

**Making Sense of the Label:
What Emerging Adults Can Tell Us About
Growing Up with a Mental Health Diagnosis**

by

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ABSTRACT

Despite increasing numbers of children diagnosed with mental health disorders, there is limited research on how children come to understand these diagnoses in childhood. Drawing on 42 in-depth, semi-structured interviews with emerging adults between the ages of 18 and 22 who were diagnosed with attention deficit hyperactivity disorder (ADHD), depression, generalized anxiety disorder (GAD), and/or bipolar disorder before the age of 17, this study examines how emerging adults recount making sense of their diagnoses in childhood. Interviews elicited participants' life history narratives, including how they learned about, experienced, and discussed their diagnoses in childhood, and their recommendations for how diagnoses should best be delivered and explained to children.

Participants' accounts suggest that parents play an instrumental role in delivering diagnoses to children, often acting as translators and withholders of information. Parental knowledge about children's mental health affects children's experiences, and withholding diagnoses can exacerbate stigma. Children actively seek and obtain additional information about their diagnoses as they make sense of them over time. Rather than simply absorbing information, children actively interpret, embrace, and challenge narratives from multiple sources throughout their childhoods. While diagnoses may empower children by providing an explanation for their symptoms, motivating them to make changes, and opening doors to treatment, children often experience and fear stigma associated with diagnoses and treatments as well.

This study demonstrates the importance of sharing information openly with children in developmentally appropriate ways. It underscores the importance of educating and supporting parents in the crucial role they play in this process. To help minimize stigma, participants suggest that adults share information simply but directly with children and provide assurances that diagnoses are common, not their fault, not a reflection of their intelligence, and legitimate. This study raises the question of whether there are ways to achieve the goals of providing explanations, legitimizing problems, and shifting blame away from individuals without stigmatizing, labeling, and pathologizing children's conditions. By inviting children into the discussion, both in research and in practice, we can give voice to – and learn from – children's experiences.

CHAPTER 1

Introduction

And then finding out from a professional adult that you have this, this, and this, and you need to take this medication because, 'We don't like the way you act and we don't like the way you think,' I felt like I was rejected. And that's why I struggled the most.

-Shannon, diagnosed with attention deficit hyperactivity disorder in third grade; depression and generalized anxiety disorder in seventh grade

Before depression – I would hate still living how I used to live... Being diagnosed really helped me shape who I am, and tied everything together, and made up for all of the nonsense I was thinking when I was younger, like, 'Why is this just me?' Having the concrete and being like, 'Yeah, you do have this,' made me realize like, 'Okay, I can do it.'

-Teresa, diagnosed with depression in eighth grade and attention deficit hyperactivity disorder in tenth grade

I was motivated to write this dissertation by my experience working with a six-year-old boy at a transitional housing program in 2006. I was a volunteer coordinator at the time for a group that provided a nurturing play environment for children while their mothers attended life skills classes. One week, a little boy whom I will call Brian was notably absent from our weekly volunteer sessions. While not privy to all of the details, I was given a brief explanation of Brian's situation in hopes that I could then help volunteers work with him in future sessions. I was surprised to learn that he had been experiencing hallucinations and had recently been diagnosed with bipolar disorder and attention deficit hyperactivity disorder (ADHD).

I wondered at the time whether Brian's manic states, hallucinations, and distractibility were related to his tumultuous situation – experiencing homelessness and having likely

witnessed domestic violence – rather than disorders in his brain. Further, I grappled with the question of whether the label of a ‘mental illness’ would have a lasting, negative effect on his self-identity. On the other hand, I wondered whether he found relief in an explanation for his symptoms and behaviors. His mother, meanwhile, was negotiating a handful of conflicting messages. It was my impression that the school was contesting the diagnoses, while the hospital was defending them. Amidst this contradictory information, I asked: how did *Brian* feel about what was going on? How did *he* come to understand his diagnoses? How was he told, or more importantly, what did he hear when he was told? Did he think something was ‘wrong’ with him? Or rather, did he find the diagnoses comforting, as an explanation for his struggles? These questions have driven my desire to capture the perspectives of children with mental health diagnoses in my dissertation research.

I began this chapter with the voices of two participants in this study, illustrating both the negative and positive feelings that children with mental health diagnoses may experience. These perspectives cannot be captured in statistics, and these voices have been largely absent from theoretical discussions about the effects of diagnosis on children’s experiences. The aim of this dissertation is to explore how children come to understand and experience their mental health diagnoses. While I was not able to interview six-year-olds, I was able to find answers to these questions by talking with emerging adults who had been diagnosed with mental health disorders in childhood. Through an exploration of emerging adults’ recollections of their childhood experiences, I examine how children learn of their diagnoses, how they negotiate explanatory narratives about mental health, and how they experience these diagnostic labels and the treatments they receive. I also explore how those who were diagnosed as children think

diagnoses should best be delivered and explained to children. My goal is to capture how children like Brian make sense of it all.

The Context

Nationally representative data suggest that 22% of U.S. adolescents have experienced a mental health disorder with severe impairment (Merikangas et al., 2010). Even in young children, serious emotional problems can be comparable in severity to those experienced by adults. The identification of children's mental health problems¹ in young children is especially important, given that if left unaddressed, they can become worse over time (National Scientific Council on the Developing Child, 2008).

Practitioners historically “shied away from” diagnosing children with mental health disorders partly because they were reluctant to label children², and due to challenges in applying diagnostic classification systems to children (U.S. Department of Health and Human Services, 1999, p. 168). The classifications are derived from criteria used for diagnosing adults with mental health disorders, yet the presentation of these problems may differ in children (Olin, Romanelli, & Stein, 2008). Behaviors that are considered normal signs of development at one age may be symptoms of disorder at another (Olin et al., 2008; U.S. Department of Health and Human Services, 1999). For example, the length of a child's attention span increases with age, and thus an attention span that may be indicative of ADHD in an older child may be developmentally appropriate in a young child (Olin et al., 2008). Further complicating diagnosis, children are often unable to verbalize their thoughts and feelings as articulately as

¹ While I use the term ‘problems’ throughout the dissertation, I recognize that this implies a problematizing of children's behaviors. I often use this terminology instead of ‘mental health disorders,’ however, because the term ‘disorder’ implies a medicalization of this construct, in addition to a problematization of it.

² When I use the term ‘children’ throughout this dissertation without specifying the age group (e.g. adolescent), I am referring to all those under the age of 18.

adults, and thus practitioners must rely on the accounts of parents and teachers, who may not fully understand children's experiences (Olin et al., 2008; U.S. Department of Health and Human Services, 1999).

The diagnosis of childhood mental health disorders started to become more common in the 1980s partly due to changes in reimbursement standards that now typically require children to have formal diagnoses in order to receive services (Olin et al., 2008; U.S. Department of Health and Human Services, 1999). Several studies have documented an increase in the diagnosis of specific disorders among children over time. For example, Blader and Carlson (2007) find that there was a large increase in the number of children discharged from inpatient psychiatric care with the primary diagnosis of bipolar disorder between 1996 and 2004. While bipolar disorder was one of the least prevalent diagnoses among children being discharged in 1996, it was one of the most common among children being discharged in 2004 (Blader & Carlson, 2007). Similarly, there has been an increase in the diagnosis of ADHD in recent years. The number of children diagnosed with ADHD increased an average of 3% per year from 1997 to 2006 (Pastor & Reuben, 2008). Current estimates demonstrate a lifetime prevalence of ADHD of 8.7% among a nationally representative sample of adolescents (aged 13-18), including 4.2% of females and 13% of males (Merikangas et al., 2010).

Research has also documented an increase in the use of medication to treat children's mental health problems (Zito et al., 2002, 2003). This research suggest that the total psychotropic medication use for youth (under age 20) increased 2- to 3-fold from 1987 through 1996, with most of the increase taking place between 1991 and 1996 (Zito et al., 2003). Antidepressant treatment among youth (under age 20) increased 3- to 5-fold from 1988 to 1994 (Zito et al., 2002). Brody (2006) describes several factors leading to the increased use of

psychotropic medication in child psychiatry, including the role that legal changes played in this trend. For example, he describes laws passed in the early 1980s that eliminated many of the “checks and balances” provided by the Food and Drug Administration and independent research (Brody, 2006, p. 95). These changes allowed companies to conduct their own clinical trials, giving them the power to choose which results to make public. According to Brody (2006), these laws, among others, have helped fuel the rise in psychotropic medication use in child psychiatry. Conrad (2007, p. 135) describes children’s problems as a “growing market” for pharmacological treatment.

Both the increasing diagnosis and pharmacological treatment of children’s mental health problems have sparked controversy among researchers and clinicians. In particular, many have questioned whether the increasing diagnosis of disorders such as bipolar disorder in children actually reflects an increase in prevalence. An increase in bipolar disorder, for example, might result from improvements in clinicians’ ability to detect the disorder in children, the ‘re-branding’ of the same clinical phenomena that existed in the past now being labeled bipolar disorder, or the ‘upcoding’ of behavior problems by clinicians in response to more stringent requirements for obtaining authorization for inpatient care (Blader & Carlson, 2007).

Critics of the increasing diagnosis of psychiatric disorders in children have noted concerns about the classifications used in *The Diagnostic and Statistical Manual of Mental Disorders* (DSM), which provides practitioners guidelines for diagnosing mental health disorders. For example, Burston (2006) identifies the proliferation of categories in the DSM as a potential source of labeling children. Kirk (2004) concludes that revisions of the DSM have made it easier for clinicians to diagnose ADHD in children, and that using DSM diagnostic criteria may lead to a high rate of false positives, whereby children who do not have disorders

receive diagnoses. In particular, normal expressions of distress and responses to life circumstances may be mislabeled as mental health disorders in children. According to Horwitz (2002), the DSM treats all symptoms as signs of disorder, whether or not they are expectable given the social conditions. Separating normal sadness from depressive disorder in adolescents, for example, is particularly difficult because levels of negative affect caused by negative life events are extraordinarily high in adolescence; adolescents' normal negative emotions may therefore be particularly prone to being mislabeled as depressive disorders (Horwitz & Wakefield, 2009). Horwitz and Wakefield (2009, p. 686) criticize the use of symptom checklists to screen for depressive disorders as a "decontextualized approach," noting that these measures are likely to mislabel common emotional distress in adolescence as mental disorders. According to Horwitz (2002, p. 6), mental health disorders can be seen as a social construction resulting from "cultural rules that define what is normal or abnormal." Many mental health disorders are viewed as "objective natural entities" when they are actually "recent creations" (Horwitz, 2002, p. 5).

Critics have also pointed to the negative psychological effects of the diagnosis and labeling of children. They warn that children can view diagnoses as the core of their identities, and may attribute their successes solely to the medications they take, rather than to their own abilities (Burston, 2006; Nylund, 2000). According to Nylund (2000), diagnosing a child with a disorder such as ADHD can have negative psychological effects partly because of its emphasis on the child's deficits. Using the psychiatric approach may minimize the concerns and knowledge of parents and children because of the power imbalance between the family and physicians (Nylund, 2000).

Clinicians have also expressed concern regarding the potentially negative effects of treating children's mental health problems with medication. In particular, there is concern about medications once reserved for adults now being used to treat very young children, including medications for bipolar disorder now used to treat children as young as two years of age (Burston, 2006). According to Brody (2006, p. 92), the use of psychotropic medication for children "signals a profound insensitivity to the root causes of their suffering and developmental needs."

Yet, clinicians and researchers have cited the benefits of diagnostic labels as well. Diagnoses are a tool for communication allowing mental health professionals to discuss problems across cases. They facilitate research by allowing researchers to group together individuals with similar conditions. Diagnostic labels also facilitate the development of guidelines for treatment, so that clinicians can identify treatments that work well in treating those with similar problems. Further, diagnoses facilitate the system of reimbursement for services (Olin et al., 2008).

Diagnoses may also bring relief to parents of children struggling with mental health problems (Klasen, 2000; Olin et al., 2008). Klasen (2000), for example, finds that the diagnosis of hyperactivity brought a sense of relief to parents in Great Britain, providing them a sense of control, legitimizing their children's struggles, and alleviating their guilt. Many parents welcomed the diagnosis, which they perceived as better than labels such as 'stupid' and 'naughty' (Klasen, 2000).

Increased diagnosis may also help fill the gap in services, in a complex system in which many children do not receive care. The U.S. has never had a formalized mental health policy that provides a mandate for mental health services for all children. Rather, policies have been

borrowed from other systems, such as child welfare, juvenile justice, special education, and adult mental health. The resulting policies are “informal, incomplete, and piecemeal” (Lourie & Hernandez, 2003, p. 8). There are “multiple pathways into treatment” (U.S. Department of Health and Human Services, 1999, p. 179), with children being identified by practitioners in the school, child welfare, and juvenile justice systems, as well as by pediatricians and clinicians at mental health agencies. Services include inpatient hospitalization, residential treatment, day treatment, and outpatient therapy. Many services are also provided through schools, which are mandated by the Individuals with Disabilities Education Act to provide special education services to children and youth with disabilities that interfere with their education. Services are funded through multiple funding streams, including private insurance, public health programs such as Medicaid, community-based mental health agencies, schools, and the child welfare and juvenile justice systems (U.S. Department of Health and Human Services, 1999). Agencies serving children, such as schools, the child welfare system, and the juvenile justice system are often considered “silos,” working separately to meet the mental health needs of children with little collaboration and coordination (Lyons, 2004, p. 7).

Within this patchwork system, there is a high unmet need for children’s mental health treatment. Nationally representative data indicate that only about one third (36.2%) of adolescents with mental health disorders (aged 13-18) have received services (Merikangas et al., 2011). Although the severity of the disorder increased the likelihood that children received services, only about half (47.4%) of those with severe impairment in the study had ever received treatment (Merikangas et al., 2011). Research demonstrates racial/ethnic differences in the receipt of mental health services, suggesting that minority children have higher rates of unmet need for adequate mental health care and lower rates of counseling in clinical settings

(Alexandre, Younis, Martins, & Richard, 2010; Cummings, Ponce, & Mays, 2010; Kataoka, Zhang, & Wells, 2002; Merikangas et al., 2011). Research has also documented barriers that families and children face in accessing care, including: (1) structural barriers, such as a lack of providers or financial constraints, (2) barriers related to perceptions about mental health problems, such as a belief that the problem is not severe enough to warrant treatment, and (3) barriers related to perceptions about mental health services, such as a lack of trust in providers (Owens et al., 2002). Contrary to concerns that children are being over-diagnosed with mental health disorders, this research suggests that many children are not receiving the care that they need.

Further, some argue that concerns regarding the increasing use of pharmacological treatment among children are unwarranted. Merikangas, He, Rapoport, Vitiello, and Olfson (2012, p. E5) find that there is “no compelling evidence for either misuse or overuse” of these medications. Noting that only 14.2% of adolescents with mental health disorders in a nationally representative sample (aged 13-18) report being treated with a psychotropic medication in the past year, Merikangas et al. (2012) find that the majority of those who were prescribed psychotropic treatment had serious impairment. This suggests that fears of over-diagnosis and over-medication of children may be unfounded.

Much of this debate rests on disagreements regarding the etiology, or cause, of children’s mental health problems. On one side is the medical model, which stresses the neurobiological antecedents of mental health and views mental health problems as the result of internal dysfunction; on the other side is the social model and psychosocial perspective, which emphasize that emotional distress is a response to adverse events and environments (Lyons, 2004; Root, 2009). The latter includes the theory that poverty affects children’s mental health (Lyons, 2004).

Research has demonstrated that poverty and exposure to violence are significant risk factors for poor mental health outcomes in children (Buckner, Beardslee, & Bassuk, 2004; McLearn, Knitzer, & Carter, 2007). Studies have also shown that stress and trauma can induce developmental changes, suggesting an interaction between biological and environmental factors. Early and chronic exposure to stress, abuse, and trauma can cause neuro-chemical changes that negatively affect young children's stress response systems (D. Davies, 2004). According to the 1999 report by the Surgeon General, there is "evidence that *both* biological factors and adverse psychosocial experiences during childhood influence—but not necessarily 'cause'—the mental disorders of childhood" (U.S. Department of Health and Human Services, 1999, p. 129). Traumatic experiences can spark biological changes, and biologically based behavior can be modified by environmental factors (U.S. Department of Health and Human Services, 1999).

Amidst this controversy, an increasing number of children are living with diagnostic labels that define their emotional and behavioral problems as mental health disorders. Whether or not the increase in diagnosis of children's mental health disorders reflects an actual increase in the prevalence of disorder, it raises questions as to how the increasing number of children who are being diagnosed with mental health disorders understand and experience their diagnoses. *Their* voices and perspectives have been largely absent from this discussion. While sociologists and clinicians theorize about whether diagnoses of mental health disorders in children bring stigma or empowerment, little research has examined the perspectives of the children who experience these diagnostic labels. Those with mental health problems "can best inform us" based on their own experiences and "in their own words" how they experience stigma (Wahl, 1999, p. 468). Rather than simply testing theories of stigma, however, research on children's perspectives should be open to examining a range of experiences. In addition to sharing how

they experience labels, those with mental health diagnoses can explain how they *understand* and *make sense of* their diagnoses. By sharing their accounts of the diagnostic process, including how they came to understand their diagnoses and how they negotiated explanatory narratives about mental health, those who were diagnosed with mental health disorders in childhood can provide insight into how the framing of their mental health problems shaped their experiences.

The Current Study

This study explores how emerging adults recount making sense of mental health diagnoses in childhood. By exploring their accounts of this process, I sought to better understand how children learn about and experience diagnostic labels: How are diagnoses delivered? How are messages perceived and interpreted? How do children understand the impact of their diagnoses? How do they experience the effects of diagnoses and treatments? The aim of this study is to examine how 18 to 22 year-olds who were diagnosed with ADHD, depression, generalized anxiety disorder (GAD), and/or bipolar disorder before the age of 17 came to understand their diagnoses in childhood, and how they think diagnoses should best be delivered and explained to children. It is my hope that findings from this research will help improve the management of mental health problems for the increasing number of children living with these diagnostic labels.

In Chapter 2, I review the literature relevant to this study. I begin by discussing the sociology of childhood approach that I draw upon in this study. My review of the existing literature includes a discussion of the sociological literature on the medicalization of mental health, illness experiences, stigma, and doctor-patient communication. I examine research on parental perspectives on children's mental health, followed by a review of research on children's perspectives on mental health, including the perspectives of children diagnosed with mental

health disorders. Chapter 2 concludes with a critique of this literature. I then describe the research methods used to collect data for this study in Chapter 3.

In the following three chapters, I present the empirical findings of this study. Chapter 4 examines how participants recall learning about their diagnoses, including how diagnoses were delivered and explained to them from their perspective. Findings suggest that parents play an instrumental role in this process, often translating medical diagnoses to children (Bringewatt, 2011).³ Parents act as both translators and withholders of information, and children often ‘piece together’ information about their diagnoses over time. My findings suggest that withholding diagnoses can exacerbate the stigma that children experience (Bringewatt, 2011). The level of parental knowledge about children’s mental health affects children’s experiences. I conclude the chapter with participants’ recommendations for how diagnoses should best be delivered to children. In particular, my findings suggest the importance of providing children with information about their diagnoses.

In Chapter 5, I explore how children make sense of their diagnoses over time. This includes an examination of the process by which children seek and obtain additional information about their diagnoses, as well as an analysis of how children negotiate narratives from multiple sources throughout their childhoods. I find that rather than simply absorbing information, children actively interpret, embrace, and challenge these narratives. I describe participants’ recommendations for sharing information and providing explanations to children. A key finding is that participants suggest adults be open and honest with children, sharing information simply but directly; they suggest that explanations include assurances that diagnoses are common, not their fault, not a reflection of their intelligence, and legitimate (Bringewatt, 2011). I conclude

³ This cited work is based on findings from the first ten interviews conducted as part of this study. Themes that were first introduced in this cited chapter, and are expanded upon in the dissertation, are cited here.

the chapter by discussing mixed responses to the framing of their mental health problems as medical disorders, arguing that we must examine whether there are ways to achieve the goals of providing explanations, legitimizing problems, and shifting blame away from individuals, without pathologizing children's conditions. Narrative therapy is one promising approach, and its principles can be applied both within and beyond clinical practice.

I turn to children's experiences with mental health diagnoses in Chapter 6, including their experiences with stigma and empowerment, treatment, and sharing diagnoses with others. I demonstrate that children experience *both* empowerment and stigma associated with their diagnoses (Bringewatt, 2011). While diagnoses empower children by providing an explanation for their symptoms, motivating children to make changes, and opening doors to treatment, children also experience and fear stigma associated with diagnoses and treatments (Bringewatt, 2011). My data suggest that sharing information about treatment openly and providing children strategies for managing diagnoses can help empower children, and minimize the stigma that they experience (Bringewatt, 2011). I examine feelings of secrecy contrasted to the relief participants experienced when they revealed diagnoses to others. Next, I discuss participants' experiences with treatment, and the exclusion of children's voices from treatment decisions. The chapter concludes with a discussion of participants' recommendations for treatment. They suggest that when possible, adults should listen to children, including in treatment settings (Bringewatt, 2011), and invite children to participate in decisions regarding their care.

In my final chapter, I discuss this study's contribution to the sociological literature, as well as social work practice and policy implications. I describe the limitations of this study and provide suggestions for future research. This exploratory study is hopefully but the first of many

studies examining the perspectives of those with mental health diagnoses in childhood. By exploring *their* perspectives, research can validate children's experiences.

CHAPTER 2

Literature Review

To understand how children make sense of mental health diagnoses, I draw from the sociology of childhood and several other bodies of literature, which provide important context for my study. First, I describe the sociology of childhood approach, which provides a lens for examining children's experiences with mental health diagnoses. I then describe the sociological literature on medicalization and the illness experience – processes that have gained great attention from medical sociologists, and to which this study adds empirical data. Next, I review literature on stigma and empowerment associated with mental health, which informs my analysis of children's experiences with mental health diagnoses and treatments. I then turn to research on doctor-patient communication, demonstrating the lack of information shared across medical contexts; my study extends these findings by gaining insight into strategies used to communicate mental health diagnoses to children. I next review research on parents' involvement in and perspectives on children's mental health care, which provides context for findings in the current study that parents often play a crucial role in providing their children information and support. I examine previous research on children's perspectives on children's mental health, and the small body of research on children's experiences with mental health diagnoses, to which my study contributes. I conclude with a critique of the literature, identifying limitations to research that has been conducted in these areas.

The Sociology of Childhood Perspective

The 'new sociology of childhood' is an 'emergent paradigm' in sociology that emphasizes treating children's lives and experiences as worthy of study and capturing the voices of children who are often silenced in social science research (Prout & James, 1990). The 'new sociology of childhood' (hereafter 'sociology of childhood') emphasizes the importance of viewing childhood as a social construction, rather than as a universal, natural stage in human development (Prout & James, 1990). The approach treats childhood as "a variable of social analysis," tied to variables such as gender, race, and class, and views children's social relationships as "worthy of study" (Prout & James, 1990, p. 8). Furthermore, the approach emphasizes that children should be seen as active participants in their social lives and in the societies in which they live, rather than as passive beings merely responding to the social structures around them (Corsaro, 2005; Prout & James, 1990).

According to Turmel (2008), this emergent paradigm in the sociology of childhood is a 'post-socialization theory' of childhood, very different from socialization theories embraced by sociology in the past. In Turmel's (2008) review and critique of classical socialization theory, he notes that a scientific division of labor was created between psychology and sociology at the end of the nineteenth century, whereby children fell into the realm of psychology, while sociology focused on the family. According to Prout and James (1990), psychological discourses were infused into sociology's socialization theories during the 1950s because they offered a 'scientific' account of children's entrance into society at a time when positivism was growing in popularity in the social sciences. Sociologists therefore embraced the socialization theory, based heavily on the developmental model from psychology, as a frame for understanding the transition from childhood to adulthood (Turmel, 2008). Critics of this traditional model have

criticized its view of children as passive and incompetent in an ‘ahistorical’ and ‘acultural’ context (Turmel, 2008). Corsaro (2005) adds that classical socialization theories are too outcomes-based and individually-focused. Prout and James (1990) also criticize this model’s depiction of children as ‘irrational’ beings in stark contrast to the mature, rational adults that socialization transforms them into.

An alternative to the traditional, deterministic model of socialization, in which children are seen as being passively trained for adulthood, is the *constructivist* model of socialization, in which children are seen as playing an active role in their development by constructing their own meanings of the world around them (Corsaro, 2005). Constructivism focuses on understanding individuals’ lived experiences from their perspectives, including their cognitive, meaning-making processes and interpretations (Crotty, 1998; Freeman & Mathison, 2009; Schwandt, 1994). This ‘post-socialization’ theory differs from the traditional model by emphasizing children’s agency in the development process.

Corsaro (2005) criticizes the constructivist perspective, however, for continuing to focus on individual development with a ‘forward-looking’ approach. Instead, he proposes the interpretive reproduction model, which goes a step beyond the constructivist perspective by viewing children as active participants in society who are both constrained by social structure and who act as *contributors* to culture and social change (Corsaro, 2005). As Corsaro (2005, p. 29) notes, children “affect and are affected by society.” In their review of studies on peer culture, Corsaro and Eder (1990, p. 200) demonstrate that rather than merely imitating adult culture, children “creatively appropriate information from the adult world” to create their own cultures. They argue that “socialization is not only a matter of adaptation and internalization, but also a process of appropriation, reinvention, and reproduction” (Corsaro & Eder, 1990, p. 217).

As researchers, we must not *assume* that we understand children's meanings and understandings. In particular, we cannot assume that we understand children's meanings simply "because we were children once and because we see them so often" (Fine & Sandstrom, 1988, p. 35). The social meanings of adults and children may differ dramatically (Fine & Sandstrom, 1988). Using a sociology of childhood approach, we must explore children's understandings from *their* perspective.

The sociology of childhood provides a lens through which we can explore and better understand the lived experiences and perspectives of children with mental health diagnoses. Rather than viewing them as passive, innocent, unknowing, and in need of protection, the sociology of childhood perspective can be used to examine how children actively participate in the process of learning about, making sense of, and experiencing their diagnoses. In particular, we need research on how children appropriate and develop understandings of mental health diagnoses. The sociology of childhood approach can guide future research in which the lived experiences and meaning-making processes of children with mental health diagnoses are examined.

Review of Existing Research

Medicalization

Medicalization is the process through which problems once understood as non-medical issues are re-conceptualized using medical frameworks, with an emphasis on the need for medical intervention (Conrad, 1992, 2007). The literature on medicalization is especially relevant to my study in that the increasing tendency to diagnose children with mental health disorders is an example of medicalization: children's emotions and behaviors that were once

seen as ‘bad’ or problem behaviors, such as hyperactivity, are redefined in medical terms as ‘disorders,’ and medical interventions are embraced as solutions (Conrad & Schneider, 1992).

Children’s behaviors and struggles may be especially prone to medicalization because children are considered less responsible for their actions than mature adults; society may be inclined to medicalize children’s behaviors in an effort to resist blaming them for their deviance (Conrad & Schneider, 1992). As Riessman (1983, p. 5) notes, “structurally dependent populations,” such as children, are disproportionately susceptible to medicalization; being “powerlessness” legitimates “‘protection’ by medical authorities.” This is in line with visions of children as innocent, passive, unknowing, and in need of protection.

Hyperactivity, in particular, has been identified as an example of the medicalization of children’s behaviors. Conrad (2006, p. xvi) notes that ADHD is a “touchstone in our understanding of children’s problems and medicalization.” The diagnosis of ‘hyperkinesis,’ a behavior disorder marked by hyperactivity and short attention spans, which were once considered ‘bad’ or problem behaviors rather than symptoms of medical illness, became popular in the 1960s and 1970s (Conrad & Schneider, 1992). Noting that it was named a disorder twenty years *after* the discovery of stimulants for children, and that its popularity emerged along with the “pharmaceutical revolution in mental health” and heightened interest in child psychiatry, Conrad and Schneider (1992, p. 159) question whether the label was invented to facilitate the use of the psychoactive medications. Since the 1970s, the diagnosis and treatment of ADHD have continued to expand. Conrad (2006) concludes that this suggests a broadened definition of ADHD, rather than an increase in its prevalence or identification. According to Conrad (2006, p. xvi), this “expansion” of ADHD has resulted in rising diagnosis and treatment of the disorder

worldwide. It therefore continues to be a disorder of particular interest to those exploring the medicalization of children's emotional and behavioral problems.

Sociologists and clinicians have highlighted both the promises and pitfalls, or “brighter” and “darker” sides of medicalization (Conrad & Schneider, 1992, p. 246), which have fueled the controversy over the benefits and drawbacks of increased diagnosis of children's mental health disorders discussed in Chapter 1. On one hand, medicalization may offer hope for finding a cure and may absolve blame by legitimating behaviors (Conrad & Schneider, 1992). Furthermore, diagnoses may bring “an end to uncertainty” by identifying the source of the problem (Maynard, 2003, p. 17). As noted previously, Klasen (2000) finds that diagnoses may bring parents of children with hyperactivity a sense of relief, legitimization, and control. On the other hand, medicalized labels may be stigmatizing, and may deflect attention away from the broader social context and towards the individual (Conrad & Schneider, 1992). By treating children on an individual basis in the medical realm, primarily with medication, clinicians may be ignoring the underlying social problems that need to be addressed (Burston, 2006). Viewing ADHD as a medical problem may also deflect attention away from the education system and its responsibilities to meet the needs of children (Timimi, 2002). Medicalization can be seen as a mechanism for “controlling problematic experiences” considered “deviant” (Riessman, 1983, p. 4). It may broaden our societal views of what is deemed problematic (Conrad, 2007).

The increasing medicalization of children's behaviors as mental health disorders can also be seen as part of a larger shift – the medicalization of childhood and adolescence. As Finn (2009, p. 56) argues, the medicalization of troubling youth behaviors promotes a construction in which childhood and adolescence are becoming “equated with pathology.” The expanded diagnosis, pharmacological treatment, and residential care of troubling adolescent behaviors now

labeled ‘disorders’ (such as conduct disorder and oppositional defiant disorder) can be seen as part of an increasing market for ‘controlling’ and ‘containing’ adolescence (Finn, 2001). These scripts go hand in hand with the view of social workers as ‘helpers,’ and a growing emphasis on interventions that ‘save’ youth (Finn, 2001). Mapping these discourses onto historical shifts in capitalism, Finn (2009, p. 55) demonstrates that this medicalization of childhood and adolescence has accompanied a shift to a global, service economy, with child and adolescent pathology seen as “a major growth industry.” As Finn (2009, p. 58) notes, these corrective interventions are being *sold* to parents, professionals, and even children. The current study adds empirical evidence to these discussions, shedding light on the effects of medicalization on children’s experiences.

The Illness Experience

Given my interest in how children experience their diagnoses, I now turn to the literature on the “illness experience perspective,” which focuses on examining the everyday aspects of having a chronic illness (Schneider & Conrad, 1983, p. 9). In their seminal book, *Having Epilepsy: The Experience and Control of Illness*, Schneider and Conrad (1983, p. xi and 4) “tell the story of what it is like to have epilepsy” and explore how individuals “experience and attempt to control chronic illness in their everyday lives.” This focus on the everyday experience of illness can be integrated with the sociology of childhood’s emphasis on the everyday experiences of children, to motivate my research on children’s everyday experiences of their diagnoses.

Capturing the illness experience has implications for clinical practice. Kleinman (1988) suggests that psychiatrists should go beyond their own professional models to understand patients’ interpretations of their own experiences. In particular, psychiatrists can compare their own understandings to patients’ explanatory models, including their explanations of the cause,

onset, and course of their problems. A psychiatric diagnosis is but one interpretation of a patient's experience, which may at times differ from patients' own perceptions (Kleinman, 1988).

The current study builds on recent findings in research on the illness experience that have documented an increase in patients' utilization of the internet to seek information on their health conditions, including psychiatric conditions (Conrad & Stults, 2010). Research by the Pew Internet and American Life Project demonstrates that 80% of American internet users (113 million adults) have searched for information on at least one of 17 health topics, including 'mental health issues' (S. Fox, 2006). The internet has changed the experience of illness in that patients' conditions are discussed in a public forum over the internet, rather than in a private manner with doctors, family, and close friends, and access to experiential information on the internet "blurs some distinctions between patient and expert," challenging the expertise of medical professionals (Conrad & Stults, 2010, p. 181). The ability to access information on the internet can "empower patients with knowledge" that was previously unavailable to them (Conrad & Stults, 2010, p. 182). However, patients may be misinformed by the information they obtain, as they may be "ill equipped" to identify accurate information from credible sources online, given the high volume of information available and its varying quality (Ayonrinde & Michaelson, 1998, p. 582).

Research has also shown that the internet is a primary source of health information for adolescents (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005). Adolescents may prefer obtaining health information online to seeking information from peers, parents, and teachers, because they can avoid embarrassment and perceived judgment (Skinner, Biscope, Poland, & Goldberg, 2003). Gray et al. (2005, p. 1471) describe an adolescent focus group participant who

explained that patients are motivated to seek information on the internet because of the empowerment it brings, allowing them to know what is wrong and what to do to “help themselves.” One concern with this trend, however, is that children may be more vulnerable to misinformation from online resources, and indeed adolescents in a study by Skinner et al. (2003) acknowledged challenges and gaps in their internet-searching skills used to find health information online. However, Gray et al. (2005, p. 1476) find that adolescents show “sophisticated critical appraisal skills,” recognizing the information found on the internet might be inaccurate, and that some develop strategies for testing the reliability of information, such as looking for markings of credible institutions. This provides context for findings in the current study that participants utilized online sources for information on their diagnoses.

Stigma, Empowerment, and Mental Health

The current study can be understood in the context of a large body of research on stigma and empowerment in the field of mental health. In particular, my interest in children’s experiences with their diagnostic labels is informed by theoretical discussions of the effects of labeling on those with mental health problems. The labeling theory of mental illness, as first proposed in 1966 by Scheff (1966), purports that when those who break ‘residual rules,’ or subtle norms of social interaction, are labeled mentally ill, they internalize the negative reactions of others, leading to ‘careers in residual deviance.’ This theory has been controversial, and has received considerable criticism. According to Gove (1970), psychiatric patients are hospitalized because of a significant mental disorder rather than because of labeling.

In 1989, Link, Cullen, Struening, Shrout, and Dohrenwend (1989, p. 404) proposed a modified version of labeling theory, which purports that labeling and stigma do not “create mental illness directly,” but are “possible causes of negative outcomes that may place mental

patients at risk for the recurrence or prolongation of disorders.” Individuals “internalize societal conceptions of what it means to be labeled mentally ill,” which begin to develop even before they become patients (Link et al., 1989, p. 402). Responses to perceived stigma include, for example, secrecy and withdrawal. This process can negatively affect support networks, jobs, and self-esteem, thus increasing the risk of repeated episodes of mental health problems (Link et al., 1989).

In their review of the literature, Link and Phelan (1999) conclude that labeling has *both* negative and positive effects. While the label produces stigma and negative reactions, psychotherapeutic and pharmacological interventions may greatly benefit individuals (Link & Phelan, 1999). In 2010, Link and Phelan (2010, p. 587) argued that the stereotypes of dangerousness and incompetence, associated with ‘mental illness,’ have “either changed little or actually become stronger.” Research has also examined the coping responses that individuals facing ‘stigma-related stressors’ attempt to employ (Link, Mirotnik, & Cullen, 1991; Miller & Kaiser, 2001). The current study adds empirical data to this discussion, examining how children experience diagnostic labels associated with mental health.

The current study must also be understood in the context of previous research on the stigma children with mental health diagnoses experience. While there has been less research on the stigmatization of children’s mental health problems as compared to that of adults, studies demonstrate that such stigma does exist (Hinshaw, 2005). According to Hinshaw (2005, p. 725), stigma is “a process with major developmental implications” that can multiply over time. It is exacerbated in children by their low status and lack of authority (Hinshaw, 2005).

Stigma can be especially destructive during adolescence, given that this is a crucial time in identity formation and a challenging time for youth’s self-esteem. Identity formation in

adolescence involves “redefining the self” as youth consider the roles they will adopt as adults, while maintaining their past selves; this involves “the need to *integrate* the various identities that one selects into a coherent theory of self” (Harter, 1990, p. 376). Acceptance into one’s peer groups becomes especially important as adolescents aim to construct identities that will be supported by society (Harter, 1990). This involves an “immersion in peer identifications and conformity to stereotypes” (Harter, 1990, p. 377). Peer groups and peer cultures also play a crucial role in adolescent development, as teens strive for psychological independence from their parents (Brown, 1990). Many youth struggle with their self-esteem in early adolescence; research suggests that self-esteem is at its lowest point between the ages of 12 and 13 (Harter, 1990). In particular, adolescent girls experience significant stress (Pipher, 1994). Although findings have been mixed, and the gender difference may be small, research suggests that males score higher on measures of self-esteem than do females, with the largest difference in late adolescence (ages 15-18) (Kling, Hyde, Showers, & Buswell, 1999). These challenges and pressures make adolescence a particularly challenging time for children to face stigma associated with diagnoses and treatments for emotional and behavioral problems. Adolescence is a “particularly vulnerable phase of life” and a critical time for “widening peer relationships” when labeling and separating children into special classrooms, for example, can be particularly damaging to a youth’s self concept (Rosenberg & Gaier, 1977, pp. 489 & 496). The challenges adolescents face in developing their identities during adolescence can be “compounded” for those who are diagnosed and receive treatment for mental health problems, and who may be “particularly susceptible to negative evaluation” from their peers (Elkington et al., 2012, p. 292).

Several studies have documented the public’s stigmatizing attitudes towards children’s mental health problems. Studies using data from the National Stigma Study—Children (NSS-C)

module of the 2002 General Social Survey, for example, have explored these attitudes. Pescosolido, Perry, Martin, McLeod, and Jensen (2007) analyzed respondents' answers to questions about their perceptions of stigma associated with children's mental health problems, finding that almost half of the participants believed that children's mental health treatments are stigmatizing and that this continues to negatively affect those with mental health problems in adulthood. Findings from other studies show that the level of rejection is highest for children with ADHD, followed by depression, 'normal troubles' and then physical illness (Martin, Pescosolido, Olafsdottir, & McLeod, 2007). Interestingly, findings suggest that the endorsement of medical attributions is not likely to minimize stigma for children with mental health problems (Martin et al., 2007). Respondents are also more likely to rate children with depression and ADHD as being dangerous than children with asthma and 'daily troubles' (Pescosolido, Fettes, Martin, Monahan, & McLeod, 2007). Findings from studies exploring the NSS-C have therefore demonstrated the stigmatization of children's mental health problems, including ADHD and depression. These studies have also highlighted the association between these disorders and perceived dangerousness among the public. Research has also documented children's negative attitudes towards peers with mental health diagnoses, and how stigma is actually experienced by children with mental health problems, as described below. These studies provide important context for understanding children's stigma experiences, documenting the prevalence of these stigmatizing attitudes and stereotypes.

While much research has focused on experiences of stigma, some research has examined experiences of empowerment, which also helps to frame the current study. Corrigan (1997, p. 50) defines empowerment for those with 'severe mental illness' as "the ability of individuals to make independent decisions about their treatment and living situation." He notes that mental

health interventions can be designed to enhance empowerment, especially by creating a safe space for individuals to participate in decision making and by clarifying choices available to them (Corrigan, 1997). As described below, researchers have called for the empowerment of both parents and children in the field of children's mental health, noting the importance of involving both in children's care (Walker, Thorne, Powers, & Gaonkar, 2010). This literature raises questions as to whether diagnoses are empowering or stigmatizing for children, and thus motivates the current research on how children experience their diagnoses.

Doctor-Patient Communication

This study must also be understood in the context of a large body of literature on gaps in doctor-patient communication. There is an extensive literature on doctor-patient interaction with physically ill adult patients, dating back to the 1960s (Heritage & Maynard, 2006; Roter & Hall, 1989), much of which has identified the lack of information professionals provide to patients (Thompson, 2000). In their seminal work, *Awareness of Dying*, Glaser and Strauss (1965) examined practitioners' reluctance even to share the terminal nature of patients' conditions with them. In her extensive review of the literature, Thompson (2000) points to research illustrating the lack of, or insufficient, explanations that patients receive in the medical context. Further, she highlights research indicating that poor doctor-patient communication is related to a myriad of negative outcomes, including patient dissatisfaction and non-compliance with treatment regimens (Thompson, 2000). In their review of the literature, Gillotti and Applegate (2000) highlight the ethics debate that surrounds medical disclosure, in which some purport that patients *deserve* to be informed of their health conditions. Thompson (2000, p. 27) notes that explanations provide more than just content; they also have a "relationship dimension," signaling

that doctors care about whether patients understand their problems and treatment, and engendering a “relationship of mutuality” whereby patients are a part of their care.

Thompson (2000) also reviews work exploring linguistic strategies and general guidelines for explaining physical illness to adults. She highlights the need for thorough, yet simple, explanations of physical illness, devoid of medical jargon. She describes research demonstrating the need for doctors to gauge patients’ understandings prior to and throughout the explanation process, and adapt explanations to the needs of the patient (Thompson, 2000).

Research has also documented the poor dynamics in professional-*parent* relationships for parents of children with physical illness and developmental disabilities. Similar to the literature on doctor-patient communication (both for adults and children), research on professional-parent communication has documented the general lack of explanations provided to parents of children with physical illnesses and developmental disabilities (Korsch & Negrete, 1972; Svarstad & Lipton, 1977). In their groundbreaking study, conducted over five years at the emergency clinic at the Children’s Hospital of Los Angeles, Korsch and Negrete (1972) discovered that almost a fifth of mothers reported leaving the visit without receiving a clear description of what was wrong with their child; nearly half left without an explanation of the cause of their child’s illness. Research has also highlighted the incomplete understandings of parents of children with developmental disabilities, uncovering parental uncertainty regarding the care their children should receive (Lipton & Svarstad, 1974). Findings from a study on communication between professionals and parents of children with developmental disabilities highlight the lack of information parents received; in just over a quarter of the cases were parents even provided an explanation of the concept of “mental retardation,” and in only about half of the cases did parents receive specific information about their child’s testing results (e.g. mental age and I.Q.)

(Svarstad & Lipton, 1977). The lack of information shared in doctor-parent communication is especially concerning given that the receipt of explanations affects parent satisfaction, which is correlated with parents' compliance with the medical advice they receive (Francis, Korsch, & Morris, 1969).

Research on doctor-parent communication has also documented the variability in information shared about children's physical illnesses and developmental disabilities. For example, research has shown that doctors alter their styles of communication based on their assessments of parents' education levels (Anspach, 1997). As Anspach (1997) finds, staff provided simplified information to lower-class parents in an intensive-care unit for newborn infants; in turn, these parents were less likely to assert their wishes regarding the life-and-death decisions staff made about their babies' care. Similarly, research on doctor-parent communication in the field of developmental disabilities demonstrates that clinicians share varying information about children's diagnoses of "mental retardation;" this variation is related to several factors, including the severity of the diagnosis, clinicians' perceptions of the parents' general emotional adjustment and ability to cope with this news, clinicians' previous experiences communicating diagnoses, and clinicians' level of experience in the field (Lipton & Svarstad, 1977). Svarstad and Lipton (1977) also find that professionals discuss diagnoses of developmental disabilities with varying levels of detail and openness with parents. Importantly, this research indicates a significant relationship between professional-parent communication and parental acceptance (assessed in interviews with parents before and after doctors informed them of their child's diagnosis); parents who received 'frank' reports of their children's diagnoses were more likely to accept the diagnoses (Svarstad & Lipton, 1977). This suggests that being

open with parents when delivering this information can help parents process and acknowledge their children's diagnoses.

Research also suggests that consistent with the lack of doctor-parent communication regarding physical illness and developmental disabilities, professionals often give parents very little information about their children's mental health diagnoses and treatments. Collins and Collins (1990) note that while little research has examined actual interactions between parents and professionals, research has documented parental dissatisfaction with these interactions. This includes parents' complaints that professionals assume they are "incapable of understanding" their children's mental health problems and the system of services (Collins & Collins, 1990, p. 523). In a study exploring children and parents' understandings for admission into an inpatient psychiatric unit in Scotland, Chesson, Harding, Hart, and O'Loughlin (1997) found that parents had trouble identifying their children's reason for admission throughout the study, which was conducted over an 18-month period during their stay. Parents of youth transitioning to adulthood, in a study by Jivanjee, Kruzich, and Gordon (2009), identified the lack of information they received about their child's treatment as a barrier to supporting them during this time. Furthermore, Moses (2011) finds a relatively high level of uncertainty among parents in her study regarding the causes of their children's mental health diagnoses. Parents in the study reported a sense of confusion about the diagnoses their children received (Moses, 2011). Further, findings from a study of young adults who had mental health diagnoses in high school suggests that parents *and* adolescents are poorly informed about mental health problems, including where and when to obtain treatment (Mowbray, Megivern, & Strauss, 2002). In particular, participants suggested that they were dissatisfied with the level of information they received from psychiatrists regarding the medications they took (Mowbray et al., 2002).

There has also been extensive research on the lack of information regarding physical illness shared with children. In their review of this literature, Eiser and Eiser (1987) describe research studies finding that chronically sick children are inadequately informed of their illnesses. They highlight two theories that have been proposed to explain this finding: (1) children receive the information but do not comprehend or remember it, or (2) children are not told (e.g. doctors discuss the illness with the parent and not the child) (Eiser & Eiser, 1987). Eiser and Eiser (1987) argue that the reasons to share information with children outweigh any fears that this information might distress them. Educating children about their physical illnesses is especially important to minimize their fears and improve treatment adherence (Eiser & Eiser, 1987). Further, children may be more distressed by misunderstandings (e.g. from overhearing adult conversations) than by information about their illnesses (Eiser & Eiser, 1987).

A solid understanding of the developmental changes in children's concepts of chronic illness are crucial in order to educate them appropriately (Eiser & Eiser, 1987). According to Bibace and Walsh (1981) children's conceptions of illness are related to their developmental status. They present three levels of understanding based on children's progression through the Piagetian stages of development: (1) 'prelogical' explanations (ages 2-6), in which children view illness as being caused by things they perceptually experience, based on their inability to separate themselves from their immediate environments and perceptual experiences; (2) 'concrete-logical' explanations (ages 7-10) in which children identify the external causes of illness, based on their ability to differentiate between the self and others; and (3) 'formal-logical' explanations (age 11 and older) in which children view illness as being located internally within the body but caused by external agents, based on their increased ability to differentiate between the self and others (Bibace & Walsh, 1981). Bibace and Walsh (1981) note that an improved

understanding of children's illness conceptualizations throughout development has the potential to improve professionals' empathy for children, explanations provided, and health education for children. Eiser and Eiser (1987, pp. 286–287) argue that there is an “urgent need” to improve methods of presenting information to children and emphasize that “better explanations of illness to children doubtless require a better understanding of children's own thoughts about feelings about illness.”

Whaley (1999) notes that a better understanding of what children *want* to know about their diagnoses, and how *they* suggest illnesses should be explained, is also necessary in order to improve strategies for sharing this information with children. Whaley (1999) criticizes the literature for focusing on strategies for explaining the medical nature of disease (e.g. etiology) to children, arguing that children, like adults, are more interested in information about their illness experience – the normalcy of their illness and how it will affect their lives. In addition to better understanding what children know and think about illness, it is also important to capture what they *want* to know in order to develop strategies to best explain diagnoses to children.

Similarly, Korsch (1974) underscores the importance of exploring what children want to know in order to receive their consent before medical procedures and include them in decisions regarding their care. She highlights the importance of providing patients information about their bodies and their health, and underscores the importance of assessing the extent to which patients want to take part in treatment decisions. However, Korsch (1974, p. 329) also identifies the difficulty in doing so, noting that it is important to learn what a patient “needs to know” in order to make an informed decision, but also identifying what “he is better off not knowing,” to avoid “undue anxiety and doubt.” She identifies obtaining informed consent for children as a challenge for physicians, and in her pilot study, she examines procedures for obtaining children's

informed consent for experimental and research procedures. She explores the types of decision making that children are able to take part in and the concerns they have about this type of involvement, with the aim of helping physicians to better inform and reassure children when included in these types of conversations. She finds that children and parents “deserve frank discussion” of procedures, however, these conversations should “be carried out in light of the readiness, needs, and concerns of the particular patients” (Korsch, 1974, p. 332). With few exceptions, patients must be 18 years of age to legally provide informed consent for medical care (Kuther, 2003). Physicians are encouraged to seek children’s *assent* to participate in treatment, however, informing children in developmentally appropriate ways and including children in decision making to the extent that they are developmentally capable (Kuther, 2003).

