked to wait until child develops further, was not diagnosed early, provider not calling it what they thought it was, first child not getting diagnosed until same time as second, assessment process is slow, worse to wait
        - Late Diagnosis Causing Problems: E.g., prevents advancement, hurts the child, makes the mother view the child negatively during the undiagnosed time, missed windows of opportunity, can't get the proper treatment either because out of age range or Regional won't provide services without the diagnosis, could have been farther along
    - Treatment Delays: E.g., couldn't get coverage, needing to do treatment at home before getting services, told to wait, not covered, hadn't heard about it before, missed appointment and need to reconnect, professionals drop the ball ("lost in the pile of paper"), needing to restart process, lack of IEP, "hurry up and wait", long waiting list
- Denial: E.g., don't want to admit the diagnosis, denying services, rejecting others pointing out symptoms, denying despite evidence, misattributing symptoms, rejecting professional opinion, rejecting because of misunderstanding the disorder, responding indignantly, normalizing the problems, not wanting to believe it, denying because seeing things that contradict the classical portrayal, denying own emotional problems with handling the diagnosis
- Differential Diagnosis
    - Differential Diagnosis Outside the Spectrum: E.g., sensory processing disorder, don't have physical characteristics like some other disorders, speech delay related to bilingualism, ADHD, deafness
    - Differential Diagnosis Within the Spectrum: E.g., on the "borderline", PDD, autistic-like behaviors
    - Experiencing Difficulties due to Differential Diagnosis: E.g., not getting diagnosis early because higher functioning, denying the diagnosis because shows characteristics that are not stereotypically autistic (e.g., has eye contact), not getting services because other autism spectrum disorders not covered, getting treatment for the wrong thing, not getting services because too high functioning, symptoms misattributed to comorbid issue, need switch to dsm 5
- Experiences Increasing Awareness: E.g., experiences helping them understand others' experiences better (e.g., other MCDAs or mothers with kids with disabilities), past experiences such as occupation helping understand the disorder better, having a family history of autism increasing understanding, having personal experiences with medication, learning how to be more patient and compassionate through the experiences with autism, learning more how to deal with things by going through the process, having a better idea of expectations for the child through the experiences, understanding autism better now because of the

experience with it, having gone through similar experiences as the child, having family members who had experiences with children with disabilities they could share with the mother

- Experiencing Grief or Loss: E.g., had expectations of what the child would be able to do before getting the autism diagnosis, feeling a sense of loss, feeling robbed, feeling grief, grieving the loss of the child she thought she would have/the ideal child, feeling devastated when received the diagnosis, comparing to death, feeling like had to delay feelings of grief to deal with getting the child the help needed, feeling like a victim, thinking child is broken, yearning for the type of bond a mother would have with a typical child, planned ideal changed with diagnosis, "I grieved for the child I thought I would have", wanting the child to be normal, believing the grief never goes away but just different stages of it, grief can be re-triggered at certain holidays etc or with certain remarks from others, initial shock, being depressed, a suggestion from a book said to have a funeral "because the normal kid or the kid that I anticipated I was going to have is not that child", "I had to let go whatever I thought I wanted", upset/worn/cried, "Your dreams for your child die", physical symptoms (e.g., trouble sleeping), believing grief and acceptance of the reality of the disorder are two separate processes ("Just because I'm grieving doesn't mean I haven't accepted it", having to go through cycles of grief at different life stages
- Family System: E.g., being concerned if sibling would have to take care of the child, needing to take care of everyday family life still, seeing treatment challenges of other family members with a child with autism
    - Autism Changing Family Interaction: E.g., family needing to adjust, having a child with autism is challenging for everyone in the family, child influences the entire family system, autism as a whole lifestyle, needing to adjust everyday interactions because of the child with autism (e.g., lower their voices so does not disturb child), not being able to do things they used to because of the child (e.g., travel), "every aspect of your life changes, what you eat, what you drive, where you go, how you sleep. Every, every component of your life completely changes…How you wear your hair." Sibling can't do activities because of resources going to child with autism or being worried about what peers will think of the child, forgoing basic self-care (e.g., brushing own hair) because "they wear you down", needing to make sacrifices for the benefit of the child, altering everyone's diet to match the child's
    - Family Structure: E.g., mother working, dad being stay at home dad, child has two households, dad not in life, mom going to school, mom needing to take multiple jobs, having multiple children in the household, getting married, husband working late, extended family in a different country, being an older mom, working opposite shifts as husband so someone can always be home, large age gap between siblings, military family, mom changing job to spend more time with child, stopping moving around so child can have a consistent address, stopping working, returning to work, dad breadwinner

