

Parental “Sense of Agency”: A Qualitative Study of Parents Experiences Assisting their Children in Outpatient Community Mental Health Treatment.

ABSTRACT

In the United States, there are approximately 17 million children under the age of 17 that have commonly diagnosed mental health disorders which include ADHD, behavior problems, anxiety, and depression (Bitsko et al., 2019). In efforts to provide access to mental health treatment, there are approximately 11,682 mental health facilities as of 2018, 62% of which are comprised of community mental health centers and outpatient mental health clinics that provide mental health services for children and families (SAMSHA, 2018).

The purpose of this qualitative phenomenological study is to explore the experiences of parents and/or primary caregivers “sense of agency” in reference to working with mental health professionals in outpatient community mental health settings. For the purposes of this study, “sense of agency” is defined as actions that are experienced as voluntary and in which we may not feel as simply happening to us rather, we experience agency when we are in control of our actions (Synofzik et al., 2008; Moore, 2016). The assumption in the study is that parents “sense of agency” is a critical aspect of parents being able to effectively engage and implement evidenced based interventions utilized for their children in outpatient community mental health settings. Furthermore, parents increased or improved “sense of agency” would have a lasting impact on their ability to assist their children with mental health conditions even after their children are no longer receiving mental health treatment. The theoretical framework that was utilized in the study to explore parents “sense of agency” was Bowen’s Family Systems Theory.

The study was comprised of N=10 participants who had one or more children participating in one outpatient clinic in Central Harlem. Parents engaged in a one-hour semi-structured interview which explored their experiences assisting their children in mental health treatment and their interactions with their child, mental health practitioners and other supports. After the study was completed, four major themes emerged. The four themes included: parents locus of control, parental activation, parental attributions, and issues related to the utilization of psychotropic medication by some of the children in the study. These themes impacted parents “sense of agency” in how they were able to engage in their child’s treatment, what they believed were potential causes of their child’s mental health condition, their orientation of control (whether external or internal) in reference to their child’s progress in treatment, as well as, navigating their children’s resistance to psychotropic medication.

Social work practice implications would incorporate interventions that can increase parents “sense of agency”, specifically due to its relational nature which may lead to a transmission of agency to future generations considering the ongoing systemic challenges that families may face in their own communities. The implications for future studies may focus not only on parents “sense of agency” during their child’s mental health treatment but parents “sense of agency” before the start of their child’s treatment process in relation to their capacity to implement interventions that are formulated alongside the mental health practitioner.

Furthermore, studies may seek to follow up with parents after their child's completion of treatment in efforts to understand parents' experiences or changes in their "sense of agency" as it relates to their children's mental health. These studies would further allow to improve the understanding between parents "sense of agency" and long-term outcomes in mental health treatment for their children.

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**Parental “Sense of Agency”: A Qualitative Study of Parents Experiences Assisting their
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Dedication

I dedicate this work, my entire life and career to the woman who has exemplified agency, strength, courage, and unconditional love throughout my entire life. My Mother.

Carmen Erickson-Lara

“Mami, eres el primer amor de mi vida. Te quiero tanto. Eres y siempre será la mejor parte de mi vida y la inspiración para seguir luchando”.

Tu hijo – Eric

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Chapter I: Introduction

In the United States, there are approximately 17 million children under the age of 17 that have commonly diagnosed mental health disorders which include ADHD, behavior problems, anxiety and depression (Bitsko et al., 2019). In efforts to provide access to mental health treatment, there are approximately 11,682 mental health facilities as of 2018, 62% of which are comprised of community mental health centers and outpatient mental health clinics that provide mental health services for children and families (SAMSHA, 2018). In New York State alone, there are approximately 100 community outpatient mental health centers (Non-Profit Metrics, 2021). These outpatient community mental health clinics are intended to provide and increase access to mental health services to individuals, children and families that live in “underserved” communities. Fifty to seventy percent of the funding for outpatient community mental health programs come from Federal and State block grants through Medicaid and Medicare which families qualify for when they are living under the poverty line (MHA, 2021). Since the term “underserved” identifies various factors, children and families living in poverty is a common denominator that represents the majority of families that access outpatient community mental health centers and is reflective of the participants in the study.

Research Question

What are the experiences of parents that have children in outpatient community mental health settings in relation to their “sense of agency”?

The purpose of this qualitative phenomenological study is to explore the experiences of parents and/or primary caregivers that engage their children in outpatient community mental health services. Specifically, the study is intended to provide an understanding about parents

and/or caregivers “sense of agency” in reference to working with mental health professionals in outpatient community mental health settings. The assumption in the study is that parents “sense of agency” is a critical aspect of parents being able to effectively engage and implement evidenced based interventions utilized in outpatient community mental health programs in response to their children’s mental health conditions. Furthermore, it is theorized that parents “sense of agency” would have a lasting impact on their ability to assist their children with mental health conditions even after they are no longer receiving mental health treatment in community outpatient mental health clinics. The theoretical framework that will be utilized to explore parents “sense of agency” will be Bowen’s Family Systems Theory.

I. “Sense of agency” defined in reference to the experiences of parents and caregivers engaged in outpatient community mental health settings.

A person’s “sense of agency” can be defined in many ways. For the purposes of this study, “sense of agency” is defined as actions that are experienced as voluntary and in which we may not feel as simply happening to us rather, we experience agency when we are in control of our actions (Synofzik et al., 2008; Moore, 2016). If we apply this definition to parents and primary caregivers who have children in outpatient community mental health settings, it brings focus to the parent’s participation and experiences in the course of mental health treatment of their children. A possible critique to positioning parents “sense of agency” as a major component to treatment outcomes of their child’s mental health treatment would be that these outcomes are also contingent on the other person in the treatment “equation”, which would be the clinician or provider. For example, one can argue that a clinician’s skill level or clinical experience can also be a key component on the outcomes of a child’s mental health treatment. However, if the parent lacks a “sense of agency”, they may perceive that outcomes were not based on what they were or weren’t able to do in their child’s mental health treatment, but solely on what the clinician’s

clinical practice and expertise had to offer. In most cases, clinicians in outpatient community mental health settings rarely have insight or are present when parents attempt to integrate interventions in the home. The parent therefore becomes the main “connector” between the clinician’s office and the implementation of mental health interventions for the child in the home. In essence, the course and outcomes of mental health treatment are not necessarily contingent on what happens “inside” the clinical setting but rather on the “outside”, or the environment in which the child resides with the parent or caregiver. It can be argued that even if the clinician is highly skilled, they will always need to depend on the parent in efforts to have the ability and drive to effectively develop these interventions in the home. This study doesn’t propose that parents “sense of agency” is the only way to determine the outcomes of children’s treatment. In fact, there can be an array of factors that impact outcomes in a child’s mental health treatment. However, the proposed study does suggest that the parent’s “sense of agency” or the ability to “drive” their child’s mental health treatment and believe in their capacity to do so, is a critical factor in which their children improve their overall wellness, despite the presence or influence of other “outside” factors.

II. Why study the experiences of parents and/or caregivers in community outpatient mental health settings in reference to their “sense of agency”?

In outpatient community mental health settings, parents and caregivers obtain services from mental health professionals in effort to assist in the emotional and behavioral issues which their children may present in the communities. Community may be defined in the general sense in which the parent and child interacts, not only within the family unit, but how they also interact within their environment. For example, children may enter the community mental health system through parents and primary caregivers’ belief that the child may benefit from obtaining mental health services due to observing moods and behaviors a child may exhibit that may negatively

impact their overall level of functioning in the home. Whether it is their children's difficulty following rules in the home, completing school and/or home related tasks or exhibiting an inability to cope effectively with stressors that may arise within the family dynamic or family related events (i.e., parental separation, parent's mental illness, sibling conflict, family loss, etc.), parents may find that seeking a mental health professional may improve their child's overall mental wellness and coping strategies. On the other hand, children may enter the outpatient community mental system from "outside" the family unit, which may include but are not limited to the following: recommendations and/ or referral of the child's school, inpatient units, family courts, and foster care or preventive agencies that attempt to preserve the family unit. In most cases, parents and/or primary caregivers voluntarily bring their children to outpatient community mental health settings in efforts to assist in improving their child's mental health and thus overall level of functioning. The study seeks to understand the experiences of these parents and/or primary caregivers with the notion that in efforts for any mental health treatment of their child to have a positive outcome, the mental health practitioner must depend on the agency of the parent and/or primary caregiver in order to formulate and implement evidence based interventions that are theoretically designed to address the behavioral issues that their children may exhibit. The exception to this notion are children that request and access outpatient community mental health services on their own volition and independently "drive" their own treatment (children over the age of 18) or children who are wards of the state. Once children are admitted into outpatient community mental health clinics, parents are tasked with the process of not only understanding how to assist their children in the home, but also be able to effectively work with the clinician in efforts to assist the child manage identified symptoms. The parent's experiences in attempting to integrate interventions in treatment is the focal point of the study through the lens of parental

agency. If the parent or primary caregivers, “sense of agency” is negatively impacted, it is assumed that this will heavily influence the parent’s ability to not only effectively assist the child in the treatment process but more importantly how they understand their role in their children’s progression in mental health treatment.

III. Why are parents and primary caregivers “sense of agency” important to study when considering mental health in outpatient community mental health agencies?

Most outpatient community mental health settings rely on empirical data to determine the effectiveness of mental health treatment for children and their families. This data can be interpreted in various ways. These interpretations can be constructed on the “micro-level” which may be defined by evidenced based practices that are formulated in a treatment plan between the child, parent and/or caregiver and the mental health professionals involved in the treatment. For example, a child’s treatment plan may include an objective to decrease symptoms related to a particular mental health symptom by quantifying the number of tantrums that the child may have in a week through the utilization of cognitive behavioral therapy. If the child exhibits fewer tantrums, it is therefore assumed that the treatment was effective through the parent’s utilization and integration of CBT techniques in the home. On the other hand, the data collected to observe effectiveness of community outpatient mental health settings can also be analyzed through “macro-level” outcomes. These outcomes often times influence the community outpatient clinics viability in the community. For example, a community mental health clinic may report the number of psychiatric hospitalizations as a marker to determine the effectiveness of the community mental health program as a whole. Whether the outcomes related to children in outpatient community mental health services provided are assessed on the “micro” and/or “macro” level, the proposed study contends that these measures lack utility for a parent who may feel that they don’t have the capacity to effectively “broker” the child’s treatment when

attempting to implement interventions formulated in therapy. Furthermore, even if their child obtains the level of wellness that would warrant completion of treatment, the parents “sense of agency” would be important to consider in their ability to not only understand their role in the successes and/or failures of their child’s mental health treatment but also how they are able to effectively “translate” evidence based practices offered in outpatient community mental health treatment into their unique home environment and circumstances related to unique family patterns (i.e., culture, race, gender, language, etc.) and environmental stressors that may impact the family unit (poverty, food insecurity, immigration, unemployment, community violence, etc.). The proposed study assumes that parents “sense of agency” plays an integral part in the parent’s ability to navigate through internal and external “forces” that not only influence the child’s mental health but the mental health and functioning of individuals that comprise the family unit. Notions of locus of control, parental activation and parental attributions will be further discussed in relation to parents “sense of agency” as a way to further explore parents’ experiences in assisting their children through the stages of mental health treatment in outpatient community mental health settings.

Chapter II: Brief history of “Sense of Agency”

In the following chapter, a brief history of the concept of agency will be discussed. The following points will be explored: (a) early notions of agency, (b) modern theories of agency, (c) present day notions of agency and finally, (d) the paradigm shift from individualistic notions of agency to relational agency in connections to family therapy and practice.

A. Early notions of Human Agency

The concept of agency has its philosophical origins that could be traced back to Aristotle and his notion of human action. Aristotle’s conceptualization of human action is divided into two notions, the practical and the technical, with the assumption that all actions by individuals are rational and voluntary. The practical notion of action by individuals pertains to the inherent ability for individuals to make decisions even if it is caused by an outside source. The technical aspect of action refers to the ways in which individuals pursue a result or goal. In essence, Aristotle attempts to answer the “how” we approach situations that we would like to achieve in the practical sense and the “what” we implement, in the technical sense, in efforts to achieve what we would like to see as a desirable result (Judson, 2018; Crespo, 2018).

Aristotle’s explanation of agency becomes separate mechanisms in which a person’s actions can be defined or explained. Later in the 17th century, English philosopher John Locke proposed a similar theory that can be related to current notions of human agency in that individuals willfully enter into a social contract in efforts to establish a desired result of a civil society. The creation of government and laws to protect an individual in his description of the *state of nature* through enforcement of the laws and the consent of individuals (Laskar, 2013).

These early concepts of individuals and their will to achieve a result, whether through individualistic means in Aristotle’s notions of human action or collectivist in efforts to protect

individual rights by Locke, serve as early foundational ideas of agency in regards to individuals having the capacity, knowledge, ability and power to manifest and influence the conditions in which they live.

B. Concepts of human agency and its relationship to institutions in the Modern Era

In the late 20th century, the philosophical origins of the concept of agency could be found in various disciplines including economics, psychology, neuroscience, and sociology. In the late 1960 through the 1970's, various theorists approached the concepts of agency in different ways. For example, Bandura's theory of "self-efficacy" is usually associated with "sense of agency" but it is based on the assumptions of belief of mastery of experiences (Bandura, 1977). However, it can be implied that before we are able to believe we can master a particular task as in self-efficacy, we would need an awareness of our capacity. The subjective experience or awareness of our capacity or ability to master experiences is what is more closely related to "sense of agency".

In economics, in the mid 1970's Steven Ross and Barry Mitnick, developed a theory of agency in relation to institutions. As Mitnick (2008) explained:

Ross introduced the study of agency in terms of problems of compensation contracting; agency was seen, in essence, as an incentives problem. Mitnick introduced the now common insight that institutions form around agency, and evolve to deal with agency, in response to the essential imperfection of agency relationships (p.393).

As we approached the 21st century and beyond, models of agency have been heavily influenced by neuroscience and psychology. In the next session, I will discuss and exemplify some of these new conceptual developments.

C. Current Theories of Agency: Comparator Model vs. Theory of Apparent Mental Causation.

Among the various current types of theories in reference to agency include but are not limited to: Instrumental Agency developed by Gyorgy Gergely, Communicative Agency developed by Jurgen Haberman, and Navigational Agency developed by Frank Leslie, just to name a few. However, there are two leading theories in respects to understanding “sense of agency”, The Comparator Model by Chris Frith and Theory of Apparent Mental Causation developed by Daniel Wegner and T. Wheatley (Moore, 2016; Frith, 2005; Frith et al., 2000; Wegner & Wheatley, 1999; Wegner, 2004).

The Comparator Model created by Chris Frith is a model that focuses on sensorimotor control as a way to account for the way in which “the motor system can be considered a control system with the input being a ‘desired state’ and the output being the ‘estimated actual state’” Synofzik et al, 2008, p.220). (See Figure 1)

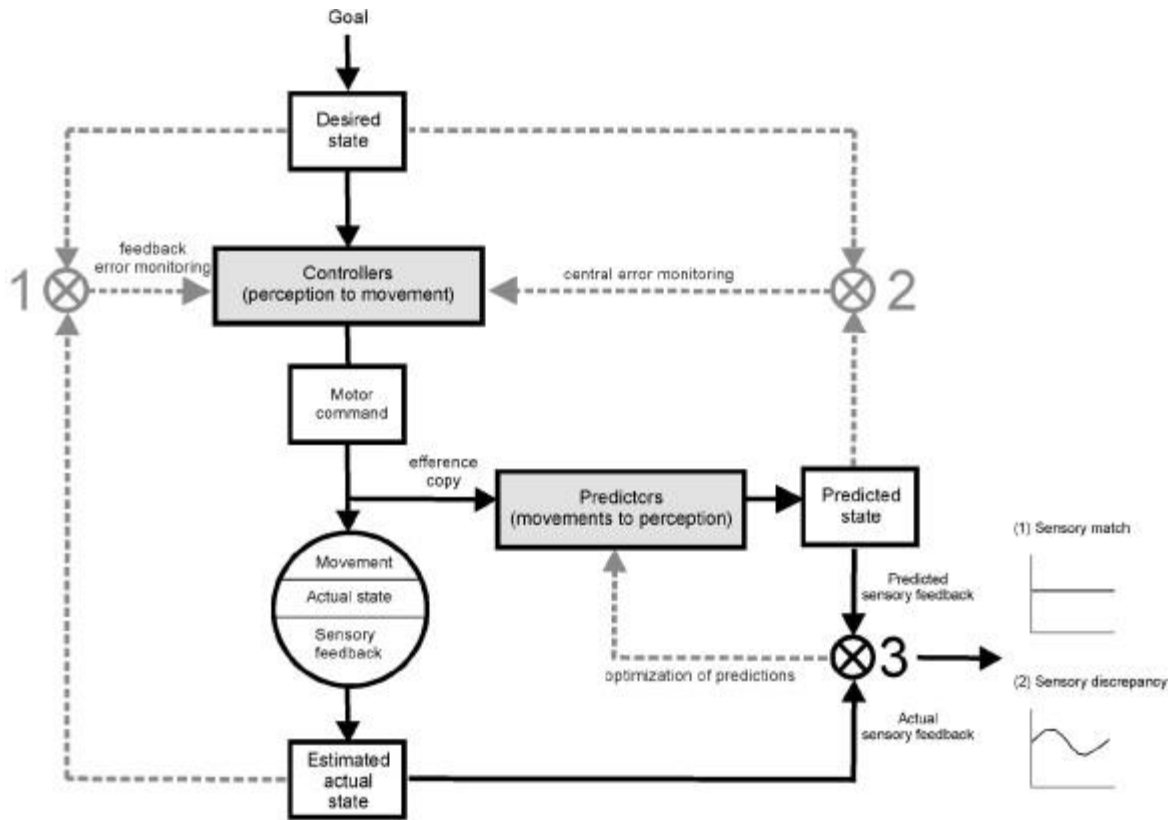


Figure. 1

However, the Comparator Model could be not only applied to sensorimotor control but also a neurocognitive model related to “sense of agency”. As Synofzik et.al (2008) further explained:

According to this model, the comparators not only serve a pragmatic, executive function on the level of sensorimotor control, but also assume an evaluation function on the level of action awareness: They may directly underlie our sense of agency, i.e., the registration that we are the initiators of our own actions, in that they ‘label movements as generated by oneself or an external source (p.221).

In contrast, The Theory of Apparent Mental Causation, developed by Daniel Wegner and T. Wheatley makes a slight departure from the Comparator Model in that it doesn’t focus its theory

so much on sensorimotor control but rather a source outside the motor system or the unconscious. As Moore (2016) explained:

According to the theory of apparent mental causation when we make a voluntary action there is an *unconscious* causal pathway that is responsible for the action. This pathway corresponds to the workings of the motor control system. There is also an unconscious causal pathway that is responsible for the associated thoughts about actions (i.e., intentions). In addition to these unconscious causal pathways, there are certain events that we are conscious of, namely the intention to act and the act itself. According to Wegner it is the relationship between the thought and the action that determines the sense of agency (or in Wegner's term, the 'experience of conscious will'). If our intention to act happens before we act, is consistent with the action, and is the only plausible cause of the action, then we feel as though we have caused the action (p.3-4).

Cue Integration Theory developed by Idit Shalev, strives to integrate both The Theory of Apparent Mental Causation and the Comparator Model as a way to understand "sense of agency". Cue Integration Theory proposes psychological experiences that are influenced by their momentary interpretations of perceptual cues. As Shalev (2018) explained:

Theories of embodied cognition suggest that bodily sensations and physical environmental cues are stored as analogous psychological concepts in memory, and their activation by such cues automatically spreads from their physical experiences to their metaphorically related psychological representations and vice versa. In other words, higher level processing is grounded in the organism's lower level sensory and motor experiences, indicating that psychological experience is associated with sensual characteristics (p.4).

