

ABSTRACT

Title of dissertation: "I'VE GOT TO HELP AS BEST I CAN:" THE EXPERIENCES OF PREDOMINANTLY LOW-INCOME AFRICAN AMERICAN PARENTS AND CAREGIVERS INVOLVED WITH THE MENTAL HEALTH CARE SYSTEM AND THEIR RESPONSES TO ADOLESCENTS' DEPRESSIVE DISORDER DIAGNOSES

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Many mental health disorders are often diagnosed in adolescence, suggesting the well-being of adolescent mental health should be a public health priority. The prevalence of adolescent mental health issues has led researchers to investigate treatment utilization and effectiveness. Findings suggest there is a vast underutilization of care for adolescents and an even greater deficit in family involvement in adolescent mental health care. Yet, existing research neither offers a sound understanding of how parents interpret and understand their child's mental health diagnosis, nor how the parent-child relationship and parental involvement in treatment is experienced.

A qualitative approach examined parents' and caregivers' perceptions of their adolescents' mental health disorder and how parents made decisions about their involvement in their adolescent's treatment in a sample of families already engaged with the mental health care system. Semi-structured interviews with 33 predominately low-income African American parents and caregivers who had parented a teenager diagnosed

and/or treated for a depressive disorder when the family was the recipient of Medicaid were conducted. The Ecological Risk and Resilience Framework facilitated an understanding of the dynamics shaping parental involvement in adolescent mental health care.

Grounded theory was used to analyze the data. Findings suggest parents' involvement in the diagnosis process may be initiated after a build-up of problematic events, often identified from sources outside the family. Parental responses to the teens' diagnoses included feeling relief but also confusion, while advocating for the needs of their teenager. The parent-child relationship post-diagnosis reflected four actions: parents being protective, showing patience and empathy, increasing communication with their teen, and teaching the teen accountability. Parents reported they had agency in making decisions about the teen's treatment. They wanted active involvement and saw their involvement as having mutual benefits for both themselves and their teen. Three encouraging components enhanced parental involvement: positive mental health care provider and parent interactions, the parents' own mental health and exposure to mental health care, and spirituality. The availability of insurance also positively supported more involvement. Care barriers included family or teen resistance and lack of resources. Race/ethnicity shaped the expectations parents had of the mental health care system but did not shape parental involvement in treatment. Strategies for forging greater parental connections with mental health treatment and the role mental health care professionals play in this partnership are discussed.

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“I believe the world is one big family, and we need to help each other.”

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There is still much work to be done to improve the mental health of children, adolescents, and families.

Table of Contents

List of Tables	ix
List of Figures	x
Chapter 1: Introduction	1
Chapter 2: Review of Literature	10
Prevalence of Mental Health Disorders among Adolescents	10
Depressive Disorders in Adolescents	13
Adolescent Mental Health Care and Service Usage.....	17
Racial/Ethnic Disparities in Adolescent Mental Health Care and Service Usage	21
Contexts of Low-income Black/African American Families and Mental Health Care	23
Adolescent Mental Health and Family Process.....	30
Income and Insurance Status as Barriers to Family Involvement	35
How Families Shape Adolescent Mental Health Care and Service Usage	38
Parents’ Perceptions of Adolescent Mental Health Struggles	39
Parents’ Perceptions of How Adolescent Mental Health Struggles Shape the Family	44
Parents’ Self-efficacy.....	46
Parents’ Self-blame.....	47
Benefits of Parental Involvement in Mental Health Care	49
The Ecological Risk and Resilience Framework	52
Ecological Theory.....	55
Risk and Resilience.....	60
Family Resilience.....	64
Summary.....	66
Definition of Terms	67
Research Questions	68
Chapter 3: Methods.....	70
Approach	70
Design.....	72
Investigator Perception and Experience.....	72
Participants.....	73
Recruitment.....	78
Data Collection	81
Memos.....	85
Pilot Study.....	86
Data Management.....	86
Data Analysis	87
Ethical Treatment of Human Subjects.....	89
Data Quality	90
Credibility	91
Transferability.....	92
Dependability.....	93

Confirmability.....	94
Researcher Bias and Reflexivity.....	94
Summary.....	97
Chapter 4: Parents’ Involvement in the Diagnosis Process	98
Co-occurring Diagnoses.....	99
Agency Involvement	101
Parental/Caregiver Awareness	103
Outside Sources	104
Severity of Behavior	106
Life Situational Experiences.....	108
Chapter 5: Parents’ Responses and the Parent-Child Relationship Post-Diagnosis	112
Parents’ Responses Post-Diagnosis.....	112
“‘It kind of made sense’’: Parents’ Suspicions Confirmed yet Confusion Remained	112
“‘I need help.’’ Advocating as a Response to the Diagnosis	119
The Parent-Child Relationship Post-Diagnosis.....	123
“‘I have to be on vigilant patrol.’’ Parents’ Protective Approach	123
“‘Cause I’m more understanding.’’ Patience and Empathy.....	129
“‘Because everything was ‘nothing’.’’ Communication between Parents and Teenagers	132
“‘Let them know that’s right and what’s wrong.’’ Teaching Accountability.....	136
Chapter 6: Parental Involvement in Mental Health Care.....	141
Agency in Decision Making.....	141
Parents as Active Participants in Mental Health Care.....	144
“‘Help me help my kid.’’ The Collective Benefits of Parental Involvement.....	146
Encouragements of Parental Involvement.....	149
“‘They show concern for my child.’’ Mental Health Care Provider and Parent Interactions.....	149
“‘Because I deal with it myself.’’ Parents’ Involvement Shaped by Their Own Mental Health.....	152
Other Exposures to Mental Health Care	155
Spirituality.....	157
Barriers to Parental Involvement.....	158
Family or Self as an Obstacle	159
Lack of Resources.....	161
Chapter 7: Family Characteristics.....	164
Insurance as a Bridge	164
Insurance as Supportive.....	168
Convenience.....	168
Personalization of Care	169
Insurance and Income.....	172
Race and Ethnicity.....	175
“‘I don’t think race has anything to do with it.’’ The Perception that Race/Ethnicity Does Not Shape Families’ Experiences with Mental Health Care	176
“‘It’s different backgrounds and they don’t really understand.’’ The Perception that Race/Ethnicity Does Shape Families’ Experiences with Mental Health Care	178

Chapter 8: Application of the Ecological Risk and Resilience Framework	182
The Family Process of Adaptation	182
The Process-Person-Context-Time Model	186
Process	186
Person.....	187
Context.....	189
Time	192
Risk and Resilience	193
Family Resilience	195
Major Implications of the Ecological Risk and Resilience Framework.....	197
Chapter 9: Discussion	198
Parents’ Involvement in the Diagnosis Process	200
Parents’ Reponses Post-Diagnosis.....	206
The Parent-Child Relationship Post-Diagnosis	211
Parental Involvement in Adolescent Mental Health Care.....	217
Family Characteristics	224
Limitations.....	227
Limitations of the Sample.....	227
Limitations of Data Collection.....	229
Major Implications	230
Practice and Program Implications	230
Best Practices for Mental Health Care Professionals and Agencies.....	233
Policy Implications	235
Research Implications.....	238
Conclusion.....	241
Appendices.....	243
Appendix A: Detailed Demographic Characteristics of the Sample	243
Appendix B: Recruitment Flyer	248
Appendix C: Script to Recruit Participants	249
Appendix D: Resources on Adolescent Depressive Disorders	250
Appendix E: Interview Protocol.....	256
Appendix F: Informed Consent – University of Maryland	260
Appendix G: Informed Consent – Sheppard Pratt.....	262
Appendix H: Demographic Questionnaire	266
Appendix I: Code List and Definitions	268
Appendix J: IRB Approval Letter – University of Maryland	272
Appendix K: IRB Approval Letter – Sheppard Pratt	274
Appendix L: Application of Theoretical Concepts with Interview Questions, Open Codes, & Findings	276
References.....	281

List of Tables

Table 1: Prevalence of DSM-IV Disorders in 13-18 Year Olds.....	11
Table 2: Prevalence of Major Depressive Disorder or Dysthymia by Gender.....	16
Table 3: Prevalence of Major Depressive Disorder or Dysthymia by Age.....	16
Table 4: Demographic characteristics of the sample.....	76

List of Figures

Figure 1: Mental Health Service Usage by Racial/Ethnic Group.....	22
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Chapter 1: Introduction

In recent times, a nationwide discussion about the mental health and well-being of adolescents has been ignited. The public has witnessed the repercussions of untreated or undertreated adolescent mental illness, which devastatingly can manifest as antisocial behaviors, suicidal ideations and attempts, and at its very worst gun violence inflicted on innocent people. Within this discussion lies a pivotal question: where was the adolescent's family? The increased awareness of adolescent mental health has raised questions about family involvement in mental health treatment. This issue is of grave concern, given both the prevalence of adolescents with mental health disorders and the low rates of mental health service usage for this demographic.

Approximately one in 10 adolescents suffer from a mental illness severe enough to impair their everyday functioning (National Institute of Mental Health [NIMH], 2001) and compromise their well-being. It is estimated that mood disorder diagnoses, including major depressive disorder, bipolar disorder, and dysthymic disorder, inflict about 14% of 13 to 18 year olds in the United States (U.S.) (Merikangas et al., 2010), although such statistics may underrepresent the number of teens struggling with mood disorders because such diagnoses are thought to be under-referred for mental health treatment (Wu et al., 1999). Still, the manifestation of mood disorders in adolescents can be quite disturbing; teens may display aggressiveness, irritability, hypersensitivity, negative self-judgment, and shifts in mood (National Alliance on Mental Illness [NAMI], 2011). Considering depressive disorders as a subset of mood disorders, in a representative sample, about 30% of adolescents reported experiencing depressive symptoms (Rushton, Forcier, &

Schectman, 2002). The pervasiveness of childhood psychopathology exceeds the prevalence of the most frequent physical health problems children and adolescents face, including asthma and diabetes (Merikangas et al., 2010), yet, perhaps surprisingly, many do not receive treatment for their mental health illnesses.

Despite the prevalence of mental illness in children and adolescents and efforts to raise awareness about mental health (Hogan et al., 2003), a major barrier is that an underutilization of care still exists and low levels of family involvement in adolescent mental health service usage are common (Ingoldsby, 2010). Among children and adolescents either diagnosed with a mental health disorder, or identified as needing mental health services, research suggests that about half (50.6%) to upwards of 80% do not receive the mental health care needed (Kataoka, Zhang, & Wells, 2002; Merikangas, He, Brody, Fisher, Bourdon, & Koretz, 2010). With a focus specifically on mood disorders, it is estimated that only about 43.8% of those diagnosed under the age of 18 engage in treatment (Merikangas et al., 2010). It is particularly important to recognize that children (ages seven to 17) with internalizing problems, such as a depressive disorder, may go unidentified despite their need for help (Wu et al., 1999). Further information about the lives of children and teens with depressive disorders is critical because children with depressive disorders are more likely to report needing services compared to those with disruptive disorders, but they still utilize services less (Wu et al., 1999).

Contributing to the urgency of studying depressive disorders in youth is an awareness that if untreated or undertreated, psychopathology, and particularly depressive disorder diagnoses, can become an enduring struggle which may be carried into

adulthood and continually impact one's quality of life. We know adolescents with major depressive disorder are two to seven times more likely to experience depression as an adult (Flisher, Hatherill, & Dhansay, 2004). A depressive disorder diagnosis in adolescence also increases risk for later anxiety disorders, alcohol abuse, unemployment, and early parenthood (Fergusson & Woodward, 2002). From adolescence into adulthood, the longitudinal nature of depressive disorders can impair an adolescent's interpersonal relationships, academic success, and enjoyment in life (Flisher et al., 2004), which necessitates more research exploring the experiences of adolescents diagnosed with depressive disorders before the disorder pervades into adulthood. Lastly, the serious nature of struggling with a depressive disorder could include suicidal ideations. Suicide is alarmingly the third leading cause of death for 15 to 24 year olds (Centers for Disease Control and Prevention [CDC], 2012). Suicide rates considerably increase with age, with 1.2% of 10 to 14 years olds dying by suicide compared to 12.1% of 20 to 24 year olds (Schwarz, 2009). This dramatic increase substantiates the need for a better understanding of how to involve parents in adolescent mental health treatment.

Additionally, it should be noted that the barriers to utilization of treatment are notably higher for adults and children who are ethnic minorities (i.e. African Americans and Latinos) (Department of Health & Human Services [DHHS], 2010). Ethnic minorities in need of mental health care are least likely to receive the services that meet their needs (Snowden & Yamada, 2005). Parents' and caregivers' perception of how race/ethnicity shapes the type, quality, or duration of services received is underexplored. Particularly for African American or Black families, stigma about mental health diagnoses and treatment still exists (Alvidrez, Snowden, & Kaiser, 2008). Within this

demographic, seeking mental health treatment may be seen as a sign of weakness or not appropriate for Blacks (because of perceptions that mental health care is designed for Whites) (Alvidrez et al., 2008). African American family members of individuals with mental illness report a negative perception of how society views mental illness (Franz, Carter, Leiner, Bergner, Thompson, & Compton, 2010). Spirituality may also be a barrier to involvement in treatment; African American families may feel they should turn to their church for support (Alvidrez et al., 2008) instead of seeking mental health treatment. Parents' perceptions of their child's mental health may be different from that of professionals (school or mental health based), which further can contribute to whether or not a child receives mental health services (Owens et al., 2002).

Indeed, parents and caregivers are often the gatekeepers to adolescents receiving treatment. Yet it may also be the case that family dynamics contribute to an adolescent's mental health struggle. Adolescent mental health disorders impact families (Farmer, Burns, Angold, & Costello, 1997) and have been observed concurrently with negative family relationships (Ogburn et al., 2010). Family processes have been linked to a variety of mental health and well-being outcomes for children and youth. Levels of cohesion in a family, parental disengagement from care, and permissive parenting have been associated with adolescent mental health disorders and antisocial behavior (Cuffe, McKeown, Addy, & Garrison, 2005; Lindah (1998); Schaffer, Clark, & Jelic, 2009). Research also suggests that parental and family characteristics may contribute to if an adolescent obtains treatment for a mental health concern (Cornelius, Pringle, Jernigan, Kirisci, & Clark, 2001). The contexts of parental involvement in adolescent mental health treatment are understudied, but important to explore. For example, research suggests that family-based,

systemic treatments are effective at addressing a range of child and adolescent focused problems, including emotional problems like depression (Carr, 2009). Yet, the literature lacks a full understanding of parental perceptions of adolescent mental health issues and how parents make decisions to be involved in their child's treatment.

Another treatment barrier may be a family's socioeconomic status and insurance status, which could shape the way parents are involved in an adolescent's mental health treatment. A family's income status is an important context to consider when exploring the process of family involvement in treatment and the trajectory of an adolescent's mental illness. A well documented association between childhood financial hardship and mental disorders exists in the literature (McLaughlin et al., 2011). Additionally, disparities in access to and utilization of care exist for low-income families (Newacheck, Hung, Park, Bridis, & Irwin, 2003). Limited income may shape a family's access to mental health services, such as therapy or medication. Treatment options for adolescents in low-income families may be constrained by Medical Assistance (Children's Health Insurance Program [CHIP] or Medicaid) standards. A deeper understanding of the context that poverty might play in parent-adolescent dynamics around treating an adolescent mental health disorder is necessary to learn how to increase service usage and decrease mood disorder symptoms within vulnerable families.

How families shape adolescent mental health services usage has only peripherally been explored. Not much is known about how parents or caregivers interpret and understand their adolescent's diagnosis and the process of parental involvement in adolescent mental health treatment. The little research that has explored parents' conceptualizations of their adolescent's mental health problems has found most parents

may describe their child's problem according to psychiatric labels, such as using the terms "mental illness" or "mentally handicapped" (Moses, 2011). Given we know ethnic minorities have lower rates of utilizing mental health treatment, parents' conceptualizations of their child's mental health problems may vary based on the parent's racial/ethnic status or parents' personal experiences of mental health treatment (Moses, 2011). Parents may also blame themselves for their adolescent's mental health problems, by attributing their poor parenting or lack of oversight in seeking help for the adolescent's psychopathology as reason for any problematic issues present in the family (Moses, 2010). Less is known about how parents perceive the diagnosis or treatment to influence the relationship they have with their child and how parents make decisions about being involved in treatment. A better understanding of the process parents undertake and the behaviors they employ may help elucidate avenues for increasing parental involvement in adolescent mental health treatment. Parents' understanding of their adolescent's mental health issue may contribute to parents' decision making about treatment for the adolescent.

Parental involvement in adolescent mental health treatment can be crucial to the adolescent obtaining the help needed. Most clinical research on treatment for adolescent depression has not included families, so the impact of parental involvement in treatment is largely unknown (Sander & McCarty, 2006). Parental involvement may take many forms, and how parents make decisions to be involved in the variety of ways possible is not understood. Parental involvement in treatment may help increase the family's commitment to services (Taylor & Adelman, 2001). Engaging parents or caregivers in treatment may also enable the parent to facilitate the attainment of therapeutic goals for

the adolescent (Taylor & Adelman, 2001). Additionally, involvement could take the form of parents directly being a part of family therapy sessions; such an approach has proved effective at improving family relationships and decreasing depressive disorder symptoms (Carr, 2009). Given the potential benefits of parental involvement in treatment, understanding how and why parents make decisions to be involved in the ways they do, could contribute to improving the way parental involvement in adolescent mental health care is approached.

The Ecological Risk and Resilience Framework is particularly appropriate to facilitate an understanding of the dynamics that shape parental involvement in adolescent mental health diagnosis and treatment. This framework, which combines Bronfenbrenner's ecological theory with a risk and resilience perspective, takes into consideration the context of families' lives and acknowledges the influence environment has on outcomes (Fraser, 1997). It recognizes that families may have a range of responses to a particular stressor (Demo, Aquilino, & Fine, 2005) and enables an exploration of the family process of adaptation and parental involvement in adolescent mental health treatment. Within the current study, this framework allows for an exploration of the diverse responses parents may have to receiving their adolescent's mental health diagnosis and the different processes parents may employ when making decisions about their own involvement in their adolescent's treatment. The Ecological Risk and Resilience Framework allows for an exploration of parents' perceptions and decision-making processes, as well as an exploration of how parents adapt to incorporating the teen's diagnosis into the parent-child relationship.

Ecological theory's Process-Person-Context-Time (PPCT) model is used in this study to explore the proximal processes, the personal characteristics, the broader contexts, and the role of several dimensions of time (Tudge, Mokrova, Hatfield, & Karnik, 2009) as related to parental involvement in adolescent mental health diagnosis and treatment. The process of adaptation and resilience is examined through this framework. With a focus on parent-child relationships, the concept of family resilience is also explored.

With tools from the Ecological Risk and Resilience Framework in mind, this study has two goals, to explore 1) how parents make sense of and understand their adolescent's mental health diagnosis and 2) how parents are involved in their child's treatment. The importance of learning more about family dynamics and adolescent mental health seems critical, given the underutilization of mental health service usage for low-income populations and African American families, alongside the heightened public attention to alarming behaviors perpetrated by mentally ill adolescents. A better understanding of how parents' perceptions of adolescent mental illness impacts family relationships and treatment decisions is needed (Farmer et al., 1997). To best encourage parental engagement in treatment, this study expands our understanding of predominately low-income African American parents and caregivers whose children are already receiving mental health services. Since these families were previously engaged with the mental health care system, they represent a unique subset that has been able to successfully obtain insurance, connect with mental health providers, and are receptive to mental health treatment. This study provides insight into parental involvement in the diagnosis process of adolescent mental health issues, as well as how parents respond to

receiving their adolescent's mental health diagnosis and how they make decisions to be engaged in their adolescent's treatment.

The following chapter is a literature review on adolescent mental health mood disorder prevalence, service utilization, and the benefits of and obstacles to family involvement in care. The contexts and barriers of income, insurance, and race/ethnicity in the utilization of mental health treatment and parental and caregiver involvement in care are explored and the theoretical perspective, the Ecological Risk and Resilience Framework, is discussed.

Chapter 2: Review of Literature

This chapter explores the existing literature on adolescent mental health disorder prevalence, how families shape and are shaped by an adolescent's mental health struggle, and family involvement in adolescent mental health service usage. The contexts of income, insurance, and race/ethnicity are also outlined. The guiding theoretical perspective, the Ecological Risk and Resilience Framework, is examined. Additionally, the role this research plays in furthering knowledge about parental involvement in adolescent mood disorder treatment is discussed, along with the specific research questions that guide the study.

Prevalence of Mental Health Disorders among Adolescents

Healthy People 2020 defines mental health disorders as “health conditions that are characterized by alternations in thinking, mood, and/or behavior that are associated with distress and/or impaired functioning (DHHS, 2013). About half of all Americans will meet the diagnostic criteria for a mental health disorder at some point in their lives (Kessler, Berglund, Demler, Jin, Merikangas, & Walters, 2005). The onset of mental health disorders most often occurs in childhood or adolescence (Kessler et al., 2005). The World Health Organization defines adolescence as age 10 to 19 years old (World Health Organization [WHO], 2013). It is estimated that one out of every four to five youth will experience a mental health disorder in a given year (Patel, Flisher, Hetrick, & McGorry, 2007). Nationally representative samples of adolescents in the U.S., ranging in age from 13 to 17 years old, found that disorders from the Diagnostic and Statistical Manual (4th edition) (DSM-IV) are highly prevalent and persistent in American adolescents (Kessler et al., 2012).

Incidence of adolescent mental health disorders has been examined with a number of nationally representative samples. Findings from the National Comorbidity Study – Adolescent Supplement (NCS-A) offer insight into the lifetime prevalence of mental health disorders in U.S. adolescents in a nationally representative sample where 65.6% of respondents were non-Hispanic White, 15.1% were non-Hispanic Blacks, 14.4% were Hispanic, and 84.5% of adolescents had parents who completed at least high school (Merikangas et al., 2010). Face-to-face surveys of over 10,000 adolescents between 13 and 18 years of age (with a mean age of 15.2) found high prevalence rates for mood disorders, anxiety disorders, behavior disorders, substance disorders, and eating disorders (see Table 1). The NCS-A also found that rates of severe emotional and behavioral disorders are more frequent than major adolescent physical health concerns (e.g. asthma and diabetes), in spite of the fact that these physical health issues have received extensive public health attention and awareness to alleviate the burdens of disease.

Table 1

Prevalence of DSM-IV Disorders in 13-18 Year Olds

Mood Disorders % (SE)	Anxiety Disorders	Behavior Disorders	Substance Use Disorders	Eating Disorders
14.3 (1.0)	31.9 (0.8)	19.6 (1.2)	11.4 (0.7)	2.7 (0.2)

Poor mental health constitutes a health disparity for some low-income and minority adolescents (DHHS, 1999). For example, Hispanic and African American adolescents report higher rates of feeling sad or hopeless compared to non-Hispanic White adolescents (36.8 % and 27.5 % compared to 27.3%) (CDC, 2013). Non-Hispanic Black (8.8%) and Hispanic (11.3%) adolescents in ninth to 12th grade attempt suicide more often than non-Hispanic Whites (6.3%) (CDC, 2013). Death by suicide rates are

notably high for American Indian/Alaskan Native adolescents (ages 15-19), with 20.7% of these adolescents dying by suicide compared to 8.9% of non-Hispanic White adolescents of the same age (DHHS, 2010). Growing up in poverty is also thought to have a direct influence on adolescent mental health (Dashiff, DiMicco, Myers, & Sheppard, 2009); children and adolescents from lower income families report more symptoms of poorer mental health compared to adolescents in higher income families (Vandivere, Gallagher, & Moore, 2004). Furthermore, growing up in a low-income family increases the likelihood of experiencing emotional distress into adulthood (Fan & Eaton, 2001; Gilman, Kawachi, Fitzmaurice, & Buka, 2002).

Diagnosable mental illness in adolescence is also an indicator of later mental health status. A mental health diagnoses in childhood or adolescence is considered a major risk factor for later psychiatric problems (Copeland, Shanahan, Costello, & Angold, 2009). Additionally, most adulthood-diagnosed mental illnesses, in fact, begin in childhood or adolescence (Kim-Cohen, Caspi, Moffitt, Harrington, Milne, & Poulton, 2003). Long term struggles with a mental health diagnosis can have implications for one's interpersonal relationships, academic and work success, and economic stability (Patel et al., 2007).

The prevalence of poor mental health in the youth population, as well as the short and long-term implications of coping with such disorders, has been recognized as an important public health issue, which has received attention from the federal government. *The President's New Freedom Commission on Mental Health* (Hogan et al., 2003) aimed to transform the mental health system. Included here was the need to promote the mental health of children and encourage early screening of mental health issues (Hogan et al.,

2003). More recently, Healthy People 2020 included specific objectives aimed at addressing the mental health of adolescents. Improving the status of mental health in the U.S. by reducing the amount of suicide attempts by adolescents and reducing the proportion of adolescents (12-17 years old) who experience a major depressive episode are two of the benchmarks Healthy People 2020 has established (DHHS, 2013). The treatment expansion objectives of Healthy People 2020 also include increasing the number of children and adolescents with mental health problems who receive services.

Depressive Disorders in Adolescents

Mood disorders is a category of mental illness defined as a disturbance in a person's emotional state, or mood (NIMH, 2012). This includes expressing an inappropriate mood at times, having exaggerated emotional expressions, or displaying a limited range of feelings. A mood disorder is present when the dominate feeling is expressed to an extreme, such as perseverating on hopeless thoughts about one's future. Depressive disorders are a subcategory of mood disorders in the DSM-IV (American Psychiatric Association [APA], 2000). A focus on mood disorders is warranted because these disorders are some of the most common mental health diagnoses among adolescents (Merikangas et al., 2010) and adolescents with depressive disorders are likely to experience recurrent episodes and significant impairment (Kessler & Walters, 1998). While anxiety and behavioral disorders are more commonly diagnosed in children and adolescents compared to mood disorders (Merikangas et al., 2010), research suggests that children and teens struggling with mood disorders may be under-referred for treatment (Wu et al., 1999). It may be more challenging for parents, caregivers, and professionals to notice depressive disorder symptoms in teens and adolescents may be better at masking

their depressive symptoms compared to other diagnoses. Additionally, youth with depressive disorders are more likely to report needing help for their mental health struggles compared to youth with disruptive disorders, but they still utilize services less (Wu et al., 1999).

The DSM-IV category of depressive disorders includes major depressive disorder (single episode or recurrent), dysthymic disorder, and depressive disorder not otherwise specified (NOS) (APA, 2000). The onset and trajectory of depressive disorders can take a variety of forms. Some research findings suggest that depression can begin in the preschool years (ages three to six) (Luby, 2010). Yet epidemiological and clinical research suggests that depressive disorder onset is commonly seen during adolescence and young adulthood (Weissman & Shaffer, 1998). Summarizing findings from various mental health status assessments and research, Knopf and colleagues (2008) report that “about one in five [adolescents] report symptoms of mental health problems, depression being the most common” (p. 4). Adolescent depression may manifest as frequent sadness and crying, decreased interest in activities, persistent low energy, low self-esteem, extreme sensitivity, increased irritability, anger, or hostility (American Academy of Child and Adolescent Psychiatry [AACAP], 2008). There has also been some exploration into how depressive disorder symptoms look in females versus males.

Similar to statistics about general mood disorders, female adolescents are more likely to report depressive symptoms compared to males (Rushton et al., 2002). The expression of depression symptoms in boys and girls was further explored in a sample of adolescents receiving outpatient mental health treatment by Bennett and colleagues (2005). Adolescents between the ages of 11 and 20 were administered the Childhood

Version of the Schedule for Affective Disorders and Schizophrenia (K-SADS-IIIR, IV; Ambrosini, 2000; Ambrosini, Metz, Prabucki, & Lee, 1989) and the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) to determine if gender differences in depression symptoms are present during adolescence. Findings from this study reveal that generally, boys and girls experience similar depressive symptoms, although some differences are present. Adolescent girls reported more guilt, body image dissatisfaction, more sadness, self-disappointment and blame, fatigue and trouble concentrating, as well as concern over health issues. Conversely, boys reported higher ratings on the scales of experiencing a depressed mood and fatigue in the morning, as well as an inability to feel pleasure, or anhedonia.

Further exploration of the demographics of adolescents who report depressive symptoms by using a nationally representative sample of 7th through 12th graders, the incidence and severity of depressive symptoms for adolescents was assessed by Rushton and colleagues (2002). In this study, 11.5% of parents were on public assistance and 25.4% of adolescents came from single-parent households. The Center for Epidemiologic Studies – Depression Scale (CES-D; Radloff, 1977) was utilized to assess depression levels and 30% of adolescents reported depressive symptoms in a sample that was 68.0% White, 15.0% African American, 12.4% Hispanic, and 3.4% Asian. Other research on adolescent depression has assessed this mental illness using surveillance questions.

The Youth Risk Behavior Surveillance System (YRBSS; CDC, 2013) measures a range of risk behaviors in its national school-based survey of adolescents in ninth through 12th grade. The YRBSS evaluated depression by asking the question “Have you ever felt so sad or hopeless almost every day, for two weeks in a row, that you couldn’t do some

of your usual activities?” Using data from 2012-2013, 39.1% of females and 20.8% of males responded affirmatively to this question. Ethnic differences were also present; Hispanic students responded affirmatively to this question at higher rates (36.8 % compared to non-Hispanic Black (27.5 %) and White peers (27.3%).

The previously mentioned NCS-A also offers insight into the specific prevalence of major depressive disorder and dysthymia in the adolescent population (Merikangas et al., 2010). The presence of mood disorders was measured by using the Composite International Diagnostic Interview Version 3.0 (CIDI; Kessler & Ustun, 2004), which assessed the lifetime presence of mood disorders, anxiety disorders, behavior disorders, and conduct disorders. As seen in Table 2, females were twice as likely as males to experience major depressive disorder or dysthymia. Table 3 demonstrates how depression increased uniformly with age, through early adolescence and into the late teen years.

Table 2

Prevalence of Major Depressive Disorder or Dysthymia by Gender

Female % (SE)	Male
15.9 (1.3)	7.7 (0.8)

Table 3

Prevalence of Major Depressive Disorder or Dysthymia by Age

13-14 yr % (SE)	15-16 yr	17-18 yr	Total
8.4 (1.3)	12.6 (1.3)	15.4 (1.4)	11.7 (0.9)

Considering the prevalence of mood disorders by race/ethnicity or income is also worth noting. Using data from The National Health and Nutrition Examination Survey III, Riolo and colleagues (2005) found that in a representative sample of participants ages 15 to 40, White participants had the highest rates of major depressive disorder whereas African American and Mexican Americans had significantly greater rates of dysthymic disorder. Additionally, this research found that individuals living in poverty had 1.5 times the prevalence of major depressive disorder. These findings suggest that the contexts of race/ethnicity and income play a role in the prevalence of mood disorders, and also that the type of depression must be closely examined.

With a focus on adolescents, the National Survey on Drug Use and Health (NSDUH) surveyed 12 to 17 year olds and found that Black non-Hispanic adolescents were less likely to have a major depressive episode in their lifetime (Perou et al., 2013). The NSDUH also concluded that adolescents living at or below the federal poverty level were more likely to report a major depressive episode in their lifetime and within the past year (Perou et al., 2013). Such findings suggest that the context of income may play a more prominent role in adolescent depressive disorder prevalence compared to race/ethnicity.

Adolescent Mental Health Care and Service Usage

Despite the high prevalence of adolescent mental health disorders, perhaps surprisingly, an underutilization of care for both adolescents and families of adolescents struggling with a disorder still exists. Knowing that the process and dynamics of a family can shape an adolescent's mental health status, and that parental and family characteristics may contribute to the likelihood of obtaining treatment, an increased

understanding of the contexts of parental involvement in adolescent treatment may provide insight into how to encourage families who are not using treatment to begin seeking services. When an adolescent is diagnosed with a depressive disorder, the meaning the parents attribute to this diagnosis as well as the parent's process of decision making around treatment and the parent's involvement in treatment are unknown. An illustration of these dynamics may then lead to insight into how to further encourage all parents to, first, get their teen the help the teen needs, and second, to be involved in that help alongside the teenager. Estimates of the number of children and adolescents who need mental health care and do not receive it range from 50% (Merikangas et al., 2010) to about 80% (Kataoka et al., 2002). This problem is not limited to the U.S.; in developing countries unmet mental health needs are near 100% (Venhulst et al., 2003). Underutilization of care spans across the variety of care options that are available in the U.S.

Mental health services and treatment can take many forms. A broad understanding of the different types of mental health services comes from a study by Garland and colleagues (2005). They differentiate mental health care into three categories. First are outpatient services, which include mental health clinics and private providers. This option can also include non-specialty outpatient care, such as meeting with a pediatrician to discuss a child's emotional or behavioral struggles, and may include prescriptions for medication. Second are inpatient services, which provide twenty-four-hour care, such as at a psychiatric hospital, residential treatment center, or a group home, which could also include prescriptions for medication. A third type of services described by Garland and colleagues are informal services such as counseling by clergy, self-help groups, or

services by alternative healers. Finally, not mentioned by Garland and colleagues is a fourth prominent venue for mental health services, especially for adolescents, namely school-based mental health services. These school-based services can include individual therapy, group sessions, or special programs aimed at improving students' mental health.

Within the U.S., mental health treatment utilization was studied by Kataoka and colleagues (2002). This cross-sectional, nationally representative study of children three to 17 years old utilized secondary data from three surveys: the National Health Interview Survey, the National Survey of American Families, and the Community Tracking Survey. Compiling questions from these three surveys, analysis focused on assessing how many times a child received mental health services or talked to a mental health professional. The study found that only six to nine percent of children and adolescents ages six to 17 years old used mental health services, and out of those defined as needing treatment, approximately 7.5 million children did not receive assistance. Children and adolescents who were on public insurance were more likely (than those who were uninsured or had private insurance) to use mental health services.

Exploring patterns of mental health service usage for children and adolescents was completed by Wu and colleagues (1999) using data from the NIMH Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) study. The sample's income was higher than the median family income for the areas where data were collected and racial/ethnic groups were not fully representative in the study's sample (Lahey et al., 1996). Wu and colleagues explored service usage and type of disorder in a sample of nine to 17 year olds. They found that children and teens with depressive disorders may be unidentified or under-referred for treatment despite their need for help.

In this sample, youth with depressive disorders were more likely to report needing services compared to those with disruptive disorders, but they still utilized services less, suggesting the underutilization of care is even greater for those struggling with depressive disorders.

Overall, the vast underutilization of treatment is alarming. The underutilization of mental health services, particularly for adolescents with internalizing or depressive disorders, may be related to several factors. The underutilization of care for depressive disorders could be related to the idea that the burden may be on the parent to identify symptoms and seek out treatment options for their adolescent with depression, which makes treatment contingent on parental identification (Gudino, Lau, Yeh, McCabe, & Hough, 2009). When parents report a perceived need, children are more likely to engage in mental health services (Wu et al., 1999), which suggests that the parent's involvement in initiating treatment is critical.

Other parental or family characteristics may also contribute to whether or not an adolescent in need of services receives mental health treatment and how effective that treatment may be. An examination of the correlates of mental health service usage in a sample of adolescent males explored a variety of parental characteristics and assessed what role they played in the adolescent male's unmet mental health needs (Cornelius et al., 2001). While this study focused on externalizing disorders, it found several parental and family characteristics that were associated with unmet service utilization. Unmet service usage was predicted by mothers' drug use, the number of siblings in the family, and the parent's history of having an anxiety disorder. Such findings indicate that the

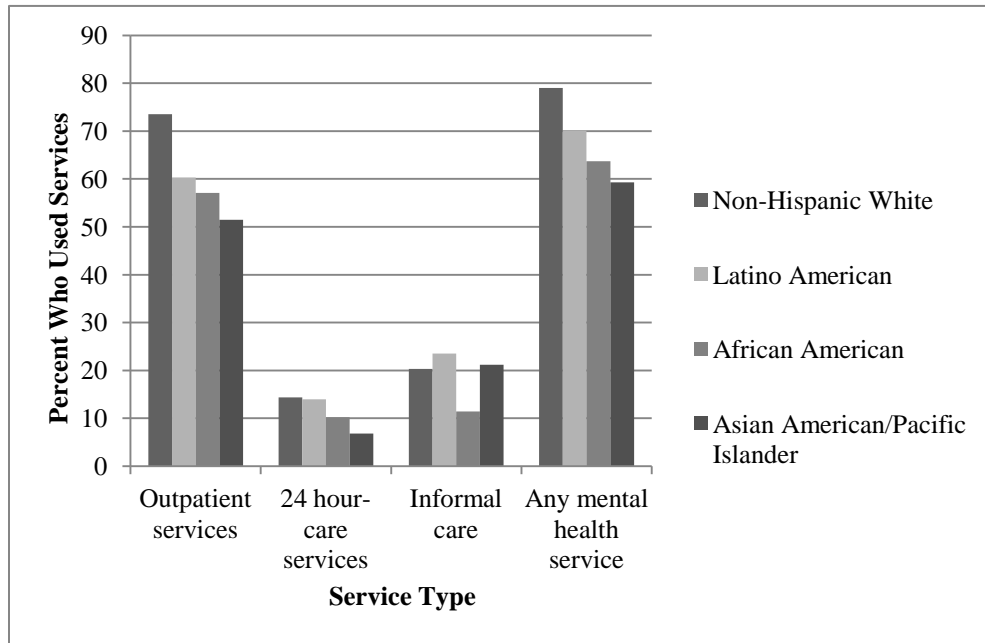
family context and parent's struggles play a role in adolescent mental health treatment. It is also important to consider how treatment and service usage differ by race/ethnicity.

Racial/Ethnic Disparities in Adolescent Mental Health Care and Service Usage

Disparities in treatment utilization occur across racial/ethnic groups. Ethnic minorities (i.e. African Americans and Latinos) are less likely to use mental health services and when they do, they receive poorer quality mental health care (DHHS, 2001). Additionally, at-risk racial/ethnic minorities are less likely to receive mental health services (Slade, 2004) compared to at-risk non-Hispanic White youth.

Racial/ethnic minorities are more likely to have mental health needs that are unmet (Garland et al., 2005). Data from the Patterns of Youth in Mental Health Care in Public Service Systems (POC) study offers insight into racial/ethnic differences in mental health service usage (Garland et al., 2005). The POC study is a representative sample of about 1,700 children and adolescents between the ages of six to 18 years. To be included in the study, youth had to have active cases with the San Diego County public sector of care, such as with child welfare services, juvenile justice, or mental health services. In this sample of high-risk youth, significant racial/ethnic differences in mental health service usage were found (see Figure 1; Garland et al., 2005). Non-Hispanic White youth had the highest rates of service usage, while Asian American/Pacific Islanders had the lowest utilization rates.

Figure 1. Mental Health Service Usage by Racial/Ethnic Group



Utilization of mental health treatment may also differ for racial/ethnic groups when the type of disorder is taken into consideration. Data from the POC, which examined “pathways into and through public service sectors of care and short-term outcomes for youth at high risk for significant mental health problems” (Gudino et al., 2009, p. 5) offers insight into if and how the type of problem an adolescent is facing plays a role in their engagement in treatment. The study assessed treatment utilization rates across racial/ethnic demographics and compared these rates to the type of diagnosis or impairment the youth exhibited. Diagnoses were assessed by administering the National Institute of Mental Health Diagnostic Interview Schedule for Children, Version IV (DISC-IV; Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000). Mental health service usage was assessed using the Services Assessment for Children and Adolescents (SACA; Horwitz et al., 2001) and outpatient and school-based mental health service

usage was explored. Hispanic Americans, African Americans, and Pacific Islander American youth were more likely to use mental health services when they had externalizing (such as behaviors associated with Attention Deficit Hyperactivity Disorder [ADHD]) or comorbid symptoms whereas non-Hispanic Whites with internalizing disorders (such as a depressive disorder) were more likely to receive mental health services. This research suggests that African Americans, Pacific Islander Americans, and Hispanic American youth with internalizing disorders are undertreated.

As with overall mental health service usage, racial/ethnic differences also exist when considering specific types of mental health services. A more detailed examination of the POC data by Wood and colleagues (2005) analyzed racial/ethnic differences and age of first school-based service receipt. Study participants were mostly male (66.0%), non-Hispanic White (39.8%), and came from households with a median income of \$20,000 to \$24,999. This study found that compared to ethnic minority children, non-Hispanic White children are more likely to receive school-based services. Also, African American, Asian/Pacific Islander, and Latino children were less likely to report using school-based mental health services, especially at younger ages. Such findings provide support for the unfortunate disparity in mental health service usage between White and minority youth.

Contexts of Low-income Black/African American Families and Mental Health Care

Of particular interest are the experiences of Black/African American families of low-income. The contexts of low-income families of color embody both unique strengths and challenges which may contribute to how parents or caregivers respond to a teenager's mental health struggles. Indeed children's contexts influence their developmental

outcomes and parents' goals, perceptions, and interactions with the child contribute to these outcomes (Garcia Coll, 1990).

A dominant context of low income African American families is the importance of extended family and kinship relationships (Boyd-Franklin, 2003). It is common for African American families to engage in reciprocity, or the exchanging and sharing support and help (Boyd-Franklin, 2003). Reciprocity may be relevant in the current study as family members may help one another obtain and sustain a teen's mental health care. Additionally, kinship care and informal adoption are two contexts of these families' lives, where relatives, friends, or other family members may undertake the parenting role for a child whose own biological parents are unable to meet the child's needs (Boyd-Franklin, 2003). In this study, it may be the case that kinship care relationships are the ones that end up establishing the teen's connection to mental health treatment.

Another notable context of low-income African American families is the prevalence of "family comorbidity" which is that notion there may be co-occurring physical or mental health problems among all family members within the family unit (Burton & Bromell, 2010). Family comorbidity is a part of the cumulative disadvantage families in poverty endure, and family comorbidity is thought to shape low-income mothers' own health (Burton & Bromell, 2010). Family comorbidity in the current study could take the form of both parents and teens struggling with psychopathology, or caregivers discussing their physical ailments alongside of the teen's depressive disorder diagnosis.

Exposure to violence and trauma is also important to consider. Rates of violence are thought to be greater amongst Black/African Americans compared to other racial

groups (Hill, 1999), and exposure to violence is associated with one's mental health status. Fitzpatrick (1993) explored exposure to violence and presence of depression in a sample of low-income African American youth (ages seven to 18 years old) and found that being the victim of violence was significantly associated with more depressive symptoms. Furthermore, such exposure could be traumatic for children and teens and may contribute to the onset of a mental health struggle.

One of the other key contexts, and perhaps challenges, these families face is stigma of mental health care, which can play out in multiple ways. The concept of "double stigma" was proposed by Gary (2005), who argues that individuals struggling with mental health concerns who are also minorities may face discrimination and prejudice on two fronts - because of their ethnic group membership and because of the burdens of mental illness. Research findings suggest that perceived discrimination can impact African American youth well-being. Perceived racial discrimination is associated with increased depressive symptoms and decreased self-esteem in African American and Caribbean Black youth (Seaton, Caldwell, Sellers, & Jackson, 2010). Therefore, concerns about or experiences with discrimination could shape an African American family's involvement in mental health services. Cultural attitudes about mental health care and concern about stigma could also play a role in this group's involvement in mental health treatment. It is possible that a family's race/ethnicity shapes parents experiences with their adolescent's mental health diagnosis and treatment.

Personal perceptions of mental health issues and mental health care can contribute to an individual's decision to pursue treatment. Stigma against mental health care and service usage was explored through qualitative research by Alvidrez and colleagues

(2008). Interviews with 34 Black adult mental health consumers were completed in an effort to develop an intervention geared towards reducing stigma. The majority of participants displayed symptoms of depression, were unemployed, and most participants had some college education. The interview results revealed that stigmatizing messages about mental illness were very prevalent in the sample's discussion of how mental illness was described within their families and communities. Participants reported feeling as though their mental illness was not appropriate to discuss with their family members and almost any type of mental health diagnosis, from mild to severe, could be equated to being "crazy." Furthermore, seeking help for a mental health struggle was seen as a sign of weakness within this sample. The researchers found that Black participants reported perceptions that mental health care is designed for White people, and therefore it is deemed inappropriate for Blacks to engage in treatment. Such feelings contributed to the participants' lack of willingness to seek treatment at various time points. Family members' perspectives on mental illness and treatment may also contribute to an individual obtaining the services needed to alleviate disorder symptoms.

Family members' perspectives could encourage or discourage an individual from seeking treatment. Indeed, a strength of Black/African American families is their strong kinship bonds and relationships with extended family members (Boyd-Franklin, 2003), which could mean family member's negative perception of mental health influences treatment engagement. Mental health stigma was also explored in a qualitative study of 12 relatives of persons receiving treatment for mental illness (Franz et al., 2010). All participants were African American; the mean age of participants was 48 years old and the majority of participants had a household income well below the median household

income for families in the U.S. Interview subjects were the mothers, fathers, sisters, grandmothers, or uncles of individuals hospitalized with schizophrenia-spectrum symptoms. Interviews with these participants revealed strong negative perceptions of how society views mental illness. Concern for their family member being ‘labeled’ was common, especially when initiating treatment. Yet, family members’ own beliefs about mental illness were perceived to be less negative by participants. Expressions of empathy and compassion were evident in the interviews, although a resistance to the formal label of “mental illness” remained. Perceptions of the stigma surrounding treating depressive disorders, in particular, may also shape a family’s experience engaging with mental health care.

Using the same sample of data described above in the study by Alvidrez and colleagues (2008), Ayalon and Alvidrez (2007) further examined barriers to mental health treatment among Black adults. Among the barriers discussed in this qualitative study, concerns about medication, lack of trust in treatment and providers, and lack of knowledge about the availability of services was reported. In this sample of mostly males, where 35% of participants had a high school education or less, further consideration of system-level barriers revealed that participants reported feeling as though they did not receive adequate information about mental health treatment and that referrals were not always provided. Lastly, participants cited inadequate or perceived incompetent treatment as a barrier to care. For example, some participants felt the mental health providers they interfaced with did not listen well or explain the medication or therapy treatments adequately.

While spirituality is widely considered a strength for African American families (Boyd-Franklin, 2003), spirituality or the perception of religion could be another challenge to parental involvement in mental health care. Ayalon and Alvidrez's (2007) qualitative findings also suggest that the religious beliefs of African American families may shape perspectives on mental health treatment. Several participants in their study reported feeling as though their religious beliefs and mental health treatment were incompatible. Black individuals may feel that the church should be their sole source of support beyond their family (Alvidrez, Snowden, & Kaiser, 2008). These barriers may then alter an African American parent's perspective on seeking mental health care for their child.

Where recommendations to seek mental health care for a child or adolescent come from could be another challenge low-income African American families face, especially if the recommendation comes from the child's school. African American parents and caregivers may be wary of such recommendations due to concerns that their children are being unfairly labeled by the school system (Boyd-Franklin, 2003). Particularly African Americans of low-income may view the inner city school system as unresponsive and hostile (Boyd-Franklin, 2003). Parental perceptions of the need for mental health care after their child was suspended or expelled from school was explored by Slade (2004) using longitudinal data from the National Longitudinal Survey of Youth; Mother-Child database (NLSY-MC; Center for Human Resource Research, 2002). In a sample of White, African American, and Hispanic children ages five to 12 years old, findings indicate that racial and ethnic disparities in mental health service usage may be, in part, due to differences in how parents perceive information from the school about their child's

behavior. Data from the NLSY-MC were used to demonstrate the differences in parents' reactions across ethnic groups when a child is expelled or suspended from school for the first time. For the African American families in the sample, 60% of which had incomes less than \$25,000 a year, first-time school suspensions or expulsions had no effect on child mental health service usage. These findings suggest that African American parents may be less responsive to information from schools about a child's behavior problems or need for mental health care.

A "perceptual barrier" regarding the need for adolescent mental health care of African American parents may also be evident in a study sample of predominately low-income, inner city, African American parents (Owens et al., 2002). Barriers to care were assessed using the SACA (Horwitz et al., 2001). Of the over 500 families interviewed, 116 parents indicated the identified child needed or used mental health services in the past year. Despite the need or usage of mental health services, parents commonly reported barriers related to perceptions of mental health problems. Specifically, parents scored high on questions indicating that they did not think their child's mental health problems were serious enough to warrant treatment and that they desired to handle any problems on their own, instead of seeking mental health care. Other prominent barriers reported by this sample were a lack of confidence in the person recommending the parent seek treatment for the child, parents reporting that they lacked knowledge about where to obtain help, and concerns help would be too expensive to obtain. Part of these barriers to treatment may be the parents' concern that seeking treatment for their child will result in consequences for themselves or their child, such as the child being labeled "severely emotionally disturbed" (Slade, 2004). Such a label can have significant consequences for

Black youth. Black youth with serious emotional and behavior disturbances are more likely than White youth to be placed in correctional facilities or foster care, compared to hospital placements (Sheppard & Benjamin-Coleman, 2001).

The research stated above strongly suggests that race/ethnicity shapes individuals and families experiences with mental health care, yet much is still unknown about this topic. Some of these findings, including the multiple contexts within which they reside, suggest parent-child dynamics may contribute to an adolescent obtaining mental health treatment. A clearer picture of how race/ethnicity contributes to the patterns of parental involvement in treatment is needed. Exploring how African American families in their contextual environments have been able to overcome barriers, perceptual or otherwise, can provide an understanding of how to better engage and involve parents in the mental health care of their children.

Adolescent Mental Health and Family Process

Adolescents are embedded in families and family functioning shapes adolescent mental health. Several studies have examined the relationship between family process and adolescent mental health. For example, levels of cohesion in a family, as a measure of family process, have been associated with the onset and perpetuation of adolescent mental health disorders (Cuffe et al., 2005). Family disorganization and low cohesion levels have been found in families of boys diagnosed with ADHD (Foley, 2010). Permissive maternal parenting is linked to poor emotional empathy development in college-aged students, which may result in antisocial behavior such as substance use, theft, or assault (Schaffer et al., 2009). Other research focuses specifically on the role

family process has played in the development and progression of adolescent depressive disorders.