- Finding Support Within Family: E.g., talking to family, doing activities with family, feeling rewarded by time with family, visiting family, reconnecting with family, sibling helping with caregiving, spouse being supportive, family informing themselves and doing what they can to help
- Interacting with Extended Family: E.g., they respected the structure she wanted, disagreeing with what others think she should be doing, others confused, others blaming her, others educating themselves, others getting involved, others not knowing what to do, not understanding, noticing differences, pressuring mother, providing info, providing respite, needing to set boundaries, others in denial, doing things to help child develop, throws things in her face, connecting with them, having negative interactions with, valuing the opinion or advice of the mother's mother, mother's sister worrying about if her child will be autistic, family eliminating themselves, "It's crazy how people will scatter when things get tough",
- Interaction between Mother and Child: E.g., interaction between child and mother's emotions and reactions, child won't listen to her even when will listen to others, being consistent with child, feeling rejected by child, liking clinginess, trouble communicating with child, difficult experiences with child, letting go of the reins, playing to child's strengths, recognizing limitations, not trusting others can handle the child, being hard on child, knowing child better than anyone else, being around child all the time, spending time together, needing to set boundaries of what child can do, child lying to mother, having to work with the child constantly to make sure work gets done, believing in the parent being the biggest influence on a child, being frustrated with child, needing to explain things to child, picking battles with child, needing a lot of prep to do simple things with child making it stressful, guiding the child in the right way, loving the child, mother and child being "best friend"s, needing to change things about self to be able to take care of child (e.g., can't wear heels because need to be able to catch child), playing games with child, communicating with child, doing enriching things with child, needing to teach child everything, needing to monitor everything child is doing ("Just that constant supervising"), protecting child, child getting "mouthy" with mom, child not communicating problems to mom, mother disciplining child, not forcing the child to do a treatment he didn't like, child being angry with parents, needing to encourage the child ("You're not weird, you're just special. Like everyone else…Everyone is special in their own way." Child asking mom if she wanted to "fix him" and needing to explain to him that there was nothing to fix and he was okay the way he was – from focus group),
  - Fostering Child's Independence: E.g., teaching child to be his own advocate, fostering independence, standing back, letting the child speak for himself
- Recognizing Symptoms in Other Family Members: E.g., runs in the family, suspecting other family members might be on the spectrum, seeing

    traits in family members, recounting symptoms in self (e.g., personally had speech delays as a child)
  - Sibling Interactions: E.g., sibling needing to tag along to child's treatments
    - Mother with Sibling: E.g., doing separate things with them, having a strained relationship, needing to repair relationship, making time, finding something the kids can do together, noticing symptoms in second child, doing everything she could to support typical child, having a sense of pride in the sibling's achievements, finding support group for the sibling, being overly active with sibling, trying to make sibling's life normal and healthy as possible, feeling like sibling's "childhood has been taken", making sure sibling doesn't need to take on parental role, different discipline strategies for sibling, wanting sibling to have a chance to get away, feeling appreciation for sibling, comparing sibling, seeing positive qualities in the sibling (e.g., calm and resilient), sibling not getting as much attention
    - Sibling with Sibling: E.g., being a positive influence, conflict between siblings, being inspiring, sibling feels dictated by child with autism, learning to get along, learning to help, sibling having to deal with people thinking she is on the spectrum too, sibling having own set of issues, sibling being child's only friend, burden on the sibling, sibling protects child, sibling learning how to be inclusive, needing to have own life, sibling being embarrassed or humiliated, babysitting
  - Spouse Interactions: E.g., husband in denial, husband intervening, supportive, date night, defers to mother, husband hands off, feeling like husband doesn't care, parents separating because of different beliefs about what was going on with child and how to approach it, child's father burning bridges with mom, needing to get over the father, getting divorced, father remarrying, father not paying child support he owes, can talk about anything with, husband understands, husband not mentioning family history of special needs, "Even when he's home he's not there. I'm virtually a single mom." Having different approaches (e.g., structured vs relaxed), lean on husband, husband having a job that helps him understand better (e.g., pediatrician), still being close with ex-husband
- Feeling Judged or Blamed: E.g., thinking others see her as a Munchausen by proxy parent, feeling like others blamed her for child developing autism, feeling like professionals judge her by taking a one-up position to her, worrying about other people's perception of her, people judging the child/thinking he was just bad, people saying negative things to her, "I'm not used to dealin' with the looks…the words", people accusing the mother of doing the child's work, people thinking the behaviors are the mother's fault or that she was not doing enough, "people don't accept differences", "Maybe it was me they didn't like", "I've had people tell me I wasn't trying hard enough", "they probably made me feel like I was being, like, a burden or a hassle", people staring rather than asking, "you feel

judged", people questioning mother's choice to have a bilingual home, "I would say it's more like these little mommy words, little comment about how to properly raise your child"