There is a lack of research, however, on how *mental health* diagnoses are explained to children and the effectiveness of these strategies. A fact-sheet describing how parents should talk to children about mental health more generally, posted on the American Academy of Child and Adolescent Psychiatry (2011) website, suggests that misinformation can fuel anxiety and enhance stigma, and that parents must be knowledgeable about mental health to talk to their children about this sensitive issue. They provide several strategies for parents, such as comparing mental health problems to physical illness, communicating in a straightforward and developmentally appropriate way, talking to the child when they feel “safe and comfortable,” monitoring children’s reactions, and slowing down the conversation if the child becomes confused or upset. They note that children can handle higher levels of specificity with increased age (American Academy of Child and Adolescent Psychiatry, 2011). Parents need more guidance and research, however, on strategies they can use when talking to children who are diagnosed with mental health disorders.

Furthermore, national standards and guidelines for how practitioners should discuss mental health diagnoses with children are also needed. Several organizations have developed general guides for practitioners to use when working with youth, especially adolescents. For example, the National Association of Social Workers (1993) has developed a list of standards for social work practice with adolescents, and in a toolkit for youth, Grealish and Chenven (2011) describe ways adolescents can participate in mental health treatment plans. To my knowledge, there are no national standards dictating whether and how mental health professionals should explain mental health diagnoses to children. The current study aims to fill a gap in research, examining strategies used in delivering and explaining children's mental health diagnoses.

Parent Perspectives on Children's Mental Health

To understand how children make sense of their mental health diagnoses, we must explore the experiences of their parents. Parents' understandings may greatly influence their children's, and their experiences may affect the type of support their children receive. Research documenting their perspectives provides an important context for the current study.

The shift away from institutionalization towards treating children while living with or near their families has led to an increasing emphasis on the importance of involving parents directly in their children's care (Heflinger & Bickman, 1996). Treating parents as collaborators in the planning and delivery of mental health services for children was identified as a key principle in the system of care movement over 25 years ago (Stroul & Friedman, 1986). Parent advocacy groups have since played a key role in advocating for parents' inclusion in their children's treatment (Collins & Collins, 1990). A key to parental involvement is the development of strong parent-professional partnerships, in which both parents and professionals play an active role in collaboratively defining problems, setting goals, and making decisions

about children's care (Heflinger & Bickman, 1996). Research indicates that family involvement in children's mental health services is correlated with family empowerment (as measured by the Family Empowerment Scale) (Curtis & Singh, 1996). In their review of the literature, Heflinger and Bickman (1996) conceptualize a model of family empowerment that includes improving family knowledge (e.g. information about services), skills (e.g. ability to find community resources), and self-efficacy (e.g. participation in collaborative relationships with professionals). However, there continues to be a large gap between the intended levels of family involvement in children's mental health care and the level to which they are actually involved (Heflinger & Bickman, 1996). Mental health professionals continue to exclude many parents from this process, or even deem them the *cause* of their children's problems, as described further below (Heflinger & Bickman, 1996). In their review of the literature, Collins and Collins (1990) suggest that professionals' negative attitudes towards parents may act as a barrier towards increased collaboration.

Some research has explored the experiences of parents in their efforts to support and advocate for children with mental health diagnoses, especially in the medical and educational realms. For example, Blum (2007) describes mothers as 'vigilantes,' advocating on behalf of their children as they navigate the medical and educational systems. Harden (2005) describes parents' concerns that mental health professionals undermine their expertise in their care-giving role.

Research has demonstrated that fathers are often less involved in clinical interventions for children diagnosed with mental health disorders than mothers (Lee, 2006; Phares, Fields, & Binitie, 2006; Phares, Rojas, Thurston, & Hankinson, 2010). This is not surprising given that fathers may not be as involved with their children in general, and may not use the limited time

they spend with children in therapy sessions (Phares et al., 2006, 2010). Further, they may disproportionately face the structural barriers faced by all working parents, such as difficulty attending therapy appointments during business hours (Phares et al., 2006, 2010). Clinicians' low expectations for the inclusion of fathers may also contribute to their lower levels of involvement in children's therapy (Phares et al., 2006, 2010). Fathers may also be less involved in children's mental health treatment because 'masculinity scripts' are at odds with help seeking in general, and seeking psychological help in particular (Mahalik, Good, & Englar-Carlson, 2003).

In response to the lack of information clinicians share with parents of children with mental health diagnoses described above, parents often seek information on and knowledge about their children's diagnoses on their own (Rafalovich, 2004). Harden (2005) finds that parents engage in strategies of 'reskilling' when in contact with mental health professionals, challenging the experts in psychiatry by gaining knowledge about their child's diagnosis. Similarly, Rafalovich (2004, p. 17) assesses how parents become "informal experts" on ADHD after their child is diagnosed, which in turn affects their interpretation of the disorder. He describes parents in his study having a "voracious appetite" for information on ADHD, purchasing books and acquiring printed reading materials on ADHD (Rafalovich, 2004, p. 160). Rafalovich (2004) views this as a means of better understanding and empathizing with their children. He also reports that parents express "contentment through knowing the 'truth' about the disorder" through information in these resources, noting that this "parent-oriented literature" tends to focus on the biological causes of ADHD (Rafalovich, 2004, pp. 161 & 163).

Similar to interventions that focus on involving parents in children's mental health treatment, interventions have also focused on providing parental education about children's

mental health (Mendenhall & Mount, 2011). Psychoeducation, for example, is a type of intervention that focuses on educating patients and caregivers about mental health disorders, services, and symptom management (Mendenhall & Mount, 2011). Research evaluating such programs suggests that improved parental knowledge about children's mental health treatment may encourage parents to seek services of better quality and advocate for better treatment for their children (Mendenhall, Fristad, & Early, 2009). Future research using the sociology of childhood approach could examine how this improved parental knowledge about children's mental health affects children's experiences.

Researchers have called for the inclusion of fathers in parent education and training initiatives. Garfield and Isacco (2012), for example, suggest that health professionals educate fathers on proper medical care for their children, and help to increase their 'self-efficacy' and involvement in their children's health care. Similarly, Lee and Hunsley (2006) note that psychological services that provide parent training have focused on mothers; they underscore the importance of including fathers in these services as well.

Research on families' understandings of and attitudes towards children's mental health problems has focused on parents' conceptualizations of the causes of their children's problems. This has included mixed findings as to whether parents endorse biological or environmental causal models for their children's problems. In a study examining parents' understandings of the causes of their sons' ADHD, Harborne, Wolpert, and Clare (2004) found that parents viewed ADHD as biologically caused, but perceived doctors and relatives as endorsing psychological and social causes. This discrepancy led parents to feel blamed for their sons' behaviors, resulting in conflict with professionals and significant emotional distress (Harborne et al., 2004). Findings from other studies suggest, however, that parents are often resistant to biological

models. For example, Wilcox, Washburn, and Patel (2007), explore the explanatory models of parents whose children were diagnosed with ADHD and were being treated at a community-based non-profit in India, finding that few parents accepted that their child had an illness, employed biomedical explanatory models, or accepted the use of biomedical treatments for their child's ADHD. Alternatively, many parents attributed their child's problems to psychological and learning difficulties; some blamed themselves or their spouses for their children's behaviors. Many rejected the label of ADHD (Wilcox et al., 2007). Research has also found socio-demographic differences in parental beliefs, in which parents belonging to racial/ethnic minority groups and parents with less education are less likely to endorse biopsychosocial etiologies and use psychiatric terminology to describe their children's problems (Moses, 2011; Yeh, Hough, McCabe, Lau, & Garland, 2004).

Parental understandings regarding children's mental health problems are especially important given their effects on help seeking. Studies have also examined how parents form beliefs about the causes of children's mental health problems, and how these in turn affect decisions to seek care (dosReis, Mychailyszyn, Myers, & Riley, 2007; Singh, 2003). For example, dosReis et al. (2007) explored how parents of children diagnosed with ADHD made sense of their child's problematic behavior and decided to seek treatment. The researchers found that while some parents noticed that their child's behavior was different from what was expected, teachers, clinicians, relatives, and friends alerted others to their children's problems. DosReis et al. (2007) identify four patterns by which parents came to terms with their children's ADHD: (1) 'the immediate resolution pattern' in which parents' primary interest was finding a solution for their children's problematic behaviors, such as medical solutions, (2) 'the pragmatic management pattern' in which parents viewed their children's behavior as symptoms of a

medical or biological disorder that needed to be managed with long-term care, (3) ‘the attributional ambivalence pattern’ in which parents did not see their children’s behaviors as symptoms of ADHD, but rather the result of other factors, and (4) ‘the coerced conformance pattern’ in which parents did not view their children’s behaviors as problematic or symptoms of ADHD, and were motivated to seek care only by a third party. In a similar study, Mychailyszyn, dosReis, and Myers (2008) find that parents go through several stages in the process of forming their conceptualization of their child’s ADHD condition: (1) forming opinions, such as whether their child was ‘normal’ or not, (2) contemplating the origin of their child’s behavior, focusing especially on environmental factors, and (3) reevaluating their child’s ability to control behaviors after learning of their diagnoses. Parents ‘made sense’ of ADHD as a medical illness, a general problem, or they rejected that it was a problem altogether. Interestingly, some parents sought help from medical professionals even though they did not view their child’s behavior as being caused by an illness (Mychailyszyn et al., 2008).

Parental characteristics may also influence parents’ willingness to seek services and the types of treatment they seek for their children. For example, research suggests that higher levels of parental knowledge may be a predictor of the use of pharmacological treatment (Garland, Brookman-Frazee, & Gray, 2012). Documenting gender differences in parents’ help-seeking behaviors, research also suggests that mothers are the “prototypical help seekers” for children’s psychological services (Lee, 2006, p. 40). This may in part be because fathers view the causes of their children’s struggles differently and do not perceive the same need for and benefit of therapy for their children (Phares et al., 2006, 2010). For example, Singh (2003) finds that while fathers of sons with ADHD recognized their problematic behaviors, only 18% initially agreed that they warranted medical attention. All mothers in the study endorsed medical explanations for their

sons' behaviors. Meanwhile, fathers' explanations emphasized the role of mothering, their sons' lack of motivation, and the belief that their sons were just acting like boys and would outgrow the behavior. Fathers' perspectives fell into two categories: (1) 'reluctant believers' who noted the improvements in their sons' behavior when on medication, but continued to question whether their behavior actually warranted pharmacological treatment, and (2) 'tolerant-nonbelievers,' who did not believe medication use was helping their sons. 'Tolerant-nonbelievers' were skeptical, but tolerant, of both the diagnostic process and pharmacological treatment (Singh, 2003). Furthermore, research has documented racial differences in parental help seeking, suggesting that structural barriers to accessing care, including out-of-pocket expenses, difficulty attending appointments due to inflexible work hours, and the lack of transportation to services, might be exacerbated for minorities who suffer disproportionate economic disadvantage (Gonzalez, 2005). In a study reviewing the obstacles that African Americans face in accessing services for ADHD, Bailey and Owens (2005) suggest that African American parents may not be as well informed about the symptoms, causes, and treatment of ADHD, and may be distrustful of the medical community. They also discuss obstacles in the healthcare system, such as the lack of African American clinicians (Bailey & Owens, 2005).

Parents may also be reluctant to seek help for their children due to fears of stigma and discrimination. Research demonstrates multiple barriers to parents' help seeking, which include embarrassment and concerns about being labeled or judged a poor parent (Sayal et al., 2010). Parents may fear that their children will receive labels that will be attached to them not just in their school years, but into adulthood (Sayal et al., 2010). In some cultures, they may fear that diagnoses will bring shame upon their families (Olin et al., 2008). Parents may normalize their children's behaviors and resist the idea that mental health problems are present, which can

prevent them from seeking treatment from professionals (Marsh & Marks, 2009; Rafalovich, 2004).

Family members of children diagnosed with mental health disorders may receive a ‘courtesy stigma,’ whereby they are stigmatized and sometimes blamed for the child’s condition (Hinshaw, 2005). Research has focused, in particular, on the mother-valor/mother-blame binary, in which some mothers are valorized as ‘fit’ and others are vilified as ‘unfit’ mothers (Blum, 2007). Based on this standard, mothers are held accountable for their children’s mental health outcomes (Blum, 2007). For example, in her study examining the experiences of mothers of children with ADHD, Malacrida (2003, p. 136) argues, “professional-maternal interactions are heavily imbued with presumptions of maternal fault.” Harsh critiquing of mothers emerged in the 1930s in child psychiatry and child guidance clinics, igniting ‘mother-blaming’ for children’s psychological struggles (Jones, 1998). The ‘schizophrenogenic mother’ was a prominent theory in the 1940s through the early 1970s, theorizing that maternal overprotection and rejection caused schizophrenia (Neill, 1990). According to Ladd-Taylor and Umansky (1998, p. 13), neo-Freudian thought, which reached its heyday in the 1940s and 1950s, provided “‘scientific’ justification for mother-blaming.” It emphasized the family as a source of psychic distress, which often led to blaming mothers in the postwar years, at a time when mothers were seen as being bound again to the home and children (Ladd-Taylor & Umansky, 1998). In a first-hand, biographical account of mother-blame, McDonnell (1998) describes her experiences as the mother of a son with autism, and discusses possible reasons professionals are so eager to blame mothers for their children’s disorders. She describes the difficulty in using medical explanations for disorders such as autism because children look ‘normal.’ McDonnell (1998) argues that professionals may also scapegoat parents when frustrated with the difficulties in treating children

with disorders such as autism, and as a way of simplifying the causes of what appear to be such complex disorders.

One question addressed by research on mother-blame is whether an increase in ‘brain-blame,’ whereby biological causes are blamed for mental health problems, diminishes the blame experienced by mothers (Blum, 2007). Through in-depth, semi-structured interviews with 45 mothers as well as ethnographic fieldwork including observation of special education parent meetings, Blum (2007) explores how mothers raising children with ‘invisible special needs’ understand and evaluate their caregiving. Although fewer mothers are blamed directly for their children’s conditions due to an increase in ‘brain-blame,’ findings suggest that many mothers still continue to experience stigma, especially if they are viewed as not taking appropriate actions to treat their children’s conditions (Blum, 2007). Studies demonstrate parents’ mixed reactions to medical diagnoses. Rafalovich (2004, p. 155), for example, finds that parents of children with ADHD diagnoses reacted to medical interpretations of their children’s struggles with “mixed emotional experiences” of “relief and fear.” Parents of children diagnosed with ADHD in a study by Malacrida (2003, p. 214) report experiencing relief and hopefulness upon first receiving the label, but that “blush of optimism” later “wore off.” In a review of the literature, Hinshaw (2005) notes that empirical research has not fully supported the prediction that the belief in biomedical and genetic causes of mental health problems would decrease stigma. Hinshaw (2005, p. 726) notes that models that include the interaction between biological and environmental factors could diminish parental blame, but there is a general tendency to endorse “either-or” perspectives.

These findings differ from those of Klasen (2000), who found that many parents find comfort in medical diagnoses for their children. As described in Chapter 1, he finds that

diagnoses can bring a sense of relief and legitimization to parents. While some parents found it difficult to accept the ‘chronicity’ of diagnoses, many parents welcomed their children’s diagnoses, noting that they alleviated their guilt, gave them a sense of control, and encouraged them to seek help (Klasen, 2000).

While not examining parents’ perspectives per se, the current study highlights the importance of parental understandings and knowledge about mental health. Many participants underscore the important role that their parents played in delivering diagnoses, and helping them to make sense of their diagnoses over time. Previous research on parental perspectives helps to frame this discussion.

Child Perspectives on Children’s Mental Health

While considerably less research attention has been paid to children’s views of mental health problems than those of adults, a small literature on how children view mental health has emerged. This includes research on their understandings of the causes of mental health problems, as well as their acceptance of and attitudes towards those with mental health problems. While focused on the understandings of children in general, rather than children who are diagnosed with mental health disorders, this research helps us to understand how children’s understandings of mental health develop more broadly.

Several studies have explored how these understandings of mental health problems develop throughout childhood (Wahl, 2002). Based on “scattered observations,” Scheff (1999, p. 74) concludes that children are exposed to imagery of deviance at a very young age and can grasp the meaning of ‘crazy’ in their first years of elementary school. Children’s understandings of mental health problems then become more sophisticated with age (Wahl, 2002). Research suggests that children learn about mental health primarily through the media, but also through

schools, parents, and exposure to those who are diagnosed (Armstrong, Hill, & Secker, 1998; Lopez, 1991).

Much research on children's understandings of mental health problems has used vignette techniques, highlighting a developmental trend in children's understandings of mental health by demonstrating that children's ability to identify multiple causal explanations, select appropriate treatments (e.g. less punitive interventions), and demonstrate more sophisticated understandings of the consequences and curability of mental health problems improves with age. This technique involves asking children to read a vignette describing someone with mental health problems and to respond to questions about them. For example, in a study by Spitzer and Cameron (1995), 90 children in grades one, four, and seven were given three vignettes including a vignette of a 'normal child,' a child with antisocial character disorder, and a child with psychotic or borderline psychotic behavior, and asked to answer questions about the fictional character. There was a developmental trend with children's understandings of the definitions of mental health problems, their ability to identify multiple causal explanations, and their ability to select appropriate treatments improving with age (Spitzer & Cameron, 1995). In a very similar study, Poster (1992) asked 168 children in third through sixth grade to read and answer questions about vignettes describing three children and three adults exhibiting problematic behaviors that are characteristic of depression, anxiety disorder, and schizophrenia. This study demonstrates a developmental trend in children's recommendations for interventions, whereby younger children were more likely than older children to recommend punitive responses (Poster, 1992). Similarly, Fox, Buchanan-Barrow, and Barrett (2007), presented 89 children between the ages of 5 and 11 in England with vignettes of individuals with depression, anorexia nervosa, schizophrenia, and dementia, followed by a series of 'choice' cards assessing their thinking about the causes,

consequences, timeline, and curability of the problems. Older children demonstrated a more sophisticated understanding of mental health problems, suggesting that this understanding improves as children age. In particular, younger children tended to endorse the medical model and suggest more medical responses than older children. For example, younger children were more likely to describe schizophrenia as resulting from brain damage and to suggest that vignette characters with schizophrenia should take pills. Meanwhile, older children were able to identify both internal and external factors contributing to schizophrenia, and were more likely to suggest that vignette characters with schizophrenia should see a psychiatrist (C. Fox et al., 2007).

Research demonstrates that children have negative attitudes towards those with mental health problems even at a very young age (Adler & Wahl, 1998; Wahl, 2002). In a review of this literature, Wahl (2002) concludes that despite their lack of understanding about what mental health problems are, young children still hold negative attitudes towards those with mental health problems. For example, in a study examining third-graders' attributions about individuals labeled 'mentally ill,' a group of third-graders were asked to tell stories in response to pictures of adults who were labeled 'mentally ill' and to answer questions about the expected behavior of the fictional characters (Adler & Wahl, 1998). The participants described those labeled as 'mentally ill' more negatively than those labeled as physically disabled, using more negative descriptors when describing the characters identified as 'mentally ill' in the stories they told. Adler and Wahl (1998) conclude that while children of this age might not have a clear understanding of what mental health problems are, they believe that adults labeled as 'mentally ill' have negative characteristics.

Despite evidence that children's understandings of mental health problems become more sophisticated as they age, some research indicates that these negative attitudes towards those

with mental health problems do not necessarily improve as children age (M. F. Weiss, 1986, 1994). In a study by Weiss (1986), children in kindergarten through eighth grade were asked to draw stick figures, illustrating how close they would feel comfortable to a person in the following seven groups: 'normal,' 'physically handicapped,' 'emotionally disturbed,' 'mentally ill,' 'mentally retarded,' 'crazy,' and 'convict.' The study demonstrates that a preference hierarchy illustrated using social-distance measures is established as early as kindergarten. Children of all ages tended to have more positive attitudes towards the 'mentally ill' than those labeled as 'convicts' and 'crazy,' but less positive attitudes towards the 'mentally ill' than those labeled as 'normal' and 'physically handicapped.' These attitudes did not change significantly with age; kindergartners' attitudes were overwhelmingly similar to the attitudes of the eighth-graders (M. F. Weiss, 1986). In a follow-up study eight years later, 34 of the 65 kindergarten students who participated in the original study repeated the projective figure placement test. Findings were nearly identical to those from the 1986 study, suggesting that attitudes toward those with mental health problems develop by kindergarten and remain relatively stable over time (M. F. Weiss, 1994).

Other research suggests that these negative attitudes may actually increase with age, as Wahl (2002) concludes in his review of the literature. Findings from a study by Royal and Roberts (1987), demonstrate that ninth-graders and college students were significantly less accepting than third-graders of one disability among twenty types measured: 'mental illness.' Students in third, sixth, ninth, and twelfth grades, as well as college, were read a description of twenty different disabilities, and asked to answer questions assessing their perceptions of the visibility, severity, and their acceptance of each disability. In general, participants were more

accepting of disabilities as they matured, with the exception of mental health problems, for which the opposite trend was observed (Royal & Roberts, 1987).

Research has also explored children's attitudes towards *peers* with mental health problems, documenting the peer stigma that many children in the current study experienced. In a review of the literature, Hinshaw (2005) explains that it is challenging for children to grasp the concept that other children have mental health problems before reaching adolescence. Yet, Hennessy, Swords, and Heary (2007) suggest that early in elementary school children are able to identify deviant behavior in peers with psychological problems and identify possible causes. They conclude that children's understanding of the extent to which their peers are responsible for their behavior affects their attitudes towards them (Hennessy et al., 2007).

Several studies using the vignette technique have explored the negative attitudes that children and adolescents hold towards their peers with mental health problems. For example, Walker, Coleman, Lee, Squire, and Friesen (2008) report on findings from the first national study of children and adolescents' stigmatization of peers with emotional and behavioral disorders, in which 1,318 children and adolescents between 8 and 18 years of age completed surveys in which they were asked questions after reading a vignette about a fictional peer with asthma, ADHD, or depression. Findings indicate that depression and ADHD are more stigmatized than asthma, with depression being more stigmatized than ADHD. This research demonstrates few differences by demographic characteristics, and the authors conclude that stigmatization of peers is similar across subpopulations and thus a "relatively constant and universal problem" (Walker et al., 2008, p. 918). In another vignette study, a group of 303 adolescents were presented vignettes of a peer with a mental health problem, a mental health problem caused by a brain tumor, alcohol abuse problems, and leukemia, and asked to respond to

a questionnaire (Corrigan et al., 2005). Adolescents were less likely to stigmatize peers whose mental health problems were caused by a brain tumor than those with mental health problems with an unidentified cause (Corrigan et al., 2005).

Research has produced mixed findings as to whether behaviors or diagnostic labels generate this stigmatization of peers. In a vignette study, Law, Sinclair, and Fraser (2007) explored the attitudes and behavioral intentions of 120 children 11 to 12 years of age towards fictional peers demonstrating symptoms of ADHD. The children used negative adjectives when describing the hypothetical peer, even when a label for the child was not presented. These negative attitudes, as well as children's willingness to engage with the hypothetical peer, were not affected by the addition of a diagnostic label. The authors therefore conclude that these views are independent of labeling information (Law et al., 2007). Meanwhile, Harris, Milich, Corbitt, Hoover, and Brady (1992) found that both having ADHD and holding the expectation of a behavior problem had negative effects on peer interactions. In this experimental study, 68 pairs of unacquainted boys in third through sixth grade were asked to participate together in two tasks. The boys were assigned to two roles: the perceiver role, which included all 'normal boys,' and the target role, which included both boys with ADHD and 'normal boys' who were randomly assigned to this role. Some perceivers were told that their partners had a behavior problem, while others were not. The study shows that both the perceivers' expectations of their partners' behavior as well as their partners' actual diagnostic status negatively affected their interactions (Harris et al., 1992).

Research has also begun to explore factors that affect children's attitudes towards help seeking for mental health problems. Findings suggest that children and youth (ages 12-25) who use 'lay labels' such as 'stress' and 'paranoid' to describe a mental health problem experienced

in a vignette are less likely to indicate they would seek help if they had a similar problem, suggesting that these lay label may limit help seeking among youth (Wright, Jorm, & Mackinnon, 2012). Surveys indicate that boys have more negative help-seeking attitudes and are less likely than girls to report a willingness to seek mental health services if needed (Chandra & Minkovitz, 2006; Garland & Zigler, 1994). Children who reported depressive symptomatology on a survey also had more negative attitudes towards help seeking than their peers (Garland & Zigler, 1994).

This research suggests that stigma towards mental health problems is pervasive among children. In summary, this research shows that children's understandings become more sophisticated as they age. Yet, children develop negative attitudes towards those with mental health problems at a young age, and these negative attitudes do not necessarily improve over time. They may in fact increase with age, leading to peer stigma and reluctance to seek help for mental health problems. This helps to explain the stigma that many children with mental health diagnoses face from their peers. Next, I assess research on the perspectives of those children actually diagnosed with a mental health problem who experience this stigma.

The Perspectives of Children with Mental Health Diagnoses

A small body of research has examined the perspectives of children who themselves were diagnosed with mental health problems. The current study directly builds on this research. In particular, this study is informed by burgeoning research on how children with mental health problems understand children's mental health. In their study on children's understandings of mental health, Armstrong et al. (1998) included a sub-sample of 16 children who had identified psychological, emotional, or psychiatric problems. While many findings were similar, Armstrong et al. (1998) highlight the differences between this sub-sample and the main sample.

For example, when asked what factors make young people feel mentally healthy or happy, children with mental health problems listed factors such as drugs and alcohol, which were not identified by children in the main sample. Interestingly, children in the sub-sample did not have more knowledge about specific mental health problems. Perhaps surprisingly, they expressed less sympathy in response to vignettes of characters with mental health problems than those in the main sample (Armstrong et al., 1998).

Other research has explored the causal attributions of mental health problems endorsed by children with mental health problems. In a study by Watson, Miller, and Lyons (2005), high school students who self-identified as having a ‘mental illness’ did not score significantly differently than those who did not. For example, contrary to the authors’ predictions, students who self-identified as having a ‘mental illness’ were equally likely to endorse causal factors for mental health problems (Watson et al., 2005). Meanwhile, findings from a sample of 1,091 children who read vignettes about a peer with depression, ADHD, or asthma, demonstrate that children with mental health diagnoses (except ADHD) were more likely to endorse parenting and substance abuse as causes of the fictional mental health conditions; those diagnosed with ADHD were *less* likely to endorse parenting as a cause, however, perhaps because neurological explanations of ADHD are so widespread (Coleman, Walker, Lee, Friesen, & Squire, 2009). In a study by Cooper and Shea (1998, 1999), exploring the understandings of 16 children (ages 11-16) attending a school for students with learning and behavioral problems in the United Kingdom, findings suggest that children view ADHD as being biologically determined. Only one student in the study endorsed the role of environmental factors. The current study adds further evidence to these findings by also examining the understandings of those diagnosed with mental health disorders as children.

The current research also builds on the limited body of research on how children experience symptoms and diagnoses. For example, drawing from interviews with children diagnosed with bipolar disorder, as well as adults whose symptoms emerged in childhood, Anglada (2006) describes children's experiences of depression and mania, and the dread and anxiety that often comes with this 'tug of war' between mood states. Meanwhile, in the study described above, Cooper and Shea (1998, 1999) find that some children welcomed the ADHD diagnosis as an explanation for their behaviors and necessity to access medication, while many experienced stigma associated with both their ADHD diagnoses *and* the behaviors associated with ADHD. They viewed themselves as being impaired in some way, and considered the diagnosis central to their sense of self (Cooper & Shea, 1998, 1999). Leavey (2005) explores the coping strategies youth use to adapt to their new identities once their diagnoses have been identified and symptoms are under control.

Researchers have also very recently begun to explore the stigma experiences of children diagnosed with mental health problems. Research has documented that youth experience discrimination and rejection within their families, in the school environment, and among peers (Elkington et al., 2012; Kranke, Floersch, Townsend, & Munson, 2010; Moses, 2010). Both Elkington et al. (2012) and Moses (2010) find that youth report families communicating negative messages to them about their diagnoses. Nearly half of the participants in Moses' (2010) study reported stigmatization within their families, including for example, distrust, avoidance, and gossip. Moses (2010) finds, however, that the greatest number of youth experienced stigma among peers. Kranke et al. (2010) notes that adolescents' families and school environments can either exacerbate or help minimize the stigma that they experience. Family support, in

particular, can help neutralize the stigma they experience in the peer context (Kranke et al., 2010).

Research has documented adolescents' reluctance to disclose mental health problems, as well as efforts to conceal their problems and treatments, especially from peers (Elkington et al., 2012; Moses, 2010). Many adolescents report experiences of rejection after disclosing their diagnosis or participation in therapy to others; however, many report receiving support and acceptance as well (Elkington et al., 2012). Elkington et al. (2012) finds that many youth experienced a period of shame, which some 'outgrew.' Especially older youth had difficulties, however, in adapting to their new identity as someone with a mental health problem (Elkington et al., 2012).

Research suggests that children may not identify themselves using the terminology of disorder. For example, reflecting on their experiences with mental health problems in high school, participants in one study suggest that high school students seldom identify themselves using the term 'mental illness,' which they reserve for those with extremely severe problems (Mowbray et al., 2002). In a study examining adolescents' self-labeling, Moses (2009a) finds that youth use psychiatric terms to varying degrees; over a third of participants did not self-label as having a mental disorder, but rather, understood their problems in other ways. Many saw themselves as having a behavior problem, which they viewed differently than a mental health problem. Further, many reported uncertainty and confusion about the nature of their problems. Those who did self-label as having a mental disorder had higher levels of self-stigma and depression (Moses, 2009a). Meanwhile, reporting findings from over 18 months of ethnographic field research at day assessment and treatment mental health programs for children and adolescents in Ontario, Canada, Stride-Darnley (2009) finds that youth chose not to use

medicalized language to describe the day treatment center and their problems; they avoided psychiatric terms, such as ‘disorder,’ and they identified themselves as students rather than clients or patients.

Research exploring children’s experiences with stigma associated with their mental health diagnoses has also focused on ways in which children actively resist stigma. For example, in the study by Elkington et al. (2012, p. 302) described above, youth reported resisting the label of mental disorder by distancing themselves from “those they considered ‘crazier.’” Hepper, Weaver, and Rose (2005), also report on strategies many of the children in their study used to actively resist stigma and protect their social identity, such as legitimizing their illness, limiting whom they told about their treatment, and controlling others’ impressions of the in-patient treatment unit by glamorizing it as ‘cool.’ Similarly, Stride-Darnley (2009) describes the ways that youth receiving day treatment services attempt to overcome the stigma associated with mental health problems as well. For example, as noted above, he describes youth’s attempts to ‘pass for normal’ through language choice, choosing not to use medicalized language to describe their treatment and conditions. The youth also used educational success as a strategy for resisting the view that adolescents with mental health problems cannot succeed, and attempted to minimize differences between themselves and other adolescents by succeeding in the classroom. But the youth also viewed resistance to education as a sign of normal adolescent behavior, and thus at times resisted education as a means of resisting stigma as well (Stride-Darnley, 2009).

The current study also draws on the small body of research that has begun to explore children’s experiences with psychopharmacological treatment. In the study by Cooper and Shea (1998, 1999) described above, children described medication as helping them in their studies. However, many shared a concern that medication is used as a source of control, serving the

interests of parents and teachers. In their review of the literature on the ‘subjective experience’ of taking psychotropic medication, Moses and Kirk (2005, p. 389) argue that the potential effects of psychotropic medication use on youth’s sense of control, self-reliance, shame, stigma, and identity are “central concerns.”

This research has also begun to examine youths’ attitudes about obtaining and adhering to treatment regimens. Research suggests that youths’ understandings of their mental health problems can affect their willingness to obtain and adhere to treatment. For example, in a study exploring the subjective experiences of adolescents diagnosed with depression, Wisdom and Green (2004) find that youths’ conceptualizations of depression affect their attitudes towards treatment. Those who interpreted the diagnosis as confirming a part of their identity, for example, were more likely to view possible interventions “with suspicion and hopelessness” (Wisdom & Green, 2004, p. 1235). Meanwhile, Draucker (2005) uncovers several concerns that affect youths’ willingness to obtain treatment for depression, including fears that clinicians will view them as ‘crazy,’ use private information against them, and be unable to understand their experiences. Research examining barriers to youth’s adherence to treatment has also theorized ways to increase their compliance (Gearing & Mian, 2005; Gearing, Schwalbe, & Short, 2012).

Research on children’s experiences with mental health diagnoses has also called for empowering children in their mental health treatment. Taking an active role in shaping one’s own treatment and children’s mental health services more generally is a crucial aspect of “empowerment,” which Walker et. al (2010, p. 52) note “has been used to describe a desired outcome that reflects the shifting perspective on the nature of consumer participation in services and systems.” The concept of empowerment is based on the “idea of subordinated people gaining or attaining the capacity to control their lives and to influence the community and social

structures that affect their lives” (Walker et al., 2010, p. 52). The movement to involve parents in treatment, as described above, has more recently expanded to include an emphasis on including children as well (Walker et al., 2010).

Research suggests that children wish to play a more active role in treatment decisions about their mental health care. Hepper et al. (2005), for example, find that children in an inpatient unit feel that they are excluded from and wish to be more involved in decision making and goal setting in their treatment. In a similar study examining children’s understandings of their own psychiatric hospitalization, Roth and Roth (1984) also conclude that children should be provided information about their treatment and that older children should be given greater rights in making decisions about their care. As Moses and Kirk (2005, p. 399) note, “too often” children are “not fully informed or consulted” about taking psychotropic medications, and if they are consulted, their opinions are “discounted.” They argue that youth should be given “the maximum opportunity to influence treatment decisions” (Moses & Kirk, 2005, p. 399).

Research assessing children’s experiences in family therapy also highlights their wishes to play a larger role in therapy. Strickland-Clark, Campbell, and Dallos (2000), for example, interviewed children, ages 11 to 17, after family therapy sessions at two clinics in England, finding that children want to be heard, accepted, and included in the family therapy sessions (Strickland-Clark et al., 2000). In a similar study, Stith, Rosen, McCollum, Coleman, and Herman (1996) interviewed 16 children at two family therapy clinics, ages 5 to 13, who had participated in family therapy sessions. They found that children want to be involved in therapy sessions, and that they are more comfortable if provided an explanation of the process (Stith et al., 1996).

Research on the experiences of children in treatment also strongly suggests the importance of listening to children. In a review of the literature, Davies and Wright (2008) note that ‘looked-after children’ highly value involvement in their therapy and treatment decisions, and emphasize wanting their suggestions to be heard. Similarly, in a report describing findings from five experimental projects funded by the Mental Health Foundation throughout England, aimed at capturing youth’s experiences with mental health services, Laws (1998) notes that youth emphasized the importance of being listened to and taken seriously by professionals. They also highly valued receiving full information about their treatment options and being included in decision making about their care. They were angry that their views regarding treatment were often not respected, especially regarding medication. Beyond wanting to participate in decisions about their own care, they emphasized wanting a greater influence over how mental health services operate more generally. Laws (1998) concludes that consultation with youth needs to be seen as a key aspect of their care. Research on the experiences of youth with co-occurring mental health and substance abuse problems and their families, funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), also demonstrates that “most importantly, youth and their families want to be heard and respected” (Federation of Families for Children’s Mental Health & Keys for Networking, Inc., 2001, p. 2). Similar findings in the current study add to this research.

Critique of the Literature

Previous research on children and families’ experiences and understandings of children’s mental health has several limitations, both methodological and conceptual. First, much of the existing research is based on surveys and vignette studies, which fail to capture children’s meaning-making processes. Questionnaires and interviews with limited response options, such

as those used in many vignette studies, do not allow respondents to expand upon their views. Surveys capturing children's attitudes towards mental health, for example, shed little light on how children developed those understandings. Many studies are also cross-sectional, rather than longitudinal, and thus do not capture how understandings, attitudes, and experiences may change over time. A better understanding of how attitudes develop and are shaped over time could inform strategies to change them.

Furthermore, much of this research captures behavioral intentions rather than actual behaviors. The vignette technique asks participants to respond to fictional characters. For example, youth read vignettes of fictional characters experiencing symptoms of mental health problems and are asked what interventions they would recommend and whether they would seek help if they had a similar problem. These studies may not capture how individuals behave in actual situations. Similarly, research using surveys and questionnaires, especially in assessing stigmatizing attitudes, fail to capture participants' actual interactions with children with mental health problems. Respondents may be more likely to discriminate against children with mental health problems in actuality than they indicate on surveys and questionnaires.

Many studies have small and homogenous samples, and thus findings might not reflect the experiences of other populations. For example, research that includes children or parents of children who are accessing services fails to capture the perspectives of those who decided not to seek care or terminate treatment. Many of the samples used in these studies are also homogenous in terms of race and ethnicity, and many studies on parents' perspectives focus on the perspectives of female caregivers. There is also relatively little research that explores how parental beliefs differ across sub-populations and cultures.

Furthermore, the sociology of childhood approach should be further applied to research in this area. We must think critically about how notions of childhood affect the way children's mental health is broadly understood. As noted above, children's behaviors may be particularly susceptible to medicalization because society resists blaming them for their deviant behaviors (Conrad & Schneider, 1992). Riessman (1983, p. 5) suggests that through medicalization, medical authorities can be seen as 'protecting' "structurally dependent populations," such as children. The romantic view of children as innocent and in need of protection may therefore reinforce the process of medicalization. Meanwhile, one might argue that this view of children may have the opposite effect: perhaps adults resist labeling children with mental health problems because the labels taint their idealized notion of the child as pure and innocent, or they resist sharing diagnoses with children due to their 'innocence.' Researchers should explore these possibilities.

The sociology of childhood could also inform research on the experiences of children who are themselves diagnosed. A limitation of the existing scholarship is the lack of research exploring the understandings and attitudes of children who are diagnosed. Much discussion is from the perspective of clinicians and researchers. To my knowledge, research on parental perspectives has not examined the interaction between these views and their children's perspectives. We must capture children's perspectives in order to explore this interaction. We also need more research that captures the experiences of stigma from the children themselves. Perhaps signaling a "devaluation of those with psychiatric disorders," Wahl (1999, p. 468) notes that the real-life experiences and views of those with mental health problems are "conspicuously absent" from research on stigma and mental health. Those with mental health problems can best inform us what stigma is and how it is experienced (Wahl, 1999). Further, children with mental

health problems can best explain how their diagnoses are perceived and experienced in childhood.

The limited research that does explore children's experiences with mental health diagnoses has not yet fully examined how these conceptions develop. While research exploring their experiences with and understandings of diagnoses, as well as research highlighting how they resist stigma, greatly adds to the literature, further research could explore how children develop these understandings. Cooper and Shea (1999, p. 244), for example, note that their study is "merely the first step in what should become a major research enterprise" aimed at understanding how children diagnosed with ADHD in different circumstances experience this disorder. Future research could explore how children make sense of a range of mental health diagnoses throughout childhood.

Furthermore, much research on children's mental health problems continues to view children as passive, unknowing objects, rather than active agents in their lives. For example, it tends to assume that children absorb media and adult representations of mental health problems, rather than focusing on how children actively appropriate information from these representations to construct their own interpretations. Some researchers theorize about the negative effects of stigma on children as if they are passive recipients in this experience. More research, similar to the studies that examine children's agency in resisting stigma, and guided by the sociology of childhood, could help us to understand the active role children play in experiencing their mental health problems and diagnoses.

This study helps to fill this gap by examining the life history narratives and retrospective accounts of emerging adults who were diagnosed with mental health disorders in childhood to explore how they came to understand their diagnoses throughout childhood. The goal of this

dissertation is to examine how emerging adults describe making sense of their diagnoses in childhood and how they suggest diagnoses should best be delivered and explained to children. It examines not only how they are told of their diagnoses, but also how they negotiate narratives about mental health, how they obtain information about their diagnoses, and how they experience them.

CHAPTER 3

Research Methods

To better understand how children make sense of their diagnoses and how to best deliver and explain diagnoses to children, the research questions are:

1. How did emerging adults who were diagnosed with mental health disorders in childhood make sense of their mental health diagnoses throughout their childhoods?
 - a. How did they learn about these diagnostic labels?
 - b. How did they experience these diagnostic labels?
2. From the perspective of emerging adults who were diagnosed with mental health disorders in childhood, how can these diagnostic labels best be delivered and explained to children?

In order to examine these research questions, I conducted 42 in-depth, semi-structured interviews with emerging adults between the ages of 18 and 22 who were diagnosed with ADHD, depression, GAD, and/or bipolar disorder before the age of 17. The interviews elicited participants' life history narratives, including information on how they recall learning about, experiencing, and talking about their diagnoses in childhood. These narrations of their childhood experiences provide insight into how children make sense of diagnoses throughout their childhoods. Interviews also elicited participants' recommendations for how diagnoses should best be delivered and explained to children.

Research Paradigm

Approach

According to Mantzoukas (2004, p. 1003), it is essential that researchers conducting qualitative research begin their work by presenting their epistemological stance, demonstrating “the rules by which they have agreed to play.” Thus, I begin here by describing my epistemology, or “beliefs in the form and the nature of reality, truth, and knowledge” (Mantzoukas, 2004, p. 996). Crotty (1998) identifies three epistemologies, or theories of knowledge: objectivism, constructionism, and subjectivism. While the objectivist epistemology assumes that an objective meaning or Truth exists outside of consciousness, constructionism holds that meaning is *constructed*. Guided by Crotty’s (1998) framework for classifying research paradigms in social science research, I have taken a constructionist epistemological stance. By exploring participants’ narratives, I examined *their* ‘truths,’ focusing on how they constructed meanings about their diagnoses. Further, unlike subjectivism, which focuses on how structures (rather than individuals) inscribe meaning, I am interested in the interaction between participants and the diagnoses to which *they* actively construct meaning. For example, I examine how individuals recall negotiating narratives about their mental health diagnoses. Taking a constructionist epistemological stance, I explore meanings that are constructed by children “as they engage with the world they are interpreting” (Crotty, 1998, p. 43).

While the terms “constructivism” and “constructionism” are sometimes used interchangeably and both emphasize that knowledge is socially constructed through interactions and social context, constructivism focuses on individuals’ meaning-making processes while constructionism emphasizes a social dimension whereby culture influences and shapes individuals’ understandings of the world around them (Crotty, 1998; Freeman & Mathison,

2009). Constructivism is generally focused on understanding individuals' lived experiences from their perspectives, including individuals' cognitive, meaning-making processes and interpretations (Schwandt, 1994). This differs from social constructionism, which focuses on the collective generation of shared meanings (Schwandt, 1994). Social science research on childhood has been influenced by both approaches (Freeman & Mathison, 2009, p. 13), and I draw on both in this research. Utilizing a constructionist perspective, I explore how children negotiate societal constructions of mental health. However, I rely heavily on constructivism, focusing on individual children's meaning-making processes as well. My theoretical perspective is interpretivist, focused on capturing individuals' interpretations of the social world.

This study is informed by the sociology of childhood approach in several ways. Although I interviewed emerging adults, the questions focused on their experiences in childhood; I asked them to reflect on their childhoods to capture their perspectives, attitudes, and experiences *as children*. This focus on capturing the perspectives, attitudes, and experiences of children, rather than the perspectives of their parents, teachers, and other adults in their lives, is in keeping with the approach of the sociology of childhood. This study is also consistent with this approach in that I focus on exploring how children actively create meaning while negotiating explanatory narratives about mental health (e.g. how their diagnoses were explained to them), rather than solely looking at how cultural meanings are imposed upon them. Utilizing the interpretive reproduction model, I examine how they are affected by and contribute to narratives about their diagnoses. Furthermore, rather than focusing on how diagnoses in childhood affect later outcomes in adulthood, this research focuses on how diagnoses affected participants' lived experiences in childhood. This research therefore values the experiences of children without a forward-looking, outcomes focus.

This study also draws from Schneider and Conrad's (1983) 'illness experience perspective,' described in Chapter 2. They propose multiple lines of inquiry utilizing this perspective:

A bona fide illness experience perspective must consider people's everyday lives lived *with* and *in spite* of illness. Relevant questions include how people first notice 'something is wrong' and what it means to them, what kinds of lay theories and explanations they develop to make sense of such strange and frightening events, how they come to seek medical care and with what concerns and expectations, what impact discovering their diagnosis has for them, and how they cope with a medical label and managing medications. We must examine relationships with family members, friends, and work associates. We must consider how people contend with formal and informal disenfranchisements based on a diagnosis, what it is like to make routine visits to the doctor or hospital, how these medical personnel look to patients rather than vice versa, and what strategies people use simply to 'get by' in their lives. A developed insider's view of illness would address the ways in which people feel their disease, disorder, or disability has changed them in their own and others' eyes. It would, finally, confront questions of illness, self perception and self worth. While not exhaustive, these issues begin to define an insider's view (Schneider & Conrad, 1983, pp. 9–10).

Utilizing this approach, I examine what participants' mental health problems and diagnoses 'meant to them' and how they 'made sense' of them. I also ask more broadly about their experiences in school, with family, and friends, and the strategies they employed to manage their diagnoses.

Using this approach, I attempt to capture the 'insider's view' of children's mental health problems. Just as Schneider and Conrad (1983, p. 15) were unconcerned with what physicians and "various 'experts'" think it is like having epilepsy, and focused exclusively on "the *perceptions* of the experience of epilepsy" by those who have it, I focus exclusively on the retrospective accounts of those who experienced children's mental health problems themselves. I am unconcerned with the accounts of parents, teachers, and mental health professionals in this study, and aim to capture emerging adults' recollections of their childhood experiences instead.

Methodology

I collected life histories from emerging adults about their childhood mental health diagnoses, which I analyzed thematically using methodological tools from grounded theory (as described below). While I diverge from traditional life history analysis in that my interviews do not focus on capturing participants' entire life histories, I draw from this approach in several ways. Cole and Knowles (2001, p. 11) explain:

In as much as it is humanly possible, life history inquiry is about gaining insights into the broader human condition by coming to know and understand the experiences of other humans. It is about understanding a situation, profession, condition, or institution through coming to know how individuals walk, talk, live, and work within that particular context.

Here, I examine how participants 'walked,' 'talked,' and 'lived' in relation to their mental health diagnoses in childhood.

I used mental health experiences as a guide for framing the discussion. Cole and Knowles (2001, p. 74) suggest that when developing questions to guide 'life history conversations,' it is essential that researchers keep the focus and purpose of their research central, and ask questions that elicit information and insights related to the researcher's area of interest. They note that the research conversation will flow more smoothly when researchers maintain this focus.

Yet, I also strived to honor Cole and Knowles' (2001, p. 101) suggestion that researchers aim to understand participants' experiences "in context" and in a "holistic" way, without "slicing" them into "discrete bits." I recognized, for example, that it would be difficult to understand a child's experience with a mental health diagnosis without understanding their school experiences, family situation, relationships with peers, and self-identities. I asked if participants could describe "what was life like" both before and after diagnosis – thus, opening

the floor for them to talk about the pieces of their life histories that they found salient. When asked about their lives before and after diagnoses, participants varied in how far they strayed from talking about their experiences with mental health diagnoses. While some responded to these broad prompts by describing how they experienced their mental health problems before and after diagnosis, others provided very broad information about their childhoods and described generally what life was like ‘growing up.’

I draw from narrative analysis that story- and meaning-making are important. As Riessman (1993, p. 2) notes, the purpose of narrative analysis is to understand how respondents “impose order on the flow of experience to make sense of events and actions in their lives.” While not strictly analyzing the structure and form of participants’ stories, I prioritize their telling of their experiences making sense of diagnoses over time. I am not as interested in how diagnoses *were actually* delivered, but rather, how participants *interpreted* this experience. As Stivers (1993, p. 410) notes, there is not a “hard and fast line” between fact and interpretation from the ‘postpositivist’ perspective. This research treats “the subject’s understanding of her life” as “inherently valid” (Stivers, 1993, p. 420).

As discussed in more detail in Chapter 5, I am also interested both in how children actively construct narratives about children’s mental health and how they negotiate societal discourses. It is particularly important to examine the societal discourses that children use when constructing narratives about children’s mental health because these narratives affect mental health interventions. Wells (2011, p. 3) notes, “...language frames how individuals construct problems and their solutions.” Drawing from Wells (2011, p. 83), I am interested in the words participants use to “construct their reality” (e.g. whether they use the terms genetic and disorder)

and “how individuals draw on discourses that are widely available in society” (e.g. whether they embrace cultural understandings of children’s mental health).