Although The Cue Integration Theory aims to have a more holistic notion of individualistic notions of agency, it has its limitations in the realm of socialization and the impact influenced by the ongoing process of relationships between individuals. In current notions of agency in family therapy, there is a shift in the paradigm of agency being individualistic to having a relational definition, as explained in the following section.

D. From individual “sense of agency” to a relational “sense of agency” in the context of Family Therapy.

To better understand the development of the concept of agency in the field of social work and family therapy it is important to consider the ideas of social psychologist, Kenneth Gergen’s who theorized, in the early 1990’s, that all human actions and experiences are constructed through relationships. Therefore, individual actions are based or constituted by the relationships in which we engage in with others. Furthermore, the individual experience cannot be understood without the influences of social conditions, culture and historical contexts (Gergens, 1991; Sugarman & Martin, 2011).

The paradigm shift from the individualistic notions of agency to a more relational definition can be attributed to the ideas of English sociologists, Anthony Giddens and Margaret Archer. Giddens is known for his *Theory of Structuration* in the early 1980’s, which posits that *structures* (rules and resources) exist internally for individuals as memory and exist externally when individuals create these structures based on their memory through social interactions (Giddens, 1979). Archer is best known for coining the term *elisionism* which refers to the idea that the social and the individual could not be disconnected or thought of as separate (Archer, 1995). Archer would later offer a critique of Giddens theory which was based on her belief that structures exist before agency and therefore an individual’s actions would be dictated by the environment in which they are situated.

In family therapy, the individualistic notion of agency has its limitations due to the importance of interpersonal interactions between family members in the overall well-being of the child within the family unit. Therefore, an individual's agency within the family dynamic is best conceptualized as relational (De Mol et al., 2018). Although relational agency is important in all social interactions, it is critically important in intimate or close relationships due to having the experience of making an impact on the relationship. An individual would get the sense that they are contributing an important aspect to the other, to the individual himself and the relationship, as a whole (Bertando & Arcelloni, 2014; De Mol et al., 2018; De Mol & Buysse, 2008; Sugarman & Martin, 2011). When exploring parents "sense of agency", we must reconsider the ways which parents influence change in their children's mental health treatment that may veer from traditional views of systemic therapy in which the parent unilaterally influences the child's mental health outcomes and examine the mutual transmission or bidirectional view of agency in family mental health treatment.

Unlike Bandura's theory of "self-efficacy", a "sense of relational agency" is not having the ability to control another individual to attain a specific goal in the relationship. The idea of controlling another dismisses the others agency, the type of relationship and the context in which the relationship exists. Relational agency requires a dismissal of one individual causing action in another and shifts to a more dialectal concept in which individuals are creating new meanings in the interaction. Therefore, relational agency requires a separation between the intentions and effects. Due to the need of understanding other interpretations, we can never control the impact of our intentions on others. On the other hand, when a person has a diminished sense of relational agency within the interpersonal dynamic, they may attempt to use power to influence the other with the possibility of alienating the other person, oneself and ultimately the actual

relationship itself (De Mol et al., 2018). The attempt to control the other in a relationship is similar to parents having an external locus of control when attempting to discipline their children and therefore resorting to an authoritarian style to retain their power. In Bowens Systems Theory, this can also be reflected in poor “self-differentiation” between parent and child which leads to an attempt of either the parent or child trying to control the other.

The way in which the concept of agency has been developed by early philosophers to present day scholars in psychology and social sciences, can be mostly derived from an individual perspective or individual experience. Upon review, parents “sense of agency” is heavily influenced by not only their own experiences but their children’s responses, experiences, and outcomes in mental health treatment. Furthermore, ongoing family interactions that facilitate change in mental health treatment may not only impact parents “sense of agency” but also their children’s “sense of agency”. Finally, the impact and role of the therapist and interventions utilized to foster a “sense of agency” within the family dynamic can shift the bidirectional concept of relational “sense of agency” to a multi-directional one.

When considering a multi-directional concept of agency, Open Dialogue, a therapeutic intervention developed in Finland in the 1980’s, seeks to engage individuals in need of treatment, their families and their community or network. The aim of the intervention is to eliminate the hierarchical structure of treatment into a restructured power dynamic through the reconstruction of meanings and language that move away from symptoms and problematic behaviors (Wates et al., 2022; Olson et al., 2014; Siekkula & Trimble, 2005). The creation of a new language between family members that seek to understand the other’s experiences in the mental health treatment process rather than focus on traditional evidence-based treatment, may be a way to

transmit and reinforce all who are involved in the parent and child's mental health treatment experience.

Chapter III: Bowen's Family Systems Theory, Locus of Control, Parental Attributions and Parental Activation in relation to Parental Agency: Review of the Literature

I. The Bowens Family System Theory

In developing the qualitative study, the Bowen Family Systems Theory was utilized. The foundation in Bowen's theory is that human behavior can be understood within the family unit in which individuals belong. The individual is in a system that dictates the way in which they feel and experience emotions. In other words, there is an emotional interdependence between family members within the family system. The following is a list of the 8 tenets of the BFST.

1. Triangles
2. Differentiation of Self
3. Emotional Cutoff
4. Nuclear Family Emotional Process
5. Family Projection Process
6. Sibling Position
7. Multigenerational Transmission Process
8. Societal Emotional Process

For the purposes of conceptualizing this study, several of BFST concepts will be explored in relation to the questions proposed in the phenomenological investigation. It is important to note that BFST is grounded on two principal factors. As Erdem & Safi (2018) explained; "one factor of chronic anxiety, which stems from the dilemma of maintaining self while making meaningful connections with significant others. The second key factor is differentiation of self, defined as

adaptive strategies to regulate chronic anxiety” (p.470). The three concepts that will be utilized in this study will be as follows: 1) Differentiation of self, 2) the Family Projection Process and finally, 3) the Nuclear Family Emotional Process.

II. “Sense of agency” and locus of control in relation to differentiation of self.

Bowen describes “differentiation of self” as an attempt for individuals in a family system to gain a sense of autonomy from the system itself. Poor levels of differentiation of self is characterized by a strong impact by others in the system, on the individual’s functioning. Conversely, this low level of differentiation can lead to the individual trying to control the functioning of others in the system. Bowen theorizes that there are “building blocks” or “inborn” characteristics of the self but it is then developed through interaction in the family system. The motivation to which parents and/or primary caregivers may bring their children to mental health treatment can be due to the conflict that may arise in the parent-child dyad or family unit (Bowen, 1972). It is important to point out that the BFST is based on an “intact” family. In other words, the theory was based on relationships in which both parents are in the family system. For the purposes of this study, parents and caregivers that participated in the study, may or may not represent the “intact” family system in which Bowen bases his theory. Parents and/or primary caregiver’s “sense of agency” can possibly lead to mitigating the negative impact of lower levels of differentiation because the parents “sense of agency” may lie independently from the levels of differentiation of individuals in the family system. For example, if a child’s disruptive behavior has increased due to conflict between parents in the home, the parents may perceive that the child is attempting to draw attention which attributes to the parental conflict. Or, the parents may perceive that the child’s behavior is a result from the parental conflict. Furthermore, both perceptions may be valid when a clinician is not only offering family-based interventions that

may be helpful for the child but also the entire family system. The parent's "sense of agency" would serve to not only consider all possibilities of family functioning related to the parental conflict but also be able to improve their capacity and ability to implement interventions offered in treatment to effectively address the child's disruptive behavior.

When we consider ways to understand a parents "sense of agency", we may find that the ideas associated with locus of control may, at times, be utilized interchangeably with "sense of agency". However, as Tyler et al., (2020) explains:

As Rotter (1966) suggests an individual's motivation for autonomy or agency is likely to influence the strength of their outcome expectancies and therefore locus of control orientation. Personal agency refers to 'an individual's capacity for, and engagement in, intentional, goal-directed action' and the cognitive, affective, and individual learning experiences that influence this. Given the hypothesized relationship between locus of control orientation and agency, we suggest it may be helpful to consider how increasing an individual's capacity for agency may also help to reorient an individual's locus of control (p.2).

In other words, a parents "sense of agency" influences their locus of control orientation, whether its external or internal. The proposed study seeks to provide insight on the multidimensional nature of parent's involvement in their child's treatment rather than the linear models, as suggested earlier, which are based on specific markers that signal effective treatment (i.e., rate of hospitalizations, treatment compliance, medication adherence, etc.) or behavioral markers utilized in evidenced based practices (reduction or increase of depressive episodes, tantrums, etc.) (Kane & Prinz, 1999).

The notion of parental locus of control can also be considered in parents experiences and approach to the mental health treatment in combination with their capacity or “sense of agency” to effectively help their children in mental health treatment. Parental attributions impact the parent and child relationship and consequently their children’s behavior. Parents with an internal locus of control may experience a greater belief in their ability to assist their child in their behavior and therefore are able to make changes in their approach contingent upon how easily or difficult the child may be in improving their behavior. On the other hand, parents with an external locus of control may be less reliant on their parenting and may become more indifferent when dealing with a child with problematic behaviors and feel defeated and take on a more passive approach. These parents may compensate for these feelings by utilizing a more authoritarian style to their parenting. (Bugental & Shennum, 1984; Kane & Prinz, 1999; Jansens, 1994). The construct of an “easy” or “difficult” child is a perception that can vary depending on the parents’ ideas about what an “easy” or “difficult” child may demonstrate in their behavior. These perceptions may be reinforced by others within the family dynamic or the family environment. Furthermore, when we consider a parent’s use of an authoritarian style to managing a child’s behavior its not to say that parental authority in it of itself is not useful. In fact, parental authority may need to be established in efforts for any mental health treatment to be effective. However, a parent having the ability or capacity to utilize other “styles” that may be more effective rather than defaulting to a strictly “authoritarian” one, may offer a more enduring individual impact on the child, parent and family system, even after treatment is completed. The individual impact of introducing other styles of parenting may also serve as ways to increase levels of differentiation, unlike the authoritarian style that may decrease differentiation between family members and therefore negatively impact outcomes for parents and their children in

mental health treatment. The concept of parental attributions will be discussed in the next section in reference to the family projection process.

III. “Sense of Agency” and Parental Attribution in relation to the Family Projection Process.

Parental Attributions refers to the ways in which parents perceive possible causes related to their child’s mental health. Bowen describes the family projection process as a way in which parents transmit their problems, as well as their strengths onto their children. This projection can lead to problems in behavior and/or emotional disturbances within the child. The family projection process is a three part process that includes the following: 1) Parent focuses on a child due to their own fears that there is something is wrong, 2) the child’s behavior confirms the parents fear and finally, 3) the parent treats the child as though there is something wrong with the child (Bowen, 1972) When considering parents and/or primary caregivers “sense of agency”, this study will explore ways in which the family projection process impacts how parent’s perceive mental health issues related to their child. The study will seek to examine parents and/or primary caregivers fears and how it may influence their “sense of agency” in efforts to implement interventions formulated in treatment. In theory, if a parent is able to alleviate their own fears through there “sense of agency”, it can be assumed that the family projection process can be interrupted and therefore allow the parent and/or primary caregiver to be able to effectively redirect their care to the conditions that create and/or sustain their child mental health issue rather than identifying the child as the “problem”. In effect, the symptoms associated with the diagnosis treated in community outpatient mental health programs would be externalized to relieve the fears or anxieties associated within the family projection process that may lead to a diminished parental “sense of agency”.

When children engage in outpatient community mental health clinics, they are given a diagnosis once they are admitted. At times, parent's response to their child having a mental health condition may lie within the spectrum between the confirmation of the child's "problem" to a complete rejection that there is something wrong. To better understand the process of parents' experiences in relation to their children's participation and behaviors in outpatient community mental health programs, the notion of parental attributions will be explored. More specifically, parental attributions in the context of the family projection process and its impact on parents' "sense of agency" will be reviewed.

In a recent systematic review titled, *Transdiagnostic Associations Among Parental Causal Locus Attributions, Child Behavior and Psychosocial Treatment Outcome: A Systematic Review*, the researchers identified 67 studies that showed that "biased child-responsible attributions were associated with elevated child internalizing and externalizing symptoms and behavior across diagnoses, while findings on the association between parent-causal attributions and child behavior were inconsistent" (Kil et al., 2021, p.267). Parents' ideas about their behavior towards their children, the behaviors that children exhibit and the way parents experience their relationship to their child is referred to as parenting cognitions (Kil, et al, 2020). Parenting cognitions has been the focus of parental attributions, which is defined as "parent's perceptions of and explanations for the cause of their children's behavior...as such parents' causal attributions about their children's behavior can influence the parent's behavior" (Kil et al., 2020, p.268). Parental attributions are often categorized in two ways: parent-causal attributions and child-responsible attributions. When considering parental-causal attributions, parents may think that their own parenting style contributes to their child's behavior. On the other hand, when

considering child-responsible attributions, parents may feel that their children's problematic behaviors are created by the child and are intentional (Kil et.al, 2020).

In comparison to child-responsible attributions, there has been limited research on parent-causal attributions when they are engaged in their child's treatment. In most studies in which children's behaviors are examined, children exhibiting elevated externalizing behaviors (i.e., ADHD, ODD), parents often experience that they may have less control in managing their children's behavior and thus believe that their children are responsible for their disruptive behavior (Kil et al., 2020). In a recent study of 276 parents of middle school children in an outpatient mental health program associated in an urban mental health hospital, it was found that parent-causal attributions were directly and indirectly associated with parent's readiness for treatment (Kil et al., 2020). Of course, parent's readiness for treatment with their child should be placed in context. The family projection process suggests that there may be fears and/or anxieties that may impact parents readiness in their child's treatment, because parents may need to also consider their own contributions to the child's behavior.

When considering stressors within the context of the family projection process, we are able to widen the scope of the "parent-child" dyad related issues to include not only their readiness to engage in their child's treatment, but ways in which these factors influence the parents "sense of agency" in participating in the treatment process. If a parents "sense of agency" is negatively impacted by stressors within or outside the family dynamic, parents may project their lack of agency onto their child's behavioral issues. Furthermore, parents' readiness to engage in their child's treatment may shift from a parent-causal attribution to a child-responsible attribution. For example, if a parent is experiencing marital related stressors within the family dynamic and their experiences are projected onto their child's disruptive behavior, they may

attribute the cause of their marital issues to their child's maladaptive behavior. Thereby, attributing marital issues, to the child's behavior ultimately impacting the parents "sense of agency" in regards to the parent's ability and capacity to not only manage their marital issues but also be able to participate and understand ways to utilize and implement interventions in outpatient mental health treatment that may assist in their child in improving the child's mood and behaviors.

One of the most important steps in child's mental health treatment in any setting is the screening and intake process. Outpatient community mental health programs usually have the preliminary completion of intake documentation (agreement for treatment, confidentiality related forms, informed consent, etc.). Once the parent completes the initial administrative process of intake, the clinician is tasked in performing an initial assessment which describes the reasons why the parent has taken their child for mental health treatment. The assessment may include a series of questions of the child's symptomatology that warrants mental health treatment along with questions about the child's developmental, medical, educational history, etc. Once this initial process is completed, the child is then formally admitted into the community outpatient mental health program and thus the treatment planning process begins. This study seeks to explore not only parents' experiences in this process and their notions about how they attempt to implement evidenced-based interventions (CBT, DBT, etc.) but how they attribute the changes (whether positive or negative) in their child mental health treatment. During the course of treatment, parental attribution to their child's behavioral issues may be overlooked even when they engage in collateral sessions that may offer clinicians a better understanding on how to effectively assist parents in improving their "sense of agency" and therefore positively impacting

their capacity to implement evidenced based treatments that may assist in improving their children's overall mental health.

In a recent study conducted in Australia with 163 families with middle-school aged children engaged in specialist clinics that treated children with conduct issues it was found that in utilizing Behavioral Parent Training (BPT) an effective evidenced based intervention, mothers' parental attributions impacted treatment results which included negative emotions towards their children. Furthermore, the results of the study recommended establishing personalized interventions for parents that would target parental attributions in efforts to improve negative relationships patterns between parent and child that would ordinarily result to negative outcomes in treatment (Sawrikar et.al, 2019). The study utilized parents use of "harsh discipline" and feelings about their child as measures to determine the impact on parental attributions to the child's behaviors when utilizing BPT. Researchers in the study also found that mothers difficulties in changing parental attributions were connected to decreased level of improvements in the parents' emotional state which resulted in parents utilizing harsher methods of discipline towards their children (Sawrikar et al, 2019). Obviously, a major limitation in this study would be its application to society in the United States. However, the study may offer some insight on how parental attributions may impact their children's mental health treatment when considering the experiences of parents in the early stages of child treatment in outpatient community mental health settings.

The study also aims to explore parental attributions in relation to their "sense of agency" who are in different stages of outpatient community mental health treatment in efforts to provide ways of understanding their experiences in attempting to assist their children during the course of mental health treatment. Furthermore, parental attributions associated to the personality traits and

behaviors of their children have been known to predict the quality of interactions between children and their parents, as well as, outcomes in parenting focused interventions (Palm et.al, 2019). Parents “sense of agency” may offer ways to understand the quality of these interactions based on their notion of their own ability and capacity to assist their children in the mental health treatment process. If a parent attributes the outcomes of a child’s mental health treatment to the child’s personality traits and behaviors, the study may also offer other ways in which parents attribute outcomes in treatment outside the parent and child dyad. Whether it’s the quality of the skills of the clinician, the adherence to their child’s psychotropic medication or the environmental and systemic stressors that impact the parent-child relationship and family unit; parental attribution may serve as a major factor that either positively or negatively impacts parents “sense of agency”. For example, if a parent attributes their child’s outcomes to whether the child adheres to a medication regimen that alleviates depression, a parent’s agency may be impacted by their child’s outcomes in treatment solely based on the effects of the psychotropic medication rather than the parent’s perception about their ability to implement interventions in the home that may produce positive outcomes in their child’s mental health despite the presence of psychotropic medication. A brief discussion of the possible role of medication and programs to empower parents will be provided later in reference to possible impacts of parents “sense of agency”.

IV. “Sense of agency” and Parent Activation in relation to the Nuclear Family Emotional Process.

Shifting from parental attributions to parent activation in the family nuclear emotional process, the SFBT concept of the nuclear family emotional process list four basic relationship patterns: dysfunction of one spouse; marital conflict, emotional distance and impairment of one or more children. For the purposes of discussion, the proposed study will focus on the

impairment of children. In this pattern, the parent focuses on the child more than the child focuses on the parent. This dynamic leads to the child becoming more reactive and negatively impacting the child's differentiation from the family system which increases the risk of the child's internalization of family tensions (Bowen, 1972). Ultimately, the child may develop anxiety that negatively impacts his/her overall functioning including social relationships, school performance and overall health. In respects to parents and/or primary caregiver's "sense of agency", the parent would be able to assist the child in their "impairment" by redirecting the focus of the child's impairment or mental health condition to their own ability or "sense of agency" to integrate interventions formulated in mental health treatment that can circumvent the child's internalization of family tensions.

When exploring the family treatment process, parents may not be aware of all of the issues (whether internal or external stressors) that may contribute to the development of mental health issues for their child. For example, a child may come into treatment because he is unable to concentrate in school and therefore referred to community mental health treatment in efforts to assist the child in decreasing his inattentive behavior. These issues can be formulated as a school-based behavioral issue. However, upon further assessment, a clinician may discover that a child has been impacted by an array of psycho-social stressors that also contribute to the child's lack of concentration. After the assessment process, a treatment plan is usually formulated to "target" the child's symptoms rather than parent's ability to "drive" to mitigate and manage effects of stressors. The parent essentially becomes "the broker" of the treatment plan and therefore is held with the responsibility of effectively implementing the interventions offered by the clinician that may encompass a variety of treatment approaches. In this case, *parent*

activation becomes an important component in the treatment process which is argued to be closely associated with the parent's "sense of agency". As Green et al., (2019) explains,

For parents of youth with emotional and behavioral disorders, activation or having the knowledge, skills and confidence to access and engage in appropriate services for their children, is important for managing their child's mental health care (p. 306).