- Feeling Negative Emotions: E.g., bad, "all the emotions at once", "I felt like it was unfair", "a lot of negative and painful emotions", emotional rollercoaster, helpless, hopeless, horrible, defeat, beyond hurt, "I felt like somebody had just taken all the wind out of my sails", "I hated Christmas", powerless, shocked
    - Anger: E.g., angry, frustrated, mad, bitter, agitated, furious, pissed off, aggravating, irritation, irritability, resentment, irate, "I was gonna snap again", misplaced anger, lashing out, screaming, about – insurance, not receiving help, getting the diagnosis, red tape, at own fighting behavior, at child
    - Anxiety or Stress: E.g., stress of being MCDA, traumatic stress, anxious about future, crazy, exhausted, like a minefield, overwhelmed, stress, tired, worried, breakdown, anxiety, "I don't want to have to keep apologizing 'cause stress kills you", traumatized, needing to let it out, anxiety attack, shut down, nervous, becoming more vigilant, having physical effects (e.g., breaking out, getting sick more often), concern for future, developing an anxiety disorder, panic
    - Confusion: E.g., confusing, don't understand, asking what happened
    - Fear: E.g., fear, scared, terrified, worry, freaked out, about – diagnosis, future, need for long-term care, decreased services, something's wrong, don't' have a solution, it's chronic, "the internet will scare you half to death"
    - Guilt and Shame: E.g., about – vaccinating, not being as involved, the diagnosis, her reaction, others shaming her and saying it's her fault, feeling like it's her fault, feeling like God is punishing her, wondering if it's something she did to cause it, about waiting so long to get the child help, not recognizing problems in the system earlier,
    - Sadness: E.g., depressed, hopeless, helpless, down, like a victim, raw, lonely, rejected, devastated, sad, defeat, having a meltdown, low points, hurt, crying, not wanting to leave the house, about – child's daily challenges, lack of progress, not understanding, lack of support, comparing to others, for child's experience, getting the diagnosis, "Autism is devastating to every dynamic of your life", about negative events (e.g., no one showing up to child's birthday party, bullying), blaming self
- Feeling Positive Emotions: E.g., empowered, confident, grateful, fortunate, lucky, in control, prepared, happy, glad, relief, enjoying life, excited, hope, joy, feeling better, secure, not crazy "Finally, somebody believes me.", hopeful, proud
- Finding Treatment: E.g., gathering info on treatments, choosing treatments, becoming more open to different treatments, cautious about trying services, finding multiple services, feeling like no one helps with finding everything, not having one place for everything, distrusting treatments, felt like the search was done "blindly", looking online, getting recommendations from doctor, finding conflicting information on treatments, looking for breadth of treatment, identifying needs of the child, choosing based on fit with child, rejecting

treatments, not finding a good match, pursing all options, prioritizing treatments for biggest issues, not finding what is wanted, seeking a specialist, looking for better, finding treatments through word-of-mouth, looking outside of insurance, starting with Regional Center, targeting symptoms with specialized services, starting medically, trying a treatment over again, feeling like don't know if a treatment is helpful until you try it