Research exploring family process in families where an adolescent has a depressive disorder has produced important findings. Comparing two groups of children and adolescents (eight to 17 years), one who met the diagnostic criteria for major depressive disorder (n=31) and one who did not (n=34), the Family Environment Scale (FES; Moos & Moos, 2002) was used to assess levels of cohesion, expressiveness, and conflict in the families (Ogburn et al., 2010). Families in the major depressive disorder group were mostly White (51%) or Hispanic (39%) and on average the parents' who participated in the study had received a partial college education. Families of children with major depressive disorder demonstrated less cohesion and expressiveness, and higher levels of conflict compared to the families with children not diagnosed with any mental health disorder. The families of adolescents with depression also reported lower levels of being active in recreational activities and scored lower on the degree of emphasis the family places on ethical and religious values. These findings suggest qualitative differences exist between such families and highlight the notable link between family process and adolescent depressive disorders.

The association between family functioning and depressive disorders in adolescents has also been explored by asking participants to recall their experiences of childhood adversities. A cross-sectional, nationally representative community survey of more than 5,000 adults, ages 18 to 60 years old, assessed risk factors and adversities faced in childhood and mental health status (McLaughlin, Green, Gruber, Sampson, Zaslavsky, & Kessler, 2010). The National Comorbidity Survey Replication (NCS-R)

looked at twelve childhood adversities, including parental violence and neglect. Among adults who retrospectively recalled enduring childhood adversities, these adversities significantly predicted the persistence of a mental health disorder into adulthood. Furthermore, maladaptive family functioning, including parental psychopathology, family violence, and child maltreatment, was modestly, significantly associated with persistence of major depressive disorder and dysthymic disorder, among other mood disorders, in the sample. These findings provide evidence that the family environment and family processes a child experiences while they are young shapes an adolescent's mental health well into adulthood.

Struggling with a mental health disorder as an adolescent or young adult may also have implications for when adolescents become parents themselves as well as the childrearing behaviors they engage in. Indeed, a previous history of depression by age 15 has been associated with higher rates of childrearing by age 20 in females (Hammen, Brennan, & Le Brocque, 2011). An association between having a depressive disorder and parenting behaviors was explored in the Children in the Community Study (CICS), which was a longitudinal study of close to 400 participants (Johnson, Cohen, Kasen & Brook, 2008). Here, the Diagnostic Interview Schedule was administered to participants at the mean ages of 14, 16, and 22 years old. The study assessed a range of mental health diagnoses, including depressive disorders, in the sample that was mostly White and representative of the northeastern U.S. Having a depressive disorder present by age 22 (that became evident during adolescence or early adulthood) was associated with parenting children with harsh discipline, high parental control, possessiveness and rejection, and inconsistent parental discipline. Such findings demonstrate the need for

early intervention at the family level, to cease the cycle of poor family functioning and negative family processes when a mental health disorder is present. When family characteristics, such as maternal depression symptoms, are modified through treatment, the quality of the interaction between the parent and child may improve (Goodman, Broth, Hall, & Stowe, 2008).

These findings also remind us that a parent's mental health status can shape the family's process and well-being. Parental depression is considered a risk factor for children's health (Billings & Moos, 1983). Similar to depressed adolescents reports of poor family functioning, research on depressed parents also shows low cohesion and expressiveness and greater conflict in families where a parent has diagnosable depression (Billings & Moos, 1983). More specifically, maternal depression is significantly associated with childhood rates of internalizing and externalizing behavior problems (Goodman, Rouse, Connell, Broth, Hall, & Heyward, 2011). Maternal mood disorders are associated with poorer family relationships (Esposito-Smythers et al., 2006). Paternal depression is associated with decreased warm, affectionate, sensitive, and engaged parenting behaviors and an increase in hostile, restrictive, coercive, and critical parenting behaviors (Wilson & Durbin, 2010). Indeed, "Depression in parents can have serious biological, psychological, behavioral, and social consequences especially for children who rely on a parent for care giving, material support, and nurturance" (National Research Council & Institutes of Medicine, 2009, p. 16). Conversely, a positive association between parental depression and the mental health status of the parent's child has been explored in research examining the effects of treating maternal depression on offspring symptoms (Verdeli, Ferro, Wickramaratne, Greenwald, Blanco, & Weissman,

2004). Such research suggests that when maternal depression is treated, both mother and offspring depressive disorder symptomatology and functioning improve.

Other research sheds light on preventing adolescent depression alongside of parental depression. Using a cognitive-behavioral prevention program, Beardslee and colleagues (2013) assessed its effectiveness in a sample of over 300 adolescents (ages 13-17) who had at least one parent/caretakers with a depressive disorder during the past three years. In this sample, 24.7% of adolescents self reported as being a racial/ethnic minority (Garber et al., 2009). Assessments conducted at several time points, including two years after implementation, revealed the cognitive-behavioral program slowed the onset rate of depressive disorders compared to those adolescents who received the usual care. Yet, considering the role of parental depression, the researchers found that the effectiveness of the prevention program was conditioned upon parent's depression at the intake of the program. The cognitive-behavioral program worked significantly better when parents were not depressed at the baseline. These findings highlight how parental depression can influence the effectiveness of treatment for an adolescent and suggest that prevention or intervention programs may be most effective when the delivery coincides with the absence of parental depression.

The relationship between parental depression and childhood and adolescent mental health has been explored from many angles. It is possible that parental depression hinders parents' ability to readily and steadily respond to their child's needs (Goodman & Gotlib, 1999). In their meta-analysis of 46 articles exploring maternal depression and parenting behaviors, Lovejoy and colleagues (2000) concluded depressed mothers are more irritable, hostile, disengaged, and exhibit more negative behaviors towards their

children compared to non-depressed mothers. Parents with unipolar depression often may exhibit high psychological control and overprotection (Alloy, Abramson, Smith, Gibb, & Neeren, 2006). In addition to considering parents' own mental health status and family processes that impact adolescents, a family's income and insurance status is another context that may play a part in parents' involvement in adolescent mental health care.

Income and Insurance Status as Barriers to Family Involvement

Having strained financial resources is an important context to consider when exploring adolescent mental health and parental involvement in treatment. Growing up in poverty is a distinct context that is thought to have an effect on adolescent mental health. Childhood financial hardship is predictive of mental health disorder onset across every stage of the life-course, from infancy through adulthood (McLaughlin et al., 2011). Additionally, enduring financial hardship through childhood and adolescence is associated with increased risk of onset for mood, anxiety, behavior, and substance disorders (McLaughlin et al., 2011). With a focus specifically on depressive disorders, lower childhood socioeconomic status is significantly associated with a higher lifetime risk of major depression for both men and women (Gilman et al., 2002). Adolescent perception of their family's financial difficulties is associated with both internalizing and externalizing maladjustment outcomes (Fröjd, Marttunen, Pelkonen, von der Pahlen, & Kaltiala-Heino, 2006).

A family's low socioeconomic status may shape the parent-child relationship, as adolescents are likely to be aware of their family's financial struggles. Parental concern over finances may lead to adolescent worry about the family's financial stability (Fröjd et al., 2006), which may be related to depression or anxiety symptoms. Parental distress

may make it more challenging for parents to exercise control over their children, which in turn may contribute to internalizing or externalizing problems (Stern, Smith, & Jang, 1999). Parents who report living in poverty are more distressed, and parental distress can indirectly lead to adolescent internalizing problems through disruptions in the discipline parents exercise (Stern, Smith, & Jang, 1999).

Furthermore, a family's income status may be associated with whether or not the family has health insurance. If the family is eligible for insurance, income and employment status can dictate the type of insurance they are enrolled in; for low-income families these options may include government funded insurance programs, such as Medicaid or CHIP. Medicaid is the largest payer of mental and behavioral health services in the U.S. and it provides coverage for about 27 million children under 18 years of age (Centers for Medicare & Medicaid Services, 2014a). While Medicaid is a federal program, "states establish and administer their own Medicaid programs and determine the type, amount, duration, and scope of services within broad federal guidelines" (Centers for Medicare & Medicaid Services, 2014b).

State-run Medicaid programs are required to cover "mandatory benefits" and can opt to cover "optional benefits." Therefore, mental health benefits under Medicaid may be covered through a combination of mandatory and optional service categories. Mandatory benefits include services from federally qualified health centers, where families may be able to receive mental health counseling (Centers for Medicare & Medicaid Services, 2014b). Mandatory benefits also include developmental and behavioral screenings during early childhood (Centers for Medicare & Medicaid Services, 2014b). Optional benefits states can choose to cover include inpatient

psychiatric services for individuals under age 21 and whether or not to cover prescription drugs, which would include psychotropic medication (Centers for Medicare & Medicaid Services, 2014b). States can also elect to cover services provided by other licensed practitioners, such as psychologists (Herz, 2012) and optional services, such as family therapy (American Association for Marriage and Family Therapy, 2014). Then, as previously stated, states set limits on the duration and scope of services covered under state-approved Medicaid plans (American Association for Marriage and Family Therapy, 2014).

CHIP is insurance available to families whose income is too high to qualify for Medicaid, yet the family is still not able to afford private coverage (Centers for Medicare & Medicaid Services, 2014c). CHIP enables over eight million children to have health insurance. Benefits vary by state because states can design their own programs within Federal guidelines (Centers for Medicare & Medicaid Services, 2014d). Yet, Medical Expansion CHIP programs include coverage for mental health services as well as the standard Medicaid benefits (Centers for Medicare & Medicaid Services, 2014d).

Income and insurance status has implications for the pursuit and commitment to treatment. Research demonstrates that families of higher socioeconomic status are more likely to receive specialty mental health care, such as seeing a professional psychologist, psychiatrist, or counselor, or engaging in services at a community mental health clinic (Gudino et al., 2009), possibly because they can pay out of pocket or these services are covered by their insurance. While Medicaid eligibility has been strongly associated with the use of mental health services with some adolescents (Deck & Ley, 2006), low-income families may be struggling to meet their basic daily living needs, and this responsibility

may interfere with accessing and maintaining adolescents' mental health services (Koroloff, Elliott, Koren, & Friesen, 1996). While Medicaid remains the primary source of public funding for mental health care, Medicaid eligible adolescents may use services at rates that are notably low when compared to the estimated prevalence of mental health disorders for 12 to 17 year olds (Deck & Ley, 2006). Indeed, disparities in access to and engagement with adolescent health care continue to exist for low-income families (Newacheck et al., 2004). Thus, it is important to explore the unique needs of low-income families with adolescents diagnosed with a mental health disorder.

How Families Shape Adolescent Mental Health Care and Service Usage

In addition to considering how the contexts of income and race/ethnicity influence parental involvement in adolescent mental health care, how the family and parental characteristics shapes adolescents' usage of mental health services is also important to consider. Attaining a better understanding of the patterns of family involvement in treatment from a sample of parents and caregivers already involved with the mental health care system has implications for providing more effective services to families and adolescents and may provides insight into how to encourage non-service using families to embrace effective mental health care. While parental involvement in treatment could be beneficial to treatment outcomes (Taylor & Adelman, 2001), most tested treatments for adolescent depressive disorders have not included parents (Restifo & Bögels, 2009), so how parental involvement may shape adolescent depression treatment is unknown (Sander & McCarty, 2005). Families, namely parents, may play a part in initiating treatment and helping to sustain the adolescent's use of mental health services. Parental involvement in treatment planning and therapy sessions may contribute to parents

forming a working alliance with the therapist (Noser & Bickman, 2000), which could encourage the continuation of treatment. Caregivers may also be involved in mental health care alongside the adolescent in a family therapy context. Several characteristics of families may modify an adolescent's mental health service usage. Family involvement in service usage is related to parents' perceptions of the adolescent's mental health disorder, parents' self-efficacy and self-blame, and the family's coping strategies and abilities. Parents' ideas of the causes or reasons behind an adolescent's emotional or behavioral problems have been linked to the pursuit of treatment.

Parents' Perceptions of Adolescent Mental Health Struggles

Parental perceptions and attributions about the causes or reasons for a child or adolescent's mental health struggles may play a part in mental health service usage. Yeh and colleagues (2005) examined data from the previously mentioned POC study, in a sample of mostly non-Hispanic White youth from families with a median household income of \$19,000 to \$19,999 per year. With a focus on the relationship between parental explanatory etiologies for child problems with mental health service usage, parents completed the Beliefs about the Causes of Child Problems—Parent Version (Yeh & Hough, 1997) measure. This measure assesses parental beliefs of the causes of any emotional, behavioral, or alcohol/drug problem on 11 belief scales that were grouped into three broader categories: biopsychosocial (physical causes, personality, relational issues, familial issues, trauma), sociological causes (friends, American culture, prejudice, economic problems), and spiritual/nature disharmony causes (spiritual causes and nature disharmony). Parents who believed their child's mental health problem stemmed from a physical cause or from trauma were more likely to utilize mental health services.

Notably, parents' reports of familial issues contributing to the child's mental health struggles was not related to mental health service usage. The authors hypothesized that attributing the child's emotional or behavioral problems to a physical cause or traumatic experience might be less stigmatizing for the parent, which then might make it easier for the parent to justify utilizing treatment, such as psychotropic medication or trauma counseling.

Additional analysis of this dataset looked at racial/ethnic patterns in parental beliefs about the causes of children's and adolescents' mental health problems (Yeh, Hough, McCabe, Lau, & Garland, 2004). Significant differences in parents' beliefs about the causes of youth's mental health problems along racial/ethnic lines were found. Generally, ethnic minority parents (African American, Asian/Pacific Islander American, and Latino) were less likely to attribute their child's mental health issues to a physical cause, relational or family issue, or trauma. Cultural differences in the way families perceive depressive symptoms have been hypothesized, but it is unclear if such differences result in minority parents feeling less concerned about their adolescent's mental health (Gudino et al., 2009). This quantitative study falls short of providing a comprehensive understanding of the meaning parents attribute to their adolescent's diagnosis and how this relates to mental health service usage and family involvement in care.

A qualitative analysis of similar topics was explored by Harden (2005), who looked at parents' perceptions and experiences with their child's mental health problems and how this related to service usage. Harden interviewed 25 parents of adolescents with a range of mental health problems, including depression. All parents were White and the

families varied in their socioeconomic status. This study explored the parents' perspectives on the nature of their child's health problem, the parents' relationships with healthcare professionals, and parents' perceptions of how their lives changed alongside their child's mental health problems. Harden found that parents reported recognizing a behavior change in the adolescent that led to the initiation of the diagnostic process. Parents shared that they took responsibility, at this point, for assisting their child in "problem solving", their ability of which was sometimes limited by their own lack of knowledge about the diagnosis. Parents also reported experiencing some confusion when hearing from doctors that their child was just "being a typical teenager", especially, when to the parent, it was obvious that something more alarming was taking place. These findings highlight the importance of the provider-parent relationship; mental health professionals are positioned to help educate parents in understanding their child's diagnosis, normalizing parents' concerns, and empathizing with a parent when an adolescent's behaviors are deemed to be alarming.

Parents' and guardians' perspectives of their child's mental health problems was further studied by Moses (2011), who used mixed-methods to explore how parents conceptualize their adolescent's mental health disorder while in treatment. To investigate parents' thoughts about the nature of their child's mental health problems, 70 families were recruited from a wraparound program that served adolescents between 12 and 17 years of age. All parents were interviewed for the qualitative portion of the study and adolescents in the sample were diagnosed with a range of mental disorders, with ADHD as the most prevalent and depression the second most prevalent diagnosis. Quantitatively, parents completed measures that assessed their personal mental health experiences and

their attitudes towards mental health treatment and psychotropic medication.

Demographic questionnaires determined the sample was mostly White and low-income; more than half of the families received state medical assistance.

Conceptualization of adolescents' problems by parents was differentiated by the degree of uncertainty the parent had about the validity and relevance of psychiatric terms for their child. Parents endorsed either an alternative explanation, were uncertain, or ascribed to the psychiatric explanation of their child's mental health problem. Parents who ascribed to an alternative conceptualization (8.6% of the sample) explained their child's mental health disorder as non-medical and related to external life experiences. These parents described the mental health issue as simply related to issues faced by teenagers in general, or that the disorder was related to choices the adolescent made about her/his behaviors. Parents in the "uncertain conceptualization" group (37.1%) recognized the presence of a disorder but expressed confusion about the condition, its changing symptoms, and the severity of the condition. Lastly, the majority of the sample (54.3%) in this study used medical or psychiatric terms to describe and label the adolescent's emotional or behavioral problems. The notable portion of the sample that was uncertain about ascribing to psychiatric labels has implications for relationships between parents and mental health service providers; this could lead to a fragile relationship between the two throughout treatment. Not explored in this study is how parents' conceptualizations of adolescents' mental health problems shapes family involvement in treatment.

Perceptions of an adolescent's mental health issue *within* a family may also vary. Differences in parental perceptions and adolescent perceptions have been noted. Young (1994) explored the attributions adolescents and their parents make about the

adolescent's behaviors related to their mental health. Young's study sought to expand upon the work of Young and Childs (1994), who found that parents often identify their adolescent's mental health struggle as a difficulty within the adolescent whereas adolescents locate the problem as between themselves and others, such as between the adolescent and her/his parent. Young's study consisted of a sample of mostly middle income, White parents and their adolescent children, ages 14 to 18 years, who were admitted to the hospital for self-harm behaviors, depression, and suicide attempts. Families filled out a battery of assessments within four weeks of the adolescent's hospital admission, including the Q-Sort of Adolescent Images (QAI; Block, 1978; Stephenson, 1953), which measures family member's images of the adolescent on six clinical dimensions of individual and interpersonal functioning. Young's study found important differences in the ways adolescents and their parents make sense of an adolescent's mental health struggles. The researcher surmised divergent understandings of adolescents' pathological behaviors and functioning may often exist between parent and child. Within this sample, which included both mothers and fathers when both parents were present, suicidal/self-harmful adolescents reported being isolated from both their family and others. Parents of these adolescents did not report seeing the adolescent as alienated in this way. Noting the important role parent-child relationships play in adolescent development, the disparate attributions made about adolescents' mental health may have implications for the successful treatment of the disorder and for the need for a family level intervention to foster a mutual understanding of the adolescent's diagnosis between the parent and the child.

Parents' Perceptions of How Adolescent Mental Health Struggles Shape the Family

The process through which an adolescent's mental health struggles shape the family may relate to family involvement in treatment. Parents or caregivers may feel overwhelmed by their child's mental health issues and may struggle with a lack of knowledge and poor resources about mental health care (Owens et al., 2002).

Specifically, caregiver strain has implications for parents' engagement in an adolescent's treatment. Caregiver strain and children and adolescents' use of mental health services was studied by Brannan and colleagues (2003) in the Fort Bragg Evaluation Project (FBEP; Bickman, Guthrie, Foster, Lambert, Summerfelt, Breda, & Helfinger, 1995). Over 500 children between the ages of five to 17 from mostly middle class families received mental health services and were assessed by the FBEP as having at least one diagnosis. The researchers used a family stress and coping model to explore if various family variables predicted child mental health service utilization. The family stressors assessed focused on the child's clinical status as well as reports of stressful life events. Family resources consisted of material resources, family functioning, social support, and caregivers' psychological well-being/distress.

Caregiver strain was measured using the Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickerman, 1997). The sample was predominately White (72%), followed by African American (18%) and other/mixed races (11%) and the majority of caregivers in the study had completed some college (58%). Caregiver strain consistently predicted how the children and adolescents in the study used mental health services, whereby caregivers who experienced lower subjective strain and reported feeling sad or worried had children who only utilized outpatient mental health services. Caregivers with

higher subjective strain, who reported experiencing disruptions or adverse events in their life, were associated with having children needing higher levels of care, such as in-patient or residential treatment. Therefore, having a caregiver who reported more subjective strain was predictive of the level of involvement the child had with the mental health system. These parent-level characteristics are connected to the types of treatment an adolescent received. Not explored was family therapy as a treatment, or how parents were directly involved in the teen's mental health care. While these findings elucidate how parents perceive themselves to have adapted to their adolescent's mental health struggles, the findings fall short of expanding an understanding of the contexts that encourage or discourage parents from being directly involved in treatment.

Further research on how an adolescent's mental health problems shape the family and how this relates to service usage was examined longitudinally in a predominately rural sample. Using data from the Great Smokey Mountains Study (GSMS; Costello, Angold, Burns, Erkanli, Stangl, & Tweed, 1996; Costello, Angold, Burns, Stangl, Tweed, Erkanli, & Worthman, 1996), Farmer and colleagues (1997) studied the impact of adolescent's mental health problems on the family. Youth in the study were in the late childhood/early adolescence (ages nine, 11, and 13), were mostly White, and 27% of the sample lived below the federal poverty line, which for a family of four in the U.S. is \$24,250 (DHHS, 2015). Families completed three measures: the Child and Adolescent Psychiatric Assessment (CAPA; Angold, Cox, Prendergast, Rutter, & Simonoff, 1992); the Child and Adolescent Services Assessment (CASA; Burns, Angold, Magruder-Habib, Costello, & Patrick, 1992); and the Child and Adolescent Impact Assessment (CAIA; Patrick, Angold, Burns, & Costello, 1992). Service usage, in this study, focused on six

sectors: specialty mental health services, education, child welfare, juvenile justice, general medicine, and informal services. Farmer and colleagues found that children who first entered mental health services between 10 and 15 years of age were more likely to have parents who reported that the youth's behaviors impacted the family. The CAIA provided measures of parental well-being and parental feeling of incompetence, which were both associated with the adolescent's service usage. This study's findings suggest that the more negatively the parent perceives the adolescent's mental health problem to impact the family, the more likely the child is to receive services. These findings call attention to the need for more research that explores how family perceptions relate to decision making about service usage.

Parents' Self-efficacy

Self-efficacy is the perception of one's skill in a given area (Bandura, 1977, 1986, 1989). The self-efficacy of parents, or parental self-efficacy, in managing their adolescents' depressive disorder diagnosis may shape the course of treatment and the type of treatment the adolescent receives. Since the parents and caregivers interviewed here were already engaged with mental health care, they may have a heightened sense of self-efficacy that enabled them to be receptive to treatment and feel confident they could effectively connect their teen with help. Parental self-efficacy may also have implications for caregivers' involvement in an adolescent's treatment and increased involvement could increase the benefit of that treatment modality (Reich, Bickman, & Heflinger, 2004). Parental self-efficacy of handling the mental health issues of one's child is under-researched.

Within the domain of "mental health services self-efficacy", Reich and colleagues

(2004) sampled 250 parents of children ages six to 17 years old. Families were mostly White and all children were receiving mental health services during the time of the study. The mental health services self-efficacy of parents was assessed through completion of the Vanderbilt Mental Health Services Efficacy Questionnaire (MHSE; Bickman, Earl, & Klindworth, 1991). As one of the first studies to look at this construct of self-efficacy, Reich and colleagues found caregivers' attitudes about collaborating with mental health professionals was strongly related to the mental health services self-efficacy of parents. Additionally, knowledge about mental health services was positively related to changes in mental health services self-efficacy scores of parents. These findings highlight the importance of the relationship between parents and providers. Additionally, the contexts of having knowledge and being educated about mental health seem to be important constructs of self-efficacy.

Parents' Self-blame

Parents' blaming themselves for an adolescent's mental health disorder may also shape service utilization and the types of services sought. Self-blame is understood as parents "holding themselves responsible for causing, contributing to, or exacerbating their child's mental health disorder" (Moses, 2010, p. 103). Research on parental self-blame for child mental health disorders has demonstrated parents or guardians who self-blame attribute poor parenting, ineffective monitoring and the lack of seeking help for the child's mental health, genetic transmission of a disorder, and a negative family environment as factors contributing to the occurrence of the disorder (Moses, 2010). Notable differences may exist between biological and non-biological parents raising children and adolescents with mental health disorders. Adoptive parents or extended

family members who serve as caregivers may be more likely to believe they are not at all responsible for the child's disorder (Moses, 2010). Furthermore, biological parents who are more inclined to not blame themselves for their child's disorder have reported going through a "process of *unblaming*" themselves, where they rationalize that they did all they could (Moses, 2010).

Qualitative research on the experiences of parents with a child with a mental health disorder was further studied by Crowe and colleagues (2011), who compiled written responses from 85 parents who were involved in a study on psychotherapy for young people with bipolar disorder. The target age of young people was 15 to 34 years old; of the parents who responded, 75 were mothers, one was a father, five were from both parents, and four responses came from extended family members, foster parents, or a family friend. While this study looked at bipolar disorder, parents often noted that they first noticed depressive symptoms in their child during early and mid-adolescence (between 10 and 16 years old). Parents often reported it was not until later (approximately 19 years of age) that mania symptoms also became apparent. Unprompted, when given the space to write about anything else they wanted to share, parents used the opportunity to describe what they believed contributed to the onset of bipolar disorder in their child. Parents' responses fell into three categories: childhood adversity, parenting, and substance abuse. The category of parenting is where parental self-blame became apparent. Here, parents described feeling they were an inadequate parent or that they had done something wrong. Further exploration of this category revealed parents blamed themselves for not being able to bond with the child, for moving the child to a new country, or for emotional distance between the parent and child due to

the parent's own mental health struggles. Crowe and colleagues (2011) recommend family-based interventions to help parents understand and manage the disorder, which may reduce self-blame and enhance communication in the family.

Benefits of Parental Involvement in Mental Health Care

Family involvement in mental health care can lead to beneficial outcomes for adolescents with mental health diagnoses. A review of evidence-based psychosocial treatments for child and adolescent depression supports positive treatment effects regardless of the nature of parental involvement or the treatment modality (David-Ferdon & Kaslow, 2008), suggesting parental involvement may not be a priority in such forms of treatments. The same authors argue that future research should focus on exploring the impact of family-based interventions (David-Ferdon & Kaslow, 2008) and newer findings on this topic reveal that family-based psychotherapy treatment for depressed preadolescents significantly increases remission rates and decreases depressive disorder symptoms (Dietz, Weinberg, Brent, & Mudson, 2015). Since parents are often the gatekeepers to an adolescent's mental health care, the parent must consent to treatment and is often responsible for making arrangements for the teen to see a mental health provider. It is important to consider the ways parents make decisions about their involvement in the adolescent's mental health care, such as managing the timing and frequency of appointments with providers or being directly involved in sessions. With this study's focus on interviewing parents and caregivers already engaged with the mental health care system, such considerations are possible to explore.

Families who are involved in treatment may feel a sense of commitment to the services the child is receiving (Taylor & Adelman, 2001), which could lead to more

stable and regular treatment for the child. Involving family members can also help the progression of treatment goals, whereby family members can help facilitate and nurture the desired changes in the teenager (Taylor & Adelman, 2001). Taylor and Adelman (2001) conceptualize that parental involvement can fall on a continuum with three notable categories: highly involved, marginally involved, and reluctant to highly resistant. Parents who are highly involved are motivated to obtain treatment for their child and actively participate by seeking out resources and being involved however possible. Parents who are marginally involved embody less motivation and may also be considered to be less cooperative. Lastly, parents who are highly resistant to treatment are uncooperative or avoidant. It is possible that this last group of parents found themselves in the mental health system because of a recommendation or requirement by schools or the justice system.

In addition to the ways parents facilitate their child receiving mental health care, parents may also be involved in treatment by engaging in family therapy. Family-level, systemic services for a range of child-focused problems have been found to be effective at alleviating youth's symptoms and improving family dynamics. Family therapy and other systemic interventions have proved effective in reducing the risk of physical abuse and neglect in families (Carr, 2009), multi-modal programs that include the family have been effective in treating ADHD (Carr, 2009), and family therapy may be more effective than individual therapy at treating adolescent drug abuse (Williams, Chang, & ACARG, 2000). Research also suggests that family therapy is a cost-effective approach to managing mental health problems, as engaging in family therapy is associated with reduced health care visits post-treatment and also does not appear to raise the cost of

healthcare while in treatment (Crane, 2008). Other studies have explored family therapy as a treatment for depressive disorders.

The effectiveness of family therapy as a treatment modality for mood disorders, and specifically depression, has been explored. Family-based interpersonal psychotherapy for pre-adolescents (seven to 12 years old) was found to lower depressive symptoms post-treatment (Dietz et al., 2015). Yet, most of the tested treatments for depressive disorders do not address family factors or involve family members (Restifo & Bögels, 2009). Family therapy is an important treatment route to consider because some adolescents do not respond to medication (Goodyer et al., 2007) and others choose to not take medication, possibly due to concerns about potential side effects. In the treatment of a depressive disorder, family therapy seeks to increase the support the adolescent experiences within their families (Carr, 2009), which may often be lacking for the adolescent who experiences depressive symptoms (Shortt & Spence, 2006). Curry and colleagues (2003) assessed the effectiveness of a Cognitive-Behavioral Treatment (CBT) for depressed adolescents who also abused substances in a sample of adolescents and their parents. In this small sample, the participants were mostly White and middle class. The intervention included both a group therapy and a family therapy component. This multi-modal treatment, that required family involvement in care, was found to be associated with short-term improvements in target symptoms. This finding substantiates the importance of family involvement in treatment in managing depressive disorders in adolescents. Exploring the state of research that addresses family characteristics in the treatment of youth depression, Restifo and Bögels (2009) suggest more research is needed to explore effective treatments that address family-level contexts and include

family members within the treatment modality. To effectively address family process in treatment, parent involvement is necessary and less is known about parents' perceptions of their child's mental health issues, how decisions to be involved in treatment are made, and how involvement with mental health care shapes parent-child relationships.

The Ecological Risk and Resilience Framework

The Ecological Risk and Resilience Framework builds upon Bronfenbrenner's ecological theory while taking into consideration how risk and protective processes shape resilience outcomes in individuals and families. The Ecological Risk and Resilience Framework offers a balanced view of the systems that shape developmental outcomes by examining both risks and strengths (Corcoran & Nichols-Casebolt, 2004). Ecological theory considers both the individual and the context, or a "person-in-environment" perspective (Fraser, 1997). Considering risk and resilience through an ecological perspective allows for an exploration of individual and family processes and the contexts that promote and repress healthy outcomes.

It is appropriate to use the Ecological Risk and Resilience Framework in this study because this framework allows us to better understand family process. Process is understood as "a course of action, functions, operations, and methods of working" (Mancini & Roberto, 2009, p. 573). Family process is the nature and quality of family relationships and dynamics (Salem, Zimmerman, & Notaro, 1998). Exploring family process enables a theoretical focus on the diversity of responses families have to certain challenges (Demo et al., 2005). Families shape the experiences of individuals. Family process is relevant here because this study explores how parents shape adolescent mental health care. This study seeks to gain insight into the actions or changes parents undertake

once learning of their child's depressive disorder diagnosis. More specifically, this research examines the process through which families experience adaptation.

Adaptation is a behavior that alters the state of a system, environment, or both, which is necessary for the progress of a living system (Bubolz & Sontag, 1993). Adaptation requires families to “detect information, select from a range of possible alternative responses, and effect a response” (Bubolz & Sontag, 1993, p. 433). This study explores the process through which parents or caregivers detect information about diagnosing and treating a depressive disorder. How parents or caregivers make decisions, or “select,” from the available treatment options as well as how they select to be involved in the treatment is explored. How the parent or caregiver sees their relationship with their teen to have adapted once learning of the diagnosis is also examined. The responses parents' effect when finding out their teen has a depressive disorder is researched in this unique sample of parents and caregivers who were able to utilize resources to obtain a mental health diagnosis for their teens.

The family processes of decision making, management, perception, organization and communication help explain how adaptation unfolds (Bubolz & Sontag, 1993). Parents' perceptions and understanding of adolescent depression and mental health treatment are underexplored family processes. The experiences and dynamics that encourage and discourage parental involvement in adolescent mental health care, and how these relate to decision making is a component of this research. Parental involvement in treatment may be comprised of organization and management processes. Communication about the implications of the diagnosis with the adolescent and others, as

well as communication with mental health providers and between the parent and child, is explored in the study.

Researching family process suggests that psychological and interpersonal experiences are considered (Arditti, 2012); in this study, this includes the experiences of the parent as well as the adolescent (through the parent's perspective). The framework facilitates a discussion on how parents and caregivers encourage resilience in adolescents struggling with mental health disorder as well as how resilience may manifest at the family level. A systemic approach to understanding the family processes in the development of youth depression was explored by Restifo and Bögels (2009). The researchers explain that using a systemic model allows for the examination of a variety of contexts, such as within the individual, family, school, and community. Consideration of these different system levels encourages a deeper understanding of youth depression that facilitates clinical application. Individual parental characteristics and individual child characteristics that may shape depression in youth include personality/temperament differences and cognitive styles. The parent-child subsystem characteristics that may shape youth depression includes attachment, conflict and support, autonomy and relatedness, and expressed emotion. Beyond the family, the extra-familial subsystem may be subject to stress and poverty. Culture or ethnicity also may shape the trajectory and treatment of youth depression. Finally, family processes may also contribute to the meaning parents attribute to their child's depressive disorder and the process of involvement in the child's treatment that parents embrace.

Ecological Theory

Ecological theory explains development as unfolding within the context of complex systemic relationships of an individual's environment (Bronfenbrenner, 1979). Development is contextually bound, and parents and caregivers can modify these contexts in both positive and negative ways. Parents and caregivers socialize children by incorporating cultural knowledge about adult tasks and conveying strategies for gaining competence (Ogbu, 1981). Ecological theory has been used to explore the adaptive strategies and child outcomes of ethnic minority families, who are thought to face unique challenges because of their minority status (Harrison, Wilson, Pine, Chan & Buriel, 1990).

Bronfenbrenner's **Process-Person-Context-Time** (PPCT) model allows for an exploration into the proximal processes, the personal characteristics, broader contexts that may shape development, and lastly, the role of micro, meso, and macro-time (Tudge et al., 2009). Proximal **Process**, according to Bronfenbrenner and Morris (1998) are interactions within the immediate environment that are enduring. Tudge and colleagues (2009) further explain that it is through these proximal processes that "individuals come to make sense of their world and understand their place in it" (p. 200). A developmental perspective considers how proximal processes contribute to disordered outcomes in children (Cicchetti & Toth, 1992). The current study explores the proximal processes of parent-child interactions, from the parent's perspective. Here, the parent's or caregiver's perception of her/his relationship with the teen before and after the diagnosis is considered, as well as how parents and caregivers perceive themselves to have changed as a result of incorporating the diagnosis into their relationship with the adolescent. These

topics are explorable because of the participants' prior experience with and exposure to mental health treatment. This component of the theoretical framework also enables an investigation into how parents and caregivers make sense of their adolescent's mental health diagnosis and the ways in which parents and caregivers adjust themselves to meet the perceived needs of their struggling teen.

The **Person** component of the PPCT model explains the relevance of individual level characteristics. These include biological and genetic aspects, as well as personal social characteristics (Bronfenbrenner & Morris, 1998). Social characteristics can be conceptualized as *demand*, *resource*, and *force characteristics* (Tudge et al., 2009). Examples of *demand characteristics* include age, gender, and ethnicity; these characteristics may influence the expectations and interactions one has with another person (Tudge et al., 2009). Within the current study, how race/ethnicity shapes parents' experiences with an adolescent's mental health diagnosis and treatment is explored.

Resource characteristics are not immediately apparent from an outsider's perspective; these characteristics can be thought of as mental or emotional resources (Tudge et al., 2009). Included here are past experiences, skills, intellect, and access to social and material resources (Tudge et al., 2009). In relation to the current study, parents' past experiences with mental health care could shape how they respond to their adolescent's diagnosis. Parents' knowledge about the mental health care system and depressive disorders could play a role in parental involvement in treatment. Lastly, parents access to treatment options and information about adolescent depression could also shape how parents make decisions to begin and then be involved in their teen's mental health treatment.

Lastly, *force characteristics* are an individual's temperament, motivation, and persistence, and how this may vary across persons (Tudge et al., 2009). The treatment trajectory for a teen's depressive disorder may vary based on the force characteristics of the parent/caregiver, who is the gatekeeper to treatment. The current study explores what motivates parents and caregivers to seek a diagnosis and treatment for their adolescent and how this might be different across families. Determining the ways parents display their persistence in obtaining their children treatment and how parents can be resolute in the face of barriers against treatment is examined.

At the **Context** level of the PPCT model, the environment is composed of four levels, or systems, that interact to shape the functioning of an individual (Bronfenbrenner, 1986). Two proximal systems are the microsystem and the mesosystem and two distal systems are the exosystem and the macrosystem (Bronfenbrenner, 1986; Powers, 2010). The systems of ecological theory can be applied to further an understanding of how a mental health diagnosis may shape the parent-child relationship and the different processes of parental and caregiver involvement in treatment. The microsystem, or a person's immediate setting and interpersonal relationships (Bronfenbrenner, 1977; Bronfenbrenner, 1986), includes the interpersonal relationship between the adolescent and the parent. Parents may adjust their processes of involvement with their teen upon learning about the presence of a depressive disorder. For example, if a parent is not able to fully understand the diagnosis and therefore becomes less willing to be involved in treatment, this may result in increased psychosocial stress for the parent (fueled by a frustration over lack of symptom alleviation) and adverse health outcomes for the adolescent (whose treatment may be delayed or less effective). The mesosystem level is

the interaction between two microsystems, or the major settings that contain the developing person (Bronfenbrenner, 1977). The parents' relationships with other family members may shape the treatment of an adolescent's mental health disorder. For example, two parents within the same family may have different perspectives on the cause of the disorder, and therefore may approach treatment differently. Additionally, information exchanged between parents and mental health care providers could shape parents' involvement in care at the mesosystem level.

Of the distal environmental systems, the exosystem level consists of environmental situations one does not have control over but which affect the person (Bronfenbrenner, 1977). The interaction between the exosystem and families is a context to consider. Engaging in treatment options when there are only certain mental health services offered in a particular area could be one such context. Perhaps parents feel less inclined to be involved in treatment because only individual services to the adolescent are available and opportunities for parental involvement are scarcely provided within the available services. Cultures and subcultures make up the macrosystem (Bronfenbrenner, 1977) and this may shape the parent-child relationship (when the adolescent has a mental health disorder) in that cultures have varied perspectives on the causes of mental illness and where "blame" can and should be placed. Cultures may share belief systems about mental health diagnoses and treatment. For instance, the culture of a certain neighborhood might be to distrust school personnel and thus any suggestions for mental health care for children are dismissed because the parents do not see recommendations from school personnel as valid and in their child's best interest. Or, cultures organized

along racial/ethnic boundaries may also differentiate groups' perspectives of the mental health system.

The last component of the PPCT model is **Time**. Micro-time, meso-time, and macro-time constitute this element of the model. Micro-time is “what occurs during a specific activity, [and] meso-time [is] the extent to which activities and interactions occur with some consistency” (Tudge et al., 2009, p. 201). Macro-time is synonymous with the chronosystem, which draws on patterns in history and of time that affect people's lives (Bronfenbrenner, 1986). The element of time is the most challenging to explore within the current study. Meeting with parents and caregivers for interviews only once limits the conclusions that can be drawn from time at these various levels. Still, some components of time are explored. Parents are asked to look back into the past and recall their own behaviors and perspectives. They are also asked to report on what their current relationship with their teen is like. This information may give some insight into the elements of micro- and meso-time, by exploring what occurred between the parent and adolescent when diagnosis and treatment options were sought. Additionally, the consistency of parents' activities and interactions may become apparent in the study. Furthermore, at the macro-time level, the economic situation of the U.S. over the past several years, with high unemployment rates, is one such context that could contribute to a family's perspective of mental health as not being a priority. Especially in low-income families where financial stability is a continual struggle and job security may be hard to come by, such chronosystem level contexts may trickle down to the family level and could make mental health unimportant or less likely to be addressed.

Risk and Resilience

The study of risk and resilience spans clinical, developmental, and family science theory and centralizes on comprehending how youth effectively adapt to their environment. The question of what makes some children more likely to be successful compared to others has dominated the literature on this topic. Masten and Coatsworth (1998) suggest that resilience and competence are inherently related, with resilience referring to the “manifestation of competence in the context of significant challenges to adaptation or development” (p. 206). Rutter (1987) offers a similar perspective of resilience, as “individual variations in response to risk” (p. 317).

According to Masten and Coatsworth (1998), attempts to change children’s and teens’ competence must be multifaceted, taking place at various levels that include influencing children’s capabilities, their contexts, and seeking a “good fit” between a child and her/his context. Competence, as part of resilience, strongly relates to children meeting developmental tasks. For example, Masten and Coatsworth (1998) propose that for adolescents to effectively display competence, and therefore resilience, they must transition to high school successfully, experience academic achievement, engage with extracurricular activities, develop close friendships, and form a coherent sense of self. Vulnerabilities also change with age, as adolescents are more likely to be susceptible to experiences of loss related to friends, school, and their own future (Masten & Coatsworth, 1998).

The characteristics of resilient children and adolescents are also multifaceted, including individual, family, and extrafamilial contexts, all of which may contribute to a child or teen being able to adapt effectively to hardship or risk. Relevant to this research

are the family-level characteristics of resilient children and adolescents, which includes close, warm relationships with caring, prosocial parent figures and connections to supportive family networks (Masten & Coatsworth, 1998). Therefore, risk and protective processes alter development over time and parents and caregivers have the ability to shape the arch of developmental outcomes for children. The presence or absence of attributes in parents and caregivers can alter a child's development over time. Indeed, even if a child had a previous experience of poorly adapting, her/his "level of functioning can change at any time during the life course" (Cicchetti & Toth, 1992, p. 491), particularly during transitions such as adolescence. For example, if a child's own biological parents are unable to care for him or her and they find they are with a compassionate and capable caregiver, this caregiver may embody a collection of protective processes for that child. Without this caregiver, the possible risks the child faces may not be addressed and therefore, the outcome for the child would change.

There are varied developmental pathways that may lead to a depressive disorder diagnosis. The concepts of equifinality and multifinality help explain the similarities and differences in these pathways for teenagers (Cicchetti & Rogosch, 1996). Equifinality occurs when teens are exposed to different circumstances, or different beginnings, that lead to a common diagnosis, or a similar outcome (Parritz & Troy, 2011). Considering the concept of equifinality in the present sample, diversity in the teens' experiences, as reported by the parent or caregiver, could include exposure to different family structures or varied experiences of success in school. Despite experiencing different circumstances, all adolescents in this sample share the common outcome of being diagnosed with a depressive disorder. The concept of multifinality explains how teens initially exposed to

similar circumstances end up experiencing different outcomes (Cicchetti & Rogosch, 1996). Multifinality may be relevant in the current sample if, for example, the participants all report their teens endure a comparable condition, such as exposure to maternal psychopathology, but the outcomes for the teens were quite different. Exploring multifinality and equifinality as concepts related to risk and resilience brings enhanced understanding to the “individual, familial, and social variables that influence children’s developmental pathways both toward and away from disorder” (Parritz & Troy, 2011, p. 30). Therefore, it is relevant to explore how the perceptions and characteristics of parents and caregivers, as familial variables, contribute to a teen obtaining a mental health diagnosis.

A risk and resilience perspective presupposes that protective processes will buffer the experience of risk processes, thereby encouraging resilience (Powers, 2010). This idea is at the core of Rutter’s (1987) explanation that protective processes do not equate to evading risk, but rather successfully coping and engaging with risk. Risk “involves exposure to experiences or conditions that raise the probability of negative outcomes for individuals, dyads, or groups” (Demo et al., 2005, p. 121). Resilience is the ability to rebound from hardship and difficulty and to become stronger after dealing with adversity (Walsh, 2006). Resilience is dynamic; an individual’s resilience changes across time and circumstances (Margolin, Oliver, & Medina, 2001). Protective processes include individual and environmental characteristics (Margolin et al., 2001) which help individuals resist or ameliorate risk (Fraser, 1997). Finally, a risk is a psychosocial or biological circumstance that increases the chances of a negative developmental outcome (Margolin et al., 2001). This perspective hypothesizes that one’s reaction to a stressor

exemplifies an interaction between the nature of the stressors as well as the person's individualized capacity to respond (Margolin et al., 2001). Some risk and protective processes may exist on the family level, therefore also sharing the designation of a family process.

In the current study, protective and risk processes may shape the development of a supportive, healthy parent-child relationship post-diagnosis as well as parental involvement in mental health care. Since "protection stems from adaptive changes that follow successful coping," (Rutter, 1987, p. 381) protective processes here are thought to be the processes that enable parents, and thereby teens, to effectively adapt to and cope with learning about the teen's depressive disorder diagnosis. Potential protective processes (at the individual and family level) may be self-efficacy experienced by the parent and the adolescent (Kirby & Fraser, 1997) and a strong relationship between the parent and adolescent (Jenson & Fraser, 2006; Kirby & Fraser, 1997). Potential risk processes (also at the individual and family level) may be parental psychopathology (Kirby & Fraser, 1997) and weak economic opportunities within a community (Jenson & Fraser, 2006). Other family processes at play may include family protection strategies, parental resource-seeking behaviors, or parental advocacy efforts (Burton & Jarrett, 2009). Such family processes have been explored in research examining the relationship between urban neighborhoods, child development, and the role of the family (Burton & Jarrett, 2009).

A parent's perception of their ability to make decisions about and manage their child's diagnosis and treatment may be a part of the family's risk or protective processes. The parents and caregivers in this sample already demonstrate a unique group who has

engaged in the protective process of seeking mental health care. The way the caregiver responds to the stressor of learning her/his child has a mental health disorder can be conceptualized as an interaction between the parent's assessment of what it means to have a child with a mental health diagnosis, combined with the parent's own ability to react and take action effectively to begin treating the disorder. A parent's assessment of what it means to have a child with a mental health disorder may vary greatly, from finding the news devastating and overwhelming to dismissing the information as unimportant and trivial. The parent's own capacity to respond and adapt may also vary greatly, from being proactive from the onset to lagging in deciding upon a course of action. Furthermore, the parent's or caregiver's ability to take action may be complicated by characteristics such as the parent's poor mental or physical health, lack of financial resources, or the teen's resistance to care. These various contexts of risk and resilience may further shape a parent's experience of seeking and obtaining treatment for their adolescent struggling with depression.

Family Resilience

Often resilience is thought of as an individual level characteristic or outcome. The idea here may be that a combination of risk and protective factors produces resilience in some children and in others, a lack of resilience. Quantitatively, resilience may be equated with finite endpoints or events. In contrast to this perspective, it is argued that resilience should be conceptualized as an ongoing process. Resilience has been defined as "a dynamic process wherein individuals display a positive adaptation despite experiences of significant adversity" (Luthar & Cicchetti, 2000, p. 858). This research explores families "being resilient" – or the actions, occurrences, and processes through which

families may end up reaching some type of finite, quantitative endpoint. Since the focus is on families, or parent-child relationships, the concept of family resilience is worth considering.

Walsh (2006) offers a perspective of resilience on the family level. Here, family resilience is thought of as the “key interactional processes that enable families to withstand and rebound from disruptive life challenges” (Walsh, 2006, p. 3). The family is thought of as a functional unit, where family processes are thought to contribute to overcoming distress and prevailing through crisis. Such processes include the family’s belief system, their organizational patterns, and their communication processes (Walsh, 2006). Thinking of resilience at the family level, Walsh (2006) explains “How a family confronts and manages a disruptive experience, buffers stress, effectively reorganizes, and moves forward with life will influence immediate and long term adaptation for every family member *and* for the very survival and well-being of the family unit” (p. 15). Considering family resilience in the context of this study can further an understanding of how a family, working together with interconnected processes, shapes adolescents’ mental health treatment.

Parents receiving a mental health diagnosis of their adolescent child can be considered a disruptive event. Family resilience comes into play in the ways, as a unit, the family responds to the diagnosis and the subsequent actions taken. For the purposes of this research, “family” specifically focuses on the parent-child relationship, while still allowing flexibility to consider the role of other family members in treatment. An adolescent’s mental health diagnosis may require adaptation on the part of all family members, and their ability to adjust could be an indicator of the family’s resilience

capabilities. Then, as Walsh (2006) suggests, the ability of the family to adapt to the stressor of the adolescent's diagnosis will have implications for the family's well-being as a whole.

Summary

Utilizing the Ecological Risk and Resilience Framework in this study allowed for an exploration of the process of parental involvement in the mental health care of adolescent depressive disorders. The current study examined the risk and protective processes within the PPCT model of ecological theory in a sample of parents and caregivers already engaged with the mental health care system. Proximal processes and personal, individual level characteristics were examined. The proximal processes of the parent's perceptions of the parent-child relationship, changes to this relationship, and how parents made sense of and adjust to finding out their child's depression diagnosis were examined. Demand and resource characteristics were examined through questions asking parents to report on how their experiences were shaped by their race/ethnicity as well as parents' past experiences with mental health care. Force characteristics were determined through assessing parents' levels of persistence and their motivation for obtaining their child mental health care.

The element of Context was investigated by considering the four systems outlined by Bronfenbrenner. At the microsystem level, for example, parents were asked how the adolescent's diagnosis shaped the parent-child relationship and the contexts that increased family involvement in treatment were examined. Mesosystem level processes revealed how parents were involved in the diagnosis and treatment of the adolescent's depressive disorder diagnosis. At the exosystem level, processes beyond the family

relationship that increased family involvement in treatment or were a barrier to engagement in treatment were explored as well as how parents' income and insurance status and race/ethnicity shaped the treatment the adolescent receives and the parent's or caregiver's involvement in the adolescent's mental health care. Barriers to treatment at the macrosystem level were examined. Comments about the element of Time within the PPCT model were limited, given the nature of data collection. The description and consistency of parent-child interactions was explored. Finally, utilizing the risk and resilience perspective enabled an examination of risk processes and protective processes – which occurred at the individual level for the parent or child, as well as at the family level (and therefore can be considered family processes). The patterns through which risk and protective processes and family resilience converge were explored.