The term parent activation derives from the term *patient activation*, As Green et al., (2019) further explains, patient activation is defined as

A patient's willingness to manage their health and health care based on understanding one's role in the care process and having the knowledge, skills and confidence to do so. Furthermore, 'highly activated' clients are more likely to engage in preventative behavior, engage in healthy behaviors, seek out health information and adhere to treatment (p.306)

Therefore, when working with a "highly activated parent", we can expect better outcomes for the child in treatment. Unfortunately, there is minimal research on parent activation. Also, the research that does exist in regard to parent activation, primarily focus on medical conditions of the child, not psychological ones. (Green et al., 2019)

The relationship between parent activation and a parents "sense of agency" can depend on the parent's access to treatment and their understanding of how to actively implement treatment strategies offered in outpatient community mental health services. When considering traditional outpatient mental health services, parents are tasked in not only attending therapy sessions with their children, but also being able to develop treatment plans with the guidance of a clinician in efforts to effectively implement personalized evidence-based interventions in the

home. However, when developing these treatment plans, children may find that they are usually engaged in individual therapy sessions with sporadic involvement of the parent. The decreased involvement of the parent may reinforce low levels of differentiation between parent and child. The proposed study seeks to explore parent's experiences in their ability to participate in their child's treatment and their understanding of their role in treatment outcomes. As in the previous discussion related to locus of control, the proposed study seeks to understand how parents "sense of agency" impacts parental activation when they engage in community outpatient mental health treatment with their children.

In the article, "*Parent Activation and Child Mental Health Service use in African American Families in a large Cross-Sectional Study*", researchers published their findings on parent activation in a cross-sectional study in 2010 involving 325 African American parents in North Carolina. The study examined activation skills of African American parents that had children with mental health needs. Furthermore, the study investigated the link between the parents activation skills and the use of mental health services by their children. Similar to families that receive services in the site for the proposed study (Upper Manhattan Mental Health Center), 87% of the children in the North Carolina study were covered by Medicaid or state medical insurance program. The results of the study showed that parent activation increased the probability of their children being engaged in outpatient services which included: psychiatrist, nurse practitioner, medical doctor or physician's assistant. However, the researchers also suggest that parent activation was not associated with their children ever having had a psychiatric hospitalization. Furthermore, parent activation was also not associated with children engaging with a therapist. (Thomas et.al, 2020)

When we assess the many functions of outpatient community mental health facilities, psychiatric hospitalizations often become the focal point as a measure of effectiveness in treating children in the community. However, the achievements of low hospitalization rates, as per the lack of association between parent activation and hospitalization, Thomas et al., (2020) suggests,

A brief stay in a community hospital psychiatric ward may be preferable to a stay in a long-term state psychiatric facility and thus reflect high activation skills. Moreover, even when families are good at getting the services they want, inpatient psychiatric stays might be driven by child need more than parent skills. (p.6)

In other words, parent's ability to implement interventions would not be a factor in measures of parent activation but based on the behaviors of the child that warranted hospitalization. Parents "sense of agency" and their ability to assist their children when they are referred to outpatient community mental health services after being discharged from an inpatient unit may be a major component in complimenting highly activated parents in the process of their children's recovery.

Highly activated African American parents' utilization of medical providers over mental health providers (medical doctors vs. therapists/social workers) presents issues in reference to the conceptualization of mental health treatment by African American parents. As the researchers recommend "there may be value in investing in the development and implementation of interventions that teach parent activation skills and facilitate their use by practices in order to help reduce disparities in child mental health service use" (Thomas, et.al, 2020, p.6) Therefore, the way in which treatment is formulated and understood by parents who have a high level of parent activation, can increase the probability of increased use of mental health services. Highly activated parents may need a higher "sense of agency" which would improve their understanding of how treatment is formulated and implemented in collaboration and participation with their

mental health therapist. Furthermore, the identification of the “problem” may also offer ways to improve parents “sense of agency” in reference to the treatment factors that may influence a child’s mental health condition rather than the treatment of the child. Shifting in the examination of the “identified child” in treatment to family relational patterns and environmental stressors can offer ways to foster increase differentiation and reinforcement of highly activated parents to implement interventions in the home that broaden the scope of the array of issues that can impact all individuals within the family dynamic rather than the “identified” child.

In the article, *“Latino/a Parent Activation in Children’s Mental Health Treatment: The Role of Demographic and Psychological factors”* researchers examined the impact of an intervention MEPREPA through a randomized control trial with 181 Latino parents at a mental health clinic in North Carolina, which was a four-session psychoeducational group intended to teach activation skills to parents with children who were in the process of obtaining mental health services. The study found that the activation intervention was more effective than parents engaged in social support groups. The research measured five areas which included: demographic characteristics, parental activation, language acculturation, parental depressive symptoms and perceived severity of child psychopathology. Furthermore, as researchers explained, “parenting stress and perceived severity of child psychopathology emerged as the factors significantly associated with activation”. (Stein et al., 2017, p.298). Language acculturation and demographic information did not correlate with parental activation. As for parental depressive symptoms, as Stein et al., (2017) further explained,

Parents seeking mental health services for their children, their activation is more closely associated with their feelings of efficacy and contentment as captured through parent stress measure rather than with depressive symptoms more broadly The depressive

symptoms on activation are accounted for by parenting stress and the perceived severity of psychopathology (p.298-299).

When we consider parent stress and perceived severity of psychopathology as factors in parental activation among parents, clinicians may be tasked in understanding how parents manage stress and if they associate the stress with their children, rather than the family dynamic as a whole. The perceived severity of psychopathology by parents can be impacted by parents “sense of agency” in regards to their understanding and ability to implement interventions which reflect holistic positive outcomes, rather than specific evidence-based approaches utilized in community mental health clinics that may not incorporate culture, parents strengths and parents understanding of their child’s mental health condition along with systemic factors that may also impact their family’s access to treatment (i.e. insurance coverage, transportation, clinic waiting lists). The purpose of the study seeks to understand parents experience of their “sense of agency” in reference to their perception of the severity of their child’s mental health condition. If parent’s perception of their child psychopathology is high, parental activation alone would not necessarily improve the child’s outcome in treatment. It is theorized that if a parent has an increased “sense of agency”, parental activation may not only increase but also mitigate the effects of their perceptions about their child’s psychopathology and how they perceive and manage stress. A highly activated parents “sense of agency” would allow parents to not only increase their involvement in their child’s treatment but also increase the parent’s ability to improve their sense of being able to effectively construct ways to implement interventions with the child’s therapist that are culturally relevant to the entire family. Thereby reorienting an external locus of control to an internally driven orientation.

IV. Parental engagement and Empowerment programs as a way to increase “sense of agency”.

In outpatient community mental health settings, therapists may utilize collateral sessions to engage parents, without their children, in efforts to gain an understanding of the possible challenges or stressors that may arise for parents during the child’s course of treatment, which may lie “outside” issues related to the child’s mental health. Collateral sessions may also serve as a way to understand the parents’ experiences in having their child in outpatient mental health treatment and their understanding of the issues that the child may present in their environment. In this study, parents understanding about the child’s issues may impact the parents “sense of agency” depending on the degree of engagement in their child’s mental health treatment process. Parents who engage in the treatment of their adolescent children increase the probability of interventions effectiveness for a variety of disorders. However, parents who believe that interventions should target adolescent maladaptive behaviors exclusively, may be less apt to participate during the child’s treatment and assessment process (Kane & Prinz, 1999).

In 1998, the PEP program was established in NYC in efforts to empower parents through family advocates in efforts for parents to become active agents of change in the mental health treatment of their children. Parental empowerment was defined as, “process of recognizing, promoting and enhancing [parents’] abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives” (Olin et al., 2009, p.464). However, The PEP framework did have limitations in accounting for the macrosystemic factors that impact parents “help seeking behavior” other than the intentions of parents to seek mental health for their children. In implementing the program, stakeholders “recognize implicitly, if not explicitly, the change agency is not merely and individual act. Parent

activation can also facilitate more collective action to promote and advocate for macrosystemic change” (Olin Et al, 2009, p.469).

The utilization of psychotropic medication for children in outpatient community mental health settings may also impact the nuclear family emotional process and therefore impacting parents “sense of agency”. A parent may feel that if their child is “properly” medicated and improving their overall behavior and mood, it may reinforce that the child is the “problem” as well as influence parent’s levels of involvement and feelings of empowerment in the child’s treatment process. Furthermore, if the treatment planning process is devoid of any concurrent process, the parent’s “sense of agency” would be perceived as contingent upon whether or not they are able to consistently give their child medication. Therefore, medication adherence and its effectiveness may offer a parent a false “sense of agency” rather than align with a more parental attributional approach that is influenced by an array of psych-social factors that may impact the parents’ role and their power to drive their child’s treatment. In other words, parents who rely on medication as the only remedy to their children’s mental health issues may not take into account the importance of management skills related to parenting. Also, parents who may not be fully committed to their child’s treatment plan, may not consistently implement interventions and may be inconsistent in implementation, thereby decreasing the potential benefits and negatively impacting the fidelity of the treatment itself (Kane & Prinz, 1999). How parents attribute their children behavioral changes in mental treatment may ultimately impact their “sense of agency” in regards to effectively implementing interventions in the home and navigating the stressors that may impact the parents’ engagement in their child’s mental health treatment.

Chapter IV: Methods

I. Design

The study aimed at understanding parents' experiences in their work with their children who received outpatient mental health services. Particularly, the dissertation assessed parents "sense of agency" in reference to assisting their children in the mental health treatment process. The study utilized a qualitative design in efforts to understand how parents perceived their ability to assist their children in outpatient treatment. A qualitative design lends itself to view the occurrences in the background and unexpected outcomes that exist in clinics where transformative change fails or succeeds (Padgett, 2017). A phenomenological approach was utilized in efforts to understand the experiences of participants and the environmental factors that impact these experiences (Padgett, 2017).

II. Setting

The Upper Manhattan Mental Health Center (aka The Emma L. Bowen Community Services Center) is a Harlem nonprofit organization that was founded in 1969 by the civil rights activist and public health leader Emma L. Bowen to enable individuals and families, regardless of age, to effectively and productively address "problems of living" and to ensure that young people of color had the same opportunities as their White counterparts. When UMMHC opened its doors in 1986, it quickly became one of Harlem's largest community-based multi-service centers. UMMHC is staffed by several psychologists, social workers, nurses, chemical dependency counselors, case managers, vocational rehabilitation counselors and early childhood teachers. These helping professionals provide outpatient mental health services for children, adolescents and their families as well as community-based and telehealth treatment services for adults with mental health and substance use disorders.

Upper Manhattan Mental Health Center provides multiple supportive services for families and children in various areas in New York City, predominantly in Harlem, Washington Heights and South Bronx. These areas are often impacted by various poverty and health disparities on its region's population of 635,152, which are comprised of predominantly Black and Latinx residents. In Central Harlem, where most residents identify as Black (56.1%) and Hispanic (22.9%), the 2018 poverty rate was 25.1%, or 8 percentage points higher than the citywide rate of 17.3% (NYUFC, 2019). Also, areas of East Harlem, Washington Heights and the South Bronx, where most neighborhoods are predominately Hispanic (46.5%-69.5%), the poverty rate is as high as 37.7% (NYCDOH, 2020). In the past year, Black and Hispanic residents have suffered more COVID-19 cases. The impact of the pandemic on the behavioral health of Upper Manhattan and the South Bronx has been compounded by pre-existing disparities. The 2017 ACS data reports 25% of children 18 years and younger consist of the largest percent of those living below the poverty line in New York City (CCNY, 2018). Furthermore, East and Central Harlem have the highest concentration of children under the age of 18 in Manhattan (36.5%) and rank first and second among neighborhoods in the borough most likely to pose severe risks to children. Mott Haven in the Bronx ranked first within the entire city (CDFNY, 2021).

The most vulnerable children, children in foster care, more than half (61%) of Manhattan's foster care placements come from East and Central Harlem. In education, although Black students make up 26% of the student population, they represent 57.8% of school-based arrests and 46% of "school-based child in crisis" encounters with NYPD. The children in this community face many dangers, including abuse and neglect; exposure to substance abuse; domestic violence; teen pregnancy; high psychiatric hospitalization rates; juvenile incarceration;

lack of medical treatment; and school dropout (NYCACS, 2019). In NYC, 16.9 per 1000 distinct children under 18 had indicated reports of abuse or neglect (CCNY, 2017).

Mental health disorders that appear early on, when left untreated, are associated with disability, school failure, teenage childbearing, job instability, marital instability, death by suicide, and violence (NHHSH, 2011). Considering the many socio-economic, educational and health related disparities, parents and caregivers that live in these areas are tasked in ensuring that their children are able to cope with the variety of stressors on a daily basis by engaging in community mental health programs like UMMHC in efforts to alleviate and cope with potential triggers that impact the mental health of their families.

III. Recruitment and Sampling

After approval from the University of Pennsylvania Institutional Review Board, participants were recruited at Upper Manhattan Mental Health Center through purposive sampling. After purposive sampling was utilized, nominations sampling was utilized through therapists who identified parents that were eligible to participate in the study.

The sample size comprised of 10 participants that identified as legal guardians of the children that received mental health services at UMMHC. The following table (See Table 1) illustrates the composition of participants in the study. The participants ranged from 28-68 years of age and had children under the care of eight different therapists at Upper Manhattan Mental Health Center who provided mental health treatment to a total of thirteen children ranging from ages six to fifteen. Half of the participants were currently receiving mental health services for themselves and half of the parents in the study had children receiving psychotropic medication. There were 2 parents who had multiple children in treatment. In the case in which children had

both parents or multiple caregivers, the identified parent was the parent who was primarily involved in the child's treatment which would include the parent who would speak with assigned clinician and in some cases, the parent that would engage in monthly medication management sessions with their psychiatrist or psychiatric nurse practitioner. None of the children had more than one parent directly involved in the child's sessions or medication management sessions at the time of the study. Anyone who was involved in the treatment other than the participant, was considered a support to the parent. Of course, this does not mean that other caregivers or parents (other than the participant) were not influential in the child's process of treatment, however, the focus of the study was on a parent's sense of agency, not the agency of multiple parents or caregivers that would be involved in the child's treatment.

Table 1.

Name	Age	Ethnicity	Location	Child's Age	Child's years in tx.	Parent in Psychotherapy (Y or N)	If Child is on psychotropic medication
Sarah	36	AA or Black	Bronx	15	2	N	N
Donna	41	AA or Black	Bronx	12	3	N	N
Maria	42	Hispanic or Latina	Manhattan	13	1	Y	N
JT	59	AA or Black	Manhattan	10, 9, 8	2	Y	Y
Janet	39	Hispanic	Manhattan	12	7	Y	N
Brianna	42	AA or Black	Manhattan	13	8	Y	Y
Karen	28	Hispanic or Latina	Bronx	9	2	N	Y
Linda	68	Hispanic or Latina	Manhattan	12	2	N	Y
Gina	41	Hispanic or Latina	Manhattan	12	1	N	Y
Molly	41	White	Manhattan	9, 6	2	Y	N

Inclusion Criteria

In the original IRB proposal, the inclusion criteria for participating in the study was that the participant had to be over 18 years of age in order to be able to provide informed consent. Furthermore, the participant had to be the parent or legal guardian of the child who was currently receiving mental health treatment that were between the ages of 5-18. Although Upper Manhattan Mental Health Center has clients that receive services until they are 22 years old, children in the 5-18 age bracket would need consent from their parents to not only enroll in the clinic but receive mental health services. It is assumed that children over the age of 18 could conceivably receive mental health services without their parents' consent. Required consent from a parent also implies that the parent has an active role in the child's treatment. Parents active involvement may not necessarily be reflected by the frequency of collateral and family sessions they may attend with or without their children, as may be suggested in quantitative analysis. Parents participation or parental activation may be defined in other ways including their work to initially attain treatment for their children and their work with their children "within" and "outside" the clinical setting.

Exclusion criteria

The exclusionary criteria was modified after initial approval from IRB due to the lack of responses during initial recruitment. The exclusionary criterion that was omitted was whether parents received or had received mental health treatment in the past. Originally, the literature review provided did not include whether or not parents had a history of mental health treatment. Most of the literature that was found explored parent's "sense of agency" in relation to their child's mental health treatment, not the possible impact of their children's treatment of parents who were in mental health treatment themselves. If parents had a history of receiving mental

health treatment or were concurrently receiving their own mental health treatment along with their children, it would be difficult to decipher if parents ‘sense of agency’ derived from their experiences in own mental health treatment or derived from their experiences in assisting their children in mental health treatment without having any previous experience in treatment.

However, upon further review, whether or not their “sense of agency” derived from either source (whether parents either having or not having their own experience in mental health treatment in combination in assisting their children in the mental health treatment process) their “sense of agency” would not be less than or more impactful if these factors were or weren’t present.

However, excluding these parents with prior experiences in mental health treatment may have placed limitations on the study’s goal of exploring all of the factors that may contribute to parent’s “sense of agency”.

Participants were asked in the beginning of the interview if they were or had ever been engaged in mental health treatment in the past to account for the number of parents in the study who had received mental health treatment at the time of the study. The significance of the question relates to whether or not their own experiences in mental health treatment contributed to their “sense of agency” in relation to their child’s mental health treatment. It should be noted that further questions about participants experiences in mental health treatment were not posed other than whether or not they had engaged in mental health services in the past. Clarifying questions were posed in the event that participants included their own experiences in treatment in relation to assisting their children in mental health treatment. Finally, parents who were not English speaking were excluded due to the difficulties of being able to translate experiences in a phenomenological design. As Padgett (2017) noted “errors in translation can result from the lack

of familiarity with dialects and meanings as well as deliberate, even if well intentioned, bias” (p. 148).

IV. Institutional Review Process

After approval from the Upper Manhattan Mental Health Center (Appendix D) and IRB approval, recruitment procedures consisted of distributing flyers (please see attached Appendix B) that promoted the participation in the study. Participants were be paid \$30 dollars through a e-gift certificate for their participation. The researcher completed CITI training prior to the start of the study. Furthermore, the researcher followed ethics protocols provided by the State of New York Office of Mental Health and federal regulations (HIPPA). The feasibility of the study was based on participants not being asked to do anything different except consenting to the research study along with other documents that would ensure confidentiality. Sample size was obtained during a 3-month window after IRB approval. Due to the participants engaging in one interview, comprised of semi-structured questions for 60 minutes (Appendix C), there were no issues in reference to attrition since participants would not need to return to complete the interview.

Before the interview, the researcher asked questions pertaining inclusion criteria prior to the start of the interview. After inclusion criteria was met, the researcher scheduled the participant to the study interview via Zoom. Once eligible, the researcher sent the IRB approved consent form to the participants after participants verbally consented to participate in the study. Informed consent can be a controversial issue when the questions are posed of who is being informed and who is consenting. If the informed consent process is to protect participants by allowing them to withdraw from a study due to potential harm, it can free the institution from any wrongdoing and subsequently transfers the process of research to the person conducting the study (Fine et.al, 1996). Informed consent in this particular study added an extra layer of

complexity due to the fact that parents were not only exploring their own experiences but how, at times, depicted the experiences of their children when working with them in the mental health treatment process.

Risk during Interview process

The risks were described in the IRB Consent Form (Appendix G) . None of the participants experienced distress or discomfort during the interviewing process. The researcher explained that in the event that the participant experienced difficulty or distress, he would have discontinued to study and provided professional mental health consultation at that time (Appendix F). The researcher would also have ensured proper referral to mental health treatment along with risk assessment to ensure participants safety from harm.

V. Instruments. Data Collection and Analysis

After the interviews were completed, they were transcribed. After transcription, videos of the interview were deleted. Each interview was saved in the researcher's computer via encryption. It is important to note that the researcher gave the participants the option to not use their video during the interview. However, all participants felt comfortable with using their video during the Zoom session. Also, participants were given aliases in efforts to sustain anonymity and confidentiality (Appendix E).