- Focusing on Self: E.g., pampering self, doing something to relax, taking time for self, getting own counseling, going back to school, maintaining a separate identity/self from the child, needing own needs met, taking breaks, caring for own needs, changing to a healthier lifestyle, getting support for self, paying attention to self, "I had to help myself before I can help her.", taking own medication, being mindful, getting respite, having a separate life from autism, balancing self, forcing self to do things for self (e.g., go out with friends, go to a movie), dealing with own feelings, retiring from the military
- Focusing on the Positive: E.g., son is good despite autism, child is a blessing, appreciating time with child, autism is better than child dying, focusing on capabilities of the child, having a positive perspective, autism is not as bad as some other things, counting small victories, finding the good, focusing on benefits over costs, reframing (e.g., restricted interest as "expertise", autism as "special"), looking at strengths, noticing what is functional, recognizing child's hard work, positive spin on symptoms, viewing others as positive, seeing challenges as positive, "it's all perspective", appreciation for what she has now, working hard to uncover the "gems" that fill the child's mind, "In the long run it pays off", looking at what is the best the child can do and being proud of it, "I always presume competence", seeing positive qualities in the child (e.g., affectionate, smart), "It really is not the ride I expected. Um, but it's a fun one."
- Functional Support: E.g., a lot of people involved, Regional Center as a top resource, being provided with things, being taught skills, insurance helped, workers supporting, respite, communication with professionals, legal support, getting advice from specialist, academic supports, financial support, provided with a service, collaboration with professionals, tailoring treatment to child's ability, help finding resources, social worker, referrals, case worker, assistance through autism organizations (e.g., Autism Speaks), help taking care of child
    - Getting Resources: E.g., getting connected to resources, having resources
- Gaining Understanding of How to Help Child: E.g., addressing emotions to benefit behavior, being patient with guiding the child, learning things that can be done at home to help the child (e.g., change diet or environment), learning to be flexible, learning how to provide structure, learning skills from the treatment providers, finding a balance between understanding and change, having a better understanding of the diagnosis helps the mother to be more understanding of her child, learning what works for the child, learning and growing alongside the child, learning how to teach things in a different way, relearning how to discipline, teaching self what to do, using the child's interests as a tool, setting boundaries, seeking education on advocacy skills, learning little things that help the child (e.g., a tight hug, jumping, using pictures), being consistent,

- Gathering Information: E.g., at a resource fair, online/internet/Google, researching, educating self, taking classes, getting confused by so much different information, word-of-mouth, personal experience, autism organizations (e.g., Autism Speaks, International Autism Network), searching, asking questions to professionals, reading, looking at articles, reading testimonials, books, going to conferences
- Getting a Diagnosis: E.g., being told to wait, getting the diagnosis helps with getting treatment, diagnosis provided, expecting the diagnosis, getting a second opinion, needing to get a separate “diagnosis” from school, struggle for diagnosis was a long process, early diagnosis helps get early intervention, taking child to multiple specialists to find out what is wrong, getting a different spectrum diagnosis initially, getting diagnosis gives sense of control of “something to work with”, getting the name gives power to address it,
- Having a Hard Time: E.g., implementing treatment tough, journey hard, believing self was a terrible person through the fighting process, experience has been difficult, having a hard time dealing with the situation, having a lot to handle, never being ‘done’, not coping well with it, struggling, when one symptom is contained another becomes a problem, “your whole life is turned upside down”, being in a “black, black place”, tough, didn’t come easy, draining and tiring, had suicidal ideation, not an easy task, hard to find resources, having to deal with own problems along with child’s, “for a while, yeah, it was just hell”, challenging, “it was one of the hardest times in my life”, being in a bad situation, “it was extremely difficult when it really shouldn’t have been”, wishing she could run away – from focus group, rough, horrible, defeat, isolated, not easy, difficult, “Describe my journey of finding treatments for him? Oh my God, it was a nightmare.”, “It was a really bad time”, a hard adjustment, a lot to take in, “I think that first year was the hardest year…because you’re wrapping your brain around it. You’re trying to wrap your kid around it.”, “it’s been a hell of a road”
- Having Comorbid Issues: E.g., medical problems, anxiety, suicidal thoughts, depression, epilepsy, learning disability, ODD, mood disorder, associated features (e.g., sleep problems, digestive issues), needing ear tubes to drain fluids, seizures, small size, deletion 1p36, asthma, needing myringotomy, ear infections, trouble breathing
- Having Concern for the Future: E.g., wondering what the child will be able to do, concern that child will encounter obstacles as an adult, what’s going to happen when she dies, worried about experiences at new school because of previous experiences of bullying at past school, worried about the possibilities of college/job/leaving home, worried about challenges/negative experiences the child might face, terrified of child moving on to adulthood
- Having Negative Expectations: E.g., not sure of possible level of functioning, might not get married, might need her for the rest of his life, assistance needed long-term, catastrophizing child’s future, low expectations of treatment, minimal/low expectations, hopeless about future, pessimistic attitude, thought it was going to be worse than it is
- Having Positive Expectations: E.g., about a treatment being able to help, will get better, progress is possible, able to function with a disability, improvement with

limits, symptoms will decrease, possibility of a normal life, knowing she got through her own challenges giving her hope for her child to do better, tailoring expectations of child to do their best based on ability level, having hope, may have a gift that hasn't been tapped into yet, thinking it won't always be this difficult, thinking child will thrive if given the right environment, seeing child make progress gives hope for future, presuming competence, thinking the child has capability, believing child can do certain jobs that match is ability level (e.g., work on a farm), believing child can make small steps, taking hope in seeing that others on the spectrum have been able to lead successful lives