Definition of Terms

Adolescence: A period of development marked by significant cognitive, social/emotional, and physical changes, which coincides with the onset of puberty (DeHart, Sroufe, & Cooper, 2004); the period of development that occurs after childhood and before adulthood, from ages 10-19 (WHO, 2013).

Caregivers: For the purpose of this study, caregivers are the dominant persons fulfilling the parental role towards the adolescents discussed; this includes biological parents, biological grandparents, adoptive parents, foster parents, and other kin functioning in the parent role.

Depressive disorders: Includes the diagnoses of major depressive disorder, dysthymia, or depressive disorder not otherwise specified.

Low-income: For the purpose of this study, low-income is defined as families who are eligible for Medicaid.

Mental health care/Mental health treatment: Family's involvement and interactions with mental health agencies or organizations which provide therapy services and/or psychiatric medication.

Mental health disorder: A diagnosable condition characterized by changes in thinking, mood, or behavior (or some combination of these) that can cause a person to feel stressed out and impair his or her ability to function (Murphey, Barry, & Vaughn, 2013).

Parents: For the purpose of this study, the terms parents and caregivers will be used interchangeably, unless it is necessary to refer to a specific care giving group. In such a case, the subset will clearly be designated, by for example stating "biological parents."

Racial/ethnic minority: For the purpose of this study, racial/ethnic minority focuses on individuals who identify as Black or African American.

Research Questions

The literature summarized above concerning adolescent depressive disorders and patterns of parental involvement in diagnosis and treatment contains several gaps. First, there is limited qualitative research on these topics. A qualitative approach enables a fuller understanding of parents' perspectives of their adolescent's mental health that paper assessments or surveys may not capture. Second, the existing literature does not offer a full exploration of parents' perceptions of incorporating the context of an adolescent depressive disorder diagnosis into a family's functioning and the family process of adaptation within this context. Third, there has been a lack of effort focused on exploring how parents and caregivers make decisions about their own involvement in

their adolescent's treatment. Lastly, extant literature suggests, but under-addresses, the health disparities in diagnosis and treatment based on income, insurance status, and race/ethnicity. These gaps in literature are explored in the following study through the research questions.

1. How are parents involved in the diagnosis process of their adolescents' mental health issue?
2. How do parents respond to their adolescents' mental health diagnosis? How do parents perceive their relationship with their adolescent to change post-diagnosis?
3. How do parents make decisions about their involvement in their adolescent's mental health care? What encourages increased parental involvement in treatment? What barriers inhibit parental involvement in treatment?
4. How do the characteristics of families shape the diagnosis and treatment process? In what ways does insurance usage shape parents' experiences with their adolescent's mental health diagnosis and treatment? In what ways does race/ethnicity shape parents experiences with their adolescent's mental health diagnosis and treatment?

Chapter 3: Methods

Approach

A qualitative approach was used to investigate parents' perceptions of their adolescent child's mental health struggles, how the adolescent's diagnoses shapes parent-child relationships, and how parents are involved in their adolescent's mental health care. Qualitative methods best enabled an exploration of the research questions, which focused on understanding the meaning parents attribute to an adolescent's mental health diagnosis and the process of parental involvement in and adaptation to adolescent mental health treatment. Additionally, qualitative methods facilitated an exploration of questions about how parents make sense of their child's mental health diagnosis and how a diagnosis can shape family relationships.

Qualitative methods were well-suited for this research since this approach explores how individuals interpret, understand, and experience their social world (Mason, 2002). Specifically, this research explored how parents interpret, understand, and experience a mental health diagnosis of their child and how this shapes the parent-child relationships and service utilization. The unique characteristics of the family were taken into consideration in this study; particularly, families' race/ethnicity, income, and insurance status were explored to determine if and how these contexts shape parental perceptions and involvement in adolescent mental health care. From here, these methods enabled the construction of a theory and the generation of questions about this subject matter (Sofaer, 1999). Qualitative research methods employ both sensitivity and flexibility that allow for context to be explored (Mason, 2002). Parent-child relationships and knowledge of and access to treatment options are some of the contexts explored.

My epistemological stance in this study falls in line with the social constructionism or interpretivism paradigm, where the focus is less on deciphering actual events that occurred and is more concerned with how individuals made sense of the events (Daly, 2007). My perspective is that all reality is constructed, first by the individual which is then exchanged with others to create shared meaning (Daly, 2007). In this study, I sought to explore individual parent's experiences and meanings, and then looked across cases to formulate a theory about the potential shared meaning parents may hold regarding the concepts explored in this research. Within this paradigm, I also followed the belief that meaning is constructed through social interaction (Daly, 2007). I acknowledge that I, as the researcher, was an active part of the process, which led to a co-construction of meaning between myself and the participants. Furthermore, the theories and meanings generated from this research are but one of many interpretive understandings of these concepts.

Analysis of these data followed a grounded theory approach. This method allowed for the construction of a substantive theory that was specific to my area of inquiry, which took into consideration the multiple realities of the participants and myself. The findings from this study propose a way for those external to the concepts explored here to comprehend these concepts as they are rooted in and substantiated by data (Daly, 2007). Further aligning with my epistemological stance as a social constructionist, I specifically used a constructivist grounded theory analysis approach, where I acknowledged my role in generating meaning and theory of the concepts of interest in this study.

Design

Investigator Perception and Experience

My position as a therapist both in a clinic in College Park, Maryland and at an agency in Washington, D.C. allowed me to intimately work with families of diverse incomes and racial/ethnic backgrounds. My exposure to the needs of these families contributed to my research interests in child and adolescent mental health and family involvement in treatment. Traveling to families' houses to carry out therapy sessions, I became closely involved in the families' lives and comfortable in their homes. I observed family interactions in their home environment. When working one-on-one with adolescents, I questioned if and how their parents wanted to be involved in the therapy process. When I worked with the family as a whole, I wondered about the parents' willingness to consider changing their own behaviors for the betterment of their child. I observed the confusion parents had with multiple mental health professionals coming in and out of their lives and the resistance from adolescents when I was the 'replacement therapist' for someone who had previously worked with the teen. I observed parents' uncertainty over the multiple diagnoses their teen received and also the advocacy behaviors the parents engaged in as they fought for their child to get the help deemed necessary. I observed what I perceived to be flaws in the mental health care system for low-income families and wondered what could be done to improve it. I was curious if the parents perceived these to be flaws as well and how the parents were making sense of the information about their teen's depressive disorder. My work in the field for four years contributed to these observations and experiences, which inspired this project.

Participants

The participants recruited for this study reflect a unique group of parents and caregivers already engaged with the mental health care system. Participants interviewed had prior experience with mental health care and had already, to varying degrees, received some form of mental health treatment for their teenager. This sample is not reflective of a random sample of parents and caregivers, rather, participants were recruited for this study through purposive sampling. Parents and other caregivers were selected to participate because their characteristics were relevant to the study's research questions (Mason, 2002) and their experiences helped the theoretical development of the study's findings. The goal of purposive sampling is to identify people who enable the researcher to explore the phenomenon of interest without concern about representativeness (Daly, 2007). Furthermore, to be interviewed for the study, participants had to be connected to an insurance provider, namely Medicaid. This connection in itself makes this group distinct; these participants had the knowledge and ability needed to connect their family or child with an insurance provider. Participants were also receptive to the mental health care suggested to them, demonstrating this subset of parents as quite open and amenable to introducing mental health services into their family's routine.

Thirty-three interviews were completed for this research. Data saturation typically occurs when 20 to 25 interviews are completed (Daly, 2007). Saturation is the point during the data collection process when no novel information is acquired (Morse, 1995). Reaching saturation has little to do with the quantity of data collected; it is more significantly related to the quality, or richness, of the details provided in the data (Morse,

1995). As anticipated, saturation of data directly related to the research questions occurred around the 23rd interview. At this point, parents' answers to key interview protocol questions were consistently repetitive and seemed isolated around common themes. Additional interviews were collected to ensure further saturation and to explore themes around other topics ancillary to the main research questions. The additional interviews allowed me to focus on specific questions related to these supplementary themes, to increase the data addressing these themes and my own understanding of parents' experiences related to these themes.

Participants were included in this study if they were the primary caregiver of a youth who was diagnosed and/or treated for a depressive disorder (major depressive disorder, dysthymia, or depressive disorder NOS) during adolescence. Additionally, participants were receiving Medicaid during the time period the adolescent was diagnosed and/or treated for the disorder.

The demographic characteristics of this sample are summarized in Table 4 below and detailed information about the parents and adolescents can be found in Appendix A. All but two participants identified as African American/Black. Of the remaining two, one was White and the other was Caribbean. Two participants were male and 31 were female. Eighteen were the biological mothers of the adolescent discussed in the interview. Four participants were grandmothers who had custody of the teen for a substantial part of the adolescent's life. Other participants (n=11) were the aunts, foster parents, adoptive parents, or step-parents to the teenager. In many cases, caregivers parented the teens because the biological parents struggled with their own serious mental health issues such as substance abuse. Interview participants ranged in age from 27 to 70 years old, with an

average age of 47 years old. In terms of marital status, most participants (n=18) were never married while eight reported currently being married. Three reported being divorced, two were widowed, and two were separated. All interviews were completed in English.

In terms of education level, the majority of participants (n=18) had a high school diploma or less. Most participants (n=17) were currently not working outside of the home. Several were employed part-time (n=7) or unemployed due to disability or retirement (n=4). Five participants reported being employed full-time when the interview took place.

Seven participants lived in Maryland and 26 lived in Washington, D.C. All participants reported that either they or their child were on Medicaid when the adolescent was struggling with a depressive disorder. Eligibility for Medicaid is dependent upon family size; based on the standards for a family of three in 2012, D.C.'s Medicaid income eligibility is at 206% of the federal poverty level (FPL) (Kaiser Family Foundation, 2012), or approximately \$37,000 a year. For a family of three in Maryland in 2012, it is 116% of the FPL (Kaiser Family Foundation, 2012), or about \$21,495 a year. The upper income limit for both Maryland Children's Health Program and for D.C.'s CHIP is 300% of the FPL, or \$51,510 for a family of three (Kaiser Family Foundation, 2012). Medicaid expansion through the Patient Protection and Affordable Care Act (ACA) changed the eligibility requirements as of January 1, 2015 to 221% of the FPL, or \$43,735, for a family of three in D.C. and 138% of the FPL, or \$27,310, for a family of three in Maryland (Kaiser Family Foundation, 2015).

The age range of children at the time of interview ranged from 10 to 27 years old, with the average age of 15 years old. Most children (n=29) were reported to be Black/African American by the interview participants. Of the remaining adolescents, one was “Mixed Races,” two were “Two or More Races,” and one was White. The age at which the child was diagnosed with a depressive disorder ranged from five to 17 years old, with an average age of about 11 years old. Most of the youth (n=23) had either physical or mental health co-occurring diagnoses – meaning they had other health issues or another mental health diagnosis in addition to a depressive disorder. The most common co-occurring diagnosis parents reported was ADHD. Other co-occurring mental health diagnoses included ODD and bipolar disorder. Other physical health diagnoses parents indicated were present were sickle cell disease and diabetes.

Table 4

Demographic Characteristics of the Sample

Characteristics of Parents/Caregivers	N	%
Sex		
Female	31	94
Male	2	6
Race/ethnicity		
Black/African American	31	94
White	1	3
Caribbean	1	3
Ages of parents/caregivers*		
20-29	2	6
30-39	6	9
40-49	10	30
50-59	9	27
60 +	3	9
Education		
Less than high school	7	21
Completed high school or GED	11	33
Some college or trade school	15	45
Employment status		
Employed full time	5	15
Employed part time	7	21

Not current working outside of the home	17	51
Not employed due to disability/retirement	4	12
Relationship status		
Never married	18	55
Married	8	24
Divorced	3	9
Separated	2	6
Widowed	2	6
Recruitment method/agency		
ABF Associates, Inc.	16	48
Family Service Agency of Washington, Inc.	6	18
Families Together, Inc.	2	6
Snowballing	5	15
Other/Recruited from nonprofit	4	12
Relation to the adolescent		
Biological parent	18	54
Biological grandparent	4	12
Extended family member	4	12
Step parent	2	6
Parent by adoption	2	6
Foster parent	3	9

Characteristics of Adolescents

Sex

Female	19	58
Male	14	42

Race/ethnicity

Black/African American	29	88
White	1	3
Two or more races/Mixed races	3	9

Age at time of interview

10-14	15	45
15-19	15	45
20+	3	9

Age at time of diagnosis*

5-10	12	36
11-15	18	54
16+	2	6

Length of time with caregiver

Since birth to current	3
1-5 years to current	3
6+ years to current	4
Between 6 months and 5 years, not currently in caregiver's care	2
Between 6 years and 12 years, not currently in caregiver's care	3

*Indicates not all respondents reported for this category

Recruitment

The names of all agencies and organizations where participants were recruited have been changed to further protect confidentiality. Recruiting participants for the study began by leveraging connections with ABF Associates, Inc., a mental health agency which serves Medicaid families in the D.C. metro area and provides individual and family psychotherapy as well as diagnostic assessments to children, adolescents, and adults. At the time data collection began, I was employed as a contract Individual and Family Therapist with ABF Associates, Inc. I attended a training they held where I made an announcement to the other contract therapists about the project and distributed the flyer found in Appendix B. This led to a connection with several therapists who were willing to share information about the study with their clients. I provided the clinicians with a script they could use when recruiting participants, which can be found in Appendix C. Four therapists connected me with a total of 16 participants.

In addition to ABF Associates, Inc., I solicited assistance from connections at Families Together, Inc., a mental health agency located in a suburb of Maryland. Families Together, Inc. provides a range of services (mental health, substance abuse, early childhood, community support, school-based, and domestic violence services) throughout several counties in Maryland. Families Together, Inc. has an outpatient mental health clinic that serves mostly Medicaid families. I received permission from the clinic director to recruit families to participate in the study. Since Families Together, Inc. is part of the Sheppard Pratt Health System, I sought and successfully received Institutional Review Board (IRB) approval from the Sheppard Pratt IRB. Once this approval was obtained, I attended a staff meeting and discussed the project with the clinic

staff to inquire if they were working with any families who might be eligible to participate. I provided the staff with handouts and flyers with information about the project. I then attended a second staff meeting of the school-based mental health providers through Families Together, Inc. Through these efforts, I acquired two participants, both of whom reached out to me after seeing the flyer advertising the study in the waiting room of the outpatient clinic.

Through a professional relationship with the Executive Director of Maryland's branch of a mental health education and advocacy nonprofit, I created a survey which included questions about participants' willingness to take part in a research study. Individuals who responded they were open to be interviewed and who seemed to meet the inclusion criteria for this study were contacted by the non-profit's staff and further screened for willingness to participate. Several names were passed along to me, but upon inquiry, no participants fully qualified to be interviewed. In July/August, the non-profit sent out an email to their listserv members advertising the study. Several participants responded but only one met the inclusion criteria. This participant was successfully interviewed.

Connecting through a social media website led me to form a relationship with the Director of Mental Health for the Family Service Agency of Washington, D.C, another mental health agency in the D.C. metro area. Similar to Families Together, Inc., the Family Service Agency of Washington, D.C., Inc. provides a range of services to families in the Washington, D.C. area, including mental health services. I was able to meet with the Director of Mental Health to discuss my project and inquire if any of the families served by the Family Service Agency of Washington, D.C. might be interested in

participating. One of the supervisors shared information about the study with her employees and was able to generate a list of six names, all of whom were successfully contacted and interviewed. I also attended a staff meeting at the Family Service Agency of Washington, D.C. to speak with the clinicians about the study and inquire if any families they were working with might be interested in being interviewed. I brought flyers to the meeting and answered questions from the clinicians. Unfortunately, this method did not generate any more interviews.

In addition to these methods, I was also able to recruit two participants who were past clients I had worked with at ABF Associates, Inc. I was one of several mental health professionals these participants interfaced with over several years. These families also sought services through a number of agencies and had interactions with hospitals and other institutions related to mental health care. The interviews occurred four and seven months after I ceased working with these clients as their therapist; both of the families had continued to seek some form of mental health care for the teens post my work with them. I reached out to the parents, having had their contact information from our prior relationship, and informed them about the study. Both agreed to participate and were successfully interviewed. I was also able to secure one more interview by reaching out to a colleague who worked for a core service agency in Washington, D.C. This colleague reviewed her caseload and informed clients about the study. She referred me one participant, who I interviewed.

Last, the technique of “snowballing” was used to further recruit participants into the study. Aligning with purposive sampling, snowballing is a method of recruiting other participants through an individual who meets the inclusion criteria for the study. Five

participants were recruited through snowballing. At the end of the interview, I asked participants if they knew of anyone who was in a similar situation to their own who might want to be interviewed. Several existing study participants recommended others. In accordance with the concept of snowballing, the recommendations were for individuals whom they knew within their own social or community circles and who had similar characteristics to them to be involved in the study (Small, 2009; Trotter, 2012). Participants then shared the contact information of their friends or family members with me. After I received confirmation that I should reach out to them, I called the person to pitch participating in the project. A benefit of this recruitment procedure was that participants were more likely to be involved in a study once a friend could share they had a positive experience with the researcher (Small, 2009).

I spoke with all participants on the phone prior to scheduling the interview. During this phone call, I briefly explained the interview process. I confirmed that the participant had parented a teenager diagnosed with a depressive disorder, and that a family member was insured by Medicaid at this time. I explained that the interview would take about an hour to an hour and a half, and the interview would explore what it is like to parent a teen with depression. I informed participants that they would receive \$25 cash and resources on depression in adolescents, found in Appendix D, for participating. If they consented, we explored times and dates they were available to meet as well as the most convenient location for the participant.

Data Collection

The in-depth interviews for this study followed a semi-structured format and asked questions about participants' understanding of and the meaning they attribute to the

youth's mental health diagnosis, how parents responded to the diagnosis, and how the diagnosis shaped parent-child relationship dynamics. Questions were used to prompt responses, while flexibility was granted to explore the unique experiences of the respondents as they unfolded (Daly, 2007). The interview guide for this study is found in Appendix E. The semi-structured nature of the interview guide served as a reminder of key topics to address when I was speaking with the parent. The guide consisted of both full questions and key phrases that were formulated into questions as became natural through the interview processes. This style of interviewing allowed for a conversation to unfold that revealed the participants' perspectives on the subject matter, which is the goal of qualitative research (Marshall & Rossman, 1995). Asking additional questions not outlined in the guide was, at times, also necessary to ensure the interviews fully explore the parents' experiences, and a clear understanding of the parents' narratives became apparent. All interviews were conducted by me, the investigator.

When pre-screening participants to be interviewed, I informed them that I was happy to meet them at a time and a place that was convenient for them. If they were willing, I went to their homes to do the interview, or I made arrangements for us to meet at a local library or community center, if they preferred. I was cognizant of the privacy of the space to ensure the participant would feel comfortable to fully and truthfully answer the interview questions. Most participants elected for me to go to their houses. We either sat at the kitchen table, on the couch in the living room area, or on three occasions, in their bedrooms. In addition to meeting at the families' homes, I met one participant at a local community center, two at the neighborhood libraries, one at a participant's place of employment, one at a mall, and one at a McDonald's. In all of these settings, I strove to

encourage the comfort of the participant and asked if they were okay proceeding with the interview, given the surroundings. No one objected to participating in the interview once we were in one another's company.

Upon meeting the participant at the established location, I waited for her/him to instruct me where to sit. I engaged in casual conversation about how their day was and also thanked them for taking the time to meet with me. Then, I took out my materials and told them I had a form for us to look at. I used this opportunity to explain the Informed Consent, found in Appendices F and G. I verbally reviewed the procedure, confidentiality, risk, benefits, and freedom to withdraw from the study. I addressed any questions the participants had about the Informed Consent and then, after the Informed Consent was signed, I turned on the audio recorder and began the interview.

At the end of each interview, the demographic questionnaire, found in Appendix H, was completed by reading the questions to participants and marking their responses. I elected to read the questions to the participants instead of handing them the form, to continue to encourage conversation and the comfort of the participant. Several of the questions I believed could be answered through what emerged in the interview, so I was able to ask the question directly to confirm what I had recalled the participant stating. Also, by reading the questionnaire, I believe the process was quicker and did not ostracize anyone who may have had trouble comprehending the wording of questions.

The interviews were digitally recorded using an Olympus Digital Voice Recorder VN-702PC. The audio files were between 40 to 115 minutes long. The average length of an interview was one hour and 15 minutes. A total of about 42 hours of audio data were recorded for this project. After the interview was complete, the audio recorder was turned

off and the demographic questionnaire was completed. Next, I gave participants the resources on childhood and adolescent depression as well as \$25 cash. When time permitted, I asked participants if they knew anyone else who might want to participate in the interview and shared a copy of the recruitment flyer with them. After every interview, I thanked the participants for their time and informed them that the information they provided would be very helpful to the project.

After each interview, the audio files were uploaded to a password-protected computer. The demographic information was typed up into an electronic file. Pseudonyms for the participants were assigned and noted in secure documents. When relevant, a brief summary of the interview and key points addressed were noted on an electronic file. Next, all interviews were transcribed verbatim.

Interviews were transcribed by me and by trained research assistants. A total of 630 pages of interview data were generated from this research; the average length of a transcribed interview was 19 single-spaced pages. Seven undergraduate research assistants helped with the transcription process. Three students volunteered to transcribe the interviews and four students completed the transcriptions for Independent Study credits. All students completed an online training through the Collaborative Institutional Training Initiative (CITI Program, 2012) in social and behavioral research before beginning transcription. Additionally, I trained the undergraduate research assistants in person prior to beginning work on the project. We discussed the nature of the research, my expectations of them as a volunteer or an independent study student, and the goals for their work on the project. Students who volunteered were required to sign an agreement committing to a certain number of hours per week or committing to completing a certain

number of transcriptions. Independent study students agreed to work a designated number of hours per week on the project. Regular meetings, both in person and over the phone, were held with research assistants. Meetings addressed any questions they had about the material being transcribed, any reactions or thoughts they had about the material, and any themes they noticed while working on the project. All transcriptions were ultimately reviewed by me for accuracy.

Memos

In addition to the interview transcriptions, I also produced more than 30 theoretical and methodological memos related to the study. Memo-writing is an important step in qualitative research that enables the researcher to begin making connections and to theorize about the potential findings of the study (Charmaz, 2006). Memos were either recorded and transcribed or written. Memos written by hand were typed electronically and saved on a password-protected computer. Memo writing took place throughout the data collection and analysis process.

My theoretical memos explored what I thought I was observing in the interviews. During each interview, I took notes of names, places, and terms I thought were relevant. After the interviews, I typed up a brief summary of these key points in a document that was shared with the undergraduate research assistants. I also wrote and recorded memos after conversations with the research assistants, my advisor, and my peers. I asked the research assistants to tell me what stood out to them about the interviews and when they had transcribed a number of them, what themes they remembered hearing. After such conversations, I wrote up the key points and considered them when formulating the codebook. When I discussed the project with my advisor and with my research and

clinical peers, I wrote memos about the highlights of these conversations, which also informed the formation of the codebook.

Methodological memos were made to note any changes made to the interview protocol or the analysis approach. I noted in these memos when questions were phrased differently from interview to interview. The protocol was slightly revised during the first few weeks of data collection. The revisions focused on rewording questions so they were more conversational. All transcriptions and memos were then uploaded to Atlas.ti (2013).

Pilot Study

After the first two interviews were complete, I paused to consider if the interview protocol was generating the data I anticipated. I considered the interview questions, the memos written, and the transcriptions of the interviews to assess if I was receiving the depth and substance necessitated for this project. At the end of the first few interviews, I asked participants how they thought the interview went and if there were any questions they thought I would ask that I did not. All participants reported they thought the interview went well and there were no common themes of questions they thought I would ask or areas they anticipated us discussing. This assessment led to minor adjustments to the interview protocol to increase the conversational nature of the interview, as noted in the methodological memos.

Data Management

As previously mentioned, a digital voice recorder was used to record all interviews. The digital files were labeled with identification numbers instead of the participant's name. The files were stored on one password-protected computer and also

on an external hard drive, which served to backup the files. All transcriptions included the pseudonyms of the participants. Research assistants were instructed to share the final transcript, which included the pseudonyms, with me and then to delete any copy left on their computer. The signed consent forms were kept in a locked filing box. Any notes or memos written by hand were typed up in an electronic version and de-identified so they could be shared with the research assistants as appropriate. Original hand-written notes were kept in locked cabinets.

Data Analysis

Data analysis began alongside data collection. The analysis first took the form of writing theoretical and methodological memos. These memos allowed for initial ideas and hypotheses about the data to be uncovered (Charmaz, 2006). From these memos came the initial codes that began to form the codebook for this project. When more than half of the interviews were transcribed, formal analysis of these data began. A constructivist grounded theory approach was utilized to analyze these data, which included the technique of constant comparison, or a cross-case analysis where responses are grouped by category and then evaluated to assess for common themes (Dye, Schatz, Rosenberg, & Coleman, 2000). The triadic coding scheme of open, axial, and selective coding was followed (LaRossa, 2005).

Analysis began with open coding, where a line-by-line assessment of the text was completed and codes were applied to text which illustrated the concepts explored in the research (Daly, 2007). This phase of coding focused on applying concepts, or labels, to indicators (words, phrases, or sentences) within the interview transcripts (LaRossa, 2005). This type of 'line-by-line' assessment allowed for data to be divided into

manageable segments. Open coding with concepts was driven by answering the question “What is being talked *about*?” (LaRossa, 2005). Reading line-by-line often reveals a single word that prompts a concept. Identifying multiple indicators was necessary to ensure theoretical saturation of a concept (LaRossa, 2005). Open codes came from the review of literature and from memoing, where initial ideas about the data were explored. Once initial codes were generated, subsequent interviews were read and assessed to see if existing codes were applicable to that interview, or if new codes needed to be developed. When open coding was complete, the process of dimensionalization of categories occurred. Categories are groupings of concepts (LaRossa, 2005) and in dimensionalization, concepts were grouped together because they shared some characteristic, but were still distinguishable from one another (LaRossa, 2005). This process enabled codes to be collapsed together if they were similar in definition, while recognizing a range may still be present (Daly, 2007).

Once several interviews were read and open coded, the axial coding phase began. If the open coding phase was conceptualized as the development of variables, the axial coding phase could be understood as exploring the relationships between and among variables (LaRossa, 2005). Axial coding fleshed out the categories developed from grouping together codes. Categories that were relevant and prominent in the data became the focus of analysis. Categories were collapsed and theoretical saturation of each category was achieved (Daly, 2007). Cross-category analysis was also explored at this phase of coding, to determine how categories were interconnected (Daly, 2007). The list of codes and their definitions can be found in Appendix I.

Selective coding was the final stage of analysis, which involved theory development and assessing the relationship between categories of codes. Through this last phase, answers to the research questions became apparent through the stories of the participants. The objective of selective coding was to develop a theoretical story that describes how complex concepts and categories were interrelated (LaRossa, 2005). A central step in selective coding was to identify a core or central category that became the basis of theory generation (Daly, 2007). The core category was strengthened by its position central to other categories of the data. The core category had a firm grounding in the data, which could be seen by reviewing the indicators and concepts revealed in the data (Daly, 2007).

Ethical Treatment of Human Subjects

Participants in this study were protected in several ways. The initial approval from the university IRB was obtained on November 25, 2013 to ensure this research respected the rights of all interview subjects. A continuing review approval was granted on October 28, 2014 and can be found in Appendix J. Since a second IRB approval from one of the recruitment sites was required, initial approval from the Sheppard Pratt IRB was granted on February 19, 2014 and continued review was granted on January 9, 2015. The initial approval letter for this IRB can be found in Appendix K. Parents were asked to sign the IRB-approved informed consent, available in Appendices F and G, which outlined that they were not obligated to partake in the interview, they could withdraw at any time, and they did not have to answer all of the questions posed. Every effort was made to ensure the confidentiality of the information shared during interviews, and participants were made aware of this at the onset of the interviews. Confidentiality of the

information provided by participants was protected by assigning all participants and family members pseudonyms shortly after the interview was completed. Additionally, I also assigned pseudonyms for all agencies and organizations where participants were recruited. These pseudonyms were used in memos, in interview transcriptions, and in the final write-up of this study and will be used in any subsequent articles or presentations given using these data.

It was possible that participants experienced distress when discussing their child's mental health status. Effort was made to create a comfortable interview environment for all participants, and they were informed they could pause or end the interview at any point. Indeed, in four of the interviews, the audio recorder was paused to either allow the parent to take a private phone call or because the parent requested to take a break from the interview. Psychoeducational resources (handouts, brochures, and a resource list found in Appendix D) about adolescent depressive disorders were provided to all participants at the end of the interview. Parents appeared to appreciate these materials and most reported they anticipated reading them.

Data Quality

Replicability of findings is a common goal in research. Yet, it is important to recognize that this is not necessarily the case in qualitative studies because qualitative work recognizes the continuous changing nature of reality (Marshall & Rossman, 1995), which inhibits reproduction of findings from one time point to another. By memoing about data collection decisions and the rationale to support these choices, researchers are able to inspect my procedures and protocols if they are pursuing replicability (Marshall & Rossman, 1995). Additionally, all data for this study were organized in an easily

retrievable form so they are accessible to others who many want to reanalyze it (Marshall & Rossman, 1995).

Assessing the rigor of data utilized in this study followed Guba's (1981) and Lincoln and Guba's (1985) model of trustworthiness in qualitative research. This model evaluates data trustworthiness on four levels: truth value, applicability, consistency, and neutrality. These four aspects are relevant for both qualitative and quantitative data but are defined differently in the two divergent forms of research (Krefting, 1999). Within qualitative research, these four aspects are known as credibility, transferability, dependability, and confirmability.

Credibility

Credibility is gained by discovering the unique lived experiences of the participants. It is reflected in how well the researcher represents the participants' experiences. A qualitative study is deemed credible when individuals or families who share the same qualities as those involved in the study are able to recognize the descriptions and theory presented in the findings. To secure the credibility of this study's findings, several strategies were employed. Member checking is a credibility assessment technique that requires the researcher to obtain participants' feedback on the interpretations and conclusions drawn from the data (Lincoln & Guba, 1985). This technique ensures the researcher has appropriately translated the participants' viewpoints (Lincoln & Guba, 1985). Member checks took place while completing interviews with participants. Within the interview I said to participants "I've heard from other parents that..." or "Another parent shared..." I was then given the opportunity to see if the participant agreed or disagreed with the experiences of the prior parent as well as my

interpretation of that experience. I also followed up with participants who consented to be contacted post-interview to discuss the findings as part of the member checks.

Peer examination is another technique that enhanced the credibility of this research. Peer examination involves discussing the research findings with colleagues external to the study (Krefting, 1999). Peer examination was carried out by arranging consultations with colleagues who were not involved in the research but who were familiar with the concepts studied. I asked three peers within the Department of Family Science to read pre-selected interview transcript passages and consider the codes within the codebook. These peers were selected because they all have clinical training and have worked as therapists in a community-based setting. Additionally, these peers have doctoral-level training in qualitative research methods. Through peer examination, we discussed the applicability of the codes and explored any new suggestions they had on how to interpret the interview transcriptions.

The feedback obtained from these meetings was integrated into the study's findings. Utilizing this technique mirrors a type of collaborative ethnology that has been implemented in prior research and is seen as a method to increase the amount of data at one's disposal (Buford May & Pattillo-McCoy, 2000). The discussions explored the codes developed in the data, the existence of negative cases, and hypotheses aimed at explaining the study's findings (Krefting, 1999).

Transferability

Transferability is concerned with the application of the findings from a qualitative study to other groups and contexts (Krefting, 1999). Findings are transferable when they can successfully be applied to contexts different from, but similar to the study situation

(Krefting, 1999). Transferability suggests I am responsible for providing substantial descriptive data to enable others to transfer the findings of this study to other situations with other participants (Lincoln & Guba, 1985). Next, the burden of demonstrating transferability falls on the new investigator who wants to assess the applicability of the findings to other contexts (Marshall & Rossman, 1995). To meet the construct of transferability of these data, I supplied detailed descriptions of the data collection process and analysis, as well as the theoretical findings of this study. Providing “dense background information” enables other researchers to assess the transferability of these findings (Krefting, 1999).

Dependability

The dependability of data is a criterion of consistency, or if the findings would be replicated if analyzed by someone else (Krefting, 1999). While variability is assumed in qualitative work, the dependability of a study is supported by providing a dense description of the research methods and implementing peer examination. Memos documented how data were collected, any changes made to the interview guide, and initial ideas about codes and hypotheses. Detailed memos described the analysis process for this study. Peer examination, to increase dependability, took the form of dissertation committee members completing an in-depth review of the analysis plan for this study. Meetings with committee members, namely my advisor, informed them of my fidelity to the data collection plan. Such feedback assisted in ensuring that bias in data collection was kept to a minimum.

Confirmability

Confirmability is a criterion of neutrality in which bias in findings is explored (Sandelowski, 1986). This aspect of trustworthiness was met when a type of audit was performed. Here, an external person reviewed the study's data collection and analysis procedures to assess how and why decisions were made and if the conclusions drawn from the data would be drawn by others examining the same data (Krefting, 1999). The dissertation committee served as the external auditors, who considered the data, findings, and interpretations (Lincoln & Guba, 1985) and provided independent perspectives to evaluate if the study met the standard of neutrality. In addition to this strategy, confirmability was also met by reflexively writing memos to guard against bias and assess if a particular perspective was prioritized.

Researcher Bias and Reflexivity

Daly (1997) explains reflexivity as critically monitoring and understanding one's role as a researcher. The researcher must consider her own role and impact on collecting, analyzing, and interpreting data. Deliberately monitoring potential biases and predispositions was done through reflexive writing of memos, which enabled me to become more self aware (Johnson, 1997). As a part of the memos written throughout this study, I reflexively considered my position as researcher in this study and my relationship with the study participants. Reflexive writing often requires researchers to explore how their personal background may influence the study, and if this occurs, what will be done to address it (Johnson, 1997). Concerns about my outsider as a barrier to connecting with participants were addressed by putting concerted effort into making sure the participants felt safe and comfortable sharing intimate details of their lives. I built rapport at the onset

of all interviews by asking participants about their day, complimenting them in any way possible, and taking direction from them on where they would like to sit. I explained in lay terms my motivation for conducting the interview and my gratefulness for their participation. I proficiently framed questions, gently probed for elaboration and clarification, and utilized my strong listening skills (Marshall & Rossman, 1995) to ensure the success of the interviews. I anticipated that my skills and training as a therapist and my status as a helping professional who regularly works with diverse families would assist me in forming a connection with the participants.

I acknowledged that I am an outsider in several ways. I am not a parent and I do not have personal experience managing the mental health diagnosis of a family member. During the interviews, some participants asked me if I was a parent. I was forthcoming about my own background and open to hearing their experiences of parenting children at different ages. I recognized that my position as a non-parent and non-caregiver could have made it challenging for me to understand the participants' perspectives. If I ever felt this was the case, I made the effort to ask further questions and clarify the points of discussion.

I also recognized that compared to the participants of this study, I found myself to be of a different socioeconomic status and education level. When prompted, I explained to participants that I was completing this project to finish up my degree at the University of Maryland. I quickly followed this with information that I am also a therapist who works with teens in D.C. and Maryland and wanted to complete a project to improve the type of work I do and the services provided to families like their own. I was careful about the words I chose and shied away from saying I was a "doctoral candidate"

working on my “dissertation.” Throughout the data collection process, I was consistently aware of how I dressed and presented myself to the families. I was conscious not to dress in formal business attire, but to certainly look professional. I never wore excessive jewelry and refrained from accessing my mobile phone while at families’ houses. I did not want to come across as having material items that families could not afford. Furthermore, I tried to be as relaxed and comfortable in their home environments as possible, despite how different they might be compared to my own. It was important for me to know I was doing what I could to make the participant comfortable and to ensure that at no point in time did they feel judged by me.

I also acknowledged that I am of a different race/ethnicity compared to the majority of the sample. I entered into this project with the resources and intention of obtaining an ethnically diverse sample. Yet, the connections led me to recruit families within D.C. who were predominately Black/African American. Having worked as a therapist with this population, I felt somewhat familiar and comfortable interacting with individuals of different backgrounds than my own. I leveraged these personal experiences to form connections with my participants. Since the protocol required me to ask questions specifically about race/ethnicity, the differences between the participants and myself were openly discussed. Discussing this topic was mildly uncomfortable for me, as I worried the participants would not understand the point of my line of questioning or would not be completely forthright about their experiences. I discussed the responses from participants with my advisor, research assistants, and peer reviewers to assess my presentation of the questions and feedback received from the parents.

Summary

This project was developed after several years of experience providing direct clinical services to parents, teenagers, and families who were often low-income and ethnic minorities. Recognizing the dearth of research on the experiences of parenting teenagers with depressive disorders, connections were made to access the sample for this study. The described methods enabled the collection of robust, high quality qualitative data from a unique sample of predominately low-income African American parents and caregivers already engaged with the mental health care system. Grounded theory analysis was suitable to develop sound answers to the proposed research questions. The following is an in-depth explanation of the findings of this study. It includes quotations from participants with particular words, phrases, or sentences italicized for emphasis. The italicized parts of the quotations reflect the particular themes for the sections below. The un-italicized sections provide additional context to further explain and expand upon the participant's responses to the questions asked and their perspectives on the topics discussed.

Chapter 4: Parents' Involvement in the Diagnosis Process

In this chapter, I address the research question, “How are parents involved in the diagnosis process of their adolescent’s mental health issues?” Participants were asked when they were first concerned about their child’s behaviors or mental health status. The interview explored how services were initiated and the ways parents were involved. Participants were probed to think about how decisions were made about engaging with mental health care services.

I identified several aspects of the process through which parents obtained a mental health diagnosis for their teenager and how this process typically unfolded for participants in this sample of families already engaged with the mental health care system. There were three avenues by which parents initiated the diagnosis process. First, there were youth who had co-occurring diagnoses present from young ages, which led to engagement with mental health care providers early on in the child’s life. These diagnoses often were identified because primary health care providers referred families to mental health professionals. Often these families had had long-term involvement in the mental health care system. Second, for some families, the diagnosis process was stimulated by the involvement of agencies in the family’s life. Agencies such as Child Protective Services (CPS) or the court system required or mandated an evaluation of the youth for various reasons discussed below. Third, for families where co-occurring diagnoses did not spark the diagnosis process and agencies were not involved, the diagnosis process began with awareness by the parent or caregiver of the mental health struggles of their teens. Awareness unfolded in three contexts; first, awareness came about because of the influence of outside sources, such as the school or primary health

care providers. The second context was parental acknowledgment of the severity of the teenager's behaviors. The last context was parents' attributions of the youth's mental health struggle to the adolescent's life situations or experiences. Each of these avenues was not mutually exclusive, as some parents reported a combination of the following ways the diagnosis process was initiated. The following is an in-depth exploration of these themes. All identifying information of the participants, including the names of the parents and children, as well as the agencies and hospitals involved, have been changed to protect the participants' confidentiality.

Co-occurring Diagnoses

A co-occurring diagnosis (of a physical or mental health concern) that was apparent when the adolescent was a young child contributed to some families (15%) entering the mental health care system and being involved in mental health care over a long period of time. These diagnoses were recognizable when the child was young and often before the depressive disorder appeared. Co-occurring diagnoses included, for example, ADHD or an intellectual disability. Additionally, when such concerns were present alongside of a depressive disorder, these types of struggles sometimes seemed to take precedent over the depressive disorder diagnosis.

This theme was evident in the interview with Deborah, who spoke of her 13-year-old daughter Dominique and explained Dominique's long-term struggles in school. Deborah explained that she advocated repeatedly for Dominique to be evaluated and have an Individualized Education Plan (IEP) put in place because Dominique was falling behind in school. Dominique was not on grade level and continually struggled to pass her city's standardized tests. It was Deborah's concern about Dominique's academic

achievement that pushed this family into the diagnosis process when Dominique was in grade school. Deborah reported that Dominique was subsequently diagnosed with an intellectual disability and ADHD when she was about nine years old and was later diagnosed with depressive disorder NOS when she was 11 years old. Getting Dominique the help needed to be successful in school was Deborah's primary concern, which led Deborah to seek mental health services for her daughter.

Families who spoke of co-occurring diagnoses were characterized by continually receiving mental health services over many years and/or perceiving the co-occurring diagnosis to be more significant than the depressive disorder diagnosis. Anita's story was somewhat similar to Deborah's. Anita was 51 years old, unemployed, never married, and the mother of Tommy. She explained that at age five, as she understood it, her son Tommy was diagnosed with ADHD, Oppositional Defiance Disorder (ODD), and a depressive disorder. He began receiving mental health treatment at this time and continued to receive such services for 10 years; Tommy was 15 years old at the time of the interview. When asked if Tommy's diagnosis changed over time, Anita responded:

I think he still... I don't know about the ADHD. Uh... I can't say, I mean he's had the uh, what's the test called, the test they give you, the Coxle or something, uh. You know to see where you are mentally as well as... Whatever that test, yeah he's had that. Um, to me the language seems, you know, I'm trying to figure out, I'm trying to catch onto the words and understand them when I hear them, but I, I think that as he's getting older I think his progression is greater. Um, I think that's only because, *if you have a child that's depressed, and this child is also ADHD or ODD or anything else and you don't deal with those individual issues. The other ones tend to take over the latter. So at this particular point I think that they're more so working on Tommy's behavior. It's not that he's not intelligent but I think they are working on his behavior over his mental issues.*

Anita has been managing her son's mental health care for 10 years, and she still is striving to understand what her son is going through. She mentions how his treatment

seems to focus on his behaviors and not on his ‘mental issues,’ meaning his depression. Anita’s assessment is that Tommy’s mental health services have primarily targeted his diagnosis of ADHD and ODD. The presence of these other diagnoses was the reason Anita first sought mental health care for her son and through the years, the services received continue to primarily focus on Tommy’s behavioral struggles versus addressing his depression. Therefore, one way parents enter the mental health care system and end up obtaining a diagnosis for their child is because of co-occurring concerns evident at young ages.

Agency Involvement

A second way adolescents ended up receiving a mental health diagnosis and entered the mental health care system was because the family was in some way involved with an agency such as CPS, the foster care system, or the court system. This was the case for about 24% of families in the sample. When CPS was involved, typically the teenager who was the focus of the interview had been mistreated in some way by their caregivers as a young child. CPS became aware of this behavior, removed the child from the home, completed a mental health evaluation of the child, and made the recommendation for mental health services. It was also likely that CPS placed the child in a new home with the participant who was interviewed for this research.

This was the situation for Yvonne and her nieces. Yvonne spoke about caring for her nieces, particularly for Carlee, who was 17 years old at the time of the interview. Yvonne, who was 58 years old at the time of the interview and had less than a 12th grade education, explained that Carlee’s parents struggled with alcoholism so Carlee and her sisters were removed from their home when Carlee was five years old. Now a part of the

CPS system of care, Carlee began to receive mental health care at the age of five when she showed symptoms of depression; according to her aunt this was when Carlee was first diagnosed with a depressive disorder, indicating this family had long-term involvement with the mental health care system. Yvonne shared that from this young age, Carlee and her sisters were seen by a number of psychiatrists and specialists, and they worked with numerous therapists over the years. Betty's story was similar to Yvonne's.

Betty came to be the primary caregiver of her niece, Melinda, after Melinda was removed from the care of her mother, who was neglectful and struggling with mental health issues of her own. Betty reported that Melinda was diagnosed with "manic-depression" at a "pretty young" age, around 10 or 11 years old. The diagnosis came about because of Melinda's involvement with CPS.

Dorothy and Amia's stories involved the court system as the impetus for seeking a diagnosis for their respective teenagers. Dorothy explained her son, Kevin, was diagnosed as severely depressed, as well as having a major mood disorder and ADHD. These diagnoses came about after Kevin, who was 17 years old at the time of the interview, got in trouble acting out in school. Dorothy, a Caribbean woman who was 39 years old, explained Kevin ending up meeting with a psychiatrist because he was mandated to get care after an incident in school.

So he was forced to and because he was so stupid. He did it in school on a day where they had alcohol awareness program. So they had cops in school giving presentations to the classes. And you know, some kid had reported him and the cop came and gave him a Breathalyzer test. And then they discovered how drunk he was. And he got a citation. A juvenile citation. And I've never had to deal with that before. I didn't know what it meant. I had to go looking up and you know find out what a juvenile citation means. And part of that, he had to go to the [substance abuse program for juveniles] around here in Maryland. Just substance abuse something. I can't remember the name of it. And um they mandated that

he be in substance abuse program. And um to have his, this I guess, sealed or removed, it wouldn't be on his record if he did this program. So that's what and also we had to go see a psychiatrist so I felt in a way that it was at the time immediately I could see it as a good thing. But it was a good thing that that happened because it brought his issues to light and we were forced to get him help, even though he has been very resistant.

Dorothy shared that she had suggested Kevin see a therapist prior to this incident but he was repeatedly opposed to it. With the court system involved, Dorothy saw the mandate to see a psychiatrist and attend a program for alcohol abuse as helpful.

Amia, the 42-year-old mother of Kailee (15 years old), spoke of how Kailee “came into contact with the courts,” who required and arranged for Kailee to have a psychological evaluation. Amia reported that because of this court interaction, she was able to get Kailee help. So, for some families, their involvement and interaction with social service agencies was the catalyst for the diagnosis process, and these agencies required the child to be assessed for a diagnosis.

Parental/Caregiver Awareness

When youth did not have a long-term co-occurring diagnoses requiring mental health care and the involvement of agencies was not present, parents and caregivers had to gain an awareness of what was going on for the adolescent in order to initiate the diagnosis process. Noticing unhealthy behaviors or statements made by the teenager that suggested they were in distress precipitated parents' beginning to think about engaging in mental health care. For some of these parents, there may have been a time gap between when they were first concerned about their child and when the diagnosis process was initiated. Awareness for parents consisted of three sub-components, all of which could build upon one another; when present, these sub-components motivated parents to seek a diagnosis and treatment for their teenagers.

Outside Sources

One way the theme of awareness took form in the sample was through someone outside of the family contacting the parent to discuss the teenager's mental health struggles. About 39% of parents and caregivers in the sample spoke about someone else recommending they seek a diagnosis and/or treatment for the teenager. When this happened, the outside sources noticed the teenager was struggling and shared this concern with the parents. These outside sources included teachers, school counselors, and pediatricians. Outside sources were different from agency involvement in that when agencies were involved, they mandated the diagnosis process to be initiated. The outside sources discussed here provided suggestions, recommendations, and referrals for which the parents were then given the opportunity to follow-up or not.

The influence of outside sources in increasing parents' awareness was seen in Ms. Coldwell's interview. Ms. Coldwell was 35 years old at the time of the interview; she identified as Black/African American, never married, and unemployed. Ms. Coldwell spoke of connecting her daughter, Tara, with mental health services after the counselor at school contacted Ms. Coldwell to suggest Tara may be depressed.

R: Well, it was, *it was help from her counselor at school*. But then she, you know, she would always bust out crying she was like always like very sensitive to anything. You know when someone probably correct her or say something to her she didn't like or she would just cry. She would just very easily just cry about everything. Yeah.

I: So she was working with the counselor at school?

R: *Yeah, she was working with the counselor and the counselor noticed that she had, you know, some issues, dealing with, coping with stress and anxiety, as they call it. And, um, they wanted me to get her checked out at [the hospital] And the [the hospital] said she was okay. She just had mild depression. So I took her to the doctor and they recommended some people, you know, for her to see.*

In Ms. Coldwell's experience, a person outside the family system noticed the teenager's behaviors and then made the recommendation to seek mental health services to the parent. The parent was then able to decide what steps to take. Similarly, Tonya's experience was that multiple people spoke with her, concerned about her daughter Felicity. Felicity, who was 15 years old, was diagnosed with diabetes and was regularly meeting with an endocrinologist, who suggested to Tonya that she seek therapy for Felicity. Tonya, who was 38 years old, unemployed, and never married, shared that in addition to hearing this recommendation from the endocrinologist, she also heard it through Felicity's school and her mentor.

The teacher, I'm going to say that it was a mentor too that also, she sent me an email saying that she thinks that she suffers with depression. So like I said, it went on for a while. It went on for a while, and I'm like, okay well since she, since the boys are going to Families Together [the agency], let me just see if, once I received the email from the mentor, let me just see um if I take her to Families Together, what, what they will say there.

The combination of multiple outside sources brought awareness to Tonya about what Felicity was going through and helped Tonya recognize that securing Felicity mental health services may be beneficial. Therefore, for many parents and caregivers, receiving a recommendation or referral suggesting they engage in obtaining a diagnosis and then treatment for their adolescent was an important component of the parents initiating the diagnosis process. Parents in the sample took these recommendations seriously, even if it may have taken some time for them to act. They utilized the recommendations of outside experts to pursue mental health treatment for their teenager.

Not all members of the sample had positive experiences interacting with outside sources, as several parents reported negative exchanges with the schools regarding their

child's behavior. Participants spoke of schools not being receptive for the parent or caregiver's requests for help from the school, or parents' concern becoming elevated because their teen was consistently getting into trouble at school. Parents and caregivers who had negative experiences with the schools reported desiring the schools to have done more to help their teenagers. Also, some parents reported that when their teen was younger, a recommendation for mental health care was made and the parents did not initially act on it. Indeed, for some participants it took time for them to agree with the outside source's suggestion that mental health care may be helpful. Along these lines, when parents were asked what they would have done differently regarding their teen's diagnosis and treatment, a common response was parents reporting they would have sought mental health services earlier than they did.