Topics during the interview ranged from participants experiences in working with their child in the home to working with their child's therapist in the mental health clinic. Due to the COVID-19 pandemic, most parents and children engaged in virtual sessions with their therapist during the course of mental health treatment. Although, Upper Manhattan Mental Health Center began to allow clinicians and providers to conduct sessions in person, it was on a highly limited

basis due to therapists having only one in-person day to see clients. As for prescribers (which include psychiatrists and psychiatric nurse practitioners), all sessions were conducted virtually. Since participants mainly had communication and interactions with therapists, the focus of some questions in the interview related to their experiences with working with the therapist. The questions in the interview (See Appendix C) ranged from asking parents about their experiences in obtaining mental health treatment for their children to the ways in which they worked with their children in conjunction with their child's therapist. In the processing of the data, the researcher went through the transcribed interviews to ensure that the transcription correctly reflected words that were said by the participants. Next, the researcher went through each interview and began coding by creating general themes that arose through each line of the interview. As common themes arose, code book was developed to reflect experiences discussed by parents. The code book was developed through inductive and deductive process that allowed the formulation of themes that derived from the theoretical lens of 'sense of agency' and the common experiences of parents working with their children in mental health treatment. Quirkos software was finally utilized in efforts to organize data collected in the interview.

VI. Reflexivity Statement

In the process of conducting of developing this study it was important to understand how my own experiences as a first-generation cis-gendered gay Latino male impacted my perspective in understanding the experiences of the participants in the study. Understanding the privilege of having most of my formal higher education in primarily elite, predominantly White institutions, was an important factor in my approach to the study. Having been raised in the community in which the study took place along with not having the experience of having my own children also

was important to consider in my interactions with the participants which were all women and may have different perspectives in their experiences in New York City.

When conducting a qualitative study, there are two issues that arise when attempting to give a voice to others. First, that we cannot overlook our own social location due to its effect on the meanings in which we assign our claims. Second, when someone who is privileged and attempts to represent the views of less privileged or marginalized groups, there is a risk of reinforcing oppression (Alcoff, 1992). All participants in the study identified as female, half of the women identified with a ethnicity other than Latin or Hispanic. Therefore, as a Latino male, I recognized that my social location may impact the way meanings were formed and clustered to create themes that were impacted by my own views. Furthermore, my privilege as a researcher and economic status was important to factor into my work in developing the study.

My views of agency regarding assisting children may also be impacted by my own experiences as not only a mental health practitioner but also having a disabled sibling who was and still is heavily reliant on my mother to dictate not only my sibling's mental health treatment but all facets of her life. Being raised by a single mother who is a Dominican immigrant and who has been able to successfully advocate for all of her children was also important to reflect on as most of the participants weren't immigrants and were currently navigating through systems that have, for better or worse, changed in the last 35-40 years. As Villenas (1999) explains, "as researchers, we can be insiders and outsiders to a particular community of research participants at many different levels and at different times" (p.772). It is important to note that much of the conversations related to parental involvement tend to disregard mothers and minorities. These groups are usually associated with pathological behavior which inevitably marginalizes them. (Crozier, 2003) This issue arose when considering an exclusionary criterion originally integrated

into the study and then later eliminated and resent to the IRB approval process. The original exclusionary criterion would not have allowed parents who had been in their own mental health treatment to be included in the study. After further review, the researcher decided to eliminate the exclusionary criteria due to the importance of including parents who could potentially offer a different perspective on their perceptions of their own sense of agency when discussing their role in the mental health process of their children. Finally, my views on the utilization of psychotropic medication in the mental health treatment of predominantly black and brown children in Upper Manhattan Mental Health Center was also important to consider in relation to its impact on parents “sense of agency” and not excluding parents who had made a decision to have their children take psychotropic medication.

Chapter V: FINDINGS: Parental Attributions and “Sense of Agency”.

In this chapter, findings in reference to parental attributions will be discussed. In the study, parents explored their thoughts and experiences in reference to potential causes or origins of their child’s mental health issue. The question relates to parents “sense of agency” due to their understanding of potential causes and whether they perceived these causes to have a life-long negative impact and if they had an ability to assist their children in the process of change. In the interviews the following three themes emerged in relation to parents “sense of agency” regarding attributions: (a) Parents views on the causes of their children’s mental health condition were parent-causal rather than child-responsible (b) Parents explored the issue related to biological factors that may have impacted their child’s mental health condition and (c) Parents explored the issues related to race/ethnicity and stigma as factors in contributing to their child’s overall well-being and self-concept in relation to engaging in mental health treatment.

A. Parent-Centered Attributions to children’s mental health condition and its impact on parents “sense of agency”.

It should be noted that the way in which outcomes are reported by parents and their children may be distinct based on differences in the perceptions and attributions of behaviors. For instance, parents may attribute the behavior of children based on their mood. In contrast, children may attribute their behaviors to their living environment which can impact the way in which treatment plans are formulated which suggests other factors to their children’s behavior other than their mood or emotional state (Rodriguez et al., 2015).

Parents “sense of agency” could also be impacted if they attribute their child’s behavior to an array of factors that they may not be aware of and may find difficult to assist them if they

are not given the proper “tools” in therapy sessions. As Gina describes in trying to understand her child’s behavior prior to deciding to bring her into outpatient mental health treatment:

Gina: So, initially it was like, no way, she doesn't need that (mental health treatment) I'm not doing this. Then it came to a point that I was like I'm going to try everything because maybe I really don't know, I don't know it all. I knew I didn't know it all and maybe someone can help me figure out what I should do, for her, because you get everyone's opinions and your family (opinions) but, when it comes to a point when the kids are acting out, like she was acting out too much, and I just didn't know what to do for her. It was too much for me, you know, so I gave up and I said I'm going to do this. I'm going to try this out. How bad can this be?

When considering children that receive mental health treatment, there is a scarcity of research that explore parental traits that impact their decisions in the attainment of services for their children and engaging in services for their own mental health needs (Patel et al., 2021). In the following responses by parents, they explore how they have dealt with their decisions. Donna conveys her “sense of agency” towards her children by reaffirming her role in outpatient mental health treatment.

Donna: Like I said, I'm not emotional person, I'm not someone who speaks out, rather keep everything for myself, so the fact that they'll tell me what they're thinking and how they feel, you know, which is hard in the beginning, because they were so worried about hurting my feelings and I will let them know, 'I only have one job here and that's to protect you and you can't worry about my feelings because I'm going to be fine because I'm a lot tougher than you think you know', and you know once they realized that they could open up more, it made things a lot easier.

Gina's decision to enter her child in mental health treatment was a last resort:

Gina: Like I gave up, I said I'm going to do this; I'm going to try this out. How bad can this be. Everyone says go to therapy or you know, you hear that it will help you. So that was a little difficult for me to go in, but at this point, it was like my last straw, and I said, let me just do it.

Maria describes her own challenges and reclaiming her "sense of agency" by understanding her role and her own challenges in relation to her child's mental health condition.

Maria: So, like working on myself to kind of address you know why did certain things or didn't do certain things and letting go of things and getting back to the basics of what I thought a good parent should be and not trying to meet some kind of society norm that is a lot of bs right now, Just coming to terms with who I was as a parent why or what I wanted to be. So, I think it took a lot for me to kind of take time to process what my role was in having her struggle the way she was. Sometimes I think her dad is still working on his journey. But you know, just me kind of coming to terms with what I did or didn't do right, and I think that's number one, addressing my own challenges as a parent and as an adult.

In a recent qualitative study titled "*Mothers' Experiences of Having an Adolescent Child With Depression: An Interpretive Phenomenological Analysis*" eight mothers of depressed adolescents described their experiences after completing a clinical assessment at a children's mental health clinic and it was found that mothers often blamed themselves for their children's depression. These findings correlated with the greater evidence that parents who have children who have mental health issues often tried to understand why their children were having difficulties which led to negatively impacting the parent's feelings about their child being in

treatment (Armitage et al., 2020; Harden 2005; Stapley et al, 2015). As Donna explains her process in her own mental health treatment to cope with the guilt she experiences:

Donna: I hated this, it's really rough and a big part of my therapy is kind of like the guilt associated with the conditions that both my kids deal with because they were both a party to what I was going through with their dad, even though they didn't see the physical aspects, they were there for the emotional abuse that was involved in the situation and it's really tough and it's really hard to try not to blame myself for what she's dealing with but it's how I feel, it's harmful, I basically feel like if I left sooner maybe she wouldn't be dealing with this so much, but you never really know.

Repetitive negative thoughts and distress intolerance often came up when parents explored their thoughts about their role in the child's treatment. Repetitive negative thoughts is defined by thinking about one's problems and experiences that are negative in repetition. These thoughts are sometime intrusive and difficult to manage (Armitage et al., 2020). Distress intolerance is defined by not being able to tolerate negative emotions which may lead to avoidance in efforts to cope (Patel et al., 2021). Donna's engagement in her own mental health treatment becomes a way to reclaim her 'sense of agency' in efforts to cope with self-blame and assist her child in mental health treatment.

Donna: It's not always easy. Again, it can be hard when you want to avoid it because you feel it's your fault, so the fact that you know, I blame myself a lot for the anxiety that my children feel, and you know, the things that they've experienced, it makes it tough sometimes to have those conversations because you're sitting there and you're watching them struggle and at the same time you're thinking Okay, this is on me, you know, but as

a parent those feelings have to get pushed aside, so that you can do what's best for your child.

Maria's feelings of guilt and shame also impacted her "sense of agency" despite being a school counselor. However, like Donna, Maria finds agency in continuing the process of engaging in her child's mental health treatment.

Maria: Still, I'm a parent of a teenager and its difficult for me as a counselor to say, 'Oh my God, this can't happen to my kid, I'm like letting go of that, so I've been very open about it, it's not anything that I'm embarrassed about and it's not anything that I want my daughters to be embarrassed about either. Like I said, about my own therapy, I knew I was going to look at my own face to handle whatever I needed to do. So, letting go of that, letting things go through its natural course has really gotten us to this point.

How parents perceive outcomes and their preferences in obtaining mental health treatment impact their ability to sustain mental health treatment, attendance and outcomes for themselves and their children (Patel et al., 2021). Therefore, parent centered attributions are relevant when considering parents "sense of agency" in relation to assisting their children in mental health treatment. It is less likely that parents will be able to assist their children in treatment if they may feel like they are not able to manage and cope with their own emotions and thoughts about the process of not only participating in their own mental health treatment but also actively participating in their child's mental health process.

B. The impact of perceived biological/genetic causes to their child's mental health condition in relation to parents "sense of agency".

Another sub-theme that arose in interviewing parents in relation to attributions was their perception that their children's mental health issues may have been attributed to genetic or biological factors from either parent. Parental attributions to biological/genetic factors were

associated with parents who had children that were also taking psychotropic medication at the time of the study. As JT explains in reference to her children's biological mother:

JT: She has a lot of mental issues. She was physically and mentally abused by the girls' father and the mother. She has mental issues, that's what I was told when I got the girl. She was schizophrenic bipolar and it was a couple of ones I can't remember all of them, she had five different diagnosis.

Maggie also reports her child's parental history as a possible cause of her child's mental health condition along with her dilemma about giving her child psychotropic medication.

Maggie: No, I don't mention those things (child's mental health condition). I sometimes don't even think about, I mean, I don't think about it until he do something but I don't want him to take this pill. His mother is suffering from depression, is schizophrenic. His mother and his grandmother, that is my daughter. That's on the father side. You understand.

Finally, Karen expresses her own mental health issues and the prevalence of mental health issues to normalize her child's experience in mental health treatment.

Karen: I mean it makes it a little bit easier to interact with him and know how he's doing and why he's doing things because I have a history with my mom, always running and moving and can't sit down and so I have understanding from my personal life. His father has ADHD and bipolar. It also runs in my family, my mom, my father, his mom. His brothers, sisters, so it does run in the family on both ends.

In twin studies, parent's mental health issues, parenting styles and stress factors have been utilized to study the genetic and environmental impact on children's mental health issues (Linkenheil et al., 2021; Bøe, et al; 2018; South & Jarnecke, 2015; Yin et al., 2016). However,

based on research, family history seems to be the strongest indicator of the causes for mental health conditions in children. Therefore, it is important to study family history in relation to the ability for parents to identify behavioral issues in their children as well as parent's behavior in obtaining treatment for their children. Clinicians should be mindful of the impact of parent's mental health on their children as environmental and genetic factors have a small impact on the risk of their children developing mental health issues (Linkenheil et al., 2021). Comprehensive approaches by clinicians should be made when considering the impact of parent's mental health conditions on their children and their children's mental health condition's impact on their parents (Bartels, 2021). When considering parents with children in mental health treatment, it is important to account for various intergenerational factors of poverty, lack of resources, lack of quality education and institutional racism, as these factors may negatively impact a parents "sense of agency".

C. Racial/Ethnic factors and stigma when considering parents "sense of agency" with children in outpatient mental health settings.

Research supports that when individuals have stigma related to mental health conditions, they are less likely to seek mental health services. Social stigma or negative views held towards those who have mental health conditions and self-stigma or negative views one may have towards their own mental health issue are two factors that strongly impact ethnic minorities compared to those who identify as White/Caucasian (Tsang et al., 2020; Becker et al., 2018; Pattyn et al., 2014). Maria, who identifies as Latina/Hispanic explores her experiences with the stigma related to having a child in mental health treatment.

Maria: So that's part of what I think my job as a parent has been, to help with the stigma of mental health, particularly in making the Latino world, you know BIPOC communities, where you know, sometimes people don't really want to talk about mental health, so you

know I'm a proponent of like breaking that barrier so, to be part of it, I think she [child] recognizes that problem in our community on a greater scale. You know she [child] sees that she's kind of breaking her own barriers and managing and coming to terms with what a lot of people deal with and working on it, like active and taking her [child] own world and rectifying and naming things.

When considering Latinx parents, a substantial amount of research has shown that stigma becomes a barrier to attaining mental health services for their children compared to White, Non-Hispanic parents. Further studies revealed that Hispanic family members of those trying to obtain mental health services also experience stigma due to association within the Hispanic community. Also, mistrust of providers also impacts Hispanic/Latinx parents from seeking mental health services for their children (Dixon De Silva et al., 2014; Clement et al., 2014; Lopez-Cevallos et al., 2014).

Along with stigma, racism can often be attributed to stressors that trigger crises and mental health conditions for parents and their children. Brianna describes the impact of racial discrimination that she believes led to her child being hospitalized before being referred to outpatient mental health services.

Brianna: The worst part for me was when she actually had to go in Bellevue Hospital. I think I was going to go in the G building and because I couldn't even see that, you know, leaving my daughter, because my daughter is always with me you know and, to this day it kind of hurt, but I understood that my beliefs, with the Lord I pray, and I say 'you know what God, I have to do this'. But I was there every day, I sometimes spent the night there just to wake up to go and see her, I still cry, thinking about that, because it was weird like them people in that school really did things to my daughter. 'You black, you monkey you

this, she that', It really tore her up, it really did.: So yeah, that's just the part right there because she wasn't home for holidays, you know. It was hard to take a cake for her birthday.

African American children that experience racism tend to perceive stressors more significantly, along with greater symptomatology of decreased self-esteem, mood and behavioral dysregulation and suicidality. Some scholars have posed that racial discrimination should be considered as a particular form of trauma related stress (Bernard et al., 2021). Brianna's understanding of the racial issues that impacted her child's mental state was compounded by the feelings of loss and regret in leaving her in an inpatient unit but regaining her "sense of agency" through her belief system and physically being close to her daughter up until her daughter was discharged from Bellevue Hospital in New York.

In summary, parental attributions in the interviews reflected more parent-causal attributions rather than child-responsible attributions. Parent-centered attributions related to their feelings and actions that led them to decide to enter their child in mental health treatment along with parental attributions related to their children's biological predispositions and parent's awareness of the negative impacts of ethnic/racial issues on their child's mental health are important factors when considering parents "sense of agency". These issues may either increase parent's motivation and ability to help their children or challenge their belief that they can help their children based on their own views about how these factors impact their child's mental health condition. Parents actions in response to children's needs will be explained in the next section related to parental activation.

Chapter VI: FINDINGS: “Sense of Agency” and Parental Activation.

I. Parental Activation

In the study, parents “sense of agency” was explored through the lens of parental activation. Parental activation reflects the parent’s ability and motivation to be an active participant in their child’s treatment which becomes an important component to the development of the child’s therapeutic process. The parent becomes the “broker” between the child and therapist in efforts to implement goals and objectives formulated in their child’s mental health treatment. Although parental activation can be observed in various ways, three themes emerged in the study. The three main themes that reflected parental activation were: (a) the process of obtaining treatment, (b) parents experiences in working with the child “within” treatment and (c) parent’s experiences in working with their child “outside” of treatment.

A. Parental Activation and the process of obtaining mental health treatment

Before engaging in mental health treatment with their children, parents described their experiences in attaining services at Upper Manhattan Mental Health Center. For some parents, they began the process of obtaining outpatient mental health services through other institutions (i.e., school, foster-care, child protective services, primary care). Obtaining mental health treatment through these institutions appeared to be the way in which parents initially became active in addressing concerns about their child that was perceived by others as warranting family therapy. As Sarah describes, she and her child discussed issues related to her daughter’s mental health issues and was able to obtain a referral to outpatient mental health services. “*We just went*

through her primary care provider so when she went to the doctor and so I mentioned it to the doctor to elaborate more about why she wanted it.”

Donna describes how her previous involvement in Child Protective Services led to a recommendation based on a CPS worker’s observation of her child’s mood.

Donna: We started out because of the situation that happened with my older daughter, and her dad and then Upper Manhattan Mental Health Center was recommended through their primary care physician. So, basically, because of what happened, when my oldest daughter was involved with CPS (Child Protective Services) and they of course, have to interview the kids to see how they're doing and one of the workers said you do realize that she, one of the youngest, has anxiety. When she met her intake person, they just clicked automatically, it was crazy, so that was it. Once, I saw how well they did together the fact that she actually spoke to him. She doesn't really speak to people, she doesn't really open-up, but as soon as they had a conversation they clicked and that was it.

Karen engaged her child in outpatient mental health treatment after a school had recommended it due to the school’s lack of resources in reference to school counseling. She mentions not having prior knowledge of resources but would have actively researched possible options.

Karen: So, he has an IEP. The school recommended me to the Center. They knew that he needed outside care because he does have counseling in school but they saying there wasn't enough, so they actually referred me to you guys. So it was easy because the school referred me. Like to be honest, I don't know no resources, so I probably would have googled it.

When parents did not initiate obtaining mental health services through other institutions, parents relied on web-based research to obtain mental health treatment for their children. However, once parents were able to designate Upper Manhattan Mental Health Center as a viable option, some of them encountered the difficulty for the child to be seen by a mental health professional. As Molly describes:

Molly: She was on the waitlist for a long time, I think probably we first, probably end of the Summer, was when we reached out and it took a while, back and forth, and then we finally got her a psychiatric evaluation.

Gina also experienced a long wait before treatment began and shared her emotional response:

Gina: Well, the only thing that I have to say that was difficult was when I reached out, it took such a long time. I was literally dying like, I was like okay, I need your help, and I do what I need to do and I now, I got to wait a month until I get just an evaluation call. Then wait like another two or three weeks, just to speak to a therapist that's the only thing that I felt like I was going crazy about because I was like Oh my God, I really need help, I need to talk, and it was taking so long.

Parents connections or awareness of access points to mental health treatment through various institutions doesn't necessarily guarantee that parents will initiate a process to obtain mental health treatment for their children. However, their willingness and receptivity to recommendations made by others and following-up with the recommendations can be viewed as being active in the process in addressing their child's mental health needs. Coping with stressors related to their child being placed on a "waitlist" once they have designated an outpatient mental health center could be viewed as an element that may negatively impact parents "sense of agency" despite being highly activated in the process of seeking mental health treatment.