- Having Process Get Easier Over Time: E.g., if need to do it again with a second child, once you know what to do, finding balance between self and child, knowledge increases, child being able to do things they didn't used to, having better services now, knowing kid better, "I have good days. I have bad days. But now, I'm having, like I said, more good days than bad days.", "It's now like you can exhale just a little bit more."
    - Feeling Less Negative: E.g., negative emotions decreasing, building confidence, being more calm, experienced more challenges during first year, less anxiety after finally receiving treatments, less shock second time, less stress over time, feeling relief after finally getting the diagnosis
- Helping and Informing Others: E.g., changing from mentee to mentor, giving others advice, giving help, giving other's information, providing support, becoming an advocate for others, volunteering, creating a community
- Interacting Systems: E.g., getting referrals
    - Within Level Interactions: E.g., social and spiritual community, school and family, peers and family, others interact with family, one provider referring to another for continuity of care, treatment and family, referrals to other services
        - Interacting Levels of Support: collaboration between services/providers, spiritual and family, family and friends
    - Non-Interactions: E.g., school and medical not working together or not agreeing, assessments not being accepted across places, school autism eligibility not applying to medical diagnosis, professionals not seeking out info from the parent of what is needed, professionals excluding mother from participating in the treatment or not showing her what to do with her child, professionals provide the diagnosis with no follow-up with the mother, professionals not acknowledging the mother, not being provided with info
    - Between Level Interactions: E.g., Regional center as gatekeeper to other services, culture with treatment approach, increase in autism increasing awareness of professionals, media influence on mother's beliefs
- Misdiagnosis: E.g., inaccurate, conflicting assessments, wrong one, being told nothing is wrong
- Mother Interacting with Other Systems: E.g., being self-conscious about what others think, others expect child to behavior typically, social pressure for vaccination, cautious of who to connect with, excluded from friend circles, creating a multidirectional support system, having a negative interaction with a

professional (e.g., being told "obviously" when asking about autism, being told "dim and grim" expectations, meeting antagonism, questioning her choice to have more children, insensitive remarks, being rushed on the providers schedule, not caring, not being concerned about the mother, taking a one-up position/position of power, not giving any information, "they make you feel bad", having no compassion, giving a high-five because of high IQ without explaining anything, believing the mother or child is making it up, not acknowledging child's troubles because still doing well even though it's not up to child's potential [e.g., getting Bs when is gifted], being told doesn't need services that he does, not believing the mother's intuition on her child, not believing the child has troubles because "he looks normal"), negative interactions with other, trouble trusting others to help take care of child, leaving it to the professionals, not trusting others, networking, participating in research, partnering/collaborating, showing gratitude to professionals, other MCDAs get upset when she gives advice, perception she needs to make child fit in, telling others about child's diagnosis, mother listening to others about their thoughts of what would be helpful, defending self against insensitive remarks, mother interacting with school staff, others blaming the mother (e.g., not disciplining enough)

- Mother Learning or Growing: E.g., learning to be an advocate, to adjust, a lesson, skills, new info about associated issues, how it can manifest in different ways, gaining a better understanding, learning how to handle the process better (e.g., record meetings, ask for time to make a decision), growth, "got to learn in order to make your family work", "I think it's still a learning process…an ongoing education", "you learn a lot about yourself"
- Mother Taking Action: educating self, being involved, being proactive, being biggest influence, changing insurance, creating her own network, doing what she can, making appointments, doing things with child at home before could get treatment, seeking out help and communication, making requests, observing treatments, taking charge, taking initiative to make contact, teaching self what to do, trying treatments on her own, taking knowledge from what was learned into the home, leading groups so her child could have similar experiences as typical children (e.g., a girl scout troupe), doing things on her own, taking child wherever needed for treatments, taking an active role with leading the teachers on her child's needs
- Mother's Characteristics/Identity: E.g., wage-earner, resourceful, patient, from another country (acculturation), advantaged, disadvantaged, conservative, treating everyone the same, calm, viewing the fighting as against usual nature, depressed, persistent, has resolve, not an extremist, her mother was hard on her, stay-at-home mom, a teacher, religious, spiritual, educated, Christian, culture of food, questions others' authenticity which can be viewed as disrespect, keeps guard up, introverted, laidback, had own developmental delays as a child, had a hard life, involved in a business, military background, emotional, educated, doesn't trust easily, empathic, intellectual
- Mother's Personal Agency: E.g., mother directly involved, believing mother's perspective is important, being involved between sessions, beliefs parents need a voice, believes she is the biggest influence on her child, entering interactions with

a game plan, seeing changes, making it a personal mission to understand how to help her child, mother evolving and growing, mother providing structure as part of treatment, taking an active role, “It wasn’t until recently where I just went in there with the attitude of, ‘No, this is my meeting’”