Severity of Behavior

The second sub-component of awareness for about 18% of parents in the sample related to the parents' perceptions of the severity of the teenager's verbal expressions or physical behaviors. Families in the sample initiated the diagnosis process at a time of extreme duress for either the teenager individually or for the family as a whole. Severity of behaviors also was linked with outside sources; in several cases, there was a person outside of the family who noticed the teenager's alarming behaviors and shared this information with the parents. For example, Ms. Coldwell explained that when her daughter, Tara, spoke with the school counselors, it was disclosed that Tara felt like hurting herself. Tara's mental health was in a critical state – and the combination of the school counselor (an outside source) and the severity of Tara's emotional well-being led Ms. Coldwell to realize her daughter needed mental health treatment.

The level of unhealthy, critical behavior played a role in parents initiating the diagnosis process. Ms. Greentree (42 years old) spoke of her goddaughter, Coraline, being suicidal when she was younger. When asked about how she became aware Coraline (16 years old) was struggling, Ms. Greentree stated:

R: She was like... probably seven or eight I think it was.

I: And what was going on then?

R: Um, *she told the people she wanted to um kill herself*. Something in her head kept telling her that she needed to kill herself. So she was trying to set herself on fire.

From here, Coraline stayed at the hospital for a few days and then was released with several mental health services in place. Similarly, Mary said she became aware of her step-son's mental health struggles when he threatened to commit suicide. Mary shared that when Andrew threatened to kill himself with a knife, this behavior confirmed to her that Andrew needed help. It is possible it is harder for parents to detect their child's mental health status when they become adolescents because teenagers often desire privacy. However, once this privacy is dismantled and the parent becomes aware, the severe behaviors often produce immediate action in parents. This was the case for Juliette and her daughter Kira.

But when I really, really became concerned was when the school called me saying that she was cutting herself. And, she also lied and told the school that "oh yeah my mom know that I am cutting myself." I had no clue. No clue, no clue at all. And I immediately got her into counseling, like immediately, like two weeks, the first, you know, the first person that called me back I was like when can you see us both and, blah, you know.

Juliette, not knowing about her daughter's self-mutilation, found this revelation quite surprising. Juliette expresses how once this destructive behavior was brought to her attention by the school, an outside source, she immediately got Kira help.

The second way the severity of behavior shaped parents' initiation of the diagnosis process related to teenagers' distracting or destructive behaviors at school. Parents spoke about seeking a diagnosis and treatment for the teenager because their child either was consistently getting into trouble at school or was at risk of being permanently expelled from school. This was Eve's experience regarding her daughter, Dawn. Eve (27 years old) shared that seeking a mental health diagnosis was, in part, meant to alleviate the stress of Dawn possibly getting expelled from school. Eve stated:

R: And they was gonna throw her out of DC public schools because of her behavior. So I had to just like, I needed help and I went for help because I don't want her to get thrown out of school.

I: The school was threatening that?

R: Yeah to throw her out of school. They, they not the school she's in now, but her other school was calling me every day. They ain't miss a day. It was different times but they was calling me every day, every day. And I'm like what is going on?

For these parents, the severity of their child's behavior, perhaps compounded by an outside source making a recommendation they seek treatment for their child, was the impetus to initiating the diagnosis process.

Life Situational Experiences

The last sub-component of awareness which was discussed by about 30% of parents in the sample was parents' understanding of their teenager's behaviors and emotions as connected to life experiences. It seemed easier for parents to make sense of obtaining a mental health diagnosis and subsequent treatment for their teenager when they could justify the youth's emotional state and/or behaviors as a reaction to events that occurred in the teenager's life. Parents and caregivers made connections between the situational circumstances the teen was exposed to and the teen's poor mental health. The

situational reasons given for the teenager's current behavior were, for example, their negative relationship with their birth parents, a loss or death of a loved one, or experiencing a distressing event.

These situational reasons helped the parents "make sense" of what their child was going through, and thereby further encouraged the parent to initiate the diagnosis process. For example, Carla attributed her grandson, Malik's, sadness to the absence of his mother, who was incarcerated numerous times throughout Malik's childhood. Carla, who was 70 years old at the time of the interview, saw Malik's (13 years old) sadness and depression as a reaction to his mother not being consistently involved in his life. Similarly, I asked Tina (57 years old) when she first became concerned about her granddaughter Ashley's (17 years old) mental health. Tina's reply linked Ashley's mental health to a death in the family and to her unstable relationship with her biological mother, Caleena.

Um [it] was like um when she graduated from the sixth grade. *Her mom was in a manic state, so she didn't come to her graduation, and of course that hurt.* Now she's getting closer to the eighth grade and her mom is acting up. And she was like in the seventh grade and what happened is, I think, somebody died. *I think maybe my brother died or something like that.* And so that like, that's the, you know, *cause Ashley, she feels everything so deeply, so she got a little bit depressed.* And um and cause Caleena was in this raging manic phase and I don't know what she said to Ashley. Like cause Ashley has strong family ties and I never try to take her from her parents...because if her mother's fine she can go there anytime. But if she's not fine, I'm not going to let Ashley go there because she'll hurt her.

Linking her granddaughter's mental health with the situational circumstances the family had endured seemed to help Tina see how mental health treatment could be valuable for her granddaughter.

Similarly, Solange, a 40-year-old mother of 17 year old Omari, talked about a distressing event her son witnessed when he was a child and how she did not think this would stick with him, but she came to learn Omari was struggling to process the event from his childhood. Additionally, current experiences like being the victim of a stabbing and having a friend who was murdered were all contributing to his current depression.

R: The first time, um, this about years back when he was little. *The first incident, my sister got stabbed*, and he wasn't just an eyewitness to that. Three of my other kids were too. So that's when I knew like ok, at that time I was like how am I going to deal with this? Like I didn't know like exactly what to expect, but I knew to expect something. *I just didn't know like how it was going to come, like how he is going to react, but I knew something was coming.*

I: So how old was he then? You said he was little.

R: He, Omari couldn't of been more than like 4 or 5, so he was young. And it's crazy that he remembered it. I didn't know that kids remember stuff, but it just goes to show you that people think that kids don't remember, but they remember. *Let me take it back before this; he also seen domestic violence between me and his father.* So I'mma say before that, he seen that and I honestly didn't think that by him being so young then, that he would remember that but he remembered that. So I'm like wow, oh wow, like now he's getting older it's coming out.

I: Ok so, Omari witnessing domestic violence when he was young and then this instance when he was four or five with your sister...

R: Yeah and then to experience been cut on his self because my sister was actually cut on, she was actually stabbed. *Actually, to, for him to experience that, I just imagine like, I know he got so much stuff, like just going through his mind. Cause like when we went to court, like, the judge asked me and his aunt to like step out the court room, and that's when he start like breaking it down that like he been, I guess, having nightmares about the fact that the guy jumped out the car and he cut on him and he was having nightmares because one of his friends that he went to school with had been murdered.* And it's just the whole nine.

Solange began to make sense of her son's emotions by linking situational events to Omari's current depressive feelings. Recognizing the connection between these events seems to help Solange and other parents in the sample initiate the diagnosis process. In

summary, the precipitation of engaging with mental health services in order to obtain a diagnosis for their adolescent was not the same process for all families.

Chapter 5: Parents' Responses and the Parent-Child Relationship Post-Diagnosis

In this chapter, I address the research question, “How do parents respond to their adolescents’ mental health diagnosis?” as well as the sub-question “How do parents perceive their relationship with their adolescent to change post-diagnosis?” Participants were asked to recount their thoughts and perceptions once they received their teenager’s diagnosis. They were also prompted to consider if and how their relationship with their adolescent changed after receiving the diagnosis and/or obtaining mental health treatment. Several salient themes emerged, which elucidated how the participants responded to learning about their teen’s mental health diagnosis and how they perceived their relationship with the teen to be different post-diagnosis.

Parents' Responses Post-Diagnosis

“It kind of made sense”: Parents' Suspicions Confirmed yet Confusion Remained

When asked to think about their own reactions upon finding out their teen was diagnosed with a depressive disorder (and in some cases other co-occurring disorders), parents in the sample described having a simultaneous response of recognizing their concern about their teenager was valid, while remaining confused about the diagnosis. Participants in the sample had, at various points in time, concerns about their child’s behavior. Upon receiving the depressive disorder diagnosis, the parents received confirmation that there had been a reason to be concerned. The diagnosis also brought them some relief. Ms. Henry shared that when she heard her grandson was diagnosed with a depressive disorder she was not surprised. She stated:

I wasn't surprised at all. I know there was something, you know something. I thought maybe he might be ADHD. And then I kept looking and the more he kept doing it, I say – he depressed.

Later on she went on to explain how the diagnosis also provided her with relief:

I: What do you think changed for you as his caregiver?

R: *A little relief, a little relief.*

I: Knowing what's going on with him?

R: *Right. I felt relief. Cause I know now how to make Ty go forward. I know how the things I got to take care of.*

Ms. Henry's concerns about Ty's (13 years old) mental health and his behaviors were confirmed upon receiving the diagnosis; the information was not surprising to her at this point in time. Ms. Henry, a 60-year-old widow who was not employed due to disability, also saw the diagnosis as providing relief and a direction of where to go next.

Deborah's concerns were also confirmed through the diagnosis process, which then provided her with some reprieve as well. When asked about her reactions to finding out her daughter's depressive disorder diagnosis, Deborah reported that she felt relieved – having the diagnosis put a “name and a face to what's wrong.”

Still, even with the confirmation of suspicion and acknowledgement that the parents and caregivers were right to be concerned, parents' responses to their teen's diagnosis also included some tentativeness – such as saying “*It kind of made sense*”, indicating that parents could see how the diagnosis was applicable to their child, while at the same time parents' were still somewhat hesitant. Parents' confusion about the depressive disorder diagnosis related to the challenges they faced differentiating typical and atypical adolescent behavior. Parents sometimes attributed the teenager's behavior to their adolescent's stage of development (and not a mental health struggle). Parents

reported thinking the youth simply “wanted attention” or they would “grow out of” whatever behaviors they displayed that were alarming. Ms. Coldwell described how she suspected something “was going on” with her daughter, Tara, but did not necessarily think Tara was depressed.

Well I kind of knew. I kind of figured something was probably going on with her but I didn't think it was probably depression. I don't know, I just probably thought Tara just wanted her way on everything, you know, she just... that was just her way of trying to get it... just crying. You know. She just don't like authority. Don't like to be told what to do or don't like to be corrected. Don't like nobody correcting her on anything. So I just didn't think it was depression.

Ms. Coldwell initially attributed her daughter's behaviors to Tara just not getting her way and not effectively handling a situation. Shortly after providing this explanation of her response to hearing Tara's diagnosis, Ms. Coldwell added:

You know I could see, it could be, you know, it could've been depression, you know. She could've been going through some, some things, you know. She's becoming a teenager, just as, when they go through things. So she could have been going through one of the, you know, adolescent stages.

As she pieced it together, Ms. Coldwell reflected on accepting that the struggles her daughter dealt with could be a depressive disorder. Evident here though too is Ms. Coldwell's understanding Tara's stage of development: adolescence. Ms. Coldwell suggested there is a link between Tara's mental health status and her age.

Similarly to Ms. Coldwell, Ms. Innis described her reaction to finding out her daughter, Tanay, was diagnosed with depression with a mix of tentative acceptance and lingering confusion. Ms. Innis, a 35-year-old Black/African American woman who was married and unemployed, stated:

R: I mean, it was kinda, I, I, it was kinda believable. Because she had stayed confined to her room. She didn't want to eat. She didn't want to be

around nobody. She didn't want to watch TV. I'm like – there's nothing in her room because she used to do so much. So I'm like – you just gonna be punished until you can get it together. So she had no TV in her room. Just walls. All day in her room. All day in her room. You got to call her. Come and eat. She would eat but she would eat very little and then she gone back in her room. Sitting on, looking at... she gone back in her room to go whatever. She didn't participate in nothing.

I: So when you saw her do that – how did you make sense of it? Like what did you think was going on for her?

R: *I thought she was – she went into a depressed mode. Cause most depressed people stay in a box. Like I don't want to talk. She didn't want to do nothing. And like I said it was stressful for me cause I'm like – this is one of my own children. She don't want to sit at the table and eat like normally. Everything was just abnormal. It was nothing that she normally does. She don't normally stay in her room for hours, I have to call her. You okay? You okay? And she go right back in her room just to make sure she wasn't in there – she had not done something to herself.*

Ms. Innis' description of Tanay's behaviors is bleak; still her mother's response is that the depressive disorder diagnosis was “kinda believable” – suggesting that Ms. Innis was not fully convinced her daughter was struggling with a mental health issue and that punishing Tanay (13 years old) might fix the situation. Ms. Innis continued to be tentative in accepting the diagnosis while also acknowledging that her daughter's behaviors were alarming.

The symptoms of depression in adolescents were not always clear to parents in the sample. The ways in which a depressive disorder may manifest in an adolescent and whether that looks different from the parent's understanding of depression led to confusion for the participants. Ms. Pilsin described her response to hearing her adopted son, Chris, was diagnosed with major depressive disorder as follows.

Well, I mean I didn't see it because, I always thought of depression, when you depressed you don't really want to talk really about it. Don't want to do anything. ...To me he didn't seem depressed. He is defiant. And argumentative, stuff like that. I know when I'm depressed I get quiet,

wouldn't want to be with people so, for him to be angry and all that kinda stuff. I guess it was his way – what you wanna say – of him acting out.

Ms. Pilsin (45 years old) thought of her own experiences with depression and had a hard time understanding depression in Chris (15 years old) – who she saw as argumentative and defiant, not quiet and isolated. Tamara had a similar experience. When asked if it made sense to her that her son was diagnosed with a depressive disorder, Tamara replied:

So, yeah, I can say that I can see the depression part only when...the little sadness. Yeah. But has far as like...because my definition of depressed is gonna die, in other words. You're just depressed, you don't wanna do nothing, you don't wanna do this. He's the opposite.

Tamara, who was 38 years old, never married, and employed part-time, reported that she can see how the depressive disorder diagnosis is applicable to her son, Ameer (11 years old), especially when he demonstrated sadness. Yet when Tamara thought about her own definition of depression, – which included being suicidal and having no motivation to do things, – she became conflicted in her understanding of her son as depressed. Tamara's experience of her son was the opposite of what she understood depression to be, which led to confusion.

Parents' pursuit of trying to clarify their confusion about the diagnosis constituted an attempt to understand and make sense of this new information. Responses along these lines resulted in parents attributing the causes of the diagnosis often to several factors, such as the parent looking at themselves or caregivers looking at biological parents as contributing to the adolescent's current mental health. Additionally, corresponding to the theme of life situational events described above, parents in the sample also responded to the diagnosis by attributing its presence to experiences the adolescent had undergone.

Participants who were the biological parents of the teenager at times expressed guilt or blame for the presence of the diagnosis. Yet, these participants also quickly turned to examining the other biological parent's possible contribution to the presence of the disorder rather than their own role. In an effort to understand her daughter's struggles, Chandra (42 years old) spoke about how her daughter had a negative relationship with her father – which Chandra thought contributed to current stress. Additionally, when thinking about how the family got to this place, Chandra noted how she learned about her daughter Jackie's father's own struggles.

Even with like *them being stressed out real bad by their dad...* I get frustrated with stuff, you know, *like it's my fault* that their having these problems. Umm even though I found out, of course after the fact, that their *dad has a lot of things going on with them*. Some hereditary stuff.

Chandra's response to Jackie's diagnosis is to make sense of it by first looking at herself and then attributing stress to the poor relationship Jackie, who was 15 years old, has with her father.

Caregivers interviewed attributed the presence of the diagnosis in part to characteristics of the teenager's biological parents or the state of the relationship between the teen and the biological parents. Caregivers were commonly parenting the adolescent because the biological parents of the teenager were abusive or neglectful, struggled with addiction, or had a significant mental health concern that impaired their ability to effectively take care of the teenager. Given such challenges, caregivers often related the teenager's mental health struggles to the biological parents. Yvonne talked about her tumultuous relationship with her niece, Carlee, who was in her care since Carlee was five years old. Yvonne expressed feeling like Carlee's depression and her defiant behaviors all related to Carlee not being able to live with her own mother, who struggled with

alcoholism. Betty's impression of her niece Melinda's struggles was similar. Betty's response to Melinda's diagnosis was to attribute it to Melinda's relationship with her biological mother. When asked about Melinda's depressive disorder diagnosis, Betty (56 years old) replied:

So and I feel, I'm thinking that *that was as a result of her earlier childhood and being taken away from her mother*, because like I said she loves, she does love her mother, she cherishes her mother.

Melinda's biological mother, according to Betty, was neglectful of her children and had mental health issues of her own. Melinda was removed from her mother's care at age 11, and at this age came to live with Betty. Betty made sense of Melinda's diagnosis in terms of Melinda's unstable relationship with her own mother.

In sum, one salient theme of parents' responses to learning about their teenager's depressive disorder diagnosis was a combination of confirmed concern with lingering confusion and questions. Parents acknowledged their own concern for their child's behavior and well-being and that having the diagnosis was at times not surprising; rather it upheld the parent's own thoughts that something was going on for the teenager. Alongside this realization was continued hesitancy to fully accept the diagnosis. Skepticism around the diagnosis was associated with parents' confusion with the symptoms of depressive disorders and understanding typical versus atypical behavior in teenagers. This confusion was managed by parents trying to make sense of the diagnosis by attributing its presence to multiple causes. Parents turned the blame inward or looked at their child's other parent for insights into why the depressive disorder was present. Caregivers also attributed the teenager's struggles to their experiences or relationships with their biological parents.

“I need help:” Advocating as a Response to the Diagnosis

The second theme that emerged when considering parents responses to learning about their teen’s depressive disorder was the theme of “I need help.” Parents and caregivers recognized that the struggles the adolescent was enduring were more than they, as the parent, could manage on their own. The theme of “I need help” built upon the awareness parents’ gained, as they began to recognize their child’s struggles. Parents reported their reactions to learning about the teen’s depressive disorder quickly included some notion of needing to put together a plan to deal with their teen’s current situation. Parents took responsibility for piecing together the plan out of obligation and out of concern for the teenager’s well-being and long-term success. Parents’ perspective turned to trying to alleviate their teen’s symptoms and help the teen cope with their struggles. When asked how she made sense of her son’s depressive disorder diagnosis, Lakeisha’s reply indicated that her focus shifted to wanting to figure out all she could so she could help Oscar (14 years old) get better. She stated:

Um I really wanted to get down to the bottom of everything that Oscar was going through. So that I could figure out how to better him. I mean, you know just figure out what needs he actually needed. If you don’t know the root of the problem how can you get to the bottom of it? It’s just like the tree you trying to get up. You have to get to the root before you can even try to get to the top of the tree. Or get to wherever you’re trying to cut this try down. That was my main thing is finding out really, and the extent of everything.

Lakeisha’s priority, after finding out her son was diagnosed with depression, was getting “to the bottom of everything” so that she could “figure out how to better him.” Her response to learning of his diagnosis included taking action to determine how to ameliorate the situation for Oscar.

Parents and caregivers in the sample also reported learning more about the diagnosis by seeking information themselves. The participants in this sample were active consumers of information and sought information from a variety of sources. Sources included family and friends, mental health professionals, other healthcare professionals, and the schools. One particularly salient place where parents sought information was the internet. Parents turned to the internet to acquire information about depression, and also to provide them with insights into how to cope or manage the diagnosis. Calvin, foster-father to Andre, spoke of turning to the internet for these reasons.

Well I, *I looked online for different webpages dealing with behaviors and mood disorders so I was always seeking knowledge to find out something I could do differently to make the situation better.*

Calvin, who was 59 years old, saw this action as a way to help him with Andre, to increase his knowledge about behaviors and mood disorders, and to gain insight into anything Calvin could do differently to improve things at home for Andre. Dorothy had a similar strategy in seeking help for her son, Kevin. Dorothy turned to the internet as well, to both help herself gain an understanding of what Kevin was going through, and to see what resources she may have access to that would help her and Kevin manage his depression. Within the interview, Dorothy stated she tried to do research about her son's diagnoses. When prompted to explain where she acquired information, she shared about her experiences looking online.

R: *All over the Internet. All over the Internet.* I really kind of, you know, it was all those science site. Wikipedia. What was that place? You know all of those doctors' sites and why they don't come to my head right now.

I: Like Web MD?

R: Yes, *like Web MD and PsychologyToday.com* and a lot of places where you go they have pamphlets in the waiting area, I pick them up and I go to

you know read. Whatever website. And it gives you suggestive things on the side. And so, I mean copious amounts of places. Whatever would pop up I would just, like I'd have 15, 20 windows open. And not, I did not sleep many, many nights and days just researching things and what to do and how to handle it and different suggestions. Even parenting blogs and stuff that people who have kids with the same issues, how they handle things or I had to figure out like my normal ways of using positive or negative reinforcement as punishments with behaviors or rewards for behaviors.

Dorothy mentioned specific websites she turned to where she felt she could learn about how to handle her son's depressive disorder. She also mentioned reading pamphlets, presumably which she obtained from an agency or doctor's office. Participants saw accessing information about their adolescent's depressive disorder as a way to help both themselves to effectively deal with the challenges their families were facing and also to directly assist the teenager in overcoming depression.

An important component of advocating was being willing to ask questions. Asking questions enabled parents to feel as though they could better help their child and also to confirm if the treatment or services being recommended would be adequate for the child's needs. Asking questions was particularly important when parents dealt with IEP meetings at their teen's schools. Being the voice for the child to the school and ensuring the teenager's needs were met at school was a salient venue through which parents saw advocating and asking for help as important. Deborah, shared that in response to her daughter's diagnoses, Deborah's learned to be vocal during IEP meetings.

So even when we have IEP meetings now, I highlight different things that I don't understand. So, and then I'll go back and research it like "why did they say this" and "why did they say that"? "Okay, what does this point system mean?" "Why do they have that"? So I learn like advocating for yourself is the best.

Deborah felt that asking questions helped ensure she understood the school's approach to helping her daughter Dominique. Chandra had a similar strategy towards not being afraid to ask questions. She shared her process of going back over materials from IEP meetings to help her learn.

R: I have a tendency to go back over evaluation especially when I'm trying to prepare myself for the IEP meetings. Because it's stressful and stuff be going over your head. And you know even though I may kind of have it in my head but you know you tend not to be looking at it, so I read over the information and... *help try to better understand how to deal with them because their frustrating me.*

I: Sure. Did somebody suggest that to you or did you...how did you decide?

R: No, I just do that. I have a tendency to I don't know I just do I don't know what made me, I'm glad I do. You know but I don't like...I guess my habit of wanting to be prepared. And I like to know what is going on, I don't want to be, or if I don't know I'm like I don't understand. *I don't have a problem saying "can you explain that to me?"*

Chandra hoped that reviewing her daughter's evaluation would help her learn more about how to manage her daughter's behaviors. Chandra also pointed out that she would not hold back if she had questions about something discussed, demonstrating her willingness to advocate and ask for help when needed. Anita described her advocating and getting help for her son, Tommy, as follows:

R: Again, if *I can't help him, I need to have people who can help him put in place like that.*

I: And you were saying before that if you couldn't get him the help that you would go to other people and you would advocate...?

R: Yeah, advocate. I would ask them 'how long you know this?' 'Has that worked out for you?' 'Can you give me some recommendations'? I don't mind asking, I mean I hate to be nosy but I have that similar situation and *I'm trying to figure out what I can do to help my child succeed where he is.* And people are generally really open with information.

Anita's reaction to her son's diagnosis was that she was responsible now for putting people into place that can help him, and if this meant asking questions, she was very willing to do so.

As seen above, parents responded to learning of the adolescent's depressive disorder diagnosis by recognizing the need for help and then engaging in advocating behaviors. Parents responded in this way in part due to their individually felt obligations to help the teenagers and their desire to see the adolescent experience symptom reduction. Parents advocated by seeking information on their own, to increase their own knowledge of the diagnosis and treatment options, and to learn what they, as parents, could do to help the youth. Parents also advocated by being proactive in asking questions.

The Parent-Child Relationship Post-Diagnosis

Parents were also asked to think about if and how their relationship with their teenagers changed after the family's involvement with the mental health care system commenced. In response to this set of questions, some parents readily stated that they could see changes to their relationship with their teenager. Other parents thought they and the teenager were close before and continued to be close after the diagnosis and treatment process. Further questioning revealed several themes of changes to the parent-child relationship post-diagnosis were evident. Not all parents expressed all of the themes described below, but it was certainly possible for a parent to report multiple ways they saw their relationship with their teen change.

“I have to be on vigilant patrol:” Parents' Protective Approach

The first salient theme regarding how the parent-child relationship changed post-diagnosis related to parents' protective behaviors over the teenager. About 60% of the

parents and caregivers descriptions of their teenagers suggested that after receiving the diagnosis, they saw the teens as somewhat vulnerable. Generally speaking, parents reported they were not concerned about other people knowing about their teenager's diagnosis or if they were receiving treatment; concern became relevant when parents thought about others trying to take advantage of their adolescent. Parents expressed their own desire to protect the teenager from assorted factors that could negatively influence them and further impact their mental health. Parents concerns were varied, and included mention of the harmful influence of peers and others. Tonya spoke of how she felt that because of her daughter's depression, Felicity was "easily peer pressured into doing something that you shouldn't do or want to do." In lieu of this, Tonya monitored Felicity more closely and restricted who Felicity could spend time with. Deborah, mother of Dominique, expressed her concern about "wolves" who Deborah worried could target her daughter.

I want my child to be successful. I'm not gonna be here for the rest of my life. So I gotta find ways to get her prepared for the world because there are wolves. They're not, and when we were going there used to be sheep, then when I was going there was, you know, wolves in sheep clothes and now it's no more sheep anymore. I feel like all the sheep are deceased and just wolves. I mean these guys don't care 'oh I'm 10 years old.' 'Oh, let me talk to you baby, you look so sexy, let me boo boo boo boo' and all this nastiness and you'll be like 'oh my god you're like 26 and my baby is like 10.' I'm having problems now, like okay she's about to go into high school. Oh god, I'm just like, you know, tensing up like I don't know what to do.

Thinking about her daughter's transition to high school and the potential new influences was alarming to Deborah. She positioned herself to be proactive in finding ways to prepare her daughter for the world in lieu of possible threats or people who may try to take advantage of Dominique. Adrian, stepfather to Lashauna, spoke about how he felt

Lashauna was also easily influenced by her peers. He expressed worry that Lashauna put herself in risky situations to fit in with her peers. Adrian's protective behaviors took the form of trying to boost Lashauna's self-esteem, to protect her from the sway of others.

She's easily influenced so um the little girl will like, she's not little, she's a big kid. She easily.... she would boss her around and talk down to her and I'm like 'why do you let her talk to you like that?' And I had another friend cursing at her at the bus stop. You don't need to be around people like that and um it's just that she like I said she has low self-esteem. And I try to build it up.

Adrian's protective behaviors took the form of trying to coach Lashauna to see that those she surrounds herself with may have an influence on her self-esteem and her mental health.

Protection also took the form of the parents guarding the teenagers from "triggers." Participants noted that they were concerned something they would do or say could set off a reaction in their teen. They also gained an awareness of potential triggers in the environment that could impact the youth. Parents were more aware of their own words and behaviors and how this could influence the youth. Caroline, who was Black/African American, divorced, and employed part-time, talked about being on "vigilant patrol" around her nephew, Denzel, out of concern that something he could see on the television or on the computer might make him "get all carried away." Caroline worried that such exposure could make Denzel upset and depressed and she positioned herself as the one to protect him from this, by even changing the types of television shows she watched. Caroline later went on to explain that she recognized she is more protective of Denzel, especially when others try to discipline him. Denzel was removed from his biological mother's care after it became apparent he was being neglected by her. In addition to a depressive disorder, Caroline shared that Denzel was diagnosed with post

traumatic stress disorder and he was on the autism spectrum. Caroline and Denzel's story was one where CPS mandated the diagnosis process and Caroline attributed Denzel's struggles to life situational events. Caroline stepped in when other family members attempted to reprimand Denzel; she felt they should not be imparting discipline to Denzel because they did not understand his background and his diagnoses. She explained:

They don't have the same knowledge that I do as to what all went on in that household and with him. Emotionally and physically they have not seen him kicking and screaming and crying at night like I have, you know. And I feel that it's just different, that's what makes it different, you know. *I, I know the emotional state of his mind right now. I know the emotional state of his heart. They really don't. But they love him nevertheless, but it's just, it's, it's like I'm guarding him. So it's just a little different.*

Caroline expressed feeling like her standing up for Denzel in this way and protecting him from the discipline of others, was a new behavior she engaged in in an attempt to guard him from a potential trigger.

Parents in the sample were particularly concerned about the teen's suicidal thoughts and behaviors. Participants wanted to protect the adolescents from triggers that may produce suicidal thoughts. Tonya shared that she changed the way she spoke to her daughter out of concern she might say something to trigger suicidal thoughts in Felicity.

I mean my thing is, um, something, you don't want to say something that make a person want to commit suicide or feel like they just don't want to be in a home, so, yes. *There is a different way that I have to talk to her.*

In an effort to protect Felicity from such thoughts, Tonya changed her approach to talking with her daughter. Participants also strove to guard the teens from hurting themselves because of suicidal thoughts. For example, Dorothy spoke of a family friend's daughter who overdosed on medication several times because of suicidal thoughts. Dorothy related this story to her own monitoring behavior of her son, Kevin, and him taking his

medication. Dorothy saw herself as protecting Kevin from suicidal behaviors by keeping his medication in her possession and distributing it to him as needed.

Along these lines, protection also took the form of parents monitoring the teenager's use of psychiatric medication. Parents hesitated when it came to medication in that they felt their teen may become dependent on the medication or that their personality may drastically change while on medication. Ellia, the 29-year-old mother to 11-year-old Anton, expressed concern that with medicine, her son might not be able to truly be himself.

Because when he's at, he don't take the medicine when he's at home. He take the medicine when he at school and then it's only for eight hours so by the time he get back home he got the extra ... Yeah, so. I gotta deal with that part. But I don't want him, *I want him to be himself. I want him to be who he is. I just want him to be able to focus and make the right decision. So that's why I don't choose to give him medicine in the day, medicine in the night, just for school. Let's work on that part first, and we can work through home without the medicine, that's how I feel.*

Later, Ellia went on to further explain her mixed feelings about putting Anton on medication.

I just, I just, felt bad I didn't want him to be doped up and not being himself and drowsy. And I thought that was how it was going to be. That he wasn't going to be himself. *And I don't want to change who he is I just want to help him.* So, I was scared of that.

To address her concern about allowing Anton to “be himself” Ellia was willing to manage his behaviors at home, at night, when his medication is no longer effective. She strove to balance her concern for his ability to “make the right decision” with protecting who Anton truly is and not changing this.

Parents also expressed concern wanting to protect the teens from the potential side effects of medication. Tamara spoke of her hesitancy to put her son, Ameer (11 years

old), on medication because of the side effects. Tamara tried to reason that the side effects were normal and expected, but it was still hard for her to see her son uncomfortable.

R: But I did, I still did the research because when they gave me the medication *I was kinda hesitant after he was on it because he was just going through all these changes. But it was expected. But at the same time he was suffering. So I'm like no I can't do this even though it's expected,* like 4 to 6 weeks for, um, side effects or contraindications. He had to stay in the hospital for like 2 to 3 days so they could see the negative effects of the medicine. So being as though I went to nursing school I know a lot. And um, I was like no, no, *I'm not gonna have his stomach hurt. And he's calling me from school, he's throwing up, he's moody, he's crying. But it's expected. But it was just too much for me.*

I: Right, yeah...to see you suffering, him suffering.

R: To see him suffer. Right? *Because when he suffers, I suffer. So I'm calling out, I'm asking, I'm asking, I even took him to his primary care physician.* He was having headaches. It was all this craziness. But now I think it's more stabilized. And he's still having symptoms from the medication but it's not as bad.

Through this process, Tamara was positioned to protect Ameer – she tried as best she could to help him cope with the side effects of his medication and did what she thought she could to make him more at ease. Solange had similar concerns, and took it further and expressed her worries about how the medication might impact her son, Omari's, school performance and possible suicidal thoughts.

My whole concern is the side effects. I don't want nothing that's going to have him hallucinating. Nothing that's going to have him feeling like he want to, oh excuse me, commit suicide, or, oh excuse me, nothing like that. Uh, so it just the point of finding him the right medication to get, and they had him on the Abilify and I felt like he was doing good with that. But all he would do is just sleep, and I'm like that's not good. And he would be sleeping in school. So I'm like what is he learning, he not learning nothing, so.

For Solange, protecting Omari came in the form of trying to make sure the medication he took worked well and the side effects were appropriately managed. She worried about hallucinations and thoughts of suicide because of the medication.

Parents' protective approach to the teenagers post-diagnosis was common in the data. As mentioned, parents were particularly aware of their child being negatively influenced by their peers and also about triggers, especially possible triggers of suicidal thoughts and behaviors. Due to these concerns, parents attempted to boost their child's self-esteem, becoming more aware of triggers that could set off a reaction in the teenager, and by protecting them by monitoring their use of psychiatric medication.

“Cause I’m more understanding:” Patience and Empathy

The second notable theme of changes to the parent-child relationship centralized on parents gaining more patience, empathy, and understanding of their teenager's thoughts and behaviors, which was reported by about 42% of participants. Learning about the teen's diagnosis and coming to understand what the diagnosis entailed helped caregivers and parents gain a different perspective on the teenager. This new perspective influenced the way parents approached and interacted with their teenager. When asked if she thought her granddaughter, Shree's, mental health struggles brought them closer together, pushed them farther apart, or there was not any change, Martha stated she thought it brought them closer, in part because Martha's understanding of Shree changed. Martha reported:

You know *with me understanding what she has been going through* as opposed to thinking she was just the baddest kid on the block, you know.

Martha's explanation here indicated that once she comprehended Shree's mental health struggles, it changed the way Martha, who was 61 years old, Black/African American,

and divorced, thought about Shree's behavior. In turn, Martha saw this understanding as contributing to bringing her and Shree closer together. Calvin, foster father to Andre, reported that knowing about Andre's mental health diagnoses impacted his interactions with Andre in that Calvin strove to be more loving. He shared:

Because one, you know, um, you try to go a little further in your parenting with a kid that's having issues. I did... So *you tend to be more open-minded, more, um, loving, to him because of his issues.* And he looked normal, you wouldn't think nothing was wrong but you saw, I saw issues that normal 11-year-olds wouldn't be dealing with, you know.

Kalvin explained that knowing what his foster son had been through and knowing his diagnosis made Calvin more open to Andre and Calvin made an effort to be more understanding of Andre's issues. He was able to understand Andre's past and empathize with Andre's struggles. Ellia had a similar experience with her son, Anton. Ellia shared that learning about Anton's depression enabled her to recognize some symptoms of depression in herself – which led to Ellia being able to empathize with Anton and relate to him.

I, um, didn't feel like I was depressed but I was. I didn't feel like I wasn't. I didn't feel like I needed the medicine. I didn't want to talk to a therapist or psychiatrist. *I didn't want to do any of it. Cause I didn't feel like anything was wrong with me. And I think that's what he was going through too.* He didn't think he was ADHD. *He didn't know if anything was wrong with him. So I guess we, um, I can relate here cause when, I when I read about depression when they started telling me about it I'm like, oh I do feel that way. So, I knew then I was really depressed.*

Ellia expressed that her recognition of depression symptoms in herself led her to relate to her son's experience of questioning his own diagnosis. Later on in the interview Ellia explained her feeling that everything she had gone through getting Anton help for his diagnoses brought them closer together. Ellia expressed feeling “more focused on what he's doing” and putting effort into “trying to help him to stay focused.” Her ability to

relate, and her empathy for Anton, led to changes in their relationship. When Lori, mother to Danny, was asked if the way she talked with her son changed, knowing Danny (11 years old) was struggling with depression, Lori, who was 44 years old, married, and employed full time, expressed being able to empathize with him.

Yeah because it's bad. Um, it's, let me say this, sometimes in your head it gets so bad that you just want to give up. But then you're like - you know others depend on you, and you try push a little more, but it gets bad sometimes. *So I deal with it myself, I can only imagine how it is for a kid. You know cause it gets pretty bad.*

Lori's own experience with depression and recognition of the diagnosis in her son enabled her to strive to understand what he was going through and this knowledge altered her relationship with him post-diagnosis.

Over time, through positive interactions with mental health care providers as well as parents increasing their own knowledge about the teen's diagnosis, participants reported feeling they gained an understanding of what was happening for their teenagers and this influenced how they, as the parent, began to patiently respond to the teen.

Dorothy stated:

The most thing that changed *was trying to relate to him in regards to his diagnosis. And that helped me a lot.* So instead of me being quick to get angry and to possibly yell at him, it's more okay I understand why he's doing this. *Maybe, you know, I need to be more patient. I need to stay calm and not react.*

Dorothy came to recognize that a change in the way she responded to her son may be warranted; relating to him through his diagnosis helped her get to this place. Dorothy also described that she felt she became more understanding of Kevin and eventually was able to adjust to meet his needs. Similarly, Juliette spoke about noticing her daughter Kira's cuts and scars resulting from Kira cutting herself. Juliette, who was 47 years old, White,

and married, talked of adjusting her own reaction, based on feedback from her own therapist, in an effort to show her daughter Kira (13 years old) she was attempting to understand what Kira was going through.

When she came back that's when I noticed there was a huge X up here, and like something underneath. And that when my heart just sank. But I remembered what my therapist said to me, and I was like ok my heart sank. Do you need a Band-Aid? Does it hurt? Do you need some Neosporin? Let me know if it starts getting really red. And I didn't want to say that I actually wanted to freaking strangle her, it was just like, like, what are you doing?

Juliette's reactions and behaviors towards Kira changed over time, once she gained a better understanding of Kira's cutting behaviors. Her empathy for Kira also changed as she struggled with depression and Juliette was more patient in her responses to Kira's cutting behaviors. Parents made an effort to become more aware of their own interaction with and disposition to communicating with their teenager. This awareness contributed to changing the parent-child relationship post-diagnosis.

“Because everything was ‘nothing’”: Communication between Parents and Teenagers

The third theme salient to the question of what changed in the parent-teenager relationship was the premise of communication. Around 45% of parents and caregivers reported communication with their teens typically improved over time post-diagnosis. Parents recounted how prior to the diagnosis, the teens would often isolate themselves. When parents either perceived treatment to be successful or the teenager's depressive symptoms to have subsided, they also thought the teenagers became more willing to speak with the parents and share intimate details with them.

Increased communication between the parent and teenager happened because teens became more open to sharing with their parents. Comparing before their involvement with mental health care to when the interview took place, Ms. Innis, mother to 13-year-old Tanay, described this change in the following quote.

R: *Because everything was 'nothing.' Like, 'what's going on?' – 'Nothing.' 'What's wrong?' – 'Nothing.' 'Why you in your room?' – 'I don't know.' Everything was just 'nothing.' 'I don't know.' There was no elaborating. None of that.*

I: And that was when she started to get some help? That's when she started to work with the therapist?

R: Right. And she, when they came they had a hard time because everything was 'nothing' and 'I don't know.' So, the therapist can't get past 'I don't know' and she can't get past 'nothing' if this is what you telling her. So, yeah. After the medication started to help her along the way, *she started to come out of that box and open up a little. And then she was – sometimes she would just talk to them. But now it's more so – she'll talk to me more than she ever did.*

Ms. Innis' experience was typical of parents who saw positive changes in their teenagers over time; the positive changes became evident in the increased amount of communication between the parent and child. Parents felt their child became less isolated and also did not just react, but rather talked and shared openly with their caregivers.

This change in communication was not just something the teenagers initiated, it was something the parents initiated as well. Perhaps linked to parents being more patient and empathic, parents learned to find pathways to encourage communication between themselves and their children. Ellia explained her experience as follows:

I mean *I just tell him to let me know how he feels.* It feel better when you talk about it and maybe we could find a way that make you feel better about it or what we could do about why you feeling the way you feeling about whatever it is. So, *we just communicate more.* Instead of just having a bad day. *I make him talk about it.*

Ellia took some responsibility in increasing the communication between her and her son Anton. She stated that she actively encouraged him to tell her how he felt. Ellia explained to Anton the benefits of talking about what he was going through. She even went as far as to say that she “makes him talk” – in a beneficial way. Ellia’s behaviors towards her son and his behaviors towards her changed post-diagnosis in that communication increased.

Parents not only initiated communication more, they also changed their perspective on the importance of good communication with the youth. Similar to Ellia, when I asked Tamara what she thought has changed for her and her son since he was diagnosed and treated for depression, Tamara responded that them talking to each other was what changed.

Because we talked about it. I mean we talk about it before we came here. Ameer told me that the reason why he was acting bad, the reason why he was doing the things to me, the reason why he acts the way he acts is because a voice inside of him was telling him to be mean to me and to do the opposite of what I tell him. So he told me that.

Tamara and Ameer reached the point in their relationship where they could have open conversations about Ameer’s misbehaviors. Later on Tamara stated she is “more aware of why he was doing the things he was doing,” indicating her understanding of her son’s diagnosis changed through increased communication.

Linda also described how she came to communicate better with her daughter, Lindsey. Linda was 59 years old, employed part-time married, and the mother of 17 year old Lindsey. Linda expressed that for her as the parent, she needed to learn to listen to her daughter better and that contributed to changes in their relationship post-diagnosis.

But I know it’s different now, you know, from when I was brought up. You know you have to be seen and not heard. See I know now that children has a right to be heard as well as seen. I had to learn that. I’m still learning.

For Linda, learning to listen to her daughter became an important part of the change to their communication; prior to Lindsey's diagnosis and involvement with mental health care Linda defaulted to the idea that children should be "seen and not heard."

Shira, 52 years old, highlighted how recognizing traits in herself that her daughter was replicating helped Shira encourage positive communication between herself and her daughter. Shira described the changes to her relationship with her daughter, Erica, 17 years old, as follows.

I'm not one of those people who really don't open up and talk to people. *You know I just basically keep everything inside, you know, and I found out that it's not good for me, because you know it could actually hurt me. So and my Erica does the same thing and its worst with her. Um and I keep talking to her to let her know, that she has to let out. You have to let it out you cannot hold that stuff in.* It is not hurting the person that it's directed to it's hurting you. And uh were dealing with this and I want you to be better and you have to, you have to, *you have to talk about it. Whatever it is you have to talk about it, you have to work through it.* And uh and I'm her biggest supporter, you know a mom's always there.

Shira's own disposition to talking changed when she noticed how detrimental it was for her daughter to observe those behaviors. Shira and Erica's communication changed when Shira took the position of encouraging discussions between them; Shira explained to Erica the benefits of sharing what was on her mind. Carla, grandmother to Malik, talked about how knowing her grandson was struggling with depression made her more conscious of talking to him and spending time with him. She stated:

I had to help him as much as I could. He would come home with his homework and stuff. I would help him with his homework and *I would sit there and talk to him.* We played games together.

In sum, parents' reports revealed that the amount, quality, and content of communication they had with their teens changed post-diagnosis. This change was attributed, in part, to

the teenagers effectively learning to manage their diagnosis and also to changes in the parents. Parents began to initiate conversation more often and their perspective on the importance of communicating with the teens was also altered post-diagnosis.

“Let them know that’s right and what’s wrong:” Teaching Accountability

The fourth theme apparent in exploring the dynamics of the parent-child relationship post-diagnosis was the theme of teaching the teenagers accountability, which was reported by about 66% of participants in this unique sample. Faced with the information that their child was struggling with a mental health disorder, it appeared important for parents to instill in their teenagers the idea that success was still obtainable and the teen was inevitably, independently responsible for getting there. Parents and caregivers spoke of how eventually the youth would have to take care of themselves one day, so parents strove to do what they could to prepare the teenagers for this, especially with the added context of struggling with a depressive disorder.

Parents and caregivers expressed to their teens that the diagnosis was not to be thought of as something holding them back. Anita talked about her goals for her son, Tommy. She shared she wanted him to graduate high school and not go to jail, and she also wanted him to not let his diagnosis be something that deterred his success. She stated:

And to not let his diagnosis make him. You know, if others say ‘That’s the boy, don’t he have something wrong with him?’ ‘He look alright to me.’ You know, looking fine, being fine – and being able to manage without my help. And being able to say – you know what I’m still struggling. Let me go ahead and continue with this – even though I’m an adult now. Let me go on and move forward so what I went through as a child I don’t go through as an adult.

Anita’s intention was for Tommy to be able to manage his mental health on his own and continue with his treatment into adulthood if he sees fit. This intent became part of her

approach to parenting post-diagnosis. It was similar for Cathy, the caregiver to 14 year old Jimmy, who explained that bringing Jimmy into her family gave him some structure. She believed she was able to teach Jimmy what behaviors will and will not be tolerated, and that overall he should see himself as someone who can persevere beyond his diagnosis.

I think as a family, we always been close as a family in this house. It gave Jimmy some structure it makes Jimmy know how a family is supposed to be. You know, which it makes him; it lets him know what he's supposed to be doing. *Let him know that's right and what's right. What should be tolerated and what shouldn't be tolerated. How to grow up to be a man and be somebody. You don't have to because you suffer from what you suffer... people live with this everyday and they survive with it and you can survive too.*

It became important for Cathy, who was a 48-year-old unemployed widow, to make it clear to Jimmy that he will survive beyond his diagnoses and also that he should not use it as an excuse for his behavior or for him not growing up to “be somebody.” Jimmy came to live with Cathy after Cathy found out he was being neglected by his biological mother, whom Cathy reported was struggling with schizophrenia. Marissa, foster mother to Adam, put it this way:

The real world does not care when you're an adult, what your problems were as a child. So, knowing that is you have to be able to function, *you have to be a productive member of society.*

Her parenting approach to Adam included the component of needing to be able to contribute to society in a productive way.

Parents wanted the teenagers to also be accountable despite any treatment they received. It was important to the parents that their children learn to control themselves. Ms. Innis described the conversation she had with her daughter, Tanay, about this topic.

So what I had to do is like instill in her head, and myself as being her mother, *you don't need medication to control you. You don't need these people to control you. Cause can't no body control you but you. So if you don't wanna then you are not gonna.*

Ms. Innis described making it a point to instill in her daughter that Tanay is accountable for her own behavior. No therapist or medication could or should control her. Rather, as Ms. Innis saw it, Tanay needed to want to control herself.

Another way parents strove to teach accountability to their teenagers was helping the teens learn how to manage their own mental health issues. Obtaining treatment and talking through any depressive thoughts were seen as ways to move past the diagnosis. Parents relayed messages to the teens that if they regularly took their medication and contributed to their therapy sessions, it was a way for the teenager to become invested in their own future and success. Ms. Henry spoke of how she talked with her grandson, Ty, about her desire for him to be successful despite his depressive disorder diagnosis. She explained how she talked with Ty about this topic as follows:

I says, so you need to talk to somebody cause I want you, baby, to go on with your life and I want you to be able to focus and to be very successful with your life. When you have anything hanging over your head like that you can't be successful. It will beat at your head at you. And I said it might even make you feel like you want to kill yourself, so, you want to make sure, you know... Sometimes kids be saying no, and you never know in your life.

Ms. Henry recounted her explanation to her grandson of why it was important for him to discuss his depressive thoughts; her interactions with him were different as a result of the diagnosis. Knowing his struggles and still wanting him to be successful, Ms. Henry urged Ty to become accountable and take care to meet his own needs.

Participants viewed themselves as cultivating responsibility in the teenagers and also recognized the teens could learn accountability from other sources as well. Tina (57

years old) spoke of wanting to teach her 17 year old granddaughter, Ashley, to take care of her own mental health and drew a comparison between how Ashley's mother, Caleena, did not take care of herself or her bipolar disorder diagnosis, but other family members do.

That it has to be done and that shows Ashley to be responsible for her illness. And also seeing her cousin, cause Iyana is her cousin and Iyana and Caleena, they're the same age, and bipolar – and that helps too. Cause she, you know, I think it helps when you see other people in your family take responsibility for their illness.

For Tina, getting Ashley to the place where she is responsible for her illness and proactively taking care of herself is important. This strategy became part of the parent-child relationship post-diagnosis. Enabling the teenagers to have the motivation to and knowledge of how to manage their own symptoms was important for these parents.

The last way parents attempted to teach their teens to be accountable was by having boundaries in their relationships with their teens and rules in their homes.

Lakeisha was 41 years old, unemployed, married, and the mother of Oscar. She spoke of how she asserted herself as an authority figure to Oscar, and in this way, she established rules and regulations that Oscar was accountable to.

And I never feared my son, I never feared anything. Like I told him, I'm still the mother and I'm going to run my home whether you want to be in it or you don't. But if you let them think that you fear them, they will run all over top of you. No child of mine is going to break my arm. No child of mine is going to make me give them what they want, even if I say no. You know, and you still have to have, anywhere you go you gotta have rules and regulations.

For Lakeisha, establishing boundaries in her relationship with Oscar was important to teach him responsibility. Lakeisha's reasoning for doing so extended beyond her own household – she tried to impart to Oscar that anywhere you go there are going to be

guidelines for behavior. Eve also spoke of boundaries in her relationship with her daughter Dawn. For Eve, boundaries were an important part of her making sure Dawn learned what behaviors were acceptable within the family.

You just have to be a parent instead of being your child's friend. *You have to be a parent. You have to put your foot down at some point in time. If you don't then they're gonna walk all over you.* Excuse my language, I'll be damned if they walk all over me. I ain't having that.

The boundaries established by Eve helped cement her as an authority figure to her daughter and was a piece of molding Dawn's behavior. Solange's experience was similar. She shared about finding herself providing "tough love" to her son, Omari. Solange's explanation of her exchanges with her son indicated she wanted him to be accountable to his actions.