Rather than focusing on analyzing the structure of narratives, Plummer (1995, p. 19) argues that “a sociology of stories” should examine “the social role of stories,” including how they are produced, change, and their role in the political process. In this study, I examine how children construct these stories, how they interact with societal discourses about children’s mental health, and whether their interpretations are valued by social institutions (e.g. in the medical realm). The stories about children’s mental health play an important role not only in constructing mental health interventions, but also in constructing children’s identities.

Research Procedures

As indicated above, I conducted in-depth interviews with participants to elicit their stories of learning about and making sense of their mental health diagnoses in childhood. Interviews were semi-structured, whereby I asked follow-up questions based on their responses to questions in my protocol. Given my epistemological stance described above, and my interest in capturing participants’ interpretations and perspectives, I valued the narratives that participants provided in the interviews as the sole source of data for this study. Rather than conducting participant observation in a mental health professional’s office, for example, here I rely on how participants recount this experience, and how they recall interpreting these events. In this section, I describe the sample for my study, followed by my data collection and analysis procedures.

Study Participants

Eligibility criteria and recruitment:

I began by conducting ten interviews with 18-22 year old participants who had been diagnosed with (1) ADHD. This included participants who were diagnosed with attention deficit disorder (ADD), which is subsumed under ADHD in the *Diagnostic and Statistical Manual of Mental Disorders IV-TR* (American Psychiatric Association, 2000), and is hereafter referred to as ADHD. I then chose to broaden the sample to include those diagnosed with (2) depressive disorders (identified as “depression” throughout this dissertation), (3) GAD, and/or (4) bipolar disorder. The four disorders I selected for this study include several types of disorders, including mood disorders (depression and bipolar), anxiety disorders (GAD), and behavioral disorders (ADHD). These disorders have particularly high prevalence rates among children and youth. A study of a nationally representative sample of adolescents (aged 13-18) indicate an 11.7% lifetime prevalence rate of depressive disorders (Major Depressive Disorder or dysthymia), 8.7% of ADHD, 2.2% of GAD, and 2.9% of bipolar disorder (Merikangas et al., 2010). I excluded disorders such as autism, given that they might limit participants’ ability to reflect on their experiences and articulate their interpretation of others’ perspectives about their diagnoses. Furthermore, unlike autism, I focused on disorders that are typically identified once children become engaged in school.

I partly chose to interview emerging adults between the ages of 18 and 22, rather than children, after facing challenges recruiting minors in a pilot study.⁴ Individuals under the age of 18 are considered a special class by the Institutional Review Board, and there are several protections in place in order to recruit them for research studies. For example, parents must

⁴ I recruited participants aged 10-16 through flyers directed towards their parents in a pilot study. After several months of recruitment, I only received calls from two parents, whose children participated.

approve of minors' participation in research, which may limit participation. It can also be challenging to receive approval from sites from which to recruit children, such as schools, camps, and community centers. Further, I would only be able to include children who were *aware of* their diagnoses, which could limit my sample. There are several other challenges in interviewing children as well. Children may be reluctant to talk to researchers, and may have a limited ability to narrate at length about this type of experience. Children's narratives may also be shaped by their parents' presence, either literally or figuratively.

There are limitations to the approach I have taken. While it is my hope that having recently been through childhood, participants aged 18-22 were able to accurately report on their childhood experiences, I capture emerging adults' recollections, or current narrations, of their past experiences. Participants' perspectives and attitudes may have changed over time and their recollections of past experiences may be inaccurate. The stories they tell about their childhoods are filtered through their current worldviews, and thus I capture their current *interpretations* of past experiences. The sociology of childhood emphasizes the importance of including children directly in research, and thus capturing children's voices and perspectives in the moment is a goal of future research.

There may, however, be some benefits to capturing the retrospective accounts of young adults, rather than accounts of children themselves. Whereas children could provide their perspective at the time of the interview, emerging adults have a unique vantage point, with the ability to reflect back upon their entire childhoods, describing how they made sense of their diagnoses over the span of their childhoods. In constructing the stories of their childhoods, participants likely chose the most salient aspects of their past experiences, thus underscoring the childhood experiences that had the most impact. As young adults, they may have also been

better able to articulate and express themselves than children. By interviewing emerging adults, I was also able to capture the experiences of those who were not fully aware of their diagnoses in childhood; some participants did not fully learn of their diagnoses until young adulthood, and were able to reflect back on and describe their limited understandings of their mental health problems in childhood. Furthermore, the technique of interviewing young adults about their past experiences to shed light on children's experiences is likely better than interviewing parents, teachers, or other adults in children's lives and using their perspectives as proxies.

I began by recruiting at a large, public, Midwestern university. I recruited via a flyer announcing the study, requesting that those interested contact me for more information. The flier described the monetary compensation that they would receive for participating⁵. Fliers were posted in campus locations and forwarded to students via email by the university's office for students with disabilities. I also used a snowballing technique whereby I gave fliers to participants at the end of their interviews, and encouraged them to pass the fliers on to those who they thought might be eligible and interested in participating.

After completing ten interviews with participants diagnosed with ADHD at the first recruitment site, I expanded recruitment in two ways. I invited participation from individuals diagnosed with depression, GAD, and bipolar disorder, in addition to ADHD. I also added two additional recruitment sites: a private, mid-sized university in an eastern city and an urban, public university in the east, which included a community college program. I received approval from the Institutional Review Boards at these two institutions, in addition to the original site. I recruited by posting fliers (see Appendix A) on these campuses, and through an email that staff at their offices for students with disabilities forwarded to students. I also used the snowballing

⁵ Participants in the first ten interviews received a \$15 gift card to Target. The incentive was increased to \$20 in cash when the protocol was broadened (as described below), given that interviews were expected to take more time.

technique described above for this phase of interviewing. I attempted to distribute fliers through a local not-for-profit mental health agency, as well as local Children and Adults with Attention Deficit/Hyperactivity Disorder support groups, but these organizations were not able to accept my request at the time, given the high level of recruitment they were experiencing for other research studies.

I hoped that by including three types of colleges, I would be able to recruit participants with diverse racial, ethnic, and socioeconomic backgrounds. Only one participant was recruited from the urban, public university (and its affiliated community college), however. Nearly all participants from the other two universities reported that they heard about the study through the email that staff at their offices for students with disabilities forwarded to students. I met with two counselors at the urban college's two offices for students with disabilities (one specifically for their community college), and both predicted that very few students would respond to the email that they forwarded. Indeed, the one student from this school who did participate noted that she saw one of the fliers I had physically posted on campus. Given the difficulty in reaching students via posted fliers, additional strategies must be explored in the future to reach participants who may be less inclined to respond to fliers distributed via email.

Interested participants contacted me via my email address or phone number posted on the recruitment flyer. I asked two screening questions: (1) Were you diagnosed with ADHD, depression, GAD, and/or bipolar disorder before the age of 17? (2) Are you currently between 18 and 22 years of age? I interviewed those who met eligibility requirements and were interested in participating.

Sample characteristics:

As illustrated in Table 1 below, the sample was predominantly female (n=29 female; 13 male), white (n=31 white; 2 Asian; 2 black/African American; 2 Hispanic/Latino; 2 bi-racial; 3 missing), and middle/middle-upper class (33 participants report having at least one parent with a college degree; 6 report that neither parent had a college degree; 3 missing). Given participants verbally expressed difficulty reporting their parents' income in the early phase of interviewing, I removed this question from the demographic information form when I expanded and finalized it for the eleventh interview; I used parents' education levels as a proxy here for socio-economic status.

One third of participants (n=14) had more than one diagnosis; in total, 36 participants were diagnosed with ADHD, 15 with depression, 8 with GAD, and 4 with bipolar disorder (see Tables 1 and 2).⁶ Participants ranged in age from 18 to 22 when they participated in the interview (as limited by the eligibility criteria), with nine participants age 18 years, seven age 19, eleven age 20, eight age 21, and seven age 22. All were diagnosed between the early 1990s and late 2000s, with two participants learning of their first diagnosis prior to elementary school (before kindergarten), seventeen in elementary school (kindergarten through fifth grade), eight in middle school (sixth through eighth grade), and fifteen in high school (ninth through twelfth grade). Including multiple diagnoses, two participants learned of one of their diagnoses prior to elementary school, seventeen in elementary school, eleven in middle school, twenty-eight in high school, and four after high school (one missing) (see Table 1).⁷

⁶ Total does not equal 42 because 14 participants had more than one diagnosis.

⁷ Total does not equal 42 because 14 participants had more than one diagnosis.

Table 1: Characteristics of Study Participants

Demographic Characteristic		n (N=42)	Percent (N=42)
Current Age	18	9	21 %
	19	7	17 %
	20	11	26 %
	21	8	19 %
	22	7	17 %
Diagnosis*	AD(H)D	36	86 %
	Depression	15	36 %
	GAD	8	19 %
	Bipolar	4	10 %
Age at which Learned of their Earliest Diagnosis	Prior to Kindergarten	2	5 %
	Elementary School (K-5th grade)	17	40 %
	Middle School (6th-8th grade)	8	19 %
	High School (9th-12th grade)	15	36 %
Age at which Learned of Any Diagnosis*	Prior to Kindergarten	2	5 %
	Elementary School (K-5th grade)	17	40 %
	Middle School (6th-8th grade)	11	26 %
	High School (9th-12th grade)	28	67 %
	After High School	4	10 %
Sex	Missing	1	2 %
	Female	29	69 %
Race/Ethnicity	Male	13	31 %
	Asian	2	5 %
	Black or African American	2	5 %
	Hispanic or Latino	2	5 %
	White	31	74 %
	Bi-racial	2	5 %
Mother's highest level of education	Missing	3	7 %
	Less than high school	1	2 %
	High school or GED	6	14 %
	Some college	4	10 %
	College graduate	19	45 %
	Post-college degree	9	21 %
Father's highest level of education	Missing	3	7 %
	Less than high school	2	5 %
	High school or GED	2	5 %
	Some college	3	7 %
	College graduate	14	33 %
	Post-college degree	18	43 %
Parents' education levels	Missing	3	7 %
	Neither parent with a college degree	6	14 %
	At least one parent with college degree	33	79 %

Notes:

The time of diagnosis is reported as grade-level because most participants remembered the school year in which they were diagnosed, but not their age. For the few who only remembered their age, I recoded age as school year, with 7 being recoded as 1st/2nd grade and so forth. Some could not recall which of two years they were diagnosed, and some were diagnosed between grades; in these cases, both years are listed.

Table includes diagnoses received after the age of 17. Percentage totals may not equal 100 due to rounding.

*Total does not equal 100 because 14 participants had more than one diagnosis.

Table 2: Participants List

Pseudonym	Diagnoses Received	Grade in School When Diagnosed*
Abby	Bipolar	11 th grade
Amanda	ADHD	11 th grade
Andy	ADHD	11 th grade
Angela	ADHD Depression GAD	9 th grade 9 th grade 9 th grade
Ashley	ADHD	2 nd grade
Autumn	ADHD	2 nd grade
Blake	GAD ADHD	9 th grade After high school
Chloe	Depression GAD ADHD	9 th /10 th grade 9 th /10 th grade 11 th grade
Christine	ADHD	4 th /5 th grade
Cindy	GAD	8 th grade
Courtney	ADHD Depression	2 nd grade 9 th grade
Crystal	ADHD	2 nd grade
Daniela	ADHD	1 st grade
Devin	ADHD Depression	6 th grade 8 th grade
Erica	ADHD Depression GAD	9 th grade After high school After high school
Faith	ADHD Depression GAD	9 th /10 th grade 9 th /10 th grade 9 th /10 th grade
Gary	ADHD	6 th grade
James	ADHD	2 nd grade

Jennifer	Depression Bipolar ADHD	8 th grade 11 th /12 th grade 11 th /12 th grade
Joe	ADHD	4 th grade
Josh	ADHD	9 th /10 th grade
Kimberly	ADHD	3 rd grade
Krista	ADHD Depression	Before kindergarten Not reported
Leslie	ADHD	9 th grade
Lilly	ADHD	8 th grade
Mark	ADHD	Elementary school (not able to specify grade)
Matt	ADHD	Before kindergarten (“As long as I can remember”)
Max	ADHD	3 rd grade
Melissa	Depression	10 th grade
Michelle	Depression Bipolar	7 th grade After high school
Monique	Depression Bipolar	10 th /11 th grade 10 th /11 th grade
Natasha	ADHD	9 th grade
Nathan	ADHD	4 th /5 th grade
Paige	ADHD	1 st grade
Sam	ADHD	3 rd grade
Sarah	ADHD	3 rd grade
Shannon	ADHD Depression GAD	3 rd grade 7 th grade 7 th grade
Stephanie	ADHD Depression GAD	3 rd grade 10 th /11 th grade 10 th /11 th grade
Tabitha	ADHD	9 th grade
Ted	Depression	11 th grade
Teresa	Depression ADHD	8 th grade 10 th grade
Whitney	ADHD	7 th grade

Notes:

*The time of diagnosis is reported as grade-level because most participants remembered the school year in which they were diagnosed, but not their age. For the few who only remembered their age, I recoded age as school year, with 7 being recoded as 1st/2nd grade and so forth. Some could not recall which of two years they were diagnosed, and some were diagnosed between grades; in these cases, both years are listed.

Notably, five participants reported that they had a parent who was a mental health professional. Children of mental health professionals may be more likely to participate in studies such as this one because they highly value the mental health profession and thus research related to it, or perhaps they are more comfortable discussing mental health because they are more familiar with it. Alternatively, perhaps children of mental health professionals are more likely to be diagnosed because their parents are better able to detect symptoms and/or are more likely to seek a diagnosis. Further, as noted above, over two-thirds (n=29) of participants were female. This cannot necessarily be explained by prevalence rates. Nationally representative data indicate that while the lifetime prevalence of depressive disorders and GAD is twice as high among female adolescents (aged 13-18), and rates of bipolar disorder are also slightly higher among females, the prevalence rate of ADHD is three times higher among males than females (Merikangas et al., 2010). Women may have been more likely to respond to fliers recruiting participants for this study because they may be more comfortable discussing mental health, emotions, and experiences because of normative gender roles. It is also possible that young women with mental health diagnoses are more successful academically and/or experience less stigma in college than their male counterparts, and were therefore more willing to participate. Future research could examine these possibilities.

This dissertation is an exploratory one, with a limited sample that is predominantly female, white, and middle/middle-upper class, as described above. The sample is particularly limited given that participants were recruited on college campuses. Participants may have had particularly positive experiences managing their diagnoses or have been particularly high functioning, given their later enrollment in college. The sample is also limited in that it includes those who voluntarily responded to fliers about the study; those who were higher functioning,

had more positive experiences, or were currently experiencing less distress and fewer symptoms may have been more likely to respond to the flier. If my results are biased due to these limitations, they are likely to be biased in the direction of participants experiencing fewer struggles and having more positive experiences with their diagnoses, given that their families may have had better access to resources and information than the general population (coming generally from middle/middle-upper class families), and as indicated by their enrollment in college and willingness to talk about their experiences. I may thus underestimate the difficulties of diagnosis for young people.

Data Collection

I attempted to make the interview environment as comfortable as possible. Interviews were scheduled at a time of participants' choosing and were held in private rooms reserved on the college campuses or at the local library. Before beginning interviews, I asked participants to read the Informed Consent Waiver (see Appendix B) informing them of the purpose of the study and potential risks and benefits of participation. I then asked participants to complete a Demographic Information Form (see Appendix C), including items about age, sex, race/ethnicity, education, employment, religion, and living situation, as well as parents'/guardians' marital status, occupation, and education. All interviews were audio-taped for subsequent transcription. On average, interviews lasted 70 minutes.

When I broadened the sample to include depression, GAD, and bipolar disorder after the tenth interview, I modified the interview protocol (see Appendix D) by broadening my questions to better invite participants to share 'their stories' (see Appendices E and F for full protocols). At this time, I also added a question to elicit participants' recommendations for delivering and explaining diagnoses to children (see question II.5 in Appendix D). Recommendations were

discussed in the first ten interviews, but not elicited through a direct question in the interview guide.

Trying to avoid the “phony posture that pretends the interview process is not an interaction,” (Stivers, 1993, p. 414), I recognized that I played a large role in guiding the discussion and attempted as best I could to limit my own judgments and reactions to participants’ accounts and create a space for them to share *their* stories. Based on participants’ answers to my broad questions, I asked follow-up questions and prompts, which were influenced by my own viewpoints. While recognizing my role in guiding the conversations, my goal was to provide a comfortable space for participants to share their experiences and perspectives. I tried as best I could to not interject with follow-up prompts until participants had fully finished answering my main questions. Of course, there were times when participants spoke at length in response to my broad questions, and other times when they provided short responses that required many more follow-up questions and prompts. My goal was to follow Cole and Knowles (2001, pp. 74–75) advice that researchers use broad questions as “starting points,” and that we then listen carefully, at times “gently suggest[ing] directions” and asking clarifying questions. The aim was to create an environment where participants felt comfortable sharing their stories.

Data Analysis

Interviews were transcribed verbatim during the data collection phase. I also documented my observations immediately following interviews, including the following: the atmosphere of the interview (e.g. whether there was anything unusual about the setting, what time of day it took place), the participants’ perceived level of comfort (e.g. whether they seemed relaxed, energetic, defensive, reserved, eager to talk), my level of comfort (e.g. whether I felt at ease, energetic, or rushed), and any initial thoughts on their experiences (e.g. aspects of their experiences that I

observed them emphasizing throughout the interview). I wrote brief fieldnotes describing themes I saw emerging and noted comparisons across cases. These jottings helped to guide thematic coding to follow. This early analysis also helped generate strategies for improved data collection, as I at times modified my follow-up questions (Miles & Huberman, 1994, p. 50). As Emerson, Fretz, and Shaw (1995, p. 144) note, this process is “at once inductive and deductive,” with analysis taking place in all levels of the research project.

Once all interviews had been conducted and transcribed, I used HyperResearch qualitative software program to code the data. I analyzed the data thematically using methodological tools from grounded theory, predominantly using unanticipated codes that emerged from the data during the coding process. During ‘open coding,’ I read transcripts line-by-line to identify themes that emerged, while in ‘focused coding,’ I conducted a line-by-line analysis focused on specific topics of interest to develop sub-themes and compare across cases (Emerson et al., 1995). Through this process, I used several coding methods, including holistic and structural coding used to identify topics and segments of data for further detailed coding and analysis, as well as process coding (identifying actions and events), emotion coding (identifying participants’ feelings), and in-vivo coding (identifying participants’ experiences, drawing directly from their language) (Saldaña, 2009). As new analytic categories emerged, I returned to previously coded data and applied these categories.

Throughout this process, I wrote notes, or informal ‘memos,’ on the themes that emerged (Emerson et al., 1995). This included bulleted lists of themes that I identified, which later became the outline for my findings. I organized my list of codes, grouping more specific codes into larger categories, which helped me identify larger themes emerging across the data. Throughout the writing process, I referenced reports that I created using the HyperResearch

qualitative software program, in which I pulled passages to which I had assigned specific codes. I often returned to the original transcripts to put the passages in these reports into context.

Given the insights that can be gained from participants' narratives and the language they use to describe their own experiences, I present many direct quotes from participants throughout the following chapters. I have made some minor edits; for example, I removed extraneous words and phrases (e.g. "umm" and "you know"), removed minor repetitions in speech (e.g. "it, it was" to "it was"), and standardized colloquial speech (e.g. changed "I dunno" to "I don't know"). I never supplied words, rephrased, or altered the meaning of a quote, however. This approach was a compromise between a 'preservationist' approach, which preserves the literal transcriptions of original speech, and the 'standardized' approach, which encourages rephrasing that makes original speech easier to understand (R. S. Weiss, 1994, pp. 192–193). I chose to retain the original language as much as possible, and only make minor edits (as described above) when I believed the minor edits could make quotes more "accessible" to readers without altering participants' meanings and presentation of self (R. S. Weiss, 1994, p. 194). I have changed all of the participants' names to pseudonyms to preserve their anonymity.

Reflexivity

The researcher makes key decisions at every point along the way in a study, deciding who to interview, what to analyze, and what to include in the findings (Mantzoukas, 2004). My perspectives on children's mental health clearly affected this research project at every step of the way, starting with the selection of the research questions. Rather than understanding my own viewpoints about children's mental health as a "bias" as one might in the positivist tradition, consistent with my epistemology I view my perspectives as having "shaped" my research (Wells, 2011, p. 119). As noted in Chapter 1, I became interested in how children understand their

mental health diagnoses when volunteering at a transitional housing program, where I met a six-year-old boy who was diagnosed with bipolar disorder and ADHD. I wondered whether his symptoms were a normal response to his environment, rather than signs of disorder and questioned whether these diagnostic labels would negatively affect his self-identity. My experiences with this case positioned me in a very critical stance, as I questioned the potential consequences of diagnosis, especially in young children. On the other hand, my experiences have also encouraged me to consider the potential benefits of diagnoses. Even in this case, I wondered whether the concept that he had a medical disorder would be comforting for him as an explanation for his behavior, and whether this would help facilitate access to treatment. Through volunteer and internship experiences, I have also worked with children who have benefited greatly from mental health diagnoses and treatments. I therefore came to this research seeing both pros and cons of the medicalization of children's mental health. As Wells (2011, p. 119) notes, "the central question is not how to control for 'investigator bias' but rather how the investigator can use knowledge of him- or herself to enhance understanding of the phenomenon under study." It is my hope that having reflected on the variation and complexities I have seen in children's experiences with mental health diagnoses prepared me to better listen to participants' often differing experiences, and to be open to a range of interpretations and perspectives.

I tried to present myself to the participants as a *listener*, rather than an *expert*. Two participants, including one diagnosed with ADHD and one diagnosed with depression and bipolar disorder, asked if I myself had been diagnosed with these disorders. Both inquired when describing the symptoms they experienced, asking if I was personally familiar with them. Hoping that my inability to fully empathize with their experiences would not create barriers in our interaction, I explained that I had not been diagnosed, which is why I was so interested in

hearing *their* perspectives. When participants suggested that they assumed I was an expert in clinical psychiatry during interviews (e.g. saying ‘you must know all about that’ when discussing medications), I explained that I am far from an expert in this area. I suspect that these assumptions that I was an expert in the field may have distanced me more from participants than other factors, such as race, class, and gender, especially given that my sample was predominantly female, white, and middle/upper-middle class like I am. My goal was to position myself as a ‘non-expert,’ so as to create an atmosphere where participants felt comfortable sharing their stories. I tried to experiment with different postures, and I found that when I took fewer notes during interviews and sat back and made direct eye contact with participants while they spoke, their responses to my questions were longer. I suspect that when I took notes, I created the atmosphere of a clinical interview setting, and when I sat back and made eye contact with participants, I made them feel as if they were sharing a story with someone.

I attempted to gauge how participants perceived me by asking at the end of the interviews: “How did it feel talking to me about your experiences during this interview?” Four participants noted that they felt particularly comfortable with me and/or the style in which I asked questions. One explained, “To be straight with you, I feel like I’m just having a conversation with a – with *a person*... For me, it wasn’t a formal, ‘Answer this, that and that.’ It was just more like, ‘What’s going on?’” Another participant reported liking that I was “empathetic.” Yet another noted: “It was more relaxing than talking to my friends or my psychiatrist.” I suspect that she felt this way because I did not respond to and pass judgments on her experiences, but rather allowed her to tell *her story*.

When I asked how participants felt talking about their experiences, most reported generally positive experiences. They said that it was “cathartic,” “relieving,” “refreshing,”

“fun,” and “interesting” to reflect back on their experiences. Several suggested, however, that some questions were difficult to answer because they had never thought about their own experiences, or it had been a long time since they had done so. One participant said he was surprised that I asked how he *felt* about his experiences and not just *what* happened, and another noted that it felt “more personal” than he had expected. Another participant suggested that the interview might be difficult for those who had not come to terms with their childhood experiences. Only in one case did a participant report this type of experience. The participant noted that it was “hard” talking about some of her childhood experiences and at times she wanted to cry thinking back on her difficult past. She further noted, “But I’ve never actually talked about it, so it’s really helpful in that regard.” I always provided participants a list of resources in the community if they wished to seek counseling services after our interview.

Asking how participants felt sharing their experiences also provided insight into their motivations for participating. Several participants suggested that they were interested in the opportunity to reflect back on their experiences. Seven noted that they do not often (or ever) have the opportunity to talk about these experiences. Two said that reflecting on their experiences made them see how much “better” things are now than in the past. As one put it: “It’s always good to reflect on life... good to share it with others.” While the monetary compensation participants received may have motivated some to participate, they also suggested that they were motivated to participate because they thought their participation might benefit others. Eight participants noted that they were hopeful that sharing their experiences would ‘help others’ and that their participation was for a ‘good cause.’ Some pointed out the need for greater awareness of children’s experiences with these diagnoses, and noted the general importance of this study. I am grateful for their willingness to share their stories and feel

indebted to them to do all I can as a researcher to translate findings into implications that can benefit other children with mental health diagnoses. I too hope that this research will 'help others,' including the increasing number of children being diagnosed with mental health disorders today and in the future.

CHAPTER 4

Delivering Diagnoses: Parents as Translators and Withholders

In order to understand how children make sense of their mental health diagnoses, I begin by exploring how participants recall first learning of their diagnoses. In this chapter, I explore whether, and how, diagnoses were delivered to participants, and how they recall experiencing this event. I also discuss how participants suggest children should best learn about their mental health problems. Findings from this study highlight the lack of communication between mental health professionals and the children they diagnose. Often these professionals delivered diagnoses to parents, who were expected to pass the information on to their children. Parents, in turn, did so to varying degrees. In some cases, children were simply never told.

These findings can be understood in the context of a large body of research on the gaps in doctor-patient communication discussed in Chapter 2, including literature documenting the lack of information professionals provide to adult patients (Thompson, 2000), the poor dynamics in professional-parent relationships for parents of children with physical illness and developmental disabilities (Korsch & Negrete, 1972; Svarstad & Lipton, 1977), the burgeoning research on the lack of information professionals provide parents regarding children's mental health diagnoses and treatments (Chesson et al., 1997; Collins & Collins, 1990; Jivanjee et al., 2009), and the lack of communication with children regarding physical illness (Eiser & Eiser, 1987). Findings presented in this chapter suggest that children may be poorly informed of not just physical illness, but mental health diagnoses as well. I extend findings from previous research on doctor-

parent relationships, demonstrating that varied levels of parental knowledge about children's mental health affects how children in turn experience their diagnoses. Findings also shed light on how adults treat children as passive, innocent, and in need of protection from diagnostic information. Using the sociology of childhood perspective, I examine how children *actively* piece together information about their diagnoses.

To my knowledge, no national standards dictate what professionals should (or should not) tell young children about mental health diagnoses, and what guidance they should (or should not) provide parents on talking with their children about this. Further, research has yet to examine the effectiveness of techniques used in these types of discussions. The current study helps to address this gap by capturing the perspectives of those who were on the receiving end of this communication.

I begin the chapter by examining how diagnoses were first delivered to participants. The direct quotes presented here were generally in response to my interview question: 'Tell me about how you became aware that you had ADHD/depression/GAD/bipolar disorder.' I focus on how this information was shared with participants – by whom and in what environment and manner. Researchers have highlighted the importance of studying *how* medical news is delivered. As Maynard (2003, p. 12) explains:

There is, of course, much more to the experience of receiving the bad news of cancer, understanding what it means, accepting the condition, and undergoing treatment, than what happens during the few moments of initial news concerning the disease. However, that informing event is a graphic one in its own right and, as it starts the movement of someone into a new social world, the practices of language and social interaction are its medium.

For those who remember those few moments in which their diagnoses were delivered, I am particularly interested in this event in their story. Who told them? Where and in what manner did they tell them? How did they react to this news? How did it feel to receive this news, from

their perspective? This ‘informing event’ sheds much light on the process by which children make sense of their diagnoses.

Participants strongly emphasize their parents’ involvement in this process. I describe the role that parents play in translating diagnoses to children, and in some cases, withholding diagnoses from them. This included two types of withholding: (1) withholding the diagnostic term, but discussing children’s challenges and extra needs, and (2) withholding the diagnosis entirely. In line with the sociology of childhood perspective, I examine how children actively piece together information about their diagnoses when information is withheld from them. I then discuss parental knowledge about children’s mental health, as reported by participants, as well as its effects on children. Parents with high levels of understanding may be better able to help children process information about their diagnoses, support them, and act as advocates in accessing treatment. This has implications for social work, suggesting the need to educate and support parents in this role.

I conclude by discussing how participants suggest diagnoses should best be delivered to children, examining their responses to the interview question: ‘If there was a child who was being diagnosed today, what are your thoughts about the best ways for that child to learn about their diagnosis?’ Participants’ recommendations from this study can inform the development of guidelines for practitioners and strategies for parents, given that they come from those with first-hand experience with this process.

Being Told: Parents as Translators

Participants’ accounts of how they learned of their diagnoses demonstrate that mental health professionals often tell parents, rather than children themselves, and parents then pass this information on to their children in the way they deem appropriate. I use the term ‘translators’ to

describe the role that parents then play; as liaisons between mental health professionals and their children, parents often translate diagnoses to children. In Chapter 5, I discuss the narratives that parents use in this translation process. While some use the medicalized frame embraced by the mental health professional when passing information on to their children, others translate this information into non-medical narratives. Here, I focus on the delivery of diagnoses as *an event*: Who told children of their diagnoses? What was the environment and atmosphere in which they were told? How did they react? How did it feel when they received this news? I then discuss the experiences of those who were unable to fully understand this information when first presented to them.

The Delivery of Diagnoses

Based on their recollections, nearly as many participants were informed of their mental health diagnoses by their parents than directly by mental health professionals who diagnosed them. While 18 recall a mental health professional⁸ delivering the diagnosis, 17 recall their parents sharing this information with them. Two participants, who were diagnosed with more than one diagnosis, recall a mental health professional informing them of one of their diagnoses and their parents informing them of another; two report that they were *never* informed of their diagnoses in childhood; and three note that they cannot recall who first delivered this news to them.

Participants who were told about their diagnoses by mental health professionals (n=18) describe the impersonal tone of this communication. Melissa, who was diagnosed with depression her sophomore year of high school, criticized her doctor's "bedside manner," noting that it felt like "he was just so much more cut and dry as if he just opened up his manual and was

⁸ This includes counselors, social workers, psychologists, and psychiatrists. It also includes one pediatrician who made the diagnosis.

like, ‘Okay, this is depression. You have symptoms A, B, C, and D, just to let you know.’” She notes that he could have been “more human about it.” Meanwhile, Natasha provides an illustrative example of a participant who physically remained in the room, but was treated as a mere bystander. She recounts being diagnosed with ADHD her freshman year of high school:

They sat me down in this weird round table and – not even round – some weird shape. And they talked to my parents and not at me really, which I thought was kind of odd since it was about me. But I guess it’s because I wasn’t 18 or something. And they just explained that, ‘So your daughter has – we tested her and we think that she might have ADHD based on this test, this test, this test.’ And then they showed the results... I remember just sitting there and I was just like, ‘What is going on?’ Because no one was really explaining it *to me*.

She goes on to describe feeling like a “test subject” throughout this process. Her experience illustrates an extreme example of mental health professionals treating children as objects of the discussion, rather than active participants in it.

Only one participant, Andy, reports being asked whether he wanted his parents in the room when the mental health professional delivered the news of his ADHD diagnosis to him (his junior year of high school). He recalls that the psychologist asked if he would be comfortable inviting his parents into the room, and Andy explains: “I was like, ‘Can we just do it us two?’ Because that was strange for me.” While no pattern was detected in the data, one might suspect that practitioners are more likely to talk privately with older children. The fact that Andy was a junior in high school at the time, which was significantly older than many other participants when diagnosed, might help to explain why his experience differed.

Meanwhile, in cases where parents told participants of their diagnoses (n=17) and cases where children were never told (n=2), professionals delivered diagnoses to parents without including their children. Two participants even describe being asked to physically leave the room when their parents were told. Interestingly, Daniela, who was diagnosed with ADHD in

first grade, notes that it was her father's decision to have her leave the room when the diagnosis was delivered:

Actually for some reason my dad didn't want me in the room when the doctor was going to tell my mom and him the news. I guess he just didn't want me to find out or he didn't want the doctor to see my face or something. And so I just remember waiting for them, sitting outside of that room and just waiting for them to come out so that we could go home. [In] the car ride home, there was just silence and I guess whatever my mom and dad needed to say to each other, they talked about it after I had gone to sleep... I don't know if it was a protection thing or just not wanting the doctor to reveal that news to me.

Daniela describes the event as if she was being shielded from the information. Interestingly, she suggests that her father, rather than the doctor who diagnosed her, made the decision to 'protect' her from this information. As described below, participants often emphasized that their parents were responsible for sharing information with them, and thus were seen as the withholders of information. Daniela notes that after the doctor delivered the news to her parents, they were then expected to be translators of this information. Similarly, Whitney, who was diagnosed with ADHD in seventh grade, notes: "My mom was more of the explainer or the one between me and the doctor." As Whitney describes, parents become the liaison between the mental health professional and their child.

Parents who passed this information on to their children (n=17) did so outside of the mental health professionals' offices. Two participants note that their parents 'sat them down' to tell them the news of their ADHD diagnoses. Christine describes her parents telling her about her diagnosis at her grandmother's summer home when she was diagnosed the summer before fifth grade. She recalls: "We were sitting in her living room and they were like, 'Christine, we have to tell you something.'" She notes that she liked how they told her in a place where she felt "comfortable," and during the summer, when she had time to process the information and ask questions before going back to school in the fall. These provide examples of parents presenting

diagnoses as one might present any other important news: while sitting down, in a quiet, comfortable setting, allowing time for children to discuss and process this information.

By contrast, Sarah provides an example of a child being told the news outside of the mental health professional's office in a much more haphazard way. After being diagnosed with ADHD in third grade, she recalls:

[The psychologist] sent me out of the room and he talked to my parents. And I never questioned why they took me there or why, like what happened after that. [...] [Until a month later] I think I had gone to the grocery store with [my mom]... somehow I brought up the conversation. I was asking her about that time we went to the doctor and she finally just blurted it out 'Sarah, you have AD[H]D.'

She describes her mother presenting this in an abrupt manner, as if in a desperate attempt to stop Sarah from digging for information. Sarah describes feeling a lack of space to ask questions and thoroughly discuss what she had learned. Her experience varied greatly from participants whose parents sat them down to officially deliver the news.

Participants' experiences of being told therefore varied greatly; they describe being told by different people, and also in differing physical settings. The setting affected the type of conversation that followed the actual delivery of this diagnosis. Not surprisingly, findings suggest that participants were more comfortable when they learned the news in settings that felt more personal and familiar to them, for example, their grandmother's cozy living room, rather than their psychologist's office – or the grocery store.

Immediate Reactions to Diagnoses

A lack of clarity in the explanations, especially those provided by mental health professionals, caused a sense of confusion among some participants. A few participants (n=4) describe being confused when they first learned of their diagnoses. Mental health professionals delivered the news to three of these four participants, and all four describe the lack of clarity in

the explanations they received. They also describe the sense of anxiety that came with this confusion. Natasha, for example, recalls experiencing the following emotions when told she had ADHD her freshman year of high school: “I wanted to know what was going on. I was just very confused and when you’re confused, you tend to get kind of nervous.” It took time for these participants to fully process and understand this information.

About a quarter of the participants (n=11) note that they were not surprised when told of their diagnoses. In particular, those diagnosed with depression and GAD explain that they were not surprised because their symptoms were so severe that they had already noticed they were different than their peers. As Ted, who was diagnosed with depression his junior year of high school, describes: “I always knew something was different kind of thing.” Similarly, Michelle notes that she “wasn’t too surprised” when she was diagnosed with depression in seventh grade because she knew she was always less content than her peers. Faith explains that when she was diagnosed with ADHD, depression, and GAD early in high school: “I hoped to get a diagnosis out of it because I knew I had a problem.” Similarly, Angela explains that she already knew she had anxiety and depression when she was diagnosed her freshman year of high school; the diagnosis was “just something that was just written down in front of me.” Meanwhile, those who were not surprised by their ADHD diagnoses note that they were already familiar with the diagnosis, perhaps because of its higher prevalence.

Several others (n=6) describe being surprised, or even “shocked,” when told of their diagnoses. Perhaps because they had less severe symptoms, they were surprised to receive the label of “disorder.” Andy explains that he simply “never suspected” he had ADHD before being diagnosed his junior year of high school. Similarly, Courtney describes being surprised by her ADHD diagnosis, noting that she did not think she was “doing anything abnormal” and thought

that she “behaved just like everyone else” when she was diagnosed in second grade. So while some had observed and identified ways in which they were different from their peers, others were unaware of these differences and were less prepared for this news. Five of these six participants recall being told of their diagnoses by a mental health professional, which may have contributed to the ‘shock’ they experienced. It may be helpful for adults who deliver diagnoses to assess whether children are aware of their struggles and how surprised they will be by the news, as ‘shocking’ news is perhaps best delivered even more delicately.

Several participants (n=9) describe being upset when told of their diagnoses. They were told by both parents and mental health professionals, in different types of settings, and with different diagnoses. They suggest that the finality of this news was difficult to hear. Monique, who was diagnosed with depression and bipolar around her sophomore/junior year of high school, describes: “It kind of hurt me when I found out like, ‘Wow, depression.’” They also describe immediately thinking that the diagnosis implied something “bad” about them. Sam recalls crying when his mother informed him that he had ADHD in third grade, noting that he was afraid it meant he was “stupid” or “couldn’t succeed.” He notes: “I took it pretty hard.” Abby says she “immediately recoiled” when she was diagnosed with bipolar disorder her junior year of high school. She describes perceiving it as an insult that she was not “perfect.” Despite being pleased that her parents sat her down to deliver the news in a place where she felt comfortable and was able to ask questions, Christine also recalls feeling “really bad” and thinking that something was “wrong” her with when she learned of her ADHD diagnosis the summer before fifth grade. This suggests that children may find the news upsetting, even when delivered in a way that they find comforting. As noted above, mental health professionals and

parents should attempt to gauge how children will react before (and while) delivering this news; given the variance among individual children, this needs to take place on a case-by-case basis.

Lack of Understanding When Told

A handful of participants (n=5) recall not listening, or suspecting that they may not have been listening, when told. Mark, who was diagnosed with ADHD in elementary school, recalls: “They explained it to me, but again, I wasn’t listening. I was like, ‘ADD – we’re going to do some math today, great! Let’s do that!’” He recalls hearing what they said, but not understanding what it meant. Autumn, who was diagnosed with ADHD in second grade, notes: “Someone probably tried many times to sit down and explain it to me, but I don’t think I wanted to hear it.” Similarly, Monique notes that a doctor at her group home tried to talk to her about depression and bipolar disorder when she was diagnosed in high school, but she refused to listen: “She explained to me, but it went in one ear and out the other because I didn’t want to know, I didn’t want to hear it.” Krista, who was diagnosed with ADHD before kindergarten, questions: “Maybe they *did* tell me... But I don’t remember it, so clearly, so *clearly* it never registered.” Some may have had difficulties focusing and listening to this information. Others may have listened, but not been able to comprehend it. Still others may not have listened because they did not *want* to comprehend it. As this research suggests, adults struggled to present the diagnoses so that children were able to listen and comprehend.

Participants’ lack of understanding was exacerbated by the inability to ask and receive answers to questions when diagnoses were delivered. Some note that they did not have anyone to answer their questions. Teresa, who was diagnosed with depression in eighth grade and ADHD her sophomore year of high school, recalls: “I had so many questions and no one was there to answer them for me.” Similarly, Monique explains: “I never had nobody to be like...

‘We can talk about it.’” Others describe simply not being invited to ask questions by those delivering their diagnoses. Sarah recalls:

[My mother] was kind of angry because I had been asking her questions and she was like, ‘Sarah, you have AD[H]D’ and then that was the end of it. And she didn’t ask me, ‘Do you have questions about it?’ I feel like there needs to be more of a conversation there.

She emphasizes the importance of providing the space for children to ask questions and discuss this news. Meanwhile, Natasha describes the mental health professionals who diagnosed her with ADHD her freshman year of high school asking her parents if they had questions, but not extending the invitation to her. Others note that they asked questions that were simply ignored. Melissa recalls: “Nobody wanted to give me clear answers.” Krista notes: “I asked a lot of questions. A lot of them were just kind of dismissed... My parents were good parents. I think it’s just, it’s *hard* to know how to deal with that sort of thing.” While some felt that they did not have anyone to turn to with questions, others felt discouraged from asking questions because they were not invited to do so; other participants’ questions were simply ignored. In each case, adults devalued children’s questions and their need to discuss their diagnoses when delivered.

Participants’ confusion may have also been exacerbated when adults disagreed about whether they should be diagnosed. Michelle, for example, recalls her mother rejecting her diagnosis when she was diagnosed with depression in seventh grade: “‘These are the results... This is just really upsetting. This can’t be true.’” Michelle describes the confusion this caused. Meanwhile, Natasha describes the confusion caused by the differing results she received when she was re-tested for ADHD throughout high school. She explains that she was first tested and received the diagnosis from a professional in a private office her freshman year of high school. She notes that the school “didn’t believe the diagnosis” and required a diagnosis by the school counselor in order to receive in-school services. Noting that her test results were swayed by

“politics” among adults, Natasha explains that her school counselor wanted to prove she did not have ADHD because she did not like an outside mental health professional challenging her authority. When Natasha was re-tested about a year later, the school counselor concluded that Natasha did *not* have ADHD. She recounts: “The politics are very confusing... it wasn’t even hidden. It was obvious that she wanted to have her diagnosis be the correct one and for it not to be questioned.” Later in high school, when her peers were being tested for college accommodations, Natasha asked her parents if she could be tested yet again. She recalls: “I just wanted to know if I had this or not.” She notes: “I just went back to this place and I was like, ‘Test me. Tell me the truth.’” When tested a third time, they reversed the decision yet again, concluding that she did have ADHD. She explains:

Getting diagnosed in the first place is kind of, I guess not traumatic, but it’s an experience. And it’s pretty jarring. But then... to be told, ‘Oh, wait, we don’t think you do have it,’ it just makes things even more confusing. And I’d say I would not put anyone through that.

Natasha’s case underscores the confusion caused when children are presented with conflicting information about their diagnoses. She explains: “That was very confusing being told, ‘Oh, you have it.’ ‘No, you don’t.’ It’s like being told, ‘Oh you have cancer. Wait a minute. We did radiation for no reason.’ That’s probably an extreme example, but.” While second opinions can lead to differing results, which cannot necessarily be avoided, Natasha’s case highlights the importance of preventing adult “politics” from swaying decisions regarding children’s mental health diagnoses, demonstrating how difficult this can be for children who are caught in the middle. This also raises the question of whether and how much information should be shared with children when second opinions are sought; it is perhaps best to make this decision on a case-by-case basis.

While participants' experiences of being told about their diagnoses differed, a pervading theme was a sense of confusion and lack of understanding. This was the case both for children who were informed by mental health professionals, and those whose parents translated this information to them. These findings build from research on delivering news of physical illness to children, demonstrating that both theories Eiser and Eiser (1987) identify in the literature on delivering physical illness to children – that children receive the information but do not comprehend or remember it, and that doctors discuss the illness with the parent and not the child – apply to mental health diagnoses as well. The confusion that participants experienced underscores the lack of clarity in the information that is presented to children, making it difficult for children to understand and retain this information, even when told.

Piecing Together the Puzzle: Parents as Withholders

Nearly one fifth of the participants (n=8) report that they were not told of their diagnoses by professionals or parents, at least immediately following diagnosis. These participants suggest that professionals likely expected their parents to pass this information on to them, but that their parents may have been incapable or felt uncomfortable doing so, or they may have chosen not to share diagnoses in an attempt to “protect” their children. I use the term ‘withholders’ to describe parents withholding not just pieces of information, but also entire diagnoses from children. Drawing from the words of a participant who described the process of learning about her mental health diagnoses as “putting the puzzle together,” when diagnoses are withheld from children, they are often left to piece the information together on their own.

Participants describe two ways in which parents and professionals withheld their diagnoses, at least when first diagnosed. Half of those who report their diagnoses being withheld (n=4 of 8) note that their parents told them that they needed extra help in school and had

struggles, but did not fully inform them of their diagnoses, including the diagnostic labels they had received. Autumn, for example, says that she heard the term ADHD for the first time in middle school, despite being diagnosed in the second grade. She describes, “In lower school I didn’t really know what was going on.” Her mother explained that she needed to go through testing and receive extra support to improve her grades, but did not explain that it was because she had ADHD: “I think when I was younger, they didn’t really want to tell me what it was.” Similarly, Gary recalls attending a center where he received extra help on homework. He was not aware that he had ADHD until eighth grade, even though he was diagnosed in sixth: “So I knew that I had a learning issue. I just didn’t know that it was a mental disorder.” Both James and Max, diagnosed with ADHD in second and third grade respectively, also describe their parents saying they had problems paying attention, without telling them about the specific diagnosis. James notes: “I don’t think I knew that it was specifically ADHD or anything.” Interestingly, James was grateful that his parents did not introduce him to this terminology at such a young age. James reports that he liked having the “chance to develop without being affected by society and their perception of ADHD.” He suggests that this is a beneficial approach:

I mean don’t actively hide it from them. Just be indifferent about it. Society has this horrible habit of pegging people with stereotypes and those stereotypes can be incredibly harmful sometimes. If someone grows up and then becomes not immune per se but capable of dealing with social pressures, then they can be all like, ‘Okay, I have ADHD. This is how I deal with it. I’m going to move on in my life.’ Rather than, ‘You’re special. You get accommodations.’ I don’t know. I just think that the kid should have a chance to develop before having to handle such a social burden.

His experience suggests that some children might prefer that adults not share the label of diagnosis.

In the other four cases, mental health professionals and parents completely withheld diagnoses from children, at least for a period of time after diagnosis. This ranged from a month to years after diagnosis. They describe uncovering their diagnoses, piecing the puzzle together on their own in bits and pieces. Krista explains: “It was kind of like a realization over time.” Shannon describes learning of her mental health diagnoses as “putting the puzzle together,” first discovering her ADHD diagnosis in sixth grade, then depression in seventh grade, and finally learning of her GAD diagnosis in eighth grade. Shannon describes figuring out that she had GAD using the internet in eighth grade: “I knew I was really anxious and I’m like, ‘This is not normal.’ And I Googled stuff... I would go through them and I’m like, ‘Okay, not like that, not like that, not like that. Oh, I’m like that.’” She describes her psychiatrist confirming the diagnosis of GAD when she confronted him about it in eighth grade: “I asked... and they were like, ‘Yeah.’ And then I was like, ‘*Aren’t you supposed to be telling me this?*’ ... I kind of had to fight for my own thing.” Shannon’s case illustrates the role children sometimes play, acting as detectives trying to uncover their hidden diagnoses. This sometimes involves uncovering them in bits and pieces over time. Shannon’s case also demonstrates the active role that children can play in this process.

When they later discovered their diagnoses, several participants (n=5) describe wondering why their parents did not inform them earlier. Daniela and Shannon questioned whether their parents might have been trying to protect them from this information. Daniela notes: “[I did] wonder why my parents didn’t play a more active role in addressing the situation and informing me about it.” She speculates that her parents may have been trying to ‘protect’ her from the ADHD diagnosis she received in first grade by not discussing it with her. Similarly, Shannon describes her mother as “really over-protective.” They speculate that their parents may

have had good intentions, hoping to shield them from potentially distressing information.

Meanwhile, Krista questions whether her parents withheld her ADHD diagnosis because they did not feel comfortable informing her, because they did not think she would understand, or because they thought it might upset her:

I don't know if they just didn't ever feel comfortable enough to sit down and tell me. I think they honestly just felt really bad about it. Because we still don't really talk about it. [...] I don't know if they just figured I wouldn't understand it or that maybe telling me wouldn't help any because then I'd just be like, feel as if I can't do anything. I mean telling a little kid that there's something wrong with her head is probably a difficult thing to tell them.

She emphasizes that this is not an easy discussion to have with one's child.

Similarly, Abby suggests that not all parents are capable of passing information about diagnoses on to their children. When asked whether the mental health professional provided Abby with a full explanation of bipolar disorder when she was diagnosed her junior year of high school, Abby noted: "I think that she probably felt more comfortable talking to my mom about it because she probably thought my mom was a competent mother, which she shouldn't have assumed." She suggests that her psychiatrist *expected* her mother to provide Abby with information about her diagnosis, and that a "competent mother" would have done so, but she and her parents "never" discussed it. She raises an important point that holding parents responsible for not only delivering, but also further explaining diagnoses, assumes that they are capable of taking on the difficult role.