- Mother’s Self-Appraisal: E.g., ineffective, was a “terrible person”, doing the best she can, blaming self, comparing self to ideal, seeing experiences as accomplishments, feeling like needs to do more/better, developing qualities she does not like in self, looking back as having done pregnancy ‘by the book’, doing well, seeing self as lazy, seeing taking care of a child with autism as a lot of work/another job, not stupid, needs help, believing she needs to prioritize better, thinking she let her child down, seeing that she needs to reverse how she reacted to child, believing needs to be a better parent and understand the child better, seeing self as being on top of things, “Do I think myself as being an expert in autism? No. But living with it and seeing it. I can say this is what I see and this is what I understand about autism.”, thinks she is not as passionate as could be, seeing self as active, viewing self as being negative, thinks husband handled situations with the school better than she would have, was starting to wonder if she was crazy, not handling it well, “just going through the years maybe you do become a really bit more resilient”, “You build up kind of a thick skin”, “I wish I would have been up on top of it”, “I’m doing something right”, “we do the best we can”, wishes she was more organized, “I think I could help him if I had my act together a little better”, thinks she is not a good advocate because “not very good on the honey” (i.e., isn’t pleasant with the people she is trying to work with), seeing self as laidback, wondering if it was her fault for something she did that caused child’s autism, “I’m not the best example of self-care”, realized she was freaking out, “as a parent I didn’t do half bad, I don’t think”
- Needing to Pay for What is Wanted: E.g., for services not covered by insurance, “out of pocket”, privately, paying to try out a service to provide evidence that it is an appropriate one, expensive, needing to pay for things at home (e.g., gluten-free food, vitamins)
- Normalizing the Child: E.g., autism not an identity, wanting people to separate the autism behaviors from the child, child learns a different way, autism not a deficit, autism just another factor about child, looking at child as normal, everybody has problems, “he is who he is”, “realize that this is just again a variation of human experience”
- Not Focusing on Self: E.g., declining help for self, disregarding own feelings, trouble attending to own needs, “You neglect yourself”, don’t have time for self, making sacrifices, “I had to literally put everything on pause”, “I had to put my own self second”
- Not Knowing: E.g., not understanding what autism is, what’s available, options, what to do, what to expect, different features of autism, associated issues (e.g., sensory problems, gross motor issues), spectrum, what is needed, how to respond, what to believe, not understanding a treatment, don’t know what you don’t know unless someone tells you about it, not having much information, things not explained to her, about a resource (e.g., SSI), hard time understanding the IEP, “I don’t know what tomorrow’s going to look like”, where to look, that barriers and

roadblocks would come up, about disparities in services until experienced them personally, how to help, "if you're on the outside looking in, it's foreign to you"

- Participating: E.g., attending meetings, involved in all aspects of treatment, modeling a skill, directly involved in the treatment (e.g., being taught ABA skills), taking classes, asking questions and getting feedback, being hands on, "Whatever homework they give me to do, I do that.", participating in IEPs, having parent meetings, entering in to the treatment, "Making sure I follow through and I try it", attending child's extracurricular classes
- Perceiving a Lack of Support: E.g., being on her own, believing family is not supportive, believing professionals do not provide support, needing to figure things out on her own, feeling alone, not getting support from friends, not receiving support from school, not seeing MCDAs as supportive of her, believing people don't want to hear where she is coming from, losing her social support (e.g., her own mother dying), "I had no one to go to", family living far away, "I didn't feel supported at all", "I don't think anyone gets it", professionals weren't there, "I couldn't talk to nobody", didn't have a role model, somewhat isolated, no support from the school, "Nobody ever gave me any help. Nobody ever suggested anything for me personally at all", "I expected my family to really step up, and be more. And I expected my mother to make sure my siblings be more involved…That didn't happen.", family scattering, not seeing other MCDAs because only visible during special events,
- Poor Functional Support: E.g., general school population can be harmful experience for the child, insurance-provided services inadequate, believes should not have needed to stress out about finding services, school has too much demand for the resources they have, shuffled between schools, disappointed by the system, choices limited, not being asked to be involved in the assessment, getting stuck, having more problems with services as child gets older (e.g., less available after turns a certain age, not many transitional services), inconsistency within/between service provision, not getting proper services, no regular contact with providers, mother needing to keep her own records, providers not showing up, not getting the supports wanted in the IEP, school staff not caring for the child's safety (e.g., child ran off and no one noticed), school not following through with things they said they would do, the advocate provided not being on her side, family not helping care for the child, school not willing to work with mom, not getting financial support, agencies not held accountable
- Receiving Services: E.g., accepting what is offered, getting services – early intervention, ABA, OT, speech, social skills, respite, medication, evaluation, IEP, counseling, regional center, home-based services, genetic testing, psychiatry, parenting classes, getting services through the school, taking what you can get, getting a specialist, getting accepted, being given resources
- Recommendations for Professionals: E.g., provide info about the diagnosis when it is given, include everyone in the evaluation process, recommend services, explain all treatment options, listen, give resources, co-create plans, give a hug, classes, professionals should learn from the mothers, be available to answer questions, take time, provide education, hold parents accountable, test parents' knowledge, have a less negative perspective, provide guidance, more support for