So there would be times where I might not even speak to Omari. And I'm just like it's tough love time right now. And I'm like because I refuse to have ways that you feel like you can disrespect me and then you come to me and like "oh can I have." I was like uh, you not going to have that type of relationship. I was like no, *I was like there is going to be a line where you are going to respect me.*

Solange attempted to instill in Omari that he had to respect her; her approach to this parenting behavior included not speaking to him when she felt Omari disrespected her.

To summarize, changes to the parent-child relationship post-diagnosis took four forms. Parents' own behaviors changed in that they became protective of the youth post-diagnosis. Parents' reports also displayed evidence of them becoming more empathetic, patient, and understanding upon learning of their teenager's mental health struggles. Participants shared they saw both themselves and the teenager contribute to better communication between the parent-child pairs. Lastly, parents described striving to teach their teenagers to be accountable as part of the post-diagnosis parent-child relationship.

Chapter 6: Parental Involvement in Mental Health Care

In this chapter, I address the research question, “How do parents make decisions about their involvement in their adolescent’s mental health care?” as well as the two sub-questions “What encourages increased parental involvement in treatment?” and “What barriers inhibit parental involvement in treatment?” Participants were asked to describe the ways they were involved in their teen’s mental health care and how they made decisions to be involved in treatment. Interview questions explored what parents believed helped them to be involved and what hindered their involvement in the adolescent’s treatment. Through these questions, several themes emerged which explained the process of decision making for the participants in the sample, as well as the context within which decisions were made. Lastly, the meaning parents attributed to their decisions and their level of involvement also became apparent. It should be noted that for these families, receiving the mental health diagnosis and securing treatment came in tandem and were closely related. The goal of seeking a diagnosis often is requisite to be able to engage in treatment (both therapy and medication); in order to obtain insurance reimbursement for mental health care treatment for Medicaid and other forms of insurance a diagnosis code is required.

Agency in Decision Making

Parental involvement in adolescent mental health care for the participants in this sample began when parents perceived the mental health care provider to make a recommendation and then the parent provided their consent for treatment. Parents reported that the suggestion for a treatment modality (such as individual therapy, family therapy, or medication) often came from the agencies which provided mental health

services. Parents regularly agreed with whatever treatment plan the agency recommended and thus gave consent to their treatment strategy. Parents viewed treatment as the family getting the “help” they needed. The way parents spoke about making decisions about their teen’s mental health care indicated parents felt they had agency in the process – that their consent, their say, their agreement was a necessary piece and that their actions produced a particular result. When asked how decisions were made about getting her daughter, Lindsey, individual and family therapy sessions, Linda put it this way:

They did an assessment with her and they was saying that, I was telling them everything that was going on and so they suggest to have a therapy and also have a family therapy. I said I wanted both.

Reflecting on this experience, Linda explained treatment options were presented as after the diagnoses were received, and the suggestion for two modalities of therapy was made, and she then agreed to both. Similarly, when Ellia was asked how it was decided that her son meet with an individual therapist weekly, she reported the following.

*Um I guess ABF [the agency]. ABF, when I had him, when the doctor for this came out. I had him evaluated; she told me *that he could do therapy. He could do one-on-one therapy. So I said okay. I wanted to try it. I told her I would try it, whatever it would take to get him back on track.**

Ellia traced this decision making back to a suggestion from the agency that provided the diagnosis. As she remembered it, the doctor who evaluated her son was the one who first suggested he obtain individual therapy. Ellia saw this as a suggestion and decided to consent because she thought it would be helpful to her family.

Parents typically expressed agreement and approval of the therapy treatments suggested. Ms. Coldwell explained her daughter was receiving individual therapy at the time of the interview. When prompted to think about how decisions about getting Tara therapy were made, Ms. Coldwell stated:

Well yeah, I mean, I kind of agree you know because the, all I saw like the behavior just getting worse. You know, it was kind of coming more frequent so. You know, once I did the intake at the, at the place, I kind of, I agree. You know. I knew that she needed, needed some therapy. Needed something probably that I wasn't able to do, I'm not a licensed doctor so I don't know how to talk to her in ways to get through. Yeah so I agree with the counselor when she said... When we was going to create a plan for Tara and then they, they talked to Tara herself and they got a clear picture of, you know, what would probably be best and that what would work. And you know, I agreed and we agreed on certain days depending on our schedule.

For Ms. Coldwell, the context of deciding on getting her daughter mental health care was that she first received the diagnosis and soon after a recommendation was passed to her from the counselor. Ms. Coldwell expressed that her agreement to get Tara therapy was a way to help Tara with her struggles, she saw her agreement as collaborative, indicated by her use of the pronoun “we.” Furthermore, in this quote Ms. Coldwell also expressed how she had to recognize that as the parent, she did not have all the knowledge and skills needed to help Tara effectively manage through her mental health struggles. We can also see through this quote Ms. Coldwell’s recognition that her daughter needed help beyond what Ms. Coldwell could provide – aligning with the theme of “I need help” mentioned above.

The process of engaging in mental health care therefore started with a recommendation or suggestion from an agency or provider. Parents and caregivers next had the ability to take these suggestions or not. In this sample, parents regularly accepted the suggestions from the agencies and agreed with the treatment modality proposed. This process enabled parents and caregivers to exercise agency in decision making. Parents reported considering their own ability to address their child’s struggles and affirmatively securing help when they realized it would be beneficial for their teenager.

Parents as Active Participants in Mental Health Care

Exploring how parents made decisions about their involvement in their adolescent's mental health treatment yielded the theme of parents as active participants in care. Parents talked about being involved in their teen's treatment in ways which might typically be anticipated. Parents scheduled and confirmed appointments, escorted their teenagers to treatment, refilled and picked up prescriptions, and strived to make themselves available to the mental health professional when requested. Beyond coordinating treatment in these instrumental ways, parents also described perceiving their involvement as beneficial to the therapy process and to their teenager. Participants talked about wanting to help the teenagers experience symptom reduction, seeking advice from the therapist, and desiring progress updates on how treatment is going. Involvement, to these parents, meant actively helping the teenager get better by their participating in, contributing to, or being aware of what was happening in their child's mental health care. For example, Marissa, foster mother to Adam, described her interactions with Adam's therapist as follows:

So yeah, um, I would ask them, you know, well what is it that we can do at home to make this work for him? And I would get, you know, them to give me information of what they were working on so I could piggyback on and so that we can make it work.

Marissa took the initiative to assert herself into the treatment process. She intently inquired for feedback from the clinicians about what she might be able to do to “make it work” – as in help treatment be more effective and help Adam overcome his mental health struggles. Mary had a similar perspective about her involvement in her step-son Andrew's care. Mary was 46 years old at the time of the interview; she was never married and unemployed. Mary shared:

And a lot of these therapists and stuff was coming to us like “Well, what are y’all doing to improve that he don’t...? *I’m like I don’t know what to do that’s why I’m sitting here talking to you to help me figure out what to do...*”

Mary’s perspective of her step-son’s treatment was that the therapists should utilize some of the time to talk with her, to help her “figure out what to do”, to better interact with and help Andrew, who was 18 years old. Mary’s position demonstrated that she wanted to be involved; she did not want to be a passive bystander to Andrew’s treatment.

While parents tended to conceptualize themselves as active participants in their teen’s treatment, not all parents and caregivers felt they were given this opportunity by the mental health care providers working with their children. Ms. Henry, grandmother to Ty, spoke of how she wanted to be more involved in her grandson’s treatment, yet she felt the burden was on her to make this happen in her interactions with her grandson’s therapist.

I have to keep saying, How is Ty doing? What’s going on? All they do – all she do – it’s weird. They come in my house. She talks to Ty or whatever. I sign the paper and she leaves. I want to know when are you ever going to say Ms. Henry, come down and talk. Ty’s progressing. He’s not progressing. This is going on....he’s a child. I’m, I’m his guardian. When are you going to sit down and talk to me?

Ms. Henry went on to further describe how she perceived herself to be able to help as an active participant, if given the chance by the therapist.

But like I said she never says Ms. Henry...or calls me and says – you know. I have to say “Ms. M. how are things going with Ty?” and she still just keep it real simple. And I’m like – we are not in a court of law and it’s not like what Ty say can’t be discussed like with the psychiatrist. There really should be something discussed with me about what’s been going on with Ty.

It is possible Ms. Henry misunderstood the bounds of confidentiality during therapy sessions. Still, she strongly stated how as Ty’s guardian, she had a role in his treatment,

which at the very least could mean updating her on how Ty is progressing. Carla, grandmother to Malik, had a similar experience. When asked what she would have liked to be different about Malik's mental health care, she said she would like to be more involved.

They didn't necessarily let me stay back there... but at least call me in before they brought him out and *let me know like what was going on - if he needed more help or needed me to do something more or something different you know but they didn't.*

Carla would have liked to be included more in Malik's treatment; she was open to receiving feedback about her own parenting of Malik and if there was something she could have done differently to help him improve. In sum, for parents in the sample, one context of decision making was parents' perceptions of themselves as active participants who were able to influence the effectiveness of the treatment and outcomes for their teenager who was struggling with depressive disorders.

“Help me help my kid:” The Collective Benefits of Parental Involvement

Building upon the theme of active participation, parents also perceived their involvement in their teen's mental health care would be mutually beneficial to both them and their teenager. Parents described that their involvement in their child's mental health care was self-reinforcing; parents saw their involvement as a way for them to fulfill their job as a parent. The context of acquiring care for the teenager was a venue through which they could demonstrate their commitment to their child's well-being and success. Eve expressed this theme in this way:

Cause I think things will be better if I be involved with her therapy sessions or if it's just between her and the therapist, *and Dawn may say where's my momma? Like why am I always meeting with you by myself? That's the stuff she will say. So I don't go because she will say that, I go*

because I feel as though that's my child and I need to be there....she can't back herself up. I need to be there to back her up. So that's why I go.

Eve's involvement in her daughter's treatment became how Eve showed her commitment to her daughter, and this would help both the parent and the child. Similarly, Ms. Pilsin saw her involvement with her adopted son Chris's mental health care as a way of showing Chris her commitment to him and to getting him help.

I would say "Chris, we are trying with you." So if later on down the road you don't take the help you can look back and *say at least mom did try*. You know, at least someone could see it that way. I don't know how he will see it. *You can't say I never did try with you. I was there and I went through it* – regardless of what you tell people.

Ms. Pilsin saw her involvement as a way to show Chris she was committed to him and would be there with him through his struggles. She saw her involvement as something Chris may look back on and appreciate – that "at least mom did try" – she was there for me, she put effort into helping me. Framing her involvement this way seemed to help Ms. Pilsin see value in her actions in both the short and long term, especially as it related to her relationship with her son.

Parents reported that they learned and benefited from their child's engagement with mental health care. Parents and caregivers felt that their child's participation in treatment ended up helping the parent understand the teen more. Tamara described that she appreciated hearing explanations from the therapists about what her son was feeling and experiencing in a "kid-friendly" way; this helped Tamara feel confident her son was gaining an understanding of his depression. Joy, foster-mother to Katrina, described her perspective on her involvement in treatment as a way for Katrina to see what a priority she was to Joy.

I put my kid first. I put myself into my kid's position. If all's he going to do is come and drop me off and you sit out there and read a book, are you really interested in what's going on with me? So, for me to know what's going on with my kid. I insert myself and I want five minutes with your time. I want her to have the bulk of the time because she needs more help than me. But I want you to tell me; okay you've met with my kid. What can I do better and different? What is it I need to understand about my kid? What is it that my kid is going through that I may not know? Help me to help my kid.

Ellia's similar perspective was as follows:

I just was curious to understand what he was thinking. I thought that that would help. Just curious that's all. Just wanted to know, or try, curious of what it is that I'm suppose to do or what I can do to help the situation cause it's starts with me I gotta be able to, I gotta know what to do to help him.

Their involvement was seen as having collective benefits – for both the parent and the teenager. The parent/caregiver gained knowledge about mental health concerns, mental health treatment, how to interact with their child in a healthier way – and this ended up improving their relationship with the teenager. Ms. Henry believed that her involvement in treatment will be useful to both her and to Ty.

I want to be aware of things. He's my grandson and I'm not just going to sit him out there and tell him to fly into the wind. Oh no. So, yeah, I need to know these things. It's going to make it better for me and Ty to know.

Furthermore, some parents reported that having their child in mental health treatment had improved the parent's own well-being. Ellia explained that getting her son care helped her stay active and motivated.

Just the fact that I love him and I want him to do better so it's helping me to be very involved. Yeah, just that. And I, the school part. I'm really worried about, I want him to get on, on track. It's helping me to stay motivated get up, take him to it, whatever appointment he has. Make sure he taking the medicine. Checking in on what the teacher and with the principal and making sure their letting him know, that they see him changing. Because when he was doing negative they let him know they

saw that. So I want them to let them know that I see that you're doing good.

Therefore, parents' decisions to be involved in their teenager's mental health care started with their goal of getting their child help, but progressed beyond this initial goal to result in benefits for both the parent and the child. Parental involvement in treatment helped parents validate they were fulfilling their duties as parents. Parents also saw their involvement as mutually beneficial to both them and the teens; parents perceived their involvement helped them as parents, and that their improved parenting could enhance their relationship with their teenager.

Encouragements of Parental Involvement

Parents and caregivers were also asked to consider what has helped them be involved in their adolescent's mental health treatment. This exploration sought to address the research question "What encourages increased parental involvement in treatment?" Three themes of encouragements were apparent in the data. The first pertained to parent interactions with mental health care providers. The second explained the context of parents own experiences with mental health care and how this influenced their involvement with their child's treatment. The third related to how parents coped by turning to their spirituality.

"They show concern for my child:" Mental Health Care Provider and Parent Interactions

The first theme that explained increased parental involvement in their child's mental health care was the nature of the interaction between the parents and the mental health care providers and the care the providers displayed to encourage parental involvement. Parents and caregivers reported that when the therapists and clinicians made

it a point to talk directly with the parents, this encouraged parents' involvement and assisted in parents feeling like their involvement would be helpful. Parents appreciated feeling like the mental health care professionals were making parental involvement a priority. When asked what has helped her be involved in her nephew's treatment, Caroline responded as follows:

The fact that I was invited in. And the fact that I was invited in by [the therapist] in the beginning helped me understand and wanna be there. Uh, also the fact that the things that we do, you know, that she talks about with him and he expresses, I wanna be there to hear those things. I wanna be there to, you know, see how it is that he is getting better. See how I can help, however I can participate in those, those events. So it really has been beneficial to me too because I wouldn't know how to deal with this on my own. I, I barely know how to deal with my own depression.

We can also see in this quote how Caroline came to see her involvement as mutually beneficial to both her and Denzel; it helped her help Denzel. She acknowledged that she initially lacked knowledge and that Denzel's treatment educated her on how to better interact with her nephew. This quote also exemplifies Caroline's commitment to being actively involved in Denzel's treatment; she wants to "be there" to see and hear how he is getting better as well as how she can "participate in those events."

Seeing someone outside of the family dedicated to helping the teenager overcome the current challenges they faced was transformative for parents. The commitment and dedication displayed by some of the mental health care providers ended up strengthening parents commitment to their own involvement in and dedication to their teenager's treatment and future. When asked about how her interactions with her daughter's mental health care providers shaped her own involvement, Linda, mother to Lindsey, put it this way:

They helped me to appreciate that you know, *they showed concern for my child* as well, and I saw that. And so when I was, you know, you know. *So when a stranger don't even know my child, they putting all of their effort to come to help her to get on the right track, to help her thinking ability. You know what I'm saying? How to reason. And hey, I have to get involved, you know.*

Caregivers and parents took note of when they felt like the providers went outside the scope of normal practice to provide care to the teenagers. Ms. Innis spoke of her daughter, Tanay's therapist as offering that Tanay "call her at any time." Ms. Innis saw this as the therapist's dedication to Tanay's well-being. Shira reflected on her experiences with her daughter, Erica's mental health providers by discussing how the providers made it a point to keep Shira informed, and this has helped her see her daughter's progress. Shira also noted her perception of the effectiveness of therapy and of the relationship established between her daughter and the Community Support Worker (CSW) as beneficial to Erica.

Yes, they, uh, *keep me informed*. I can see her progress that she's made you know I could see the progress you know. Uhh her CSW um, Ms. L. *She has done a wonderful job with her you know she comes to see her, she checks on her when she's in school, um, you know, she comes takes her places you know she talks to her regularly. You know they text each other and you know and it's good that my daughter really likes her you know and she opens up to her.*

Similarly, when Anita was asked what helped her be involved in her son's treatment, she stated the following.

Just asking. You know, just allowing me and not taking over because you're the therapist, the psychologist. *Allowing me to still be a part of the plan. Asking me my opinion.* You know, what I think. All that. *It helps me feel confident that we're working together for a greater cause.* So that's how it kinda comes out.

When mental health care providers demonstrated concern and commitment towards the teenager as well as made overt efforts to include parents in care, this positively

encouraged parental involvement. Parents and caregivers noted when they felt the mental health care providers went beyond the scope of normal practice to attend to their teen's needs, and that this both helped the parent want to be involved more and helped the parent realize their involvement could be beneficial to both them and their teenager.

“Because I deal with it myself:” Parents’ Involvement Shaped by Their Own Mental Health

The second theme regarding what encouraged parents involvement in teen's mental health care related to the parent's own mental health. When parents had personal prior experience with mental health care, they used their experiences to understand what their child was going through, and this helped them get their child help and to be involved in the treatment. Trying to prevent their teenager's struggles from becoming more severe was also mentioned as part of what encouraged parental involvement in treatment. This theme was explained by Solange as follows:

*What helped me be involved is just making sure he gets the help he need because I don't want him slipping through the cracks. And um, *being an adult with mental health issues is not good. Because I just, it's just something I see in myself. And I feel like me at 40 I shouldn't still be dealing with anger issues. So I want to deal with his before he gets to my age.**

Solange's personal experiences struggling with anger issues as an adult enabled her to see the benefit of getting her son, Omari, mental health treatment and also of the importance of Solange's involvement in that treatment. Solange took responsibility for Omari's treatment in stating “I want to deal with his...” She saw herself as positioned to help her son. Similarly, Juliette described the depressive phase of her bipolar disorder in depth and followed it up quickly with a statement about her daughter, Kira's, own mental health.

I went through complete depression where I mean like brushing my teeth was like climbing a mountain, you know. And uh, but my husband was always here for me and he took care of Kira. And I always had, when I went through these depression moments, I always had someone, like she was like on the top of my mind. Like, ok, *as long as someone is taking care of Kira*. You know, and yeah I'm sure she's mad at me but you can't, can't help it if you're depressed. I mean I finally started getting help in October and got on medication, and finally getting my ass out of bed, and enjoying life again, you know. *And I just I want Kira to get help*.

Juliette's continued commitment to Kira appeared in her statement about making sure Kira was taken care of while Juliette was going through her own depression. Now that Juliette got herself help – her focus turned to advocating for help to meet Kira's needs.

It became apparent that parents and caregivers were able to leverage their personal experiences with mental health care to then be involved in their teenager's care. Parents' personal experiences with mental health care occurred at various time points in their life, with some parents simultaneously receiving treatment (therapy or medication) at the same time as their adolescent. Ms. Henry talked about her own experiences with depression and taking medication to treat it, which she deemed quite effective and beneficial to her. Facing her grandson's (Ty) depression, Ms. Henry expressed wanting to advocate to the mental health professionals Ty was working with to consider placing him on medication as well.

R: But I – *I'm gonna let her know that she [the psychiatrist] could put him on Prozac. And I, I prefer Prozac. Prozac was the best thing they ever put out*. I, I been on other medications – and it's not doing it. When I take Prozac, it's good. I've been doing it since I was in my 30's.

I: Right, so the psychiatrist doesn't think he needs to be on medication until a little while – until he feels safer.

R: No, she didn't say anything to me yet. Nothing.

I: Oh, ok, she didn't explain it.

R: She didn't explain it. So that's *why I have to call there and talk to her. And I am gonna talk to her in person.*

Ms. Henry's own experience with Prozac led her to believe this might be an effective form of treatment for her grandson. She felt encouraged to involve herself in Ty's treatment and to make the recommendation that Prozac be considered as part of the treatment plan. We can also see here that Ms. Henry expressed her desire to be an active part of Ty's care, as previously described.

Parents spoke that recognizing the symptoms of their own mental health struggles helped them notice such symptoms in their teens. This recognition encouraged the parent to be involved in the teen's treatment. Anita spoke about learning about her own depression and the different ways depression can be expressed. She talked about better understanding the many ways her son Tommy's depression can show itself in the following quote:

To me depression has a variety of faces, I know because I deal with depression myself. Um, so to me, people think that depression has to be, no. You could be very upbeat, you could be very motivated but you learn how to keep what has you, a way, from what people see, so they don't know that dirty little secret, and half of the world has that same dirty little secret.

Anita also normalized the experience of having depression by stating that "half the world has the same dirty little secret" – as in half the world is struggling with depression. Her personal understanding of the mental health concern and her knowledge about its prevalence both encouraged her to be engaged in Tommy's treatment.

Parents and caregivers used their own experiences with mental health care to normalize receiving mental health treatment. They tried to lessen stigma and negative ideas about mental health care by offering up information about their own experiences

and their own success receiving treatment. Some parents spoke of how they and their teen took their respective medications at the same time. This experience doubled as a way for the parent to monitor the youth's medication consumption and also to normalize the experience of taking psychiatric medication. Lori spoke of her son Danny's gesture of help towards her by getting both of their medications, so they could take them together.

The medicine cabinet is right here. I tell him to go get it, he know what it is. He starting to get like, um, I have him go get it. He knows which one it is, um, that's his little way of - because he always wants to help me. He's into this thing that he always wants to do something for me, so in the mornings getting ready that's his little thing to do. *He go get his and he go get mine.* And I take way more because I take like three different high blood pressure medications *but he go get all the bottles, he know my side is one side, his side is the other side.*

Lori's approach to her son's medication was to make it something they could do together.

Adrian, 53 years old, spoke of talking with his step-daughter, Lashauna, and trying to encourage her into treatment. He explained:

Now the point I try to get across to them *is because you see a therapist or psychiatrist, it don't mean you're crazy*, you know. So when I found out about [the agency], I hurried up there. You know, trying, because I said if I don't I'm going to go crazy. I'm really going to go crazy. I've been working since I was 17 years old and I'm 58 years old. And I'm not used to sitting around doing nothing; driving me crazy just sitting here. Lately, I just try to do a lot of spiritual reading to keep my mind set, to keep my heart set. I found that, um, since I've been going to [the agency], especially when I see Ms. J...that lady is great.

Adrian felt without seeking treatment for his own depression he may really "go crazy", and spoke with his step-daughter about how much he has benefited from meeting with his therapist in an attempt to encourage Lashauna to partake in regular treatment herself.

Other Exposures to Mental Health Care. In addition to parents and caregivers who had their own experiences receiving mental health care, another salient context apparent in the data was parents' exposure to mental health care through other family

members or from employment positions. When parents and caregivers were prompted to recall if they had interacted with the mental health care system prior to obtaining the diagnosis for their teenager, in addition to speaking about being in therapy or taking medication themselves, parents also pointed to immediate or extended family members who had received mental health care. These family members' engagement with care may have made parents' involvement easier, knowing how to navigate the system from helping another family member or feeling confident they could because a family member already had. Tonya spoke of how her two younger sons both had diagnoses of ADHD and were already receiving therapy services at Families Together when it came to light that Felicia was struggling with depression. Tonya decided to contact Families Together to see about getting Felicia help; Tonya chose to reach out to the agency she had a prior relationship with and to consult with the staff there on treatment for Felicia.

The next context through which parents were exposed to mental health care was through their own employment positions. Working in the field, for example as a nurse or at a group home, positioned parents to learn about mental health diagnoses, symptoms, and treatment. Parents used their knowledge gained from these experiences to both initially seek out the diagnosis and also to become actively engaged in the services their teenager received. Lakeisha spoke of her prior employment position as providing her insight into how to manage her own son's mental health concerns.

I work with Alzheimer's units. I work with all of them, dementia, everything and depression. I would do like psych patients and stuff like that too so. So I really, when you work at places, they don't really give you in depth of everything. I mean some of the families, they share a lot of stuff with you. So you really have to know how to deal with them, even with talking to them. Some things you want them to do, the family can't get them to do. You have to approach it a different way. And some of them become combative. So you have to, like I said, they become more

combative if they think that you fear them or you don't know what to do for them you know. So, you really have to, *because I've been in the medical field, like I've said I've been doing it for fourteen years.*

Lakeisha's experiences working in the medical field with adults exposed her to the type of care needed and different approaches for working with challenging populations. She counted this as experience with mental health care and therefore the knowledge gained and comfort level obtained by having this experience may have helped her get involved in her son's treatment. Parents' own experiences with mental health care or their exposure to the mental health care system through family, friends, or work all helped encourage parents' involvement in adolescent mental health care.

Spirituality

The third salient theme of encouragements came from parents and caregivers who reported being spiritual; spirituality was a coping mechanism for parents. Parents reported that praying provided them with support and comfort as they managed their child's mental health struggles. Praying and turning to spiritual figures enabled parents find a sense of calm within themselves, which then facilitated their active engagement in their teen's treatment. Parents did not talk about a direct connection between the mental health services obtained and spirituality. Rather, spirituality and prayer was a personal experience for the participants, which helped them cope with managing their child's challenges and helped enable them to sustain their involvement in their care. Shira put it this way:

My perseverance, uh, that comes from God. He's number one in my life and he gives me the strength to keep moving forward even when I don't see a clear way. You know, and I constantly talk to him every day and I ask him for strength to keep moving on, to give me the will, the knowledge. You know, give me a sign, you know, that I'm doing the right thing, you know, as her mother.

Other parents shared a similar perspective, that praying to their god enabled them to “have faith” and to “keep going.” They prayed for themselves and for their teenager. These participants also noted their spiritual beliefs were a part of their motivation to obtain help for their child, that children are “a blessing” that should be protected. Participants talked about how prayer and spirituality was a personal comfort, enabling them to cope with their current stressors as well as have hope that their teenager will have a healthy future.

In sum, for participants in this sample, these three encouragements to parental involvement in treatment were seen in the data. When parents and caregivers had positive experiences with mental health providers who shared the parents’ perspective that they should be active participants in mental health care, parents expressed this interaction helped them be involved in the youth’s treatment. Additionally, parents who had personal experiences with mental health care used these experiences in several ways to be involved in their child’s treatment. Parents’ involvement was shaped by their own mental health in that they felt they could empathize with their child’s struggles, having been through something similar challenges themselves. Parents also used their own involvement with mental health care to normalize the experience for their teenagers. Lastly, turning to one’s spirituality helped parents cope with their child’s struggles. Parents turned to their spirituality for a sense of guidance, relief, and comfort, which then further enabled them to be actively involved in their teen’s mental health care.

Barriers to Parental Involvement

Parents’ perception of the barriers that inhibited their involvement in the teen’s mental health care was compelling to explore. When I asked parents what made it hard

for them to be involved in their child's treatment, parents responded "Nothing." These parents initially could not think of anything that made it challenging or difficult for them to be involved. In this vein, Ms. Innis exclaimed "Nothing comes in between getting her the help that she needs" when asked about barriers to being involved in daughter, Tanay's mental health care. Still, when these parents were probed further and compared to other parents who did think they faced some difficulties being involved, these barriers can be described as two themes: family or self as an obstacle and lack of resources.

Family or Self as an Obstacle

Parents spoke of concerns within their family, with specific family members, or of personal issues which could impede their involvement with their teen's mental health care. Personal issues included discussions of one's own physical health and how tiring or strenuous it felt at times to keep up with the teenager and their care. When asked what might make it difficult to be involved in her son's treatment, Solange put it this way:

Just my health issues that I'm facing now. That I was not facing a couple years ago, and it's just like everything is kind of just like hitting me all at once. Cause I get over one obstacle and then there's just another obstacle just come and slap me in the face. So with that being said I'm just like after Omari said something about my back I was just like oh wow. And then to go back to the doctor and find out I might have lupus I was just like oh wow. So I was just like I'm just going to wait until I get retested and put my faith in god and just ok well I'm hoping I don't have lupus. So, that is not something that you play with. So that would be the only thing; it just slows me down. Dealing with a pinched nerve, two disks in your back messed up, arthritis, and scoliosis yes...So it's kind of hard for me to be able to get up and function to like get up but I still get up and I still try to do as much as I can. I don't never try to beat me down. I still try to get up and do as much as I can.

Solange's multitude of health problems sometimes made it hard for her to physically get out of bed and interact with Omari and his mental health providers. Yet, despite her complicated health, Solange still felt like she did what she could, she got up and was

involved, when possible. She did not see her personal health issues as something that was a complete barrier to her involvement, as other parents also reported.

It was also apparent that for some caregivers and parents, the teenager's own disposition to treatment was a barrier to their involvement. When teenagers were resistant and rejecting of treatment, parents found it harder to be involved. The teenager's opposition to treatment made parents feel their own efforts were not appreciated. Ms. Pilsin described this experience with her adopted son, Chris. Chris had been in and out of therapy for a few years and Ms. Pilsin felt it became harder and harder for her to be involved the more Chris resisted.

The part about it being difficult is that a lot of stuff that we did – he – first of all he was ungrateful for a lot of things that we did. And then he wasn't really working with us. It's hard to work – to try to work – and do something together when the person is not working. It takes everybody involved. And he was not doing his part, which was frustrating.

Chris's disposition and his lack of commitment to his own treatment was a barrier Ms. Pilsin faced in staying engaged herself. Chris' gradual resistance eventually culminated in him refusing to take his medication or participate in therapy sessions. Ms. Pilsin expressed continued frustration over trying to obtain help for Chris and not understanding his resistance.

Lastly, participants spoke of other family members' opinions against mental health care as a barrier to their own involvement in the teen's treatment. When caregivers oversaw the mental health treatment of the teens, it was possible that the birth parents could be a barrier. When family members or biological parents had contradictory opinions about seeking mental health care and shared these with the teen and/or the parent, this gave parents pause about their decision to pursue treatment for the teenager,

although this reaction did not completely prevent parents' involvement in care. Tina spoke of this experience as follows.

I'm not in denial that mental illness is real, you know...But my, most of my family, *they have like, the stigma. "Oh you can't be..." They call it "crazy". You can't take medication and that stuff, you know.*

Tina spoke of her other family members' perspectives on mental illness alongside of her commitment to making sure her granddaughter, Ashley, gets "the best care" and "isn't afraid to take care of herself." Tina's quote displays how her family members' perspectives are something she has to negotiate around and she hopes these perspectives do not interfere with Ashley's pursuit and successful obtainment of mental health services. Therefore, parents and caregivers saw their own health concerns, the teen's resistance to treatment, and other family members' negative opinions of mental health services as possible obstacles to involvement in treatment.

Lack of Resources

The second way barriers arose was in participants' discussion of struggling because of a lack of resources. Parents and caregivers spoke of it being hard to be involved in their teen's treatment because they did not have enough money to get back and forth to therapy sessions, or because they did not have the time to attend all appointments. Decisions about being involved in treatment had to do with time as a resource; parents were pulled away from their interactions with their teens and the mental health care providers because they had to work. Caroline spoke of caring for her nephew, Denzel, and how she did not have anyone to fall back on financially. Having to go to work sometimes meant she could not be involved in Denzel's treatment. Even stating this, Caroline quickly followed up with "...but other than that, there's nothing I wouldn't

do,” suggesting that her commitment to Denzel would exceed any barrier she felt was placed in front of her.

Similarly, Lakeisha reported that managing her finances, given her son’s mental health struggles, was difficult. Her story summarized the struggles of some of the parents in the sample. Lakeisha’s situation was such that she ended up leaving her job to manage the mental health treatment of her son, Oscar. Lakeisha spoke of making this financial sacrifice for the sake of her son’s well being. This financial struggle became part of what made involvement in his treatment a challenge.

R: Well, I’ve always been involved in anything you know, they are doing. So it wasn’t like, that wasn’t hard for me. *It was just that knowing that as far as the financial part, and be able to live, that was my concern.*

I: So that’s part of what made it difficult - is that you had to make some big sacrifices.

R: *Yeah it was like I had to put other things in a place or get a process going where I could still be able financially you know.* It was like, you know like I said, you don’t know, everybody can say what they would do but you don’t know what you’d do not unless you’re going through it. You could tell someone this is what I would’ve done. But if you are not the one that’s physically going through it... at that time, that might be what you saying, but if you not going through it you don’t know what you would do.

Lakeisha did not see her financial struggles as a complete barrier to her involvement. In fact, she stated that she always was involved despite this barrier. Rather she expressed the lack of financial resources as an additional stressor, something else she had to figure out alongside of Oscar’s mental health treatment. Lakeisha reported feeling like she did what she had to do to “be able to live.”

In conclusion, the two barriers to parental involvement in adolescent mental health care related to personal or family factors and a lack of resources described by the participants in the sample. On the personal level, parents’ health sometimes impeded their

involvement in their teen's treatment. Within the family, the teen's own resistance to treatment or other family member's negative opinions about mental health care also were barriers. Limited resources, such as time and money, sometimes stood in the way of parents being fully engaged with their teen's treatment. However, as noted, parents and caregivers in the sample readily expressed that none of these barriers were significant enough to completely prevent them from getting the teenager help or totally prohibit them, as parents from, being involved.

Chapter 7: Family Characteristics

In this chapter, I address the research question, “How do the characteristics of families shape the diagnosis and treatment process?” as well as the two sub-questions: “In what ways does insurance usage shape parents’ experiences with their adolescent’s mental health diagnosis and treatment?” and “In what ways does race/ethnicity shape parents experiences with their adolescent’s mental health diagnosis and treatment?” Since the study focused on low-income families who had experiences with Medicaid, and the sample was mostly Black/African American, these specific contexts warranted exploration.

To address the first sub-question, participants were asked to reflect on their experiences utilizing their insurance plans. Participants were probed to think about how their insurance was helpful during the diagnosis and treatment process or how their insurance provider made things more challenging for the family. Parents and caregivers were also probed to think about having limited financial resources and how that may have shaped the treatment their teen received. I found two components to how insurance usage shaped parents experiences with their adolescent’s mental health care: insurance as a bridge and insurance as supportive. I also found that parents perceived their income and insurance status to be inextricably connected.

Insurance as a Bridge

The first component of how insurance usage shaped parents experiences with the diagnosis and treatment process was parents’ perspective that insurance was a bridge that connected families to mental health care. Indeed, this sample was unique in that the parents and caregivers had the resources needed to enroll themselves and/or their child

with an insurance provider. When parents were asked about their experiences with their insurance, a similar response was repeatedly given. Different parents reported some version of the statement “So far, I have no problems with them,” referencing their insurance provider. Similar words were used by Ms. Greentree, godmother and caregiver to 16 year old Coraline. When asked what her experience has been with Medicaid, Ms. Greentree responded, “They’ve been helpful. I ain’t never had no problems. I ain’t never had no problems.” This sentiment about Medicaid was further expressed by Cathy, the caregiver of Jimmy. Cathy stated:

I haven't had no problem with it. You know I can't say anything bad. I mean I haven't had no problems with them...They have been helping me. I mean they come to me and tell me like I don't have to come out of my pocket to pay for anything because Jimmy got straight Medicaid.

The assistance the insurance provided on several levels made obtaining treatment for Jimmy easier for Cathy. Through covering the complete cost of the services and providing transportation, Cathy’s perspective was that straight Medicaid was helpful to her as she sought to help Jimmy with his depressive disorder diagnosis. A similar perspective was expressed by Martha, who raised her granddaughter Shree. Shree was diagnosed with depressive disorder, NOS and was hospitalized for a short time because of her depressive symptoms, though she had not received consistent mental health care since the hospitalization. When asked about her perspective on how Shree’s insurance shaped their experiences with mental health care, Martha reported a sense of comfort knowing the insurance benefits exists if and when Shree needed care. Martha stated

Her main things is that I'm glad she does have it [insurance], you know, and that it covers it if she needs it. That's the main thing...I think it [insurance] made it easier, it was easier. Yeah it was easier for her...She knows that it will work for all the, you know, what she would need as far as mental health issues.

Insurance became a bridge between the family and mental health care that was largely described as helpful, not problematic, and making care possible for families in the sample. Having insurance was helpful in that it also provided a level of ease in accessing services. For several parents, initiating the process of obtaining mental health care went smoothly, such as described by Ellia, mother of Anton. When asked about her experiences with insurance, Ellia stated

I mean I haven't had a problem. I haven't had a problem with them. I mean he, um, I love his doctor... This is the first time with any kind of medication he ever really needed. I haven't had a problem with getting that. As soon as I found out that I needed to get him help and I was getting all my resources together, I mean everything just went into play. I haven't had a problem with it.

The lack of barriers or troubles one could have run into when beginning a new process of engaging with mental health care was notably absent from Ellia's experience.

Members of the sample who had experiences with Medicaid as their insurance provider during the time the adolescent was struggling with a depressive disorder also reported insurance as a necessary piece through which parents and caregivers were able to access services. Without insurance, parents reported their child would not have been able to access the care received because of their limited income. This component of insurance usage also enabled parents to feel competent in getting their child the help needed. Mary, stepmother to Andrew, shared the following perspective when asked about her experiences with Medicaid:

They've been very helpful. The lord knows that if I had to pay for any of this stuff, they wouldn't be seeing hardly probably nobody. I mean unless they're gonna do it pro bono out of their pocket, cause, I couldn't afford to pay for it.

The mental health benefits Medicaid provided enabled Mary to obtain services for her step-children and she actively acknowledged she would have struggled to connect them with care without her insurance benefits. Caroline expressed it this way:

And fortunately for him right now all of the services that he, is provided for him, it's been fully paid for. They got, I do not have to worry about that. He is straight DC Medicaid which means they pay for his therapy sessions. They pay for his medication. They pay for, um, any hospitalizations. Anything he may need right now, they will pay for it. So the services are out there for him, you know, for us to partake in and I take full advantage in every service that I can for him because I want him to have the best.

Caroline saw her nephew's insurance provider as something that alleviated worry and enabled her to feel competent in seeking help for his diagnoses. She strove to "take full advantage" of what her insurance provided and this enabled her to perceive Denzel is getting "the best" care possible. Insurance as a bridge between the families and mental health care was also closely linked with parents' perspectives that they felt supported by their insurance provider and mostly had positive experiences utilizing the benefits allotted to them. This is similar to the sentiment expressed by Ellia above, where she mentioned she was the one who needed to get her son help, and it was her insurance provider that enabled her to feel successful in accomplishing this task.

Here we can see that parents and caregivers saw their insurance coverage as the bridge that connected them to mental health services. Parents largely reported that utilizing their insurance was non-problematic; the process was smooth and the insurance was helpful. We also saw that without insurance in place, accessing mental health services may have been too financially burdensome for these low-income families. Therefore, insurance also shaped the receipt of services in that it helped parents and caregivers feel competent in getting their child the help needed.

Insurance as Supportive

Parents and caregivers in the sample also described their insurance providers as continually supportive. As active users of their insurance on a regular basis, participants felt the services and benefits received from their insurance providers were accommodating to their needs. Parents reported their insurance benefits and services facilitated the process of obtaining mental health care in two ways – through increasing the convenience of engaging in mental health care and personalizing the experience of obtaining mental health care.

Convenience

One of the ways insurance was seen as supportive to the families was that some insurance benefits increased the convenience and therefore accessibility of care. Providing transportation to and from sessions that did not take place at the home was cited as a benefit some insurance companies provided, which notably assisted parents in ensuring their teenager obtained the care needed. Parents talked about how having transportation to and from sessions lessened the hassle for them as well as the financial burden of paying for bus or metro rides to appointments. Deborah, mother of Dominique, described the convenience of this service as follows:

Yeah, yeah, you know through her insurance she gets transportation and through ours we get transportation. And sometimes it takes so long to get there... So, its okay, they pick you up, you know, boom, boom.

Deborah saw these benefits of her daughter's insurance as simplifying the potential barrier of getting to therapy sessions. The door-to-door transportation service decreased the amount of time families may spend commuting back and forth. Even when families were able to pay for public transportation, they still acknowledged transportation as a

support. This was particularly expressed by Christine, mother to 15-year-old Yvette.

Christine stated:

Yeah if we need transportation to go to [the agency] the only thing I have to do is call down to there and the only they said is to call 2 days ahead of time and they would get us transportation. And they come after we are finished and come and get us. But most of the time we catch the bus or the train.

So, the support and convenience of transportation was there for parents to readily utilize and parents felt capable of engaging in this service because it increased the convenience of accessing services for their youth.

Additionally, when services were held at home instead of at agency offices, parents reported appreciating this convenience. When I asked Cathy about the availability of providers who took Jimmy's insurance and the ease of obtaining therapy services, she replied

I did have to travel far, I had to travel from here to 14th Street downtown. And I was doing it like once a week. That's when I told the man 'Look, I can't keep doing this. I have kids I take care of in the morning, early in the morning. Then so, he said, so we can do it in the evening time. And I was like no. And he said but we'll come to you. And I said well, okay. I can deal with that. If you can come to me once or twice a week, we good. And that's what we do.

Cathy's spoke up about the inconvenience of traveling with Jimmy to therapy sessions and how this became challenging for her. This led the agency she worked with and the insurance Jimmy had to provide at-home therapy services. This convenience enabled Jimmy to continue working with his therapist on a regular basis.

Personalization of Care

Furthermore, some parents talked about the personalized care they felt they received from their insurance companies. This personalized care took a few forms. First,

some parents reported feeling like their insurance providers truly cared about the youth's needs. This was particularly true for the insurance Health Services for Children with Special Needs (HSCSN) in Washington, D.C. When asked about her experiences with HSCSN, Amia, mother to Kailee, said "Oh, her health insurance is wonderful. I love health services. I love health services." Similarly, Deborah described her experiences with HSCSN as follows:

I love them. They came to the house and they were so warming and welcoming. And you know we have this and we have presentations, and we have this and we have that, and I was like oh good. Like I'm just so excited like ooh, okay....I mean they cause they have food stuff and they're really caring about what's going on with the children. And I love that about them.

Deborah's affinity for HSCSN is clear; she felt this insurance provider was quite caring and involved in an intimate way in her daughter's physical and mental health treatments.

Another way parents saw their insurance as supportive and personalized was through gestures such as providing reminders for appointments to the families. When asked what the insurance might do to support Ms. Coldwell, mother to Tara, who was 12 years old, in her pursuit of treatment for Tara, she stated:

I mean they send reminders if she needs like checkups. They send things in the mail, they send you a phone call. They even give you a phone call if they have like events. You know, wellness or nutrition events going on.

The individualized attention displayed in sending appointment reminders helped Ms. Coldwell stay on top of Tara's physical and mental health care. Some parents also had experiences where their insurance provided a type of case manager to their child, and regularly checked in on how things were going for the youth. Linda expressed some surprise when this service was implemented after her daughter Lindsey was hospitalized for suicidal thoughts and behaviors. Linda reported:

Well you know I was just kind of surprised with AmeriHealth. I think she is the coordinator or director or something. *She was concerned when Lindsey has the mental health thing. And she called and talked to me and she talked to Lindsey. She got acquainted with Lindsey....that's the first time the insurance company did that.*

Tonya had a similar experience to Linda; she spoke of a case worker from the insurance company calling to find out if there was anything her daughter, Felicity, might need or that the insurance could assist with further. This personalized care was seen as supportive to the parents and may have helped parents feel more comfortable with the mental health care and insurance systems.

In addition to insurance being a bridge which connected families to services, we see here that services provided by insurance companies can be more comprehensive, and thus supportive, of families. When accessing services was convenient for families, whether it was through having therapy services come to the house or by obtaining transportation to and from sessions, this support seemed to increase families ability to effectively engage in mental health treatment. Additionally, when services were personalized, parents reported appreciating this attention and the dedication the insurance company expressed towards helping improve their child's health.

While the salient themes here were insurance as a bridge and supportive, participants' responses were not completely void of criticism of their insurance providers. Less prominent but worth mentioning were the ways participants reported they felt their insurance providers could improve. These comments included the suggestion that Medicaid benefits be expanded to more providers so families have even greater access to care. When families were only able to access a limited number of providers, they reported having to wait longer for appointments. Also suggested here was enabling Medicaid

benefits to function equally across county and state lines, and parents/caregivers expressed confusion over having to comprehend differences in plans when their multiple children had plans with different Medicaid subsidiaries.

Insurance and Income

An important context of the families interviewed for this study is that they were low-income. Income ranges were inferred by the parents and/or child's eligibility to receive Medicaid as their insurance. For these families who struggled financially, utilizing government programs and resources became inextricably linked, as they often talked about their income status in relation to receiving government benefits. When asked about how being low-income may have shaped their experiences with mental health care, parents responded by citing their perspective on and experiences with their insurance provider. It seemed hard for parents to separate out these two contexts. Since parents generally reported satisfaction with the services they received through their insurance, when asked about how their income level may have shaped treatment, most parents maintained their position that the services received were adequate and helpful. Betty, who raised her niece Melinda, took the position that other parents also expressed: a higher income would not have changed the care received. She stated:

No I don't think that, I don't think more of an income would've helped her any more than the help she was actually receiving. I don't think that the insurance had an effect on her in that aspect. And so I think it was, um, I just don't think the insurance affected anything in that aspect or treatments or anything because she basically got all the treatments and all the meds that she needed...I didn't have any problems with [paying for medication]. They paid for her meds; it wasn't a problem.

Due to the strong connection between income and insurance status, as well as parents' general satisfaction with their insurance providers, income status was not then seen as an impediment to receiving adequate care.

Furthermore, because this part of the parents' "responsibilities" was taken care of due to the benefits provided by insurance, parents reported that if they had increased financial resources, they may funnel this money elsewhere, such as moving into a better house or apartment, paying off bills, purchasing items their children requested, buying healthier foods, or using the money to do activities together with their family members. Juliette talked about how her house was in foreclosure and she had to file for bankruptcy because she was unable to pay her bills. Her financial situation suggested that if she had more financial resources, her first priority may not be directing additional funds to Kira's mental health treatment, despite Juliette's fierce dedication to getting her daughter help. Similarly, when Anita, mother to 15-year-old Tommy, was asked about how having a limited income shaped Tommy's mental health treatment, Anita's response focused on accessing healthy foods.

It doesn't, um, a lot of times they tell you that the food you eat helps you balance out. *When you have a limited income you can't – there's no such thing as affordable anything.* I get \$110 in food stamps. And by time I get 6 packs of meat, some sides, some drinks, some vegetables – the majority of that is gone. So now they are opening up, they got an Aldi's over here. They got Safeway. They got a Giant. They are getting ready to open up a Whole Foods. So, they are trying but you have to learn to do what you do to get more. I mean you get more services for new mothers, like WIC and fresh vegetables. And for seniors. Then we, the little people in the middle, now we have to try to figure out how we do what we do to make things a lot better. *And you know when children have more nutritious good stuff to eat they tend to thrive more compared to the Capri Suns and the pack of Oodles of Noodles, and the hot dog.*

Anita expressed information she learned about the connection between a healthy diet and being “balanced.” Her response indicated that if she had access to more money, she may try to direct this resource towards purchasing healthier foods for her children to help them achieve this “balance.” Mary, stepmom to Andrew, stated how her income influenced her family as follows:

I don't think that more income would've gotten me more help. More income would've gotten me more things. I could do with them what they [the therapists] were suggesting...Cause like I said when I first took them to the movies and it was \$25 and then they all wanted nachos and popcorn and yeah. I was like...I didn't I just give ya'll pizza? I just spent \$70 on pizza. So it makes a difference because the stuff that they suggest the child do...If I had it to get out of Maryland and all that, to take them to Six Flags. That was very expensive. So we don't have many things that cost a lot of money to do up here. It's much cheaper for me to go rent a movie, get some popcorn, you know, some pizza from Dominos and do it like that, which may cost me all of like \$70 compared to four or \$500.00.

Mary's satisfaction with the mental health care she received led her to think she would end up spending any overflow of money doing activities with her step-children. The increased cost of going out with the children was an impediment to her following through on some of the suggestions she had received from mental health professionals, so she may focus her spending on such activities instead of mental health services. When asked if the mental health services Amia's daughter, Kailee, received would have been different if she had access to more money, Amia's response shifted away from mental health care and to the stress she experienced trying to manage the household on limited funds and to her daughter's desire for “nice things.”

...that's our biggest problem... And we like, despite what you see, we like nice stuff. You see what I'm saying. But, unfortunately, I don't have the resources.... It's always been me and my children. You know, and... it's just, it's just like it's not enough money. You know and Kailee is like bickering now, that's why she hadn't been home. Because she feel like because she get a check of \$720 a month, that she should be getting every

pair of Jordan's that come out. *No, this check is for to take care of the home, where you reside at or whatever. Now, if I have some extra money to a certain extent, I don't mind buying her Jordan's.*

Despite asking about the perceived connection between mental health care and income, Amia's focus shifted elsewhere when this topic arose – to how her limited income was a problem she has managed for a long time and it led her to, at times, make tough decisions about where to spend the funds she did have. It was an issue that sometimes created tension between herself and her daughter. Amia stated here that with extra funds she would consider spending the money on items her daughter requested, which perhaps Amia suspects would improve her relationship with Kailee. Amia clearly states here how she feels the money she has is “not enough” to meet the needs of her family. Yet, what we also see here is no mention of funneling additional resources towards Amia's mental health care.

The inherent relationship between income and insurance status for these low-income families seemed to make it difficult for parents to isolate how income may have shaped their experiences with their adolescent's mental health care. As seen above, this discussion turned to talk about insurance coverage. If families were satisfied with the mental health services received; they tended to not think their income level influenced the care obtained. Furthermore, since these were financially strained families, when the idea of having more financial resources was proposed, parents suggested such money would be directed to other spending streams and not to mental health care for the adolescent.

Race and Ethnicity

To address the second sub-question, participants were asked if they perceived their experiences with their adolescent's mental health care to be shaped by their racial or

ethnic background. Participants were probed to think if they were ever concerned with finding a therapist who understood their background and culture. I found divergent perspectives on if race/ethnicity shapes parents' experiences with adolescent's mental health treatment.