B. Parental activation “within” the therapeutic process and the utilization of a “safe space”

Once parents were able to engage their children in mental health treatment, their ability to provide a “safe space”, in conjunction with their child’s therapist emerged as a way in which parents “sense of agency” was reinforced. The ability for parents to create a “safe space” related to their ability to allow the child to engage with their therapist and establish a therapeutic relationship that facilitated the process of mental health treatment. As Lahad (2001) notes, “the need to provide a safe and secure environment, contained by the therapeutic relationship, becomes crucial. Like infants, troubled individuals need to feel safe before they can explore” (p.63). As Maria explains:

Maria: So as far as the clinician, just providing like I said, a place to kind of talk, a safe space right, to hold space for her and to also support both on the right coping mechanisms, and really bring perspective about how she could have handled situations better or to validate kind of what she's feeling. The clinician was very honest with me as far as what I could do better and more like my phrasing, so she [therapist] supported me and how I feel when I talk to my daughter. It's okay to be that way, but you know wording and delivery is important, so that's part of what we've worked on, is just how I can bring conversations with my daughter.

Gina describes the need to provide “space” in efforts to increase an understanding of her child’s perspective and working “through” the therapist to increase her ability to communicate and her “sense of agency” on how to explain topics that may be difficult to discuss in treatment.

Gina: So, I tried to give her as much space when it's time for her therapy. We'll talk about, 'hey this is popping up, this is going on, or I'm thinking about this'. I feel like I

work through her [therapist], like I'll talk to her about what I see her do or done or what's going on and then she could just bring it up. I feel like she'll be more open with me when she [therapist] throws in whatever I mentioned as I don't know how to explain certain things to my child.

Similarly, Molly also explains the importance of giving her children “space” in working with them in treatment. Furthermore, parents are able to draw from their own experiences in working with their children to assist them in being able to understand their needs in relation to the therapeutic process.

Molly: We try to talk about things, but we also try to give space, and so I'm a nurse practitioner, I work in pediatric oncology, and so I feel like I have a decent skill set with kids and just like posing a question and stepping away and letting them come back to you when they're ready to talk about it and I think, my husband actually has that skill which is really nice to see, so I think we do that a fair amount where we're alike.

Sarah, like Molly similarly draws on her own work with children.

Sarah: I guess, because I work with other children, so it just kind of, I kind of adapted to it, to listen more. I've always gave my children the right to their opinions, like, I want to know how you feel and what they are thinking, I want to know their mindset so that I can go from there, opposed to just shutting them down. I don't do that.

It is important to note that parent’s ability to establish a “safe space” for their children in mental health treatment is an ongoing process. Whether parents are familiar with establishing a “safe space” in their work with children outside the home and/or they rely on the therapist to assist them in establishing a “safe space”, parents are confronted with the juxtaposition of sustaining an

active role in their child's treatment by taking a "step-back" and allowing their children to express themselves in the therapeutic process.

C. Parental activation with children "outside" of treatment.

The final theme that developed in interviewing parents in reference to activation, were discussions on how they assisted their children "outside" of mental health treatment. It can be argued that parents "sense of agency" was reinforced by implementing their own ways along with the ways they worked with their children with the assistance of therapists. The current literature mostly reflects parents work with their children "outside" of the clinical space and refers to their actions in the context of treatment recommendations. Given that therapy is often only an hour a week, the bulk of a patient's time is at home and integrating the home environment with the therapy is essential (Croghan & Brown, 2000; Tobon et al., 2015). Parents are challenged to continue the care at home and take charge of it. For example, Karen implements a reward system that incentivizes their child in improving their behavior.

Karen: So, I had told you, the school referred me, I used to get phone calls every single day from the school. So, I will reward him whenever he will have a whole week if the school haven't called me. Buying some Re-Bucks, taking him to go get a toy, whatever he wants, As that went on, he was doing better and better and then I'll give him one courtesy day, so if he messes up one day out of the week, I'll give him one courtesy day...So he's been doing good. He likes the bribes. So, he tries his best to do good in school, I mean that's why I give him one courtesy day because we're all human you know, sometimes we slip up and we don't feel like it.

Molly describes how she rewards her child when she does not engage in aggressive behavior in the home.

Molly: Sometimes they have allowance and sometimes they get an extra dollar if they [child and sibling] don't fight and I'm like you know what, I'm all for incentives. So, we try not to do it with food because she's had historically, was actually one of the things that got us to call initially, she was trying to sneak food and we just didn't really want to go into that world, and so we yeah, but we do, we definitely do celebrate along the way.

Similarly, JT shares her experiences in not only rewarding her children through monetary rewards but also with experiences that the children enjoy.

JT: You know they get five dollars. We do what they want, and whatever it is, if it's affordable and reachable it's there. You know they get bikes, scooters, all the tablets, all they got is a bunch of junk. They like to go out to eat a lot. So now we go to City Island, Coney Island stuff like that, with the girls they like to do things like that. They love it, they come and give you a hug, they say thank you when can we do it again? that type of thing. They enjoy stuff like that.

Parents also explained how going out, engaging in recreational activities with their children also assisted them in their relationship with their child and their association with an outing as positively contributing to the parent and child relationship. As Sarah explains, “for my daughter on a personal level, I like one-on-one dates with them, because I have four children, so I do like one-on-one dates for her and give her, her own alone time.” Janet associates her child’s engagement in recreational activity as ways to improve symptoms related to his diagnosis.

Janet: Since he was five, he's been in baseball just so that it can help him. He's actually in the Harlem little league and helps him with confidence, so I like to keep him into that but he's the type that doesn't like to stick with anything for long, so I have to like practically beg him to do it because I know it helps him with his diagnosis just keeping

him active, it helps him with his distractions. It actually helps him focus when he is playing baseball so that way, he can see that he can focus if he tries hard enough.

Karen utilizes her environment outside the home in efforts to actively engage with her child in an activity that assists her child when she notices her child's difficulties in settling down in the home.

Karen: So, like I noticed that, when we are in the house and he's getting a little antsy or he can't stay still, I'll get him dressed, I'll take a walk with him, take a little walk for a couple of blocks, you know, when he comes back in the house he's more calm, because he got to burn off some of that energy. Its cold right now, but I would take him to the park, I like to take him to like the trampoline parts were there's jumping all the time, he has a bike, so he rides his bike, he has a scooter and where we live, they have the bikes where you go rent and we'll go bike riding for a little while, We live by a lot of parks, I'm by Pelham, so there's a lot of parks over here I do take him out to the movies but he's not really good at the movies, we got to go back and forth, to the bathroom sometimes, but he does good, not too bad.

Maggie entrusts outside services to engage her child in outdoor activities due to her physical limitations but also recognizes the needs to establish consequences when the child does not do well in school.

Maggie: Well, they have this guy that comes to the house, and he takes him out to places and things like, that it's very good. I'm old, I can't do things that he wants to do, he doesn't want to go out with me. Or, he goes out with my granddaughter, they take him out to places and sometimes he gets bored. He just likes to stay home and watch videos and play with a PlayStation that's what he likes really to do, he's a pro on that. So right now,

he's punished because the teacher called me that he didn't finish his work, that he's not doing good, so I took everything from him, took the phone, I took the PlayStation and put everything on lock.

Establishing and sustaining a structured environment also reflects parent's active role in creating experiences in the home that foster the child's psychological wellness. Gina explains how sustaining a structured environment is also helpful in fostering a good relationship with their children:

Gina: I like to keep her active, I feel like when she's active the mind doesn't have time to wander. So, her after-school is great when she's happy I try to keep her there and I always kept on schedule. I make sure we get home, we do homework, sleep at a certain time, get up, keep her going, you know routine and just busy and that's why I was so adamant about that, after school program because they got a lot of things for her to do you know and for her to look forward to like a sport, something that she's into which I feel helps a lot, because when you like something. you're going to think about it like 'I can't wait', you know, so that's what I tried to do, try to keep active, I don't want her to just watch YouTube or watch TV or on a phone you know, that's why I was so like against the phone for such a long time.

JT draws on her own childhood experience in having a structured environment to assist her children and also foster their level of independence and learning.

JT: My dad was in the service, when my father left the service and came home, you know the kids coming, he had a house that was run like the military, everything had to be on schedule, a set time, everybody had chores. I like to do things on schedule, there's showers, they can fix their own breakfast., they do their own hair now, they clean their

own room, they have chores. So, everything is run on the schedule and they're pretty good with that. They get paid to do chores so they're learning, they're doing pretty good. It works better for them and then, plus all of them take medicine, so I have to stay on top of that. Without the medicine, things does change, its hectic around in the house.

Parents were able to explore their experiences with their children “outside” of treatment through reward systems, recreational activities and structured environments, Whether these actions taken by parents are ones that they had learned prior to engaging their child in mental health treatment or understood the impact of their work in alliance with their child’s therapist, parents activities with their children in the home is a critical component in impacting their capacity and “sense of agency” to foster positive mood and/or behavioral changes in their children.

In summary, the distinction between parent’s work with their children “within” and “outside” of treatment is important to note due to the possibility of parents engaging in activities with their children that may not necessarily be defined and/or captured in their child’s treatment plan but would be beneficial to the child therapeutic process. For example, if a parent decides to reward their child by taking them to a movie (working with their child “outside “of treatment) and the child has a temper tantrum, the parent may be able to assist their child with the practice of emotional regulation techniques (i.e. breathing exercises) learned “within” the clinical setting. Therefore, the parent is not only working with the child’s mood and behavior, but they are also engaging in an activity that both child and parent may enjoy. It is possible that parents engaging in recreational activities with their children could be recommended by a therapist on its own, in efforts improve a child’s mood or bonding with the parent. However, engaging in a recreational activity alone may not necessarily foster parent’s ability to assist in improving the child’s mood if the parent is not actively engaging in a process to understand how to manage and negotiate the

child's behavior when they return to therapy sessions and process these challenges with the therapist. Therefore, parents "sense of agency" would be improved when a parent is able to understand how to actively work with their children outside of therapy sessions along with the effective utilization and the application of tools/interventions "inside" the clinical space. Parent's "sense of agency" is reinforced by their child's responses to their efforts to provide ways to fully engage in all aspects of the therapeutic process most similarly reflected in the concept of parent participant engagement or PPE. Strictly focusing on parents work or attendance in the clinical setting may limit the general understanding of parents "sense of agency" in their child's therapeutic process. As Hain-Schlagel and Walsh (2015) explain, "PPE reflects the parent's active, independent, and responsive contribution to treatment and is a distinct construct from alliance, which represents the relationship between parent and provider" (pg.3).

Chapter VII: FINDINGS: Parents “sense of agency” and the utilization of psychotropic medications in their children’s mental health treatment.

The utilization of psychotropic medication to address children’s psychological issues have increased in the last several decades (Torelli et al.,2022; Carlson et al., 2019; Olfson et al., 2015). Some studies show that children in families that receive Medicaid benefits, are also prescribed psychotropic medication at higher rates (O’Brian & Rapp, 2021). Since approximately 30-40% of children at the site of the study take psychotropic medication, the controversial issue of parents deciding to medicate their children evolved in exploring parents’ experiences in assisting their children in the mental health treatment process. In the following chapter, parent’s “sense of agency” and their child’s utilization of psychotropic medication will explore the following four areas: (a) researcher’s dilemma in including parents with children receiving psychotropic medication in the study, (b) the impact of children’s developing awareness of parents “sense of agency” related to them taking psychotropic medication , (c) challenges posed to parents “sense of agency” by their children in the study in reference potential stigma of taking psychotropic medication, and (d) parents “sense of agency” in relation to the possibility of the discontinuation of psychotropic medication for their children in mental health treatment.

A. Researcher’s dilemma in including parents with children receiving psychotropic medication.

At the start of the study, a dilemma arose in deciding on whether to include parents with children who were actively taking psychotropic medication. This dilemma was based on whether children who took psychotropic medication as part of their treatment plan would present substantial improvement in the treatment process and therefore would create a false “sense of agency” for parents. In other words, the administration of psychotropic medication to their

children and subsequent change in symptomology would be more heavily attributed to the psychotropic medication rather than the parent's actions in therapy. To bring resolution to this dilemma, the only question in the interview that was posed was whether the child had been or currently taking psychotropic medication. Therefore, the topic of the impact of parent's decision to medicate their children would come up "organically" when discussing their work with their children in the mental health treatment process. There were no questions about the psychotropic medication effectiveness or overall experiences in their administration of the psychotropic medication posed during the study. Seven of the ten parents interviewed in the study received Medicaid benefits. Five out of the ten parents that participated in the study had children who were actively taking medication at the time of the study which accounted for eight out of the thirteen children represented in the study. The other five parents that did not have children taking psychotropic medication, did not discuss or elaborate on their views about the utilization of psychotropic medication during the interview. The issue related to the utilization of psychotropic medication offered multiple ways in which half the parents in the study experienced their role in their child's treatment, its impact on their relationship and their "sense of agency".

B. The impact of children's developing awareness on parents "sense of agency".

In the study, parents discussed how they attributed their children's improved behavior after starting a psychotropic medication regimen. Despite parents' positive associations of psychotropic medication to their child's behavior, their children's growing awareness or lack thereof, impacted parents' experiences in deciding to medicate their child. In the following excerpt, Gina describes how her child's improved behavior is an indicator of the utility of psychotropic medication despite her child's lack of understanding in the treatment process starting psychotropic medication three months prior to the study:

Gina: I think she remembers how she used to act prior to the medication and just really thought of it as she was, doing certain things she wasn't supposed to but she doesn't see herself...she didn't see herself doing certain things that I knew weren't correct, you know what I mean, how would she know? So, at this point she's doing so well on the medication. I don't think she gets it at all, like she doesn't get what it really, what it was and how good she's doing now, I don't think so, I don't think she gets it.

A child's increased awareness of the purposes of psychotropic medication and the parent's observation of their improvement can also impact the parent's comfort level and reinforcement to others that they are making the right decision despite stigmatization and perceived cultural beliefs as Brianna explains:

Brianna: I don't want her to think she's crazy because you know some kids, I'm going to be honest, a lot of black, African American people they think if they are in therapy, oh, something's wrong with you and I don't teach my kids that, I said no actually, will be taking a big step you don't necessarily have to be on medication. But, you can speak to somebody that you don't know (therapist) if you're afraid of people telling your business. You can go to somebody you don't know (therapist) and if they tell your business they can lose their job, its confidential, so why not, you understand. I actually think the medicine kind of really helped her. Like as me being her mom because she's very aware, you know and she's very smart so overall it helps her, not just in school, if that makes sense.

Brianna explains how she educates her children on the decision of whether to be on psychotropic medication. At the same time, she explains the general benefits of psychotropic medication and the importance of sustaining confidentiality to protect her children from potential stigmatization. The protections displayed by Brianna could be viewed as a way to control the potential negative

responses from others in reference to her child's mental health condition. Similarly, JT attempts to explain the benefits of her children taking medication.

JT: They want to know why they have to take the medicine, all the time. Sheila is really against taking medication. We tried to explain to them, because they always want to know why they got to take medicine, and we'll try to explain to them there's a chemical imbalance. Then they bring in the medicine, to help regulate the chemical imbalance, to make them feel better about how they feel, that type of thing. So, we sit down and try to explain it to them like that.

The stigma of having a child in mental health treatment is compounded with the cultural views that parents may hold which also impacts how parents may need to manage how they cope with views held within the family system and the environment about their children taking psychotropic medication. As Zhang (2009), notes:

It is important to strengthen rigorous evidence that shows psychotropic medications' efficacy and low risks on youth clinical populations to reduce such concerns to achieve both an improvement in access to mental health services and a reduction of racial/ethnic disparities (p.628).

Parents perceptions of psychotropic medications in the study seemed to be mixed in respects to how they managed their children's resistance to taking medication vs. their experiences in the effects of the psychotropic medication on reducing their children's internalized mood and externalized behaviors. Furthermore, parents "sense of agency" may have been challenged by their perception of how society may view their decision to have their children on psychotropic medication which further exacerbates their concerns about their decision making in their child's mental health treatment despite the probability of low-risk, efficacious psychotropic medication.

In the study, parents' decision to include the utilization of psychotropic medication to assist their children in mental health treatment spurred views about how parents assisted their children in coping with taking psychotropic medication. Parents interaction with their children in the administration of medication and their ability to assist children manage their thoughts and feelings became a precursor to parent's ability to adhere to recommendations to integrate psychotropic medications in their child's treatment plan. Linda describes her challenges in her child's resistance to taking psychotropic medication.

Linda: Right now, I have a situation with him that he doesn't want to take the medication, because he said, 'I'm not crazy why I had to be given medication to concentrate and things like that'. I told him because to help you in school and things, but still, I guess he know how to read, he's been reading, he understands, things like that. He been giving me a lot of stress about that because I don't really want, I mean I could tell him stop taking it, but I don't want to do that, if something in the future happens. So, he blames me to give him the medication, I tell him 'I didn't give it to you when you came to me you were already on this'. This is happening, this year, because he turned 12 and he got more knowledge of things, and he questions all that.

In turn, Linda is challenged by her own fears of what would happen if the child regresses to earlier difficult behaviors if psychotropic medications are discontinued but attempts to regain her agency by attempting to normalize utilization of psychotropic medication in efforts to improve child's adherence to psychotropic medication. Linda's child challenges her efforts to normalize taking psychotropic medication.

Linda: Well, the only thing he tells me about, is that 'I'm not crazy why I'm taking this pill why do they think I'm slow' (Linda responds) 'But I'm not saying that you are slower and that you crazy, you don't have to be crazy to take medication'. That's, all I can tell him, but he thinks because he taking the medication, he thinks that they think, he's crazy.

Linda explains that her child was taking psychotropic medication when she first took care of him through foster care and eventually through formal adoption. Linda recognizes her child's increased awareness about taking psychotropic medication and the child's verbalization of perceived stigma of being "crazy" due to taking psychotropic medication. It's important to note, children in foster care, approximately 18%, are likely to be prescribed one or more medications at a rate 2.7-4.2% higher than other children that receive Medicaid benefits (Leathers et.al, 2021; USGAO, 2012).

Children may exhibit difficulties in reconciling their mental health condition and sense of self. For therapists working in community outpatient settings, it may seem that the child's resistance to medication is a sign of a child denying their mental health condition. As with adults who are on psychotropic medication, adolescents should be engaged in expressing their views about their mental health care (Timlin, 2014). Parents "sense of agency" can be reinforced by therapists by assisting them in how to navigate challenging conversations with their children that may reduce their negative feelings and stigma related to taking psychotropic medication.

C. Parents "sense of agency" and discontinuation of Psychotropic Medication

Parents "sense of agency" in reference to make decisions about the discontinuation of medication seemed to coincide with their own understanding of risk and their children's change in behavior when attempting to discontinue psychotropic medication on their own. Linda, who

identifies as Latina, struggles with her own feelings about administering psychotropic medication along with the fears of discontinuation of the psychotropic medication despite her beliefs of signs of potential “weakness”. Her “sense of agency” of wanting her child to not take psychotropic medication is challenged by her fears associated with the potential risk of addiction. She explains:

Linda: I really want him off of those medications. I’m afraid of those medications.

Because I see these kids nowadays, they get addicted. That’s how his mom started using, she had a car accident, and they gave her Percocet. That’s how she started. And you know I really hate drugs. I’m very strong when it comes to that, you know I don’t like to take so many medications you don’t need to, but some people have a weak mind, it’s not the same. I don’t want him to take medications for the rest of his life.

As Alviderez (1999) noted, “beliefs that lack of moderation or willpower and weakness of character cause illness have also been identified among Latinos and African Americans” (p. 518).

In a survey of 48 caregivers of children between the ages 6-17 conducted at Dartmouth College it was found that few caregivers didn’t know the long-term risks of psychotropic medications administered to their children. Furthermore, the survey found that caregivers were active in attempting to obtain information about potential side-effects of psychotropic medications outside the clinical space. Finally, the survey found that parents did show interest in eliminating psychotropic medication in their children’s mental health treatment. (McClaren et al., 2021)

In this study, another parent describes her difficulties in reference to psychotropic medication. Brianna's "sense of agency" is challenged in her attempts to take her child off psychotropic medication and her child regressing to previous externalizing behaviors.