siblings, address the whole family system, pamphlets, actively check for questions, professionals be more educated, need to know what is available in the area, provide a resource fair, resource list with descriptions, recognize mental health needs of MCDAs, visit the home to see what environmental changes need to be made, handbook/kit, care coordinator/case manager, create a standard approach to getting assessment, offer support groups, earlier screening, open communication, empathy and understanding, explain assessment decision, follow up, comprehensive protocol, emotional support, refer for all possible associated symptoms, show they understand/care, preventative services, collaborate in treatment, not just push medicines, screening for the parents, having knowledgeable staff to be in charge, set up appointments immediately, be comfortable expressing concerns, find common ground between school and medical systems, have an office environment that would be friendly/comfortable for the child, not be antagonistic, "I think it's really working with them to overcome, um, their negative, whatever they call it now. Their negative countertransference or whatever…Or their negative responses to the parents. And it's going to be negative. I mean, you're dealing with people who are in the middle of the worst part of their lives.", train in how to deal with angry/emotional mothers, have mothers be in a service at the same time as the child rather than just in the waiting room, humble themselves, "you can't discount a parent's experience on a day to day basis…the parent knows just as much, if not more.", encourage parents to get their own therapy, explain things "in layman's terms, and not doctor terms", have specialists, guiding parents where to look if they want to do some research, make a support network, autism hotline that parents can call when they are having a hard moment – from focus group, put yourself in the mother's shoes, take a different tone when giving the diagnosis – don't be nonchalant about it or overly blunt with no bedside manner, connecting to a grief counselor for the mother after receiving the diagnosis, be familiar with associated features, "don't rush me", show compassion, provide a list of organizations that can help mother connect with other parents, "They could've given me a mentor", have a directory, interview the parent to get an idea about them and develop a plan, "don't give 'em false hope, but then don't make if feel like you're hopeless", say something nice or uplifting, have a bulletin board, professionals should take a class in sensitivity, have a standardized questionnaire for parents' issues, "What to expect when you're expecting, there needs to be a book like that for autism", don't just send the mother home to deal with the diagnosis by herself, have services spread to more areas/make them accessible, talk about what insurance covers at the time of diagnosis, invite mother to participate in the treatment, stand up for mothers who have a disparity in services, don't give dim-and-grim expectations, ask about what the mother's fears are, connect on an emotional level, be open, don't have a harsh tone

- Having Ideas about What Professionals 'Should' Do: E.g., separate the behaviors from the child, thinks professionals in our society aren't supposed to be emotionally involved, treatment should work with the child's interests, provide referrals, help the parent