Daniela and Gary suspect that their parents may have withheld their ADHD diagnoses from them because mental health problems were seen as 'taboo' subjects in their cultures. Daniela and Gary describe their parents, who were of Middle Eastern backgrounds, disapproving of their ADHD diagnoses because of their cultural backgrounds, which may have contributed to the lack of information their parents provided to them. Daniela explains: "Culturally it's just

taboo to I guess, to have it.” She notes: “I think it’s a cultural thing... it was hard for my parents to accept the fact that there was really a problem... Culturally it’s shameful I guess to have a child with a problem.” She suspects that this contributed to her parents not wanting to discuss her diagnosis with her. Similarly, Gary describes: “My parents are really old fashioned. They’re both from overseas, so they don’t believe in mental disorders whatsoever. [...] Culturally it – mental disorders just aren’t heard of.” He notes: “They’re old fashioned and they’re a different culture. They still love me unconditionally but they just didn’t believe any of that crap.” He notes that his father probably spent “hours on end” reading about ADHD after Gary was diagnosed in the sixth grade, but he still rejected the diagnosis: “He’s a well-informed person and... he probably knows a lot about it. He just doesn’t believe any of it.” He says that in their culture, it is seen as a “weakness.” He recalls his parents calling his condition “malarkey” when he was younger. He says he was “completely oblivious” to his ADHD diagnosis for two years after being diagnosed. This stigma may influence parents’ decisions to withhold information from their children.

Several participants (n=5), including Daniela and Gary, describe confusion and frustration directed towards their parents for withholding their diagnoses from them. Daniela, for example, describes feeling like she received the “short end of the stick” because her parents did not inform her that she was diagnosed with ADHD or share information about ADHD with her:

How easy it would have been if my parents had printed it out and put it on the fridge... And so just feeling like I had received a very short end of the stick because this information is out there. They could have just printed it out. But then I’m like, ‘Well my parents don’t know how to use the computer so maybe not, but somebody could have printed it out for them and given it them.’

Gary describes being baffled by his parents' withholding of his ADHD diagnosis. He recounts reading a letter regarding his education plan his senior year of high school and realizing he had been diagnosed with ADHD back in sixth grade, but not told until eighth: "I was like, 'What?' Yeah, it didn't really piss me off. It was just like, 'Really? That's how it really – you guys kind of knew?'" Shannon describes the frustration she felt towards her mother for withholding her diagnoses from her:

That's one of the things that kind of irritates me... there are all these files about me and my disorders and I'm like, 'Why wasn't I told about this earlier, Mom?' And she's like, 'Well, I didn't want you to read it. Blah-blah. I didn't want you to get upset.' And I'm like, 'Well, I'm kind of *more* upset you didn't tell me!'

Throughout these accounts is the theme of betrayal – participants feeling that their parents betrayed them by keeping something so important from them.

In particular, children may be frustrated when diagnoses are withheld because it limits their ability to manage their symptoms. A few participants (n=3) expressed frustration, noting that they could have better controlled their symptoms in childhood had they been informed of their diagnoses earlier. Shannon, for example, describes confronting her psychiatrist after self-diagnosing herself with an anxiety disorder in eighth grade, describing her frustration that she could have been able to "control" it better if she had known earlier that her worrying was not "normal":

I'm like, 'Why wasn't I told about this earlier?' Like again, I'm just going through the motions. And I'm like, if I didn't go on the internet, I would have never known or I would have known like years from now. And because to me, it was normal to worry and now that I actually see it's not, it's a lot easier for me to stop myself... I needed to control my anxiety.

Similarly, Krista suggests that she would have been able to better manage her ADHD had she been informed of her diagnosis:

It was kind of frustrating that I didn't know or really understand beforehand.... It was just kind of annoying cause it's like it would have been cool if I had known this a while back so I could tackle it a little bit better.

They suggest that withholding diagnoses limited their ability to address and manage their symptoms.

Findings also suggest that having diagnoses withheld can exacerbate the stigma that children face. Daniela, who was not told of the ADHD diagnosis she received in first grade, describes:

[I remember] feeling like there was something wrong with me because my parents never talked to me about it. I just remember the silence in the car ride home after that doctor's appointment. And I feel like after that diagnosis, I felt like a different person just because there's something about me that I don't know so my parents are acting differently... I feel like my whole life changed in that moment.

She notes: “[It was] stigmatizing because it was never discussed.” She was able to detect that something was wrong, and felt as if she had something to hide, even though she was not able to identify its exact source. Meanwhile, Sarah's mother told her that she had ADHD but withheld a full explanation, and it was never openly discussed. Sarah describes how this exacerbated the stigma that she experienced: “...for a few years after that I just felt like I was different” and “...it was all just because I wasn't educated on it. And I kind of had to figure it out on my own.” She notes:

Because my mom *never* explained it to me, so I guess I'm kind of upset that she didn't because it did kind of contribute to how I acted in school towards other people. I always felt like I was hiding something.

While parents may have been trying to protect children from distressing information, findings indicate that withholding this information is in itself distressing, causing children to feel like they have something to hide.

Withholding diagnoses may also exacerbate the lack of control that children experience. As Shannon describes, “I went along for the ride.” Similarly, Sarah explains: “They never explained it to me. They just kind of dragged me along.” These metaphors paint a vivid picture of the complete lack of control these children experienced throughout the process.

In sum, parents withheld information in two ways: (1) they withheld the diagnostic term, but discussed the child’s struggles, or (2) they withheld the diagnosis altogether. Findings suggest that the latter can negatively affect children’s experiences, inhibiting their ability to manage their struggles and exacerbating the stigma and lack of control they experience. Findings that children detect they have something to hide when not discussed are congruent with Eiser and Eiser’s (1987) assertion that children might be more distressed by misunderstandings than by information about their physical illnesses. These findings are important because they suggest that trying to protect children from this potentially distressing information can in itself cause distress.

Findings suggest, however, that there might be some benefits to the former type of withholding – withholding the diagnostic terminology. As noted above, James’ parents discussed his struggles with learning openly with him, but did not identify the problem using the diagnostic term, ADHD. As I will discuss in Chapter 5, James’ experience suggests that there might be a way to share information openly with children, without using (or at least not focusing on) the diagnostic terminology of “disorder.”

Parental Knowledge Affecting Children’s Experiences

I now turn to a discussion of the varying levels of parental knowledge about children’s mental health, as reported by participants. This is based on participants’ *perceptions* of their parents’ knowledge levels, rather than objective measurements or parents’ own reports of their

knowledge. Participants perceive varying levels of understanding. Several (n=9) describe parents seeking information on their diagnoses; while some note that their parents already ‘got it,’ others describe this information helping their parents to obtain a high level of knowledge or understanding about their diagnoses. Meanwhile, many participants (n=19) note that at least one of their parents knew little about or had little understanding of their mental health problems. Interestingly, several participants (n=7) report that their fathers were not fully aware of their symptoms, and in a few cases (n=3), not even aware of at least one of their diagnoses. Findings suggest that parental knowledge, as perceived by participants, affected children’s experiences, as described below.

Parental Knowledge: They Had It, or They Sought It

As noted above, several participants (n=9) describe at least one of their parents having a high level of knowledge or understanding, either before or after seeking (additional) information on their diagnoses. Amanda notes that her mom “just kind of got this stuff” because she is a psychologist, but learned more about her diagnosis by reading books on ADHD after Amanda was diagnosed. Paige reports that her parents were familiar with ADHD when she was diagnosed because her brother had been diagnosed previously; she also recalls that her mother attended conferences, support groups, and informational sessions on ADHD after she was diagnosed. Also describing her mother obtaining information about ADHD, Whitney says of her mother: “If anything’s ever wrong with me or my brother, she stays up all night researching.” These examples illustrate parents being or becoming equipped with knowledge about children’s mental health diagnoses via multiple pathways: acquired skills (e.g. based on their training as mental health professionals), prior experience (e.g. having had a child diagnosed previously), and active efforts (e.g. conducting research).

Lack of Parental Knowledge: ‘They Didn’t Get It’

Meanwhile, many (n=19) note that at least one of their parents had little knowledge or understanding about their mental health problems. Daniela notes that her parents had never even heard of ADHD before her diagnosis in first grade. She suspects that her parents wished that they had known more about it at the time. Others note that their parents were “new” to ADHD; they had heard of it, but had no first-hand experience with it. Andy, who was diagnosed with ADHD his junior year of high school, says of his parents: “I don’t think they knew what to expect. They were very new to this stuff too [like I was].” Andy and Ashley, who was diagnosed with ADHD in second grade, report that they learned about their ADHD at the same time as their parents.

These participants generally cited that their parents ‘just didn’t get it.’ They suggest that their parents may have had difficulty understanding because it was challenging to relate to their children. Noting different experiences with her two parents, Christine explains: “I think that my dad was really there for me because he really saw himself in me... I don’t think my mom really got it.” Others note that their parents did not know how to handle this difficult situation due to lack of experience. Describing her parents yelling at her for her misbehavior in childhood, without acknowledging ADHD as its source, Krista says of her parents:

Not like they’re bad people or anything, but I don’t think they really knew how to deal with it as well then. [...] No one else in my family has any of that sort of thing going on, so I mean, I just don’t think they really knew how to approach it.

Parents therefore struggled both due to the inability to relate, and also due to lack of experience.

Several participants (n=7) describe at least one of their parents having some knowledge about the mental health problem in general, but not fully understanding how it affected them personally. They describe how difficult it is for parents to truly empathize with their children

and understand what they are going through. When asked whether her parents understood her diagnoses of depression, GAD, and ADHD, Chloe responded:

I think they tried to understand and I think they did a little bit because they lived with me. They saw what I was like. They saw that I was crying all the time and upset all the time and they saw the kind of emotional outbursts I would have. But I also think that they attributed a lot of my emotions to just being 16 and, ‘Oh, you’re just — it’s just your hormones,’ and things like that. But I knew very well that it was a lot more than that... I think they tried to understand, or understand it in a way that made sense for them. But I don’t think they fully understand it in terms of *me* specifically... I don’t think there was any way for them to understand completely.

Interestingly, she notes that they understood it “in a way that made sense for them,” and this did not include an appreciation for how she experienced it personally. Similarly, Cindy explains that it is difficult for parents to understand how children experience their symptoms. She notes that her mother understands GAD better now than when she was first diagnosed, but notes: “I don’t think she still understands the cycle of thoughts that go through, for somebody with an anxiety disorder.” As Abby explains, the behavioral manifestations of bipolar disorder can be ‘scary’ for parents, who may not be able to fully understand what their child is experiencing unless they have experienced it themselves:

There’s just a lot of behavioral manifestations of it... I would run miles and miles and miles and not be tired at the end of it just because I had this ridiculous energy. Or I would just be depressed as hell. One of the two. And I think it definitely scared my parents, too, because I don’t think that they got it... I really can’t blame them that much because it’s like they just weren’t capable of handling it, which is why they sent me to a therapist. But I’m sure my dad did an absurd amount of research on it... [But] you can’t *really* understand something unless you’ve experienced it.

It may be particularly ‘scary’ for parents whose children are diagnosed with bipolar disorder, as opposed to parents of children with ADHD for example, given that as discussed in Chapter 2, this diagnosis is much less common than ADHD.

Interestingly, three participants note that even though their mothers were also diagnosed with depression, their parents still had trouble understanding *their* experiences with it. Their mothers, in particular, *thought* they could empathize with their children, but did not understand how *they* experienced depression. Chloe explains that because her mother's depression was managed well by taking medication and seeing a therapist, her parents assumed, ““Oh, you're on medication. You're going to the doctor. Everything's okay,”” when she was actually still struggling in high school. She describes her mother's reaction:

She'd say, 'I see a doctor, too, for depression. So I know what it's like,' or things like that. But then the things she would do would contradict that completely. It's like, 'If you know what it's like, then why are you acting like this right now?' So I mean it seemed like she would make it out so that she understood when she really didn't. And I think part of that, too, was being a parent, you want to think that you know what's going on with your child and you have it under control, that they're under your control. And so I think a lot of that was like she wanted to feel she understood what was going on. [...] I think my mom *thought* she knew it all, like, 'Oh, I know what it's like. I deal with it, whatever.' But no, not exactly. You're 40 and I'm 16. There's a big difference.

This quote illustrates the frustration that Chloe experienced when her mother thought she could understand Chloe's experiences, when really she could not relate. Similarly, Ted notes that his mother was also diagnosed and taking medication for depression, but she did not understand how he experienced it. He recalls his mother trying to look up information on how depression affects other people, so that she could try and better understand how he was feeling. Not only do individuals experience mental health problems differently, but participants suggest that children may experience mental health problems differently than adults, and thus parents with the same diagnosis as their children should not assume they understand what their children are going through. Being sensitive and open-minded might be more helpful than having personal experience with the diagnosis, to best understand children's experiences.

Lack of Parental Knowledge: ‘My Dad Didn’t Know’

As noted above, several participants (n=7) suggest that their fathers were not fully aware of their symptoms. In line with the theory that fathers may be less involved in children’s clinical interventions than mothers in part due to their lower levels of involvement with their children in general (Phares et al., 2006, 2010), some note that their fathers may not have been fully aware of their symptoms and treatment because they were not as involved in their lives as their mothers. While some note that their fathers worked long hours, and spent significantly less time with them than their mothers, others lived apart from their fathers. Leslie, who was diagnosed with ADHD her freshman year of high school, notes that her father knew she was diagnosed with ADHD but “didn’t know 100% what was going on.” In contrast, she notes that her mother, whom she describes as the “homemaker,” was very aware of her struggles and heavily involved in her treatment. Suggesting that her father was less involved than her mother because he had other issues to tend to, she notes: “He had a lot on his mind.” Meanwhile, Cindy describes her father’s surprise when he finally met her therapist her junior year of high school and Cindy described her symptoms. Unlike her mother, who had been involved in her treatment from the time she was diagnosed with GAD in eighth grade, Cindy’s father did not meet with a therapist until this time. She questions if it may have helped if her father had better understood her symptoms earlier: “It might have been better if my dad had known what it was and what I was dealing with.” Meanwhile, Crystal, who was diagnosed with ADHD in second grade, notes: “My dad still doesn’t fully understand it sometimes.” She describes her father’s frustration when she struggles with schoolwork and displays tics. Crystal suspects that he does not fully understand her diagnosis because her parents are divorced and she spends less time with her father than her mother. In particular, she explains that he does not fully see how it affects her academically.

This suggests that in these cases, mothers were more aware of and able to understand their symptoms because they were more involved in their lives.

A few participants (n=3) note that their fathers may not have even known about at least one of their diagnoses. Stephanie describes her father's involvement in discussions about her ADHD diagnosis, but suspects he may not have even known of her later diagnoses of depression and GAD:

That was actually ignored. So that was kind of weird. I'm not sure why... maybe my mom was trying to protect my privacy. But we didn't talk about it in the house at all. I don't even think my dad knows.

Both Teresa and Erica, neither of whom lived with their fathers, also note that their fathers were likely unaware of their diagnoses. Teresa describes her father as "clueless" in terms of her diagnoses. While non-resident fathers may be less involved with their children (Castillo, Welch, & Sarver, 2011), Teresa and Erica provide examples of non-resident fathers' complete lack of involvement in children's mental health care as they were not even aware of their diagnoses.

The Effects of Parental Knowledge on Children's Experiences

Findings suggest that parents' knowledge and understanding about their children's mental health problems affects how children experience them. Participants suggest that parents' level of understanding affected them in three ways: (1) by affecting decisions to seek testing and diagnosis at the start, (2) by affecting parents' ability to help children process information about their diagnoses once received, and (3) by affecting parents' ability to provide the support and care that they need.

Parents' Decisions to Seek Testing and Diagnosis:

In many cases, participants describe their parents' high level of understanding of children's mental health helping them to identify symptoms and seek diagnosis. As discussed in

Chapter 3, five participants had a parent who was a mental health professional; they note that their parents were therefore well equipped to identify their symptoms. Others explain that their parents were able to easily identify their symptoms because they had older siblings who had already been diagnosed. Kimberly, who was diagnosed with ADHD in third grade, for example, explains that being psychiatrists and having a son with ADHD made it “easy for them to spot.” Paige, who was diagnosed with ADHD in first grade notes that she was tested for ADHD at a younger age than her brother, who was also diagnosed, because her parents “knew what to look for” with their second child. Parents’ knowledge therefore helped them detect the symptoms and motivated them to seek the diagnosis.

Meanwhile, some parents acted as barriers to their children seeking testing and diagnosis; this may have been fueled by beliefs that their child was faking symptoms or was too young to have a mental health problem. A few participants (n=4) initially asked their parents to seek help and were met with resistance. Stephanie, for example, recounts researching her anxiety symptoms online and having to “convince” her mother to let her see a therapist in high school. She explains: “I had tried to tell her for a *long* time that I needed to go and she wasn’t really listening to me.” She recalls that when her anxiety symptoms escalated, her mother realized she was not “faking” it. Similarly, Melissa describes having to convince her mother of her depression in early high school: “I lived through it about a year before I finally convinced my mother to actually maybe see if I could get some medical help.” She notes that her father has depression, and her mother might have been unwilling to admit that her daughter had been predisposed because of this. She notes that her father “didn’t want to feel like the carrier for depression... [and that] it was happening at such an early age.” Similarly, Jennifer describes her mother resisting her pleas for help before being diagnosed in middle school because she thought

she was too young to be depressed. Jennifer describes showing her mother her arm that she had been cutting as a form of self-mutilation in seventh grade: “I showed her my arm and I was like, ‘There’s something wrong. I’m depressed.’ And she’s like, ‘You can’t be depressed. You’re too young.’” She recalls her mother questioning, “Well, what do you have to be depressed about? You’re too young to have any problems.” She notes, “And then that was the last we spoke of that for a long time.” Meanwhile, Faith questions whether her parents ignored her pleas to seek help in the years leading up to her diagnosis of ADHD, depression, and GAD in early high school because they “didn’t believe” her, or if “they just didn’t know what to do about it.” Participants therefore cite several reasons why parents think that their children do *not* require help from a professional: they think their child is faking symptoms (e.g. for attention); they think their child cannot possibly have a mental health problem (e.g. they are too young); or they simply do not know what to do about, so they ignore the problem. This lack of understanding led parents to act as barriers to making initial contact with mental health professionals.

Parents’ Ability to Help Children Process Diagnoses:

Once diagnosed, parents with a high level of understanding were able to help participants make sense of their diagnoses because they themselves understood them. As Amanda explains of her mother, who was a psychologist: “I was lucky to have my mom that could really process it with me.” Some also report that their parents were available to answer questions and provide information.

Others note that their experiences would have been better had their parents better understood their diagnoses because they would have had someone to turn to for information. As Teresa describes:

It would have been nice if my grandma [who raised me] would have explained to me about my diagnosis instead of me having to find out for myself. It would have been nice

to be like, ‘Oh, Grandma, what’s this? Can you explain to me this?’ It would have been nice having a parent figure explaining.

Josh, who was diagnosed with ADHD in early high school, notes: “I spoke to my parents about it but they didn’t know anything about it, too, so they didn’t – I didn’t learn much from them.”

Those who did not have a parental figure to turn to with questions felt they were lacking this important resource.

Parents’ Ability to Provide Support and Treatment:

One third of the participants (n=14) suggest that their parents were able to support them and help them manage their mental health problems because of their high level of parental knowledge about children’s mental health. Whitney, for example, describes: “I guess my parents then were really good in that sense, in like they knew what the diagnosis was and what came with it.” When she received her diagnosis, her parents realized that she needed help getting organized in order to turn in schoolwork on time, and helped her develop strategies to manage her ADHD. They also describe parental knowledge allowing parents to be supportive in general. Tabitha, for example, explains: “My mom was helpful. I guess I couldn’t really tell you why exactly. It was just everything, because she was supportive, because she also looked into it so much and cared so much about it. That was very helpful.” Cindy describes the importance of family education: “For as much as they don’t understand, they do. They’ve been very supportive... I think the family really needs to be educated.” A solid understanding allows parents to not only provide the treatment they need, but also support them emotionally throughout the treatment process.

On the other hand, those whose parents were poorly educated on children’s mental health diagnoses note that they would have received better treatment if their parents had better understood their mental health problems. Stephanie, for example, suggests she might have

received accommodations in school for her ADHD diagnosis if her parents had been better educated:

I don't want to blame them because they didn't know any better, but at the same time I kind of do because I feel like they should have. Because if they had pushed, I mean they could have done something in theory. The school was obligated to provide reasonable accommodations, and they didn't. They just said, 'No.' So I feel like something my parents could have done would have been to educate themselves better and be better advocates, but they just didn't do that.

Interestingly, she uses the term "advocates," noting that her parents would have been able to better *advocate* on her behalf, had they been better informed. Meanwhile, Andy describes his mother asking other parents for information on treatment options, because she herself was not familiar with ADHD when he was diagnosed his junior year of high school. While asking other parents for information and opinions can be helpful and is important in making informed decisions, Andy suggests that his parents were so "highly influenced by other voices" that "they didn't really have a voice of their own." Participants' experiences therefore suggest that parents would have been better advocates for proper treatment had they been better informed.

In sum, participants report varying levels of parental knowledge and understanding about children's mental health, which affects how diagnoses are sought, how children are supported, and the care that children receive. Demonstrating the gratitude that participants expressed when their parents were able to seek information and support them in these ways, James reflects:

I was very fortunate that they figured out everything and that I have had all the support that I have now. [...] It was kind of like a planetary alignment in my childhood upon deeper reflection. I hardly – I never really significantly thought about it but the probability that my parents would notice that I was having an issue, figure out how to solve it, get me to where I needed to be in the necessary time required, and that everything would line up perfectly is astronomically low and I'm incredibly lucky because of it.

Importantly, this suggests that parents can obtain this information even if they do not have a high level of understanding from the start. My analysis builds on research on doctor-parent communication, further demonstrating the importance of informing parents of children's mental health problems. The data suggests that parents can and should be educated in order to better support and advocate for their children.

Participants' Recommendations for Delivering Diagnoses to Children

Findings described below suggest that it may be best for parents to deliver and explain diagnoses to children. Some participants note, however, that parents must be better educated about mental health problems in order to do so. Above all else, they recommend being honest and open with children about their diagnoses.

Delivering Diagnoses: Who Is Responsible?

Two thirds of those who suggested *who* should deliver diagnoses (n=18 of 27) recommend that parents should do so, citing several reasons. Some note that it is a parent's duty to take on this role. Ashley, for example, explained that it is simply a parent's "job" to talk to his/her child about the diagnosis. Similarly, Paige explains that this issue is "a moral thing," and that parents should deliver diagnoses since they are "closest" to children. She objects to having a "paid professional" do so. She notes: "I have a problem with parents who put it on someone else to tell their kid about something like that." She sees this as a moral obligation. Several others note that parents should explain diagnoses because children are comfortable with and feel they can trust their parents. Both Teresa and Chloe emphasize that children are more comfortable talking about sensitive topics, like mental health diagnoses, with parent figures than counselors. Kimberly explains that children are more likely to believe their parents than adults they do not know. As Crystal explains, children trust their parents because they are "there no matter what."

Michelle notes: “The best way to do it is through the parents, because what they tell you I think is what’s most important to you at that age.” Chloe explains:

Like growing up, your parents are biologically supposed to love you and take care of you. So they need to feel like that’s still happening, like your parents are going to take care of you – that your parents understand. Even if the parents really don’t, because I’m sure it’s hard for parents to understand just as much as for the children to understand. It’s just as hard for the parents to hear that their child has ADHD or depression as it is for the child. But even if the parents just I guess in a way fake it like they understand, just so that the child can feel better. I know that sounds bad but, just to give the child some kind of support and so that they can deal with it with the child along the way so that the child has someone to go to and has someone to deal with because it’s a lot easier to talk to your parents about how you feel than some random person you don’t know or some doctor.

In this quote, Chloe touches upon how difficult it may be for parents to fill this role when they themselves do not understand their child’s diagnosis, but that it is still important they try the best that they can.

It may sometimes be helpful, however, to hear an outsider’s perspective as well. As Blake explains, while it is best to learn of one’s diagnosis from a parent, it is also helpful to discuss it with a therapist, because they are an “outside voice.” Similarly, Monique suggests children should receive a diagnosis from “the person diagnosing them *and* their parents,” or at least someone they feel “comfortable talking to about it.” Kimberly explains that it is helpful for children to have a conversation with teachers and mental health professionals, in addition to parents, if they are having a hard time accepting the diagnosis. They suggest that having multiple sources, including outside perspectives, can be helpful for children.

Several participants (n=5) also suggest that whether parents should deliver the diagnosis depends on a child’s relationship with his/her parents. Faith explains that she had a close relationship with her parents, so she preferred having them deliver her diagnoses as opposed to a mental health professional. She describes:

I guess it really depends on the relationship with the parents. But I think it's something that the parents should be involved with in the respect that like they should be there to support their kid and make it a more comfortable process because it could be scary for some people.

Jennifer, on the other hand, explains that she would not have listened to her parents because she has a strained relationship with them. Nathan notes that he would pay more attention to a professional than his parents, but emphasizes, "That's just me." They suggest that in cases where the child has a poor relationship with the parent, it is best to learn about the diagnosis from another caring adult.

A handful of participants (n=5) note that parents are *not* best positioned to deliver diagnoses. Autumn notes it would be helpful to hear about a diagnosis from a caring adult who is not a parent, such as a school counselor for example. She notes the importance of it being someone with a good relationship with the child, but not necessarily a parent or doctor. Meanwhile, Josh notes that adults who are trained to recognize mental health problems in children, such as guidance counselors and mental health professionals, should deliver diagnoses. While participants overwhelmingly thought that parents should be responsible for delivering this news to their children, it is worth noting that a few participants, who were not as close with their parents, wanted to receive the news from someone outside the family. These findings suggest that the parent-child relationship is an important factor in whether children wish to be informed by their parents.

Educating Parents, So They Can Educate their Children

A number of participants (n=12) suggest that it is important that parents be well educated about children's mental health in order to deliver diagnoses and share information with their children. As Devin notes: "I feel like a lot of parents, they just don't know. They don't understand it either so how could they possibly sit down and explain it to their kids?" Similarly,

Max suggests: “Parents need to be informed so they can talk about it.” They emphasize the importance of educating parents, so that they can in turn educate their children.

Some suggest that mental health professionals are responsible for better educating parents. Teresa suggests that mental health professionals should “tell everything to the parents as soon as possible” so they have time to “soak it all in.” She notes that mental health professionals should prepare parents to answer the child’s questions. Devin, who was diagnosed with ADHD in sixth grade and depression in eighth grade, suggests it is important for mental health professionals to educate parents so that they can help children develop techniques for coping with their symptoms. As Devin describes: “It’s really hard to ask a sixth-grader to... try all of these techniques and everything and actually reinforce them... Why not talk to the parents... [and] basically try and help out a little bit more?” Participants also note that mental health professionals should educate parents so they are more emotionally supportive of their children’s diagnoses. Daniela notes it would have been helpful if the doctor who diagnosed her “had told my parents that it was okay to have a child with ADHD, it’s not a taboo subject, it should be discussed, it’s not like a disease.” They suggest that mental health professionals are in a role in which they can provide this type of information to parents.

Others suggest parents should seek information about their children’s diagnoses on their own. They describe multiple ways that parents can obtain information. Erica emphasizes the importance of parents reading online to learn how common ADHD is, so they can inform their children. Crystal explains that parents “need to not be afraid to say, ‘My kid has a disability, what do I do?’” She urges parents to talk with other parents for advice on managing ADHD.

She further suggests:

Parents, learn everything. Google, get a book... go on YouTube, type in ‘ADHD’ and watch the five minute film that explains everything. Learn how your kid is affected. It’s

not just with schoolwork. It's with every aspect of life... Once you've gained this knowledge, show them everything. Show them the clip ... Do the research and then go over the research with them. Because they're not going to understand it on their own. You need to understand it for them to understand it.

Both Crystal and Erica emphasize that it is parents' responsibility to obtain this information so they can share it with their children. This of course requires resources, such as the skills, time, and equipment to research their child's diagnosis. Parents may vary in the resources they have available to obtain information in this way.

Others note that fully understanding a child's mental health problem requires more than simply reading information online; it requires an effort to understand how it affects their individual child. As Chloe suggests:

Put yourself in *their* position, like a 'walk a mile in their shoes' kind of thing. Because it's easy to read a book or a pamphlet and say like, 'Okay, this makes sense. I understand what ADHD is.' No, you don't know... you won't know how that child specifically is feeling or what they're dealing with, especially with things like depression and anxiety and ADHD. It's different for every single person.

Similarly, after explaining that his father probably read for "hours on end" about ADHD after he was diagnosed, Gary notes: "I still think that I know more about it than my dad just because I actually experience it rather than looking at information. There's only so much that you can put in about ADHD in a book." These participants suggest that parents need to try and understand not just the mental health problem in general, but also their individual experiences.

Being Open: Respecting Children

When describing how children should best learn about their diagnoses, participants strongly emphasize that children can comprehend more than is often expected. Stephanie notes that children are more aware of their symptoms than adults might suspect. She explains that adults "don't give kids enough credit for what they can notice." Devin says that his therapist

“underestimated” how much he could understand in middle school. He notes: “They treat you like you’re not going to understand anything.” Participants expressed frustration towards adults for underestimating their ability to comprehend their diagnoses.

Treating children as if they are capable of understanding and handling information about their diagnoses may also be a way adults can signal respect. Devin emphasizes the importance of respecting children, and treating them as able to understand their diagnoses:

But I think basically just treating people with respect is like the biggest thing, like treating kids with respect because I mean they *do* understand a lot. And I mean they *do* know what’s going on, and they pick up on a lot of things that I think a lot of adults don’t really think they do. And I don’t know if I just had bad therapists or what, but I feel like that would be one of the biggest things is just treating kids with respect and sitting down and really talking to them. And that was probably why I didn’t ever want to talk to anyone, come to think of it, is it’s just no one really respected me.

Similarly, Max suggests: “Let them know everything... instead of ‘dumbing’ it down. Respect – have more respect for the patient.” They note how important it is for children in particular, who are so often ignored, to feel they are being respected both by mental health professionals and their parents.

This analysis of participants’ recommendations for delivering mental health diagnoses for children reveals that while participants predominantly suggested that parents should share this news with children, they strongly emphasize that parents need to be educated in order to educate their children. They urged adults to treat children as being capable of handling this information as a sign of respect. Findings build from the literature on both doctor-parent and doctor-child communication, underscoring the importance of being open and sharing information about children’s mental health with both parents and children.

Conclusion

This chapter highlights the important role that parents play both in seeking care and delivering mental health diagnoses to children. It also highlights the lack of information children receive, which is perhaps not surprising given social constructions of childhood as a time of innocence, passivity, and need for protection. I began by discussing how diagnoses were delivered to participants. Parents play a crucial role in the process, often translating the information to their children. This phenomenon is poignantly described in stories of children being asked to physically leave the room, while parents are informed of their children's diagnoses. They then act as liaisons between mental health professionals and their children. Parents' strategies for delivering mental health diagnoses to their children varied widely. While some 'sat down' with their children to share 'the news,' others shared it haphazardly when questioned. Others withheld the information altogether.

Pervading the participants' descriptions of being told of their diagnoses was a sense of confusion and lack of understanding. Natasha provides an illuminating example of this, recalling mental health professionals delivering her diagnoses to her parents while she watched on, without even being asked if *she* had any questions. Many participants recall not comprehending, or listening, to what they were told, suggesting that adults were unable to present information in a way that was engaging and understandable to them. While for some, diagnoses were withheld, others were told but unable to process this information, demonstrating that both theories in research on doctor-patient communication with chronically ill children apply to children's mental health: (1) that they do not comprehend the information, and (2) that they are not told (Eiser & Eiser, 1987). In Chapter 5, I will explore the narratives used when adults delivered

diagnoses to participants, and participants' recommendations for how to best describe diagnoses to children in a way that they can understand them.

Findings suggest that withholding diagnoses can impede children's ability to manage their mental health problems and can exacerbate the stigma and lack of control that children experience; thus, diagnoses should be shared openly – albeit in developmentally appropriate ways. Participants describe feeling like they had “something” to hide when not told of their diagnoses. They describe actively piecing together bits of information about their diagnoses and experiencing a sense of betrayal when they discovered their parents had withheld information. These findings are in line with research on delivering physical illness to children, which highlights the importance of educating and sharing information openly with children who may be more distressed by misunderstandings than information about their diagnoses (Eiser & Eiser, 1987). Rather than needing to *protect* children, adults need to share diagnoses with children in developmentally appropriate ways. In order to do so, future research should identify what is developmentally appropriate for children. The sociology of childhood can inform such research, emphasizing children's ability to actively learn about and engage with their diagnoses, rather than being passive, innocent, and unknowing. This information would be especially important for parents as they help children process and understand their diagnoses over time.

While it is important to share information openly with children, there may be cases in which the diagnostic terminology can be damaging for children. As James' case illustrates, some children may benefit from viewing their struggles outside the framing of disorder. As I will discuss further in Chapter 5, we must question whether there is a way to discuss a child's struggles openly, without being beholden to this lens of pathology.

Findings also highlight the varying levels of parental knowledge about children's mental health, as reported by participants. Findings that participants perceive their parents to have been so poorly informed expand upon the literature on professional-parent communication, further documenting the lack of information shared with parents in the field of children's mental health. Meanwhile, others report that their parents 'just got it' or sought information. Paige's mother attending conferences about ADHD provides an illustrative example of a parent well equipped to obtain information. Parents' access to resources, such as the skills, time, and equipment needed to research diagnoses, likely varies greatly. Future research should examine how social class may affect parents' access to these resources and thus parental knowledge about children's mental health problems.

Findings suggest that the level of parental knowledge about children's mental health affects how children experience them, thus highlighting the importance of parental education about mental health. Parents with high levels of understanding may be better able to help children process information about their diagnoses, support them, and act as advocates in accessing treatment. In this way, this research expands upon previous research, which has focused on the understandings and satisfaction of parents, but not necessarily identifying the effects on children. This research suggests that parental knowledge can positively affect children's experiences in these ways.

While noting that it depends on a child's relationship with his/her parents and that it is helpful to also receive information from an outside perspective, participants generally emphasize that parents should deliver mental health diagnoses to children. Many emphasize, however, that it is important that parents are well educated on children's mental health problems in order to do so effectively. This has implications for social workers who support families as they receive this

information and help families manage children's mental health diagnoses. This research highlights the role that social workers can play in providing support and guidance to parents as they learn and share information about mental health diagnoses with their children. It can inform guidelines for practitioners, who should be encouraged to actively engage parents, rather than *assume* parents will pass information on to children. Findings described in Chapter 5 shed light on the strategies that professionals should suggest parents use when delivering diagnoses to their children.

Future research should explore how these diagnoses are delivered to parents and what factors play into this process, such as social class. As described in Chapter 2, Anspach (1997) finds that staff provide simplified information to lower-class parents of infants in newborn intensive-care units, and that these parents are then less likely to assert their wishes regarding the life-and-death decisions made about their newborn infants. Lower-class parents may also be poorly informed of their children's mental health diagnoses; a limitation of the current study is the inability to capture exactly how participants' parents were told. In most cases, participants were not even in the room when their parents were told of their diagnoses, and thus cannot describe these interactions. Similarly, in the current study, I was unable to examine the information that parents acquired, such as print materials and online information. As described in Chapter 2, Rafalovich (2004, p. 160) finds that the parents he interviewed in his study had a "voracious appetite" for information on ADHD. He suggests that guidebooks influenced parents' understandings by framing ADHD as "abnormal" (Rafalovich, 2004, p. 161). In the current study, I was unable to assess the framing of children's mental health disorders in the materials parents acquired. Future research could explore these areas.

Future research should also examine the factors contributing to whether or not parents and mental health professionals share versus withhold information about diagnoses with children. For example, research could examine whether adults' visions of children as innocent and in need of protection may encourage them to withhold information. It could also examine how cultural factors influence these decisions. Daniela and Gary suggest that their parents' cultural backgrounds and view of mental health problems as 'taboo' subjects may have contributed to their withholding of their diagnoses; future research could explore this possibility. Future research could also examine whether factors such as parental education and class affect parents' decisions and ability to convey information about diagnoses to children. Just as social class may affect parents' resources for accessing information on children's mental health diagnoses, it may also (directly or indirectly) affect their ability to convey information about diagnoses to children.

While research utilizing the sociology of childhood perspective would keep children's accounts central, future research could capture parents' and professionals' interpretations as well, to help make sense of children's understandings. For example, future research could capture parents' perspectives, examining how children's recollections compare to parents' experiences. Do children's attributions of parental motivation and parental knowledge align with parents' understandings of their own motivation, behavior, and knowledge? Future research could also examine mental health professionals' experiences, examining the delivery of children's mental health diagnoses from their perspectives, in addition to children's recollections of this event.

A central argument of this chapter is that parents should be better supported in their role as translators of diagnoses to children; they should be equipped to share information openly with children and create space for them to safely discuss their diagnoses. Creating this space is

crucial for children to fully process and retain this information. Mental health professionals should also take part in this process, educating parents and sharing information openly with children. Thompson (2000) highlights research showing that illness explanations should be provided in a climate of openness and support, and in a warm, empathetic manner, allowing for questions and discussion. Findings here extend these principles to delivering children's mental health diagnoses directly with children. Thompson (2000, p. 27) notes that illness explanations build a "relationship of mutuality" between doctors and adult patients, and this study demonstrates that this translates to children as well. Participants note that sharing diagnoses and explanations openly with children is important to demonstrate respect. Open discussion signals that adults both value children's questions and respect their ability to take part in the conversation. I heard it time and time again – children want to feel *valued and respected*, and as I will emphasize in future chapters, children want to be *heard*.

CHAPTER 5

Making Sense of Diagnoses: Narratives Negotiated

In Chapter 4, I discussed how diagnoses are delivered to children, and the role parents play in this process. In this chapter, I further explore the explanations children receive and obtain and how they interpret and negotiate these narratives as they learn about their diagnoses over time. How do they negotiate the many narratives that they are exposed to? How do they interpret medical accounts of their struggles? How do they come to understand their diagnoses?

Using the sociology of childhood as a frame for analysis, I view children as agents in the process of making sense of their diagnoses – not only receiving, but also actively seeking information about their diagnoses. Evidence that children seek information on mental health diagnoses online extends research demonstrating that the internet is a primary source of health information among adolescents, shedding light on how children utilize the internet to obtain mental health information. Findings from this study demonstrate that many participants actively sought information about their diagnoses and developed fuller understandings of their diagnoses over time. For many, this took place during adolescence, at a crucial time in identity formation, as described in Chapter 2. These processes are likely similar to the formation of other identities as well.

In line with the sociology of childhood's focus on children's meaning-making processes and the treatment of children as active participants in their social worlds, I examine the active role children play in negotiating narratives about their diagnoses over time. I use the term

‘narratives’ here to describe the discourse about children’s mental health, viewing them as socially constructed stories. These narratives are also ‘stories of identity,’ which can shape how children understand their experiences (White & Morgan, 2006). Focusing on how children actively participate in the process of *negotiating* narratives, I illustrate that children absorb, embrace, interpret, resist, and defend narratives, thus contributing to the discourse.

I focus on how children negotiate medical and non-medical accounts of diagnoses, make sense of narratives about its cause and effects, and resist societal skepticism (e.g. whether it is over-diagnosed, whether children are too young to have it). I frame my understanding of how children interact with these narratives through the interpretive reproduction model, which views children as both ‘affecting’ and ‘being affected’ by the world around them (Corsaro, 2005, p. 29). Children both draw from larger societal understandings, and also create their own narratives and understandings about their mental health diagnoses.

I conclude by examining participants’ recommendations for how to best present information and explain diagnoses to children. Whether using medical or non-medical accounts, participants emphasize the importance of being open with children and providing them assurances, explaining that their problems are common, legitimate, not their fault, not something “wrong” with them, not related to their intelligence, and not a “big deal.” I discuss evidence demonstrating that information is empowering for children, and that participants suggest that adults be open and honest with children, introducing information over time. Participants recommend that explanations be simple and informal, and that they focus on how children’s mental health problems will affect them.

These findings expand previous research on the guidelines for explaining physical illness to adults and children. By providing insight into children’s meaning-making processes and

capturing participants' recommendations for sharing information, findings help to fill two gaps identified in research on explaining illness to children. First, it helps to assess children's understandings about mental health. As Eiser and Eiser (1987) argue, a better understanding of children's thoughts and feelings about illness and health-related concepts is necessary to improve illness explanations. Second, it provides information on what participants *wanted* to know as children and how they think information should be provided. As Whaley (1999) notes, we need a better understanding of what children want to know, and future research should focus on children's perspectives, identifying the explanations that they prefer. Findings presented in this chapter help fill these gaps by examining how children understand mental health diagnoses and perceive the effectiveness of these strategies, from the perspective of young adults who learned of their own diagnoses in childhood.

Seeking and Obtaining Additional Information

Rather than receiving all of the information at once, participants describe seeking and obtaining additional information on their diagnoses over time. They juggled information from multiple sources, including family, mental health professionals, peers, teachers, the media, reading materials, and the internet. Demonstrating agency in this process, many sought information over time.

Findings suggest that parents often provide a source of information over time. Kimberly, for example, notes: "If I had questions, I would always ask my mom... She would always be there to talk about it or have an answer for me." Ashley recalls not having questions when her counselor told her of her ADHD diagnosis in second grade because she was "still processing it." She notes that she was more comfortable asking her parents questions later.

Peers also act as a source of information for children. Some describe information from peers being accurate and helpful. Jennifer describes her friend giving her a packet of information she found on self-mutilation when Jennifer was struggling with depression in seventh grade, before being diagnosed in eighth grade. Similarly, Chloe recalls her friend giving her a self-help book in high school that she found extremely helpful. Others received more spotty information from peers. Josh, for example, recalls other classmates who picked up medication from the health center at his boarding school talking about ADHD in high school. Natasha describes peers joking about classmates having ADHD in high school when they acted hyper. She notes: “I guess that was one way of learning as well.” She describes this as her “first exposure,” and explains: “That’s why I thought it wasn’t good to talk about.” Similarly, Christine describes the confusion she experienced in a discussion with her peers on the school bus in middle school:

When I found out about it, I talked to kids at school about it and especially people on my bus and I was like, ‘I have this – I have this disorder. I don’t know what it is though, but it makes me act like this.’ And they were like, ‘Oh, it’s probably like ADD or ADHD.’ And I was like, ‘No, like that couldn’t – that’s not it’... When they said the entire disorder it sounded different... And they were like, ‘No, one-third of the country has it. You probably have it, Christine. It’s probably not that big of a deal.’

They describe piecing together the often spotty information that they obtained from peers – sometimes accepting what their peers told them, and in other cases approaching it with skepticism.

Schools are also a source of information, often providing information on mental health diagnoses in health and psychology classes for example. Participants describe discussing, watching videos, and writing papers on mental health diagnoses in classes, which many found helpful. Monique recalls talking about bullying and how it can lead to depression in middle and high school classes, which she found useful. Ashley recalls one of her teachers talking about her classmate’s ADHD diagnosis in elementary school, using it as an “empathy lesson.” She notes

that when teachers talked openly about ADHD in high school health classes, she realized, ““Oh, this is okay.”” Some note that they wished teachers had covered mental health diagnoses in more depth. Gary recalls that the term ADHD was mentioned in middle school health class, but they did not go into detail until he had reached high school. Chloe notes that even in high school there was just a paragraph on depression and anxiety disorders in her psychology textbook. Some note that more in-depth information would have been helpful, not only for them, but also for their peers to learn about what they were experiencing.

Portrayals of mental health problems in the media may also influence children’s understandings. After being diagnosed with ADHD, depression, and GAD in early high school, Faith describes connecting with a character on a television show that showed symptoms of a mental health problem. Joe describes the impact of a commercial he saw in middle school that described ADHD as having the channel constantly changed in your brain without your control. They both note that this was extremely influential, helping them to better understand their diagnoses.

Several participants (n=6) describe receiving reading materials from adults that they found useful. After being diagnosed with depression in eighth grade, Teresa describes her counselor suggesting books that she found helpful because she was able to relate to the characters. Cindy describes receiving pamphlets and book recommendations from her therapist, but not until college, even though she was diagnosed with GAD in eighth grade: “I think that was when I really, really, really started to understand what an anxiety disorder was.” Jennifer describes her friend’s mother giving her a book about living with depression and bipolar after she was diagnosed with bipolar in late high school, which she found helpful. Amanda recalls receiving a book from her teacher her junior year of high school, describing learning types and

tips for succeeding. She also describes reading the books that her mother bought for herself to learn more about ADHD. Some note that reading materials were particularly helpful because they could read through them at their own pace.

Meanwhile, many participants (n=18) report actively seeking information on their own on the internet in childhood. This included looking up information on their diagnoses, including prevalence, symptoms, ways to manage it, and medications and their side effects. Lilly notes that by looking up “trends” about ADHD, such as the average age of onset, after being re-tested her sophomore year of high school, she was able to assess “how close [she] was to normal.” Mark describes just wanting to know whether his ADHD indicated a lack of intelligence. He recalls scanning websites when he was in middle school, looking for terms that meant “stupid.” He describes: “I just wanted to make sure they didn’t think I was stupid. That was it. I’m like, ‘I’m not – Am I stupid? No? Alright then.’” He recalls feeling “connected with the symptoms” that he read online: ““Oh, inattentiveness – hah, that’s me.”” Melissa also found the information she found on the internet her sophomore year of high school useful, noting: “I found it extremely helpful because I found information that I feel that my doctors and my parents were reluctant to tell me for whatever reasons.” They note that this information was particularly helpful. They describe feeling like they could “relate” with the symptoms, and thus with others who were also diagnosed.

A few participants (n=3) also describe finding information on their diagnoses at libraries. Gary recalls looking up ADHD in the DSM at the library in high school. In addition to reading about ADHD online in middle school, Mark recalls learning strategies for controlling his symptoms through books at the library. Teresa explains that after being diagnosed with depression in eighth grade:

I would just go to the library and learn like, ‘What is depression? What are these things that people are telling me I have?’ I would just go in my free time, because my grandma lives right next to the library... I would just do it on my own and no one would know.

Like Teresa, several participants describe looking up information on the internet in secret.

Findings suggest that participants learned about their diagnoses slowly over time, as they were able to digest the information they acquired. Chloe, for example, recalls learning about depression “a little bit at a time,” after being diagnosed early in high school:

As I was going to therapy with my counselor, it was a little bit more and more understanding... just through talking about things. She obviously knows what goes on. Because she’s not a doctor but she is a counselor. But it’d be more understanding of things that are involved and what happens when you’re depressed, why these things happen, that it started to make a little bit more sense. But things like that. A little bit at a time.

Joe explains that a full understanding takes place in stages over time. He notes:

There are different points of revelation about it... Questioning *why* you do things differently than others. And then the second sort of revelation is understanding like, ‘Oh, I *am* different from the others.’ And then the third sort of revelation is understanding what that means, and why I am that way.

As is likely similar with the development of other identities, Joe explains that he knew he was “different” at a young age, but did not fully understand what ADHD was “until much later.” It was a slow process for many participants, who were able to better understand their diagnoses over time.

Children may also better understand their diagnoses based on their personal experiences with their mental health problems over time. Stephanie, for example, explains that she developed her own understanding of ADHD as she experienced the symptoms. She notes, “[With ADHD], you’re trying to focus and the harder you try, the worse it gets. It’s not just like, ‘Oh, I’m distracted.’ There’s more to it than that.” Interestingly, she uses the term “narratives,” further commenting: “I think that is something that I was able to understand better from my own

experiences without needing narratives from other people.” This quote illustrates the important role children play in developing their own understandings, based on their own experiences.

Findings therefore suggest that participants learned about their diagnoses slowly over time, as they were able to digest the information and as some sought additional information. Participants’ ability to better understand their diagnoses over time might be partly due to an increased ability to process and understand the information as they mature. This process of slowly understanding diagnoses over time is in line with research showing that children’s understandings of both physical and mental illness become more sophisticated over time. Children’s receipt and processing of information following diagnosis takes place in the context of rapid development. However, it is also important to note that adults’ understandings may deepen over time as well, as they digest information and interpret societal narratives about their mental health diagnoses. These narratives serve as social tools for both children and adults as they make meaning of their diagnoses. The interviews suggest that children are active participants in this process – seeking, interpreting, and piecing together information over time.