Brianna: But I tried, I tried it myself. I'm not going to say she need it but, I tested her for like a month, and it was hell. I'm not going to lie, it was hell, she was talking back to me and Okay, you know I tried but, but now she remains on medication.

Brianna and Linda's dilemma about the ongoing administration of psychotropic medication may be reflective of the challenges that parents may face once they have made the decision to start their children on psychotropic medication.

In contrast, Gina explains the possible positive results in her child's ability to navigate school related stressors when she is no longer taking psychotropic medication. In some respects, Gina identifies with her child and desires her to develop her child's own "sense of agency" and not attribute her improvement based on her taking psychotropic medication.

Gina :I think she's doing it now, I'm just so scared because I'm like everything is so fresh and new. I don't know how she has really responded, there's like you know, when you're in school, every day, day in, day out. You know kids and how would you respond to things because every day is a new day, you know what I mean. I just want her to be able to. handle things without feeling the way she did before and get to a point, and maybe she doesn't need the medication, that's what I want, I just want her to be able to handle life in general.

It can be helpful to have discussions with parents about the goals of mental health treatment which include the discontinuation of psychotropic medication for their children. Informing parents about typical developmental behaviors, along with normalization of

maladaptive behaviors and how to improve parent's "sense of agency" in reference to addressing the resurgence of challenging behaviors after discontinuing psychotropic medication may be useful in assisting parents and children in ultimately completing treatment (Barnett et al., 2020). The utilization of direct assessments of children's behaviors that take psychotropic medication, may be useful to parents in understanding the medications direct impact on their children's behavior or how their children respond to interventions that may not rely on medical interventions (Torelli et al., 2020; Thompson et al., 2007). Parents being able to understand these differences ensures that their "sense of agency" is based on information that can give parents the ability to make choices on how they would like their children to continue the therapeutic process even after medication is discontinued.

Chapter VIII: FINDINGS:

External Factors that impact Parents “Sense of Agency”.

External factors that impact parents “sense of agency” are important to consider when understanding ways in which parents are able to sustain their involvement and engagement in treatment. The following chapter discusses the three sub-themes that emerged when parents were asked about what types of supports or factors improved their work with their children. The following themes will be presented: (a) positive communication and utilization of external mediums (b) parents’ relationship with their child’s therapist and (c) family supports that impact parent’s ability to assist their children.

A. Positive communication and the utilization of external mediums to enhance parent-child dialogue.

Parent positive communication is defined by parents having open discussions that relay clarity, listening and responsiveness which decrease the risk of children engaging in high-risk behaviors. Parent positive communication can also be considered as a protective factor for children in mental health treatment as well as provide a nurturing space for their children to communicate freely (Rodriguez et al., 2019). Parents “sense of agency” can be strengthened when they are able to improve their ability to communicate effectively with their children during the mental health treatment process. Children reflecting to their parents their experiences and their understanding of improvement could provide parents with an increased “sense of agency”. When verbal communication becomes difficult, the utilization of arts, play and writing can become effective ways to connect parent and child and provide a parent a “sense of agency” on how to connect with their children when verbal communication is compromised in the parent-child relationship.

In the following excerpts, parents described utilizing various means of communication to connect to their children. Sara and Donna discuss how their children's art was the vehicle in which their children were able to communicate issues related to their feelings during the course of mental health treatment. Brianna also echoed Sara and Donna's experiences by also explaining how the utilization of emails and texts also facilitated communication and externalized moods and thoughts.

Sara: Before she came into therapy, the best way I can explain, there was a picture, again like I said, she expresses through art and she made a picture of a marionette and it was on the strings, and it was like a black figure that was over kind of making her dance and that's how she felt. She felt like a puppet, and you can see it. There were times, where she's having a conversation, she had a big smile on her face, which was just a fakest smile ever and you can tell that she's hurting but you know she didn't want to admit it, and that was what was really tough, just watching her struggle with that and it's been great watching her become more herself and be more open and kind of cutting those strings. Before coming, like I will try to talk to her, we have one-on-one conversations, now she is more comfortable emailing me because she didn't have a phone at the time, so she'll send emails and we'll chat through text messages.

Donna: So, I noticed the thing with the pictures pretty early in because a lot of the pictures were very dark and I had her explain them to me, what they meant, and as soon as I realized that the pictures were about her, I showed it to her clinician. So right now, one of the things that have recently started is that she was very into art and we realized at the beginning that she was using her art to speak and to exhibit the feeling, that she

wasn't speaking, so it's really important to pay attention to that. So, I tried to make sure to nurture that and that artist in her so that she can get her story out. I'm trying to make sure she has all of the books she wants and the pencils and pens, and the markers and everything so that if there's something that's inside of her that's making her unhappy she can put it on that paper and makes it easier for her to discuss it. Also, because it's hard for her to tell me how she feels, she can write it down and she can text me. Sometimes it's easier for her to just write it out for me to read it, and then I can have a conversation with her after when she's ready.

Brianna: She [child] writes letters and we talk about it. We have this thing where I'll be laying in the bed, we will be texting each other, and then she's like 'Mommy I love you, thank you for getting me help I really appreciated you because now I'm a brave girl'. So, it's easy for her.

In addition to the utilization of email and texts, Maria explains how music and television also contributed to her ability to “connect” to her child.

Maria: So, I think we we're trying to find ways to connect with each other and that's kind of what we've done recently, its figuring out what we could connect on and just teaching each other things, right, so she mentioned music. I'm glad she goes to music and so one of the things that we do now is that she can play this [song] for me on Spotify and she shares her music with me and at first she was very hesitant for me to know the music that she listened to and she's like very private and it's just music, you know, but again thinking about where she was, what a teenager feels like, someone's going to judge me if I share the digital music tastes, things of that sort, but now that she has seen people like

alternative music, like I did around that age, we have that bond so, finding those kind of things where it wasn't like a forced thing. Like I didn't force myself to go see marvel movies, she likes to do that with her dad.

The relationship between arts and mental health can be understood in many ways. The utilization of puppets can offer children the possibility of opting different characters to represent someone in their life or an experience that existed in their family history. These ways of communicating can allow the recreation of suppressed feelings, with the possibility of gaining power over them and possibly attain emotional resolution. Music can also recreate different moods and experiences given different tones or rhythms that impact a child's mood and behavior (Moula, 2021; Novy et al., 2010; Wheeler, 2015). Positive parental communication whether verbal or through a creative externalizing medium may offer parents ways to amplify their ability to connect, interpret and discuss issues that may be difficult in the mental health treatment process. When considering the mutual connection between behavior exhibited by parents and mental health issues presented by their children, parents views of their children's symptoms (in comparison to children's own reports) as in the case of communication, may be the key in influencing parent's behaviors. Therefore, more research is needed to examine the differences between child and parents reports in reference to their ideas and possible causes or attributions for the need of mental health treatment (Rodriguez et al., 2015). The separation of reports between parents and children could also provide insight on how each perceives their own or collective "sense of agency" in reference to mental health treatment provided in outpatient mental health settings.

B. Parents relationship to their child's therapist and its impact on their "sense of agency."

Parents relationship with their child's therapist also emerged as a theme when considering their experiences in assisting their children in treatment. There is evidence to show that the therapeutic relationship is connected to prospective outcomes in therapy for children and adolescence. Furthermore, therapists that can individualize their children's treatment, can improve parental engagement and possibly outcomes in mental health treatment (Schlimm, 2021). As some parents described in their experiences with their children's therapist.

Donna: One of the things that you have to learn in going to treatment is being open to hearing this person who is trained to see and hear things that you're not trained to see and hear, hearing them tell you, you know, I see what you're doing and I understand how you feel but let's try this different tact and actually trying those tactics and You know, making sure to keep up with it, some people, you know they give some ideas of things that they can do when they try it once they go 'oh it didn't work'. You have to listen to the advice that they're giving sometimes it could take weeks it can take months for those things to actually work but you have to be patient and that's hard.

Maria: I think that she's [child] taken with her therapist to review her behaviors and her thoughts. You know, seeing what the patterns are to really get to a point where she feels, I don't say comfortable with it, but that she is at a point where she's like I know this is what I'm working with....she's [therapist] been giving tools to help us cope and I think honestly there's a kind of a sense of relief on her [child] part to pinpoint what has been the issue for some time and it's okay, you know that there's nothing wrong with her [child] , she's [child] dealing with a particular challenge and that we're working together

to support her so like I said, I feel like, for her [child] there is a relief there and I know that's like odd, to say but it's like okay, we now know what we're dealing with and letting go of the stigma that comes with a diagnosis and things of that sort, so she doesn't feel like this is something that she's only dealing with, that a lot of people struggle with this.

Therapists are often entrusted in considering both parents concerns and their child's perspectives in mental health treatment. Furthermore, therapists' ability of holding a neutral space for both parents and child and conveying empathy to conflicting positions can be a way for both parents and their children to consider each other's perspective. Therapist's neutrality allows for various realities to emerge between parent and child which also serves to move the therapist from being opposed to either the parents or child's point of view. (O'Reilly & Lester, 2015) As parents described their experiences, Gina explains how her child's therapist assisted her in communicating with her daughter in reference to topics in which the child may have "received" differently if she had attempted to discuss with her child directly. Furthermore, her child's therapist became a "vehicle" to which she could obtain feedback on her work with her child in the treatment process.

Gina: The therapist, I speak to her. We try at least talking once a week, either on a different day or maybe right after the session, which is great, because sometimes I don't want to talk to her in front of my child, because obviously you know kids are very smart and they don't understand why I'm asking, why you're saying certain things. Sometimes, it's better they hear it from someone else and not directly from you because there are things that I don't know, maybe I'm picking at stuff.

Maria also shared a similar experience in having the therapist assist her in her role as a parent but also a partner in the treatment process through the utilization of collateral sessions.

Maria: This was her [child] process right? So I had to let go of that and also trust the clinician. That was a little wonky but I was trying to figure out where's my role here, when do I step in, and when I step out. So once the clinician said listen, 'you know, you and I just do collaterals then like something urgent is coming up or you need support'. So that was great because she extended herself [therapist] to me. And you know, anytime there's a change, , while my daughter is in her sessions, she'd asked me to join the session. I feel like it's just the right amount of space to jump in. Overall, at this point, you know they [child and therapist] do their own thing when I jump in when I need to or request it. I haven't felt the need to request to join a session with things having been a lot better, which is great.

Parents may believe that their children's mood and behavior are the main issues in mental health treatment (Andolfi, 2016; O'Reilly, 2015; Gilson & Abela, 2021). Systemic therapists find ways to shift parents' position away from placing responsibility on their child. Negotiating responsibilities may have the unintended consequence of parents feeling blamed for the dysfunctional patterns that may emerge within the family dynamic. A few studies suggest parents value therapists who are fair and calm during family conflict (Gilson & Abela, 2021; Brown, 2008; Sheridan et al., 2007). Furthermore, parents are more appreciative of the increased awareness of their own vulnerabilities and possibly improving their parent's skills (Thompson et al 2007; Gilson & Abela, 2021). Parents "sense of agency" can be derived by a process in which they can see themselves as conduits of their child's mental health wellness.

When parents exhibit vulnerability in the therapeutic process with their children, , it is important to understand the need for therapists to be able to “ hold” parent’s feelings.. The process of “walking alongside” becomes a way in which the therapist can assist parents and model skills in relation to caring, the development of confidence and possibly validate the impacts of stressors related to poverty, intimate relationships, living environments, etc. (O’Rielly & Lester, 2015). As these parents describe:

JT: I love the assistance; I love that help. I appreciate that the help is there. I think my head would be off my body if I wouldn't have the help. I need the help because it's hard trying to understand how to help the girls, because I wouldn't have known how to help them to where we are today if it wasn't for the therapist, if it wasn't for the Center being there, I mean I wouldn't know what to do. I probably will be in a nut House somewhere. Because it's hard.

Janet: She has explained that I have to take time for myself, I have to ensure that I make him feel normal, as normal as I can. She'll tell me like when I'm doing well or, it's a lot of like self-care like she tells me to make sure I do a lot of self-care, because if I'm not okay I can't help him and yeah, she makes me understand my role.

Whether its assisting parents in communicating through arts, providing a neutral space or being alongside them in the process of their child’s mental health treatment, the therapeutic relationship serves as a way for parents to gain the skills to ultimately increase their agency in being able to not only connect to their children but convey ways in which they will assist and gain confidence in their role.

C. Family supports in Parent “Sense of agency”

There has been very little research between social support to parents and family wellness, parent’s capacity, and resilience in children who present mental health issues. It can be assumed that due to the lack of investigation in this area, there is minimal utilization of assessments of social supports or their role in interventions in families that experience significant everyday stressors (Armstrong et al., 2005) As some parents describe the importance of social supports is very important:

Donna: Yes, definitely she is very tight with my mom so I always ask my mom to make sure that she speak to her as well, she has cousins, that are of similar age so, you know, we talked to them so that they can all have those type of conversations about their feelings and things like that, with each other. All the adults and family know so they can be aware of her and kind of pay attention and when they see that she's kind of putting on that we can make pay attention to make sure she's okay. Her older sister lives here, so her older sister is also involved at the Center and going and so its in her favor to live here and her grandparents are very involved. Especially my mother, her grandmother, she's very much involved, and they are really close so she's very comfortable having conversations with her that she may be too nervous to have with me to start out.

Janet: He [child’s father] just explains to him [child] that he also goes through it just so he doesn't feel like an outsider. So, he can understand, like you're not the only one. Like I go through it, too, and he tries to tell him what helps him.

A deeper understanding of parental supports as a protective factor can contribute to ways in which to formulate preventative measures along with assessments and treatment models for families that have children with mental health conditions (Armstrong et al., 2005). Furthermore, it can possibly increase parents “sense of agency” by being able to draw and depend on the social supports when they experience difficulties with their children outside the clinical space.

Finally, through parent’s relationships with their social supports, they are more apt to navigate the resources in their efforts to cope with stressors in the home and be able to address their own needs as well as the needs of their families, thereby improving parent’s self-efficacy and personal behaviors (Gasper et. al 2021) As these parents explain:

Maria: We need to work on this together, I can't do this by myself, this is where we're at. like, I had to say to my mom and my brother, listen, when she's in dire straits, you need to figure something out. So just talking to family and colleagues and being honest about where I was as a parent. I think helped us. To get to where we need to be.

Gina: How does he [child's father] support me with her? He talks to her [child]. I let him know what's going on, we have different schedules so he's not there at a time when we're up. It's completely opposite. So, I have to let him [child's father] know a lot about what's going on in her day and then he talks to her, and he checks to see if there is enough medication. Let me tell you, he was completely against that too, but now that he saw the difference and saw how good she is, you know, like how it benefited her it was like he went from white to black, you know, like he was on board now. So, he supports me, like I tell him, we have to be on the same page, you know what I mean, so I tell him

what's going on, so we can both sound like we're on the same page. So, I told him, this is what it is, so this is what you got to say, he said he agrees with it. That's the support.

Molly: My family has all been in therapy. My mom was like a little like Oh, is something wrong with them? And I was like, no, no, this is just we're getting on this early. My sisters and I all had the usual like teenage girl anxiety eating disorders stuff, that a lot of people had in our community at that time. And so, I'm like I'd like get them whatever tools they need to try to help support them through that. And so, my family's been fine.

The external factors of improved communication through useful externalization of their children's feelings, alliance with the child's therapist and the importance of social supports are key factors when considering parents agency in reference to their role in their child's treatment process. Further considerations on how differences in languages, culture, social media and other systemic factors (schools, hospitals, etc.) are also important to factor in when exploring how parents "sense of agency" can be fostered in their child's treatment process.

CHAPTER IX. DISCUSSION AND IMPLICATIONS FOR SOCIAL WORK PRACTICE

In the final section of this study a discussion of the implications for social work practice based on the study's findings will be discussed. The following topics will be explored (a) the COVID-19 pandemic and the utilization of telehealth in outpatient mental health settings and its impact on the parents "sense of agency", (b) the role of external factors that impact the therapeutic process including family supports and therapeutic alliance on parents "sense of agency", (c) deprescribing and assessing parents agency after completion of psychopharmacological part of treatment for their children, (d) revisiting Bowen Family Theory and possible interventions that may support "parents sense of agency", e) final thoughts on parents "sense of agency" and the future of social work practice for social workers in outpatient community mental health settings.

A. The COVID-19 pandemic and the utilization of telehealth in outpatient mental health settings and its impact on the parents "sense of agency"

It would be impossible to leave out a discussion about the impact of the COVID-19 pandemic on the lives of everyone around the globe including all the families in the study and those who attend and work at the Upper Manhattan Mental Health Center. Seven out of the ten parents interviewed in the study had their children start mental health treatment at the beginning of the COVID-19 pandemic. In a recent study, it was found that in NYC alone there was increase of self-injury, suicidal attempts, and ideations. This increase is compared to the general decrease in overall mental health visits in emergency departments (Sokoloff et al., 2021, Chaiyachati et al., 2020, Sheridan et al., 2022). Furthermore, children in the United States experienced a decrease in socialization and were impacted by stressors caused by the COVID-19

pandemic on their families. Some studies also found that the increase in suicidality was in part due to exposure to media and the high rates of COVID -19 in NYC. (Sokoloff et al., 2021).

Among the major changes families experienced during the COVID-19 pandemic were the delivery of mental health services to families. Parents and their children in the clinic all had to transition from in-person sessions to receiving mental health services through virtual mediums like Google Teams, Doxy.com and Zoom.com. The impact of this transition is still unknown. Unfortunately, most of the existing literature has been focused on adults utilizing telehealth in comparison to children (Norwood et al., 2018; Slone, Reese, & McClellan, 2012). There are differences when considering the delivery of telehealth services to families in comparison to adults. For instance, managing multiple members in the family in one virtual “room” adds a different level complexity to ways in which family members interact and the dynamics of the family when in treatment utilizing telehealth. Furthermore, the challenge of transitioning families from a physical space to a virtual one, along with family techniques that involve physically repositioning family members during a family session may impact the ways in which interventions are received by family members. The limited amount of literature that exists in relation to family telehealth services has been relegated to mostly operational or technical advantages to conducting family sessions in the virtual space. (McLean et al., 2021; Kuulasmaa et al., 2004).

In social work practice, therapists often rely on non-verbal cues and gestures in efforts to sense whether they are adequately “joining” with families in the therapeutic process (Selvini et al., 1980). In the online space, therapists are less apt to pick up on these dynamics, non-verbal interactions and have difficulty gaging what is happening in the virtual “room”. An increase of “unsafe uncertainty” may arise in the intentions to provide adequate support and interventions to

the families in the virtual space (Selvini et al., 1980; Mason, 1993). This is particularly important when considering parents ability to improve their “sense of agency” in the therapeutic process. Parents may feel that if the therapist has difficulty in appropriately perceiving the impact of exchanges between themselves and their children, they may be less apt to be able to assist their children once the session is completed. A reliance on collateral sessions, or individual sessions with parents, may be helpful to assist them in improving their agency by reviewing the advantages and disadvantages of engaging in telehealth sessions in preparation for family sessions with their children.

B. The role of external factors that impact the therapeutic process including family supports and therapeutic alliance parents on sense of agency.

In the study, parents described the contributions in their ability to assist their children within the context of improved communication as well as therapists being able to remain neutral and supporting them in their work. These factors which assist parents in their therapeutic process are known as “therapy process variables”. Harwood & Eyeberg (2004) describe therapy process variables as:

The interaction between therapist and patient during the process of therapy which is essential to the outcome in all psychological therapies. These interaction elements affect the quality of the therapist-patient relationship. An examination of process variables in child therapy is more recent. The affective bond between the mother and the therapist has been associated with mother’s beliefs about the efficacy of child psychotherapy (p. 601).