“I don't think race has anything to do with it:” The Perception that Race/Ethnicity Does Not Shape Families' Experiences with Mental Health Care

Participants (60.6%) reported they did not think that their own racial or ethnic background shaped their experiences with their adolescent's mental health diagnosis or treatment. These participants reported they did not think race/ethnicity influenced the care their youth received or they could not say that race/ethnicity shaped their experiences with mental health care. They said things like “We weren't taught to look at the color of a person's skin” or “People all bleed, right?” to express their perspective on racial/ethnic differences and interacting with people of different backgrounds than their own. Amia, who identified as Black/African American, talked about how she felt she was treated fairly and she didn't have any “problems...like racism...” when it came to her daughter's mental health treatment. Rather, she felt the providers were “doing pretty good.” Caroline (Black/African American), talked about the mental health care her nephew Denzel (Two or more races) has received, and stated the following:

So far I don't think that [race or ethnicity] has influenced the care that he's received because I have spoke with some of, in my opinion, some of the best people. Best doctors and nurses and they have been all race, creed, and color. And they have been wonderful to me and him. So I don't think that, um, it has affected, I, personally, don't think it has affected us at all.

When further probed about any concerns Caroline had about Denzel being matched with a therapist who understood his racial background or ethnic culture, she stated:

Oh god no. *I worked with a million people and some of the best people that I know are not of my ethnicity. And trust and believe me it was not a concern. Not a concern.* And I just know that in life you're gonna come across all types of people, and I have truly learned that some of the most wonderful people that you come across are some people that are not your people. *But that was never a concern. I didn't have to worry about that. I just wanted someone for him that can relate to him.*

Caroline's stance that the care Denzel received was "wonderful" and wasn't influenced by their family characteristics was clearly stated. As she further explained, Caroline was not concerned about Denzel working with mental health professionals of varied backgrounds. Similarly, Cathy, speaking of her experiences seeking services for Jimmy (both of whom were Black/African American) stated she did not perceive there to be any differences in the services or treatment Jimmy received because of his racial/ethnic background. When asked about any preference for the therapist who Jimmy worked with to be Black or of a similar background, Cathy had the following to say:

It takes people to help people. It don't matter. People get caught up on... I've never been caught up on color. Never ever. You know so, that's what they do out there. I don't go through, I see human being. We are female, female know another female, we put our panties on the same way. God made us have the same feelings, you know what I'm saying. I don't get caught up in Black and White and Brown and all of that, I mean, we human. That's what I... if you can help me and I can help you, then we good. He [Jimmy's therapist] stepped down out the car and he White. When he come in here for Jimmy, it's not about no color. Jimmy don't see it. Jimmy really like him. Raymond really like him. I like him!

Parents in the sample expressed that as long as the mental health professional could connect and build a relationship with the youth, the parent felt confident the services would be effective despite possible racial/ethnic differences.

Parents who further explained their positions seemed to share their perspective the mental health professionals had a professional obligation to be able to work effectively with families of diverse backgrounds. This was echoed by Ms. Coldwell (Black/African

American), who expressed her perspective that everyone receives the same care for mental health struggles.

I mean I don't look at it like that. I don't, I think anybody whose going through mental um mental problems will receive the same amount of care. I think if you receive the care according to your need. You know, and my own experience with my need *I think I've received the same amount of care, if it was somebody else that was from a different background or different income bracket, they would get the same thing.*

When asked about how Ms. Coldwell felt regarding her daughter's therapist being a different race/ethnicity than she and her daughter, she stated:

No, cause, no *I didn't look at it like that. Tara didn't look at it like that either. When you in this I think you know, dealing with children you have to try to find a way to connect with them. From your professionalism, you know, and with your expertise in that field. You have to find a way what works best, how to connect with them.*

Shifting the burden back to the mental health professionals and expecting the professionals to know how to bridge differences seemed to help parents feel confident that race/ethnicity did not shape their experiences with their adolescent's mental health care.

“It's different backgrounds and they don't really understand:” The Perception that Race/Ethnicity Does Shape Families' Experiences with Mental Health Care

Contrary to the perspective described above, a subset of parents (27.3%) responded that they did think their racial/ethnic background shaped their experiences. These perspectives centered around two ideas – first that it is difficult for therapists to understand and effectively treat adolescents who are from different backgrounds. Second, participants reported they felt race/ethnicity shaped certain life experiences but these were not necessarily directly related to receiving mental health care.

Parents reported that they thought it would be difficult for mental health professionals of different backgrounds to effectively work with Black/African American adolescents. If a mental health agency asked what type of therapist would be preferred, these respondents may be more likely to ask for a therapist who was of the same background as their own family. The participants reported making this choice because they felt a Black therapist could best understand and relate to their Black child. Shira talked about her experiences with her daughter Erica's treatment. Shira reported herself and her daughter to be Black/African American. She had the following to say on this topic:

Because I don't think, I don't think um I'm trying to figure out how to say this and not sound bias or anything like that but, um okay, just for instance *if she had a therapist who was uh Hispanic or Dominican, or Caucasian, they wouldn't understand. They, it's no way in the world they could understand, you know. And even though that's their field, unless you were born black, or as they call us now African Americans, you will never understand our culture, you know. You could not relate but you would be trying to understand it yourself by the different types of persons you were asked, you know, so.... You know, so, you know, just, that's what that is. You know, I, that, I, um, this is just personal my personal opinion. I don't think any Caucasian person can understand an African American's um background period. Where they come from. You know how they think, what they think, you know. They have an idea but, you know, I don't think that um all Caucasian people are biased or racist or, you know, things like that. Its different backgrounds and they don't really understand it.*

In contrast to the participants discussed above, Shira expressed her perspective, which some parents held, that despite being professional, racial/ethnic differences could be challenging to overcome. Shira preferred a therapist who was of the same background as her daughter and felt the mental health services provided will be more effective because perhaps if the therapist shares the same background as Erica, a deeper understanding will be present. Shira also mentioned that she felt it would be more comfortable for Erica to

work with a therapist who shared her own background, and that then Erica would be more willing to engage in therapy sessions. Marissa, who was a foster mother to several Black/African American youth with mental health struggles, agreed with Shira and spoke of her concern that “White workers...have no clue of what’s real for an African American child” and further that this lack of knowledge could end up being harmful towards the child.

Other participants were somewhat more subtle in their expression that race/ethnicity ended up shaping their experiences with mental health care. These participants expressed concern that the families and mental health providers may have had a hard time relating to one another. The mental health providers were seen as “not understanding” because they “weren’t living like that.” Or they mentioned that “doctors stereotype” but did not explain further what their experiences had been. Ms. Henry (whom also identified as Black/African American) spoke about her experiences at a particular hospital and how she felt she was mistreated there, but all other places she received care for her grandson were appropriate and relieving. For the most part, these participants would go on to continue working with providers despite racial/ethnic differences and would heed their suggestions and recommendations. It was also the case that sometimes the adolescent held the concern of working with a therapist of a different background. Joy spoke about this in reference to her foster-daughter Katrina.

...because some of her workers were White and she is Black and then some of the things or the approaches that they would take, *she felt like, “oh that’s what you do with White kids, I’m a Black kid.”*

Joy went on to discuss how she and Katrina discussed these concerns and Joy helped Katrina see that someone does not have to come from the same place as you to offer

advice and suggestions and be able to empathize. According to Joy, Katrina thought the racial/ethnic differences mattered, but Joy encouraged Katrina to see past this perspective.

Exploring this topic with the participants yielded interesting findings. As stated, most parents and caregivers shared that they did not think their experiences with mental health care were shaped by their racial or ethnic background. These participants expressed the perspective that it was possible to learn from people of different backgrounds and that race or color should not be of concern. These participants also stressed that the mental health professionals had an obligation, through their training and professionalism, to know how to reach and work with teens from varied backgrounds. On the other side of the spectrum, a smaller group of participants voice an opposing opinion. These participants shared their thoughts that, for example, a White therapist would not be able to really understand what it's like for a Black teenager. Furthermore, this group talked peripherally about experiences where they did feel they were mistreated or stereotyped, or where they thought the mental health professional had a hard time relating to them or their teenager. Finally, 12.1% of participants' responses fell into both of these categories. These participants reported both perspectives, that race/ethnicity mattered in some aspects of their interactions with mental health care, and that it did not matter in other interactions and relationships in which they engaged as part of the mental health care system.

Chapter 8: Application of the Ecological Risk and Resilience

Framework

The Ecological Risk and Resilience Framework enabled a deeper understanding and enrichment of the interpretation of the data. This framework was relevant because of its emphasis on family process. Several family processes became apparent in the data related to parents' experiences of adaptation. The PPCT model was pertinent to understanding the involvement of parents in the diagnosis and treatment process, and the Ecological theory further elucidated how various contexts have an influence on an individual. The application of the Ecological theory considers both the Ecological Risk and Resilience Framework and the PPCT model when assessing changes to parent-teen interactions and the parent-teen relationship in this unique group of predominately low-income African American parents and caregivers engaged with the mental health care system. A brief summary of these theoretical concepts along with how the concepts were explored in the protocol interview questions, what open codes applied to the concepts, and which themes from the findings are associated with the concepts is outlined in Appendix L.

The Family Process of Adaptation

This study explored parents' perceptions of how their relationship with their teenager changed after involvement with the mental health care system, or the process of adaptation post-diagnosis. The adaptation process included (1) how parents made decisions, (2) how parents managed and organized treatment, (2) how parents perceived their relationship with the teen, and (4) how they communicated with the teenagers. While it was parents and caregivers who undertook changes to their own behaviors and

perceptions to adapt, these processes took place on the family level because they pertained to interactions between the parents and teenagers and any of these adaptations could alter the state of the parent-child system. These parents' and caregivers' ability to adapt to the context of having a teen diagnosed with a mental health concern is demonstrative of how this sample may be different from other parents or caregivers. Indeed, these parents engaged with their resources which uniquely situated them to both be receptive to mental health care and willing to engage in services that other parents or caregivers might reject. The concept of equifinality applied to parents is relevant here. These parents began from various starting points and came to a common end point: obtaining mental health care for their child. Similarly, the teenagers discussed had different beginnings and varied experiences which also led to a common end point: a depressive disorder diagnosis.

Parents' decision-making process adapted as a result of the teen's mental health struggles and after involvement with the mental health care system. Although the precipitation of engaging in mental health services to obtain a diagnosis for the teenager was not the same for all participants, some parents in the sample made decisions to obtain a diagnosis because of a co-occurring issue impacting school performance, often noticed at a young age. Others made decisions to obtain a diagnosis after receiving feedback from outside sources that the teen may need help or after parents gained an awareness of the severity of the teenager's behaviors. Therefore, parents made decisions to seek a diagnosis and treatment in an attempt to adapt to concerning behaviors displayed by the child at various ages.

These findings also describe how parents' adapted their decision making regarding their own involvement in the adolescent's treatment. Experiences or circumstances which encouraged or discouraged parents' involvement in treatment precipitated adaptation. Parents and caregivers described making decisions to be involved in treatment when they felt like they were given options. The presentations of options allowed for parents to have agency in how their teen's treatment would move forward. Parents also decided to be engaged in their teen's treatment not only because they might have felt an obligation, but also because they saw themselves as an integral, active part of helping the teens overcome their challenges. Parents in the sample adapted to seeing the teenager's depression as something they could have an effect on after the disorder came to light. Parent's personal experiences with mental health care and how this connected to their desire to not see their adolescent struggle or suffer also helped parents and caregivers make decisions to be involved in treatment. Through involvement in treatment, by asking questions, seeking advice, and keeping informed, parents saw their contribution as connected to the teen's well-being. In these ways, parents adapted their decision making to learn about the teen's diagnosis and to incorporate mental health care into their lives.

Parents and caregivers also largely reported adapting to the responsibility of organizing and managing the mental health treatment of the teenagers. Parents scheduled and confirmed appointments and reminded the teenager of their mental health appointment. Parents also took on the role of refilling and picking up prescriptions and keeping track of when the teenager needed to meet with certain professionals. Parents adapted their behavior in order to manage the new context of the teen receiving mental

health services. I also saw examples of how parents wanted to be actively involved in the treatment; they wanted to participate or contribute to the treatment process and to be kept aware of what was happening in the teen's mental health care. The participants saw themselves as both having something to offer to the treatment and something to gain from being involved in the treatment, which demonstrated parents selecting to actively be a part of treatment. This behavior is exemplary of parents organizing themselves to be involved in treatment.

Additionally, parents and caregivers adapted their perceptions of their relationship and their communication with their child to change post-diagnosis. Parents reported perceived changes to the parent-child relationship that took the form of parents becoming protective of the adolescent. Parents also adapted to knowing the teen was struggling with a depressive disorder by becoming more patient and empathic, as well as continually teaching the teens accountability. Parents reported that prior to their involvement with the mental health care system, the teenagers would often isolate themselves and refrain from disclosing information to the parent/caregiver. After involvement with mental health services, parents observed that the teenagers began to share more with them, demonstrating adaptation on the part of the teens. In addition to parents perceiving the teenagers' communication with them to change, parents own approach to communication changed post-diagnosis. Parents adapted by initiating communication more, and encouraging the teens to express themselves; they strived to be better listeners, and they carved out more time to just talk with the teenagers.

The Process-Person-Context-Time Model

Process

The Person-Process-Context-Time model of Bronfenbrenner's Ecological Theory can help further a theoretical understanding of these findings. In terms of proximal processes, or interactions within the immediate environment that are enduring (Bronfenbrenner & Morris, 1998), this study was interested in parent-child interactions, from the parent's perspective. Specifically, I explored the process, as perceived by parents and caregivers, of incorporating the diagnosis into parent-child interactions and how parents adjusted themselves to meet the perceived needs of their struggling teen. Here I saw processes of parent-child interactions change when parents advocated for their teen upon noticing the need for help. Parents also reported that their relationship with the teens changed because the parents became more protective, patient, understanding, and they encouraged communication with the teens in more effective ways.

How parents and caregivers made sense of their adolescent's diagnosis was also a proximal process explored in the study. This process unfolded in several ways. Parents reported feeling like the diagnosis provided them with some relief and validation of concern. Yet the participants also spoke of lingering confusion about the diagnosis. In the parents' proximal observations of the teenager, parents still struggled to understand the symptoms of depressive disorders in adolescents compared to what might typically be expected of a teen. Parents explained trying to clarify their own confusion by attributing the cause of the depression to several factors, including looking at themselves or the biological parents of the child. Parents also considered external circumstances, such as

situations and events the teen had been exposed to that may have contributed to the presence of the depressive disorder.

Person

The element of person required consideration of the personal characteristics parents brought with them to social situations; the application of this element of the PPCT model in these data focused on parents' and caregivers' development and adaptation. More specifically, demand, resource, and force characteristics in the sample were observable. The primary *demand characteristic* explored was the influence of race/ethnicity on parents' experiences with an adolescent's mental health diagnosis and treatment. As previously discussed, parents fell into two divergent categories related to this demand characteristic. The dominant perspective was that parents perceived race/ethnicity did not shape their experiences with mental health care. These parents shared they did not feel their interactions with the mental health care system was any different because of their race or ethnicity; they expected the mental health care professionals to be proficient in finding ways to bridge racial or ethnic differences to connect with their teen. The contradictory perspective expressed by other parents was that it would be difficult for mental health professionals of different backgrounds to work effectively with Black/African American adolescents. Therefore, the demand characteristics of ethnicity did shape the expectations parents had of the mental health care system.

Resource characteristics are experiences, skills, intelligence as well as social or material resources (Tudge et al., 2009). In this study, parents past experiences with and knowledge of mental health care, as well as parents' ability to access information and

treatment were evident resource characteristics related to the element of person.

Participants had varied prior experiences with mental health care – on a personal level, through other family members or friends, or through employment positions. Such prior personal or family experiences seemed to make it easier for parents to both initiate the diagnosis process and to be involved in treatment. As previously reported, parents used their own experiences with mental health care and their own mental health struggles to empathize with the teenager. These experiences became a resource which contributed to the parents' decision to obtain a diagnosis and treatment. Participants also reported actively advocating for services for the teenagers and seeking information from a variety of sources. The social resources parents accessed included mental health professionals, schools, pediatricians, family/friends, and the internet. Mostly due to having stable and accessible insurance, families felt that they were readily able to access treatment if and when they wanted, suggesting insurance was a material resource for these families.

Lastly, *force characteristics* include individuals' temperament, motivation, and persistence (Tudge et al., 2009). This element was evident in parents' motivations for seeking a diagnosis and/or treatment, parents' persistence in obtaining treatment for the teens, as well as parents overcoming possible barriers to involvement in the teen's mental health care. Parents' motivation for seeking a diagnosis seemed to relate to a buildup of awareness, including the input of others outside of the family. Parents' motivations as a force characteristic included wanting to keep the teenager safe from self-harm and wanting the teen to be successful, particularly in school. Motivations for being involved in treatment took the form of parents wanting to normalize the treatment process and parents wanting to protect the teenager from anyone who might take advantage of them.

Additionally, parents wanted to teach the teen to be responsible and accountable, despite their mental health concerns. Parents' force characteristic of persistence was seen through the theme of advocating in response to the diagnosis. Parents took responsibility for devising a plan to address the mental health diagnosis; they were not afraid to ask questions and sought to increase their own knowledge on this topic. Also evident in these data was the force characteristic of overcoming barriers to involvement. Parents reported that nothing could come in the way of them getting their child help. Even when other family members or the teen resisted treatment, even when the parent struggled with significant health problems of their own and when time and money were scarce, parents in the sample reported a persistence in getting the teenager help.

Context

The contexts explored in this research elucidated components of the microsystem, mesosystem, exosystem, and macrosystem, which influenced parents' involvement with adolescents' mental health care. Microsystem level influences were apparent in the individual traits of the parent. For example, parents not fully comprehending the diagnosis of the teenagers did not seem to deter parents' involvement in treatment. Even when confusion about the diagnosis remained, parents still advocated for help for the teenager. Yet, when parents did perceive they understood the diagnosis, this perceived knowledge notably encouraged, and perhaps empowered parents to be involved in treatment. Therefore I saw how parents' comprehension of the diagnosis contributed to parental involvement in adolescent mental health care. Furthermore, parents' desires to be actively involved in treatment and to promptly connect the teen with care once the diagnosis became apparent were exemplary of their individual traits. Parents sought

information; they wanted to understand what the teens were going through, and they positioned themselves to be involved and were willing to ask questions. Microsystem level influences were also apparent in the exploration of changes to the parent-child relationships which were discussed above.

The mesosystem context is composed of an interaction between two microsystems. There were several mesosystem influences apparent in the findings when the teen is conceptualized at the center of the model. Parents reported that, at times, other family members were a barrier to treatment. One example of this occurred when caregivers saw the teen's birth parents as an obstacle to obtaining mental health care for the teen. The interaction between other family members and the participants occurred at the mesosystem level for the teenagers. A second way the mesosystem context was evident in the data was through the involvement of agencies, such as CPS or the court system, in the diagnosis process. Parents and caregivers reported interacting with such agencies to obtain the diagnosis and receive suggested or mandated treatment. A third way the mesosystem context was apparent in the data was parents' interactions with information sources. Parents attempted to make sense of the diagnosis by increasing their own knowledge of depressive disorders in adolescents by turning to various sources. This exchange of information may have helped parents empathize with the teenagers and may have encouraged parents' involvement in treatment. Lastly, parents' interactions with the mental health care providers who treated the teen also occurred in context of the mesosystem. Parents reported that when the clinicians included the parents in sessions, showed concern for the teen, and kept parents informed, such interactions were meaningful to the parents and helped them be actively involved in the treatment process.

The exosystem context is a distal environmental system which was also discernible in the findings. The location of mental health agencies in proximity to where the families lived was part of the exosystem – families did not have control over the location of the agencies but it still influenced families' abilities to obtain care. Parents shared that when mental health agencies made accessing services more convenient, engaging in treatment was easier for the family. Agencies providing home-based services transcended the potential obstacle of the distance between parents' homes and mental health care agencies. Additionally, when the family's insurance benefits provided transportation to and from on-site therapy appointments, the potential barriers at the exosystem level were surpassed. Insurance was seen as the bridge connecting families to care; the benefits of the families' insurance made mental health care more accessible, convenient, and personalized. Parents found agencies and services to be fairly accessible. The second exosystem context seen in the data was the treatment modalities offered by the agencies. It was possible parents could feel less inclined to be involved when individual therapy for the adolescent was the treatment modality. Yet, despite when agencies solely proposed or offered individual therapy for the adolescent, parents still wanted to be involved in the treatment.

The last component of context is the macrosystem, which includes cultures and subcultures. Cultural distinctions may dictate how families perceive mental health care or where the blame for the presence of an adolescent's mental health disorder is placed. For participants in this sample, parents made sense of the diagnosis by considering multiple sources, including looking inward at themselves, recognizing the role of the other biological parent, or the biological parents when caregivers were parenting the teen.

Parents also looked to life situational events to make sense of the teen's depressive disorder. Therefore, understanding the diagnosis and assigning blame was multifaceted for these parents, which may be associated with parents' cultural experiences. At the macrosystem level, stigma particularly related to parents' concern about what others might think of the teens' diagnosis and treatment was explored. Findings suggest that parents were not very concerned with what others may think. Parents reported that it was not other people's business to know and that they did what they could to keep the information about the teen's diagnosis and treatment in the family. The parents' perceptions might be understood as a cultural preference to keep boundaries around personal information, while being protective of the youth.

Time

The component of time was less explored in this research although timing was relevant. Parents and caregivers were asked to think about changes to their relationship with their teenager over time. They were to compare the nature of their relationship prior to the diagnosis with how the teen was doing at the time of the interview. The context of time enabled parents to ascertain how their relationship with their teenager had changed. It became apparent that some families had long-term involvement with the mental health care system, and the relationship began when the teenager was a young child because of co-occurring diagnoses. This long-term involvement may have enhanced parental comfort levels and their continuance accessing care for the teenager when the depressive disorder diagnosis came later in the adolescent's life. Another element of time was related by the economic climate in the U.S. over the past decade. In this sample of low-income families with scarce economic resources, mental health care was still seen as

important. Parents actively saw a value in getting their teens' treatment once the issues came to light. The parents own financial resources, which may have been impacted by fewer employment opportunities reflective of the state of the U.S. economy over the past few years, did not notably deter parents' involvement in treatment.

Risk and Resilience

Risk and resilience processes were also seen in the data. One risk process began prior to the adolescent obtaining the diagnosis. Despite concerns about the adolescents' behaviors, parents and caregivers often delayed taking action until they gained a heightened awareness that came from obtaining information from outside sources, learning about the severity of the teen's behavior, and linking the teen's struggles to life situational experiences. The build-up of problematic behavior potentially put the teens at risk because care was delayed. Another risk process apparent in the data related to parental psychopathology. In some cases, the delay of treatment onset may have been linked to a parent first coping with their own psychopathology and thus not being able to advocate for the needs of the teenager. Further, under-education about mental health treatment could be another risk process these families' experienced. Families reported a lack of understanding depressive disorders in teens and some confusion when the diagnosis was obtained. Yet for the families in this sample, under-education about mental health care did not prevent them from engaging in care. This strength represents the equifinality for these parents; they each began from unique starting points and share the common outcome of all seeking and obtaining mental health care for their adolescents. It was also proposed that weak economic opportunities and having less income could be a risk process in the sample. For these participants, having insurance and feeling like they

could readily utilize the insurance seemed to be a protective process from this potential lack of care usage risk.

Accordingly, a number of protective processes were also evident in these findings. One notable protective process was apparent in how the non-biological parent caregivers in this sample stepped into the role of parent, were attentive to the children's needs, and fully engaged in meeting their responsibilities as a caregiver to youth with a mental health struggle. As a protective process, such kinships and shared parenting responsibly is a familiar family pattern for African Americans (Boyd-Franklin, 2003). Additionally, a grandmother taking a primary caregiver role for her grandchildren is a common experience in African American families (Boyd-Franklin, 2003). Indeed, the characteristics of these non-biological parent caregivers played an important role in shaping the developmental outcome for the adolescents, by effectively connecting them to mental health treatment.

Another protective process was seen in how the bridge to mental health care for the families was insurance. Participants reported feeling they could partake in their insurance benefits and that the insurance was supportive – suggesting this was a protective process for these families. Additionally, parents and caregivers themselves displayed resilience through protective processes by taking on the recommendations of professionals– both to get the teens diagnosed and also to move forward with certain modalities of treatment. Parents' reaction to the diagnosis of the need to “get help” also constituted a protective process; parents came to realize the struggles the teen was facing were more than the parents could manage on their own. Parents' own feeling of being able to contribute in a helpful and tangible way was also a protective process, possibly

indicative of parents' self-efficacy. Parents encouraged resilience in the teenagers through the parents' active participation in treatment and through the process of change to the parent-child relationship. Parents engaged in the protective processes of being more understanding, patient, and empathetic towards the teen while also teaching the teen to be accountable to their own behaviors. Parents' involvement in the teen's treatment became a protective process when involvement had mutual benefits for both the teens and parents. Involvement helped parents feel they were doing what they could to help the teen; they also learned more about the teen and about adjusting their approach to interacting with the adolescent. Positive parent-child relationships represented another protective process. This positive protective relationship was true for parents who felt close with the teens prior to the diagnosis and was enhanced further, especially when the parent/child communication improved.

Family Resilience

The ongoing accumulation of the risk and protective processes may give us insight into family resilience. Family resilience is built upon belief systems, organizational patterns, and communication processes, according to Walsh (2006). Walsh's (2006) explanation of belief systems which were apparent in these data pertained to the parents and caregivers normalizing the experience of receiving mental health care for the teenager and parents perceiving the mental health concern to be a shared challenge (for both the parent and teen). Parents and caregivers leveraged their personal experiences with mental health care to make involvement in the mental health care system more inviting to the teenager. Parents' personal experiences with mental health care also seemed to help parents be involved in treatment; it furthered the parents' sense

that they had something to contribute to the treatment process. Additionally, spirituality beliefs encouraged parental involvement in care. Spirituality and praying was a coping mechanism for parents in the sample and was also the place from which some parents drew their sense of helping and protecting the teenager.

The organizational patterns outlined by Walsh (2006) and present in the data were flexibility, connectedness, and social/economic resources. Flexibility was displayed in the families' ability to be adaptive to both learning about the mental health diagnosis as well as incorporating treatment into the family's regular routine. Families in the sample were able to effectively reorganize to incorporate the mental health care into their lives – including weekly therapy appointments, meeting with psychiatrists, and perhaps taking medication on a regular basis. Connectedness also was a part of family resilience in the sample. Seeking a diagnosis and treatment may have been a way for the parents to show their commitment to and support of their teenagers. Additionally, participants shared that their communication with the teens improved post-diagnosis, possibly leading to deeper connections between the parent and child. Finally, social and economic resources contributed to family resilience on this level. Parents mobilized resources to increase their own knowledge of depressive disorders. They also spoke about the structural support of having insurance, which was an essential bridge connecting families to mental health care treatment.

Finally, family resilience was evident in the sample through communication as described by Walsh (2006). Open emotional sharing increased in the families over time, post-diagnosis. Parents reported that teenagers became more forthcoming with information. Parents and caregivers also took steps to change their approach to

communicating with the teen. Parents becoming more empathetic, understanding, and patient towards the teenagers also may have impacted communication. In conclusion, family resilience was seen in the aforementioned ways families coped and adapted as a functional family unit.

Major Implications of the Ecological Risk and Resilience Framework

The application of the Ecological Risk and Resilience Framework with these data offers insights into the process of adaptation and resilience for this unique group of predominately low-income African American parents and caregivers. These findings offer evidence of the strengths of the families described here and an awareness of what positive adaptation looks like, despite the number of adversities these families have faced. Additionally, this application offers a utilization of the PPCT model with a sample of parents and caregivers already engaged with and receptive to the mental health care system. The focus here is first on parents' development and adaptation and next, understanding what parents' adaptation means for the parent-child subsystem and the family's processes as a whole.

Indeed, this application demonstrates how these parents and caregivers have been able to adapt on several levels – in their interactions with the children, in their relationship with their family members, and in their interactions with institutions, such as schools, the court system, and insurance programs. Next steps to further explore the application of this framework could include a deeper focus on how parental adaptation happens at multiple levels.

Chapter 9: Discussion

This study was informed by research regarding the staggering rates of adolescent mental health disorders in the U.S. (NIMH, 2001) as well as the vast underutilization of mental health care for adolescents (Kataoka et al., 2002; Merikangas et al., 2010).

Further, disparities in access to and utilization of care exist for low-income families (Newacheck et al., 2003) and research shows ethnic minorities use mental health services less often compared to other demographic groups (DHHS, 2001). The purpose of this study was to gain insight into how to promote parental involvement in adolescent treatment and encourage families not using mental health treatment to seek services. These objectives were met by examining the pathways to care for families involved with the mental health system and exploring parents' perceptions of their own contribution and connection to their adolescents' treatment. These findings explore what is happening for families involved in mental health care; and suggestions are made about how to enhance these contexts for families not utilizing care.

The sample discussed here represents a unique group of parents and caregivers, who were predominately African American and low-income, and were equipped with resources that enabled them to engage with mental health care. Indeed, as previously stated, participants were interviewed after they had already interfaced, to varying degrees, with the mental health care system and had obtained a depressive disorder diagnosis for their adolescent. Therefore, these parents not only had access to insurance, they also felt they could actively utilize their insurance benefits to assist them in getting the help needed. Additionally, these findings are based on a sample that also had access to mental health treatment. While connecting with care was not always immediate or easy, the

location of these families in the D.C. metro area and the accessibility of mental health services in that area perhaps differentiates this sample from other families seeking mental health care. The cultural competency of the agencies, as well as the mental health professionals in this area, could also play a part in why this group of families successfully engaged with the mental health care system. The education levels of the participants could also have contributed to their individual openness to obtaining mental health care. As a sample of parents and caregivers who had experiences accessing services via Medicaid, these participants were fairly well educated with several respondents reporting they received some education post high school. While the mental health literacy of these participants still warrants improvement, their exposure to varied educational settings could play a part in this sample's willingness to engage with mental health care. Lastly, this sample includes a number of caregivers who were not the biological parents of the adolescents discussed in the interviews. In essence this subset of teens ended up in the care of families who embodied the traits needed to connect the teens to care, which may be quite a unique occurrence.

While noting how this sample of parents and caregivers may be different from other similarly situated parents and caregivers, these findings offer important insights into the strengths of underrepresented and underserved families. A deficit model approach to the families described here could focus on stereotypes about low-income African American parents being uninterested in the health or well-being of their children and unresponsive to their teenagers' needs. Negative assumptions about this population could also include ideas that these parents and caregivers are easily overwhelmed by stigma against the mental health care system and are indifferent to accessing help when

problems become apparent. Contrary to focusing on deficits, the findings presented here offer a strengths-based approach where the positive traits of such families became apparent. These findings reveal that despite the myriad of challenges families in poverty are well known to face, this sample of predominately low-income African American families was able to transcend such challenges to both access mental health care and be actively engaged in their teen's treatment. The parents and caregivers described here share traits we hope all parents embody; the most notable of these traits is a steadfast investment in the well-being of their children. Furthermore, these parents strived to fulfill their duties as a parent and were able to advocate for the needs of their teenagers. Following is a discussion of the major themes and contributions of this research as well as implications of these findings.

Parents' Involvement in the Diagnosis Process

Entrance into the mental health care system began with adolescents receiving a mental health diagnosis from a professional. Gudino and colleagues (2009) conceptualized that the initiation of treatment may be contingent upon parental identification of the symptoms of depression. In this sample, parental identification contributed to connecting the child to mental health care, yet other familial components also became apparent. I found three thematic pathways families in this sample entered the mental health care system. These themes revealed the multiple ways in which families who are involved in the mental health system are getting connected to care.

First, parents and caregivers reported early involvement with the mental health care system due to co-occurring diagnoses of the child that were apparent at young ages. Families connecting to care because of co-occurring diagnoses exemplify how families

often manage several challenges at once. Indeed, in this sample it was rare for parents to report the teens were only struggling with a depressive disorder and were free from any other mental or physical health concerns. These findings mirror previous research on the epidemiology of mental health disorders in youth, which found that for youth with depression, co-morbidity is more the rule than the exception (Kessler & Walters, 1998) and that cases of major depressive disorder are commonly associated with co-occurring psychiatric diagnoses (Avenevoli, Swendsen, He, Burstein, & Merikangas, 2015). In a sample of children on publically funded health insurance, high levels of co-occurring physical health problems has been seen elsewhere in the literature (Mukolo & Heflinger, 2011). It may be challenging for parents to understand the presence of multiple disorders in teenagers as well as how a diagnosis may change over time.

Additionally, even when children are involved with mental health care from a young age, these findings suggest that new diagnoses can come about as the child progresses through the developmental stages. Research has found that an ADHD diagnosis at young ages (four to six years old) is predictive of later adolescent depression and/or suicide attempts (Chronis-Tuscano, Molina, Pelham, Applegate, Dahlke, Overmyer, & Lahey, 2010). The presence of multiple diagnoses as a child develops adds to the complexities of these families lives. Therefore, continued assessment and continuity of treatment are important, as well as adequate explanations to parents and caregivers if the diagnoses changes or new a diagnosis becomes apparent. Continuity is especially key as children become teenagers, since depressive disorder onset is commonly seen during adolescence (Weissman & Shaffer, 1998) and mood disorder diagnoses are prevalent during this stage of development. (Merikangas et al., 2010).

The second thematic pathway of entering care was at the mandate of an agency, such as the court system, foster care, or CPS. This theme may be similar to Franz and colleagues' (2010) qualitative finding that African American individuals report a raised threshold for initiation of treatment, such as after a confrontation with police. Parents and caregivers in the present sample were somewhat removed from the process when an agency mandate led to a diagnosis. It is notable, though, that parents did not push back against agency involvement or resist the recommendation or requirement of a diagnosis and/or treatment. Parents reported the agency mandates for an assessment helped bring issues to light and opened up the doorway to help for the teens. This unique sample's willingness to allow agency involvement into their lives may be similar to Richardson and Brakle's (2011) findings that poor families may purposefully turn to institutions, such as the juvenile justice system, to connect their teens with mental health care. To further both teen and parent involvement in care, any mandates for diagnosis and treatment need to be framed as connecting teens to services that will help both the teen and the parent or caregiver. It may be important that involvement with mental health care not be proposed or explained as a punishment or penalty. Additionally, agency professionals should strive to include parents early on, even when a third party, such as foster care, requires obtaining the diagnosis. Doing so may help families in poverty access quality, targeted care, before turning to institutions like the juvenile justice system for help with their adolescent's behaviors.

The last way families in the sample became connected to mental health care was when parents and caregivers obtained greater awareness of the teen's needs. Awareness often came about because outside sources, such as school professionals, reached out to

the parents with concerns. Educational achievement is often emphasized in African American families (Boyd-Franklin, 2003), so parents' increased knowledge of how their child's struggles were impacting their school performance could have further helped parents feel like mental health intervention was warranted. School professionals, particularly at school health centers, are practical sources of referrals for mental health care (Murphey, Vaughn, & Barry, 2013). Schools are positioned to notice unhealthy behaviors and connect families to care. Yet, in order for parents to trust the expressed concerns of school professionals, strong relationships are needed between families and school. These findings demonstrate that families such as those described here can be receptive to the recommendations of school professionals. This is noteworthy, as prior research on low-income, African Americans has suggested that these parents may be less responsive to information from schools about a child's behavior problems or need for mental health care (Slade, 2004). Parents' lack of confidence in the person recommending treatment further can be a barrier to families obtaining care (Owens et al., 2002). It is possible the lack of confidence is sometimes warranted, as teachers in inner city schools report limited knowledge about mental health issues and little consultation with mental health professionals (Walter, Gouze, & Lim, 2006).

The pathway to treatment for participants was also shaped by parents' awareness of the severity of the teenagers' behaviors. It was evident in these findings that families entered mental health care at times of extreme duress, such as when a teen was actively suicidal or the youth faced threats of expulsion from school. Certainly mental health services at these critical points can be helpful to teenagers. The mental health system has been characterized as "crisis-oriented" and adept at treating severe, persistent mental

illness (Murphey et al., 2013). The previously mentioned theme of a raised threshold for initiation of treatment also is evident where the families in the present study reported initiating care following violent or suicidal behavior (Franz et al., 2010). For some adults, entering into mental health care appears to often come at times of “high need,” when thoughts of suicide are present or when hospitalization seems necessary (Ayalon & Alvidrez, 2007). Therefore, some parents may feel mental health treatment is perhaps only needed in times of severe duress, or crisis.

Knowing families are entering care at times of such heightened stress leads to questions about how to get adolescents’ into care earlier, before they reach these points of severely unhealthy, unsafe behaviors. Strong relationships between school professionals and families are needed for families to trust recommendations about receiving mental health care early and minimize teen expulsion from school. More education to enable parents’ early recognition of the signs and symptoms could alleviate families from being “pushed” into the mental health care system because of such imminent stressors as attempted teen suicide. Recognizing behavior changes in adolescents have led some demographics of parents to initiate the diagnosis process (Harden, 2005). It is important to provide information to all parents, including low-income African American parents and caregivers, in how to recognize behavior changes that could indicate the teen is struggling.

The last thematic pathway of entrance into the mental health care system was parents connecting the teen’s mental health status with life situational experiences and events. Understanding the youth’s fragile emotional state as related to adversities the teen had faced seemed to help parents feel comfortable initiating the diagnosis process. Moses

(2011) also found evidence of some parents endorsing the conceptualization that a youth's mental health disorder may be related to external life experiences. Strong support for the association between experiencing negative life events and depressive symptoms has been previously reported (Rice, Harold, & Thapar, 2003; Young, LaMontagne, Dietrich, & Wells, 2012). Additionally, Yeh and colleagues (2005) found that parents who believed their child's mental health struggles were rooted in a physical cause or were a reaction to a trauma were more likely to utilize mental health services, indicating prior evidence of parents' conceptualizations along these lines and how this links to accessing care.

It is possible that depression may very well surface as a reaction to an uncomfortable, unfortunate life experience, such as the loss or death of a loved one or an unstable relationship with one's birth parents. For these reasons, increasing families' understanding that teens may have a hard time coping with such negative experiences could help parents recognize the teen's need for mental health treatment. If parents and caregivers were able to see that exposure to adversities may present a challenge for teens, they may be more willing to connect their teen with care. Parents could be educated about how life situational experiences are possible "warning signs" that a teenager may need some extra support and the mental health care system is this potential support. Research suggests efforts to educate parents about depression and suicide have yielded significant results, with parents reporting more awareness of signs of troublesome behavior post intervention (Maine, Shute, & Martin, 2001).

It may be the case that what helped the parents in the present study seek care was the presence of more than one of these components of awareness. This sample represents

a subset of parents and caregivers who were already connected with mental health care, and therefore exemplify openness and receptivity to mental health diagnoses and treatment. The nature of the sample provides insight into how a buildup of problematic events may be necessary for similarly situated caregivers to seek mental health services for their teens. For these families, for example, suicidal or self harm behaviors may have been noticed by school professionals and the combination of outside sources and the severity of behaviors was enough for parents to think that mental health treatment was warranted. Or outside sources made a referral recommendation and parents made the connection to a separate life situational event and the co-occurrence of these two contexts enabled parents to see mental health care as a viable option. Therefore, for families of similar demographics, entering the mental health care system may also happen after the confluence of such events.

Parents' Responses Post-Diagnosis

Exploring parents responses to the teen's diagnosis elucidated the meaning parents attribute to the diagnosis, their comprehension of depression in adolescents, and how parents' adapted to learning their child was struggling with a mental health issue. Parents and caregivers described a simultaneous response of recognizing their concerns about the teen were valid while also feeling somewhat confused about the diagnosis. Parents may have felt relief to have a "name and face to what's wrong." Notable here is an indication that parents were likely to suspect something was wrong with the teens but that they hesitated to act. A lack of clarity about the teen's emotional well-being was present in the families. Parents related this lack of clarity to an inability to discern typical and atypical adolescent behaviors. These findings mirror Moses' (2011) research

exploring parents' conceptualizations of their children's mental health concerns. Here, Moses (2011) found that parents and guardians may have an "uncertain conceptualization" where they recognize the presence of a disorder but still remain confused about a condition's changing symptoms and the severity of the problem. Furthermore, these findings somewhat contrasted with Harden's (2005) findings that parents confusion sometimes originated from hearing doctors attribute what is alarming behavior to parents as something that is typical of teenagers. Rather, the parents and caregivers in this sample reported thinking the behaviors observed were typical and it was outside sources who found the behaviors alarming. Indeed, adolescence is a difficult stage of development where the boundaries between normative struggles and psychopathology are less clear (Cicchetti & Rogosch, 2002). Where the line of pathology lies can be difficult for professionals to ascertain even with instruction; Moor and colleagues (2007) found that after receiving training, teachers did not improve in their recognition of depressive symptoms in students.

These findings suggest parents' lack of knowledge about depression in adolescence may contribute to the lingering confusion about the diagnosis; this quandary could be considered a mental health literacy issue. Parents of children with mental health conditions have been found to have low health literacy levels, and not receiving mental health services is also associated with lower health literacy in parents (Dey, Wang, Jorm, & Mohler-Kuo, 2015). Improving parental health literacy, in part by developing clear health communication messages, may help reduce child health disparities (Sanders, Shaw, Guez, Baur, & Rudd, 2009). Perhaps then, if the participants were better able to differentiate healthy and problematic behaviors and coping mechanisms, their responses

to the diagnosis may reflect less confusion and parental access to and involvement in care may be enhanced. Therefore, increased education directed towards parents about the signs and symptoms of adolescent depression is warranted. Parents and professionals need more knowledge about the varied forms depression in teens may take, as well as the potential risk posed by being exposed to an adversity. Such information may increase parental mental health literacy. Additionally, parents should be able to recognize healthy and unhealthy coping behaviors in the teens and assess whether or not the behaviors indicate the teen needs help. Such informational interventions may help parents and caregivers act on their instincts that the teen is struggling, and precipitate early action before the teen is facing suicidal ideations. Expanded knowledge also may alleviate parents' confusion once the diagnosis comes to light.

As parents and caregivers attempted to make sense of the diagnosis, perhaps to clarify their own confusion, the findings revealed these participants looked to numerous sources as contributing to the teen's current mental health state. Biological parents in the sample were willing to look inward while also considering the role of the other birth parent. Moses (2010) found parents and guardians may go through a process of blaming themselves for the presence of the youth's disorder and then "*unblaming*" themselves by rationalizing they did all they could to help the youth. It is noteworthy that parents and caregivers own explorations into the possible causes of the teen's depression did not deter them from receiving the diagnosis or treatment for the teen, even if they saw themselves as partly to blame or they did not understand the diagnosis. This receptivity may be in part due to the sample's exposure to mental health care through various sources. Parents readily reported having some experience or knowledge of the mental health care system

because of other family members or friends' involvement, or due to having worked in an employment setting pertaining to mental health. This characteristic of the sample speaks to the importance of increasing exposure to mental health care as a potential avenue for lessening stigma against accessing services. Indeed, the prevalence of exposure to mental health care in this sample may be indicative of the modest progress Behrens and colleagues (2013) note has been made in improving access to children's mental health treatment by integrating components of care.

Previous exposure to mental health care may normalize obtaining treatment and help parents to not feel solely responsible for the teen's depressive state. Caregivers who were not the biological parents of the teens often turned to considering how the relationship the teens had with their biological parents shaped the teen's mental health. This action was reflective of Moses' (2010) findings that adopted or extended family members who function as caregivers will often believe they are not responsible for the child's disorder. Consequently, in this sample, the non-biological parent caregivers deferred this responsibility to the birth parents. So, in this sample participants sought to make sense of the adolescent's diagnosis by considering the influence of multiple relationships and circumstances.

The second theme of parents' responses to the diagnosis was advocating. Once the mental health issue came to light, parents and caregivers swiftly responded with an expressed desire to get the teenager help. Indeed, prior research has shown that both parental attitude about the safety, effectiveness, and benefits of a treatment or service as well as the parents sense of control and competence in the face of the health issue is significantly linked to initiating mental health services (Logsdon, Pinto, LaJoie,

Hertweck, Lynch, & Flamini, 2013). An advocating response was similarly reported by Harden (2005) who talked about parents' taking responsibility for "problem solving" post-diagnosis. It is possible that parents' stance to advocate for the child was a way parents saw themselves as fulfilling their position as a parent. Seeking mental health treatment is tangible; it is something parents and teens can see happen on a regular basis. It is possible parents jumped to problem solving and making a plan for help because this reaffirmed to parents that they were satisfying their obligations to the child in a concrete way. This theme is similar to the concept of parental advocacy summarized by Burton and Jarrett (2009). Burton and Jarrett (2009) highlight the parental-level process of parental advocacy of families in poverty which reflects parents finding supportive institutions and ensuring the youth obtain the benefits from those institutions. Burton and Jarrett (2009) note how parental advocacy efforts can look a variety of ways, such as taking a collaborative or defensive form.

Participants' transition to advocating also may be linked to their sense of self-efficacy. Reich and colleagues (2004) research on parents' mental health services self-efficacy found that the attitudes of collaborating with professionals and knowledge of mental health services was related to how self-efficacious parents felt. In this sample, parents' previous exposure to mental health services may have increased their self-efficacy along these lines. Also, after engaging in treatment, parents and caregivers reported their interactions with mental health care professionals helped shape the parents' involvement in treatment. Therefore, to further encourage parental self-efficacy and an advocating perspective, clinicians and mental health professionals may strive to create environments where parents feel they can ask questions and engage with treatment.

The last component of advocating behaviors observed in this sample was parents' descriptions of seeking information from various sources. Parents' resource and information seeking particularly took the form of accessing the internet for information on mental health. It is possible parents turned to the internet first because this was a private experience for them, where they could seek what they were looking for and did not have to include others. Additionally, searching on the internet may have helped parents feel more self-efficacious in that it was a behavior they could do on their own without the assistance or guidance from anyone else.

Knowing families are readily turning to the internet brings to mind questions of what sources are they coming across and if the information they are reading is credible. It is possible parents are consuming information that is incorrect; the challenges with internet-based consumer health information were summarized by Cline & Haynes (2001) who highlight how internet-based health information may be inaccurate, ambiguous, or potentially dangerous. Limited evaluation skills could lead parents to "misjudge information, become information-overloaded and thereby easily confused, misinformed, or misled" (Cline & Haynes, 2001, p. 680). This challenge may be particularly true for low-income families who potentially have low mental health literacy to begin with. Accordingly, efforts should be made to ensure parents are reading research-based information written for low literacy audiences. Professionals may suggest specific, credible websites for parents to review after the diagnosis is confirmed.

The Parent-Child Relationship Post-Diagnosis

Four themes described the context of parent-child relationships post-diagnosis: the protective approach, patience and empathy, communication, and teaching

accountability. These themes both help explain what it is like for parents and caregivers when their teens obtain a mental health diagnosis and treatment and how parent-child interactions may change after involvement with mental health care. These findings can be used to encourage families not engaged in care to consider mental health service because of the mutual benefits for both the parent and child and the potential positive changes to the parent-child relationship.

Parents in the sample reported being protective of their teenagers post-diagnosis. It is possible these parents were predisposed to be protective of their child; African Americans of low-income may generally be protective of their children due to the perception it is necessary to shield them from the threats of living in a dangerous neighborhood, to prepare children and teens to be guarded in the face of such threats, and to protect youth from the psychological harm of prejudice and racism (Smetana, 2011). This protective stance, which was also summarized by Burton and Jarrett (2009) as family protection strategies, appears to extend to families once a teen has been diagnosed with a depressive disorder. Information about the teen's mental health status is an additional context for parents to incorporate into the way they approach their children, which could lead to heightened protective behaviors by parents. Parents seemed to see the teenagers as more easily influenced, in part due to the teen's mental health status.

It seems reasonable for parents and caregivers to become more protective upon knowing the teens were struggling with depression; having a mental health issue can be thought of as a real vulnerability. Notably parents in this sample reported little concern about what others would think of the teenager's mental health diagnosis and treatment, suggesting these families were less concerned about mental health stigma. Other studies

have found mental health stigma to be lower among African Americans compared to Whites (Diala, Muntaner, Walrath, Nickerson, LaVeist, & Leaf, 2001; Givens, Katz, Bellamy, & Holmes, 2007). The nature of this sample and their location in the D.C. metro area could play a part in these families' lack of concern about mental health stigma. The high accessibility of mental health services in this area as well as a pool of clinicians who perhaps were quite culturally competent could have helped these families overcome concern of being labeled or ostracized for utilizing mental health care.

Parental concerns that the teens could easily be influenced by peers could lead parents to interject themselves more in the teen's peer relationships. This response may be particularly complicated for adolescents because peer relationships are a notable component of adolescent social and emotional development (DeHart et al., 2004). It may be most helpful for parents to be able to express their concerns to clinicians working with teenagers in treatment. Such concerns could become part of the treatment plan and therapists could work with teenagers to gain an awareness of healthy boundaries in friend relationships.

Parents and caregivers also reported they became more patient and empathetic after their child was diagnosed with a depressive disorder. Franz and colleagues (2010) also saw empathy and compassion as a response to a family member's mental illness in a qualitative study of African American families. In the current study, parents shared they were more understanding about what the teen was going through; they may have reported this change for several reasons. Participants' prior experiences with mental health care may have played a role here. This exposure could have enabled parents to be more sympathetic to what the teen was going through, having seen others go through a similar

process. Additionally, involvement with treatment could also have helped parents be more empathetic, as they learned more about depressive disorders in teenagers. Parents' considerations of their own behaviors potentially impacting the teenager may also have contributed to parents being more compassionate. Participants also talked about wanting to protect the teens from anything that may trigger a negative reaction. Parents striving to be more patient could be connected to concerns about not prompting harmful behaviors in the teen. Finally, parents in the sample could have moved towards patience and empathy with help from the parent's own therapists.