Negotiating Narratives

Throughout the process of receiving and obtaining information, participants describe being exposed to multiple narratives about their diagnoses from several sources, including family, mental health professionals, peers, teachers, the media, reading materials, and the internet. Through my analysis, I demonstrate that rather than simply absorbing these narratives, children *negotiate* them: this involves actively interpreting, embracing, defending, resisting, and challenging the discourse.

In particular, participants negotiated medical and non-medical accounts of diagnoses, making sense of narratives about its cause and effects, and resisting societal skepticism (e.g.

whether it is over-diagnosed, whether children are too young to have it). While diagnoses differed, many participants recall struggling with the same types of narratives. Demonstrating “the dualistic either/or habits of thought... pervasive in Western culture” (White, 2007, p. 35), views negotiated in this process tended to fall into dichotomies. For example, it is seen as genetic vs. environmental and legitimate vs. fake. While understandings fall along spectrums, participants describe constantly negotiating the views that lie at the poles – often embracing the narrative at one end, while resisting the other. In this section, I describe these narratives negotiated.

Negotiating Medical and Non-Medical Accounts

Narratives about mental health diagnoses tended to fall along a spectrum with medical and non-medical accounts at the two poles. The medical accounts viewed mental health problems as permanent, genetic disorders of the brain. This framing of hyperactivity, anxiety, depression and mania as symptoms of *medical disorder* can be seen as an example of medicalization, “a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders” (Conrad, 1992, p. 209). On the other end of the spectrum, were what I will refer to as ‘non-medical’ accounts, which view mental health problems as temporary, everyday struggles that can be overcome.

Participants varied in their acceptance of and resistance to medical narratives. Consistent with Moses’ (2009a, p. 575) finding that the extent to which adolescents used psychiatric terms to describe their problems varied “tremendously,” findings here also demonstrate a wide range of responses to medical narratives. Many participants who initially resisted medical accounts came to embrace this perspective as they gained in-depth medical information on their diagnoses over time. Exposure to medical terminology without complete information led to confusion; this was

resolved when participants obtained medical information, often online. Meanwhile, those whose parents were open and communicative with them without utilizing medical narratives were optimistic that it is possible to share information with children using a non-medical framework.

At first resisting, and later embracing medical accounts: “It’s in my brain”

The interviews suggest that participants embraced medical accounts of their problems over time, as they received and sought medical information about their diagnoses. Many at first resisted the idea that they had a “disorder” for several reasons: they thought that their symptoms were not “bad enough” to indicate disorder; they did not allow the information to “sink in” because they did not want to “accept” it; their diagnoses conflicted with their self-identities; and/or they were influenced by others who rejected their diagnoses.

Participants’ accounts demonstrate that some may have initially resisted their diagnoses because they thought that their symptoms were indicative of regular problems that did not rise to the level of “disorder.” Teresa, for example, explains that after receiving her diagnosis of depression in eighth grade, she thought: ““This is fake. Like how can someone diagnose me?” I just thought it was an everyday problem, like... ‘Everyone has these ups and downs. I’m not the only one.’” Similarly, Blake did not think his anxiety rose to the level of “disorder.” He explains that he thought of his anxiety when diagnosed with GAD in high school: “These are just my personal worries... I didn’t think that it was a *disorder* really.” He explains:

It was something that my parents [and therapists] told me that I had... I didn’t really believe it in my heart though... I didn’t believe that it was an actual disorder that inhibits your ability to function... I probably didn’t want to make that connection because of a fear – a social fear – of being different... [That was] a factor that kept me from thinking it was a real disorder.

Both Teresa and Blake emphasize resisting the idea that their problems were severe enough to separate them from the everyday struggles their peers experienced.

Children may also resist diagnoses because they do not want to “accept” the news that they have a “disorder.” As Monique describes: “I knew it was depression. I just didn’t want to admit to it.” When the doctor at the group home told her that she had depression and bipolar disorder around the time of her sophomore/junior year of high school, Monique recalls not listening because she “didn’t want to hear it.” Similarly, Autumn notes she was resistant to her diagnosis, even into high school: “I kind of ignored it and pretended I didn’t have it.” She notes that especially in middle school, it “didn’t register.” Both Monique and Autumn describe ignoring the information that they received because they did not want to admit to having a problem.

Similarly, diagnoses may be confusing when children have preconceived stereotypes of mental health disorders that conflict with the symptoms they are experiencing. For example, Teresa explains her confusion when diagnosed with ADHD her sophomore year of high school: “At first I was like, ‘How do I have ADHD? I’m not hyper, I’m not noisy in class. I don’t fit the normal criteria for having ADHD.’” Devin explains that when diagnosed with depression in eighth grade: “I didn’t really understand that depression doesn’t necessarily mean that you’re sitting at home sobbing all the time... it’s just generally low mood, which I think actually in retrospect really fit how I was at the time.” He describes thinking when diagnosed with ADHD in sixth grade:

I thought it meant hyperactivity as in impulsive ADHD where it’s like bouncing off the walls... I was kind of the exact opposite of that as a kid. It’s where I was just totally spaced out a lot of the time. So I was just confused.

Some report initially resisting their medical diagnoses because it conflicted with visions of themselves as high-achievers in school and extra-curricular activities. For example, Abby, who describes herself as an “over-achiever” in high school, recalls thinking when told she had bipolar

disorder her junior year of high school: “No, that’s not me. I’m supposed to be a... star student, athlete, artist.” She describes, “I immediately recoiled. I took it personally... ‘How could you say that about me? I’m supposed to be perfect’... I just completely walled it off.” Similarly, Erica recalls thinking when diagnosed with ADHD her freshman year of high school:

I was National Junior Honor Society. I was the teacher’s pet... and then I was like, ‘Boom,’ like, ‘Don’t kind of – not stupid people – but people that aren’t as intelligent have it?’ I think I just had a misconception of what it was.

Similarly, Natasha explains her reaction when diagnosed with ADHD her freshman year of high school:

At first, I was just like the typical person, ‘Oh, I don’t want anything to be wrong with me. I’m fine.’ Especially since I was always told, ‘Oh, you’re an accelerated learner. You’re very smart.’ And I thought that was a handicap and I didn’t want to be associated with any of that.

These participants describe rejecting their diagnoses when they first interpreted them as conflicting with their self-identities.

Children may also resist the medicalization of their struggles when they are in an environment in which others resist their diagnoses. Michelle, Jennifer, and Melissa (diagnosed with depression in seventh, eighth, and tenth grade respectively), for example, all describe their parents thinking they were too young to be depressed. They also describe friends and peers resisting their diagnoses. Michelle, for example, notes that her boyfriend “ignored” her diagnosis: “He wasn’t trying to be mean but he was more – the same reason as my mom. He thought if you ignored it, it will go away.” Jennifer notes that several of her friends rejected the idea that she had bipolar disorder when she was diagnosed in late high school. She says of her best friend: “She doesn’t believe in mental illness. And she’s like, ‘I don’t think you’re bipolar, blah, blah, blah, blah, blah, blah, blah, blah’... A lot of my friends were in denial.” By suggesting that

her friends were in denial, she implies that the disorder was present. Their “denial” can be seen as a resistance to the medical narrative.

Three participants note that their fathers, in particular, resisted their medical diagnoses. Natasha, for example, recalls that when she was diagnosed with ADHD her freshman year of high school: “My dad was very convinced that nothing was wrong with me.” Similarly, Autumn notes:

I think for a while my dad didn’t believe that it was legitimate. I think he’s – I think that there’s a big group of people out in the world that believe that all of this is just bologna and it’s just an excuse for crazy jumping around kids to get diagnosed with something.

She explains that it was “clear” for her mom, who saw first-hand how different Autumn was from her siblings. Crystal, explains that it was hard for her father to “understand” the ADHD diagnosis she received in second grade because he was not exposed to her symptoms as much as her mother, whom she lived with. She explains: “It’s hard to understand unless you’re around it a lot. Like my mom was around it a lot, so she understands it. My dad still doesn’t fully understand it sometimes.” This suggests that some fathers resisted medicalization of their struggles because they were less involved in their everyday activities; their symptoms were therefore more hidden from these fathers.

Many of those who at first resisted their diagnoses and a medical framing of their struggles recall later embracing them, when they later obtained in-depth medical information and when their problems persisted. Teresa and Natasha, for example, obtained information on their diagnoses shortly after being diagnosed. Teresa describes embracing her diagnoses when she researched depression at the library after being diagnosed in eighth grade, as described above. Natasha recalls accepting that she had ADHD when she read about the disorder in a pamphlet

provided at a summer learning program shortly after being diagnosed her freshman year of high school:

They gave you lots of flyers about, ‘Oh, this is what it is. This is how you deal with it.’ And for some reason I read them all, which people normally don’t do. That’s how I got more knowledge about it. [...] Honestly I think I was probably bored [laughs], and I’m a big reader. But also I mean I did want to know what it was. I just knew that it was a taboo kind of a handicap thing. And then when I read about it, it was fine.

Though diagnosed in high school, Blake and Abby note that they did not fully accept their diagnoses until early college, when their symptoms worsened and they obtained more information. Abby describes “looking into” her “issues” in early college: “It’s helped me a lot dealing with my own issues and being able to say, ‘Okay, here’s why I feel this way.’ Like, ‘It’s not real. It’s just my brain chemical imbalances.’” This suggests that she was able to separate her symptoms from her personal “issues,” re-conceptualizing the source as “chemical imbalances” located in her brain. Unlike one’s personal “issues,” “chemical imbalances” are likely viewed outside of one’s control.

Illustrating the confusion caused by medical narratives when not fully explained to children, Sarah recalls thinking after being told that she had ADHD in third grade that it was “like a disease,” which had “negative, scary connotations,” because her diagnosis was not fully explained to her. She describes the explanation she received:

[My mom] just told me that it was when people have trouble concentrating in class and medication can help that. And I guess I felt kind of – because it was a disorder and so I didn’t – I was really young and I didn’t like the fact that I had to be diagnosed with something like that. [...] She didn’t really go any further and I actually kind of felt she should have explained it better to me. [...] Maybe just told me that I was no different from anyone else, because for a few years after that I just felt like I was different and I was – I don’t know – I mean it was all just because I wasn’t educated on it.

She further describes her confusion about the medical nature of her diagnosis:

I think it was kind of hard because... it was never explained to me the difference between disorder or disease. In the very beginning I almost thought of it as like a disease – this thing that was poisoning me and causing me to be different from other people. [...] Because my mom *never* explained it to me...

Sarah describes later learning about ADHD: “It wasn’t until I was older... I think it was classes that I had to take... like health classes that would tell us about it. That’s where I learned it actually.” She explains that she no longer thinks it is a “big deal” now that she is better educated on it.

Matt also describes the confusion he experienced before finding in-depth medical information on the internet in eighth grade, at which point he embraced the medical narrative. He explains: “I never really understood it until I went on the internet and got the info. Until then, I always figured there was just something wrong with me... I always just thought it was something wrong with me as a human.” He describes: “[I thought it was] some organ inside of me that was wrong.” In eighth grade, Matt discovered a medical account on the internet, defining ADHD as a disorder in the brain. He describes: “I did some research online and found out that it was actually a neurotransmitter thing rather than a body problem.” Interestingly, Matt explicitly differentiates between problems of the body and the brain in this quote. This goes a step beyond separating one’s symptoms from one’s personal “issues” as Abby did, by disembodying them from traditional illness as well. Children may view problems in the brain as even less controllable than illness in the body, and thus locating the problem specifically in the brain may further legitimize struggles and remove blame. Matt embraced this narrative as a defense against peers’ accusations that his behaviors were his fault, noting: “The next day I do remember going in [to school] and being like, ‘It’s a neurological thing. It’s my brain, punk-ass!’”

Resisting medical accounts: “There’s nothing wrong with me. Why am I taking pills?”

Two participants actively embraced the societal narratives that children are over-diagnosed and over-medicated. Courtney provides a poignant example of a child resisting the medical account provided by her parents, questioning the diagnostic enterprise and the idea that something was “wrong” with her altogether. She describes resisting her ADHD diagnosis:

The fact that... people can point [something] out medically about me that separates me from other people and that makes me abnormal, it was like being sick... I kept on having to say [to my parents], ‘There’s nothing wrong with me. Why am I taking pills? It’s not like I have cancer’... [My parents] didn’t say this, but like, ‘There’s still something wrong with your body... so we’re fixing it. Like when you have a physical illness, you fix it’... I didn’t like the fact that... I still had to take medicine, because I couldn’t see it... I think that’s something that came up in arguments, somehow. Where I fought it because like, ‘It’s not as important,’ but they were like, ‘It is as important... it’s still health-related,’ which I didn’t believe.

Courtney recalls writing a research report at the end of high school about children being misdiagnosed with ADHD. She suspects that she herself was likely misdiagnosed: “Probably that I had a lot to say or that I liked to run around. And I don’t think I was a problem to the class, but apparently the teacher didn’t like it.” She recalls: “I didn’t think that I was doing anything abnormal when I found out that I was going to start taking medicine. I thought I behaved just like everyone else.” She is the only participant who suggests that she was misdiagnosed.

Sam describes embracing the view that children are over-medicated when he was just in fourth grade:

Just in the media that it seemed like [ADHD] was something that was really prevalent. And at the time, I kind of had a feeling that it was something more of, ‘Oh, well, this is just kind of like a fall-back.’ Just say, ‘Oh the students have ADHD’ and put them on like [medication]. And that was another reason why I hated taking [the medication]... like, ‘Oh just drug these kids up.’ So even when I was young and in fourth grade, I still had that feeling.

He recalls thinking even at a young age that there may be other ways to manage his symptoms than taking medication. His case demonstrates that children can be aware of and engage in this critique of medicalization even at a young age.

Embracing non-medical accounts: “Any other kid like me could have problems like that”

Those who embraced non-medical accounts of their struggles typically recall their parents presenting their diagnoses in an open and informative, but non-medical, way. They viewed their mental health problems as something that made them struggle in a particular aspect of their lives (e.g. concentrating or being happy), rather than a disorder. Max, for example, recalls his parents telling him when diagnosed with ADHD in third grade: ““You just have some attention problems. You need to focus more.”” He recalls thinking: “Any other kid like me could have problems like that.” He notes: “I don’t think it was approached like, ‘Oh, you have a disorder.”” Similarly, Autumn describes her mother focusing on the view that she just needed extra help in school; she did not use the term ADHD with Autumn. While diagnosed in second grade, it was not until middle school that Autumn heard the term ADHD. She recalls:

She talked about the benefits of it, but I think when I was younger, they didn’t really want to tell me what it was. It was kind of just like, ‘Oh, well, you’re just going to have a little extra help from these teachers.’

While Stephanie’s parents did tell her that she had ADHD when diagnosed in third grade, she notes that they did not emphasize that it was a “disorder:” “It was basically very focused on the effects of it. Like, ‘Okay, so this is what it is, but this is how this is going to change’ rather than, ‘Oh you have a disorder.’ I’ve never felt like that before.”

These participants viewed their mental health problems as everyday struggles, and suggest that it is possible to discuss children’s struggles openly with children, without utilizing

the framing of “disorder.” They were generally grateful that their parents took this approach. James, for example, expresses gratitude towards his parents for presenting him a non-medical account of ADHD in his childhood, explaining that he had problems paying attention without using the framing of “disorder.” As noted previously, he explains that he is grateful that his parents did not introduce him to the terminology of ADHD at such a young age, noting that he liked having the “chance to develop without being affected by society and their perception of ADHD.” He suggests that this is a beneficial approach: “Society has this horrible habit of pegging people with stereotypes,” and “...the kid should have a chance to develop before having to handle such a social burden.” His experience suggests that some children might prefer that adults not share the label of diagnosis.

Making Sense of its Cause and Effects

Demonstrating a range of understandings, participants embraced several causal attributions for their mental health problems. In line with medical accounts of diagnoses, almost half of the participants (n=20) recall embracing the view that their mental health problems were genetic. Both Mark and Teresa recall learning that their mental health problems were genetic when doing research on their diagnoses in middle school. Mark recalls thinking: “It’s a defect genetically... [I would] try to not think about it, and also try to avoid it.” Teresa notes: “I read that it’s in your family, and so that helped too. And it’s like, ‘My grandma has it and my mom has it. I’m just destined.’” Others recall their parents describing their mental health problems as genetic. Both Matt and Christine describe at first blaming their parents for passing it on to them, when they explained that they had inherited it. Matt says of his father: “I did blame him for a while... But I eventually just empathized with him because he’s got it, I’ve got it, we’re okay.” Several participants describe finding some comfort in this explanation, which they could easily

understand.

Four participants suggest that while hereditary, their mental health problems may have been environmentally triggered. Daniela notes that her parents thought her struggles in first grade were due to a recent move from abroad. Daniela explains thinking that “it’s biological, but that [the] environment could trigger it,” questioning whether moving to America from abroad triggered the manifestation of the problem. Shannon describes being bullied as a child, and how this may have contributed to the development of her anxiety disorder: “And so I feel like environmentally, I was predisposed to that, but also my mom worries a lot too. So I feel like that’s also kind of biological.” They therefore drew from understandings that mental health problems are genetically and environmentally caused, thus integrating medical and non-medical views.

Meanwhile, several participants (n=7) describe their mental health problems in relation to family troubles and dysfunction, such as divorce and alcoholic parents, insinuating that these environmental factors contributed to their manifestation and/or cause. For example, Chloe explains that there were “a *lot* of issues” in her relationship with her parents, especially due to her father’s problems with alcohol. She explains that “triggered a lot of the depression and the anxiety.” She describes blaming her parents for fueling her depression and anxiety symptoms in early high school: “I felt like they were the ones doing this to me.” Abby describes her family as “dysfunctional,” with both parents and siblings dealing with alcohol and addiction problems and notes: “My emotional issues come from... my parents.” She further describes:

Probably 98% of the neuroses or whatever that I have now come from the fact that my family just kept secrets and was completely dysfunctional... I try not to hold onto that, and hold that against them. But I know that that’s why I am the way that I am.

Michelle explains that her depression was a “culmination of things,” including her parents

constant fighting and threats of divorce, compounded by the fact that she did not have “an outlet” for her emotions. She notes: “I lived in an environment where I was really prone to developing a depression.” Similarly, Teresa explains that it was after her parents’ divorce and after she moved in with her grandmother in eighth grade that “life cooled down” and she started experiencing “depressive episodes.” She notes: “Because I never had time to take in what was happening [before that].” Monique explains that she became depressed after her aunt, with whom she was very close, passed away when Monique was about 12 or 13 years old. These understandings reflect the embrace of the idea that mental health problems can be caused, or at least triggered, by environmental aspects.

Participants also report a range of understandings when discussing the effects, or future outlook, of their struggles, which may vary in part based on the diagnosis. Some recall thinking of their mental health problems as something that was permanent. Daniela recalls: “In my mind it was forever just because I couldn’t see an end to the day and night routine of taking medication.” Andy also notes that he just “assumed” that he would “have it for life” when he was diagnosed with ADHD his junior year of high school. Lilly also “thought it was forever” when she was diagnosed in eighth grade. Starting shortly after she was diagnosed with depression in eighth grade, Jennifer recalls thinking “about how it’s a chronic illness. ‘It’s never going to go away. I’m always going to feel like this.’” She recalls thinking: “‘You’re never going to go back to the way you were before you were diagnosed – before it started manifesting itself.’” While some felt like it would last forever because of its ever-present symptoms, some were explicitly told that it would last forever by parents. Sam recalls when he first learned of his ADHD diagnosis in third grade: “My mom, when she first explained it to me, told me that this would be something that I would have to live with my *whole life*.” He emphasizes: “I thought it

was going to make an impact my *whole* life,” and only now does he realize that it would become less of an issue over time.

Yet, many participants (n=16) recall thinking that their mental health problems were controllable, and that they could learn to better cope with symptoms over time. Sarah was explicitly told by her mother that ADHD was a “lifelong thing,” but she could “learn to live off of the medication” by learning strategies to stay organized and focused, like keeping good notes and creating routines. She recalls this making her feel “hopeful,” noting: “I know that people can survive with it, so it doesn’t really bother me.” Similarly, when diagnosed with ADHD in second grade, Ashley recalls her parents explaining that she would have it “forever” but that “for some people it gets better as they age.” Shannon describes looking up information on “ways to help” control her symptoms after learning of her diagnoses in middle school: “You can never get rid of it, but [you can] control it.” Similarly, Nathan explains that as you get older: “It doesn’t go away, but it’s easier to control.” As Crystal explains: “It will never leave you once you have it. But it’s just dealing with it that gets better.” Paige describes thinking that she would have ADHD forever, but recalls her parents telling her throughout childhood that she would learn to “cope with it.” She notes: “There is definitely a whole debate within psychology and everything, like whether you can grow out of it.” She explains: “My personal opinion is that you can learn to cope with it and alleviate the symptoms, but it’s never like gone.” Several participants saw their ADHD as a “disability” or “setback” that they would be able to manage over time. Kimberly, for example, recalls her parents telling her when she was diagnosed with ADHD in third grade that it was a “setback,” but assuring her that they could “deal with it.” These participants found hope in the idea that they would be able to better manage their symptoms over time.

Several participants (n=6), including those diagnosed with depression, GAD, and ADHD, describe thinking that their struggles were merely temporary, and in some cases, something they could overcome. Melissa recalls being told when diagnosed with depression her sophomore year of high school: “Depression was like having a dark cloud over you... Sometimes counseling and medication works. And sometimes it just goes away on its own.” Blake even thought at one point in high school that he had “conquered the anxiety.” Perhaps children are more likely to think they can overcome depression and anxiety, given that sadness and anxiety are sometimes temporary emotions.

Some recall struggling with conflicting views about the future outlook of their mental health problems. Michelle describes thinking that she could overcome her depression in middle and high school, but later learning that it would stay with her into adulthood. Highlighting the power of terminology, she explains that the Korean word for depression “sounds like something that everyone just goes through.” She explains that it might translate into English to “light anxiety,” noting, “It was a really over-used term in the Korean society and I felt like it was just going to go away.” She blames her mother for her misconception:

I wish my mom really explained to me what it was. Her definition of it was always like, ‘You’re really, really sad but some of that’s going to go away.’ But I wish what instead she told me was like, ‘It is like an actual disease. It is something that will last if you don’t take care of it.’

She describes her psychiatrist trying to explain to her that it would be permanent, but that this “contradicted” what she had “always known,” and she “didn’t take her seriously.” Michelle recalls thinking that she was seeing progress when her depressed periods lasted for shorter amounts of time. She notes, “This continued for several years, but then I realized that the magnitude of the opposites just worsened and worsened.” With her persistent symptoms, she eventually determined that she would not outgrow her depression.

Similarly, Matt struggled with the ‘outgrow’ and ‘forever’ narratives. He describes his excitement when he found information on ADHD on the internet in eighth grade, followed by disappointment when he read that there was no cure:

To be honest, I did a little dance like, ‘Yay, I know what’s wrong with me!’ [But] I was very dismayed by the fact that you couldn’t cure it. That was one of the bigger letdowns that I’ve ever experienced in childhood – that I would *always* have it. [...] I remember doing a little dance about it and then the realistic, ‘Oh *hell*’ as I scrolled further down the page. And I got very upset about it. I think I might have been crying about it at some point. But then was like, ‘Well you know what, if I’m going to have this, then damn it, I’m going to *make it work*.’ And I went back down and I’m like, ‘Okay, so how do you cope with this?’

He further describes weighing the contradicting messages that he received:

When I was a kid, I thought I would outgrow it. My father always told me that I would outgrow it. I think that’s a myth that needs to not be perpetuated because you *don’t* grow out of it. You grow *into* it.

Matt recalls challenging his father with this information after reading that it would be permanent online in eighth grade:

I confronted my father about the not getting over it thing... I was just like, ‘You told me I would get better.’ We had a long conversation about it. And he said that ‘you will get better. It’s just, you won’t get rid of it. You’ll get *better* at it.’ And that was a really good explanation.

Matt’s experience illustrates the challenge children face in negotiating the information they receive from multiple sources. It provides an example of a child weighing contradicting messages received from a parent and the internet. In some cases, children’s views altered over time as they pieced together information and developed their own understandings.

Resisting Negative Associations and Skepticism

Findings suggest that children resist negative associations and the societal skepticism about children’s mental health problems. For example, many participants resisted that their

diagnoses meant they were “crazy,” something was “wrong” with them, and they were “stupid.” They defended that their diagnoses were real, and that even children can have mental health problems. They resisted the idea that they were misdiagnosed or “faking it.” Whether or not participants embraced a medical or non-medical account of their struggles, they describe strongly resisting these narratives.

Resisting negative associations:

Participants describe struggling with several connotations attached with their diagnoses: that they were “crazy,” something was “wrong” with them, and that they were “stupid.” Some wrestled with these beliefs, in some cases trying to figure out whether they were accurate or not. They describe resisting these ideas, and embracing counterarguments. As these narratives constitute an attack on their identities, resistance against them reflects a defense against accusations against their character.

Participants’ accounts suggest that children may fear and actively resist the term “crazy” associated with mental health. Abby recalls in high school: “I really didn’t want to be crazy.” Chloe describes wrestling with this narrative when diagnosed with depression, GAD, and ADHD in high school: “I did think I was crazy, quote, unquote. But I mean I knew I really wasn’t, like, ‘I’m a functioning member of society.’” Shannon recalls feeling “weird” because she thought she was the only one among her peers with depression when she learned of her diagnosis in seventh grade. She recalls questioning: “‘Am I crazy or something? Do I need to go to a mental institution?’” She describes questioning her mother about this when she first found out about her diagnosis:

[My] first question was like, ‘Well, why didn’t you tell me?’ And then I kind of wanted to know like, ‘What do I do that’s abnormal? What made you think that?’ ... I asked her a bunch of questions and I was like, ‘Well am I a freak or something? Am I crazy?’ And she’s like, ‘No.’

For others, the diagnosis confirmed they were *not* crazy, and that something else was underlying their symptoms and behaviors. Ted, for example, explains the relief he experienced when diagnosed with depression his junior year of high school: “I was kind of reserved and excited about it, kind of just like, ‘I know that there’s something wrong now. I’m not just going crazy, and not just having these random thoughts. There’s something there.’” Similarly, Teresa explains the relief her diagnosis of depression in eighth grade brought her, given that others no longer thought she was “just a crazy girl:”

So when people know that this is the way – this is the reason why I was like that, it gives me a sense of relief because now they don’t think I’m just a crazy girl who has all these phases in her life when she’s really happy and really sad. And so it was kind of like a relief they know, like there’s a reason behind it.

The interviews suggest that participants experienced this relief when they were well informed of their diagnoses, and assured that it was not their fault.

Participants also struggled with the view that something was “wrong” with them. Some internalized this perspective due of a lack of information; they describe filling the silence with this idea. As noted previously, Matt explains: “I never really understood it until I went on the internet and got the info. Until then, I always figured there was just something wrong with me... I always just thought it was something wrong with me as a human.” He explains that before finding this information in eighth grade: “[I thought it was] some organ inside of me that was wrong.” Sarah also describes thinking something was wrong with her when she was told she had ADHD in third grade because it was not fully explained. As noted previously, she says of her mother: “I actually kind of felt she should have explained it better to me.” She suggests her mother could have told her that she was “no different from anyone else,” recalling that she felt she was “different” because she “wasn’t educated on it.” These findings suggest that children sometimes fill the silence with even more distressing narratives than the information their

parents withhold.

The interviews also suggest that participants resisted the view that something was “wrong” with them, emphasizing that they were just “different,” when their parents helped them understand their diagnoses in this way. Crystal, for example, recalls being teased by classmates shortly after being diagnosed in second grade when her teacher announced that she was going to a “special class” for extra help. She recalls her mother comforting her by explaining she was just “different”: “I thought it was a bad thing. And then my mother sat me down and explained to me, ‘It’s not a bad thing. It’s a different thing.’ And then I was fine with it.” Similarly, Cindy recalls her mother being “very supportive,” explaining there was nothing wrong with her, but there was something they needed to work on:

She really tried to walk a fine line between helping me accept my problem – not ‘my problem’ – but helping me accept *my condition*, and also kind of saying ‘You’ve still got to work through it’... There was no, ‘There’s something wrong with you.’ There was, ‘How can we work through this?’

Similarly, when diagnosed with ADHD in third grade, Stephanie recalls her parents pointing out all of the differences that she “had already noticed” and focusing on how to move forward:

“This is why you are this way. It’s not like there’s anything wrong with you. It’s that you have this something different that causes these differences and this is how we’re going to fix it.” She explains her reaction:

I was kind of excited because it was like, ‘Oh, all of these problems I’ve been having, there’s a way to fix it possibly and it’s not just that I’m stupid or anything.’ I mean I know a lot of people when they hear that they have a disorder or something, they get really upset and feel like there’s something wrong with them. For me, it’s more like, ‘Oh, there’s *not* anything wrong with me.’

She recalls thinking when told: “Oh, right, well, then there’s not really anything wrong with me. That’s just different.” They describe the comfort that came with assurances that they had

something that made them “different,” but there was not something “wrong” with them.

Especially those diagnosed with ADHD also strongly resisted the belief that they were “stupid.” Again, several participants note that their parents helped them find this position. Kimberly notes that her mother clearly explained to her that her ADHD was separate from her intelligence when she was diagnosed in third grade: “My mom emphasized like, ‘It’s not about that. It’s about the way your brain organizes and thinks about things like that. It’s not about being smart. It’s a separate thing.’” Similarly, Sam recalls his mother explaining his ADHD diagnosis in third grade: “This wasn’t any level of my intelligence. It was something that was based on my ability to pay attention and to learn and things like that, as opposed to my level of being able to comprehend.” Sam notes that both his mother and his teachers told him repeatedly that his ADHD “wasn’t a level of intelligence.” He recalls not being able to fully accept this, however, until he got to high school and realized he was among the top in his class. Others realized over time as well. Faith describes at first thinking that her peers who had ADHD were “dumb”: “It took me a little while to realize that ADHD doesn’t mean dumb, because I always associated the two together.” Joe recalls that when his father explained his ADHD diagnosis to him in fifth grade, he realized that he had something that could be “attributed” to his trouble in school. He realized that he was not “dumb” just because he had trouble paying attention in school. These examples illustrate participants teasing apart intelligence and concentration. They preferred to understand ADHD as causing trouble paying attention, rather than an indication of low intelligence.

Many of these participants describe the comfort brought by understanding their diagnoses as unrelated to their intelligence. When describing life before and after her ADHD diagnosis in third grade, Stephanie notes: “It’s like night and day. Things just got a whole lot better after I

was diagnosed, not even just because I had the meds but just because I understood, and then I didn't feel stupid anymore.” Joe notes:

I kind of figured out that, ‘Oh, I actually have a diagnosis. I have something that has a name that can be attributed to this. It’s not that I’m just – it’s not that I’m dumb. It’s that I just – I can’t pay attention as well as other people.

In particular, they found comfort in understanding their ADHD as causing difficulty focusing, but not indicating a decreased ability to comprehend.

Resisting skepticism:

Many (n=10) defended their ADHD diagnoses, arguing that they had a ‘real disorder.’ In particular, they defended against peers, siblings, fathers, and teachers who did not believe in the existence of their mental health problems. Faith, for example, notes that: “Sometimes people will be like, ‘Oh, it’s not a real thing.’ So then I’ll be like, ‘No, but it actually is.’” Interestingly, Christine embraced a scientific view of ADHD as a response to those who said it was not real: “I hate when people are like, ‘Oh, AD[H]D is not real’ ... Like, ‘It is. My blood flowing in the front of my head is slower than yours or whatever so I can’t organize as well.’” Teresa describes defending against her peers in high school: “With ADHD, they were still always skeptical like, ‘No, that’s made up.’ And [I’d] be like, ‘Actually, it’s not.’” She describes convincing siblings and peers that it is real:

I remember when I told my sister, she was like, ‘What?’ And like, ‘What is that? What are you talking about kind of crazy nonsense?’ And then I told my closer friends and they were like, ‘What? That’s made up.’ No one actually believed it and I was like, ‘If you guys can actually tell how many hours I put into studying, you guys would realize.’ And that’s when they were like, ‘Oh, yeah, wow.’ Like, ‘Whoa.’

Similarly, Gary describes arguments he had in high school with his father who he recalls “denouncing” ADHD:

Those conversations were really confrontational. So I would argue saying, ‘You don’t understand what I’m going through.’ Plus it was this teenage rebellion phase... My communication skills weren’t that great. So it would just be a shouting match. So I would just be saying, ‘I have ADHD. I have ADHD.’

He notes that his father’s skepticism did not cause him to doubt his own diagnosis: “I never doubted that I – after I started reading and seeing that the stuff that I’ve read matches up with how I act, there is no doubt in my mind... that I have it.” Meanwhile, Matt describes his frustration with teachers who did not take his struggles seriously in middle school. He notes: “It’s like I’ve got ADHD. I *do* have an issue and you *do* need to work with me with it. And that was one of the big things: teachers didn’t take it seriously.” Children therefore take on the role of arguing that they have legitimate problems.

Particularly those with depression wrestled with the belief that children are too young to have the disorder. Both Michelle and Melissa describe adopting this from their parents. Michelle describes her mother, in particular, saying that she was too young to be depressed when she was diagnosed in seventh grade. She describes her parents’ viewpoint: “They just thought that it was a phase because I was what, like 12, 13? They thought it was normal for kids at that age.” Similarly, as noted previously, Melissa says that her father did not want to believe “it was happening at such an early age” when she struggled with depression in early high school. She recalls thinking throughout her childhood that “young people” could not have depression.

As described above, Sam recalls embracing the idea that children are over-diagnosed and over-medicated, even at a young age, and Courtney suggests that she herself was misdiagnosed. While others may have agreed that children’s mental health diagnoses are over-diagnosed and over-medicated on a societal level, unlike Courtney, they insisted that it did not apply to them. As Paige describes: “People are ignorant towards it. They think they know more than they do. They think that there is an over-diagnosis, which there is, but that doesn’t mean that everyone

who is diagnosed with it doesn't have it." Interestingly, Paige, who reports being diagnosed in first grade, notes: "If you have succeeded until you're like 16 without it, you can keep going without it." Similarly, Kimberly explains that she knew her diagnosis was "legitimate" and not "a cop out" because she was tested and diagnosed at a young age (in third grade). She was able to distance herself from those who were misdiagnosed by focusing on the fact that she was diagnosed at a young age. While some participants accepted this, they tried to distance themselves from this phenomenon.

Especially those diagnosed with ADHD also wrestled with the view that children fake mental health problems for the benefit of treatment. In particular, they struggled with the idea that parents pay to diagnose children with ADHD to give them an advantage academically. Leslie notes that her own brothers accused parents of paying for their children to get extra time on the SATs. Autumn recalls believing her peers when they told her in middle school that her parents paid for her in-school services: "I thought it was because my parents had a lot of money so they paid for me to have extra time on tests. I think I thought that because I think someone told me that in middle school." She recalls her peers saying, "You're just a little rich girl because your parents paid for you to go through the testing so you were allowed to do it." She describes a friend explaining: "It's how rich kids pay to do better on tests." She recalls questioning, "Oh, no. Did my parents do this because they just had the money and wanted to really make sure I would do well on tests or is it because I really need it?" She noticed many of her peers being diagnosed in high school, and recalls wondering: "Do these people really have it? Do I really have it? Am I faking it?" Autumn eventually concluded in high school that she did have ADHD and needed the extra time by "monitor[ing]" herself and comparing herself with her peers. She suggests that peers were prone to accuse her of faking ADHD, because it was

invisible:

I think in high school people thought I was faking it as a crutch because they were like, 'Nothing's wrong with you.' Because it's kind of like when you have an internal inner injury and you have terrible pain all the time and people are like, 'Oh, you're just fine.' And it's like, 'No, you can't see the physical-ness of it.' I think people were like, 'Oh, you look normal. You're not – you don't need it. You don't have ADHD. You're normal. You talk normal.' I don't have the social problems. I had friends. So I think because they didn't physically *see* it on me, they were like, 'Oh, she doesn't have it. She's faking it.'

Autumn's experience illustrates the sense of insecurity children go through as they wrestle with these narratives.

Several participants (n=7), all of whom were diagnosed with ADHD, describe defending against the accusation that they were faking their mental health problems, especially among peers and siblings. Kimberly uses the term "defending," noting: "I remember kind of defending myself to others when I got a little bit older, probably in like sixth grade. [...] Because it hit a point where everyone was... saying, 'Oh, I have AD[H]D. I can't focus.'" Christine describes defending against a classmate in high school who questioned why she was able to take extra time on tests. Christine recalls: "She would just be like, 'How come you get to do that, Christine?' And [she] would be very much in my face, and I was like, 'Well, you don't have AD[H]D, so you don't get to ask me that stuff.'" Autumn describes arguing with her siblings who accused her of faking her ADHD for attention in high school:

Yeah, they thought I was faking it... They saw that I was getting all of this attention from Mom, going to these different therapists and testing people. They'd be like, 'Oh, why is she going there? She's faking it. She just wants attention.' I was like, 'No, I would love to be left alone from Mom and go to the mall or something, it's not for attention.'

She also describes defending herself against classmates who also accused her of faking her ADHD diagnosis:

I think high school was hard because people would be like, ‘Oh, I want that, too.’ Like, ‘Oh, so what do you do? You just pay money and then you get to have extra time? And you go in and just pretend you’re a little bit stupider than you are for these tests?’ And I was like, ‘No, like I didn’t pretend I was any stupider. I really tried on those tests.’

These provide examples of children actively resisting and confronting those who accused them of faking their problems.

As part of defending their diagnoses, participants also describe “proving” their diagnoses, demonstrating their struggles to those who accused them of faking their mental health problems. Crystal describes proving her ADHD to her extended family members by demonstrating her difficulty reading: “So I picked up a book and started reading out loud and I couldn’t do it. And I was like, ‘Do you think I’m kidding?’ And so they kind of realized.” Similarly, Autumn describes defending against her peers’ accusation that she was faking her ADHD in high school by explaining to them how challenging math problems were for her, showing them how difficult it was to even retain a phone number. Teresa also explains the process of convincing peers that she had depression by demonstrating her struggles to them over time in high school:

At first everyone kind of went through the, ‘No, you don’t.’ And I was like, ‘Yeah, I do.’ And then they’re like, ‘Okay, you do’ stage. But it took a while for them to realize that I had it. But yeah, I feel like people didn’t believe it because they just didn’t know. They had to –I had to explain what it – what everything was and how it affects me and compare my normal emotions... compared to their emotions. And I’d have to show them like, ‘This is what I used to think, and this is how you guys normally think. This is completely different. You guys find happiness in little things and I don’t find happiness in anything.’ So showing them how different I was helped.

She describes explaining depression to her best friend: “I had to do the comparison, like, ‘This is your feelings. These are my feelings. This is what happens. This is why I’m different.’” Teresa notes that demonstrating the difference helped her friends understand and embrace the idea that she actually had a problem.

This research therefore suggests that children actively negotiate narratives about their diagnoses. They embrace some, while resisting and defending against others. This is a clear example of the interpretive reproduction model, demonstrating that children both interpret and contribute to the discourse about their mental health diagnoses.

These findings also build on the medicalization literature, demonstrating that while some participants resisted medicalized accounts of their diagnoses, they often embraced these medical narratives when they obtained in-depth medical information over time. Demonstrating mixed understandings, some embraced the idea that they had a genetic, permanent disorder, while others viewed their mental health problems as everyday struggles that would improve over time. While some resisted the terminology of disorder and disease, others embraced scientific terminology, even employing it when defending against those who accused them of faking their problems. My interviews therefore demonstrate mixed responses to the medicalization of children's mental health problems from children's perspectives.

Participants' Recommendations for Learning about Diagnoses

Participants' recommendations for sharing information about mental health problems fall into three categories: general guidelines for sharing information, recommendations for *how* information should be delivered, and recommendations regarding what explanations should be provided. Participants strongly emphasize the need for information, and recommended several ways in which children can receive and obtain this information. They also provide suggestions regarding the narratives that should be embraced (and avoided) when explaining diagnoses to children. These suggestions contribute to our understanding of how to best share this information.

General Guidelines for Sharing Information

When asked how children should learn about their mental health diagnoses, most participants emphasized that children should be provided information. When reflecting back on their experiences, participants note that information was empowering for them. As Krista explains: “Just understanding things is empowering.” Natasha notes: “All I knew was that it was something that I did not want to be associated with. But then I learned about it.” She describes the benefit of learning about ADHD in a pamphlet provided at a summer learning program shortly after being diagnosed her freshman year of high school: “With more knowledge, it just – it got better.” Similarly, Jennifer describes the benefit of being able to research her diagnoses in late middle school and high school: “It was a really difficult time, but I guess the only way to keep myself grounded was to learn more about it.” She notes: “Having a diagnosis that I was able to research [is] what made it easier to take care of it. Because I wasn’t just different; I was different in *this way* and I could research about it.” They suggest that information and knowledge helped them manage their mental health problems.

Participants emphasize that adults should be open and honest with children, and provide information to them, even when difficult. Max notes that adults can show respect for children by telling them “everything about it.” He emphasizes: “Honesty is important.” Abby describes “openness and honesty” as the key to explaining diagnoses to children. She speculates that she would have been more accepting of her bipolar diagnosis if it had been more openly discussed with her: “If they had just been honest and sat me down and talked to me about it, I probably would have accepted it more.” Ted notes that adults should be honest that it is going to be a “struggle” and “it’s not going to get better right away.” Whitney explains that providing information to children gives them something they “can work with.” She explains that it is

important to follow the delivery of diagnoses with on-going communication and sharing of information. Stephanie warns against parents who are not open with their children:

I think a lot of parents, they don't want it to be a big deal but they really think that it is and because they are so eager to withhold information, or not want to try medication, they make it a big deal by doing that. So, I think you just have to be really open about it and you don't have to go into the nitty gritty scientific details but, I think the way that you make it digestible information for a child isn't by withholding information. [...] I guess I just wish that people – that parents weren't so uptight about it because I feel like that's more damaging than being open about it would be. And like I said, that they get really uptight because they don't want to make it seem like it's a big deal and they're like, 'How can I minimize this? How can I minimize this?' And in doing that, the kid can see that they're doing that. So I just feel like the way that parents and adults in these kids' lives should be handling it is just not getting so freaked out because the kids can see that. If they're open about it and they explain exactly what it is, not, 'Oh, well, people are going to think this.' Just say, 'Oh, well, it's just, you're a little bit different and this is what it causes for you.' Like, 'Oh, you have a hard time reading' or whatever. And, 'This is how we're going to fix it.' Like you don't have to make it a whole big thing that you have to protect them from because it's their life. You can't protect them from that.

In this powerful quote, Stephanie describes the consequences of withholding information from children. She explains the importance of openly sharing information so that children fully understand their diagnoses.

Participants also suggest that information should be introduced directly, but slowly over time. As Stephanie explains: "You would want to be introducing the child to the idea I think right away, just in whatever way is age appropriate. Moving forward, more information as they get older." She thinks that children are not developmentally able to understand the terminology of "disorder" until they are "pre-teen[s]." She suggests, however, that it is important that it is still "talked about" with "a very small child," though terminology used may change over time. Similarly, Cindy explains that while children are "very intelligent," there are "certain things that you have to build up very slowly." She notes:

The child needs to be very slowly introduced to what it is because understanding that your thoughts work in a certain way is kind of mind-blowing... I think it's important. I

think it should be done. But it has to be done very carefully... if you don't completely understand it, it's not helpful.

Krista also notes, "It probably has to be more of a process than just like telling them once." In particular, she suggests it is important to introduce techniques to manage the problem over time, or children might just think, "I have ADHD. It's not my fault, so I don't have to do anything." As Gary explains, "At a young age you're probably not going to want to hear that [you have a disorder]. But I feel like... you'll come around earlier if you hear about it earlier." Abby notes:

If it had been explained to me as not like, 'You're f***** up,' but like, 'Your brain is just different and it's not your fault. It's no one's fault. It's just how it happened and it's a build up of a lot of stuff, but there's something you can do about it and you will be happier.' Maybe, I probably would have been more receptive to it, but it probably would have taken time and it probably would have taken being told that a lot. Because I know that I had a very strong inclination to just recoil from that kind of stuff. But yeah, I'm sure if it had been presented differently, it would have at least been – I would have been closer to accepting it at a younger age.

She notes that if adults had presented information differently when she was first diagnosed in high school, and also presented it repeatedly over time, she may have "accepted" her diagnosis. Similarly, a few participants note that information about mental health problems takes time to "sink in." Tabitha suggests:

I think I'd like to just be given like, 'This is what it is.' Kind of a very straightforward – if that's possible – kind of a thing. I don't know that I would have wanted it right away though. I mean maybe I would have. I actually probably would have, knowing me. But I guess once you realize it and then it has time to sink in more, so you want to know.

Paige also references the importance of giving time for the information to "sink in," explaining, "It's going to take time."

Participants suggest presenting information simply, and informally. Mark for example suggests: "Simplify it more. 'This and that,' rather than, 'This, this, that, that, and the other.' That's too much... Say it again. Say it a third time. Ask me do I get it. Maybe ask me to

explain it back.” He notes that this would be better than the “really scientific” explanation that he received and did not understand. Kimberly explains:

In my opinion and judging based on my experience, [it’s best] to learn about it just from conversations, like nothing formal. Because I think it’s important to not treat it as like, ‘You have been diagnosed with this disease. Here are the statistics.’ I don’t think that’s the right approach to take. I think trying to have a conversation.

They emphasize that understanding takes place through informal discussions over time.

Recommendations for How Information Is Delivered

Participants note there may be ways to “show” rather than “tell” children about their diagnoses. Crystal suggests: “Show them with cartoons, show them with drawings, tell them stories.” Autumn explains that she was really able to understand her ADHD by seeing how she struggled on math problems in high school; she notes that she was given puzzles and math problems during her testing, but no one explained to her that her difficulties were due to her ADHD. She notes: “I think the best way to explain them is to show them, not tell them.”

Amanda notes that it might help to show a young child pictures to demonstrate how they feel and think differently.

Participants also emphasize the importance of giving children reading on their diagnoses. Gary suggests: “Introduce them to some literature. I mean even at a young age, you can kind of dumb it down for them.” He explains from his own experience, “I felt that the best way for me to learn about it was not to hear it from people, but to read about it.” He explains that it is easier to process written information because you can return to it again and again. He notes this is particularly helpful for those with ADHD, who need repetition to fully process information. Autumn suggests that if someone had given her “a booklet on what ADHD was” and better explained it to her, she would have been “more receptive” to learning about it. Teresa notes, “It would have just been helpful to have like, ‘Oh, here’s a book. Read. Read it whenever you want

about this' instead of it being like a sneaky process for myself.” When asked why she was not given this information, Teresa speculated that it did not ‘click’ with adults in her life that she wanted to learn about her diagnoses. Both Teresa and Tabitha suggest that there be “fun” books for children that describe their diagnoses. Teresa notes that these can be geared towards children as young as elementary school. Devin notes that it would be helpful to have books for young adults. Leslie also suggests parents might consider doing research on diagnoses *with* their children.

A few participants also suggest that children should be encouraged to look up information on the internet. Erica, for example, recommends children look up ADHD online so they can see how common it is, that there are ways to help it, and that it is possible to succeed despite it. Max notes it is important for children to look up information online because “awareness” of the problem is helpful. Many note that the information on the internet today is much more extensive than when they looked up information in their childhoods. Cindy describes recently looking up information online for a friend and thinking: “Gosh, I wish this had been there six or seven years ago.” Krista notes that it can be good to read information online privately. She explains: “Those aren’t the sort of realizations and discoveries you want to make with a lot of people around.” She notes that it is helpful to have a private space where one can process the information.

A few participants also note it would be helpful to use media to illustrate mental health problems to children. Joe describes a commercial that he saw in middle school, in which ADHD was depicted as the channel being constantly changed in a person’s brain. He notes that this “exaggerated imagery” that children can relate to could be used for them to understand their diagnoses. Crystal notes that diagnoses can be explained through cartoons, drawings, and

stories. She also suggests children relate to characters with ADHD symptoms, such as Tigger in A. A. Milne's *Winnie-the-Pooh* or Percy Jackson in Rick Riordan's *Percy Jackson and the Olympus* series. Monique suggests that an educational television show could explain depression to children.

Participants also emphasize the importance of providing information in schools. James suggests that teachers should talk about how "everyone's brain is different" in biology classes: "I mean there is already sex ed. in school, why not brain ed.?" Monique points out the importance of discussing depression in schools given the amount of bullying that takes place. She recommends that teachers and students discuss the seriousness of depression in health classes. Ted recommends showing videos about depression in schools, but warns against videos that exaggerate the symptoms.