These variables are particularly important in family therapy because although the identified client is the child, the parents “sense of agency” is contingent upon the interactions with the therapist in efforts to assist in the process of effectively implementing interventions formulated

in the child's treatment. These interventions always should include not only what is expected of the child, but what is expected from the parent in order to effectively deliver and receive the particular interventions that is being offered by the therapist.

The relationship between process variables and outcomes in treatment have been minimal in the literature concerning child therapy. In interactions between therapist and child, therapist's curiosity in obtaining new information, discussions about attributions to mental health issues were considered to improve in the child-therapist alliance (Russell & Shirk, 1998; Harwood & Eyberg, 2004). Active listening has also been associated with therapeutic gains between child and therapist (Russell et al., 1996; Harwood & Eyberg, 2004). In the family therapeutic setting, therapist that demonstrate support rather than provide directives have been found to have beneficial effects in the therapeutic process (Alexander, et al., 1976; Harwood & Eyberg, 2004). Therapists therefore must strike a balance between offering parents ways to assist their children and support them when parents seek to empower themselves with the ability to navigate the complexities that arise during the course of their child's mental health treatment.

C. Deprescribing and assessing parents "sense of agency" after completion of psychopharmacological part of treatment for their children.

Another major theme that arose in the study was the utilization of psychotropic medication. Half of the parents in the study had children who were being prescribed psychotropic medication. Children's resistance to adhering to a psychotropic medication regimen became a recurring sub-theme when parents discussed their experiences in administering psychotropic medication to their children.

It seems that there is more literature on beginning the process of medicating children in mental health settings compared to the length of time children receive psychotropic medication and what is the best practice of its discontinuation. The discontinuation of psychotropic

medications may occur if the patient has fully recovered, the patient has experienced side-effects, or the prescriber may feel that the psychotropic medication is no longer effective. A plan that is safe to discontinue medication should be as integral as the planning to begin a psychotropic medication regimen (Walkup, 2009).

Collaboration in reference to decision making with children and their guardians consists of reviewing the long- and short-term risks, benefits, goals in treatment as well as the length of time a child would be in treatment (AACAPFF, 2021; Stutzman, 2021). Reassessing the impact of psychotropics and possibly deprescribing is important due to the changes that occur in childhood development and the potential of negative side effects for children during mental health treatment (Barnett et al., 2019; McLennan, 2019; Bogler et al., 2019; Grudnikoff, 2017; Gupta, 2016; Safer, 2011)

In support of parents “sense of agency”, deprescribing should be discussed in reference to the challenges that they may encounter when their children resist taking psychotropic medication. At times, these conversations may be relegated to the therapist since they spend most of the time with parent and child. Medication management sessions in outpatient settings usually are only fifteen minutes every month which limits the possibility of prescribers having conversations with parents to assist them with their children. Furthermore, supporting the parent’s administration of psychotropic medication, as well as, having conversations about possible timelines to begin tapering off psychotropic medication in the course of mental health treatment would be important when goals are created to complete mental health treatment. These ongoing conversations maybe able to increase parents “sense of agency” when it comes to the complexities regarding appropriate management of medication during the course of treatment. For example, some children that attend Upper Manhattan Mental Health Center that are

diagnosed with ADHD and are prescribed stimulants may have “medication vacations” during the Summer in which they are not in school. These periods are opportunities for prescribers to assist parents in effectively working with their children in anticipation of the start of the new school year so that they may possibly discontinue psychotropic medication. In a sense, it’s giving an opportunity for both parent and children to decrease dependency on psychotropic medication as a way to manage the child’s externalizing behavior and therefore focusing on the interventions that the parent may implement in the home with hopes of guiding their children to completion of treatment. Giving parents the information and the decision-making power to eliminate the use of psychotropic medication may further reinforce their agency in that psychotropic medication would no longer be a factor of sustaining their child’s recovery after mental health treatment is completed.

D. Revisiting Bowen Family Theory and possible interventions that may support parents’ “sense of agency”.

The utilization of Bowens theory as a framework to the exploration of parents of “sense of agency” was useful in various ways. First, Bowen’s foundational theory of differentiation was an important element when considering the examination of personal agency. A person’s sense of agency is a subjective experience, which can be correlated to Bowen’s foundational idea of differentiation. A person’s ability to manage their own anxieties during family conflict can be a pre-cursor to developing one’s own agency as well as a determinant to personal agency which further orients a parent’s locus of control. Secondly, the notion of relational agency can account for the dynamics within the family system that may impact a parent’s capacity to impact levels of differentiation among family members and may be closely related to the nuclear family emotional process, triangles and the family projection process. Lastly, Bowen’s multi-generational transmission process within the model may also take into account the

intergenerational and cultural impact on parents “sense of agency” and the behaviors of their children.

The utilization of The Bowen System Model also had its limitations in its application to the current study. The first limitation was in reference to the Bowen model being based on an “intact” family in which both parents are in the home. In the study, the mothers of the children were primarily involved in their child’s treatment and if there was a father present, he would usually be on the periphery of the child’s treatment. Engagement of fathers in the lives of their children is usually defined by the quantity of time spent in the home. However, some studies suggest that the quality of the father’s involvement, rather than the quantity of time, is associated with more positive outcomes in their children’s mental health treatment (Cowan et al., 2009).

The presence of fathers and their involvement in their child’s lives has been viewed primarily through the lens of their impact on the social capital and financial aspects with less attention to the contributions on the nurturing aspect of being a parent. Fatherhood in most recent times, has been impacted by the increase entry of women in the workforce, as well as shifts in residence and redefinition of family structure which increase diversity in the role of fathers (Marsiglio et al., 2000; Lut et al., 2022). Furthermore, research has shown the positive impact of health interactions between fathers and their children improve mental health outcomes as well as their child’s improvement in education (Bronte-Tinkew et al., 2008; Lut et al., 2022). The exclusion of fathers in the research study was due in fact to the relatively minimal presence of fathers in their child’s treatment. However, it is not to say that their decreased presence in their child’s mental health treatment translates to a minimal impact in treatment outcomes. In fact, a father’s absence or minimal presence may be an important factor in potential causes of their child’s mental health issues.

A father's absence in their child's life, yet alone in their mental health treatment, may be attributed to many reasons. Non-custodial fathers may be divorced or separated from the child's mother and therefore may not be as involved in the treatment process. Fathers that may share custody of a child but, may have less time with the child and therefore may not be as involved as the mother in the child's day to day activities. Intergenerational and cultural notions of a father's role as mainly a provider may absolve fathers from responsibilities in engaging in their child's mental health treatment regardless if they are in or outside the child's home. These notions may be reinforced by mothers as well. Outcomes of a child's mental health treatment may not factor the impact of father's involvement because they may not necessarily engage with the therapist, or their level of involvement may be overlooked by the child's mother as contributing to the overall wellness of their child. Finally, as in the mothers in the study, a father may not engage in their child's treatment because they may attribute their child's behavior to their own shortcomings and therefore decrease their own "sense of agency" in their ability to not only participate in their child's mental health treatment but, their capacity to positively impact treatment outcomes for their children.

Future research may help social work practitioners understand father's roles in the outcomes of their child's mental health treatment and further assess how, if possible, to engage fathers in their child's mental health treatment and possibly assess whether or not they have a shared "sense of agency" with the mother. If the fathers are absent from the mental health process, it would be important to assess the mother and child's ideas and feelings about how this impacts the mental health process. Finally, social work practitioners may widen their scope of their assessment and not necessarily assume that if the father is not present that they are not interested or factor into the overall treatment process of the child.

Another critique of Bowen's System model is that it lacks attention to the affective nature of therapy (Amato, 1998; Brown, 1999). The Bowen's System model for psychotherapy is based on being rational and objective in relation to emotions which, in turn, deemphasizes emotional expression in the therapeutic process. On the other hand, The Bowen system does explore the elements of the family interactions throughout generations. As Brown (1999) explains:

My own experience of this model, with its invitation to explore the 'tapestry' of one's family across the generations, is that it is an emotionally intense therapy. While Bowen may emphasize the goal of helping the client learn about their family's emotional processes, in practice it is the experience of the emotions, embedded in family of origin relationships that is a key motivator for the client to undertake family of origin work (p. 4).

The multi-generational model offered by Bowen explores how the past influence the present and how patterns formed in the past continue to impact patterns in the family system in the present (Lieberman, 1992; Brown 1999). It is less probable that family members blame each other for individual actions when patterns between generations are recognized as the catalyst for automatic reactions to one another. (Brown, 1999). The existing literature when exploring mental health issues across generations have focused on the transmission of mental health issues from the parent to child. On the other hand, having a child who experiences mental health issues may impact the parent in developing their own mental health problems (Campbell et al., 2020; Gross et al., 2008; Lilenfeld et al., 1998). Caring for a child with mental health issues may create ongoing anxiety, negative impacts on their other relationships including their relationships in the workplace. Furthermore, parents may feel the responsibility of how their children continue to develop in treatment along with the stressors of stigma that may increase the risk of parents

developing mental illness (Meltzer, 2011; Campbell et al., 2020). Ultimately the strain created by assisting their child in the course of mental health treatment on the parents own mental health may negatively impact their agency to support their child's recovery (Nicholson & Clayfield, 2004; Campbell et al., 2020).

The Bowen Systems models emphasis on shifting blame to focusing on multigenerational patterns in the family system can be particularly important considering some parents in the study described how they would blame themselves for their child's mental health issues or their difficulties in assisting their children in the mental health process. It is also important to note that half of the parents were receiving psychotherapy themselves, at the time of the study. As familial patterns can be transmitted from one generation to the next, the hope is that parents "sense of agency" can also be transmitted not only after treatment is completed but through future generations of their children's families. The increased "sense of agency" would assist future generations learn how to manage family dynamics in reference to how previous generations improved their capacity to manage not only issues in relation to mental health but all other stressors that may impact a family including: systemic racism, poverty, poor education, physical disabilities, death and loss. For immigrant families this may also be useful in being able to retain the agency demonstrated by previous generations that led to the difficult choice of leaving their home and starting over in a new country.

E. Final thoughts on parents "sense of agency" and the future of social work practice for social workers in outpatient community mental health settings.

Parents "sense of agency" should be assessed not only in the beginning of a therapeutic process but throughout the course of treatment and beyond after completion. Assessments by mental health professionals should not solely be relegated to quantitative instruments that may

provide some information on their “progress” These assessments should incorporate the parents’ world views about how they define progress, change and agency that reflect their origin, race, ethnicity, gender and cultural norms. It would be important for parents to continue to improve their “sense of agency” with not only the tools they have learned in their child’s mental health treatment, but also the possibility of creating new ways to assist their children beyond the child’s development and into their development as adults. In the study, parental attributions to the possible causes of their child’s mental health issues was explored. However, it could also be as important to examine parental attributions to their child’s ongoing development after treatment and understand what and how interventions worked in efforts to continue to implement these tools after their child’s completion of treatment. Therapist could offer prospective ways to approach and support their child’s wellness through psychoeducation of developmental theory as well as ways for parents to understand their ongoing work in their child’s recovery.

Outpatient community mental health settings and social workers may be able to develop parents “sense of agency” in practice in a variety of ways. First, social work practitioners may start by providing psychoeducation to parents about “sense of agency” and its potential impact on their child’s mental health treatment. Second, since parents “sense of agency” can only be experienced by the parent, it would be important for social workers to assist parents in identifying factors that may contribute to their “sense of agency”. For example, if a parent states that they received a significant amount of support in assisting their child in the mental health process from a family member, it would be important for social workers to discuss this resource and explore how they contribute to their role in helping their child and their overall “sense of agency”. Finally, social workers may incorporate factors that increase parental agency directly in their child’s treatment plan. These factors may be listed as objectives within the parents’

actions that may contribute to the parents “sense of agency” to assist their child in the mental health process. For example, if a child’s goal is to decrease risk of harm to themselves, an objective may be for a parent to improve their supervision through the assistance of a family member that may be able to alert the parent if they suspect that a child is engaging in self-harming behavior. The social worker may also recommend an invitation of the family member to engage in parental collateral or family sessions in efforts to be included in their child’s safety plan. Or, that family member may be included in the child’s treatment plan by providing them with tools to assist and further support the parent if they are distressed or feel disempowered to reduce their child’s self-harming behavior.

Overall, social workers can reconceptualize parents “sense of agency” in a continuum rather than constant or static state of being. Social workers may offer parents the possibility of their own “sense of agency” to generally increase through the course of treatment and reinforcement of their agency in their commitment to assist parents on how to effectively either manage their child’s mental health symptoms and/or sustain their child’s recovery with the utilization of aftercare assessments upon their child’s completion of mental health treatment.

Parents “sense of agency” is influenced and impacted by the concepts of locus of control and parental activation. To illustrate the relationship between these concepts, please see figure 2.

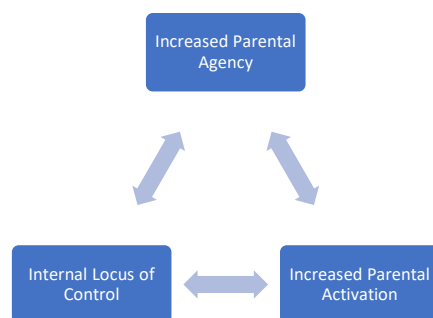


Figure 2

An increase of parental sense of agency has a multidirectional influence on their internal locus of control and increased parental activation. A parental internal locus of control and parental activation also influence and reinforce each other as they also have a combined impact on increasing a parent's "sense of agency". It is important to note that parental causal attribution disposition rather than a child-responsible attributions to a child's mental health condition may influence any of the three concepts in the diagram. Attributions may change in the course of the child's mental health treatment but its relationship to parent's sense of agency may shift as parents engage in the course of treatment and there is an integration of psychoeducation and conversations shifts from causes to potential outcomes. For example, in the beginning of their child's mental health treatment, a parent may consider a child's mental health symptoms as "child-responsible" or that the child is intentionally exhibiting maladaptive behaviors. However, in the course of treatment the parent may understand that their child symptoms maybe attributed to their own style of parenting which may shift their understanding of their child's symptoms as being parental-causal, rather than "child responsible". Finally, through psychoeducation, the therapist may be able to break this dichotomy of attribution to include other factors for their child's behavior and mood which may include other factors such as systemic, biological, developmental, educational or intergenerational.

Parental activation seems to also have a relational component as parents made efforts to sustain their work with their children based on their children's responses and their interactions with their child's therapist. Unlike in individual therapy, family therapy rests on the improvement of the other to determine if the therapeutic process has made a change yet alone a change for the better, Parents locus of control orientation determines their ideas of agency which may be helpful for mental health practitioners to assess during the course of their child's

treatment to ensure that parents locus of control has a more internal orientation, rather than an external one. This may entail that mental health professionals reinforce and assist parents and their children to continuously develop treatment goals and objectives that are attainable in shorter periods of time.

Agency is constructed by the families in which it exists. Also, agency is multidimensional in that it exists inside and outside the clinical space and beyond. “Sense of agency” is also contingent on the systemic pressures that parents experience as well as their children. As mental health professionals in family settings, we must recognize all the elements that impact a parents “sense of agency” in efforts to provide them with the ability to not only access their own agency but to continue to develop their work as their role changes throughout the lifespan of their children. This may require that therapist are knowledgeable of not only attachment and child development based theories but also systemic based theories in efforts to recreate narratives that not only lend a voice to the child and the parent but also enhance ways to navigate familial patterns that arise and are embedded in power differentials between parent and child.”.

APPENDIX A

UNIVERSITY OF PENNSYLVANIA RESEARCH SUBJECT INFORMED CONSENT FORM

Protocol Title: Qualitative Study of parents “sense of agency” that have children engaged in community outpatient mental health services.

Principal Investigator: Eric Erickson, MA, LCSW-R

Upper Manhattan Mental Health Center (Article 31
TAU)
1727 Amsterdam Avenue
New York, NY 10031

Emergency Contact: 917-569-7581 (Cell)
646-964-8924

Research Study Summary for Potential Subjects

You are being invited to participate in a research study. The study is to assess your experiences at your current clinic. Your participation is voluntary, and you should only participate if you completely understand what the study requires and what the risks of participation are. You should ask the study team any questions you have related to participating before agreeing to join the study. You do not have to agree to the study now. You can take the consent form home and review it before deciding to join the study. If you have any questions about your rights as a human research participant at any time before, during or after participation, please contact the Institutional Review Board (IRB) at (215) 898-2614 for assistance.

If you do not understand what you are reading, do not place your signature at the end of the document. The researcher will explain anything you need to understand in reference to this document. If you decide to participate in this study, the research assistant will make a copy of the signed consent form for your records.

The research study is being conducted to assess families’ experiences engaging in outpatient mental health services. The assessment will be conducted through 1-hour long interviews in which you will be asked to answer. The responses to the questions will assist in understanding ways to improve the quality of mental health services in the following ways. First, understand the impact of the pandemic in your home. Second,

bring clarity to the experiences of integrating interventions formulated in treatment in your home. Third, explore the limitation of conducting sessions in the virtual space. Finally, the questions will explore ways in which the program can improve the quality of life of you and your child.

Potential benefit to engage in the study is to improve your overall mental health during treatment. The most common risk of participation is that you may experience increased occurrence of symptoms throughout the course of treatment. It is also important to not that the specifics of your treatment plan will be in collaboration with your assigned clinician. Therefore, you will not find the specifics of the course of treatment in this document.

Please note that there are other factors to consider before agreeing to participate such as additional procedures, use of your personal information, costs, and other possible risks not discussed here. If you are interested in participating, a member of the study team will review the full information with you. You are free to decline or stop participation at any time during or after the initial consenting process.

Why am I being asked to volunteer?

You are being invited to participate in a research study because you are currently eligible to participate based on your request to receive mental health services.

If you decide to participate, you will be asked to sign this form.

Your doctor may be an investigator in this research study. You do not have to participate in any research study offered by your doctor. If you choose not to participate, there will be no loss of benefits to which you are otherwise entitled. You may also decide to discuss the study with your family, friends, or family doctor. Being in a research study is different from being a patient. As an investigator, your doctor is interested both in your clinical welfare and in the conduct of this study.

What is the purpose of the study?

The purpose of the study is to learn more about the experiences of engaging in outpatient mental health treatment and your understanding of the treatment process. It is important to note that this study is being conducted as part as a dissertation project through the University of Pennsylvania School of Social Policy and Practice.

Why was I asked to participate in the study?

You are being asked to join this study because your child is currently receiving mental health services.

How long will I be in the study?

The study will take place over a period of 12 weeks. This means that for the next 3 months, you will be asked to participate in an interview and have the interview recorded in efforts to transcribe your responses. There will be approximately 10 families involved in the study.

Where will the study take place?

You will be asked to come to the clinic in which you have requested services, Upper Manhattan Mental Health Center 4th floor.

What will I be asked to do?

You will be asked to read and sign a consent form to participate in the study.

What are the risks?

In the event you feel homicidal or suicidal (wanting to harm yourself or others) we will follow standard clinic policy in ensuring safety. Therefore, regardless of your participation in the study, we will follow clinic protocol as we would with any participant that is receiving services at Upper Manhattan Mental Health Center. It is important to note that procedures to ensure your safety are uniform as it pertains to regulations of the Office of Mental Health. We strongly encourage to speak with any clinician in the clinic, as well as the director or psychiatrist in the clinic if you are feeling homicidal or suicidal. If clinic staff can not ensure your safety we will proceed to assist in contacting EMS in order to be taken to the nearest hospital emergency room. As part of the intake procedure, you will be asked to complete a safety plan which will also indicate individuals that you would like the clinic to contact in case of an emergency. Your safety plan will also have crisis hotline information which you may contact 24 hours a day, 7 days a week.

Confidentiality of highest importance not only for the agencies involved but for participants involved in this study. All documentation collected during each day will be maintained in the director's office under lock and key for the researcher. Measuring tools, client charts, consent forms will be printed and filed away in client's chart and maintained in a locked chart room in which only clinicians and administrative staff have access. Information saved in researchers laptop will be sustained by the researcher's login and password.

How will I benefit from the study?