Parents reported seeking out therapy services for themselves, which may have contributed to alleviating the depressive symptoms in the youth and again speaks to this sample's openness to mental health services. Prior research has shown that when maternal depression is treated, both maternal and child depressive symptoms improve (Verdeli et al., 2004). The current study offers insight into how such improvements may be possible. Parents and caregivers reported their own mental health treatment helped them to further understand what was going on for the teenagers. Walsh (2006) conceptualized the exchange of empathy and open emotional sharing to be a part of the communication processes that facilitate healthy family functioning. In such exchanges, family members show interest in what one another has to say and compassion may grow from sharing personal stories and life experiences (Walsh, 2006). Therefore, engaging families in mental health care could be conceptualized and advertised as a way for parents to increase their understanding of their children. Promotions for mental health services that focus on helping parents understand how their relationship with their child could improve as a result of involvement in treatment may encourage additional parents

to seek services. Clinicians working with parents of teens with depression should consider how empowering the parent to feel they can make positive changes to their relationship with their child and how such change could potentially have an impact on the teen's depressive disorder.

The third theme of change to the parent-child relationship was communication. Parents and caregivers reported changes in the quality and quantity of communication with their teen pre and post diagnosis and/or treatment. Not only did teens adjust their communication towards their parents, parents adapted to seeing how better communication with the teen could help improve the teen's mental health status. It is possible that through involvement with the mental health care system parents learned that healthy communication has benefits for both parents and teens. Parents perhaps realized that increased communication with the teen could contribute to lessening the teen's depressive disorder symptoms because the teen might feel more supported in the family. When family characteristics, particularly those on the parent-level, are modified through mental health care, the quality of interaction between mothers and infants has been found to improve (Goodman et al., 2008); the findings presented here suggest such changes may also be possible in parent-teenager interactions. Indeed, open communication is a notable component of family resilience; when communication is clear and consistent and a wide range of feelings are shared between family members, connection in family relationships grows (Walsh, 2006). Additionally, parents changing their approach to communication may have been another tangible way parents could feel they were helping their teen get better. Accordingly, mental health professionals can both encourage teens

to open up more to their parents and also coach parents on how to communicate with the teens in a healthy, productive way.

The last theme pertained to parents teaching the teens to be accountable despite having a mental health diagnosis. Parents and caregivers teaching teens to be responsible materialized several ways. Parents expressed wanting the teens to feel confident they could persevere and still be successful even with a mental health diagnosis. Parents wanted the teens to learn to take responsibility for their own mental health care and thought one way to teach teens accountability was by enforcing rules and boundaries. It is possible that parents emphasized accountability because they knew of others who also struggled with a mental health diagnosis and persevered to be successful. An example of this familiarity was seen in parents talking with their teens about famous persons diagnosed with mental health disorders; parents used these examples to help the teen feel the diagnosis was not to be thought of as a terminal set-back. Alternatively, parents may have emphasized accountability because they also witnessed the opposite and had seen individuals with mental health concerns not manage it well.

Parents expressed repeated desires to see their teenagers become successful and wanted the teens to be able to effectively manage their mental health. The focus on teen's success and accountability may also be common to this demographic of parents. Low-income parents often emphasize the importance of success, particularly in school, as a way to move beyond poverty-stricken neighborhoods (Burton & Jarrett, 2009). Educational success is commonly emphasized in African American families (Boyd-Franklin, 2003). Also, teaching responsibility is a major theme of the parenting role in African American families (Hill, 1999). Particularly for low-income families,

responsibility and accountability may come in the form of teaching self-care where children become fairly self-sufficient at young ages (Hill, 1999). It is also possible parents drew personal satisfaction from conceptualizing their teen as successful in the future, which led them to focus on teaching the teen responsibility. Additionally, the age of the adolescents could have played a role because it is common for adolescents to desire more independence (Cicchetti & Rogosch, 2002). Therefore, parents may appreciate treatment goals that encourage teens to move towards managing their own mental health. Clinicians and parents can jointly communicate messages of accountability to the teenagers while clinicians monitor the feasibility of the parents' expressed expectations.

Parental Involvement in Adolescent Mental Health Care

Parental involvement in treatment was relevant to explore because parents' involvement may be beneficial to treatment outcomes (Taylor & Adelman, 2001) and because most tested treatments for depressive disorders do not involve family members (Restifo & Bögels, 2009). Most clinical research on treatment for adolescent depression has not included families, so the impact of including parents is largely unknown (Sander & McCarty, 2005). Yet new research suggests that a family-based approach to treating depression in pre-adolescents effectively decreases depressive symptoms (Dietz et al., 2015). The process and context of parents' decision making about being involved in their adolescent's mental health care was explored through this research. Parents and caregivers described being involved in treatment when they were given choices, from which they could make decisions about their child's mental health care. Since these families were already engaged with mental health care, their experiences provide insight

into how professionals can set the stage for strong parental involvement in care. Agency in decision making was an important component of parents being involved; parents shared that this experience enabled the parents to have input into what might be helpful for the teenager. This process may also have helped form an initial alliance between the parents and mental health providers, since parents expressed feeling like they and the providers were able to mutually agree on a course of action. Indeed self-efficacy is a component of agency (Bandura, 2001) and prior research has established a connection between caregivers' attitudes about collaborating with mental health professionals and the mental health service self-efficacy of parents (Reich et al., 2004).

Parents and caregivers in this sample reported wanting to be actively involved in their teen's care and the drive to do so may be because the parents saw their involvement as a concrete, continued way to show their care and support to the teenager. Parental involvement in adolescent mental health care may be related to the concept of parental role commitment summarized by Burton and Jarrett (2009), where low-income parents make sacrifices to be able to nurture the development of their children. Parents active involvement may also prevent parents from feeling threatened by the therapist-adolescent relationship, which could be a reason parents withdraw their children from treatment prematurely (Taylor & Adelman, 2001). Involvement in the form of family therapy can directly address communication in the parent-teen relationship, the expression of emotion in a family, and how to repair relationship breakdowns (Larner, 2009). Additionally, involvement through family therapy may increase family cohesion and resilience (Larner, 2009). Encouraging parental involvement in treatment, therefore has the potential to halt cycles of poor family functioning and negative family processes.

Parents' decision making about their involvement in adolescent mental health treatment also pertained to parents recognizing the mutual benefits for both them and the teenager. Parents and caregivers saw their involvement as a way to express their commitment to the teenager and their involvement validated them, as the parent, could have a positive influence on the teen's mental health. Prior research on the impact of family involvement in treatment through education interventions for children with depression has found that parents felt the family intervention was useful, it met their needs, and it sensitized the parents to the skills the children were trying to master and generalize (Asarnow, Scott, & Mintz, 2002).

It may be the case that parents in this sample focused on being involved in treatment because they felt they could be successful at it. Considering these families' income status, they could feel powerless in the face of systems they do not think they can actively be a part of, yet obtaining mental health care became accessible with insurance. Prior research suggests families of limited means with little social capital sometimes turn to formal resources, such as the juvenile justice system, as a source of emotional and social support (Richardson, Johnson, & St. Vil, 2014). In these relationships, parents turned to the workers within the juvenile justice system for advice and help in the absence of support from their own families or communities (Richardson et al., 2014). A similar process may have happened in the parents of this sample, who turned to the mental health system for help in learning how to improve their relationships with their teens, and for validation that they were fulfilling their role as a parent. Indeed, parents expressed they thought their involvement would help them learn how to better help their teenagers. Parental involvement in care should be conceptualized as a way to improve

parent-child dynamics. Mental health care can help parents learn to improve their communication and relationship with their teenagers, which could have a long-term impact on parent-child dynamics.

What encouraged parental involvement in treatment was also considered. The disposition of the mental health providers and the relationship between the parents and providers promoted parental involvement, when parents felt included and invited into the treatment experience. The positive nature of this relationship, as well as the relationship between the provider and the teen, aided parents and caregivers in feeling their involvement would be important and helpful. These findings are reflective of Reich and colleagues' (2004) findings about caregivers' attitudes about collaborating with mental health professionals and the mental health services self-efficacy of parents. The caregivers in my sample were open to collaborating, therefore Reich and colleagues (2004) findings suggest this openness may be related to them also feeling more self-efficacious about getting the teens treatment. It is also worth noting that the cultural competency and skills of the clinicians may have played a part in this unique group of parents and caregivers being so open and accepting of mental health care. This sample's expressed connections to the mental health providers they worked with suggests the providers may be skilled at overcoming stereotypes of African American or low-income families. Clinicians should be aware that parents are observing and perhaps seeking to learn from them, thus, mental health professionals may set a precedent about parental involvement in treatment, and should strive to do so in a culturally competent way.

A second encouragement to parental involvement in treatment was the parents' and caregivers' own mental health. These findings offer insight into how low-income

parents manage family comorbidity, or co-morbidity at the family level instead of using the individual as the unit of analysis (Burton & Bromell, 2010). Family comorbidity has been conceptualized as adding to the cumulative disadvantage families in poverty endure (Burton & Bromell, 2010). Yet in these data, intergenerational mental health concerns were seen as beneficial to parents' involvement in treatment, suggesting family resilience might be present. It appeared that parents own struggles with mental health concerns helped drive them to get the teenagers help. It seemed knowing what it was like to struggle further encouraged parents to both seek out and be involved in treatment. Contrary to previous research that parents own mental health issues is correlated with unmet service usage (Cornelius et al., 2001), in this sample parents own mental health struggles was seen by parents as helping them both get connected to and be involved in treatment. It is possible that parents' personal experiences made the process easier because parents had prior knowledge of the mental health care system. Indeed, other qualitative research has found the theme of having mentally ill peers or families is a resource for Black adults (Ayalon & Alvidrez, 2007). Consequently, clinicians should explore with parents their prior experiences with care and understand that parents may have unique knowledge and experiences with mental health services to share. It is possible parents with their own mental health diagnoses can contribute to the treatment process by discussing strategies that have worked for them to overcome their own mental health concerns and by normalizing the experience of receiving mental health care for potentially resistant teenagers.

The last encouragement to parental involvement in treatment was parents' own spirituality. Reports of spirituality here reflect previously established findings that

spirituality and the perception of religion is a strength for African American families (Boyd-Franklin, 2003). Spirituality was seen as a coping mechanism for parents, who turned to praying and to their god as an outlet. Additionally, messages from parents' faith became part of their motivation to be involved in treatment. These findings were contrary to what Alvidrez and colleagues (2008) proposed; they saw spirituality as a potential barrier to African American families' involvement in treatment because they may feel they should turn to their spiritual communities instead of mental health care providers when facing a struggle. Rather in this sample, parents and caregivers expressed feeling their spirituality supported their involvement by reinforcing that children are innocent, in need of help, and did not ask for the struggles they may face. Elsewhere spirituality has been conceptualized as a notable component of family resilience (Walsh, 2006). Particularly for African Americans, spirituality may be a buffer against suicide (Griffin-Fennell & Williams, 2006). Accordingly, clinicians may incorporate spirituality into their work with families at a level that is accessible and comfortable for all parties involved. Mental health professionals may encourage parents to utilize their spirituality as a coping skill.

Two barriers to parental involvement in care were apparent in the data. These themes demonstrate the multitude of struggles families can face and how rarely just the teen's depressive disorder is the only adversity a family is enduring. The first barrier was parents or caregivers seeing characteristics of themselves, the teen, or other family members as potential obstacles. Stigma of mental health care may be at play here, with other family members expressing negative opinions of mental health services that cause parents and caregivers to possibly hesitate in seeking treatment for the teen. Also notable

in this theme was the teen's own resistance to treatment. Elsewhere, teens have reported that depression makes them feel abnormal, disconnected, and dependent on others, which could contribute to their resistance to accepting care (Wisdom, Clarke, & Green, 2006). My research findings suggested that when teens are resistant to treatment, parents may be less inclined to be involved. Thus, it may be helpful for both parents and teens to be given information about the treatment process upfront – including possible interventions and the duration of the treatment process. Meredith and colleagues (2009) suggest that professionals talk with teens directly about treatment reluctance and preferences as a way to help reach a level of comfort. They also recommend including parents in discussions to further parents' understanding of the teen's feelings and which may enable parents to effectively support future treatment. Mental health professionals also need to be sensitive to the various adversities families may face, while recognizing parents' desire to be involved in treatment can potentially overcome such hardships.

The second barrier evident in the data was a lack of resources. Low-income families, even with the amenities sometimes provided by their insurance companies, still may have to make hard decisions about being involved in treatment alongside of competing priorities. A lack of time and a shortage of financial resources were reported by parents to impede their ability to fully engage with their teen's mental health care; and similar barriers have been echoed in previous literature (Meredith, Stein, Paddock, Jaycox, Quinn, Chandra, & Burnam, 2009). It was also apparent in the data that particularly when a teenager is struggling with multiple co-occurring diagnoses, parents must devote a lot of time and attention to their care. Yet, even facing a lack of resources, parents in the sample continued to report wanting to be involved. Larson and colleagues

(2013) research with an African American, low income urban sample found that tangible barriers – such as transportation problems, concerns about missing work, or trouble navigating the mental health care system - were not found to impact mental health care appointments. So, clinicians and providers should strive to find ways to include parents, perhaps by keeping in contact with the parent or caregiver even if they are unable to attend sessions with the teenager.

Family Characteristics

How the characteristics of the families in this study may have shaped their involvement with mental health care was also considered as part of this research. The contexts of insurance, income, and race/ethnicity were explored. This sample may be unique in that the parents and caregivers described here utilized the resources they had to acquire insurance for themselves or their teenagers. The findings suggest that participants saw insurance as the way they could get connected to care. Without insurance, it is possible that these families may not have sought or engaged with the mental health care system, as families who lack insurance typically also are unable to pay for out-of-pocket services (Deck & Ley, 2006). The families' desire for involvement may still have been present but a lack of financial resources or insurance to pay for treatment would have been a major obstacle families faced. This obstacle is particularly salient given that poor and near-poor families are five to six times more likely to be uninsured compared to middle and higher income families, despite being eligible for government funded insurance (Newacheck et al., 2003). Not only was insurance seen as the bridge connecting families to care, families reported they felt continually supported by their insurance. As regular users of their insurance benefits, parents' satisfaction seemed to

outweigh any possible complaints. Research has established that caregiver satisfaction with their children's behavioral health providers do not significantly differ when comparing Medicaid plans to fee for service plans (Heflinger, Simpkins, Scholle, & Kelleher, 2004).

Prior research has suggested that ethnic minorities receive poorer quality care compared to Whites (DHHS, 2001); it is interesting to note that the participants in this sample did not report thinking the care they received was of poor quality. This response may be a testament to the practices and policies of agencies and clinicians with whom the families interacted. Adult patient satisfaction with care with general Medicaid services has been previously established (Mainous, Griffith, & Love, 1999). It stands to reason that if someone is satisfied with the services received, they may not question how it could or should be different. Interestingly, Heflinger and colleagues (2004) found that African American parents/caregivers reported higher satisfaction ratings of their Medicaid plans compared to other races. The findings presented here offer some insights into the contexts of mental health care that create satisfaction in Black/African American parents' experiences. Parents' satisfaction with their insurance and expressed feeling of support indicate that their insurance for mental health care is working. Therefore, Medicaid benefits for low-income families seem essential to enabling access to care. Families shared that they actively took advantage of the features their insurance provided, which made mental health treatment more accessible. They appreciated several features that made the insurance more personalized. Parents and caregivers utilized transportation to and from appointments and felt home-based service helped ease any burdens of ensuring the teen obtained care. Consequently, the mental health care system should continue to

meet families' needs in these ways to help encourage low-income families to both enter treatment and sustain treatment over time.

It seemed difficult for parents to isolate how being low-income may have shaped the mental health care received. When the question of income was raised, parents immediately thought about their insurance, indicating that for these families accessing insurance was inherently linked to their income. Parents and caregivers were asked if they had access to more financial resources, did they think that might change the care they received. In response to such questions, parents often mentioned other places they would funnel extra funds. It seemed to be the case that since generally, parents were satisfied with treatment, they did not see a reason to move any extra income to increasing the amount of care or changing the types of treatment. Instead, parents spoke about potentially using any additional funds to move to a different neighborhood, to be able to purchase healthier foods, or to afford to do activities with the teens more often. It is possible that even if additional financial resources were not directly funneled into mental health care, parents use of such money on the aforementioned alternatives may have a long-term impact on teen's mental health. Indeed, a well-balanced diet is essential for healthy adolescent physical and mental development (Tomlinson, Wilkinson, & Wilkinson, 2009).

The last context explored in this research was race/ethnicity and how parents saw their racial or ethnic background shaping the mental health services obtained. In this sample of predominately Black/African Americans, two divergent perspectives on how race/ethnicity shaped care were apparent. The more common response was that parents and caregivers in the sample did not think race/ethnicity shaped their experiences with

mental health care. These participants were not concerned about being connected with mental health professionals who understood or shared their ethnic background. The second group of parents felt race/ethnicity played a role in the treatment they received, or they spoke of how race/ethnicity shaped their peripheral experiences with mental health care. When exploring this topic, the race/ethnicity of the mental health professionals the families worked with was not asked or was not always apparent; it is possible families who felt race/ethnicity did not shape care may have worked with same-race professionals. Or, it is also possible that the pool of clinicians and therapists, this unique group of participants interfaced with, were quite culturally competent. The professionals may have been willing to address racial/ethnic differences with these families head on, leading the families to feel such differences could be easily overcome or managed. Ayalon and Alvidrez (2007) similarly explored the concept of ethnic matching in mental health care through a qualitative study of Black adults. Similar to the findings here, they found most participants were not concerned with being matched with a mental health professional of their same race/ethnicity. These findings suggest it is not possible to say that race/ethnicity does not matter to these families since their experiences and perceptions were varied. Agencies should strive to ask families if they have a preference for clinicians who are of the same or different backgrounds of their family.

Limitations

Limitations of the Sample

This sample does not represent the larger population of parents and teenagers utilizing mental health care treatment since it was restricted to parents and caregivers in the D.C. metro area. Additionally, the sample does not represent all racial/ethnic groups

who utilize mental health services. Families of low-income were purposely recruited into the sample so findings about other income-levels and classes may be limited. These findings cannot be generalized to the larger population of all families seeking or utilizing mental health services. However, it was not an aim of this study to generalize to the larger population. Rather, the intention was to meet the requirements of transferability through providing substantial descriptive data that enables others to transfer the findings of this study to other situations, with other participants. The transferability of these findings to other samples can be verified through future research.

The sample was also composed of several families where the adolescent had co-occurring diagnoses. During the interviews, it was challenging to ascertain when parents were directly talking about the teen's depressive disorder and how that diagnosis shaped the family's experiences or if parents were considering the other diagnoses as paramount; perhaps parents combine the impact of all diagnoses together. For families dealing with co-occurring diagnoses what can be said about the specific ways the depressive disorder shaped the family may be limited, yet findings about parental involvement in care, in general, still hold.

Lastly, participants in the sample largely had experiences with mental health care prior to obtaining care for the target adolescent. Indeed, one participant stated "Everybody do therapy" when discussing exposure to mental health care. These findings may have been different if participants had much less knowledge and experience with mental health care prior to the adolescent's depressive disorder. This characteristic of the sample perhaps suggests that for the D.C. metro area, attempts to expand mental health care and outreach have been successful. For other areas of the U.S. with less accessible

mental health care or where state and local governments perhaps have been less proactive in addressing mental health care, this prior utilization may have differed.

Limitations of Data Collection

Limitations of the data collection methods were also present. As the sole interviewer in this study, dependability and confirmability is challenged. Trustworthiness of the conclusions drawn from the interviews may have been increased if a second researcher also completed interviews. Since this was not feasible, dependability and confirmability was supported by consulting research assistants, peer reviewers, and committee members to affirm claims made in this research.

Participants were recruited into the sample through a variety of methods, one of which was by referral from clinicians who worked with the families. As discussed, the sample largely reported being content with the mental health services received. It is possible that the clinicians selectively referred families based on who they had the best relationship with and felt most benefited from treatment. Additionally, the families interviewed may have volunteered because they were willing to talk about how their experiences with mental health care were helpful and beneficial. The data collection methods made accessing families unsatisfied with treatment more challenging. However, there were families in the sample who had not consistently been involved with mental health care resulting in some variability in the types and duration of care received.

Lastly, the data collection methods asked families to recall back in time and to report on behaviors and activities from the past as well as in the current times. It is possible parents recollection of events was not accurate or their memories of how the events unfolded which led to the diagnosis and/or treatment were amiss. Especially for

parents who had been involved with the mental health care system for several years, recollecting this process took patience and probing. It was also the case that at the time of the interview, the families varied in the amount of time they had interfaced with the mental health care system. Perhaps if there had been more consistency in these time periods, this impact would have reflected differently in these data.

Major Implications

Practice and Program Implications

This study has several practice and program implications for encouraging non-users to access mental health care and for improving family involvement with mental health treatment. Families in the sample accessed the mental health system through varied pathways. The multiple ways families can get connected to care could increase access overall and act as a safety net for one another. Particularly related to depressive disorders in teenagers, these findings suggest parents may need a buildup of problematic events to think treatment is warranted. Therefore, mental health care practitioners and health education programming initiatives should strive to educate parents and caregivers about depressive disorder symptoms in adolescents, as this is an important component of enabling parents to recognize when teens may need mental health treatment.

Educational efforts along these lines should be the burden of professionals and practitioners. Families such as those described here need low-literacy, easily understandable resources explaining typical and atypical adolescent behavior, what healthy coping in teens looks like, and how certain changes in a teen's behavior may indicate the presence of a depressive or mood disorder. Addressing the health literacy of this population should strive to clarify some of the basic terms used in mental health care.

Some of the challenges of health literacy observed in these data were using incorrect acronyms for varied mental health diagnoses and mixing up titles of mental health professionals. Additionally, professionals should strive to educate parents about the different manifestations of depression in males versus females.

Additionally, strong relationships between referral sources and families are an important element of connecting families to care. These relationships are essential to ensuring parents overcome possible concerns about their children being unnecessarily labeled, often common in African American families (Boyd-Franklin, 2003). If schools and other outside sources continue to recommend mental health treatment for families such as those interviewed here, families will likely rely more heavily on schools for insights into how to get help for their teen. Prior research on barriers to treatment for low-income African American parents reported that parents felt they did not know where to go to obtain help (Owens et al., 2002). Furthering openness and trust in school-family relationships may be important for the buildup of events parents need to believe treatment is necessary. School professionals are positioned to notice changes in teen's behaviors over time and recommend treatment to parents. Schools and other potential outside sources need to be prepared to walk families through the steps of obtaining mental health care and should readily have access to referral lists of mental health agencies that can provide a diagnosis, and if needed subsequent treatment. Ideally, outside sources would also have a system in place to follow up with families regarding the status of their obtaining care. One scalable model may be to have a paraprofessional "family advocate" to whom parents can be referred for information on accessing mental health care. Also

called a “family associate,” this model has been shown to significantly increase the likelihood that children’s mental health services are initiated (Koroloff et al., 1996).

These findings also elucidate how involvement with mental health care may shape parents’ perception of their relationship with their teenager. Parents and caregivers saw their relationship with their teens to change after involvement with mental health care. It is possible that for low-income parents, accessing mental health services is a way for the parent to show their dedication and commitment to the child’s success. Obtaining care may help validate the parent’s position as a caregiver to the teenager. Therefore, adolescent mental health treatment should be thought of as having more global benefits for the family system and not just simply address the adolescent. If parents were made aware of how connecting the teen to mental health services could improve the parent-child relationship, parents may be more inclined to access care. Also, when services and treatment positively impact the parent-child relationship, this could also have a long-term impact on the teen’s mental health status.

Regarding parental involvement in treatment, these findings suggest that parents want to be actively involved in their adolescent’s mental health care. The parents in this sample could be categorized as “highly involved” or “marginally involved,” as outlined by Taylor & Adelman (2001); indeed it appears no parents in this sample would fall into Taylor & Adelman’s (2001) category of “highly resistant,” or uncooperative or avoidant to treatment. Therefore, from these findings we can infer what mental health professionals can do to potentially increase parental involvement in care, which could have implications for the duration and success of treatment. Enabling parents to feel they have a say in how mental health services move forward may be the impetus to strong

parental involvement. The relationships parents and caregivers had with mental health care providers encouraged parental involvement in treatment and parents' own mental health struggles seemed to enable parents to empathize with the teens further. Mental health professionals need to find ways to actively include parents in treatment. Even when the identified patient is the teen, parents saw themselves as part of the treatment process and able to contribute to helping the teenager's mental health improve. Mental health professionals should capitalize upon these parents' perspectives as agents of change. Doing so may make treatment more appealing for families who are not accessing mental health care or may encourage families to continue their engagement in care through the duration of treatment.

One aspect of agency in decision making that is not clear from these findings is if the parents were knowledgeable enough about the treatments offered to question their validity for their particular teenager. It is unclear if parents or caregivers knew enough about mental health care to evaluate what types of services their teen would benefit from the most. It seems important for mental health care to not fall into a one-size fits all approach but rather to assess the specific needs of each client independently. Parents and family members would be ideal auditors, assessing if this was the case – yet this would require families to be quite well-informed about mental health care.

Best Practices for Mental Health Care Professionals and Agencies. These findings suggest that mental health professionals should continually seek ways to include parents and caregivers in care. Providers should attempt to check in before or after sessions with parents and provide parents with insights into how treatment is progressing. They should consider working with parents on what they can do to improve their relationship with the

teenagers. Clinicians should strive to see parents as a resource – as part of what can help them reach treatment goals. Trained family therapists may be more predisposed to include parents in sessions and adept at finding ways this inclusion can be done comfortably for both the parent, the teen, and the clinician. Other clinical disciplines should strive to become educated on ways to involve important family members for the benefit of the teenage client. The implications of this research can also be summarized in the below suggested “best practices” for mental health professionals working with parents and teenagers.

- **After assigning a diagnosis:** Mental health professionals should explain the diagnosis in terms low-literacy individuals can understand. The explanation should include information about the signs and symptoms of depressive disorders in adolescents and how depression can look differently in teens compared to adults. Mental health professionals should talk with parents about what healthy coping skills look like across age ranges and how teenagers can effectively manage their emotions. The explanation should also include information about the typical length of treatment and what the approach to be used entails. It should be noted that it is possible for a diagnoses to change over time and the teenager may need to be reevaluated as treatment progresses; if the diagnosis is acute or chronic should also be explained to parents in terms they can understand. Additionally, parents should be directed to trustworthy resources (hardcopy or internet-based) about adolescent depressive disorders.
- **Parental psychopathology:** Clinicians should also be aware it is possible the parents or caregivers of the teens may also be struggling with a mental health diagnosis. Parents may utilize their own experiences to normalize treatment for their adolescent. Parents could also potentially benefit from receiving individual therapy services themselves, if they are not already in treatment. After building a rapport with the parents, it is possible such suggestions may be helpful to the parent.
- **Planning for treatment:** When planning therapy services for a teenager, families should be asked if they have a preference of working with a clinician of a particular racial/ethnic background. Additionally, parents may be likely to agree with whatever treatment modality is presented to them, so it is important that the treatment planned is the best approach individualized for the specific teenager and/or the family.

- **Involving parents at the beginning of treatment:** Mental health professionals should take strides to talk with parents at the beginning of the therapy treatment process. Clinicians could explain to parents that it may take some time for the teenager to become comfortable in sessions and to open up. This situation should be normalized and the clinician should provide reassurance to the parent that she/he will work towards making the teen feel at ease during sessions. Professionals also should explain how confidentiality works when managing session with teenagers. Clinicians should be clear to both the parents and teenagers about the boundaries of confidentiality from the beginning of treatment.
- **Involving parents in treatment planning:** Clinicians should consult with parents to obtain input about the goals for treatment. Therapists and counselors can inform parents that often through engaging in therapy sessions, teenagers learn better coping skills and teens utilize therapy as an outlet to express themselves. Clinicians should consider including goals related to improving parent-teen communication, recognizing healthy and unhealthy peer relationships, and increasing the teen's autonomy in the treatment plan.
- **Suicidal or self-harm behaviors:** Parents are concerned something they may do or say could trigger dangerous behaviors in the teen. When working with clients struggling with suicidal ideations or self-harm behaviors, writing up a safety plan and including parents in the process may be helpful. Parents and teens should both be aware of what actions will be taken if the teenager is actively suicidal. Parents and caregivers are an important part of enacting a safety plan.
- **Ongoing parental involvement in care:** Mental health professionals should continually engage parents and caregivers in care by checking in with the parent before or after session or by asking for the teen's opinions about inviting the parent into sessions and potentially following through on this. Clinicians should keep in mind that parents are open to feedback about changes they may be able to make to improve their relationship with the teen and to help the teen experience symptom reduction. When possible, information should be shared with the parent that could help the parent improve their relationship with the teenager. Therapists may inquire about this with the teenager directly and then invite the parent into a session to share how the teen believes their relationship could be improved. Counselors should be aware that their recommendations may be especially helpful to improving communication between the parent and teenager. Additionally, clinicians should be prepared to direct parents to helpful, accurate resources on adolescent mental health.

Policy Implications

These findings also suggest the importance of insurance in connecting families to care. A major resource the families in this sample had was insurance, namely Medicaid,

and as regular users of these benefits families reported non-problematic experiences. As discussed, it is possible these families would not have engaged with the mental health care system if they did not have insurance, as they may not have been able to pay for services out of pocket. From a policy perspective, insurance benefits for families such as those described here need to be maintained and perhaps expanded to enable other families to access mental health care especially since children and adolescents who are uninsured are significantly less likely to receive treatment for depression (Olfson, Gameroff, Marcus, & Waslick, 2003).

Steps in this direction have been made. First, the ACA includes provisions to extend coverage options for low-income individuals (Kaiser Family Foundation, 2015) thereby reducing the number of uninsured children and adults. The ACA provisions are expected to improve access to healthcare as well as the general health of adolescents (Pilkey, Skopec, Gee, Finegold, Amaya, & Robinson, 2013). As of January 1, 2014, the ACA mandated all states provide coverage through Medicaid for children up to age 19 in families with income below 133% of the federal poverty level (Pilkey et al., 2013). Additionally, and importantly, the ACA includes coverage for mental health conditions and substance use disorders as part of the Essential Benefits package (Behrens et al., 2013). The stipulations of the ACA also allocate funding for prevention, early intervention, and mental health treatment programs, suggesting that access to such services will expand (Behrens et al., 2013).

It is also worth noting that under the Medicaid umbrella, benefits offered by all subsidiary insurance programs may not be consistent. In fact, in the present findings, families who had exposure to one particular Medicaid subsidiary seemed to report the

highest satisfaction and appreciation of the benefits offered. This particular subsidiary also seemed to offer the greatest personalization of care, with which parents identified. It may be worth considering that such benefits could become more universal as a way to make mental health services continually and equally supportive to all families, thereby potentially increasing the number of adolescents who access care. Different levels of satisfaction with varied Medicaid plans has been noted elsewhere (Heflinger et al., 2004).

Policy initiatives can also further help get families connected to care by encouraging mental health assessments and referrals. Health care professionals, such as pediatricians, may be able to both educate parents on adolescent mental health and refer teens to treatment, which could contribute to increased service usage. In addition to the previously mentioned goals of Healthy People 2020, a notable objective included here is to increase the number of screenings for depression in adolescents that occur in primary care physician offices (DHHS, 2013). Research suggests a collaborative approach that includes primary care pediatricians in identifying and referring children and adolescents to treatment may bridge barriers to mental health services for families (Aupont, Doerfler, Connor, Stille, Tisminetzky, & McLaughlin, 2013). Such screening efforts could connect families to mental health care before the depressive disorder becomes severe. The implementation of screenings could also meet parents expressed desires, since parents in this sample reported that in retrospect, they would have secured mental health services for the child earlier than they had. Also, since it may take time for some parents to think treatment is warranted, regular screenings can both help educate parents on their child's mental health needs over time and repeatedly inform parents about the benefits of mental health treatment. Another promising model of increasing access to mental health care for

children and adolescents may be incorporating mental health services directly into pediatric primary care practices, which could be supported by policy initiatives. Indeed, this model has been found to increase service use for adults (Kessler, 2012; Pomerantz, Cole, Watts, & Weeks, 2008).

Research Implications

These findings suggest that parents and caregivers such as those who partook in this research may lack an understanding of mental health disorders in adolescent. Further comprehension of low-income parents' health literacy pertaining to mental health care is warranted. Mental health care is a system unto itself with its own terms and language, which may be challenging to make sense of for potentially low-literacy audiences. It is possible that for some parents health literacy is a barrier to them getting their teenager mental health care. For example, since co-occurring diagnoses were characteristic of the current sample, exploring parents understanding of the presence of more than one mental health disorder and the implications for this for the teen may provide valuable insights into the health literacy status of this demographic. Additionally, to encourage non-users of mental health care to embrace treatment options, parents' health literacy may need to be addressed and the burden is on professionals to ensure parents and caregivers have access to the needed information to increase their health literacy.

Since co-occurring diagnoses were characteristic of this sample, interviewing parents with a focus on other mental health diagnoses teens should be explored. Sampling families based on the teen's depressive disorder diagnosis was related to the high prevalence of mood disorders in adolescents (Merikangas et al., 2010) and its status as an undertreated diagnosis (Wu et al., 1999). Externalizing, behavioral disorders are also

commonly diagnosed in adolescence (Merikangas et al., 2010). Additionally, there has been a rapid increase in rates of bipolar disorder diagnoses in adolescents the past few years (Moreno, Laje, Blanco, Jiang, Schmidt, & Olfson, 2007). Parents' health literacy of these diagnoses should be explored. A detailed investigation into how parents with teens with other diagnoses enter the mental health care system can only further an understanding of the pathways of entrance into mental health treatment that could be used to increase families' usage of mental health care.

It was interesting to see that self-blame was not a dominant part of how parents made sense of their teen's mental health diagnosis. Self-blame was moderately evident in the process parents took to explain the presence of the diagnosis in the adolescent, although participants also looked to other family members and the teen's life experiences to further explain why the teen might be struggling with a depressive disorder. Notably not seen in these data were salient discussions of feeling guilty or at fault for the presence of the teen's mental health concerns. It is possible the questions asked during these interviews did not fully explore the concept of parent/caregiver self-blame. Or, it may have been the case that the findings displayed a lack of expressed guilt and blame because of the number of non-biological parent caregivers in the sample. A final way to think about the lack of expressed blame and guilt is that this finding could demonstrate the unique ways these participants were able to successfully adapt to engage with the mental health care system and not ruminate on the causes of the teen's disorder. The findings suggest that for this set of parents, their understanding of their teen's diagnosis transcended parental blame. Future research further exploring these ideas in depth would be helpful, to further understand parents' perspectives on this topic.

Also worthy of future exploration is a more concrete understanding by this population of the different manifestations of depression across adolescence and the differences in males and females. It was not an aim of this study to determine if the participants understood how depressive disorders could look different in teen males and females, but these findings suggest that parents and caregivers have a hard time comprehending the symptoms of depressive disorders in teens. Participants seemed to report limited knowledge in these areas and thus, delving deeper into where parents' and caregivers' knowledge reaches, and where it must be extended, is an important component of both connecting needy families to mental health treatment and encouraging sustained parental involvement in care.

Not explored in this research but certainly relevant is the perspective of the teenagers obtaining treatment. Parents reported their desire to be actively engaged in treatment and their perspective that involvement in the teen's care could have some tangible positive benefits for the parent-child relationship. I would be curious to hear if the adolescents' noticed both similar changes to their relationships with their parents and how the teens made sense of their parents' involvement in their mental health treatment. It would be interesting to hear if adolescents welcome their parents' involvement and if parental involvement at all contributed to the teen's accepting the mental health care. Indeed, if the goal is to increase the utilization of mental health care, the perspective of those obtaining the care, the teens, is an important component of overcoming this dilemma.

Conclusion

An increased awareness about the potential repercussions of untreated or undertreated adolescent mental illness has led to questions about family involvement in care. The potential for teenagers struggling with depressive disorders to go unnoticed or under-referred for treatment, coupled with the long-term repercussions of struggling with this mental health diagnosis necessitated further research into these families' experiences. Through interview data collected from a unique sample of predominately low-income African American parents and caregivers, who parented an adolescent while obtaining mental health care treatment, I examined how parents are involved in the diagnosis and treatment process for adolescents with depressive disorders.

Focusing on parents connected to care, and involved in their teen's treatment, provided insight into how potentially to recreate similar contexts for families not seeking adolescent mental health care. In this sample, I found evidence for the importance of parental involvement in recognizing the need for care; where such recognition may not happen until a buildup of problematic events occurs and prompts the parent or caregiver to acknowledge a diagnosis and treatment is warranted. Increasing parents and caregivers knowledge and mental health literacy regarding the expression of adolescent depressive disorders could enable more parents to recognize at an earlier point their child's need for treatment. Additionally, a strong relationship between referral sources and families is a necessary piece of connecting teens to mental health care.

My findings suggest that parental and caregiver involvement in adolescent mental health treatment is a priority for some low-income, African American parents and caregivers and involvement can have mutual benefits for both parents and teenagers. This

study elucidates how parental involvement with adolescent mental health care can shape parents' perceptions of their relationships with their teens. Positive changes to the parent-child relationship were reported by participants in this sample as a result of their involvement in their teen's care. Therefore, accessing mental health care should be thought of as having more global benefits for the family system and not just the adolescent.

Additionally, these findings explain how parents and caregivers want to be actively involved in their teen's treatment. Participants reported that both mental health professionals who involved the parent, as well as the parents' own personal experiences with mental health care, shaped parents' and caregivers' involvement in the teen's treatment. Parents shared they wanted feedback about the teen's progression in treatment, and were open to learning what they could do help the teens face their current struggles. Mental health professionals working with similarly situated families should strive to find additional positive ways to include parents and caregivers in treatment.

Finally, these findings elucidate the important role insurance plays in connecting families to mental health care. It is possible the parents interviewed here would not have been able to connect their teens with care had it not been for their insurance. If the goal is increased usage of mental health services for children and teens, these findings strongly suggest that expanding access to insurance is a key component of enabling teens to effectively engage with mental health care. Overall, these findings offer insight into what mental health professionals and policy makers can further do to encourage and enable families, who have an adolescent needing mental health care, to get connected to and be actively engaged in their teens' treatment.

Appendices

Appendix A: Detailed Demographic Characteristics of the Sample

	Name	Age	Sex	Race	Education Level	Employment Status	Relationship Status	Relation to adolescent
(1)	Marissa	-	F	Black/AA	Some college/technical school or more	Employed part time	Married	Foster parent
(2)	Deborah	36	F	Black/AA	Some college/technical school or more	Homemaker, not employed outside of the home	Never Married	Biological mother
(3)	Caroline	-	F	Black/AA	Some college/technical school or more	Employed part time	Divorced	Aunt
(4)	Christine	-	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(5)	Martha	61	F	Black/AA	HS graduate or less	Employed part time	Divorced	Grandmother
(6)	Kalvin	59	M	Black/AA	Some college/technical school or more	Employed part time	Separated	Foster parent
(7)	Yvonne	58	F	Black/AA	HS graduate or less	Homemaker, not employed outside of the home	Never Married	Aunt
(8)	Betty	56	F	Black/AA	Some college/technical school or more	Retired	Separated	Aunt
(9)	Ellia	29	F	Black/AA	HS graduate or less	Employed full time	Never Married	Biological mother

(10)	Eve	27	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(11)	Cathy	48	F	Black/AA	HS graduate or less	Unemployed	Widowed	Caregiver who shares custody with biological mother
(12)	Tamara	38	F	Black/AA	HS graduate or less	Employed part time	Never Married	Biological mother
(13)	Ms. Greentree	46	F	Black/AA	HS graduate or less	Employed full time	Never Married	Mother by adoption
(14)	Mary	46	F	Black/AA	Some college/technical school or more	Unemployed	Never Married	Stepmother
(15)	Joy	59	F	Black/AA	Some college/technical school or more	Employed full time	Never Married	Foster parent
(16)	Ms. Coldwell	35	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(17)	Linda	59	F	Black/AA	HS graduate or less	Employed Part time	Married	Biological mother
(18)	Ms. Pilsin	45	F	Black/AA	Some college/technical school or more	Unemployed	Never Married	Mother by adoption
(19)	Tonya	38	F	Black/AA	Some college/technical school or more	Unemployed	Never Married	Biological mother
(20)	Dorothy	39	F	Caribbean	Some college/technical school or more	Unemployed	Never Married	Biological mother
(21)	Lakeisha	41	F	Black/AA	HS graduate or less	Unemployed	Married	Biological mother
(22)	Tina	57	F	Black/AA	Some college/technical school or more	Employed full time	Married	Grandmother

(23)	Juliette	47	F	White	Some college/technical school or more	Employed part time	Married	Biological mother
(24)	Ms. Innis	35	F	Black/AA	HS graduate or less	Unemployed	Married	Biological mother
(25)	Ms. Henry	60	F	Black/AA	Some college/technical school or more	Not employed due to disability	Widowed	Grandmother
(26)	Chandra	42	F	Black/AA	Some college/technical school or more	Homemaker, not employed outside of the home	Never Married	Biological mother
(27)	Carla	70	F	Black/AA	HS graduate or less	Retired	Divorced	Grandmother
(28)	Shira	52	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(29)	Lori	44	F	Black/AA	Some college/technical school or more	Employed full time	Married	Biological mother
(30)	Solange	40	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(31)	Amia	42	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(32)	Anita	51	F	Black/AA	HS graduate or less	Unemployed	Never Married	Biological mother
(33)	Adrian	53	M	Black/AA	HS graduate or less	Not employed due to disability	Married	Stepfather

Youth							
	Name	Age at time of interview	Sex	Race/Ethnicity	Age of diagnosis	Length of time with caregiver	Recruit method/Agency
(1)	Adam	27	M	Mixed races	11	7 years	ABF
(2)	Dominique	13	F	Black/AA	11	-	ABF
(3)	Denzel	11	M	Two or more races	10	1 year to current	ABF
(4)	Yvette	15	F	Black/AA	13	-	ABF
(5)	Shree	19	F	Black/AA	15	3 years to current	ABF
(6)	Andre	11	M	Black/AA	11	1 year and 6 months	ABF
(7)	Carlee	17	F	Black/AA	5	12 years	ABF
(8)	Melinda	27	F	Black/AA	11	7 years	ABF
(9)	Anton	11	M	Black/AA	10	-	ABF
(10)	Dawn	11	F	Black/AA	8	-	Snowballing
(11)	Jimmy	14	M	Black/AA	7	1 year to current	Snowballing
(12)	Ameed	11	M	Black/AA	11	-	ABF
(13)	Coraline	16	F	Black/AA	8	Birth to current	ABF
(14)	Andrew	19	M	Black/AA	9	13 years to current	ABF
(15)	Katrina	19	F	Black/AA	Unknown	6 months	ABF
(16)	Tara	12	F	Black/AA	11	-	ABF
(17)	Lindsey	17	F	Black/AA	14	-	Other
(18)	Chris	15	M	Black/AA	13	14 years to current	Other

(19)	Felicity	15	F	Black/AA	15	-	Families Together
(20)	Kevin	17	M	Two or more races	16	-	Families Together
(21)	Oscar	14	M	Black/AA	9	-	Snowballing
(22)	Ashley	17	F	Black/AA	13	Full custody for 5 years to current; caregiver before that	Snowballing
(23)	Kira	13	F	White	12	-	Nonprofit
(24)	Tanay	13	F	Black/AA	12	-	Other
(25)	Ty	13	M	Black/AA	12	Birth to current	ABF
(26)	Jackie	14	F	Black/AA	8	-	Snowballing
(27)	Malik	13	M	Black/AA	5	Birth to current	ABF
(28)	Erica	17	F	Black/AA	12	-	FSA
(29)	Danny	11	M	Black/AA	7	-	FSA
(30)	Omari	17	M	Black/AA	16	-	FSA
(31)	Kailee	15	F	Black/AA	14	-	FSA
(32)	Tommy	15	M	Black/AA	5	-	FSA
(33)	Lashauna	22	F	Black/AA	15	8 years to current	FSA

Key:

ABF = ABF Associates, Inc.

Black/AA = Black/African American

HS graduate or less = High school graduate or less

F=Female

FSA = Family Service Agency of Washington, D.C.

M=Male

Other = Participants referred through personal connections

Appendix B: Recruitment Flyer

**Are you the parent
of an adolescent?
Or a mental health
professional that works
with parents of teens?**

participants
receive
\$25
CASH

If so, please consider participating in or referring the families you work with to participate in a study about parenting adolescents with depression.

Lauren Messina, a doctoral candidate at the University of Maryland School of Public Health, is the lead researcher of the project. She is seeking to interview:

- **Parents/caregivers who are on or eligible for Medicaid**
- **Who are currently parenting an adolescent (ages 11-17 years old)**
- **The adolescent has been diagnosed with a depressive disorder**
(Major depressive disorder, Dysthymia, or Depressive disorder NOS; teens with comorbid diagnoses are also eligible)

Participants are asked questions about the adolescent's behaviors and depressive disorder diagnosis, the participant's perceptions of the diagnosis, treatment options presented and obtained, and the participant's own engagement in the adolescent's treatment. The interview includes questions such as: *What were your reactions to your adolescent's diagnosis? After the diagnosis, how did your relationship with [adolescent] change? What contributed to you feeling as though your involvement [in your adolescent's treatment] was important/would be helpful?*

- Interviews will take about 1 hour
- Interviews will be face-to-face and scheduled at a time and place that is convenient for the participant
- Participants receive \$25 cash plus resources on adolescent depression for participating in the interview.

The findings from this study will further an understanding of how to best engage parents in children's mental health treatment and will explore what more can be done to support the growing need for mental health services for adolescents and families.

**Interested in participating or know someone who is?
Contact Lauren Messina at 914-325-0428
or at LMessina@umd.edu**

Additional information about this study can be found at
www.laurenmessina.com/research/study

Appendix C: Script to Recruit Participants

- Lauren Messina, a doctoral candidate at the University of Maryland, is interested in speaking with parents or caregivers of adolescent children who have depressive disorders.
- For this research study, Lauren wants to talk with parents about what it is like to parent adolescents with depression.
- We thought you might be interested in engaging in an interview with Lauren, since you qualify based on (1) being the parent/caregiver (18 and older) of an adolescent (ages 11-16 years old) with a depressive disorder and (2) being eligible for or currently enrolled in Medicaid.
 - Adolescents should be diagnosed with either Major Depressive Disorder, Dysthymia, or Depressive Disorder not otherwise specified
 - Adolescents can have co-occurring diagnoses, but a depressive disorder must be present.
- If you are interested in talking with Lauren, I can provide you with her contact information.
- Lauren would meet with you to speak with you for about 1 hour to 1 and a half hours at a time and place that is convenient for you.
- It is important for you to know that participating in the interview is completely voluntary. Whether or not you participate will have no effect on your eligibility to receive services from any agency or organization.
- At the end of the interview, parents/caregivers will receive \$25 cash.
- If you have further questions about doing in the interview, please contact Lauren Messina. I am unable to answer any further questions.
- Are you interested in participating in this interview?
 - If no: Ok, thank you for taking the time to consider it.
 - If yes: Great, here is the phone number to call to set up a time to talk with Lauren. You can reach Lauren at 914-325-0428. Or, I can share your contact information with Lauren if you'd prefer. Where could she best reach you to schedule a time to talk?

Appendix D: Resources on Adolescent Depressive Disorders



Children's Mental Health Matters!

Facts for Families Depression in Children and Adolescents

Definition

Children with symptoms of depression show behaviors that cause problems in getting along with others and difficulties in school. The symptoms may include being irritable or grouchy, losing interest in daily activities, losing interest in friends, complaints about feeling ill (especially stomach and head aches), and doing poorly in school.

Why do we care?

When compared to their developmental peers children who display symptoms of depression:

- ☞ Have lower levels of academic performance.
- ☞ Are more likely to attempt suicide.
- ☞ Are more likely to have unprotected sex.
- ☞ Are more likely to abuse substances.

What can we do about it?

- ☞ **Actively observe your child's behavior around the house.** Consider how and where your children spend their time – in their room alone, outside with peers, in front of the television.
- ☞ **Think about the factors at home that may contribute to the child's symptoms of depression.** Write these down on a piece of paper and bring them with you when meeting with school staff.
- ☞ **Learn how to identify "cries for help" from children and adolescents with depression.** Know when your child needs immediate attention from you or a specialist.
- ☞ **Ask teachers and school clinicians about available resources in the community.** Attempt to enroll your child in a recreational league or youth organization that utilizes their strengths and talents.
- ☞ **Seek a specialist's opinion of psychiatric treatments for depression.** Visit the library to read more about the different types of medicine prescribed for depression.