Findings suggest that adults can play an important role in helping children process information that they receive over time. Gary, for example, explains:

Most of the knowledge I have about ADHD is stuff that I read in books, and stuff that I read in health class, and stuff that I read on the internet, rather than from my actual doctors and my therapists. And it would have been a *lot* more helpful if they kind of counseled me through it.

While respecting children's need for space (e.g. their desire for privacy when reading information online), mental health professionals, parents, and teachers can support children by providing and guiding them to valid sources of information, and also discussing information with them, to help children make sense of the information they obtain.

Recommendations for Explanations Provided

Providing medical information: "I want facts"

Those who obtained and embraced medical information on their diagnoses suggest that providing scientific details about the nature of mental health problems can be helpful for

children. In particular it can absolve them of blame. For example, Matt found comfort in learning online in eighth grade that ADHD was a “neurological thing.” Abby, who came to embrace the medical perspective when she researched bipolar disorder in early college, explains that learning more about the “chemical imbalance” underlying bipolar disorder would have helped her understand that she was not a “bad person” when she was diagnosed in high school. She emphasizes the importance of providing “the biology behind it” and explaining, “it’s not their fault.” Others emphasize that children want to know scientific “facts” related to their diagnoses. Teresa, who embraced the medical narrative when she read about depression and ADHD at the library in late middle school and high school, notes that she wishes she had received a scientific explanation from adults:

I just had so many questions and they were just like, ‘You have this. Come on, you can do it.’ They were just giving me words of wisdom. And it’s like, ‘I don’t actually want words of wisdom. I want facts. I want to learn what *this* is,’ which was the most frustrating part for me because no one—everyone just wanted... [to] give the nice summary like, ‘Oh, it’s okay. You’ll be fine. Medications are great.’ They just didn’t tell me like, ‘You have a chemical imbalance. Like, ‘You have *this*,’ which is what I wanted.

Tabitha warns that adults should make sure they are not “reckless” but “communicative” with “science facts.”

Several participants emphasize the importance of explaining how diagnoses will affect children, rather than simply providing the textbook definition. Teresa, for example, explains that she wanted to know “‘How is it going to affect me in the future? ... Are there different stages? When would be the ups and downs? What do I do?’” She notes:

[My counselors] didn’t give me what it was, how it affects my body, like what’s happening to me. And that’s what I wanted to know... for depression I think my counselor should have given it to me. Or at least spent like two or three hours explaining the situation. And I know time is money, but it’s going on and it’s your life. You need to learn.

This quote illustrates children’s desire to understand the illness experience, and in particular, how it is going to affect them in the future.

Informing without utilizing the terminology of disorder: “[It’s] really important to not put a stamp on the kid’s head”

Meanwhile, those who embraced non-medical accounts suggest that adults can be open with children without utilizing the terminology of “disorder.” As noted above, James, whose parents did not use the term ADHD, recommends that children have the “chance to develop” before being introduced to the medical terminology of diagnosis. Stephanie, whose parents also embraced a non-medical account of her problems, similarly suggests that while adults should talk openly with young children about depression, they should not describe it as a “disorder” at a young age:

I’m not sure if I would tell a very small child until they were in more of a pre-teen age where they would be able to sort of understand it. I think it would still be something that was talked about but not in terms of having a disorder.

Similarly, Chloe suggests that non-medical narratives should be used and that the term “disorder” should be avoided:

It’d be really important to not put a stamp on the kid’s head and say, ‘This is what you have.’... I think it would be really important to kind of explain things to them in ways obviously that they could understand on their terms. But, and not so [much in] I guess threatening of a way – in a less defining way, so that they understand that there’s something else going on that could explain how they’re feeling or things that are going on with them. But also to not *define* them... younger kids, especially, being more vulnerable and developing and growing, I think it’d be really bad to tell them that they have this disorder and things like that because I think it would end up giving them a label. Avoiding things like that would be really important. And I think if there was a way to explain things to a child like, ‘This is what’s going on with you’ without saying, ‘You have this disorder and this is what’s wrong with you,’ would be one of the best ways to go about it.

She suggests that there might be a way to share information while avoiding medical accounts that “label” children.

Focusing on assurances: “Tell a kid... ‘Don’t be ashamed’”

Whether using a medical or non-medical approach, participants strongly emphasize the importance of including assurances when describing diagnoses to children, noting that assurances can be even more important than definitions. Melissa notes that it would have been helpful if her doctor had “used better bedside manner” when she was diagnosed with depression her sophomore year of high school and reassured her that a diagnosis of depression “doesn’t mean that it’s the end of the world.” She says: “[That] would have set my brain a little bit more at ease.” Krista explains that a full explanation could be “a little bit too much to be spinning in a little kid’s head,” and acknowledges the difficulties parents face in delivering information to children: “Honestly, being told that your head works different than the rest of the population is never all that fun of a thing to hear. That always sucks.” While she suggests it might be best to provide a full explanation when a child is in late middle school, she also notes it is important to provide a basic explanation to younger children, and to emphasize that they should not feel guilty and that they will work on improving symptoms. Noting that young children can have difficulties fully understanding diagnoses, participants suggest it is important to provide assurances in a caring and empathetic way.

In particular, participants emphasize the importance of telling children how common their diagnoses are, noting that they found this information especially empowering. Before her diagnosis of depression, Teresa recalls thinking, ““Why is this just me?”” Shannon recalls feeling “isolated” after learning of her ADHD diagnosis in middle school, until she learned that other peers had similar problems in high school. She notes: “I eventually learned that there were

people who had it, not just me. And I feel like if I didn't know, I would feel like... some kind of weirdo that had these feelings inside them.” Similarly, Sarah describes feeling like her diagnosis was a secret that she had to hide until she began overhearing peers talking about it in high school: “I realized that it wasn't such a big deal because other people were talking about it.” Similarly, Ashley recalls that ADHD was a “hush-hush” thing until it was more openly discussed in health classes and among peers in high school. Some emphasize that they would have had better experiences if they had understood how common their diagnoses were earlier, and underscore the importance of sharing this information with children.

Participants also emphasize the importance of assuring children that their mental health problems are legitimate. Kimberly, for example, notes that it is important to explain to children they have a “legitimate grievance” and “deserve to deal with it.” She recalls her mother telling her: ““This *is* a real, genuine problem... but we can deal with it,”” noting that she found this helpful. In particular, this can help children as they defend against those who argue that their diagnoses are not real.

They highlight the importance of explaining that mental health problems are not children's fault and that they should not be ashamed of their diagnoses. As Michelle suggests: “Tell a kid like, ‘It's not bad to have a depression. Don't be ashamed of it,’ things like that.” Krista notes: “It's important to be like, ‘Don't feel bad.’” She explains: “I think you just kind of have to make it clear that it isn't all their fault and they have more difficulty. Try and be understanding.” She notes:

I feel like it wouldn't have made me feel as bad all the time... if I had actually understood that it wasn't all my fault [when I misbehaved]... Being told like, ‘This is why you have trouble [and] this is how you can deal with it,’ like, ‘Things are a little more difficult for you.’ I think that would have been helpful because I kind of just blamed myself for everything.

In particular, they describe the empowerment of explanations that put the blame on something outside of themselves. Devin notes:

I guess I always attributed being bad at – doing badly in school and not turning in my assignments to just lack of discipline and lack of whatever. Because all of my teachers told me I was lazy. And so I was just kind of confused and it's like, 'Wait, there might be something else there.' And I mean aside from just that. Because that was a big part of it for me. And it was a little bit of a relief at the time, too, because I always got really frustrated at myself for not focusing and getting things done and, now I had sort of an explanation for it.

Further, Cindy suggests that anxiety, depression, bipolar, and ADHD should be explained as a “facet of who you are that needs to be compartmentalized and taken care of.” She explains:

You can compartmentalize it, and you can put it in a box. And for me, one of the ways I manage my anxiety is... I'll have specified worry time, and then after that, I don't worry – I compartmentalize my worry. So when I could classify it and put those symptoms in a box for the way my brain works, it was helpful.

Assuring children that their mental health problems are something they can isolate in this way is important because it can help children separate their problems from their identities.

Similarly, many stressed that adults should assure children that their diagnoses indicate there is something “different” about them, but it is not “bad” or “wrong.” Stephanie suggests parents explain: “Well, this is why. It's because you have this difference and not like it's anything bad. It's just different. Some people have blonde hair, some people have brown hair, some people have AD[H]D.” James suggests: “Just kind of say, ‘You have a little bit of trouble concentrating.’ But treat it as a ‘you have green eyes instead of blue eyes’ kind of thing. ‘So what?’” Paige notes that some parents might not want to tell their children about their diagnoses because “there's a stigma associated with it,” but they should “present like, ‘You have this. You are different but there's ways to make it better.’” Joe suggests that adults emphasize that everyone is different:

I'm quite sure that every single person in the world has a little AD[H]D in them. It's just the severity to which it's at play. And so I think that if children understand that everybody thinks a little bit differently, just like everybody is talented a little bit differently, and that that's not necessarily a bad thing... If kids understand that everybody is different and those aren't necessarily bad things, I think that people would be much more tolerant of others.

Participants' experiences support this suggestion; as described above, participants' accounts demonstrate that children resisted the view that something was "wrong" with them, emphasizing that they were just "different," when their parents helped them understand their diagnoses in this way. As described above, Crystal recalls being comforted when her mother explained in second grade that it was "not a bad thing," but just "a different thing." Cindy recalls her mother being "very supportive," also noting that there was not "something wrong" with her, but just something she needed to "work through." Stephanie also recalls thinking that there was not something "wrong," but just "different," because her parents described ADHD to her in this way. By contrast, those who did not receive these assurances internalized the view that something was "wrong" with them. As described above, Matt recalls thinking there was "something wrong" with him "as a human" before obtaining information on ADHD on the internet in eighth grade. Daniela recalls: "[I remember] feeling like there was something wrong with me because my parents never talked to me about it." Again, these findings suggest that children can fill the silence with more distressing narratives than those that their parents withhold.

Participants also note the importance of explaining that the diagnosis does not reflect a child's level of intelligence. Kimberly suggests: "I think emphasizing that is good. Because it's important to see that it's not – kind of stressing it as a limitation less than a disability. And as something that can be worked with." As discussed previously, participants found it comforting to think of their ADHD as causing trouble focusing, rather than a reflection of their intelligence.

Participants also emphasize that parents should assure their children that their diagnoses

are not a “big deal.” As described previously, Stephanie notes that some parents are “so eager to withhold information” and resist having their child on medication, that “they make it a big deal by doing that.” Stephanie touches upon an important point – that withholding information and not talking about it can actually fuel children’s understandings of their diagnoses as a “big deal” in their lives. Whether they viewed their diagnoses from a medical or non-medical perspective, participants’ accounts suggest that they did not think their diagnoses were a “big deal” when their parents assured them they were not. Christine describes her parents explaining her ADHD diagnosis to her the summer before fifth grade: “They presented it like not in a way that it was a big deal. They were just like, ‘You have this and it’s fine.’ It was very calm. It wasn’t a big deal.” Similarly, Stephanie explains: “In my upbringing, it was just not a big deal. It’s not like it wasn’t serious, but it wasn’t a big deal – so it wasn’t a big deal to me.” She notes: “It was just like, ‘Oh, okay, so this happened. So this is what’s going to happen now. All right. Moving on.’ Like it wasn’t a big thing.” Those who did not receive these assurances, however, felt that their diagnoses were a “big deal” in their lives. Sarah explains that she felt her diagnosis was a “big deal” because her mother did not provide her a thorough explanation, and she thought she had a “big secret” to “hide.” She notes:

Now I know that it’s just no big deal at all, but then I was, I didn’t want to talk to anyone about it and I didn’t tell my friends and I felt like it was this big deal – this big secret that I had to hide.

Devin explains that he experienced his ADHD and depression as a “problem” because of the way his parents treated the diagnoses. He notes: “They were always really negative about it. It was always like, ‘You’ve got this *problem*. Instead of just, ‘You’ve got this. It makes you a little different from the other kids. That’s okay.’ It was never okay.” This suggests that parents have the power to allay children’s fears, and help them develop understandings of their diagnoses as

something that can be managed; withholding information and not discussing diagnoses can actually fuel children's perceptions of their diagnoses as a "big deal" in their lives.

Conclusion

This chapter sheds light on the meaning-making processes of children, as they obtain information and negotiate multiple narratives about their mental health diagnoses throughout their childhoods. Findings underscore the power of discourse in shaping children's experiences and understandings, as well as the role children play in obtaining information and negotiating and interpreting these narratives. In the world of mental health, which relies so heavily on medicalized language of pathology, it is imperative that social workers question how to best frame narratives to empower, rather than stigmatize. Here, I raise the question of how to best frame narratives from *children's perspectives*. Sociologists have explored the social benefits and drawbacks, or "brighter" and "darker" sides of medicalization (Conrad & Schneider, 1992, p. 246). But to what extent do *children* want (or not want) their problems to be medicalized? What explanations are best from their perspective? This has implications not only for how parents, mental health professionals, and teachers explain diagnoses to children, but also how we frame and construct narratives at a societal level.

I discuss how children seek and obtain additional information, and develop their own understandings, negotiating multiple narratives over time. The interviews demonstrate children's agency not only in obtaining information, but also actively interpreting, challenging, and embracing narratives. Their understandings change over time as they obtain additional information, mature with age, and actively negotiate and construct their own understandings. Evidence of children's narrative negotiation provides insight into the active role that children play as they develop their own understandings. As suggested by the interpretive reproduction

model, they both receive and contribute narratives throughout this process. Their views and perspectives should be treated as worthy of study. Further, viewing children as agents in this process could offer a lens for understanding other types of identity formation in adolescence as well.

My interviews indicate a mixed reaction to medicalization among participants. Diverging from previous findings suggesting that many youth avoid psychiatric terminology when describing themselves (Moses, 2009a; Mowbray et al., 2002; Stride-Darnley, 2009), the data in this study suggest that many embraced medical narratives. Many of those who embraced this terminology describe at first resisting it, and then subsequently accepting it over time as they received in-depth medical information. Suggesting the saturation of medical narratives in both popular and professional mental health literature, including books, pamphlets, and the internet, participants describe exposure to medical accounts through these sources. Participants' accounts show that children often embrace medical narratives when they obtain this information. While incomplete medical information was confusing and even "scary," in-depth medical information provided an explanation and legitimized their struggles. They recall finding this in-depth medical information helpful, for example alleviating guilt and the idea that something was "wrong" with them. Separating the problem from one's personal "issues," or even illness in the body, by locating it as a "chemical imbalance" in the brain, for example, may have helped Abby and Matt remove blame – it was no longer seen as their *fault*.

Meanwhile, those whose parents were open and communicative without utilizing medical narratives suggest it is possible to share information with children without using the terminology of "disorder." In Chapter 4, I described the gratitude James expressed that his parents did not use the term ADHD when describing his struggles, because he would have felt labeled by this

terminology. In this chapter, I presented the similar experiences of several other participants, including Chloe and Stephanie's recommendations that parents not use the term "disorder" when providing information about their mental health problems. They strongly resisted this medical terminology, noting concerns about the stigma and labeling associated with this type of medical framing.

These findings suggest that it is important to share information openly, whether using a medical or non-medical framing. If medical explanations are provided, children should be given as complete information as is age-appropriate. While Krista notes that a full explanation might be "a little bit too much to be spinning in a little kid's head," she also emphasizes the importance of being as open as possible. Information should be presented in a way that is reassuring rather than confusing or "scary." On the other hand, based on the suggestions of Stephanie, Chloe, and others, we must question whether there are ways to achieve the goals of providing an explanation, legitimating problems, and shifting blame away from children, without framing them using a lens of pathology that locates problems within the individual and relying on the terminology of "disorder."

Further, a theme throughout participants' recommendations, for both those who embraced medical and non-medical narratives, was the importance of providing assurances along with explanations. There was consensus that it is important to provide assurances to children – to explain that their problems are common, legitimate, not their fault, not something "wrong" with them, not related to their intelligence, and not a "big deal." Assurances helped children to perceive their diagnoses as "not a big deal" and allayed fears that there was something "wrong" with them. When information was withheld, however, children often filled the silence with these

concerns. Assurances can play a crucial role in minimizing children's concerns related to their diagnoses, while withholding information can exacerbate these fears.

Lastly, I discussed participants' explicit recommendations, which have implications for how diagnoses are explained to children. Findings suggest that information should be shared openly, directly, slowly, simply, and informally. In addition to telling children information, information can be shown through examples, explained in reading materials, read on the internet, illustrated through the media, and presented in classes. Adults can help children process this information, directing them to resources and discussing the information they obtain. These recommendations are particularly important because they are based on the experiences and perspectives of those who went through the process of making sense of mental health diagnoses in childhood. Just as children's perspectives and suggestions can help improve strategies to explain physical illness to children (Whaley, 1999), participants' recommendations on how to best deliver mental health diagnoses can improve strategies to do so.

These findings contribute to research on strategies for explaining illness to children, in some ways supporting and in other ways contradicting Whaley's recommendations for explaining physical illness to children. Whaley (1999) criticizes the literature on explaining physical illness to children for focusing exclusively on strategies for explaining the etiology and biological nature of physical illnesses to children. Whaley (1999) argues that like adult patients, children want information on their illness experience (e.g. the normalcy of their illness, how their illness will disrupt their lives, how their illness will affect them), rather than information on the nature of the disease (e.g. its underlying causes). Findings contradict Whaley's (1999) suggestion that there is too much of an emphasis on the nature of illness in explanations, in that some participants found scientific terminology and the etiology and definitions of their mental

health problems to be helpful. Yet, other recommendations support Whaley's theory, suggesting that children are most interested in how the mental health problem is going to affect them. Some participants were interested in learning about the illness experience, rather than the nature of the "disorder." Findings are also in line with Whaley's (1999) suggestions that providing reassuring explanations and explaining the normalcy of one's illness are important to children. Participants note that explanations should emphasize that their problems are not their fault, do not reflect their level of intelligence, and are legitimate. Findings also extend Thompson's (2000) discussion of adult patients' need for thorough but simple explanations of physical health information, devoid of medical jargon, demonstrating that this applies to children as well.

Further research should examine what factors influence the information adults provide to children. As Eiser and Eiser (1987, p. 286) note, we need research on how the severity of illness and the characteristics of children and their families "interact with the information provided." This should include how these variables affect what information is provided and how it is understood.

Future research should also examine how children's understandings change based on their developmental status, as this provides important insight into how to best explain mental health problems to children. While participants emphasize the importance of being open and honest with children, it is exceedingly important that explanations be appropriate for children's developmental levels. Bibace and Walsh (1981) emphasize that an appreciation for how children understand illness through these developmental stages can increase health professionals' empathy with child patients, improve explanations of illness and medical procedures provided to children, and improve health education for children. A better understanding of how those with mental health problems understand their diagnoses throughout their developmental stages can

similarly improve empathy, explanations, and mental health education for children. Future research could help us to better understand what explanations are developmentally appropriate for children of different ages.

Findings also have important implications for social work practice. They suggest that whether or not practitioners utilize medical or non-medical accounts, they should be open with children and emphasize the assurances that participants found so crucial. For example, as noted above, Melissa notes that if her doctor had assured her that a diagnosis of depression “doesn’t mean that it’s the end of the world,” she would have felt “more at ease” when diagnosed her sophomore year of high school. Social workers not only play a direct role in sharing this type of information about diagnoses with children, but also an indirect role by educating and supporting parents who in turn influence children’s understandings. Social workers can support parents in the role they play sharing information and assurances with children. Furthermore, evidence that children continue to obtain information and negotiate narratives over time suggests that social workers’ role in educating children and supporting parents goes beyond the initial diagnosis; they can play a key role in educating and supporting children and parents over time.

Findings from this study raise the question of whether there is a way to be open with children and share these assurances without *pathologizing* children’s conditions. One promising approach in clinical practice is narrative therapy, in which externalizing conversations are used to objectify the problem, and distance it from one’s identity (White, 2007). As Young and Cooper (2008, p. 79) note, “Counter to the practices of pathologizing and diagnosing, it seems therapy participants experience externalizing problem discourse as significant and useful.” Young (2008, p. 57) notes that in her practice, children create their own descriptions of and names for problems, such as ‘the Worry’ rather than anxiety disorder. Through this process,

children are encouraged to describe their anxiety as an outside force that makes them feel and think in certain ways. Young (2008, p. 57) notes that “the problem is no longer tied to who he or she is as a person,” and this in turn opens doors to treating the problem. This approach is in line with participants’ recommendations that mental health problems should be seen as separate from one’s identity. Cindy’s suggestion, for example, that diagnoses should be “compartmentalized,” rather than seen as “something wrong with you,” supports the idea of viewing mental health problems in this way. While some participants found medical narratives helpful because they were able to locate a specific cause of their problems, narrative therapy aims to locate a cause, but goes a step further in alleviating guilt and blame by locating the problem outside of the individual.

In addition to shifting us away from the language of pathology, this approach also empowers the voices of children in therapy. By encouraging children to create their own language about their problems, practitioners can create the space for children to develop their own narratives about mental health, inviting their narratives directly into practice. A key to narrative therapy is “a way of being with children that gives primary value to how the child views his or her experiences” (Bennett, 2008, p. 22). Social work practitioners can recognize and engage children’s agency by respecting their ability to take part in conversations about their mental health, and by sharing information openly with children, as many participants urge them to do. By inviting children’s perspectives into practice, we can begin to give voice to children’s experiences and perspectives.

As I will discuss in Chapter 7, we must also consider how the externalizing principle, in which problems are seen outside of the individual, can be applied outside of the clinician’s office. We must question how this can be extended to the ways that institutions, such as schools

and insurance companies, frame children's mental health problems, and also how we all take part in the construction of these narratives at a societal level. As Bennett (2008, p. 17) describes, "The stories dominating the lives of children like those of adults are often shaped by the significant others in their lives," including for example, parents, peers, and teachers. In order to 'deconstruct' these stories, we must begin by identifying the "events and problems that give rise to" these stories (Bennett, 2008, p. 17). This is especially important because how mental health problems are understood affects not only how they are *treated*, but also how they are *experienced*. Does the child see his/her diagnosis as something that can be controlled, or even overcome? Does the child believe there is something 'wrong' with him/her – an innate, unchangeable aspect of his/her identity? Identity can be seen as a "social, relational and collaborative project," (White & Morgan, 2006, p. vi) and by contributing to narratives of failure, we can affect how children view themselves. While children actively negotiate narratives about their mental health diagnoses, embracing some and resisting others, participants' accounts suggest that the explanations adults provide to children and the social construction of mental health problems at the societal level have a powerful influence on how children understand their diagnoses, and themselves. We all play a part in the creation of these narratives and must consider how we can best frame them.⁹

⁹ An article based on this chapter is in press: Bringewatt, E. H. (In press). Negotiating narratives surrounding children's mental health diagnoses: Children and their contribution to the discourse. *Children and Youth Services Review*.

CHAPTER 6

Experiencing Diagnoses: Empowerment, Stigma, and Treatment

In the previous chapters, I explored how children learn about and make sense of their diagnoses. In this chapter, I explore how children *experience* these diagnostic labels and the treatments that they receive. As described in Chapter 2, sociologists have theorized about the promises and pitfalls, or “brighter” and “darker” sides of medicalization (Conrad & Schneider, 1992, p. 246). There has been much discussion about whether diagnoses are empowering or stigmatizing for individuals. Yet, the perspectives of children diagnosed with mental health disorders have been largely absent from this discussion. Do children experience empowerment associated with their diagnoses and treatments, for example finding relief in having an explanation for their problems and receiving medications and therapy? Or, on the other hand, do they experience stigma surrounding their diagnoses and treatments, including shame and embarrassment associated with them? Here, I add empirical data to this debate, exploring how children recall experiencing their diagnoses and treatments in childhood. Their perspectives can shed light on the pros and cons of the medicalization of these types of struggles.

Finding that participants often experience *both* empowerment and stigma, I begin by discussing the empowerment many recall experiencing when first diagnosed and then turn to participants’ descriptions of the stigma they experienced surrounding their diagnoses. These findings shed light on the complexities of diagnoses, which can have interwoven benefits and drawbacks – often experienced simultaneously. Further, I examine the aspects of participants’

diagnoses that they found empowering, which informs ways to enhance empowerment in the future.

How participants share and discuss diagnoses and treatments further sheds light on how children experience and manage this information. I describe participants' experiences both sharing and hiding diagnoses and treatments from others, especially peers. I explore the differences in whether participants shared this information, how and when they chose to do so, and with whom. This includes a discussion of the reactions they recall receiving, and the emotions they describe experiencing when discussing their diagnoses with others. This discussion demonstrates the complexities of managing diagnostic labels and treatments.

Next, I discuss participants' treatment experiences and their involvement in decisions about their care. As described in Chapter 2, research has highlighted the importance of children playing an active role in treatment and therapy, listening to children, and involving them in decisions related to their treatment (J. Davies & Wright, 2008; Hepper et al., 2005; Laws, 1998; Moses & Kirk, 2005; Roth & Roth, 1984; Stith et al., 1996; Strickland-Clark et al., 2000). Here, I examine how participants in this study recall experiencing their treatments, and to what extent their voices were included in decisions about their care. Their perspectives on treatment have important implications for improving mental health services for children.

Finally, I present participants' explicit recommendations for treatment. Their recommendations are particularly insightful, given that they have experienced these treatments themselves. Their suggestions can greatly inform future care.

Empowerment Experiences

Participants describe several ways in which their diagnoses were empowering to them. In particular, they found diagnoses empowering when they were presented and/or experienced as

providing (1) an explanation, including an underlying cause for, validation of, and name for their struggles, and (2) the possibility for change, including motivation for change, treatment options, and coping strategies.

Providing An Explanation

Many participants emphasize that their diagnoses “made sense” and note how helpful they were when understood as an explanation for their behaviors and symptoms. In particular, participants with ADHD reported that the diagnosis helped to explain the difficulties they were experiencing in school. They note that it “made sense” that there was an underlying cause for their symptoms. Chloe recalls that after being diagnosed with depression, GAD, and ADHD in high school: “It made sense that the things I was struggling with, now there was something underlying it.” She notes:

It was actually kind of I guess a relief in a way because it just, not really gave me an excuse, but gave me a reason as to why I couldn't just sit there and read the book in class like everyone else or my homework... would take forever. It just made more sense.

Similarly, Christine notes that her ADHD diagnosis the summer before fifth grade “was really helpful,” recalling it helped to know “why I acted a certain way.” Meanwhile, Teresa recalls that her depression and ADHD diagnoses “made sense” because she could relate to the research: “Everything just clicked. It all just made sense. The way I felt was what people were writing about, so I knew what the researchers were talking about, because I was going through it.” Similarly, Gary recalls the ADHD symptoms he read about “match[ed]” what he was experiencing. Not only did the diagnoses provide an explanation for their struggles, but participants were able to connect with the symptoms described in the research.

When understood as an explanation for their struggles, diagnoses were also experienced as validating. For example, Ted describes the validation that his diagnosis of depression brought his junior year of high school:

[It] was exciting though because it was like, ‘Yeah, I’m not just thinking this stuff up. Maybe something will be better’ kind of thing. And so it was exciting just to have that confirmation of it. Like to have someone actually recognize it. Because growing up like that... inside I always felt like there was something wrong. Like, ‘People don’t see it, they don’t really know me.’

He highlights the importance of someone recognizing his struggles, thus validating his experiences. This quote also suggests that with recognition of the problem comes the potential that “something will be better,” another type of empowerment discussed below. Daniela learned a bit differently about the ADHD diagnosis she received in first grade. While never told she had ADHD, she realized in middle school that peers with ADHD were prescribed the same medication that she was taking. She recalls going online and realizing she had ADHD. She describes this information validating what she felt inside, and wishing that she had known sooner:

It was really weird. I felt like I was pregnant for some reason... It was just really strange knowing that there was something inside of me that I was trying to find information on... And then validating what was inside of me with that information, and then thinking, ‘Why didn’t I know this all along because this information has always been on the internet?’

While this describes a mix of emotions upon receipt of this information, it also underscores that knowledge of her diagnosis was “validating.” Both accounts illustrate the comfort brought by information that legitimated what children were experiencing.

Another common theme was the benefit of having “a name” for their problems. Joe recalls feeling “relieved” that his problem had “a name” when his father explained his ADHD diagnosis to him in fifth grade. Both Cindy and Jennifer also emphasize that having a name for

their problems helped them to better understand what they were experiencing. Cindy describes the benefit of the GAD terminology: “I kind of liked having a name for it. I was kind of like, ‘Oh, I’ve got something. I can name it. I can give it a name.’ And then you can compartmentalize it.” Similarly, Jennifer recalls when receiving her diagnosis of ADHD and bipolar disorder in late high school: “I’ve always liked having labels on things. It makes things easier to process.” She describes feeling “more comfortable with the feelings” when she realized they “fell into this category.” She notes that the diagnoses gave her a “sense of belonging to a category and knowing what was wrong.” Having a name for their problems brought many a sense of relief. It allowed children to compartmentalize or categorize their problems, which made them easier to understand.

Providing the Possibility of Change

Diagnoses also empowered participants when they were presented and/or understood with an emphasis on the possibility for change. For example, the diagnosis often motivated participants to make changes, encouraging them that they could better themselves and succeed despite their struggles. Teresa recalls when diagnosed with depression in eighth grade:

Before depression – I would *hate* still living how I used to live... Being diagnosed really helped me shape who I am, and tied everything together, and made up for all of the nonsense I was thinking when I was younger, like, ‘Why is this just me?’ Having the concrete and being like, ‘Yeah, you do have this,’ made me realize like, ‘Okay, I can do it.’

As Tabitha notes, “I don’t think [it] so much provoked change as like allowed for change. And to grow from it.” Diagnoses also helped motivate participants to try and better manage their symptoms. Shannon, for example, explains that when she learned of her GAD diagnosis in eighth grade, she realized that she needed to learn how to “control” her anxiety. Especially those with ADHD note that their diagnoses motivated them to increase their efforts in school. Lilly

explains that after being re-diagnosed with ADHD her sophomore year of high school: “I feel like once I realized I had a problem, I started trying harder in school.” She explains:

I feel like knowing there was something kind of wrong or different also changed my habits a little bit too, not just the medicine. I kind of felt like I needed to work harder to be on the same level as everyone else, and I think that helped a lot.

She notes: “[If not diagnosed,] I don’t know if I would have come to the realization that I needed to change something.” Kimberly recalls thinking that she could do as well as others in school if she tried to “work against” her ADHD. She explains: “I always took the approach of use AD[H]D as a reason to push myself further.” Explaining that her parents emphasized that “it had nothing to do with how smart [she] was,” she notes: “It motivated me. [...] I think it was the diagnosis and the way my parents handled it.” Similarly, Paige notes:

And that is why I am successful in living my life as normal as possible, because I know what I need to do, whereas I think that things would just go by if I had just gone undiagnosed. I’d just be everywhere. But I am not, because I know what I need to do in order to set myself straight. [...] I wouldn’t have been motivated to work at it at all if I didn’t know that it was something that I had to... I think just something that needs to be stressed is that... things are going to be very hard unless you work at it... My parents have stressed that and emphasized that, and that’s I think why I was able to deal with it successfully.

Like Kimberly, Paige emphasizes that her parents helped her translate her diagnosis into motivation to make positive changes and control her symptoms. Teaching children strategies for managing symptoms is an important way that parents can help to support their children. As noted in Chapter 4, findings suggest that parental knowledge about children’s mental health problems affects their ability to provide support. Findings here suggest that this type of parental support helps foster the empowerment that participants experienced.

The diagnoses also empowered participants, and in particular those diagnosed with ADHD, by opening doors to treatment. Tabitha and Kimberly, for example, who were both

diagnosed with ADHD, recall thinking when first diagnosed that their diagnoses might allow them to access in-school services and medications. Tabitha notes after receiving her ADHD diagnosis her freshman year of high school: “I felt more relieved... to know that for something like this, there’s ways that people try and fix it.” Kimberly recalls immediately thinking when diagnosed with ADHD in third grade, ““Yeah, cool. That might make things easier.”” They realized that the diagnosis would allow them to access treatments to help manage their symptoms.

In particular, diagnoses helped participants diagnosed with ADHD by giving them the ability to cope with their symptoms more effectively. Christine recalls after receiving her ADHD diagnosis the summer before fifth grade: “I ended up doing a lot better for myself after I found out because I knew how to approach it.” Paige emphasizes that being diagnosed with ADHD at a relatively young age (age 6), she was able to learn strategies to better manage it over time. She explains:

I knew that it was something that I had to deal with. [...] As I matured, I found ways to cope with it. I found what worked for me. [...] I coped with it as I matured... If I hadn’t been given the resources to deal with it and if I wasn’t aware that I had the issue, I would have been caught off-guard and [been] helpless... when I was *prepared* for it and I knew what I may encounter, that made it definitely easier so it wasn’t as bad per se.

Similarly, Tabitha explains that receiving her ADHD diagnosis her freshman year of high school gave her “something to work with.” Regarding the ADHD diagnosis she received in late high school, Chloe notes: “I guess it gave me something to fix then. You can work on dealing with ADHD... there’s things you can do to deal with it and take care of it.” Matt explains:

[If I was never diagnosed] I would know that there was *something* wrong, but I wouldn’t know how to deal with it. And I think that the diagnosis was one of the most empowering things I could ever have in my life.

He further explains:

I don't think that I would have learned self-control... [or the] social skills that I did, because I think I would have continued to just be a terrible little problem child. [...] I'm very, *very* happy that they diagnosed me, because while it is possible to live with, [it is hard] unless you *know* what you have. It's one of those things, you either know it and can learn how to deal with it, or you don't know and you never do.

These quotes illustrate the importance of identifying the problem, allowing children to better “deal with” their symptoms.

Diagnoses were also empowering when they opened the doors to specific strategies that participants used to help cope with symptoms, especially the symptoms of ADHD. Many whose parents were highly involved in their care note that their parents helped to translate diagnoses into coping strategies. For example, Whitney notes that her ADHD diagnosis in seventh grade led her to discover various organizational techniques. She describes: “Then we had something to work off of. My parents then – it wasn't just like, ‘Oh, she is incapable of getting it done.’ It was like, ‘Oh, you have to make her organize herself.’” Others, especially older youth, were able to find coping strategies on their own. In eighth grade, Matt read online about ways to “cope” with ADHD, and found information on keeping lists to become more organized. Gary explains that when he learned of his ADHD diagnosis in eighth grade, he became “conscious” of what he “need[ed] to work on.” For example, he realized he needed to put extra effort into studying and building routines to stay on track. Paige notes that she was able to learn strategies to better manage her ADHD in social situations:

I remember being frustrated in terms of social situations ... I'd say it was definitely a *huge* advantage that I was diagnosed at such a young age [age 6], because since I knew that I had it, and I knew that I had something against me that I had to combat, so I had to work harder, and think about it like, ‘Alright, I got to stop and think before I speak.’

Further, it gave them the ability to identify their symptoms when present. Crystal explains that after being diagnosed with ADHD in second grade, she was able to “catch [herself]” when she

was distracted or hyper. Similarly, Faith says that after being diagnosed with ADHD, depression, and GAD in early high school: “I became a lot more aware of my behavior and what was going on around me once I knew what the root of it was.” Being diagnosed gave them the awareness to identify symptoms and ways to manage them.

Participants therefore found diagnoses to be empowering in several ways. Diagnoses were empowering when understood as an explanation for their problems, providing a reason, validation, and name for their struggles. Diagnoses were also empowering when there was an emphasis on the possibility for change, providing a motivation for improvement and opening doors to treatment options and coping strategies, especially for those with ADHD. These findings highlight some of the benefits of diagnosis, or “brighter sides” of medicalization (Conrad & Schneider, 1992, p. 246). Further, these findings suggest ways to enhance empowerment when delivering diagnoses in the future.

Stigma Experiences

Fears and experiences of stigma were widespread; almost all of the participants (n=37) describe having feared or experienced stigma associated with their diagnoses and/or treatments. While providing information and assurances helped alleviate this stigma, participants with all four diagnoses and who were diagnosed at all ages, either feared or perceived some type of stigma at some point in their childhoods.

One might imagine that participants’ experiences greatly differed based on the diagnosis they received. Moses (2009b), for example, notes that the increasing rates of ADHD may help to “normalize” the experience of those with this diagnosis. One might suspect, therefore, that ADHD is less stigmatized than the other diagnoses examined in the current study. Participants with multiple diagnoses (including ADHD) had mixed opinions, however, about the

stigmatization of ADHD versus their other diagnoses. Angela, for example, who was diagnosed with ADHD, depression, and GAD her freshman year of high school, suggests that there was less of a stigma associated with ADHD because it is more common than her other diagnoses. She notes: “What I remember about ADHD was that I felt like everybody had it and... [there] wasn’t a stigma or anything against it.” Most of her peers knew she had ADHD, but she only told one of her friends that she was also diagnosed with depression. Tabitha explains:

Like depression or [GAD or bipolar disorder]... I understand why some people wouldn’t be open. But when it comes to ADHD though, I don’t think it’s as much of something that anybody should ever be embarrassed about, because there’s people who almost wish that they did have it. Or wish that they could be diagnosed with it so that they could have [medication], which is kind of ridiculous.

On the other hand, Stephanie notes that the stigma associated with ADHD has grown worse over time. She explains: “There’s all kinds of stigma there now. I don’t know if it was there when I was younger, just because people weren’t aware enough to have those kinds of misconceptions.”

This suggests that the prevalence of a diagnosis can help minimize stigma by making it ‘common,’ but also lead to the development of potentially stigmatizing misconceptions.

Findings indicate that while experiences often varied, participants with all four diagnoses feared and/or experienced stigma.

Demonstrating the complexity of these interwoven experiences, the initial empowerment of diagnoses was often hindered by experiences of stigma. Participants describe experiencing them simultaneously. As Ashley notes, “It was kind of a relief to find out what was wrong with me” when she was diagnosed with ADHD in second grade, but “kind of a stigma thing too.” She feared that if she talked about her ADHD, she would be ostracized by her peers. Joe recalls that when his father explained his ADHD diagnosis to him in fifth grade: “[I] felt relieved that my problem had a name. But at that point... I was also kind of embarrassed by it I would say. It’s

not something that you want to advertise.” Similarly, Daniela recalls when she found out about her ADHD diagnosis in sixth grade:

[I remember] being slightly comforted that other people have it, but at the same time being scared because there was a name to it. Knowing, ‘Oh yeah that is what was going on,’ but I still feel ashamed about it as if it’s something that nobody can find out about me.

This underscores the double-edged nature of having “a name” for one’s struggles, whereby it brought an explanation, but also embarrassment.

In particular, participants describe fearing the stigma associated with their diagnoses. Blake did not fully accept his GAD diagnosis in high school because he had a “fear” of “being labeled as different.” Similarly, Sam recalls fearing immediately upon learning of his ADHD diagnosis in third grade: “I didn’t want to be labeled by my peers [as] being stupid or slow or something like that.” Despite his mother’s assurances that his diagnosis of ADHD was unrelated to his level of intelligence, he recalls thinking when he first learned of his diagnosis: “I was afraid that... this was something saying that I was dumb or stupid and that I couldn’t succeed.” Ted explains: “Once I knew I had it, I felt like I couldn’t really talk to anyone about it because people would look at me differently.” As described below, some hid their diagnoses for fear of this stigma.

In addition to worrying how others would perceive them, several participants, all of whom were diagnosed in middle school or high school, also note that the diagnosis changed how they viewed themselves. Ted for example, describes this experience when he was diagnosed with depression his junior year of high school: “The way I looked at myself... was different.” Andy and Shannon perceived their diagnoses as an indication that adults did not approve of them, which made them look negatively upon themselves. Andy recalls thinking when

diagnosed with ADHD his junior year of high school: “It’s shameful. It’s like, ‘You’re not good enough. You need to change your behavior.’” Similarly, Shannon describes:

And then finding out from a professional adult that you have this, this, and this, and you need to take this medication because, ‘We don’t like the way you act and we don’t like the way you think,’ I felt like I was rejected. And that’s why I struggled the most.

She notes: “It kind of did hurt my self-esteem a lot because I was like, ‘There’s something wrong with me.’” One would imagine that children experience pressure from adults to change their behaviors even before being formally diagnosed, but these findings suggest that children may perceive adults’ disapproval of their behaviors especially at the time of diagnosis. Perhaps diagnosis sparks this perception, or perhaps it confirms it.

Especially those with ADHD describe being teased by peers not only because they were diagnosed, but because their behaviors differed from their peers’. For example, they recall being teased for their hyperactivity. Matt notes: “I was ostracized because of it.” He explains: “There was a big stigma with it... because people are people and they see something that’s different and they immediately dislike it.” Crystal recalls classmates teasing her when she was diagnosed with ADHD in second grade, noting: “Kids will get made fun of if they have [ADHD]. I did.” Both Nathan and Natasha also describe their siblings teasing them about their ADHD diagnoses.

This stigma may be exacerbated by the teasing and bullying children already experience. For example, Gary explains that he was already an “outcast” prior to receiving an ADHD diagnosis in middle school, describing the stigma that he experienced following the September 11, 2001 terrorist attacks because he was Muslim. While he notes that this was separate from the stigma he experienced for having ADHD, the stigma that children face in relation to their mental health diagnoses should be viewed in the context of other sources of stigma and isolation. As Jennifer notes, the teenage years are already a difficult time socially: “Early adolescence is hard

on anybody, but I think when you have a diagnosis like that, it's really difficult to figure out how you fit in with all of the other kids and you end up being an outsider." This is in line with the research described in Chapter 2 that highlights that adolescence is a crucial time in identity development when acceptance into peer groups is especially important, and when stigma can be particularly damaging (Brown, 1990; Harter, 1990; Rosenberg & Gaier, 1977).

One contributing factor to the stigma surrounding mental health diagnoses was the widespread derogatory use of these diagnostic terms in day-to-day conversation. Participants recall the terms 'ADHD,' 'bipolar,' and 'depressed' being used in a casual, derogatory way, especially by peers. In particular, participants note the frequent, casual use of the term 'ADHD.' Faith recalls her frustration when those who could not concentrate commented, "'I'm being so AD[H]D.'" Similarly, Paige notes: "This is what really bothered me in [high school], and it still pisses me off to this day is like how the term AD[H]D is thrown around." Participants describe this phenomenon increasing among peer groups as they aged; for example, the terms were used in a derogatory way especially in high school.

Participants also experienced stigma related to their treatment, especially their use of medications. Several participants describe suspecting that there was something "different" or "wrong" because they took medication. Daniela explains that she was "embarrassed" by the medication, noting: "[My parents were] admitting that there was something wrong and I needed to be on this drug so that I could function." She recalls: "[I remember] feeling ashamed of having to take medication because my parents never talked about it." Similarly, Courtney explains her experience taking medication after her ADHD diagnosis in second grade: "When they started putting me on medicine, I kind of got an idea that there was something different about me [and] I was insecure about that." Christine recalls thinking: "'Because I needed to be

medicated, there was something wrong with me.” Participants also describe the medication making them feel different from their peers. Both Courtney and Teresa note that having to take medication made them feel “weird.” Nathan explains: “I didn’t like taking it because I just wanted to be normal.” Christine recalls her peers teasing her for having to take medication. She notes: “There’s only one negative side to [medication] and that was the stigma of it.”

Many participants (n=20) also recall experiencing stigma surrounding in-school services for ADHD. In particular, they emphasize not liking taking tests in a separate classroom and having extra time on exams because peers would think they were “different,” “stupid,” or getting an unfair advantage. When recalling having extra time on exams in high school, Paige describes: “I’d say the social stigma, that was what I disliked about it – was having to explain it... I know that I’m going to be negatively perceived.” Nathan recalls not liking taking tests in a separate room from his peers because he “wanted to be normal like everyone else.” Similarly, Autumn explains that she did not want to “stand out in class.” She recalls feeling like her peers would think she was “stupider” if she needed extra supports in school. She notes that peers assumed that students wanted to have extra time and to take tests in a separate classroom so they could cheat. Highlighting the significance of this type of stigma, Autumn recalls in high school: “I would reject the services they would offer me because I didn’t want the stigma and the isolation with it.” This underscores the importance of minimizing the stigma associated with in-school services, so that children feel comfortable accepting the services offered to them.

Several participants (n=6) also describe stigma associated with seeing mental health professionals and being in therapy. Nathan explains: “At points, I didn’t like going because I just wanted to be normal, and I felt like something was wrong with me, but I just didn’t really understand what.” Similarly, Kimberly notes: “I didn’t like the idea of there being something

wrong with me and so I had to be in therapy, especially when I was younger.” Like taking medication, this experience made them feel as though something was “wrong” with them. Similar to their experiences with both medication and in-school services, they disliked feeling as though they were “different” from their peers because they needed to see a mental health professional.

Especially in middle school and early high school, several participants thought they were “crazy” because of the treatments that they received. Sam, for example, expressed his dislike of seeing a psychiatrist, noting: “As a child, I would think that seeing a person like that meant you’re crazy or you have mental issues or something. Obviously not true, but when you’re in fifth grade, you’re close-minded in your thoughts.” Similarly, suggesting that the media may contribute to the perceived stigma that children experience, Chloe recalls her experience seeing a psychiatrist in high school:

I did feel like I was crazy for the longest time because it’s like people my age don’t go see psychiatrists. People my age don’t go to therapy. At least that’s the impression I was under, because I didn’t know anybody that goes to therapy. Especially like TV and the media. All you see is crazy people. Crazy people go to therapy.

Chloe also describes the medication she took in high school making her feel this way:

I kind of felt like I was crazy almost. I knew I wasn’t some mental institution patient, but I still did because obviously I can’t control my emotions to the point where now I have to be on medication. So I mean it didn’t really do too much for like my self-esteem. But I got used to it.

Even before receiving any treatment, Abby recalls: “I thought if I was on medication, it meant that I was just a basket case.” The “crazy” narrative, described in Chapter 5, was therefore intertwined with children’s views of treatment, especially taking medication and seeing mental health professionals. Participants describe learning on their own as they matured, especially in high school and college, that treatment did not imply they were “crazy” as they had at first

believed. This raises the question as to whether they can learn this earlier if adults help to instill this message.

Benefits of the diagnosis were therefore experienced alongside several drawbacks. Almost all of the participants (n=37) describe having feared or experienced stigma associated with their diagnoses and/or treatments. Depicting some of the “darker” sides of medicalization (Conrad & Schneider, 1992, p. 246), these findings demonstrate that participants experienced stigma along with the empowerment described above.

Sharing and Hiding Diagnoses and Treatments

In response to the interview question, ‘In what ways did you share or talk about your diagnosis with the people in your life?’, participants often described the level to which their diagnoses were discussed at home, especially with their parents and siblings. They also focused on their experiences sharing, or hiding, diagnoses from peers. They described not only whether they shared this information with peers, but also reactions to this news, and how they felt sharing it.

Participants describe their diagnoses and treatments being discussed in their families to varying degrees, based largely on their parents’ attitudes towards this type of discussion. Some families were very open about their diagnoses because their parents encouraged this. Paige notes: “It was just kind of like a matter of fact thing in my house” since she, her brother, and father were diagnosed with ADHD. She recalls being “constantly surrounded by it,” and explains: “My parents were accepting of it.” Similarly, Kimberly explains: “In my house it was never something to be ashamed of, or to be not discussed, because it was fine. It was very much accepted.” Meanwhile, diagnoses and treatments were seldom discussed when parents treated them as ‘taboo’ subjects. In particular, parents were disapproving of their children’s diagnoses

because of their cultural backgrounds. For example, Michelle explains: “I come from an Asian background so my parents are super hush-hush about these things.” She suggests that this contributed to her suppressing her emotions and resisting the diagnosis of depression she received in seventh grade. Similarly, Teresa explains that her grandmother who raised her saw depression as something to keep secret because of her background: “How she was raised, everyone from Mexico is like, ‘You have a problem, you hide your problem and you don’t tell anyone about it. It’s just your problem and no one else’s.’” She also suggests that this may have contributed to her immediate rejection of the diagnosis. As described in Chapter 4, both Daniela and Gary describe their parents, who were from the Middle East, treating their diagnoses as ‘taboo’ subjects because of their cultural backgrounds.

Those who willingly shared their diagnoses and treatment experiences with peers generally had parents who were open about their diagnoses, or attended schools where diagnoses were discussed openly among peers. Paige notes, “I was never taught by my parents to hide it.” Meanwhile, Tabitha, notes that “nobody frowned upon it” in her high school. She adds that she had friends who told her she was “lucky” to have been diagnosed because she could receive extra services in school. Similarly, Josh notes that ADHD was “pretty common and accepted” among his peers when he was diagnosed in early high school. Jennifer explains that she has “always been very, very open” because “the stigma against mental illness” has always “bothered” her. She notes: “I feel it isn’t something to be ashamed of.”