Your participation in the study will help us understand the effectiveness of treatments which can potentially be implemented in other clinics in the future.

Will I receive the results of research testing?

Most tests done in research studies are only for research and have no clear meaning for participants. by your assigned clinician. These results will not only determine the effectiveness of the study but your progress in relation to your current treatment.

What other choices do I have?

Your alternative to being in the study is to not be in the study. You will receive treatment regardless of your participation.

What happens if I do not choose to join the research study?

You may choose to join the study or you may choose not to join the study. Your participation is voluntary.

There is no penalty if you choose not to join the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future. Your assigned the, clinician, nurse, doctor or anyone in your treatment team will not be upset with your decision.

If you are currently receiving services and you choose not to volunteer in the research study, your services will continue.

When is the study over? Can I leave the study before it ends?

The study is expected to end after all participants have completed all visits and all the information has been collected. The study may be stopped without your consent for the following reasons:

- The PI feels it is best for your safety and/or health-you will be informed of the reasons why.
- You have not followed the study instructions
- The PI, the sponsor or the Institutional Review Board (IRB) at the University of Pennsylvania can stop the study anytime

You have the right to drop out of the research study at any time during your participation. There is no penalty or loss of benefits to which you are otherwise entitled if you decide to do so. Withdrawal will not interfere with your future care.

If you no longer wish to be in the research study, please contact Eric Erickson, at 917-569-7581 and simply inform me that you no longer want to participate in the study. You may also inform your clinician that you want to discontinue your participation in the study.

How will my personal information be protected during the study?

We will do our best to make sure that the personal information obtained during the course of this research study will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. The Institutional Review Board (IRB) at the University of Pennsylvania will have access to your records.

Your records will be stored in adherence to guidelines provided by agency protocol which if governed by the Office of Mental Health and HIPPA guidelines. All related health and or medical information will be stored in a locked room within a locked file cabinet as per regulations. Electronic records will be protected by providers having their own username and passwords and having computers having automatically locked after 5 minutes of non-use.

In the event that you may require a Certificate of Confidentiality to protect from outside agency providers to obtain information about your treatment, clinicians will provide and review the Certificate of Confidentiality at the start of your treatment. An explanation of the Certificate of Confidentiality will be provided.

An exception to confidentiality is if you report child or elder abuse or neglect, or if you report suicidal or homicidal ideation or intent to the research team. Any information about child or elder abuse or intent to harm yourself or others will be reported to the authorities, as required by law.

What may happen to my information collected on this study?

- Coded: The data is assigned a unique random identifier that is separately linked to subject identifiers. Re-identification is possible.

Future Use of Data

Your information will not be stored or shared for future research purposes.

What is an Electronic Medical Record and/or a Clinical Trial Management System?

An Electronic Medical Record (EMR) is an electronic version of the record of your care within a health system. An EMR is simply a computerized version of a paper medical record.

A clinical trial management system (CTMS) is used to register your information as a participant in a study and to allow for your research data to be entered/stored for the purposes of data analysis and any other required activity for the purpose of the conduct of the research.

If you are receiving care or have received care within the University of Pennsylvania Health System (UPHS) (outpatient or inpatient) and are participating in a University of Pennsylvania research study, information related to your participation in the research (i.e. laboratory tests, imaging studies and clinical procedures) may be placed in your existing EMR maintained by UPHS. Information related to your participation in clinical research will also be contained in the CTMS.

If you have never received care within UPHS and are participating in a University of Pennsylvania research study that uses UPHS services, an EMR will be created for you for the purpose of maintaining any information produced from your participation in this research study. The creation of this EMR is required for your participation in this study. In order to create your EMR, the study team will need to obtain basic information about you that would be similar to the information you would provide the first time you visit a hospital or medical facility (i.e. your name, the name of your primary doctor, the type of insurance you have). Information related to your participation in the study (i.e. laboratory tests, imaging studies and clinical procedures) may be placed in this EMR.

Once placed in your EMR or in the CTMS, your information may be accessible to appropriate UPHS workforce members that are not part of the research team. Information within your EMR may also be shared with others who are determined by UPHS to be appropriate to have access to your EMR (e.g. Health Insurance Company, disability provider, etc.).

Will I have to pay for anything?

Participants in the study will not have to pay anything to engage in the study.

Will I be paid for being in this study?

Participants will receive a \$30 gift card for the interview.

Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with *Eric Erickson at 917-569-7581*. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the IRB at (215) 898 2614.

When you sign this form, you are agreeing to take part in this research study. If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

Printed Name of Subject Signature of Subject

Date

ME AND MY CHILD

Please join our study to assess your experiences in your child treatment!

The Study is completely VOLUNTARY and CONFIDENTIAL

Do I get anything for participating? There is \$30 gift card compensation for completion of the study.

What do you have to do? Simply ask your assigned clinician for details.

How long is the study? You will be asked to participate in the study for in an hour-long interview.

The study is conducted by Eric Erickson and will be part of his dissertation with the University of Pennsylvania.

Appendix C: Questionnaire for Qualitative study

The following is a list of questions that will be asked during the interview. If you are unable to answer any question or need clarification, please let the interviewer know in efforts to either skip or clarify the question.

Demographic questions: 5-10 min

What is your name and what name would you like to use in efforts to protect your privacy? How old are you? How old is your child? How would you identify yourself on the basis of ethnicity? Where do you currently reside? How much time (approximately) has your child had in mental health treatment?

Questions related to Differentiation of self (10-15 minutes)

1) What has been your overall experience in the understanding your child's mental health condition?

A) What factors have, do you think, impacted your child's condition?

B) What was your experience in attaining mental health services for your child?

2) What has been your child's experience in the treatment process and their understanding of their mental health condition?

A) What has been your understanding about your child mental health condition?

B) What has been your child's experience in the treatment process and their understanding of their mental health condition?

3) What is your experience or understanding in your role of implementing interventions learned in sessions, with your child?

A) How has your child responded to your efforts to assist them in mental health treatment?

B) How do you feel in when you make efforts to assist your child in mental health treatment? How do you think this occurs?

Questions related to Nuclear Family Process (10-15 minutes)

1) What has been the motivation to bring and sustain your child/children to mental health treatment?

A) Are there times in which you choose not to go to sessions, if so, why?

B) Are there times your child doesn't want to engage in sessions, if so, how do you approach this situation?

2) What has been your experience in implementing interventions formulated in treatment in the home?

A) Do you feel that you have an understanding of your child's intervention and are able to implement recommended interventions in the home?

B) Have you experienced difficulties in implementing interventions?

- 3) Have you experienced difficulties implementing interventions in the home?
 - A) If so, how have you managed these difficulties, have you felt supported in being able to implement interventions proposed in treatment?
 - C) Have you attempted to implement alternative interventions not recommended in treatment? If so, have they been effective?

Questions related to the Family Projection Process. (10-15 minutes)

- 1) How do you interpret the possible causes for your child's mental health condition?
 - A) How do you feel about these possible causes?
 - B) Do you think that you are able to assist your child in mental health treatment despite these causes?
- 2) How do you explain your child's involvement in mental health treatment to others?
- 3) What is your understanding of the clinician's role in working with your child?
 - A) Do you feel that your child's therapist has been able to assist you in your child's treatment? Do you feel like the child's therapist has helped you understand your role in treatment?
- 4) To what do attribute the progress (or the lack of progress) to your child's mental health treatment?
 - A) What is the most important factor in the success of your child's treatment.

APPENDIX D

October 1, 2021

Upper Manhattan Mental Health Center
1727 Amsterdam Avenue
New York, NY 10031

Dear Mr. Erickson:

We are pleased to support your research study:

We will provide the following for your research:

- 1) An office with computer access. Access to room where client files are stored.
- 2) Conference room in efforts to provide trainings for clinicians psychometric tool implementation

We know the value of improving our work with clients at UMMHC and we look forward to working with you in your research. Please let us know anyway we can assist and when we can begin formal training of staff in the administration of preliminary measures.

Warm Regards,

Michael Zaretsky,
Program Director

What is a Certificate of Confidentiality?

Certificates of Confidentiality (CoCs) protect the privacy of research subjects by prohibiting disclosure of identifiable, sensitive research information to anyone not connected to the research except when the subject consents or in a few other specific situations. NIH funded researchers are automatically issued a CoC through their award. Other Department of Health and Human Services (HHS) agencies (FDA, CDC, SAMSHA, HRSA, IHS) issue CoCs for research they fund. Researchers can request a CoC from NIH for health-related studies that are not funded by HHS. Issuance of CoCs for such requests is at the discretion of the NIH.

Purpose

Effective October 1, 2017, NIH has updated its [policy](#) for issuing Certificates of Confidentiality (Certificates) for NIH-funded and conducted research, as a result of the need to implement Section 2012 of the 21st Century Cures Act, P.L. 114-255, which states that the Secretary, HHS shall issue Certificates of Confidentiality to persons engaged in biomedical, behavioral, clinical or other research, in which identifiable, sensitive information is collected. These Certificates protect the privacy of subjects by limiting the disclosure of identifiable, sensitive information.

Background

Section 2012 of the 21st Century Cures Act, enacted December 13, 2016, enacts new provisions governing the authority of the Secretary of Health and Human Services (Secretary) to protect the privacy of individuals who are the subjects of research, including significant amendments to the previous statutory authority for such protections, under subsection 301(d) of the Public Health Service Act. Specifically, the amended authority requires the Secretary to issue to investigators or institutions engaged in biomedical, behavioral, clinical, or other research in which identifiable, sensitive information is collected ("Covered Information"), a Certificate to protect the privacy of individuals who are subjects of such research, if the research is funded wholly or in part by the Federal Government. The authority also specifies the prohibitions on disclosure of the names of research participants or any information, documents, or biospecimens that contain identifiable, sensitive information collected or used in research by an investigator or institution with a Certificate. If the research is not federally funded, the Secretary may issue a Certificate to an investigator or institution engaged in such research, upon application.

Scope and Applicability

The NIH Policy applies to all biomedical, behavioral, clinical, or other research funded wholly or in part by the NIH, whether supported through grants, cooperative agreements, contracts, other transaction awards, or conducted by the NIH Intramural Research Program, that collects or uses identifiable, sensitive information. For the purposes of this Policy, consistent with subsection 301(d) of the Public Health Service Act (42 U.S.C 241), the term “identifiable, sensitive information” means information about an individual that is gathered or used during biomedical, behavioral, clinical, or other research, where the following may occur:

- An individual is identified; or
- For which there is at least a very small risk, that some combination of the information, a request for the information, and other available data sources could be used to deduce the identity of an individual.

The Policy also acknowledges that the NIH will continue to consider request for Certificates for non-federally funded research in which identifiable, sensitive information is collected or used.

Policy

Effective October 1, 2017, all research that was commenced or ongoing on or after December 13, 2016 and is within the scope of this [Policy](#) is deemed to be issued a Certificate through this Policy and is therefore required to protect the privacy of individuals who are subjects of such research in accordance with subsection 301(d) of the Public Health Service Act. This Policy will be included in the NIH Grants Policy statement as a standard term and condition of award effective October 1, 2017 for new and non-competing awards. Institutions and their investigators are responsible for determining whether research they conduct is subject to this Policy and therefore issued a Certificate. Certificates issued in this manner will not be issued as a separate document. Previously, NIH provided these protections through the issuance of Certificates only upon receipt and approval of an application. However, to comply with the requirement in subsection 301(d) of the Public Health Service Act to minimize the burden to researchers, streamline the process, and reduce the time it takes to comply with the requirements associated with applying for a Certificate, NIH will now provide Certificates automatically to any NIH-funded recipients conducting research applicable to this Policy.

For the purposes of this Policy, NIH considers research in which identifiable, sensitive information is collected or used, to include:

- Human subjects research as defined in the Federal Policy for the Protection of Human Subjects (45 CFR 46), including exempt research except for human subjects research that is determined to be exempt from all or some of the requirements of 45

CFR 46 if the information obtained is recorded in such a manner that human subjects cannot be identified or the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects;

- Research involving the collection or use of biospecimens that are identifiable to an individual or for which there is at least a very small risk that some combination of the biospecimen, a request for the biospecimen, and other available data sources could be used to deduce the identity of an individual.
- Research that involves the generation of individual level, human genomic data from biospecimens, or the use of such data, regardless of whether the data is recorded in such a manner that human subjects can be identified or the identity of the human subjects can readily be ascertained as defined in the Federal Policy for the Protection of Human Subjects (45 CFR 46); or
- Any other research that involves information about an individual for which there is at least a very small risk, as determined by current scientific practices or statistical methods, that some combination of the information, a request for the information, and other available data sources could be used to deduce the identity of an individual, as defined in subsection 301(d) of the Public Health Service Act.

Recipient Responsibilities

To determine if this Policy applies to research conducted or supported by NIH, investigators will need to ask, and answer the following question:

- Is the activity biomedical, behavioral, clinical, or other research?

If the answer to this question is no, then the activity is not issued a Certificate. If the answer is yes, then investigators will need to answer the following questions:

- Does the research involve Human Subjects as defined by 45 CFR Part 46?
- Are you collecting or using biospecimens that are identifiable to an individual as part of the research?
- If collecting or using biospecimens as part of the research, is there a small risk that some combination of the biospecimen, a request for the biospecimen, and other available data sources could be used to deduce the identity of an individual?
- Does the research involve the generation of individual level, human genomic data?

If the answer to any one of these questions is yes, then this Policy will apply to the research and therefore, in accordance with subsection 301(d) of the Public Health Service Act:

All recipients of a Certificate shall not:

- Disclose or provide, in any Federal, State, or local civil, criminal, administrative, legislative, or other proceeding, the name of such individual or any such information, document, or biospecimen that contains identifiable, sensitive information about the individual and that was created or compiled for purposes of the research, unless such disclosure or use is made with the consent of the individual to whom the information, document, or biospecimen pertains; or
- Disclose or provide to any other person not connected with the research the name of such an individual or any information, document, or biospecimen that contains identifiable, sensitive information about such an individual and that was created or compiled for purposes of the research.

Disclosure is permitted only when:

- Required by Federal, State, or local laws (e.g., as required by the Federal Food, Drug, and Cosmetic Act, or state laws requiring the reporting of communicable diseases to State and local health departments), excluding instances of disclosure in any Federal, State, or local civil, criminal, administrative, legislative, or other proceeding;
- Necessary for the medical treatment of the individual to whom the information, document, or biospecimen pertains and made with the consent of such individual;
- Made with the consent of the individual to whom the information, document, or biospecimen pertains; or
- Made for the purposes of other scientific research that is in compliance with applicable Federal regulations governing the protection of human subjects in research.

As set forth in [45 CFR Part 75.303\(a\)](#) and [NIHGPS Chapter 8.3](#), recipients conducting NIH supported research applicable to this Policy are required to establish and maintain effective internal controls (e.g., policies and procedures) that provide reasonable assurance that the award is managed in compliance with Federal statutes, regulations, and the terms and conditions of award.

Recipients of Certificates are also required to ensure that any investigator or institution not funded by NIH who receives a copy of identifiable, sensitive information protected by a Certificate issued by this Policy, understand they are also subject to the requirements of subsection 301(d) of the Public Health Service Act and for ensuring that collaborators that are carrying out part of the research involving a copy of identifiable, sensitive information protected by a Certificate issued by NIH understand they are also subject to subsection 301(d) of the Public Health Service Act.

For studies in which informed consent is sought, NIH expects investigators to inform

research participants of the protections and the limits to protections provided by a Certificate issued by this Policy. For process or policy-related questions, contact NIH-CoC-Coordinator@mail.nih.gov.

Appendix F

Dear Sir/Madam:

This letter is to confirm that you have elected to discontinue to participate in the following study:

Qualitative Study of parents “sense of agency” that have children engaged in community outpatient mental health services.

We appreciate and value your consideration to participation and we highly encourage to continue your mental health treatment.

Best Regards,

Eric Erickson, MA, LCSW-R
Principle Investigator

Appendix G



Consent Form

For this study this form will be read to you if you choose to participate, and you will be able to provide verbal consent and then the form will be emailed and/or mailed to the your address for your records.

YOU MUST BE 18 YEARS OF AGE OR OVER TO PARTICIPATE IN THIS SURVEY

By checking this box, I am agreeing that I am over 18 years of age. (See additional participation requirements below.)

☐ I am over 18 years of age and meet the participation requirements outlined below.

Thank you for taking the time to participate in this study. It should take no more than 1 hour in total. All responses will remain anonymous. Your participation in this study is entirely voluntary. You may choose not to participate or exit this study at any time.

This study is being utilized to help better understand parents experiences who have children engaged in outpatient community mental health centers, specifically in regards to parents sense

of agency when assisting their children in mental health treatment. Under the supervision of Ram Cnaan, PHD, principal investigator, this survey is being conducted by Eric Erickson for his dissertation as part of graduation requirements for the Doctorate in Clinical Social Work program at the University of Pennsylvania. If you still have questions or concern about your rights as a participant in this study, you may contact the Office of Regulatory Affairs at the University of Pennsylvania by calling (215) 898-2614.

Your participation or withdrawal from the study will not impact the services that you and your child receive at Upper Manhattan Mental Health Center. Furthermore, the clinician assigned to your child's case will not know if you have or haven't participated in the study. The clinician assigned to your child's case will not have any participation in the research conducted.

Participation requirements to enter this study:

Parents of children ages 5-18 receiving outpatient community mental health treatment.

Parents would need to sign informed consent form in order to participate in the study.

You may not participate in this study if:

Parents that are not legal guardians of children that are receiving treatment in the mental health clinic.

Parents who are not able to communicate effectively in English.

Terms of Informed Consent and Study Requirements:

Purpose/Procedure: You are being asked voluntarily to participate in this study because you are a parent of a child who currently receives mental health treatment in a outpatient community mental health setting. The purpose of the study is to learn more about the experiences of parents in their ability to assist their children in the process of mental health treatment, specifically their sense of agency. This study is being conducted for a dissertation in social work. Participation in this study requires participant to answer demographic questions (approximately 5 minutes) and to respond to a series of questions during a single video interview with investigator over Zoom (approximately 60 minutes). This study is being conducted through the University of Pennsylvania.

Risks: There are no known risks involved. However, should you find the questions upsetting for any reason, you may discontinue the study at any time. You also consent to this Zoom call to be recorded. The recording of this call will not be made available to the public and will be digitally stored on a hard drive that is not connected to the Internet.

Benefits: Other than the subject payments (see below), your participation could help us understand the phenomenon of parents engaged in the mental health treatment of their children. In the future, this may help professionals, including social workers, to better understand and possibly assist parents effectively engage in the mental health treatment of their children.

Confidentiality: Every effort will be made to keep information obtained during this study confidential. We will keep any records that we produce private to the extent we are

required to do so by law. Your data will be anonymized while electronically stored. Any data collected during partial interviews (e.g. a participant chooses to exit the study mid-interview) will be immediately deleted. Your data will only be used for research purposes in this dissertation and will be destroyed following defense of my dissertation. Data collected during the study will not be stored or distributed for future research studies.

However, we cannot guarantee total privacy. Records can be opened by court order or produced in response to a subpoena or a request for production of documents. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Voluntary Participation and Withdrawal: You must be 18 years of age or over to participate in this study. Participation in this study is voluntary; refusal to participate will involve no penalty. Each participant is free to withdraw consent and discontinue participation in the survey at any time. There are no negative consequences to choosing not to participate and you and your child will continue to receive mental health services at Upper Manhattan Mental Health Center regardless of your decision to participate in the study.

Subject Payments: One \$30 Amazon gift card will be provided to each interview participant who provides data for all relevant questions in Zoom interview with investigator.

Contact Persons: If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Student Investigator, Eric Erickson at gerick@upenn.edu. If a member of the research team cannot be reached or you want to talk to someone other than those working on

the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

By checking this box, I am agreeing that I am 18 years of age or over and am agreeing to the terms of the informed consent and study requirements.

☐

I agree that I am 18 years of age or over and am agreeing to the terms of the informed consent and study requirements

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