- Seeking Help and Resources: E.g., asking for help, asking for advice, struggling to find support, finding support systems, needing resources, reaching out, seeking opinions, recommendations, seeking support for child/self/family, seeking support online, using Regional Center for resources, seeking legal help, reapplying to regional center, networking with people, seeking a referral, finding help and resources online, calling a lawyer or advocate, writing letters to people, calling to different places, going to conferences
- Spiritual Beliefs: E.g., God guided her, child is part of God's plan, prior experiences were divine lessons, her spirituality influence her life, changing to have spiritual beliefs, gets closer to God when things are going bad, "He only gives me what I can bear", believe in God, believe God was punishing her initially, believe in the power of prayer, "God trusted me with this special child…and He knew we would love him and care for him as best we could."
  - Spiritual Support: E.g., being transformed by religion, believes God is supporting them, believes her spirituality supports her, lives for service, feels cleansed of anger and bitterness because of her spirituality, identifies religion as a protective factor
- 'This is the New Normal': E.g., mental shift to adjust to life and autism-related changes, being satisfied with what the child has so far, prioritizing child's basic needs first, taking one step at a time, accepting change that comes with one's child's needs, accepting restriction's to one's lifestyle, learning to live with 'it,' accepting autism-related changes in one's life, 'constantly juggling' child's needs within family dynamic, integrating treatment into home-life, predicting child's challenges as part of her life, feeling liberated/restricted by changes in services, recognizing child's own separate 'life,' making concessions for child, recognizing child's diagnosis as a defining part of herself, viewing autism 'as part of our family,' planning a future for one's child, feeling out-of-place with mothers of typical children, believing change is constant, changing one's job/home to accommodate child's needs, recognizing accomplishments related to managing child's needs, 'this is my life,' 'it's [autism/autism-journey] is a part of me.' 'autism is a whole lifestyle,' 'just walk step-by-step with a kid with autism,' 'things could not be the way they were before,' '[accepting] this is my life,' 'you just have to learn how to make it work, […] how to make the family dynamic work,' 'this journey on being parents of autistic kids,' 'learning to live with it,' and 'this is the new normal.'
  - Acceptance: E.g., accepting diagnosis of autism spectrum disorder, accepting the loss of the expected neurotypical child, accepting the child you have, accepting differences in child, accepting because 'it' wasn't going to get better or go away, in the process of accepting 'it,' accepting the reality of the present and future, accepting treatment/service-related processes, diagnosis helping with acceptance, therapy helping with acceptance, treatment efficacy helping with acceptance, self-efficacy helping with acceptance, moving from guilt and self-blame to acceptance, experiencing grief and acceptance together, accepting autism condition as stable, feeling "at peace" with child's autism-related challenges, and accepting 'he is who he is.'

    - Focusing on Child: E.g., neglecting own needs, viewing child as whole life, considering one's child in everything one does, having it encompass one's thoughts, putting self-second to child, putting one's own plans 'on pause,' focused on addressing child's emotions, continually working for more for child, prioritizing child's welfare above own beliefs, constantly being mindful of child's needs, husband changing life-plans for child, focusing on child in personal psychotherapy, believing most parents feel their child is their whole life, 'everything in my life's my child,' 'how is it going to affect my child,' 'it's not about me anymore,' 'everything you do revolves around [child's needs], 'your life is having a child with autism,' 'he used to run the house,' '[having to] put my own self second,' 'no me, just him,' and 'life is them [children] right now, but it doesn't have to be.'
- Trying Alternatives: E.g., trying alternatives due to difficulties with healthcare system, trying more "natural" treatments due to desperation, trying an alternative diet (including gluten free diet, casein free diet, low sugar whole-food diet, sulpforaphane supplement), trying an alternative to public school (such as home-schooling and online schooling), trying an animal-related treatment, massages, reflexology, hypnosis, naturopathy, acupuncture
- Trying Multiple Treatments: E.g., trying "everything," trying "everything" reasonable and affordable, trying as many treatments as possible, trying a wide variety of treatments, trying multiple treatments for trial and error, trying multiple treatments to address specific multiple symptoms or associated issues, listing treatments (by symptoms targeted, trying treatments that aren't autism-specific, going doctor to doctor
    - [listed treatments: Medical treatments, herbal treatments, social skills services, music therapy, dance therapy, music therapy]
- Wanting (Better) Diagnosis or Treatment: E.g., more hours of ABA, less wait for ABA, coverage for "basic" ABA therapy, swim lessons tailored for child's needs, P.E. class tailored for child's needs, psychotherapy, music therapy, equine-therapy, (additional) speech therapy, feeding therapy, full integration in general education, appropriate social activities, nutritionist, social skills treatments, parent-inclusive treatment, wider variety of treatments to try, treatments that effectively address symptoms (such as GI distress or social communication difficulties), treatments that address more than just symptoms, treatments that address the child's focused interests, and a proper diagnosis
- Wanting More for Child: E.g., an easier life, a better life, a full life, successful future, productive in his/her future, accepted for who he/she is, safer, better communicator, involved in sports, to have a different impairment, to receive more resources, to receive more consideration from professionals, to be treated as a person/child, and to be happy.

Entry 30: Audit

In order to increase credibility, an audit was performed. The auditor was a master's level librarian who has some familiarity with qualitative research and grounded theory and is experienced with editing dissertations at a graduate-level health sciences university. She took a random sampling of five transcripts, including at least one done by each team member, and reviewed the coding definitions and examples. She indicated that she did not see any major information missing from what was presented to her.