Participants recall mixed reactions when they shared diagnoses with peers. Some recall their peers having misconceptions and questions about their diagnoses. Matt describes the confusion his peers conveyed when he shared his diagnosis with them in elementary and middle school:

They'd be like, 'Okay, something's odd with you. What's the matter?' Like, 'I have ADHD.' 'Oh no! Those are all capitals!' ... And so there would be a point of like, 'Uhhh, I'm not sure if I can catch it from him, you know – you know the other things that have capital letters – HIV.' And so eventually they would get over the, 'Oh okay, it's only him that's got it. We can handle him.'

He explains: "When they got past their initial, 'Oh you must be sick' stage, they tended to have interesting questions." Autumn recalls her friends responding when she told them of her ADHD diagnosis in high school: "Oh, that means you can't calm down and you're like a hyperactive child running around." She notes, "I wasn't like that. I was just a step behind everyone else. And that's how I explained it [to them]. I was like, 'I'm a little notch behind everyone else.'" Autumn recalls of her siblings: "[They were] frustrated like, 'You're wasting Mom and Dad's money and time. Stop joking around. Just be normal.'" Similarly, Leslie recalls her siblings being "rude" to her when they discovered she took medication for ADHD. She notes: "They don't really believe in it."

Others note that their peers seemed to simply accept the information when told, and asked few questions. Sarah explains:

They were just like, 'Okay, I don't really care.' And I think those reactions were kind of surprising to me when they occurred... I would have thought that they would want to know more about it. [...] I think it made me feel at ease... if they asked about it, I would be okay with explaining it but... it was kind of comforting I guess that they didn't care either way.

Similarly, Joe explains: "It wasn't like a sit-down conversation... it was something that you would like just mention at lunch and then you'd like shrug your shoulders. And be like, 'Okay.'" Ted recalls when he first told a classmate in high school: "I just wanted to get over it, like say it and move on and talk about something else." They report being pleased when peers accepted the information and did not want to discuss it in detail.

In general, those who themselves also had mental health diagnoses understood and were

especially supportive. Autumn explains: “Other people that had ADHD totally knew what I was talking about,” when she described her symptoms to them. Shannon notes that others who are diagnosed could “relate.” This is in line with findings that adolescents experience “a common bond” with peers with similar conditions (Kranke et al., 2010, p. 504), and cope by interacting with peers who are “in the same boat” (Moses, 2010, p. 992). Shannon also notes that simply knowing someone who was diagnosed helped peers empathize:

I have actually gotten a lot of positive reactions to it. They’ll give me a hug or they were like, ‘Oh, I understand.’ Like, ‘Oh, my friend has this, too, and I know what you mean.’ So it was a lot more comforting that I found people that also had it.

Knowing someone who was also diagnosed helped them empathize with Shannon.

Just over half of participants (n=22) describe at some point hiding their diagnoses and treatment experiences, especially from peers. Some even tried to hide their symptoms so that their mental health problems would not be detected. Melissa recalls after being diagnosed with depression her sophomore year of high school: “I was terrified about somebody in school noticing.” Daniela describes:

I hid it really well at school because I felt so ashamed of having it that I made a conscious effort to sit really still and be really focused and really understand what was going on. Just forcing myself to do extra credit work and all of these things. And I think I only truly released all of that energy when I was being active and playing sports and in gym class. And I didn’t really have a problem with disrupting the class the way I did when I was younger just because in my mind I associated it with ‘I shouldn’t have this therefore I need to work really hard on... showing people that I don’t have anything going on.’

She describes the great effort children may put into actively trying to hide their diagnoses.

Participants most often hid diagnoses and treatments due to the fear of stigma, as described above. Mark notes that he did not share his diagnosis with classmates and friends for fear of being seen as “stupid” or “less capable” than them. Melissa recalls in high school:

I didn't want to be labeled... I didn't want people to think that I couldn't handle it: that I couldn't handle the workload, that I couldn't handle having friends, that I was just going to be the person that you went out with and then I just started crying.

She further notes that she did not tell her peers because she did not think they had the “maturity” to “understand and not label” her. Similarly, Monique says that she did not share her diagnosis with her peers at the group home because she did not “trust” them. Teresa notes that she kept her diagnoses secret from the “rich little girls” at the private school she attended, who did not know about her rocky home life, noting: “I didn't tell those who didn't understand.” Similarly, Michelle notes that peers, especially in high school “wouldn't even have felt bad” if they found out that she was depressed. Rather, she notes: “I think, in fact, they would have made fun of me.” Blake says of his GAD diagnosis in high school: “I couldn't tell my friends because it was an embarrassing thing.” Sarah says it was a “secret” that she “had to hide,” noting: “I felt like people wouldn't like me.” As noted previously, Courtney recalls telling friends that her medication was for allergies when they saw her take it during “sleep-overs” in middle school for fear that friends would “judge [her].” They also feared being seen as using ADHD as an excuse for added benefits in school, such as extra time on tests. Faith explains: “In high school, I was definitely a lot more secretive about it, especially because I didn't want kids to think I had some unfair advantage.”

They also hid their diagnoses because of how their parents treated them. Devin, for example, notes that he may not have felt so “embarrassed” and secretive if his parents “didn't treat it like it was such a negative thing.” He notes that he did not tell “anyone,” and “barely ever talked about it with [his] parents.” He explains: “It was very, kind of shameful for them.” Autumn explains: “My parents... swept it under the rug. We didn't mention it to people once I got to high school. Just because... there's a stigma that goes along with it.” Noting that she

“kept it pretty quiet,” Faith recalls her father telling her when she was diagnosed with ADHD, depression, and GAD in early high school: “Don’t tell anyone. It’s none of their business.” Michelle notes that she hid her diagnosis because her parents are “hush-hush about these things.” This suggests that parents’ responses to diagnoses can foster secrecy.

Children may also hide diagnoses because they consider this information to be private. Josh explains that “it’s personal medical information,” which he kept to himself unless someone “need[ed]” to know. Similarly, Natasha explains that she was “very secretive” about the ADHD diagnosis she received her freshman year of high school because she “didn’t think it was anyone else’s business,” and Sarah notes that it was a “private thing.” Kimberly explains:

It was always the kind of thing that I wanted to just deal with by myself. Because it was A) never big enough of an issue, or B) I just wanted – I liked and needed to feel like I could handle things on my own.

She describes it as a personal issue that she thought should be handled privately. Others may have chosen not to discuss their diagnoses openly, while not intentionally trying to *hide* them. Stephanie, for example explains: “I didn’t talk about it very much just because it wasn’t put across to me as something that was a big deal... It was just so *not* an issue that I didn’t talk about it very much.” They only told peers about their diagnoses when asked – for example, when asked why they were taking a pill or leaving the room to take an exam.

Lilly and Teresa recall hiding their diagnoses and treatment not only from peers, but from their siblings as well. Lilly describes hiding her medication from her sisters for a year and a half after starting medication her sophomore year of high school. She explains:

I just didn’t want to seem like an outsider... so I just kept it a secret for a long time cause I was shy and embarrassed and I didn’t want people to think I was different, and I didn’t want them to think they were smarter than me or better than me, because I knew that wasn’t true.

She even recalls lying and telling her sisters that she was at detention when she stayed after school to finish exams. Similarly, Teresa describes hiding her diagnosis of depression from her brother and sister:

Two years later, I think it was sophomore year, I finally told them like, ‘Hey, I have depression. I’ll explain to you guys whatever you guys want to know.’ Because I was kind of embarrassed still and I was like, ‘No one really has depression and it’s not common and everyone kind of thinks you’re weird.’

Teresa explains that while her sister was familiar with the diagnostic terms from psychology classes, no one had ever shared these diagnoses with her before. She recalls describing ADHD and depression to her sister in “baby steps,” slowly over time. The finding that children were able to keep their diagnoses secret from their siblings raises the question of why parents chose not to tell them. Autumn notes that her parents did not tell her siblings of her ADHD diagnosis, explaining: “[They] wanted to make us all feel equal even though I didn’t feel that way... My parents had good intentions and they didn’t want to ostracize me as the dumber one.” Indicating that it is not something that can be kept hidden forever, she notes that she told her siblings when they noticed the extra supports she was receiving in and outside of school. This raises the question of whether and how parents should share diagnoses with their children’s siblings, and suggests withholding this information might foster a sense of secrecy.

Many who originally hid their diagnoses describe discussing their diagnoses openly with friends naturally over time. Stephanie, for example, explains that she could not identify a specific time when she *revealed* her diagnoses:

Whatever issues we were having, or whatever, that was something that we were just very open about. We’d talk about everything. So I mean it wasn’t like it was some big revelation. It wasn’t like I had to come out or anything.

Kimberly notes that she was at first “ashamed” of her ADHD medication, which she kept secret,

but gradually became “very open about it” as she herself “accepted it.” They often started to share their diagnoses when they noticed peers discussing their diagnoses and treatments openly, especially in high school.

A common theme was that those who shared their diagnoses with friends and siblings experienced a sense of relief when they did so. Michelle explains it was difficult to tell friends because she did not want them to think she was giving “an excuse” for her behavior, but that she was “really happy” when “they were accepting of it.” Similarly, Lilly describes her friends’ reactions in high school: “No one thought it was a big deal at all. And so it was kind of a good feeling. No one thought I was an outcast.” Teresa describes her experience telling friends in high school: “I was kind of relieved because depression is a big thing in my life. It really affects everything about me... It’s just a relief having everyone know.” She notes: “I wasn’t holding back. I was being myself at that point.”

Talking with friends about diagnoses, symptoms, and treatments was often beneficial. Chloe, for example, describes the benefits of telling her friends in high school:

They’re going to understand more than anything. I’m with them more than anything, so I’m sure they could see it a little bit more than anybody else could... Like people call their friends just talk and get it out... I was just venting to them. So it was nice having those people there to just sit there and listen... especially when my parents weren’t. I had two really close friends all throughout high school who were supportive because they were always there. My parents, even though they’re always my parents... they’re not always there because they’re not always listening...

This suggests the important role that peers can play by simply listening. Similarly, Teresa notes that her friends made up “a really good support system” in high school. As an example, she notes that her friends reminded her when she forgot to take her medication. Several also note that their siblings were supportive. Erica describes her siblings telling her not to be “ashamed”

of her ADHD diagnosis in high school, and telling her how common it is. Jennifer recalls her sister telling her that her feelings were valid, which she found especially helpful.

The data therefore suggest that sharing one's diagnoses was generally beneficial to children. While some peers and siblings reacted negatively, many accepted the diagnoses with few questions, and others were very supportive. The process of revealing diagnoses often took time, as participants gradually became more comfortable discussing them openly. The way that parents treated diagnoses often played a role in whether children chose to share this information with both siblings and peers.

Treatment Experiences

When asked the interview question, 'What was life like after your diagnosis?,' participants described the treatments they did (or did not) receive. In particular, they focused on whether or not they took medication. They also described their experiences 'seeing a mental health professional,' which includes office visits with therapists, psychologists, psychiatrists, and social workers, as most participants did not (or were not able to) distinguish between these types of professionals. They also described receiving in-school services, which they also considered a 'treatment,' or service that they received to alleviate and help manage their struggles. They described mixed experiences with all of these treatments.

Three participants note that they did not receive any treatment for at least one of their diagnoses. In all three cases, their parents were opposed to treatment. In a few other cases (n=4), parents' opposition restricted children from receiving certain types of treatments, but they did receive some form of care. Five of the seven participants who did not take medication in childhood recall that at least one of their parents was strongly opposed to this type of treatment. They describe their parents' fears that they would become addicted or sell their medication to

peers in school. Michelle notes that her parents did not allow her to take medication for her depression because it would damage her “record,” and were convinced that she was going through “a phase.” She notes that her parents thought that her psychiatrist was “just trying to make money” by prescribing her medication. She adds: “[the] issue never really got fixed.” Meanwhile, three participants describe their parents’ opposition to therapy preventing them from receiving this form of treatment. Describing her parents’ disdain for therapy, Leslie notes, they “never believed in [it].” Gary recalls his parents resisting in-school services. Noting that his mother was likely “worried about a social stigma” among his peers, Gary explains that his parents feared that he would be ostracized if he received in-school services. He further suspects that they did not want his diagnosis permanently documented in his school records.

Almost all of the participants describe the benefits of at least some of the treatment they received, with several noting the benefit of receiving treatment at a relatively young age. Kimberly explains that because she was diagnosed in third grade, she knew that she had a “legitimate” diagnosis, when “everyone” started “saying they had AD[H]D” and receiving in-school services in middle school and early high school. Especially those diagnosed with ADHD note that they were able to develop coping strategies and excel academically because they were diagnosed when they were young. Whitney, diagnosed in seventh grade, explains: “If I was older... [I’d] be playing probably catch-up and being a lot more stressed about it, and having to change more things.” She explains that if diagnosed early, “you could fix your habits earlier and learn.” Had she been diagnosed in high school, she suspects: “I probably would have already formed more bad habits, like work habits, and that would have been probably more difficult to fix.” Similarly, Autumn explains that she got “used to” having extra supports in school because she was diagnosed in elementary school. She notes that it would have been a more “drastic

change” if she had been diagnosed and started receiving these services later. Cindy, diagnosed with GAD in eighth grade, explains:

I think I probably would not be as healthy as I am right now, and as happy with where I’m at as I am right now, if I hadn’t been diagnosed when I was, and if I hadn’t started getting treatment when I did.

Also indicating the importance of early diagnosis and treatment, Stephanie, who was diagnosed with ADHD in third grade and depression and GAD in high school, explains: “I feel like it could have made a difference [being diagnosed with depression and anxiety earlier] because... I would have actually been getting help a lot sooner.”

The participants also describe drawbacks to the treatments they received, however, including the stigma described above. Most experienced some benefits and some drawbacks. In particular, they emphasize their mixed experiences taking medication, receiving in-school services, and seeing a mental health professional.

Taking Medication

Psychotropic treatments were “almost always considered treatments of last resort” for children’s psychiatric disturbances before the 1990s (Brody, 2006, p. 91). In 2006, Brody (2006, p. 91) wrote that the last fifteen years had “witnessed an explosion” in the use of these medications to treat children’s conditions. Participants in this study were first diagnosed between the early 1990s and late 2000s, and were thus diagnosed since this “explosion” began. It is perhaps not surprising therefore that most of the participants (n=35) describe taking medication at some point before coming to college. (Five of the other seven participants took medication at some point in college).

Nearly all those who took medication before coming to college (n=32 of 35) describe experiencing some side effects. This included affecting their energy, mood, sociability, weight,

appetite, and sleep patterns, as well as experiencing nausea, dehydration, “dry mouth,” fidgetiness, tics, drowsiness, insomnia, and a suppression of their creativity. Several note that the medication made them feel like “zombies.” In particular, they describe experiencing these side effects when taking the “wrong” medication or dosage. Almost all of those who took medication before coming to college (n=31 of 35) describe having their dosage and type of medication adjusted when describing their experiences taking medication. Paige recalls having to “experiment” with different medications and dosages in childhood, noting: “It was just a whole game, and that was really frustrating.” Many also report that they did not like how it made them feel and found it a hassle to take their medication every day. A few who took their medication in school note that they disliked having this disruption in the day; they also found it embarrassing having to leave class to take their medication at the nurse’s office.

Another concern was that medications affected their identities. Some worried they had become a different person on the medication. Autumn explains that medication “does affect your personality,” noting that she was “a very different person” when she was on a high dosage. Similarly, Ashley says of the medication she took starting in fourth grade for ADHD: “It kind of felt like I wasn’t me when I was on it.” Ted describes how this worried him:

It was just the thought of like changing me, because my mind’s been the only thing I’ve had safety-wise. And I felt like it was messing with that a little bit. That’s your only thing that’s going to stay the same throughout your life, hopefully, and taking the medication alters that I kind of felt. And I felt that it [was] just changing who I fundamentally was.

Andy also recalls struggling with this when diagnosed with ADHD his junior year of high school: “I started to have identity issues like, ‘If I go on this medication and I’m acting aggressive and differently, then who am I? What – is this not me?’” This highlights the distress participants experienced when they thought that medications were changing their personalities.

Another commonly cited fear was dependency on medication. Kimberly recalls thinking: “Do I need to take this for the rest of my life? Am I a slave to this [medication]?” Sarah notes that she stopped taking medication in high school as an “experiment” to test if she could focus in school without it. She notes: “I didn’t want it to tie me down and I didn’t want to be on it my whole life.” They feared being on medication permanently.

As part of the stigma described previously, many (n=18) recall being embarrassed by the medication they took in childhood. Some describe hiding it from peers. Courtney notes: “I didn’t like the fact that I was taking medicine. I felt like it made me weird. And it made me different, and that there was something wrong with me. And I didn’t want to tell anyone about it.” As described above, she recalls telling her friends that she was taking a pill for her allergies in middle school. Lilly even describes hiding her medication from her sisters. Daniela recalls trying to hide the side effects so others would not discover she was taking medication. She describes feeling “paranoid” that her peers would notice her drinking water to combat the dehydration that she experienced on medication.

Participants had mixed feelings about starting medication. Several note that their parents were open to this treatment option, and they thought taking medication was “no big deal.” Paige, for example, notes: “An advantage was that my parents were accepting of it... The medication was no big deal for me also. I just kind of thought that was normal.” Others only recall accepting their medication over time. Kimberly notes that she “pushed back” on her parents when she first started taking medication in fourth grade, but eventually “accepted” her medication, realizing, “This is how it is.” Josh notes that it became an “accepted fact” that he took medication for ADHD in high school: “It’s a part of life.”

Participants with all four diagnoses report that taking medication helped alleviate their symptoms. Teresa describes:

I would hate life if I wasn't diagnosed and wasn't taking medication for it. I think I would – probably would have – I'm not even kidding – probably committed suicide if I wasn't diagnosed with depression because it was just so bad. [...] It was both [the diagnosis and medication]. Me being diagnosed and then me reading about it helped, but the medication is what kind of set it – was [what] changed my attitude... Once I started taking the medication and it started working was when I was – everything got better. The sun was out basically.

Ted, Abby, and Chloe, who were also diagnosed with either depression or bipolar disorder, also note that without treatment, they may have become suicidal. Stephanie explains her experience with medication for ADHD:

Meds made a big difference because it was so much easier for me to function. It feels like you're walking around in a cloud all day without it and then you take it, it's like you're seeing for the first time.

She describes: “It just feels like the fog is lifted and I can focus.” Noting that she is better able to “deal with situations effectively” and “live... life as normal as possible” when on her ADHD medication, Paige notes: “My life is so much harder without it.” In particular, participants' grades improved when they started taking medication for ADHD.

Receiving In-School Services

More than half of the participants (n=23), including almost two thirds of participants who were diagnosed with ADHD before college (n=22 of 35), recall receiving some sort of in-school services in elementary, middle, or high school; they had mixed experiences with this type of treatment as well. For example, they found accommodations such as extra time helpful, but as noted previously, they felt embarrassed and singled out. Paige describes: “I didn't like that I needed to have it, but I liked having it because I needed it.” As noted above, she perceived stigma associated with receiving extra time on exams. She explains: “[People think] you're

getting an unfair advantage, whereas it's not an unfair advantage. It would be a disadvantage – an unfair *disadvantage* – if I *wasn't* given the opportunity because you have a one up on me.”

Similarly, Teresa recalls: “I wanted to explain to them like... ‘It’s not actually an advantage. I am putting myself in the same playing field as you’” by having extra time on tests.

Indicating a distancing from peers with other struggles, a few participants (n=4) also note that by grouping their ADHD diagnoses with more ‘severe problems,’ schools exacerbated the stigma they experienced. Joe, for example recalls disliking being called to the nurse’s office to take his medication in middle school along with other students who had more severe disabilities. When describing the study hall he attended in middle school to receive help with homework, Joe notes: “I disliked the stigma of going to the disability class, and the association of it.” He says:

A lot of school districts kind of wrapped that up together with every sort of mental problem you possibly could have... I took a class in middle school that was for like special students I guess... That was kind of embarrassing because I didn’t want people to know that I was there because I didn’t have autism, I didn’t have Asperger’s. I didn’t have all sorts of social problems that people associate with anybody who has any sort of a mental problem.

He further explains: “Children may be discouraged, or dissuaded from admitting they have a problem because they don’t want to be associated with other disability students. Because schools inherently have this nature of sort of rounding up everyone together.” Similarly, Angela recalls a special class she attended “for students with disabilities” in high school, which included what she refers to as “people who had really severe disabilities.” She notes: “It makes you feel a lot worse.” This distancing from others is in line with previous research on adolescent peer dynamics. Those with physical and mental disabilities are especially vulnerable to harassment by their peers (Milner, 2004). Milner (2004, p. 84) hypothesizes that verbal aggression towards handicapped peers may be an attempt to “displace hostility,” display one’s skills in putting down others, and punish the deviance from social norms that many handicapped students display. As

Elkington et al. (2012, p. 302) note, distancing oneself from others with mental health problems who are considered “crazier,” can be seen a coping mechanism and way of resisting stigma. By grouping students with differing diagnoses together, schools hindered children’s efforts to distance themselves from others. By not wanting to be grouped with students with more “severe” disabilities, these students may have been contributing to the stigma that their peers faced.

Overall, however, many diagnosed with ADHD found the extra supports in school to be crucial to their academic success. They note that taking tests in a private room and having extra time on exams was helpful to them. Sam explains that it would have been “tougher” without the extra support he received in school; without it, he thinks he would have “continued to fall behind.” He notes that he “wouldn’t have felt [he] could be intelligent” if they blamed his struggles in school on his “level of intelligence.”

Several participants (n=5) who did not receive in-school services suggest that they may have benefited from them. Stephanie, for example, notes that in-school services would have benefited her greatly; she notes that she did not receive them because her parents did not advocate having them put into place. Gary also notes that his grades would have been better in high school had he received in-school accommodations. As noted above, he did not receive in-school services because his mother did not want him to be stigmatized for his diagnosis.

Participants describe schools varying in whether or not they accepted diagnoses and the extent to which they were willing to provide accommodations. Participants also recall varying levels of supportiveness among teachers, likely depending greatly on the quality of their schools and their special education programming. Christine describes teachers being “kind” and “eager to help.” She notes that “having that support... is crucial.” Meanwhile, Matt notes that his

“teachers didn’t take it seriously.” He recalls being punished with detention because he could not focus and behave in class due to his ADHD. Similarly, Stephanie recalls that teachers seemed “angry” about her ADHD diagnosis. She notes: “It was just like they didn’t want to have to deal with it.” Some note that it depended on the individual teacher. Chloe says of her high school teachers: “Some [teachers] were more understanding than others.” Similarly, Faith recalls: “I had some teachers that were more accommodating than others. Some of them accommodating more than my documentation really needed.” For example, they would let her take additional time on tests, beyond the extra amount required. Autumn recalls that some teachers would “disregard” her requests for extra help and accommodations, while others “catered” to her needs. She explains: “Some teachers really understood, ‘Hey, I have this problem.’ Other teachers were like, ‘Okay, that sounds like just an excuse,’ and they didn’t accept it.” Some describe receiving accommodations through individual teachers, without formally receiving in-school services. For example, some teachers would stay after school to help explain concepts, or give extra time on exams even when students’ education plans did not require it. A few note that while some teachers were willing to do this, others were not. When describing a high school teacher who would not provide these extra supports, Erica laughed and said: “[You] can’t persuade everyone.”

Seeing a Mental Health Professional

Participants who continued visits with mental health professionals at some point after being diagnosed (n=32) reported mixed experiences with this type of treatment. As noted above, the term ‘mental health professionals’ here encompasses therapists, psychologists, psychiatrists, and social workers. Many participants did not, or were not able to, distinguish between these various types of professionals, and some used the terms interchangeably. Furthermore, the types

of treatment they received when ‘seeing’ a mental health professional varied: while some saw a psychiatrist who focused on prescribing medication, others saw mental health professionals who provided therapy using approaches such as psychotherapy and cognitive behavioral therapy. This of course might account for some of the variation in experiences.

Participants raised several complaints based on their experiences seeing mental health professionals. A common complaint was that they simply played games, which they found unhelpful. Krista notes: “I guess it’s a common therapy thing, like watch kids play with dolls and then evaluate it, but that’s not what I needed! I need someone to actually talk to me!” Not understanding what professionals were trying to accomplish during these appointments, she recalls telling her parents that it was a “waste of money” when she was in second or third grade. Another complaint was that sessions felt rushed, with psychiatrists in particular. Natasha notes: “It seemed like they really just didn’t care at all. And they just wanted to write the prescription and get out of there.” Describing the fifteen-minute conversations she had with her psychiatrist during office visits in high school, Chloe notes: “I just always disliked how fast he went.” A few participants also recall that the sessions felt like a ‘waste of time.’ Gary notes that he did not receive the counseling that he had hoped for:

I don’t remember if they told me to do things a different way. [...] That’s how it’s been with every doctor of mine. I kind of expect them to counsel me through it, but instead they just write me a script and have me leave their office.

As noted above, he recalls obtaining information in high school on strategies to cope with ADHD from books, the internet, and health classes, and notes: “It would have been a *lot* more helpful if they kind of counseled me through it.” They expected more from these sessions.

Many participants who saw mental health professionals recall at some point questioning how these office visits could benefit them. Kimberly describes thinking that she did not have

any “issues” to talk about. Blake recalls questioning how therapy could possibly help him in high school since he thought he was dealing with normal worries, not a “disorder.” He notes that he would have been more receptive to therapy had he understood “this is a disorder and this can be treated, not cured, but treated... this is not normal.”

Many (n=10) describe feeling uncomfortable talking with mental health professionals. Three note that they were uncomfortable opening up to a “stranger.” Four feared that the mental health professional would report what they shared with their parents. Devin, for example, explains that he did not discuss feeling excluded in school because he thought the mental health professional would pass this information on to his parents, who would then worry about him. Melissa says that she felt “uncomfortable” that her therapist could tell her parents what was disclosed during her sessions: “[It] hindered my ability to really tell her what was going on.” Stephanie notes that she felt less comfortable with a mental health professional who knew her family well. She explains that her therapist tried to link her struggles with other family issues she was aware of, “instead of listening to what I actually had to say.” Meanwhile, two participants note that doctors, as well as other professionals, intimidated them.

Many participants (n=11) actively resisted seeing a mental health professional. They recall complaining to their parents that they did not like the particular professional or seeing a mental health professional in general. Three also recall rebelling during appointments by refusing to talk or answering defiantly. Courtney, for example, describes:

When I would go into the psychiatrist’s, I would be upset that I was there because I *hate* going. I hated talking to them. And so, I would not want to talk and I would probably not misbehave, but just act kind of sour and bitter and just like stand-offish like I’m clearly, I’m being burdened by being there.

Describing how this strategy failed, she recalls: “They interpreted that as, ‘Oh she needs a higher dose because she’s not behaving normally.’”

Almost two thirds of those who saw a mental health professional on a regular basis (n=20 of 32) note at least some benefits, however. In particular, they recall that it was helpful to have someone to talk to. Autumn notes: “When you’re younger, you don’t really talk to your parents, so it was nice to talk to somebody.” They also emphasize that therapists gave them helpful tools and strategies for managing their symptoms, as well as ways to identify things that would trigger them. Chloe explains that it was helpful that her therapist provided “a different point of view... offering different ways to deal with things and handle situations.” She explains: “She’d actually be able to offer some kind of helpful solution, like, ‘Oh, could you do this?’ ... Instead of my parents who were just like [claps hands], ‘No, you’re faking. Stop crying.’” In addition to being someone to “talk to,” mental health professionals were therefore also able to offer some participants helpful strategies for managing symptoms.

One reason for this variation was that participants’ experiences in therapy often depended on the character of the mental health professional – whether they seemed knowledgeable and whether they could relate to them, for example. Several participants describe mental health professionals as “smart,” “qualified,” and ‘knowing what they are talking about.’ Several also describe them as supportive. Teresa recalls her therapist encouraging her by telling her that she could “overcome” her symptoms. She recalls thinking: “I have a great doctor telling me I can do this. I actually believe that I can now... He went to Yale and he went to Stanford Med. He knows what he’s talking about.” Abby says her therapist was a “confidante and mother-figure” to her. She notes: “She treated me like a person. She didn’t make me feel like I was weak or broken.” A few note that it was nice to have a non-parental figure to talk to and receive advice from. Blake says that the fact that “he wasn’t my parent” was “a big help.” He notes that he listened to his therapist more than his father, who was also a mental health professional. Another

common theme was that participants liked mental health professionals with whom they were able to relate and easily connect. Blake recalls of another therapist: “I was like, ‘Okay, this guy is really cool. I can relate to him.’” In particular, he notes that he was “chill” and “used to play sports,” which made Blake feel he could relate. Max says it was “important” that his psychologist was Christian, like himself, because she shared the same “values” and had a similar perspective. Shannon describes one of her psychiatrists as “nice” and “understanding,” and notes that he also had ADHD, so she could “relate to him.” Monique says she was able to “express [herself]” because she “got along with” her therapist. She notes that she was able to “actually talk” because she felt “comfortable and relaxed.” Melissa explains: “I liked having... a person that was obviously completely unrelated to me, completely unbiased, discussing with me something she had familiarity with, something she had experience with.”

Meanwhile, several participants note that they did not feel like they could relate to their therapists because of their personalities or characteristics. In particular, participants note the inability to relate with mental health professionals who were “old.” Stephanie notes: “I was seeing a really, really old woman that I didn’t feel like I could talk to.” Abby reports disliking seeing a therapist who was “condescending.” Speaking of another therapist, she notes: “It took a while for me to feel comfortable with her... it was hard for me to get honest about stuff... I had such a problem asking for help.” The findings suggest that their experiences varied based on the individual characteristics of the provider.

Learning Strategies for Managing Symptoms

As noted above, many participants, and especially those with ADHD, describe the benefits of strategies they learned for managing their symptoms. Especially those with ADHD describe techniques that they used to excel academically. Amanda notes that she learned to keep

focused by periodically changing her studying techniques. Crystal explains that she learned to complete school assignments ahead of schedule. She notes: “You teach yourself how to do things so that you don’t keep messing up.” Similarly, Gary notes that he learned techniques, such as making eye contact and building routines, “through messing up” and learning from his mistakes.

One key strategy was participating in extracurricular activities that provided children an “outlet” for their energy and frustrations, such sports and music. Michelle notes that she suffered because she did not have an outlet for her depression. After explaining that her mother pushed her to focus solely on schoolwork, she notes: “People – when they really want to vent... they need an outlet. Like for me, I didn’t do anything, basically because I didn’t have a chance to.” She notes that this made her depression “worse.” This provides an example of a parent acting as a barrier to children accessing helpful coping strategies.

As noted previously, many parents, and mothers in particular, were helpful in teaching children strategies to manage symptoms. Paige notes that her mother helped ‘push’ her to be more organized, helping her to set routines and create schedules. Similarly, Krista recalls that her mother helped teach her to check over her homework and “think before you speak.” Several also note that it was helpful when their parents, and again mothers in particular, helped with their homework, pushed them to stay motivated in school, and had high expectations for them. As noted in Chapter 2, Blum (2007) describes mothers in her study as ‘vigilantes’ in their advocacy efforts for children with invisible disabilities, in both the educational and medical systems. This study extends Blum’s findings, highlighting the importance of mothers’ involvement in their children’s educations and their efforts to help their children manage their symptoms by actively

teaching them coping strategies. Parents' education levels surrounding children's mental health problems, among other factors, may affect their ability to provide this type of support.

It is perhaps not surprising that mothers were more involved in teaching children these strategies, given that many describe mothers being more involved than fathers in their treatment in general. Chloe explains that her father was aware of her treatment in high school, but was uninvolved. She describes:

My dad knew what was going on and stuff, but he wasn't fully involved with it, in either a positive or a negative way. He was just kind of there. He understood that I was going to see the doctors and got this medication and stuff, but that was about it.

Meanwhile, Whitney explains that she did not *need* her father to be involved in her treatment.

After describing her mother staying "up all night" researching her ADHD, Whitney notes:

My dad is less involved in that way... My mom deals with more of the doctor and appointments and all of that. But he, no, he's not really involved in it. But he doesn't really need to be... if I needed him to be, he would be.

Similarly, Paige notes that her mother was naturally more involved in her treatment because she was more present in the home than her father:

My dad, he was supportive, but he wasn't that involved. In just in that department. I have a great relationship with my dad. I'm very close with him. It's just kind of my dad works all day and my mom was a housewife... So my mom was just much more involved in our lives as a whole... very active in my school, active on my sports teams, that type of thing. So especially when my brother was diagnosed, she had all—I remember seeing all of these pamphlets and [she] would attend conferences and support groups, informational sessions, stuff like that, especially when I had it too... So my mom was much more invested in that and much more like, 'You are going to have extra time. You are going to have paperwork for this. You are going to go see a psychologist'... Obviously my dad was very supportive and trying to help me with it. But my mom was more guiding me along and putting me on the track and steering me.

Others mentioned, however, that it would have been helpful if their fathers had been more involved in their treatment.

Participants therefore had mixed experiences with various treatments, including medication use, therapy, and in-school services. While they describe the drawbacks of these treatments, many also note the benefits. They also emphasize the importance of learning strategies to “deal with” their symptoms, and describe the important role that their parents, and in particular mothers, played in making these available to them. Along with treatment, these strategies helped minimize symptoms and allowed participants to succeed, especially academically.

Voices in Treatment

Many participants discussed the role that they played (or did not play) in making treatment decisions. They describe how they were included or excluded throughout the treatment process. They also suggest ways that children can be more involved in their care.

Several participants (n=9), especially those who were diagnosed in high school, note that they were actively involved in the decision to begin or end treatment; many expressed their wishes to their parents who then advocated on their behalf. Ted for example, describes telling his parents his junior year of high school that he “needed to see someone” for his depressive symptoms. Chloe notes that she was “part of making the decision to go on medication” in high school and that her psychiatrist discussed different options with her and her mother together.

Similarly, when describing going on medication, Cindy notes:

That was my senior year of high school we prescribed – *we* prescribed me that [laughs]. I say ‘we’ because it was me, my mom, my doctor, and my therapist. We all said, ‘This is a decision, you need to have this.’

Cindy also describes telling her mother when she did or did not need to see a therapist, and her mother either ending or starting treatment in response. Similarly, Sam explains that they cut back on his in-school services when he started excelling academically in middle school and

started “complaining” to his mother about the services. He notes: “My own personal input, that was being fed in through my mom.” He also notes that his mother advocated for his wishes to stop taking medication: “My mom lobbied for me once I said that I didn’t like it and I didn’t think that it was helping me.” He explains: “[My psychiatrist] took his cues from my mom.” These cases illustrate parents advocating on their children’s behalf, helping them to affect treatment decisions. Not surprisingly, children diagnosed in high school were more likely than those diagnosed at younger ages to participate in these decisions; older children may have been both more self-aware and assertive, but also more likely to be invited to participate.

While in many cases, children tried more than one treatment simultaneously, some describe being faced with a decision between alternative options; only a few participants recall helping to decide which type(s) of treatment they would receive when faced with this type of decision. Erica provides an example of a participant making this type of decision, recalling that her mother asked if she would prefer to take medication for ADHD or have tutors help with her homework when she was diagnosed her freshman year of high school. Meanwhile, Tabitha provides an example of a participant convincing her parent that another treatment option would work better than the one she was trying. After trying neurofeedback¹⁰ and still struggling with attention problems in high school, Tabitha describes helping to convince her parents to let her take medication for ADHD: “I’m just like, ‘Okay, Mom, whatever. All my friends take it. I’m not really that worried about it.’ But I’m like, ‘You’re my parents, so.’ It’s like, ‘If you don’t

¹⁰ Neurofeedback is a technique aimed at improving attention and reducing impulsive and hyperactive behaviors by rewarding positive changes in brainwave activity (Duric, Assmus, Gundersen, & Elgen, 2012; D. J. Fox, Tharp, & Fox, 2005). Sensors are placed on participants’ scalps to measure brain activity while they play a video game or watch a film; participants try to adjust their activity levels during the session (Duric et al., 2012). In their review of the research, Fox et al. (2005) conclude that neurofeedback is an efficacious ADHD treatment.

want me to, there's nothing I can do about it.” This quote illustrates the implicit understanding that parents have the power to make the final determination regarding children's care.

Many participants, with all four diagnoses and who were diagnosed at various ages, note that there was a period of struggle at some point when they resisted their parents' treatment decisions. Teresa notes that it was a “constant struggle” throughout middle school; her grandmother who raised her told Teresa to take her medication, but it was not until the end of eighth grade that Teresa noticed her own struggles and realized it would help. She notes: “I had to realize it in order to start. I was always prescribed pills, but I wouldn't take them.” Paige also notes that she “fought the medication” when she first started taking it in first grade because she “didn't get why” she needed to take it, but that she realized how helpful it was academically in middle school. Daniela describes stopping taking her prescribed medication the summer before eighth grade as a way of “rebell[ing] against [her] parents,” but then deciding to go back on it very shortly after. Looking back, some think that their parents made the right decision. Christine, for example, describes being glad that her parents had her continue to take medication throughout childhood: “I'm glad they didn't take me off of it despite my best efforts to get off of it.” Others note that their parents finally accepted their pleas. Jennifer recalls convincing her parents to allow her to stop attending therapy a few months after being diagnosed with depression in eighth grade: “Eventually my parents caved and let me stop.”

Generally participants were excluded from treatment decisions. This included whether to start or stop treatment. Andy notes that he just “assumed” he would start medication when diagnosed with ADHD his junior year of high school, noting: “My parents... were very authoritative and just bent on the idea of me taking medicine.” Courtney recalls “fighting to” stop attending therapy and get off of her antidepressant medication in high school. When

describing her pleas to stop taking medication, Courtney notes: “[My parents could have] listened to me when I said I didn’t need it. Or listened to me when I said I don’t – there’s no reason for me to go and talk to somebody.” She adds: “[They could] just trust me a little bit.” She describes the complexities in honoring children’s wishes to stop taking medication:

I understand that they won’t just be like, ‘You know what, fine,’ and just take me off of everything and just watch as my world maybe crumbles because I have AD[H]D and I need the medicine. But, if I said like, ‘Let’s go off for a little bit and see what happens,’ they could have listened. Or the psychiatrist could have listened more.

She suggests that both mental health professionals and parents can listen to children’s wishes.

While parents and mental health professionals might disagree with children, this suggests that they should at least listen to children’s opinions and respectfully discuss how and why decisions are made.

Findings suggest that some children might not even consider being included in treatment decisions. Nathan explains: “It never even crossed my mind.” He explains that he started taking medication right when diagnosed in late elementary school: “My mom wanted me to take medicine, so I would. It wasn’t a big deal.” As Andy notes when describing starting medication the day after being diagnosed his junior year of high school, “I didn’t think twice. I just took it – just kind of took orders.” Similarly, Monique explains that she did not even consider challenging her medication use in high school: “I never really asked to stop because I didn’t think I had an option.” They did not even think of this as a possibility. Meanwhile, Ashley notes that she wanted to start taking medication when she was first prescribed medication in fourth grade because she “trusted [her] parents’ judgment.”

Those whose diagnoses were withheld from them were excluded from treatment decisions entirely. Daniela for example, explains:

They never fully explained why I needed to take [the medication]. They said it would help me focus more in school. I think I saw it just as vitamins that I needed to take. And it wasn't until probably the sixth grade or the seventh grade that I actually found out like what [the medication] was for... it was never a discussion about 'this is what's going on and this is what we need to do as a family.' It was just, 'Okay we went to the doctor and now this is what you need to take.'

As noted previously, Daniela figured out that she had ADHD when she realized in middle school that peers were taking the same medication for ADHD. Meanwhile, Crystal, who notes that her mother was very open with her about her diagnosis in general, told her that her ADHD medication was "calcium pills." Crystal recalls not wanting to take medication because she thought she would be teased and did not want to be different, so her mother "trick[ed]" her into taking the pills. Her mother revealed that the medication was for ADHD when Crystal was in eighth grade and was "finally... accepting" of her diagnosis and ready to "deal with it."

Several participants also describe being pushed into treatment without much explanation. For example, Sarah explains that her mother told her she would take medication and see a doctor, when she learned of her ADHD diagnosis in third grade, but it "was all very vague." She notes, "I remember it now even as this weird kind of experience... there's no explanation to why I had to go through that." Similarly, Autumn describes her mother telling her she would get extra help from teachers in elementary school without explaining why she needed it: "All I remember from a very early age was that I needed extra help on stuff, and I didn't really know why." Natasha describes her parents rushing into treatment without providing her a full explanation. After being tested and diagnosed for ADHD her freshman year of high school, she describes her father reacting, "Okay, fine, if they say so," and her mother immediately contacting a psychiatrist. Natasha notes: "And no one really stopped to explain it to me. I don't know why no one did that. [...] I mean I understand that need to be rushed but it would have been nice to know what was going on." This lack of information contributed to their exclusion from treatment decisions.

A few participants (n=4) who were diagnosed in middle school and high school also describe being infantilized throughout the process, including during testing. Natasha, for example, comments on the professionals who tested her for ADHD when she was in high school:

They were nice people. But as a high school student, I thought that at some points, they could be a little bit demeaning. I felt kind of small and like they thought I couldn't understand or grasp some concepts that were pretty basic at the time... I thought they could be a little more grown up in the way they talked.

Meanwhile, Gary notes that when he was tested in sixth grade, it felt like “preschool.” He explains: “It felt almost like daycare, but just someone was observing me a lot more.” Similarly, Angela notes that even the physical setting was infantilizing, given she was a freshman in high school. She describes the office of the child psychologist who diagnosed her: “I remember it being like a baby room, and so that was kind of weird.” She notes: “They think you’re a child, and at that age you’re trying not to be.” In an environment where children are infantilized, it is perhaps not surprising that they are not treated as capable of participating in difficult treatment decisions.

Despite research demonstrating the importance of including children in treatment decisions (J. Davies & Wright, 2008; Hepper et al., 2005; Laws, 1998; Moses & Kirk, 2005; Roth & Roth, 1984), many recall having been excluded from this process. They also describe being tricked and pushed into treatment, and infantilized throughout. There are likely developmental differences that limit children’s ability to take part in these discussions at a young age. A child’s ability to participate in decision making about their care is likely very different in elementary versus high school. Research should assess these differences, and children should be included to the full extent possible and in increasing ways as they age.

Demonstrating that mental health professionals privileged parents’ voices and that the power to make decisions rested almost entirely among adults, many participants who *did* have a

voice in treatment recall feeding their wishes to their parents who then acted as advocates on their behalf. Future research should examine whether socio-demographic factors, such as race, class, and education levels affect parents' ability to advocate for their children in this way.

Participants' Recommendations for Treatment

Participants offer several suggestions for the treatment of children's mental health problems. In particular, they provide recommendations to mental health professionals, school staff, and parents. Through these recommendations, they provide insight into how to help translate diagnoses into sources of empowerment rather than stigma.

Especially those with ADHD emphasize that being diagnosed is only beneficial if provided strategies for managing one's struggles. Mark explains: "[The diagnosis] makes you aware of what the situation is. But it doesn't really help you any if you know what it is, but there's no solution." He notes that it helps when one can ask: "What will help me to be better in spite of this... instead of just, 'Oh I don't pay attention enough.'" Whitney notes that the neurologist she saw gave her a thorough explanation of which areas she struggled in and how she could work to improve them. She explains:

With the neurologist and how he just explained things, you'd have that to work with then. That's better rather than just telling someone, 'You have it.' Because that doesn't really mean anything. Because then you're the same person whether you were diagnosed or not... knowing exactly where you're going wrong helps.

Amanda notes that even with very young children, adults can show them pictures and explain, "If you're feeling this way, do this." They emphasize the importance of providing children strategies for managing symptoms.

Several participants also note the potential benefit of connecting with peers with similar struggles. Explaining that this would have helped her understand that she was not the only one

with this problem, Melissa says: “Having entered maybe a peer group for depression would have been a huge impact.” Similarly, Monique recommends that it is important for children to have “somebody that’s their age that’s been through it or that’s going through it,” to talk to. She notes: “There’s a lot of kids out there that’s going through depression and they don’t know how to deal with it... they don’t have nobody to talk to.”

Some participants recommend that medication at least be considered as a possible treatment option. Some rebuke the overmedication controversy and criticize parents who do not even consider this option. Stephanie notes:

I don’t want to say you have to use medications. But I wish more people were open to the possibility if nothing else is working, just to try it because it’s not going to hurt. So I feel like just being open and knowledgeable – educate yourself about the stuff, especially if you’re a parent or a teacher who has to work with this kid. And be knowledgeable about the different treatments and then be open-minded. And the bottom line isn’t to make someone normal; it’s to make them feel better.

She recalls feeling excited when she began medication in third grade because of how her mother treated it. She notes: “There wasn’t stigma against medication in my house. My mom’s attitude is if there’s a pill for that, why wouldn’t you take it?” Crystal notes: “Lots of people are very against [medication for ADHD]... but honestly, unless you need it, you really shouldn’t have a say in it.” They suggest that fears of over-medicating children may serve as a barrier to some children receiving medication that could help them.

They note, however, the precautions that need to be taken when considering medication use in children. For example, Autumn suggests that medications can be potentially addicting for youth, and recalls hearing about peers selling and misusing their medications. She adds that it is not right for “every kid,” noting: “There are other ways that you can try besides just going for a quick-fix drug.” Josh warns against using high doses, noting that some of his peers were “over-medicated.” He suggests that children should not be medicated until they are old enough to

“handle it” and understand what it is. Amanda and Sam note that learning strategies for coping with one’s symptoms (e.g. improving one’s concentration and organizational skills) can be even more beneficial than treating symptoms with medication.

Another commonly reported suggestion was that mental health professionals listen to children in therapy rather than play games and rush sessions. Courtney explains: “Stop giving them toys and... taking all these memory tests and stupid standardized things like that... and just really *talk* to the kid.” She notes: “They need to stop thinking about the information that people are telling them, and talk to the person themselves.” She emphasizes that children should be treated as capable of participating in these conversations. They also emphasize the importance of mental health professionals sharing information and coping strategies with children.

Participants also recommend that schools better support students and be more accepting of diagnoses. They emphasize the need to provide more education on mental health problems to school staff. Crystal describes the struggles she had when her high school wanted to remove her education plan. She notes: “The school systems – they need to be more accepting, more helpful, and more educated on it.” Some note that at an individual level, school staff should also be more accepting and knowledgeable. Devin suggests: “The more knowledge teachers can have about it, the better.” Melissa, who recalls that her high school teachers “didn’t want to deal with” her depression, and “stereotype[d]” her, suggests that teachers could have been “more understanding,” “reached out,” and provided “positive motivation.” They emphasize the important role that teachers can play in supporting students with mental health diagnoses.

Another prominent theme was that parents should be open with children about the treatment they are receiving. Warning against parents telling their children, ““There’s absolutely

nothing wrong with you, but you just have to take this pill” in order to “protect the [child’s] self-esteem,” Stephanie notes that she is pleased her parents were open with her about medication. She describes her parents pointing out her symptoms, which she herself had already noticed, and explaining that medication could be used to help “fix it.” Providing a similar warning, Teresa describes:

My younger cousin has ADHD and... it took them a while, like my aunt particularly, for her to let her son take medication. And the way she is doing it I think is completely off. She is telling my little cousin that, ‘This is completely normal. All kids take medicine.’ So my cousin’s growing up thinking that all little kids take one pill a day every day. I think that’s completely false. Kids are mature enough to know that they’re different. It’s like the situation with death. Kids know that death happens and it affects people. You can’t just sugar coat it for them. They’re people too.

They emphasize that children should be fully informed about the care they are receiving.

Some also note that children should be included in treatment decisions. Andy suggests that children in middle school should be presented with treatment *options*. He notes that mental health professionals should explain the side effects, and allow the child to help “weigh the options” to decide which forms of treatment they would like to try. Max notes that mental health professionals should better inform children about treatments, such as accommodations that could be made available to them in school. He emphasizes that information is crucial in “making better choices.” They emphasize that it is important to be open with children about treatment options as a form of respect. Devin notes that he interpreted the lack of openness and communication he received as a sign of disrespect: “I wanted to be treated with respect by my teachers and my parents and my therapists, or whoever. And no one really respected me enough to tell me what was going on, or how I could deal with it.” As noted previously, Max suggests: “Even in childhood years I think that’s important to establish [things] with the patient. Let them know everything... instead of ‘dumbing’ it down. Respect – have more respect for the patient.”