Resources/Links

AACAP Facts for Families

The Depressed Child: <http://www.aacap.org/publications/factsfam/depressd.htm>

Children and Grief: <http://www.aacap.org/publications/factsfam/grief.htm>

Teen Suicide: <http://www.aacap.org/publications/factsfam/suicide.htm>

Psychotherapies for Children and Adolescents: <http://www.aacap.org/publications/factsfam/86.htm>

Psychiatric Medications for Children and Adolescents: How Medications are Used: <http://www.aacap.org/publications/factsfam/psychmed.htm>

Psychiatric Medications for Children and Adolescents Types of Medications: <http://www.aacap.org/publications/factsfam/29.htm>

Psychiatric Medications for Children and Adolescents: Questions to Ask: <http://www.aacap.org/publications/factsfam/medquest.htm>

National Alliance on Mental Illness

Family guide: What families should know about adolescent depression and treatment options.

http://www.nami.org/Content/ContentGroups/CAAC/Family_Guide_final.pdf

National Association of School Psychologists

Depression in Children and Adolescents: Information for Families and Educators. <http://www.nasponline.org/resources/handouts/social%20template.pdf>

Times of Tragedy: Preventing Suicide in Troubled Children and Youth, Part I: Tips for Parents and Schools http://www.nasponline.org/resources/crisis_safety/suicidept1_general.aspx

When it hurts to be a teenager. Principal Leadership Magazine, Cash, R. (2004). 4(2). http://www.nasponline.org/resources/principals/nassp_depression.aspx

Adapted from Resources found on:
www.schoolmentalhealth.org March 2009

The Children's Mental Health Matters! Awareness Campaign is a collaboration of The MD Coalition of Families for Children's Mental Health (MD Coalition), the Mental Health Association of MD (MHAM), the MD Mental Hygiene Administration and the MD Mental Health Transformation Office to raise public awareness of the importance of children's mental health. For more information please call the MD Coalition at 410-730-8267, MHAM at 410-235-1178 or visit www.childrensmentalhealthmatters.org



CHILDREN'S MENTAL HEALTH AWARENESS

Depression in Children and Adolescents Fact Sheet

About 11 percent of adolescents have a depressive disorder by age 18 according to the National Comorbidity Survey-Adolescent Supplement (NCS-A). Girls are more likely than boys to experience depression. The risk for depression increases as a child gets older. According to the World Health Organization, major depressive disorder is the leading cause of disability among Americans age 15 to 44.

Because normal behaviors vary from one childhood stage to another, it can be difficult to tell whether a child who shows changes in behavior is just going through a temporary “phase” or is suffering from depression.

YESTERDAY

- People believed that children could not get depression. Teens with depression were often dismissed as being moody or difficult.
- It wasn't known that having depression can increase a person's risk for heart disease, diabetes, and other diseases.
- Today's most commonly used type of antidepressant medications did not exist. Selective serotonin reuptake inhibitors (SSRIs) resulted from the work of the late Nobel Laureate and NIH researcher Julius Axelrod, who defined the action of brain chemicals (neurotransmitters) in mood disorders.

TODAY

- We now know that youth who have depression may show signs that are slightly different from the typical adult symptoms of depression. Children who are depressed may complain of feeling

sick, refuse to go to school, cling to a parent or caregiver, or worry excessively that a parent may die. Older children and teens may sulk, get into trouble at school, be negative or grouchy, or feel misunderstood.

- Findings from NIMH-funded, large-scale effectiveness trials are helping doctors and their patients make better individual treatment decisions. For example, the Treatment for Adolescents with Depression Study (TADS) found that a combination treatment of medication and psychotherapy works best for most teens with depression.
- The Treatment of SSRI-resistant Depression in Adolescents (TORDIA) study found that teens who did not respond to a first antidepressant medication are more likely to get better if they switch to a treatment that includes both medication and psychotherapy.
- The Treatment of Adolescent Suicide Attempters (TASA) study found that a new treatment approach that includes medication plus a specialized psychotherapy designed specifically to reduce suicidal thinking and behavior may reduce suicide attempts in severely depressed teens.
- Depressed teens with coexisting disorders such as substance abuse problems are less likely to respond to treatment for depression. Studies focusing on conditions that frequently co-occur and how they affect one another may lead to more targeted screening tools and interventions.

- With medication, psychotherapy, or combined treatment, most youth with depression can be effectively treated. Youth are more likely to respond to treatment if they receive it early in the course of their illness.
- Although antidepressants are generally safe, the U.S. Food and Drug Administration has placed a “black box” warning label—the most serious type of warning—on all antidepressant medications. The warning says there is an increased risk of suicidal thinking or attempts in youth taking antidepressants. Youth and young adults should be closely monitored especially during initial weeks of treatment.
- Studies focusing on depression in teens and children are pinpointing factors that appear to influence risk, treatment response, and recovery. Given the chronic nature of depression, effective intervention early in life may help reduce future burden and disability.
- Multi-generational studies have revealed a link between depression that runs in families and changes in brain structure and function, some of which may precede the onset of depression. This research is helping to identify biomarkers and other early indicators that may lead to better treatment or prevention.
- Advanced brain imaging techniques are helping scientists identify specific brain circuits that are involved in depression and yielding new ways to study the effectiveness of treatments.

TOMORROW

- Years of basic research are now showing promise for the first new generation of antidepressant medications in 2 decades, with a goal of relieving depression in hours, rather than weeks. Such a potential breakthrough could reduce the rate of suicide, which is consistently one of the leading causes of death for young people. In 2007—the most recent year for which we have statistics—it was the third leading cause of death for youth ages 15 to 24.

- Research on novel treatment delivery approaches, such as telemedicine (providing services over satellite, Internet, phone, or other remote connections) and collaborative or team-based care in medical care settings will improve the quality of mental health care for youth.
- Sophisticated gene studies have suggested common roots between depression and possibly other mental disorders. In addition to identifying how and where in the brain illnesses start before symptoms develop, these findings have also encouraged a new way of thinking about and categorizing mental illnesses. In this light, NIMH has embarked on a long-term project—called the Research Domain Criteria (RDoC) project—aimed at ultimately improving the treatment and prevention of depression by studying the classification of mental illnesses, based on genetics and neuroscience in addition to clinical observation.

National Institute of Mental Health

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E-mail: nimhinfo@nih.gov

Website: <http://www.nimh.nih.gov>





DEPRESSION FACTS

Depression is a mood state that goes well beyond temporarily feeling sad or blue. It is a serious medical illness that affects one's thoughts, feelings, behavior, mood and physical health. Psychological, biological, environmental and genetic factors contribute to its development.

For many years people living with depression and their families were blamed and experienced societal prejudice as a result of their illness, partly because depression was so misunderstood. Scientific research during the past few decades have firmly established that depression is a medical illness and that it is not a sign of personal weakness or a medical illness that can be willed or wished away.

Depression affects eight percent of American adults, and will be the 2nd leading illness throughout the world by 2020. It occurs twice as frequently in women as in men. Without treatment, the frequency as well as the severity of symptoms tends to increase over time. Left untreated, depression can lead to serious impairment in one's ability to function in relationships and at work. It can even lead to suicide, the eleventh leading cause of death in the U.S.

Major Types of Depressive Illnesses

- Major Depression – people experience persistent symptoms that affect their thoughts, behavior, mood, activity and physical health.
- Dysthymia – people experience less severe depression, but it is chronic and can negatively affect one's quality of life.
- Bipolar disorder – people experience alternating episodes of mania (severe highs), depression (severe lows) and mixed states which contain elements of both high and low experiences.
- Postpartum Depression – women can experience postpartum depression any time within the first year after childbirth and the symptoms are similar to major depression.

Symptoms of Depression:

- Persistently sad or irritable mood
- Loss of interest or pleasure in nearly all activities
- Feelings of worthlessness, guilt, hopelessness and emptiness
- Difficulty thinking, concentrating, or making decisions
- Decreased energy, fatigue, and feeling "slowed down"
- Changes in appetite and/or weight
- Changes in sleep
- Thoughts of death, suicide, plans or attempts

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DEPRESSION FACTS

Causes of Depression: There are multiple causes of depression in any combination.

Some common causes of depression are:

- Genetic (family history of the disease)
- Biochemical (changes in hormones, chemical imbalance, etc.)
- Psychological (social, anxiety, stress, etc.)
- Trauma

Treatment of Depression: Many experts suggest using both psychotherapy and medications to treat depression:

- Psychotherapy – There are many types of therapy available today including cognitive-behavior therapy, interpersonal therapy and psychodynamic psychotherapy.
- Medications – There are a variety of antidepressant medications available today including selective serotonin reuptake inhibitors (SSRIs), serotonin and norepinephrine reuptake inhibitors (SNRIs), bupropion, Mirtazapine, tricyclic antidepressants and monoamine oxidase inhibitors (MAOIs).
- Psychosocial treatments – Things like psychoeducation, family psychoeducation and support groups can be very helpful.
- Electroconvulsive therapy (ECT) – For very severe depression that does not respond to treatment, ECT can be very successful.
- Self Care – Paying attention to one's lifestyle such as diet and exercise, can help recovery.

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Low-Cost Therapy Resources

University of Maryland's Center for Healthy Families – College Park, MD. Provides individual, couple, and family therapy on a sliding fee scale, with fees ranging from \$20 to \$60. 301-405-2273

Maryland Pro-Bono Counseling Project – Statewide. Links individuals, couples, and families seeking therapy with volunteer licensed mental health professionals in communities across Maryland. 877-323-5800

Maryland Psychotherapy Clinic and Research Lab – College Park, MD. Provides individual counseling and psychotherapy to adults. 301-405-5820 or email mpcrl@umd.edu

Friendship Place Health Center – Washington, DC. Requires a written referral from your primary healthcare provider. Additional information available at www.unityhealthcare.org, or call 202-364-1419

Community Clinic, Silver Spring Health Center – Silver Spring, MD. Additional information available at www.cciweb.org, or call 301-585-6184

Mary's Center of Silver Spring – Silver Spring, MD. Provides diagnostic assessments, treatment planning, medication evaluation and management by board-certified psychiatrists, individual and family therapy, play therapy, community/family support, and case management. Sliding fee scale available, some insurance accepted. Additional information available at www.maryscenter.org, or call 202-420-7122

Columbia Road Health Services – Washington, DC. Individual, couple, and family counseling for those dealing with loss and grief, depression, psychological trauma, and family dysfunction. More information available at www.crhs.org, or call 202-328-3717

Appendix E: Interview Protocol

- *Thank you for taking the time to meet with me. I am interested in learning more about what it is like to parent an adolescent who has a depressive disorder. I have some questions here I'd like to ask about what you went through to get your child diagnosed and also some questions treatment. I also want to ask some questions about your economic, racial, and ethnic background. I'm interested in hearing from you how these aspects of your background may have shaped your experiences with getting your adolescent diagnosed and treated. Overall my hope is that we can have a conversation.*
- *To begin, I have a consent form for you to sign. Let's read through it carefully [Read through consent form]. What questions do you have about the consent form? Do you understand the consent form?*
- *As indicated on the consent form, I wanted to ask if I might be able to follow-up with you once all my interviews are completed, if I have any additional questions to ask.*
- *This consent form gives me permission to record our conversation. It also explains that the recording and the information obtained through our conversation will not be shared with anyone; it will remain confidential. The audio file will be kept on a password protected computer that only I have the password to and any papers with information on them will be kept in a locked cabinet that only I have the key to. Also, the consent form outlines that there are some situations, by law, in which confidentiality would be broken. If information in the interview leads to reasonable suspicion of abuse and/or neglect of a child, confidentiality will be broken and the appropriate protective agencies will be contacted. If you do not have any further questions and you feel as though you fully understand the consent form, please sign it at the bottom.*
- *Now that you've signed the consent form, I will begin recording.*

Today is [date]. I am here with [participant]. [Participant] is the parent of [adolescent], who is [years] years old.

To begin, tell me about [adolescent].

History with Mental Health Care

I'd like to talk about [adolescent] before [he/she] was diagnosed with [disorder], to gain an understanding of what her/his history of mental health care was like.

- When were you first concerned about [adolescent]'s mental health?
- When was [adolescent] first diagnosed with a mental health issue?
 - Probe: What prompted this initial involvement?
What was going on for you as a family at this time?
Who assessed your child for a diagnosis?
- How were you involved?
 - Probe: What were your thoughts about this process? Child's/family's reactions?
- What other prior experiences had you had with mental health care?
 - Probe: Parent's personal experiences? Family history of receiving care?

Besides from a depressive disorder, what other mental health struggles/diagnoses does [adolescent] have?

Depressive Disorder Diagnosis

Now I would like you to think about when [adolescent] was diagnosed with a depressive disorder and what this process was like (if different from above)

- Tell me about how [adolescent] came to be assessed for a diagnosis at this time.
 - Probe: Significant events happen in adolescent's life?
- At what point did you know you/your child/your family might need some help?
 - Probe: Who suggested? Situation/event that led to getting help? Symptoms of depression you noticed?
- Was your child being assessed encouraged by someone? Required by someone?
- How were you involved?
 - Probe: What were your thoughts about this process? Child's reactions? Family's reactions?
 - What was it that led you to being involved in this way?
- What does depression look like in [adolescent]?
- What do you see as the connection between the diagnoses (if there are multiple)?

Parents' Reactions and the Parent-Child Relationship

Now I'd like to ask you about [name of adolescent] after they were diagnosed and what this was like for you, as the parent, and for your family. Think about right after the diagnoses and the weeks and months that followed.

- What were your reactions to the diagnosis?
- What changed for you? How did your family change?
 - Probe: How did you change? Do you think the way you interacted with your adolescent changed? How?
- After the diagnosis, how did your relationship with [adolescent] change? Did the way you spent time together change? How?
 - Probe: Who do you think was responsible for the changes? How did knowing about the diagnosis shape the way you talked with your child?
- How did your routines as a family change?
 - Probe: What parts of your everyday life changed after you received the diagnosis?
- How did [adolescent's] relationship with other family members change?
 - Probe: Siblings, other caregivers/adults, extended family
- Did these mental health struggles bring you more together as a family, push you apart, or was there no change? Tell me more about this.
 - Probe: Did [adolescent's] behaviors change? (aggression, withdrawal)
- Who did you seek information from?
 - Probe: Family, peers, friends, school counselors/ teachers, pastors/priests/ religious affiliate, internet

Parental Engagement in Treatment

Now I'd like to learn some more about if and how you and your family were a part of treatment and services [adolescent] received.

- When it came time to decide on [adolescent's] treatment for the diagnosis, tell me about how you made a decision to move forward with the treatment.

- Probe: Who did you seek information from? How did you explore your options? What past experiences did you have that may have helped you decide on a treatment?
- How were you involved in the treatment? How did you make a decision to be involved in this way?
- What kinds of services is she/he currently receiving?
 - Probe: Therapy: How often did you ask how therapy sessions went? How did you seek opportunities to know what was going on in the treatment?
 - Probe: Medication: How were you involved in your son/daughter taking medicine to address her/his depressive symptoms?
- Were there other members of your family who were involved in treatment? How?
- What was it that helped you be involved in the treatment?
- Why did you feel your involvement was important/would be helpful?
- What made it difficult for you to be involved in your child's treatment?
 - Probe: Past experiences with mental health services, lack of knowledge, education, transportation, money, time, availability
- Were you ever concerned about what other people's reactions to the diagnosis would be? Tell me about this.
- Parenting: Where does your sense of why it's important for you to be involved in your child's treatment come from?
- School: Involvement of the school; IEP/504 plan; how does the school support the child/family? How might the school hinder the child/family?

Insurance/Income/Race & Ethnicity, Diagnosis, and Treatment

We are almost done. Before I wrap up, as I mentioned earlier, I have some questions about your economic and racial or ethnic background. First, I'm interested to hear if you think any of your experiences with [name of adolescent] and their mental health care was affected by the type of health insurance you have.

- What insurance does [adolescent] have?
- What about you – do you have the same insurance?
- How did the benefits the insurance provides influence your choice of treatment?
- How was the insurance company helpful during this process?
- How might it have made things more challenging for you?
 - Probe: How do you think your options were limited by your insurance? Type of service/frequency/duration of services.

Ok, next I'm interested to hear if you think any of what you've shared so far related to your experiences with [name of adolescent]'s mental health care has to do with your income. Some families feel like if they had more money they could get their child different or better treatment.

- Tell me how not having income resources available may have shaped the treatment [adolescent] received and the decisions you made about being engaged in treatment.
 - Job status? Description?

I'm also interested to hear if you think any of what you've shared so far related to your experiences with [name of adolescent] and their mental health care differed because of your racial and ethnic background. I'm aware that families of different backgrounds can face different issues and possible barriers receiving services.

- Do you think your experiences with mental health care have at all been shaped by your race/ethnicity?
 - Probe: What concerns did you have about [adolescent] being labeled?
 - Probe: Did other family members/kinship members shape the decisions you made? How? What concerns did you have about others (family or outside family) finding out about [adolescent]'s diagnosis? How concerned were you that their reaction would change how [adolescent] was treated?
 - Probe: What concerns did you have about finding a counselor/therapist who understood your culture?
 - Probe: Did spirituality play a role here? If so, how?
- Is there anything else you'd like to share about your or [adolescent's] experiences that you think was different because of your/their race or ethnic background?

Adolescent's Current Status

I just have a few final questions for you before we wrap up.

- How do you feel things are currently going for [adolescent]? And for your family?
 - Are you satisfied with her/his services? (Outcome?)
 - What do you think has most contributed to you having a positive experience?
 - Is there anything about [adolescent]'s diagnosis that you still do not understand?
 - Is there anything you would do differently in treating or managing [name of adolescent] diagnosis?
 - What do you see for [adolescent's] future?
 - What goals do you have for their future?
 - Are there any other questions you thought I would ask or areas that we have not discussed you would like to share with me?
 - *Probe:* About [adolescent], your family, the experience of treatment?
-
- *Thank you so much for taking the time to meet with me. I truly appreciate it. I have a short demographic questionnaire I would like to ask you to complete. Here it is. I also have some educational resources for you on parenting adolescents with mental health disorders.*
 - *Here is \$25 for participating in this interview. The information provided is extremely important and I deeply appreciate your time.*

Appendix F: Informed Consent – University of Maryland

Informed Consent Form

Please read this entire form carefully.

If you would like to participate, sign the bottom of the form.

- Project Title:** Parental responses to adolescents depressive disorder diagnoses: Implications for family engagement in treatment
- Statement of Age:** You are over 18 years old and wish to participate in the study.
- Purpose:** The purpose of this project is to learn more about what it is like to parent an adolescent with a depressive disorder. You are being asked to participate because you are the parent of an adolescent with a depressive disorder.
- Procedures:** You will complete an interview where you will be asked questions about your adolescent's behaviors and depressive disorder diagnosis, your perceptions of the diagnosis, treatment options presented and obtained, and your own engagement in your adolescent's treatment. The interview includes questions such as: What were your reactions to your adolescent's diagnosis? What contributed to you feeling as though your involvement [in your adolescent's treatment] was important/would be helpful?
You will complete a brief demographic questionnaire that asks about your background information, such as your marital status and education level. The interview will be audio recorded. If you choose not to be audio recorded, the interviewer will take notes from your conversation.
With your prior consent, we may follow up with you after the interview to ask a few more questions about these topics.
Upon completion of the interview, you will receive \$25 cash for your participation.
- Confidentiality:** Your name and any other information that specifically identifies you will not be used to report information about the project. We will store this type of information separately from other information you give us to protect your identity to the maximum extent possible. There are certain situations in which we are required by law to reveal information disclosed in an interview. Required disclosure will occur if the information provided in the interview leads to reasonable suspicion of abuse and/or neglect of a child. Under these circumstances, confidentiality would be broken and Child Protective Services and the Chief of Police will be contacted within 48 hours.
- Risks:** There are only minimal risks for you during or as a result of this project, including feeling uncomfortable answering certain questions about your perceptions of your child's diagnosis, recalling the symptoms of your adolescent's depression, and discussing treatment. To mitigate these risks, you may take a break from the interview at any point, if needed. Also, you can end the interview at any time and do not have to answer questions which you do not want to answer.

Benefits: Although you will not directly benefit from participating in this interview, your participation will help us understand how to increase family engagement in adolescent depressive disorder treatment. Resource information will be provided to you about mental health services.

Freedom to Withdraw: You understand that you do not have to participate in this interview. If you choose not to participate in the interview, it will have no effect on your eligibility to receive services from any agency or organization. If you choose to participate in the interview, you understand that you can stop participating at any time you want. There is no penalty for stopping the interview. If you choose to stop the interview, it will have no effect on your eligibility to receive services from any agency or organization. You understand that you do not have to answer any or all questions in the interview.

Principal Researcher: Lauren Messina, MS (lmessina@umd.edu)
University of Maryland School of Public Health
1236 School of Public Health, College Park, MD 20742 914-325-0428

If you have questions about your rights as a research participant or wish to report a research-related injury, you can contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (email) irb@umd.edu; (telephone) 301-405-0678

Please indicate below:

Yes, I consent to being contacted as a follow up to this interview.

Please provide the best phone number where you can be contacted:

No, I prefer not to be contacted after the interview is complete.

Name (print): _____

Signature: _____ **Date:** _____

Appendix G: Informed Consent – Sheppard Pratt

Informed Consent Form

Please read this entire form carefully.

If you would like to participate, sign the bottom of the form.

Project Title: Parental responses to adolescents depressive disorder diagnoses: Implications for family engagement in treatment

Statement of Age: You are over 18 years old and wish to participate in the study.

Purpose: The purpose of this project is to learn more about what it is like to parent an adolescent with a depressive disorder. You are being asked to participate because you are the parent of an adolescent with a depressive disorder.

Procedures: You will complete an interview where you will be asked questions about your adolescent's behaviors and depressive disorder diagnosis, your opinions of the diagnosis, treatment options presented and obtained, and your own engagement in your adolescent's treatment. The interview includes questions such as: What were your reactions to your adolescent's diagnosis? What contributed to you feeling as though your involvement [in your adolescent's treatment] was important/would be helpful?
You will complete a brief questionnaire that asks about your background information, such as your marital status and education level.
The interview will be audio recorded. If you choose not to be audio recorded, the interviewer will take notes from your conversation.
With your prior consent, we may follow up with you after the interview to ask a few more questions about these topics.
Upon completion of the interview, you will receive \$25 cash for your participation.

Confidentiality: Your name and any other information that specifically identifies you will not be used to report information about the project. We will store this type of information separately from other information you give us to protect your identity to the maximum level possible. There are certain situations in which we are required by law to reveal information learned in an interview. Required disclosure will occur if the information provided in the interview leads to reasonable suspicion of abuse and/or neglect of a child. Under these circumstances, confidentiality would be broken and Child Protective Services and the Chief of Police will be contacted within 48 hours.

Sheppard Pratt has a policy to protect health information that may identify you. Federal and state laws also protect your privacy. Your Protected Health Information (PHI) is information about you and your physical and psychiatric conditions. Information that is obtained in the study that identifies you includes your name and phone number. Information that is obtained in the study that identifies your adolescent child includes his/her name and birth date. Health information that is collected includes the mental health diagnosis of your adolescent, symptoms of your adolescent, and any information about your own

mental health that you wish to share.

The authorized staff of Family Services, Inc. may see your health information and may give out your health information during the study. Your information will be used and given out to recruit participants to the study.

We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside of Sheppard Pratt Health System who receive your information may not be covered by this promise. We try to make sure that everyone who needs to see your information keeps it confidential- but we cannot guarantee this.

The authorization to use and give out health information does not end.

You may cancel your agreement to allow your health information to be used or given out by notifying the Principal Investigator or the Co-Investigator, or you may decide not to give permission. However, in either circumstance, you may not participate further in the study. No new health information will be collected about you, but information that has been collected until that time will be used.

The information which we collect will be kept confidential; all data that includes protected health information will be stored in a secure area that is accessible only to study personnel. Once you have finished your participation, the interview will be identified with identification numbers and pseudonyms; no personal health information will be shared with others beyond the study personnel.

- Risks: There are only minimal risks for you during or as a result of this project, including feeling uncomfortable answering certain questions about your perceptions of your child's diagnosis, recalling the symptoms of your adolescent's depression, and discussing treatment. To lessen these risks, you may take a break from the interview at any point, if needed. Also, you can end the interview at any time and do not have to answer questions which you do not want to answer.
- Benefits: Although you will not directly benefit from participating in this interview, your participation will help us understand how to increase family engagement in adolescent depressive disorder treatment. Resource information will be provided to you about mental health services.
- Freedom to Withdraw: You understand that you do not have to participate in this interview. If you choose not to participate in the interview, it will have no effect on your ability to receive services from any agency or organization. If you choose to participate in the interview, you understand that you can stop participating at any time you want. There is no penalty for stopping the interview. If you choose to stop the interview, it will have no effect on your ability to receive services from any agency or organization. You understand that you do not have to answer any or all questions in the interview.
- Principal Investigator: Lauren Messina, MS (lmessina@umd.edu)
University of Maryland School of Public Health
1236 School of Public Health, College Park, MD 20742 914-325-0428

If you have questions about your rights as a research participant or wish to report a research-related injury, you can contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (email) irb@umd.edu; (telephone) 301-405-0678

Please indicate below:

Yes, I consent to being contacted as a follow up to this interview.

Please provide the best phone number where you can be contacted:

No, I prefer not to be contacted after the interview is complete.

Name (print): _____

Signature: _____ **Date:** _____

Informed Consent Addendum
for Family Services, Inc. & Sheppard Pratt Participants

Please read this entire form carefully.
If you would like to participate, sign the bottom of the form.

- Principal Investigator: Lauren Messina, MS
University of Maryland School of Public Health
1236 School of Public Health, College Park, MD 20742
914-325-0428
- Co-Investigator: Arleen Rogan, PhD, LCSW-C
Family Services, Inc.
610 East Diamond Avenue, Suite 100
Gaithersburg, MD 20877
301-840-3203
- Procedure: Interviews will take place at a location convenient for the participant, which may include within the offices of Family Services, Inc.
- Duration of the Study: The interview will take between one hour and one and a half hours. If the participant agrees to be contacted after the interview, a follow up phone call will be brief (10-15 minutes).
- Study Sponsors: There are no sponsors for this study.
- Contact Information: If you are a participant from Sheppard Pratt and have questions regarding your rights as a research participant, you may contact Dr. Faith Dickerson of the Sheppard Pratt IRB at Sheppard Pratt IRB, 6501 North Charles St., Baltimore, MD 21204; (email) info@sheppardpratt.org; (telephone) 410-938-3000
- Information Provided by: The discussion about this informed consent was lead by Lauren A. Messina, the principle investigator of this study.

Name (print): _____

Signature: _____ **Date:** _____

Lauren A. Messina, MS

Signature: _____ **Date:** _____

Appendix H: Demographic Questionnaire

1. What is your race/ethnicity?

Check all that apply.

- Black or African American
- Hispanic or Latino
- White
- Asian or Pacific Islander
- American Indian or Alaska Native
- Two or more races: _____
- Other: _____

2. What is your marital status?

- Married
- Separated
- Divorced
- Widow/Widower
- Never married

3. What is your current employment status?

Check all that apply.

- Employed full time
- Employed part time
- Homemaker, not employed outside home
- Not employed due to disability
- Unemployed
- Retired
- Student

4. What is the highest grade in school you have completed?

- Less than 12th grade
- 12th grade/GED/High school diploma
- Technical school or military training
- Some college, no degree earned
- Associate's/2 year degree
- Bachelor's/4 year degree
- Graduate degree (MS, PhD, JD)

5. What is your age? _____

6. Zip code?

These questions should be answered about your child who had been diagnosed with a depressive disorder.

1. What is the sex of your adolescent?

- Male
- Female

2. How old is your adolescent child? _____

What is your child's birth date? _____

3. What is the race/ethnicity of your adolescent child?

Check all that apply.

- Black or African American
- Hispanic or Latino
- White
- Asian or Pacific Islander
- American Indian or Alaska Native
- Two or more races: _____
- Other: _____

4. What grade is your adolescent child in?

- 6th grade
- 7th grade
- 8th grade
- 9th grade
- 10th grade
- 11th grade
- 12th grade

5. Which depressive disorder has your adolescent child been diagnosed with?

(Check more than one if applicable)

- Major Depressive Disorder
- Dysthymia
- Depressive Disorder Not Otherwise Specified

6. How old was your adolescent child when she/he was diagnosed with the above depressive disorder?

- 11 years old
- 12 years old
- 13 years old
- 14 years old
- 15 years old
- 16 years old

Appendix I: Code List and Definitions

Code	Definition
"It's a lot"	Caregiver's use of the phrase "it's a lot"
Adapting/changing because of youth's disorder	Discussion of how things did/didn't change after the diagnosis, such as behaviors, thinking, etc. for the caregiver, the youth and/or the family
Adversities: Death/loss of a loved one	Youth experienced the death or loss (departure) of a loved one
Adversities: Poor/inconsistent relationship with parent	Discussion of the youth's poor relationship with one or both biological parents
Adversities: Victim of/witness to violence	Youth was the victim of or witnessed violence
Barriers to diagnosis (Dx) / treatment (Tx): Challenges accessing / understanding information	Discussion of struggling to find out info about diagnosis/treatment (and how to cope with it); lack of knowledge about programs, resources, confidentiality; information not explained by professionals
Barriers to diagnosis (Dx) / treatment (Tx): Concern/Lack of about others' reactions	Discussion about if caregiver and/or youth is concerned about other's reactions to the youth's diagnosis/treatment
Barriers to diagnosis (Dx) / treatment (Tx): Confusion about diagnosis or symptoms	Discussion of confusion, misconception, lack of understanding about diagnosis/symptoms/causes, mental health, depressive disorders (or types of disorders), changes to the diagnosis, on behalf of the youth and/or the caregiver
Barriers to diagnosis (Dx) / treatment (Tx): Importance of male therapists for male clients	Discussion of wanting a male therapist
Barriers to diagnosis (Dx) / treatment (Tx): Logistics	Talking about transportation, cost of transportation and parking, lack of time, getting meds refilled, trouble finding providers, takes a long time to get an appointment; as a negative barrier to obtaining a diagnosis/treatment
Barriers to diagnosis (Dx) / treatment (Tx): Negative/poor experiences with mental health professionals	Description of negative interactions with mental health professionals (therapists, counselors social workers, psychologists, and psychiatrists)
Barriers to diagnosis (Dx) / treatment (Tx): Overturn of mental health professionals	Description of the frequent change of mental health professionals working with the youth
Blame	Attributions of the causes of mental health issues; Caregivers are concerned about feeling blame or do feel blamed by others; Caregivers assign blame to others or other experiences; Caregivers blame themselves; Youth's expressions of blame towards others
Building a village around the youth	Getting multiple people involved in helping the youth from various places/organizations/agencies
Caregiver-youth relationship	Catch-all code for description of the relationship between the caregiver and youth; mentions of their exchanges, how they relate to one another, might include discussion of how relationship has changed over time

Characteristics of participant: Advocating/Resource seeking	Seeking help, asking for help, trying to connect with a program, asking for an explanation, applying for help, speaking up about the needs of the youth
Characteristics of participant: Frustration/Caregiver strain	Frustration with the youth's behavior, that youth's behavior isn't improving, that services are not working, that parent's influence is limited, that nothing is working, feeling 'fed up', with accessing services, with logistics of services
Characteristics of participant: Goals/hopes for the future	Discussion of what the caregiver sees/hopes for the youth's future
Characteristics of participant: Perspective of what could have been done differently or better	Discussion of what caregiver thinks could have been done to improve outcomes for the youth
Co-occurring diagnoses	Discussion of youth's other mental or physical health diagnoses
Depression in the youth: Anger	Talk about youth displaying anger, angry behaviors
Depression in the youth: Hospital stays	Talk about youth being admitted to the hospital for a mental health issue
Depression in the youth: Isolation, loss of interest, zoning out	Symptoms of the depressive disorder observed by the caregiver
Depression in the youth: Sad/crying	Symptoms of the depressive disorder observed by the caregiver
Depression in the youth: Suicidal thoughts/attempts	Discussion of youth's threats or attempt to hurt/kill one's self
Family co-morbidity and treatment	Discussion of the other physical/mental health issues of family members and treatment received
First concerned	Discussion of when the caregiver first noticed the youth may be struggling, may need help
Health literacy	Participant's misuse of terms (diagnosis, medications), forgetting terms, lack of understanding about the roles of professionals, calling professionals the wrong titles, participants misconceptions about symptoms, origin of diagnosis, long term prognosis. Coding for health literacy requires the coder to have knowledge about these topics and be able to recognize when the participant is making incorrect attributions about the mental health issue or using incorrect terms/phrases
Income	Caregiver's impressions of the role of having a limited income in the diagnosis/treatment process
Information seeking: Family/ Friends	Asking family/friends for insight/advice
Information seeking: Internet	Looking on the internet to educate one's self about treatment/diagnosis, etc
Information seeking: Mental health professionals	Talking with mental health professionals to get information about diagnosis/treatment
Information seeking: Other	Seeking information from other sources, such as support groups, a pastor

Information seeking: Pediatrician	Asking the pediatrician for information about the diagnosis/treatment and mental health
Insurance	Discussion of the caregiver's experiences with their insurance and how this shaped the youth's mental health care; includes positive, negative, and neutral experiences
Involvement of other agencies	Talk of the family interacting with other agencies such as CPS, Juvenile Justice, foster care, etc.
Involvement of other family members (In diagnosis/ treatment, youth's life)	In the diagnosis/treatment process or the youth's life; includes but isn't limited to siblings, aunts, uncles, grandparents, etc.
Involvement of parents/ caregivers in diagnosis/ treatment: Decision making	Caregiver's report of who made treatment decisions, how decisions for treatment were made
Involvement of parents/ caregivers in diagnosis/ treatment: In session and/or family therapy	Discussion of caregiver's involvement (or lack of) in youth's therapy sessions; includes discussion of family therapy (which participants may call 'group therapy') as a treatment modality
Involvement of parents/ caregivers in diagnosis/ treatment: Helpful/unhelpful	Factors that made it helpful/easy/welcoming for caregivers to be involved; Factors that made it difficult for caregivers to be involved in treatment
Involvement of parents/ caregivers in diagnosis/ treatment: Importance	Explanations of why caregivers thought their involvement would be important and meaningful
Involvement of parents/ caregivers in diagnosis/ treatment: Initiating treatment/ services	Coded in response to a question about who recommended the youth get diagnosed/treated for a mental health concern; May be the caregiver or a 3rd party
Involvement of parents/ caregivers in diagnosis/ treatment: Interactions with mental health professionals	Describes participants various interactions with therapists, such as: asking for feedback from therapist, therapist asking for feedback from participant, parent talking about what they learned from the therapist
Media	Discussion of the role of the media (shows, video games, songs) and how it relates to the adolescent's mental health and/or treatment; includes experiences they may have had with other youth and/or family members
Mental health experiences of participant	Participant's mental health history, current treatment, experiences with mental health care (their own or family members)
Perseverance, Commitment to getting the youth help	Discussion of parents continuing to seek help (esp. despite setbacks), seeking help over time, discussion of what motivates them to get the youth help
Protective strategies	Participant discusses wanting to protect or shield the youth from things, situations, people - such as experiences that may trigger a negative reaction in the youth, suffering, struggle, from hurting themselves/others; Includes when participant implicitly does this by describing the actions they have taken
Race/ethnicity	Discussion of how race/ethnicity may have shaped the diagnosis/treatment process

Reactions to diagnosis/treatment: Other family members	Reactions from family members when they find out the youth's diagnosis and/or the youth received therapy
Reactions to diagnosis/treatment: Parent/caregiver	Reaction to youth's diagnosis and/or need for treatment
Reactions to diagnosis/treatment: Youth	Reaction to being diagnosed with a mental health concern and/or needing therapy or meds
Reactions to the interview	Participant mentions thoughts/feelings associated with partaking in the interview
Reason caregiver is in the role of caregiver	Explanation of why the biological parents are not parenting the youth
Risky behaviors of youth	Sex, drug use, skip school, fighting, stealing, damaging property, running away
Role of biological parents when caregiver oversees the youth's well-being	When caregiver oversees the care of the youth, this code codes for how the biological parents are still involved in the youth's life (if they are)
School: Accommodations	Experiences with IEPs, 504 plans or other ways how the school has assisted in meeting the needs of the youth
School: Negative experiences	Threats of suspensions/expulsion; youth getting suspended; youth held back in grades; lack of accommodations/help when needed; no discussion about getting child help; poor interactions with school faculty
School: Positive experiences	Discussion of how the school was helpful, accommodating; caregivers had a positive experience interacting with the school
Spirituality	Discussion of praying, looking to a religious figure for guidance or strength on how to handle the issue their youth is facing
Teaching Accountability	Caregiver talking about teaching youth to be responsible for themselves (behaviors, own mental health, success/future, decisions)
Treatment: Frequency	How often the youth meets with a mental health professional
Treatment: Medication	Discussion of experiences with medication; Caregiver's opinion, youth's opinion, side effects
Treatment: Other (ex. group therapy)	Other types of treatment the youth has received
Treatment: Parents' experiences, opinions, perspective about youth's therapy treatment	Parent's report on effectiveness of treatment at any time point, any outcomes parent reports; does NOT include reports about effectiveness of medication
Treatment: Parents' perceived satisfaction	Participant's positive and/or negative opinion about the therapy treatment the youth has received; Coded mostly in response to the question "How satisfied are you with the treatment received?"

Appendix J: IRB Approval Letter – University of Maryland



1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE: October 28, 2014

TO: Lauren Messina, MS
FROM: University of Maryland College Park (UMCP) IRB

PROJECT TITLE: [517701-3] PARENTAL RESPONSES TO ADOLESCENTS' DEPRESSIVE DISORDER DIAGNOSES: IMPLICATIONS FOR FAMILY ENGAGEMENT IN TREATMENT

REFERENCE #:

SUBMISSION TYPE: Continuing Review/Progress Report

ACTION: APPROVED

APPROVAL DATE: October 28, 2014

EXPIRATION DATE: November 24, 2015

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 6 & 7

Thank you for your submission of Continuing Review/Progress Report materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of November 24, 2015.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

Appendix K: IRB Approval Letter – Sheppard Pratt

Sheppard Pratt

A not-for-profit behavioral health system

Institutional Review Board

*Chair: Faith Dickerson, PhD, MPH (phone 410-938-4339)
Vice-Chair: Gayle Hurt (phone 410-938-4873)*

*6501 North Charles Street
P.O. Box 6815
Towson, Maryland 21285-6815*

DATE: March 26, 2014

TO: Lauren Messina
FROM: Sheppard Pratt IRB

PROJECT TITLE: [567951-2] PARENTAL RESPONSES TO ADOLESCENTS' DEPRESSIVE DISORDER DIAGNOSES: IMPLICATIONS FOR FAMILY ENGAGEMENT IN TREATMENT

SUBMISSION TYPE: Amendment/Modification

ACTION: APPROVED

APPROVAL DATE: February 19, 2014

EXPIRATION DATE: February 19, 2015

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review

Thank you for your submission of Amendment/Modification materials for this project. The Sheppard Pratt IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this committee. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this committee.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this

procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of February 19, 2015.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Gayle Hurt at 410-938-4873 or ghurt@sheppardpratt.org. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Sheppard Pratt IRB's records.

Appendix L: Application of Theoretical Concepts with Interview Questions, Open Codes, & Findings

Concept	Proposed Theoretical Explanation of the Concept in the Present Study	Examples of Interview Questions which Explored the Concept	Examples of Applicable Open Codes Connected to the Concept	Examples of Themes from Findings Related to the Concept
Process	<ul style="list-style-type: none"> • The parent’s perception of her/his relationship with the teen before and after the diagnosis • How the parent perceived themselves to have changed as a result of incorporating the diagnosis into their relationship with the adolescent • How parents made sense of their adolescent’s mental health diagnosis and the ways in which parents adjusted themselves to meet the perceived needs of their struggling teen 	<ul style="list-style-type: none"> • What were your reactions to the diagnosis? • What changed for you (post-diagnosis)? • How did your family change? • How did you change? • After the diagnosis, how did your relationship with [adolescent] change? Did the way you spent time together change? • How did your routines as a family change? • What parts of your everyday life changed after you received the diagnosis? 	<ul style="list-style-type: none"> • Reactions to diagnosis/treatment: Parent/caregiver • Adapting/changing to youth's disorder • Caregiver-child relationship • Involvement of parents/caregivers in Dx/Tx: Decision making, In sessions and/or family therapy, Initiating treatment/services, Interactions with mental health professionals • Protective strategies • Barrier to Dx/Tx: Confusion about diagnosis/symptoms 	<ul style="list-style-type: none"> • Parent-child relationship post-diagnosis • “I need help.” Advocating as a response to the diagnosis • “I have to be on vigilant patrol.” Parents’ protective approach • “It kind of made sense.” Parents’ suspicions confirmed yet confusion remained
Person	<ul style="list-style-type: none"> • <i>Demand characteristics:</i> Characteristics that may influence the expectations and interactions one has with another person • How race/ethnicity shaped parents’ experiences with an adolescent’s mental health diagnosis and treatment 	<ul style="list-style-type: none"> • Do you think your experiences with mental health care have at all been shaped by your race/ethnicity? • What concerns did you have about others (family or outside family) finding out about [adolescent]’s diagnosis? • What concerns did you have about finding a counselor/therapist who understood your culture • Did spirituality play a role here? If so, how? 	<ul style="list-style-type: none"> • Race/ethnicity • Barriers to treatment: Concern/lack of concern about others' reactions • Spirituality 	<ul style="list-style-type: none"> • “I don’t think race...has anything to do with it.” The perception that race/ethnicity does not shape mental health care • “It’s different backgrounds and they don’t really understand it.” The perception that race/ethnicity does shape families’ experiences with mental health care

	<ul style="list-style-type: none"> • <i>Resource characteristics:</i> Past experiences, skills, intellect, and access to social and material resources • Parents' past experiences with mental health care • Parents' knowledge about the mental health care system and depression 	<ul style="list-style-type: none"> • What other prior experiences had you had with mental health care? • Parent's personal experiences? • Family history of receiving care? • Who did you seek information from? • What does depression look like in [adolescent]? 	<ul style="list-style-type: none"> • Mental health experiences of participant • Family co-morbidity and treatment • Information seeking: Family/friends, Internet, Mental health professionals, Other, Pediatrician • Depression: Anger, Hospital stay, Isolation, Sad/Crying, Suicidal thoughts/attempts 	<ul style="list-style-type: none"> • "Because I deal with it myself." Parents involvement shaped by their own mental health • "I need help." Advocating as a response to the diagnosis • Insurance as a bridge • Insurance as supportive
	<ul style="list-style-type: none"> • <i>Force characteristics:</i> An individual's temperament, motivation, and persistence • What motivated parents to seek a diagnosis and treatment for their adolescent • The ways parents displayed their persistence in obtaining their children treatment • How parents were resolute in the face of barriers against treatment 	<ul style="list-style-type: none"> • When was [adolescent] first diagnosed with a mental health issue? • What prompted this initial involvement? • What was going on for you as a family at this time? • Was your child being assessed encouraged by someone? Required by someone? • How were you involved? • What was it that helped you be involved in the treatment? • Why did you feel your involvement was important/ would be helpful? 	<ul style="list-style-type: none"> • First concerned • Perseverance/ commitment to getting the youth help • Involvement of parents/caregivers in Dx/Tx: Decision making, Helpful/Unhelpful, Importance • Reaction to Dx/Tx: Parent/Caregiver • Barriers to Dx/Tx: Challenges assessing information, Concern/lack of concern about reactions, Confusion about diagnosis/symptoms, Logistics 	<ul style="list-style-type: none"> • "Because I deal with it myself." Parents involvement shaped by their own mental health • "Let them know that's right and what's wrong." Teaching accountability • "I need help." Advocating as a response to the diagnosis • Barriers to parental involvement: Family or self as an obstacle • Barriers to parental involvement: Lack of resources
Context	<ul style="list-style-type: none"> • <i>Microsystem:</i> A person's immediate setting and interpersonal relationships • If parents adjusted their processes of involvement with their teen upon learning about the presence of a depressive disorder 	<ul style="list-style-type: none"> • What were your reactions to the diagnosis? • What changed for you? How did your family change? • How did you change? Do you think the way you interacted with your adolescent changed? How? • After the diagnosis, how did your 	<ul style="list-style-type: none"> • Reactions to Dx/Tx: Parent/caregiver • Adapting/changing bc of youth's disorder • Protective strategies • Caregiver-child relationship 	<ul style="list-style-type: none"> • "It kind of made sense." Parents' suspicions confirmed yet confusion remained • Parents as active participants in treatment

<ul style="list-style-type: none"> • What are the contexts that increased family involvement in treatment 	<ul style="list-style-type: none"> • relationship with [adolescent] change? Did the way you spent time together change? How? • What was it that helped you be involved in the treatment? 		
<ul style="list-style-type: none"> • <i>Mesosystem:</i> The interaction between two microsystems • If parents' relationships with other family members shaped the treatment of an adolescent • If parents' exchanges of information with mental health care providers shaped the treatment of an adolescent 	<ul style="list-style-type: none"> • What made it difficult for you to be involved in your child's treatment? • Were there other members of your family who were involved in treatment? How? • How did [adolescent's] relationship with other family members change? • How were you involved in the treatment? How did you make a decision to be involved in this way? • How were you involved (in the diagnosis process) 	<ul style="list-style-type: none"> • Involvement of other agencies • Involvement of other family members • Involvement of parents/caregivers in Dx/Tx: Interactions with mental health professionals • Treatment: parent's perceived satisfaction 	<ul style="list-style-type: none"> • Barriers to parental involvement: Family or self as an obstacle • Agency involvement • "I need help:" Advocating as a response to the diagnosis • "They show concern for my child:" Mental health care provider and parent interactions
<ul style="list-style-type: none"> • <i>Exosystem:</i> Environmental situations one does not have control over but which affect the person • What encouraged or discouraged parents involvement in terms of income, insurance status, and race/ethnicity 	<ul style="list-style-type: none"> • When it came time to decide on [adolescent's] treatment for the diagnosis, tell me about how you made a decision to move forward with the treatment. • What was it that helped you be involved in the treatment? • How did the benefits the insurance provides influence your choice of treatment? 	<ul style="list-style-type: none"> • Involvement of parents/caregivers: Initiating treatment/sessions, Decision making • Treatment: Medication • Insurance • Income 	<ul style="list-style-type: none"> • Insurance as a bridge • Personalization of care • Convenience • Insurance and Income
<ul style="list-style-type: none"> • <i>Macrosystem:</i> Cultures and subcultures • How culturally shared beliefs about mental health treatment shaped parents involvement 	<ul style="list-style-type: none"> • Do you think your experiences with mental health care have at all been shaped by your race/ethnicity? • What concerns did you have about finding a therapist who understood your culture? • Did spirituality play a role here? 	<ul style="list-style-type: none"> • Race/ethnicity • Barriers to Dx/Tx: Concern/Lack of concern about other's reactions • Involvement of other family members • Spirituality 	<ul style="list-style-type: none"> • "It kind of made sense:" Parents' suspicions confirmed yet confusion remained • "I have to be on vigilant patrol:" Parents' protective approach

<p>Time</p>	<ul style="list-style-type: none"> • How parents recall their relationship with the teen to have changed over time • If the economic situation of the U.S over the past several years., with high unemployment rates, contributed to families feeling mental health is not a priority 	<ul style="list-style-type: none"> • What changed for you? How did your family change? • How did you change? Do you think the way you interacted with your adolescent changed? How? • Tell me how not having income resources available may have shaped the treatment received and the decisions made. 	<ul style="list-style-type: none"> • Adapting/changing bc of youth's disorder • Caregiver-child relationship • Income • Insurance • Protection strategies • Teaching accountability 	<ul style="list-style-type: none"> • The parent-child relationship post-diagnosis • Insurance and Income • Co-occurring diagnoses
<p>Risk processes</p>	<ul style="list-style-type: none"> • Parental psychopathology • Weak economic opportunities within a community • Under-education about mental health treatment 	<ul style="list-style-type: none"> • What other prior experiences had you had with mental health care? • Tell me how not having income resources available may have shaped the treatment [adolescent] received and the decisions you made about being engaged in treatment. • How did the benefits the insurance provides influence your choice of treatment? • What were your reactions to the diagnosis? 	<ul style="list-style-type: none"> • Mental health experiences of participant • Family co-morbidity and treatment • Income • Insurance • Depression: Anger, Hospital stay, Isolation, Sad/Crying, Suicidal thoughts/attempts • Reaction to Dx/Tx: Parent/caregiver 	<ul style="list-style-type: none"> • Parental/caregiver awareness • "Because I deal with it myself." Parents involvement shaped by their own mental health • Insurance as a bridge
<p>Protective processes</p>	<ul style="list-style-type: none"> • A strong relationship between the parent and adolescent • Family protection strategies • Parental resource-seeking behaviors • Parental advocacy efforts 	<ul style="list-style-type: none"> • How were you involved in the treatment? How did you make a decision to be involved in this way? • What was it that helped you be involved in the treatment? • Why did you feel your involvement was important? • Where did you look for information? • What changed for you? 	<ul style="list-style-type: none"> • Involvement of parents/caregivers: Initiating treatment/sessions, Decision making, Helpful/Unhelpful, Importance • Information seeking: Family/friends, Internet, Mental health professionals, Other, Pediatrician • Adapting/changing 	<ul style="list-style-type: none"> • Insurance as supportive • Parental/caregiver awareness: Outsides sources • "Cause I'm more Understanding:" Patience and empathy • "Help me help my kid: The collective benefits of parental involvement

Family Resilience	<ul style="list-style-type: none"> • Belief systems • Organizational patterns • Communication processes 	<ul style="list-style-type: none"> • How were you involved in the treatment? • What other prior experiences had you had with mental health care? • Did spirituality play a role? • What parts of your everyday life changed after you received the diagnosis? • How do you feel things are currently going for your family? • Did these mental health struggles bring you more together as a family, push you apart, or was there no change? 	<ul style="list-style-type: none"> • Involvement of parents/caregivers: Initiating treatment/sessions, Decision making, Helpful/Unhelpful, Importance, In sessions • Mental health experiences of participant • Family co-morbidity and treatment • Insurance • Adapting/changing bc of youth's disorder • Caregiver-child relationship 	<ul style="list-style-type: none"> • “Because I deal with it myself.” Parents involvement shaped by their own mental health • Spirituality • Agency in decision making • Parents as active participants in treatment • “Because everything was ‘nothing’.” Communication between parents and teenagers • “Cause I’m more Understanding.” Patience and empathy
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