Participants therefore offer several suggestions for the treatment of mental health problems. They emphasize the importance of providing strategies for managing symptoms, connecting youth with peers with similar struggles, and being open to the idea of medication use. They provide recommendations for mental health professionals, school systems, and parents, noting that they should be supportive and open, and should listen to children. Further, they emphasize the importance of including children in treatment decisions.

Conclusion

I began by describing the empowerment and stigma that participants experienced. These findings expand the literature describing the possible benefits and drawbacks of medicalization. As discussed in Chapter 2, sociologists have noted both the promises and pitfalls of medicalization (Conrad & Schneider, 1992). For example, it might promise the possibility of finding a cure and may remove blame by legitimating behaviors, but diagnoses may be stigmatizing and direct attention to the individual and away from the broader social context (Conrad & Schneider, 1992). The burgeoning exploration of children's experiences with the medicalization of children's mental health suggests that it may be both empowering and stigmatizing. Cooper and Shea (1998, 1999), for example, find that children felt stigmatized by their ADHD diagnoses, but also welcomed diagnoses because they provided an explanation for their behavior and access to medication. Findings here also demonstrate that children experience drawbacks *and* benefits to diagnosis. Participants experienced diagnoses as empowering in particular when understood as an explanation for their struggles, and when seen as promising the possibility for change, suggesting the importance of an emphasis on these aspects of diagnosis. Meanwhile, almost all of the participants (n=37) feared or experienced some level of stigma associated with their diagnoses and/or treatments. As described below, findings also highlight

the opportunity adults (e.g. parents, teachers, schools administrators, and mental health professionals) have to help maximize the benefits and minimize the drawbacks that children experience.

The data show that *treatments*, and not just diagnoses, had both perceived benefits and drawbacks. While participants describe several concerns with taking medication, including experiencing side effects, identity issues, dependency, and stigma, many note that medication strongly benefited them, often alleviating their symptoms and allowing them to succeed both academically and socially. While they found several aspects of in-school services stigmatizing, they also found these extra supports to be helpful in their academics. While some did not see the benefits of therapy, others found it helpful; it often depended on the characteristics of the mental health professional. While these differing experiences may be a reflection of differing quality of services, it may also suggest that treatments are helpful to varying degrees for different children, underscoring the importance of making treatment decisions on a case-by-case basis. As described below, findings suggest that children should be part of these decisions.

The interviews point to several benefits and drawbacks to being diagnosed at a young age. In particular, there may be benefits to being diagnosed with ADHD when relatively young (e.g. elementary school). As Paige's case suggests, being diagnosed with ADHD at a young age may be beneficial because children can learn strategies to manage their symptoms over time, including strategies that help children excel academically. Whitney notes that being diagnosed with ADHD at a young age can help children improve their "work habits" early on. Similarly, Kimberly's case suggests that children diagnosed with ADHD at an early age may be protected from accusations that they are faking having the diagnosis when they are older. They note that they are grateful they began receiving treatment when they did. Furthermore, receiving a

diagnosis late in childhood may be particularly stigmatizing for children. As noted previously, Jennifer suggests adolescence is a difficult time to receive a diagnostic label, as it is already a difficult time socially. As noted above, this is line with research demonstrating that adolescence is a crucial time in identity development when stigma can be particularly damaging for youth (Brown, 1990; Harter, 1990; Rosenberg & Gaier, 1977). However, diagnoses may be more empowering in late childhood in other ways. For example, findings from this study demonstrate that children in high school were more likely to participate in treatment decisions, which participants found particularly empowering. Those who were diagnosed later in childhood may also have received, or been able to obtain, better information about their diagnoses, which findings also suggest is empowering.

The data also suggest that it is common to hide diagnoses, especially from peers, throughout childhood. This builds on previous research demonstrating that children in an inpatient unit tried to protect their social identity by limiting whom they told about their treatment (Hepper et al., 2005). Findings here demonstrate that this is widespread, with many hiding this information for fear of stigma and some because their parents treated their diagnoses and treatments as something to keep secret. Many describe the relief they experienced when they revealed this information to peers and siblings.

Findings here highlight that children's voices are often excluded from the treatment process and that children wish to play a larger role in making decisions regarding their care. These findings add to previous research demonstrating that children who are hospitalized for psychiatric disorders should be given information and play a more active role in this treatment (Hepper et al., 2005; Roth & Roth, 1984), children wish to be more involved in family therapy (Stith et al., 1996; Strickland-Clark et al., 2000), and children should be listened to and included

in treatment decisions (J. Davies & Wright, 2008; Hepper et al., 2005; Laws, 1998; Moses & Kirk, 2005; Roth & Roth, 1984). In fact, many did not even consider being included in treatment decisions. Others were excluded from decisions regarding their treatment because information was withheld from them; some were not even aware of their diagnoses, or given information about the treatments they received, such as medications they were taking. Meanwhile, some describe being pushed into treatment with very little explanation. The finding that some felt infantilized throughout the treatment process underscores the idea that children are treated as immature and incapable of understanding information. Participants' accounts show that this is distressing to many children, who want to be respected and have their voices included in decisions regarding their care. Children go through developmental stages and are indeed able to process information in increasingly complex ways over time. There may be instances in which a young child is *not* capable of fully understanding treatment options. Age and developmental stage should therefore be taken into account when determining the level to which a child can be involved in these decisions. However, findings suggest that adults should include children in these discussions whenever possible and appropriate.

Not only should children's voices be included when making decisions regarding mental health treatment at the individual-level, but children's voices should be included on a systems-level as well. Arguing that they are fully capable of "giving relevant, considered views on the services they have experienced," Laws (1998, p. 10) notes: "Young people who use mental health services are often disqualified as people whose opinions should be taken account of, first because they are young, and second because they have had mental health problems."

Participants in the current study emphasize that children want their perspectives and wishes to be taken seriously when decisions are made regarding their mental health treatment; we must also

take children's recommendations on a system-level seriously. As consumers of mental health treatment who have experienced treatments first-hand, along with the empowerment and stigma that come with them, they can provide invaluable insight into improving care. By capturing their recommendations for improving children's mental health treatment, we can begin to honor children's voices and experiences.

Through their recollections, participants made several implicit recommendations for the treatment of children's mental health diagnoses. For example, their experiences suggest that being open about diagnoses in the family environment can be beneficial. Findings suggest that parents play an important role in setting the tone for how diagnoses will be treated within the family. Their experiences also suggest that peers could be better educated about mental health problems. Schools might serve as one avenue for sharing information that could help mitigate stigma among peers.

Participants also provide several explicit recommendations for treatment. They emphasize that diagnoses are beneficial when provided with strategies for managing one's symptoms, and that connecting with peers with similar struggles may be helpful for children. Many strongly recommend that parents be open to the use of medications. They suggest that mental health professionals listen to children in therapy, that school staff be more supportive, accepting, and knowledgeable about mental health problems, that parents be open about treatment, and that all adults include children in treatment decisions. Findings underscore the opportunity that adults have to help increase the benefits and minimize the drawbacks of children's mental health diagnoses. By teaching children coping strategies, being open to treatment options, providing support, discouraging secrecy surrounding diagnoses, and including

children in treatment decisions, adults might be able to help translate diagnoses into empowerment rather than stigma.

CHAPTER 7

Conclusion

I began by sharing my experience volunteering at a transitional housing program where I met a six-year-old boy who was diagnosed with ADHD and bipolar disorder. I questioned: How did *he* make sense of his diagnoses? How did he learn about and experience these labels? Findings from this study suggest that his experiences were likely influenced by how he was informed of his diagnoses and the amount of information he received. He likely made sense of his diagnoses over time, as he gathered additional information and actively negotiated the many narratives about children's mental health, and he likely experienced both stigma *and* empowerment associated with his diagnoses and treatments.

As researchers, practitioners, policymakers, program administrators, parents, teachers, and mentors, I now ask: how can we best deliver diagnoses, treatments, information, and support in order to minimize stigma and translate diagnoses into empowerment for children? With an increasing number of children being diagnosed with mental health disorders today, it is especially important that we better understand how children make sense of these labels, and what we can do to best support them. In this study, I have captured the voices of those who experienced mental health diagnoses in childhood to explore how they recall learning about, making sense of, and experiencing these diagnostic labels, and how they think diagnoses should best be delivered and explained to children.

I begin by sharing the themes that emerged in the data. I next discuss how this study contributes to the literature, and describe implications for both social work practice and policy.

Throughout this chapter, I describe several ways in which children's voices are significant: 1) in practice, including in diagnosis, treatment decisions, and therapy; 2) in policy and systems-level change; 3) and in research. The chapter concludes with a discussion of study limitations and directions for future research in this area.

Key Themes

While experiences varied greatly by individual, several key themes emerged in this study:

Sharing information with children is important. Interviews suggest that withholding diagnoses and information can exacerbate the stigma children experience. Those whose diagnoses were withheld from them recall feeling the stigma of having “something” to hide; they felt something was “wrong” with them, even though they could not identify its source. Further, some experienced a sense of betrayal when they later learned that their parents withheld their diagnoses from them. These findings extend research on delivering physical health diagnoses to the field of mental health, demonstrating the need to share information openly with children who may become more distressed by misunderstandings than open communication and information about their diagnoses (Eiser & Eiser, 1987).

Consistent with the theory that illness explanations have a “relationship dimension” and that open communication signals doctors care about whether adult patients understand their problems and treatment (Thompson, 2000, p. 27), this study demonstrates that open communication demonstrates respect for children. Participants recall interpreting the withholding of information by mental health professionals and parents as a sign of disrespect. Children want to feel valued and respected.

Rather than attempting to protect children by withholding information, diagnoses should be shared in developmentally appropriate ways to the full extent possible. As noted below, we

must explore the best ways to present and explain information at different stages of development. The type of information provided can be seen as shifting over time, based on development, but information should be shared to the full extent appropriate at all stages throughout childhood.

Parents play a pivotal role in this process, and thus parental education is crucial. As discussed in Chapter 4, parents often play the role of liaison between medical professionals and their children. In many cases, mental health professionals provided parents information and parents then chose how to pass this on to their children. Some children were even asked to physically leave the room when professionals explained diagnoses to their parents. Natasha's case is also noteworthy; she was in the room, but professionals directed information to her parents as if she were not even present. Children are often treated as incapable of understanding and handling information. Parents then act as translators of this information, presenting information and explaining diagnoses in varying ways. Some act as withholders, choosing not to share information with their children, perhaps because they think their children will not understand or in an attempt to protect their children from this information. Participants suggest that some parents may feel uncomfortable discussing diagnoses with children, especially when mental health is a 'taboo' subject in their cultures.

A theme throughout was a sense of confusion and lack of understanding; children were typically not provided complete (or in some cases any) information about their diagnoses, or did not understand what they were told. Building on theories that children do not understand information about physical health because they cannot comprehend and/or are not told (Eiser & Eiser, 1987), findings from the current study suggest that children struggle to understand information about mental health diagnoses not because they are incapable of comprehending it, but because it is not being presented in an effective manner.

Professionals should support parents in finding ways to present this information in an effective way to children. The data suggest a need for assurances along with diagnoses, explaining to children that the problem is common, not their fault, unrelated to their level of intelligence, and legitimate. Participants note that adults can help children process information, sharing it openly and directly, but slowly over time; this can include talking to children about their diagnoses, sharing reading materials, and helping children process information received online, through the media, and presented in schools. Participants suggest that adults share resources with children, discuss the information received, and create a space where children feel comfortable asking questions. While participants note that it depends on the child's relationship with their parents, they generally suggest that parents deliver mental health diagnoses to children; they view parents as playing a crucial role in the process of sharing and helping children process information.

Many participants emphasize the importance of parental education, given their role in sharing information with children. Participants report varying levels of parental knowledge about children's mental health. Consistent with research documenting parental dissatisfaction with the information they receive and uncertainty about their children's mental health diagnoses and treatments (Chesson et al., 1997; Collins & Collins, 1990; Jivanjee et al., 2009; Moses, 2011), many note that their parents received little information from professionals, and had a poor understanding of their mental health problems. While some participants report that their parents just 'got it,' others recall their parents seeking information on their diagnoses. They describe their parents utilizing multiple resources to obtain this information, including reading books, accessing information online, and even in one case attending conferences. Surely not all parents

have the resources and skills to conduct this type of research. As noted below, future research should examine how socio-economic status affects parents' ability to access this information.

Parental knowledge about children's mental health affects how children experience their diagnoses. The data indicate that parents with high levels of knowledge and understanding about their children's mental health diagnoses are able to help their children process information, support them, and act as advocates on their behalf. This study expands upon previous research focused on parents' understandings by identifying effects on children, further underscoring the need for parental education about children's diagnoses.

Children actively negotiate, embrace, challenge, and contribute to cultural narratives about children's mental health. Rather than simply absorbing societal understandings of mental health, children actively interpret, accept and resist these cultural narratives. While some participants resisted medical narratives, many embraced them when they obtained in-depth medical information over time. Those who found medical narratives helpful note that they did the following: provided an explanation, legitimized their problems, and gave them something to blame for their struggles. Those who resisted medical narratives, especially that of "disorder," note that this terminology labels and stigmatizes children. Children's understandings of their diagnoses change over time as they seek and receive additional information, progress through developmental stages, and actively construct their own meanings and understandings. In line with the interpretive reproduction model, these findings demonstrate that children are both affected by societal narratives about mental health, and actively engage in and contribute to these narratives. Children are active participants in this process, and able to participate in the discussion.

Children often experience both empowerment and stigma; providing information and coping strategies can help to empower. While sociologists have theorized both the “brighter” and “darker” sides” of medicalization (Conrad & Schneider, 1992, p. 246), findings here demonstrate that children often experience both. Diagnoses were often experienced as empowering in that they legitimized children’s struggles and opened doors to manage and treat their symptoms. However, participants also felt labeled and embarrassed, and often wanted to keep their diagnoses hidden from others – especially peers. Participants also saw both benefits and drawbacks to mental health treatment. While they experienced negative side effects associated with taking medication, for example, many found it helped alleviate symptoms, and while some found therapy helpful, others did not see the benefit. These findings suggest that treatments are helpful to children to varying degrees, and that treatment decisions should be made on a case-by-case basis. However, a theme throughout emerged: Diagnoses and treatments were generally experienced as empowering and beneficial when children were provided with information about their diagnoses and when they understood the purpose and potential benefits of treatment. Those who received less information about their diagnoses and reasons for treatment found them less helpful. Withholding information from children often encouraged secrecy.

Children want their voices to be heard and their opinions to be included in treatment decisions. Consistent with previous research suggesting that children should be more involved in treatment, therapy, and decisions about their care (J. Davies & Wright, 2008; Hepper et al., 2005; Laws, 1998; Moses & Kirk, 2005; Roth & Roth, 1984; Stith et al., 1996; Strickland-Clark et al., 2000), findings from this study demonstrate that participants’ voices were often excluded from the treatment process and they wish that they had been included in treatment decisions. Some

did not even consider being included in discussions about their treatment; others were excluded entirely because they were not informed or aware of their diagnoses and/or treatments.

Participants who thought that their medications were vitamins provide a striking example of this. Further, some participants describe feeling infantilized and disrespected throughout the treatment process – treated as incapable of understanding what was going on. While developmental status must be taken into account when determining how a child can understand and participate in treatment decisions, findings suggest that children should be included whenever possible.

The terminology of disorder was in some cases beneficial in that it provided explanations, legitimized problems, and shifted blame away from the individual; but it also stigmatized, labeled, and pathologized children's conditions. We must question whether we can achieve the benefits participants describe experiencing with medical diagnoses *without* utilizing the terminology of disorder. As Chloe so poignantly explains, children should “understand that there’s something else going on that could explain how they’re feeling,” but it is also important “to not like *define* them.” As she explains:

If there was a way to explain things to a child, like ‘This is what’s going on with you’ without saying like, ‘You have this disorder and this is what’s wrong with you,’ would be like one of the best ways to go about it.

We must explore ways to explain, legitimate, and shift blame away from children without stigmatizing, labeling, and pathologizing children’s conditions.

Contribution to the Literature

This study integrates medical sociology and the sociology of childhood through an exploration of a research question not yet addressed by either approach. By bringing these two approaches into dialogue with one another, this research offers a perspective that has been notably absent – the experiences of children who live with diagnostic labels. In particular, this

study expands research on doctor-parent and doctor-patient communication, medicalization and stigma, and the illness experience by introducing *children's* perspectives.

This research contributes to the medical sociological literature by adding empirical data to what has previously been theorized regarding the effects of the medicalization of mental health. As Wahl (1999) notes, research should examine the experiences of those who experience mental health problems, as they can best describe their own experiences. Supporting the idea that medicalization has both benefits and drawbacks (Conrad & Schneider, 1992), this research demonstrates that participants experienced both empowerment and stigma associated with their diagnoses. It adds the important insight that adults can help empower children and minimize stigma by sharing information openly and providing assurances to children.

Drawing from the interpretive reproduction model, in which children are seen as appropriating information from the adult world but also creating their own meanings (Corsaro, 2005), this research also adds to the literature by exploring both the agency of children in their meaning-making processes as well as the effects of cultural understandings on children's understandings and experiences. It examines the social construction of mental health at the societal level, taking a constructivist view, aimed at understanding the meaning-making of children who interpret, appropriate, and challenge these constructions. Viewing mental health as a social construction in this way does not devalue the legitimacy of diagnoses or the gravity of symptoms that children experience, but rather, allows us to think critically about how children's understandings affect and are affected by societal understandings of mental health problems.

This study also calls for an integration of the child development and sociology of childhood literatures. In contrast to the view of children as passive and incompetent in the process of development, the sociology of childhood suggests that children play an agentic role in

this process. We must discuss diagnoses in ways that acknowledge children's developmental capacities, but also view children as active participants in interactions, meaning-making, and development. Further, rather than focusing on the *outcomes* of development, I emphasize the importance of improving children's *present* experiences – the day-to-day experiences of diagnoses. Rather than in conflict with one another, a child development framing can help us to understand what children at different stages can comprehend; meanwhile, the sociology of childhood perspective can encourage us to shift away from treating children as passive, unknowing and need in protection, and rather, treat children as active participants in the conversation. This calls for a shift in not only how we view children, but how adults treat them; rather than protecting children, we can aim to collaborate, discuss, and learn from one another.

Implications

This research provides insight into how social workers, along with other mental health professionals, parents, and teachers can best deliver and explain diagnoses to children, and support them as they make sense of their diagnoses throughout childhood. It has important implications for social work practice and policy.

Practice Implications

Narrative therapy provides a promising approach for practice. In particular, practitioners can utilize externalizing conversations, at the heart of narrative practice, which distance one's identity from the problem (White, 2007). For example, Young (2008, p. 57) provides examples of children defining 'the Worry' as a force outside of themselves, causing them to think and feel certain ways, rather than an anxiety *disorder*. This approach shifts the blame to something outside of the individual, to help explain and legitimate children's symptoms and struggles. This approach can achieve the same benefits described by those who found medical narratives helpful

– providing explanations and legitimizing problems, while shifting blame away from the individual – but *without* utilizing the terminology of disorder.

Practitioners can also draw upon the principles of narrative practice by inviting children’s perspectives directly into therapy. This approach addresses a key concern of participants – that children’s voices are often not valued in practice. By encouraging children to help define their problems, such as ‘the Worry,’ narrative therapy creates the space for children to develop their own narratives (Young, 2008). As Bennett (2008, p. 22) notes, narrative therapy “gives primary value to how the child views his or her experiences.”

Practitioners can also invite children’s narratives into assessments and the delivery of diagnoses as well. Just as Kleinman (1988) suggests, it is important that practitioners integrate their own professional models with their patients’ perceptions of their own experiences when making a diagnosis. Practitioners should elicit how children describe their own struggles, and how *they* interpret their problems, even before making the official diagnosis. Rather than sharing information uni-directionally in assessments and the delivery of diagnoses, practitioners can ask children how *they* describe their struggles, and prioritize these narratives and understandings in discussions.

As part of this process, practitioners should elicit and better understand the context in which children’s mental health problems occur. Using “hermeneutic dialogue,” for example, practitioners can aim to understand the socio-historical context in which patients’ emotions and behaviors are experienced, rather than “forcing the patient’s behavior into the pre-established diagnostic categories of the DSM” (Aho, 2008, p. 253). Aho (2008, p. 253) explains that this dialogue “involves a process of respectful, mutual exchange” in which patients and professionals acknowledge that there are multiple ways to understand “mental suffering.” While

acknowledging that genetic and brain chemistry influence mental health, Aho (2008, p. 248) raises his concern that mental health professionals have “uncritically accepted” bio-psychiatry “as *the only* approach to understanding mental illness.” He urges clinicians to be critical of assumptions that psychiatry must be based on “unambiguously objective and neutral” diagnostic classifications (Aho, 2008, p. 254). This practice provides another avenue for shifting away from the framework of pathology, and emphasizing the lived experience of the patient. Social workers should look beyond individual symptoms and view the context in which children’s mental health problems occur, acknowledging that there are multiple ways of interpreting their patients’ struggles.

In addition to including children’s perspectives in diagnosis and therapy, practitioners can better inform children of their treatment options and invite children to participate in decisions about their care. Participants found their treatments most beneficial when they were informed of their purpose, and many note that they wish they had been more involved in treatment decisions. I propose that we use a flexible framework – one that shifts with development, allowing for the maximum amount of openness possible. Rather than treating children and adolescents as incapable of participating in treatment decisions and needing to be protected from information until the moment they turn 18, when in some cases they suddenly are responsible for all decisions and privy to all information, this should happen incrementally over time – to the full degree possible for any given child. The amount of information provided and level of child-participation in decisions will vary by individual child of course, but for each child, it could be seen as shifting over time. We need a dynamic understanding of children’s ability to participate in decision making over time, using a developmental framework. This necessitates further research on children’s understandings over time, as described below.

There are several ways in which practitioners can also include children directly in decisions surrounding their care. When possible, practitioners can provide children with multiple treatment options. As suggested by participants in the current study, clinicians can discuss the benefits and drawbacks (such as side effects) of different treatment options with children, asking them to help weigh different options. Going beyond this, practitioners could even encourage children to propose their own ideas for how to best manage and treat their symptoms. Findings from the current study demonstrate that children often discuss treatment options, such as medications, with their peers. Practitioners can offer more structured opportunities for children to connect with other children experiencing similar struggles, so they can discuss and compare treatment options, such as through peer support groups. Including youth in this way has the potential to cause power struggles if youth and parents disagree about treatment decisions. The challenge of course is finding a way to honor parental roles while also respecting children's ability to take part in the process (Crickard, O'Brien, Rapp, & Holmes, 2010). This is likely best done on a case-by-case basis.

Findings from the current study suggest that practitioners, as well as other adults in children's lives, can also help minimize the stigma children experience by sharing information as openly as possible, teaching children coping strategies, and providing assurances that mental health problems are common, legitimate, and not their fault. This can help to translate diagnoses into experiences of empowerment for children. On the other hand, the current study suggests that trying to 'protect' children from information can in some cases exacerbate stigma. As noted previously, children sensed *something* was "wrong" when they were not informed of their diagnoses. Sharing information openly with children, with an emphasis on assurances that it is not their fault, can help children manage the stigma associated with mental health diagnoses.

The current study highlights, in particular, the importance of conversations that take place when children are first diagnosed. Several approaches and techniques for talking to families of those with mental health diagnoses can be applied to talking not only with parents of children with mental health diagnoses, but also with children themselves. In his advice on talking to families, Galynker (2011, p. 2) describes the need for “clear, compassionate communication.” He suggests providing direct answers to questions using plain language, and using medical terms only when given with clear explanations. In particular, he suggests using “less stigmatizing and less clinical language” when first sharing diagnoses with families, to make it easier for them to accept this news (Galynker, 2011, p. 87). Noting the importance of conversations when family members are first diagnosed, Galynker (2011, pp. 55–56) emphasizes that these discussions call for “a special kind of warmth, support, and positive regard.” He emphasizes the importance of discussing guilt and stigma during these conversations, helping families understand that the symptoms are separate from their family members’ personalities and are not intentional (Galynker, 2011). These strategies can all be applied to communicating with parents, as well as speaking directly with children about their diagnoses. In cases when it is deemed best for parents to share diagnoses directly with their children, practitioners could suggest that parents use similar strategies in their conversations. While communication may be limited based on the child’s developmental ability, practitioners and parents should aim to provide information to children in a direct and compassionate manner, giving clear explanations and limiting their use of clinical language, while helping children to understand that they are not to blame for their diagnoses or symptoms.

Findings also underscore the important role that practitioners play in educating parents about children’s mental health. Parents act as liaisons between the medical realm and children:

as gatekeepers to diagnoses and treatments, as translators of diagnoses and information about mental health problems, and as supporters and advocates of children as they manage their diagnoses. Findings show that parents play a crucial role in providing children assurances that can help to allay fears associated with their diagnoses. In addition to empowering parents to advocate for their children and play an increased role in their care (Collins & Collins, 1990; Mendenhall & Mount, 2011), social workers can also support parents in the role they play sharing information with and providing assurances to children. Findings that suggest parental education about mental health affects children's experiences underscore the importance of improving parental education. This includes the need for better explanations of mental health diagnoses and better communication between mental health professionals and parents, with practitioners tailoring their communication with parents based on their education levels and their knowledge about mental health (Galynker, 2011, p. 27). Given that some families may lack the resources to obtain information on their own, it is also especially important that social workers help support parents in this process, educating and equipping them with the resources to help their children process information. They can also introduce families to resources that frame mental health diagnoses using non-biological perspectives, given that much of the literature aimed at parents is focused on biological causes (Rafalovich, 2004).

The need for a shifting framework, in which information is presented to the full extent possible across developmental stages, underscores the need for practitioners to provide children and parents *ongoing* support. This is especially important given findings from the current study that children obtain information and negotiate narratives over time. Adopting the shifting framework described above means that educating and supporting children and families at the time of diagnosis is not enough. Practitioners can provide children with increasing information

and education as they age. Meanwhile, practitioners must also continue to engage and educate parents as they provide ongoing support and information to their children over time.

Policy Implications

This research has implications at a policy-level as well. For example, findings have implications for improving parental education about children's mental health not only at the individual level, but at the systems-level as well. Findings underscore the importance of using a universal approach to providing education and outreach strategies that inform and empower parents. Consistent with Moses (2010) and Elkington et al.'s (2012) findings, participants in the current study report parents communicating negative messages about their mental health diagnoses to them – some telling them explicitly to keep their diagnoses secret, and others implicitly suggesting this by withholding information. This study suggests the need for programs that combat this, such as 'family-based antistigma prevention programs' that promote open discussion about mental health within families (Elkington et al., 2012, p. 311).

Schools also provide an avenue for educational programming, including educating children about special needs and special services. Especially those who received in-school services in this study note that peers misunderstood what they were going through. This suggests that not only children who are diagnosed, but all children could be better informed of these issues. As Lopez (1991) suggests, classes can familiarize adolescent students with factual information that can improve their views of mental health. Further, schools could provide increased education and training to teachers, as participants note that school staff could be better educated on these issues as well.

Findings also underscore the need to develop guidelines for mental health professionals on the best ways to talk to both parents and children about mental health diagnoses. This should

include guidance on ways to describe mental health diagnoses to children in developmentally appropriate ways. It should also provide guidance on ways to best educate and prepare parents to discuss diagnoses with children. Future research should inform the development of these guidelines.

The current study may also inform policy changes currently taking place that will affect children's mental health services. The Patient Protection and Affordable Care Act of 2010, intended to increase individuals' access to health insurance coverage, will likely affect coverage and services for individuals with mental health conditions in several ways: by requiring benefits that include mental health services, creating incentives for coordination among primary care and mental health care services, and expanding community-based mental health services (Substance Abuse and Mental Health Services Administration, 2010). Regulations implementing these provisions are currently under development by the Department of Health and Human Services, and thus we have yet to see the practical effects of this law. Findings from the current study, however, may inform practitioners who serve children with mental health needs in this new environment. For example, this study underscores the importance of informing even young children of their diagnoses, albeit in developmentally appropriate ways, and calls for the development of guidelines for mental health professionals to share information about mental health diagnoses with parents and children. It will be important to develop similar guidelines for health professionals in primary care and community-based settings, given that children may be increasingly treated in these settings in the future.

Changes to the classification system for diagnosing mental health disorders may also affect children's experiences in the near future. In May 2013, the American Psychiatric Association (2012) is set to publish the fifth edition of the DSM, the classification system used

by clinicians to diagnose mental health disorders in both children and adults. According to a recent press release by the American Psychiatric Association (2012), the revised manual will include changes in the organization of the manual, as well as changes to descriptions of several disorders and diagnostic criteria. Some of these changes may impact the diagnosis of children's mental health disorders. For example, the release describes disruptive mood dysregulation disorder, which will be included in the revised edition for diagnosing children with frequent "outbursts," aimed to "address concerns about potential over-diagnosis or overtreatment of bipolar disorder in children" (American Psychiatric Association, 2012, p. 4). Changes such as this may have an effect on the number of children diagnosed and types of diagnoses received, which may in turn influence children's experiences. Findings from the current study suggest the importance of providing parents and children information about diagnoses, which will be especially important with a changing classification system.

The principles of narrative therapy could also be extended beyond clinical practice. This study raises the question of whether institutions, such as schools and insurance companies, could frame children's mental health problems in a way that is externalizing and de-pathologizing. For example, policymakers could consider a paradigm shift away from the medical model towards a more preventive, universal approach. Changes in reimbursement standards could move us away from current policies that often require children to have diagnoses to receive treatment.

At the policy-level, we must also draw upon the principle of narrative therapy that values children's perspectives, to help improve services system-wide. As Walker et al. (2010, p. 51) note, the "vision of partnership [has] broadened," from first including parents in their children's treatment, to including parents at all levels of the service delivery system, and to now include the participation of children as well. Researchers, clinicians, and advocates have identified the need

to empower youth voice as a key aspect of future system change, including their expertise regarding the effects of and need for services (Choi, 2000; Stevenson, 2000; Villines, 2000). As Choi (2000) argues, we need to build ‘an infrastructure’ within systems serving children that empowers youth voice, such as youth participation in councils, boards, and town hall meetings. By including them in this way, youth can help develop strategies to improve services, increase youth buy-in, and provide a line of direct communication between administrators and young consumers (Choi, 2000; Villines, 2000). Laws (1998, p. 10) argues that young people can provide “relevant, considered views” on the services they have received; they can best inform services that *they* have experienced, and they want a greater influence over how services are operated.

In order to include youth in system change, we must provide the venue for them to voice their experiences, such as through participation in evaluation research, youth councils, or town hall meetings. Mechanisms should be developed for children to speak directly to program administrators and policymakers in the future, in order to share what they see as working well and where they see a need for improvement. We must value their voice and expertise, and encourage their ability to take part in these conversations. We must equip them with the tools to advocate for themselves in these capacities, but we must also train *ourselves* to truly listen.

Limitations and Directions for Future Research

The current study is but the first step in understanding how children make sense of mental health diagnoses, and several limitations must be considered. First, this study is an exploratory one, with a predominantly female, white, and middle/middle-upper class sample. The sample is particularly limited given that participants were recruited on college campuses. As noted in the methods section, my findings may be biased in the direction of participants

having more positive experiences, given that middle/middle-upper class families may have a high level of resources for managing mental health problems, and as indicated by their later enrollment in college and willingness to discuss their experiences in this study.

Second, the current study is based on the retrospective accounts of young adults, rather than accounts of children themselves. While emerging adults have a unique vantage point, with the ability to reflect back upon their entire childhoods, their perspectives and attitudes may have changed over time, and their recollections may be inaccurate. As noted previously, I am capturing emerging adults' *narrations* of their past experiences, which are filtered through their current understandings and interpretations. While these stories shed light on their past experiences, we may receive different responses if we ask children about their experiences in the moment.

These limitations suggest several directions for future research. First, future research should include expanded pools of participants with diverse backgrounds. This would provide the ability to examine whether demographic factors such as race, class, gender, as well as other factors such as religion, family size, and school environments, affect children's experiences and understandings. This could potentially provide insight, for example, into why some children embrace medical accounts of mental health problems, while others challenge them. This could help to explain the discrepancy between findings in the current study that many children embraced medical narratives and findings from previous research suggesting that many youth avoid using psychiatric terms when describing themselves and their conditions (Moses, 2009a; Mowbray et al., 2002; Stride-Darnley, 2009). Research with participants from diverse backgrounds could also shed light on how socio-demographic factors may affect parental knowledge and how they explain diagnoses to their children. In order to better understand how

parents' understandings develop, we must further examine factors that influence what information is provided to (or withheld from) parents. For example, research could examine the factors that affect how mental health professionals deliver and explain diagnoses to parents, including race and socio-economic status.

Future research should also capture children's perspectives in the moment by including children directly in research. While emerging adults' recollections of past experiences shed light on children's experiences, future research should capture the direct voices of children to capture their perspectives in childhood. Future research guided by the sociology of childhood should also examine how children cope with and possibly resist stigma. It could also examine how children create understandings of mental health problems *collectively*. For example, research could examine how meaning is constructed in children's peer cultures and how siblings' understandings influence one another. Future research could also examine how messages are framed and negotiated in various institutional settings, such as in schools.

As children develop, their understandings of their diagnoses change. We do not know enough about how developmental status affects how these understandings change over time. Research in this area would extend research on how children's understandings of physical illness change over time (Bibace & Walsh, 1981). It could improve explanations provided, as well as mental health education for children. One line of inquiry for future research in this area would be longitudinal research, capturing children's understandings of their mental health diagnoses over time. This would capture children's experiences in the moment, at different points throughout childhood, and also explore how understandings change across childhood. It would shed light on changes in children's understandings from a developmental perspective, examining how children at different developmental stages understand mental health.

Children's attitudes towards treatment may also change over time. Longitudinal research could capture if and how these attitudes change, and how this affects children's experiences. Highlighting the importance of youth's attitudes towards treatment, research has shown that youths' positive attitudes towards psychiatric medications are positively associated with their self-reported adherence to treatment (O'Brien, Crickard, Lee, & Holmes, 2012). Positive attitudes toward treatment may also help to minimize the stigma children experience surrounding their diagnoses. Future research could inform efforts to improve children's understandings of and attitudes towards treatment.

While the current study begins to examine the messages that children receive from their parents regarding their diagnoses, and how these understandings affect their own interpretations, we should explore how children and family members' understandings shape one another. This is likely an iterative process, with parents' understandings influencing children's, *and* with children's understandings influencing their parents' views. For example, arguments that participants had with parents regarding the legitimacy of their diagnoses may have led their parents to question their own views. Further, siblings likely play a role in these discussions, also helping to shape children's interpretations. Research in this area could assess child, sibling, and parental perspectives, exploring how they compare and interact. Ethnographic research in families would allow us to examine interactions between parents, children and siblings, thus helping to uncover how their understandings might shape one another.

The views of both parents and professionals could also add insight into how adults decide what information to share with children. Research could assess the factors contributing to whether or not adults share or withhold information from children, such as the severity of the diagnoses and/or family and child characteristics. For example, it could further examine whether

and how cultural attitudes towards mental health affect parents' decisions regarding whether and how to discuss mental health diagnoses with children. It could also capture mental health professionals' perspectives as well, including how they make decisions about what explanations to provide to children. It could assess adults' views of children and childhood, and how this might affect decisions about their care; for example, does viewing children as innocent and in need of protection increase the likelihood that adults diagnose children, resist labels, or 'protect' children from information? While it would not *replace* research on children's understandings, research capturing parents' and mental health professionals' perspectives could add insight into this process. It may be difficult for children to understand the reasons parents and mental health professionals feel the need to 'protect' children; capturing their viewpoints could shed light on this.

The internet was also a key source of information for participants, who describe looking up information on their diagnoses. Given the increasing use of the internet worldwide, examining children's experiences seeking information on mental diagnoses online would be a fruitful direction for future research. While participants in this study did not describe joining online support groups or using the internet to anonymously disclose their diagnoses and experiences with others [as described in the study by Elkington et al. (2012)], this may be another trend to explore. Children may be as influenced by peers' posts on online boards and social networking sites as the information that they describe seeking in the current study. Both seeking information on the internet and joining online support groups is an important aspect of 'the illness experience,' and likely influences children's understandings of and experiences with diagnoses.

Children's perspectives are particularly important because they can provide insight into

improving services, not just for individual treatment, but on a system-wide level as well, as described above. Research should examine children's experiences with treatment, as well as their advice on how to best meet children's needs. The Research and Training Center on Family Support and Children's Mental Health at Portland State University has been a leader in advocating for youth voice in research aimed at improving services (Regional Research Institute for Human Services, Portland State University, 2009). This type of research plays an important role in improving services at the system-level, and should be expanded in the future.

Conclusion

One might ask why participants' recollections and the stories of their lives are important. As Cole and Knowles (2001, p. 119) point out, "...the remembrances selected and told earn their status as memorable and significant events for good reason. The stories we remember and tell about our lives reflect who we are." They also shed light on how participants view the world, and the events that took place from *their perspective*. What a psychologist *says* is not always what a child *hears*; how a child *looks* may not reveal how they truly *feel*; and assuming that they do not understand and question because they are young, 'immature,' and 'incapable' is a fallacy. As participants told me time and again, they understood more than adults thought they did. Their interpretations and perspectives would be especially useful, as they likely affect their experiences. This study provides a window into how they made sense of their diagnoses, and it is my hope that future research continues in this vein.

This research not only captures and shares participants' perspectives, it validates their experiences and stories. Children's mental health is often neglected because of the myth of happy childhoods, which assumes that young children in particular are incapable of suffering emotionally (McLearn et al., 2007). Yet, researchers should listen to children without

minimizing or trivializing the importance of their experiences. The sociology of childhood encourages researchers to explore the lived experiences of children with an emphasis on their present experiences, rather than focusing on the effects of these experiences on future outcomes. By researching the impact of mental health problems on children's daily lives, researchers can validate the importance of their experiences.

Conducting research exploring this process clearly has its challenges. Children can have trouble expressing themselves and describing their feelings, making it particularly difficult for adults to understand their perspectives. But while it can be challenging for children to express their feelings, "It can be even harder for us to listen, truly listen, and understand" (Anglada, 2006, p. 3). We must continue to strive towards this goal, and develop new strategies to reach it.

As researchers, practitioners, policymakers, program administrators, parents, teachers, mentors, aunts, uncles, and neighbors, we must value children's understandings of mental health problems. The narratives we use affect not only how children understand their diagnoses, but how they experience them and how they understand themselves. We all contribute to these narratives and must question how to best frame them. How might children's perspectives inform and possibly re-frame narratives about mental health? We must begin by first acknowledging and respecting their ability to take part in these conversations. By inviting children into the discussion, both in research and in practice, we can give voice to – and learn from – children's experiences.

APPENDIX B

Informed Consent Information¹²

Purpose of the Project:

My name is Betsy Bringewatt and I am a doctoral student in Social Work and Sociology at the University of Michigan. For my dissertation, I am doing a research project that explores the experiences of those who were diagnosed with attention deficit hyperactivity disorder (ADHD), depression, generalized anxiety disorder (GAD), and/or bipolar disorder in childhood. I am interested in how children experience, learn about, and talk about their diagnoses in childhood.

Participation in the Study:

Participating in this research entails that you agree to an informal, semi-structured interview that will last 1 – 1½ hours and will be audio-taped. The questions I will ask fall into two broad areas: (1) your experiences having, learning about, and talking about ADHD, depression, GAD, and/or bipolar disorder as a child, and (2) ways that you suggest this diagnosis be explained in childhood. I will also ask you to fill out a form with several general demographic questions (including your age, sex, race/ethnicity, education, employment, religion, and living situation, as well as your parents'/guardians' marital status, occupation, and education). This research study is not a treatment or an intervention; please seek assistance from a clinician for such services.

Compensation:

In appreciation of your time, you will be compensated with \$20 in cash for your participation in this project. You are responsible for any expenses that may be incurred in order to attend the interview in-person (e.g. transportation costs, parking).

Risks and Discomforts:

It is not expected that participating in this project will cause you any discomfort, although there is the possibility that there might be questions or topics that cause psychological risk insofar as you might have to talk about sensitive experiences. This could include stigma you faced as a child. You are free to not respond for any reason to any question I ask during the interview. You are also free to not respond for any reason to any question on the demographic information form. It will not affect your ability to participate in the study. Your participation in this study is completely voluntary. In addition to declining to respond to any question, you may withdraw from the study at any point. You will still receive \$20 if you withdraw. If you become upset during the interview, I will end the interview immediately. I am providing all participants with a list of resources in the community if you wish to seek counseling services.

¹² Minor revisions were made to the recruitment flyer, consent information, and demographic information form when eligibility criteria changed and protocol questions were broadened after the first ten interviews.

Benefits:

There are no direct benefits to participating in this project, however, your participation will contribute to improved knowledge about the experiences of children diagnosed with ADHD, depression, GAD, and/or bipolar disorder. It is my hope that this research is beneficial because it will increase our knowledge about ways to best manage these diagnoses in childhood.

Voluntary Participation:

As noted above, your participation in this study is completely voluntary. In addition to declining to respond to any question, you may withdraw from the study at any point. You are free to ask questions about the study at any time, including after the interview is over. If you have questions you do not feel comfortable asking me, you may ask my faculty advisor, Dr. Karin Martin (kamartin@umich.edu).

Confidentiality:

This interview will be confidential. However, as a doctoral student of Social Work, I am professionally mandated to report any information you give me about current abuse or neglect of a child or vulnerable adult to the appropriate authorities. All records will be kept confidential. I will not keep any documentation with your real name on it. All files will be identified by pseudonym only. No hard-copy files will be kept; all information from hard-copy forms (i.e. your demographic information and my hand-written notes taken during the interview) will be entered into password-protected files on my laptop and paper copies will be immediately shredded. All files and back-ups of these electronic files will be password-protected. All documents will be destroyed after ten years. If data gathered from the interview is used in any future presentations, papers, or publications, your real name and other identifying information will not be used.

Contact Information:

If at any time you have questions about this research project, please feel free to contact me, Betsy Bringewatt, at: betsyhb@umich.edu or [REDACTED] or the professor who is overseeing this project, Dr. Karin Martin, at: kamartin@umich.edu or (734) 936-0525. If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study with someone other than the researcher(s), please contact [REDACTED] Institutional Review Board, [REDACTED]

Informed Consent:

I have been informed of the information given above. I agree that I am at least 18 years of age. I understand that my participation in this interview is completely voluntary and that I may stop at any time. Betsy Bringewatt has offered to answer any questions I may have regarding this project. I hereby consent to participate in the study.

APPENDIX C

Demographic Information Form¹³

You may skip questions without affecting your participation in this study.

1. How old are you? _____
 2. What sex are you (e.g. male, female)? _____
 3. How would you identify your race/ethnicity? (check all that apply)
 - American Indian or Alaska Native
 - Asian
 - Black or African American
 - Hispanic or Latino
 - Native Hawaiian or Other Pacific Islander
 - White
 - Other: _____
 4. What is the highest level of education that you have **completed**?
 - Less than high school
 - High school
 - GED
 - 1 year of college
 - 2 years of college
 - 3 years of college
 - College graduate
 - Post-college degree: _____
 - Other: _____
 5. Are you currently a student?
 - Yes, full-time
 - Yes, part-time
 - No
-

¹³ Minor revisions were made to the recruitment flyer, consent information, and demographic information form when eligibility criteria changed and protocol questions were broadened after the first ten interviews.

6. Are you currently employed?

- Yes, full-time
- Yes, part-time
- No

7. What is your occupation? _____

8. What religion are you? _____

9. What is your current living situation?

- Live in dormitory / on-campus housing
- Live with parents
- Live with spouse
- Live with partner/significant other
- Live with roommate(s)
- Live alone
- Other: _____

10. What is your parents'/guardians' marital status?

- Married
- Single never married
- Divorced
- Other: _____

11. What is the current occupation of your mother, father, and/or guardian?

Mother's current occupation: _____

Father's current occupation: _____

Guardian's current occupation: _____

12. What is the highest level of education your mother, father, and/or guardian have completed?

Mother:

- Less than high school
- High school or GED
- Some college
- College graduate
- Post-college degree

Father:

- Less than high school
- High school or GED
- Some college
- College graduate
- Post-college degree

Guardian:

- Less than high school
- High school or GED
- Some college
- College graduate
- Post-college degree

APPENDIX D

Broadening of Protocol Questions

I. Main Protocol Questions Used in Interviews 1-10

1. Can you tell me a little bit about your childhood, including where you grew up, what type of school you attended, how many siblings you had?
2. Do you remember when you found out that you had ADHD? Can you tell me about that?
3. Do you remember how you felt when you found out you had ADHD?
4. Do you or did you ever take any medicine for ADHD? If yes: What was / is that like?
5. Can you tell me what it was like being a kid with ADHD?
6. Was there anything you disliked about having ADHD as a child?
7. Is there anything you liked about having ADHD as a child?
8. As a child, how long did you think you would have ADHD for?
9. Did you talk to your peers as a child about your ADHD diagnosis? If yes: Can you tell me about those conversations?
10. Do you think your classmates knew that you had ADHD as a child? Did you want them to know? Why or why not?
11. How did it feel talking to me about your experiences with ADHD as a child?
12. Is there anything else that you would like to tell me about?

II. Main Protocol Questions Used in Interviews 11-42

1. Tell me about how you became aware that you had ADHD/depression/GAD/bipolar disorder?
2. What was life like before your diagnosis?
3. What was life like after your diagnosis?
4. In what ways did you share or talk about your diagnosis with the people in your life?
5. If there was a child who was being diagnosed today, what are your thoughts about the best ways for that child to learn about their diagnosis?
6. How did it feel talking to me about your experiences during this interview?
7. Is there anything else that you would like to tell me about?

Note: See Appendices E and F for full protocols.

APPENDIX E

Interview Protocol 1

(used in pilot study, interviews 1-10)

[Note: If the participant mentions any indication of stigma during the interview, ask: 1) How did this make you feel? 2) What did you do when this happened? 3) Did that help?]

A. Background:

1. Can you tell me a little bit about your childhood, including where you grew up, what type of school you attended, how many siblings you had?

B. History of ADHD:

2. Do you remember when you found out that you had ADHD? Can you tell me about that?

Follow-up questions if not covered in answer to question above:

- a. Can you remember how you found out that you had ADHD?
 - b. Who first told you that you had ADHD?
 - c. How did they tell you?
3. Do you remember how you felt when you found out you had ADHD?

C. Medication:

4. Do you or did you ever take any medicine for ADHD?
 - a. *If yes:* What was / is that like?

Follow-up questions if not covered in answer to question above:

- i. How long did you take / have you been taking medicine?
- ii. Did / do you dislike anything about taking the medicine?
- iii. Did / do you like anything about taking the medicine?

D. Experiences with ADHD in Childhood / Attitudes Towards ADHD Diagnosis:

Note: Ask for specific examples whenever possible...

5. Can you tell me what it was like being a kid with ADHD?
6. Was there anything you disliked about having ADHD as a child?
7. Is there anything you liked about having ADHD as a child?
8. As a child, how long did you think you would have ADHD for?

E. Stigma and Sense of Self and Self-Esteem:

9. Did you talk to your peers as a child about your ADHD diagnosis?
 - a. *If yes:* Can you tell me about those conversations?

Follow-up questions if not covered in answer to question above:

- i. How did you explain it to your peers?

- ii. How did you feel when you explained it to them?
 - iii. Did they understand?
 - 1. How did they react?
 - a. How did this make you feel?
 - iv. How well do you think they understood what it's like having ADHD?
 - v. Were there things that they didn't understand about ADHD and what it's like to have ADHD?
10. Do you think your classmates knew that you had ADHD as a child?
- a. Did you want them to know?
 - i. Why or why not?

F: Final Questions:

- 11. How did it feel talking to me about your experiences with ADHD as a child?
- 12. Is there anything else that you would like to tell me about?

APPENDIX F

Interview Protocol 2 (used in interviews 11-42)

[Note: I will use the following types of prompts as needed: Can you walk me through (X)? Can you tell me more about that? How did that make you feel?]

Thank you so much for your willingness to talk to me about your experiences. If there is anything I ask you that you would rather not talk about, we can always just skip to the next question. Please feel free to ask me any questions you have as we're talking.

I. LEARNING ABOUT THE DIAGNOSIS:

1. Tell me about how you became aware that you had ADHD/depression/GAD/bipolar disorder?

➤ Potential prompt areas: experiences being diagnosed; experiences learning about the diagnosis; experiences learning about the disorder

II. EXPERIENCES WITH DIAGNOSIS:

2. What was life like before your diagnosis?

➤ Potential prompt areas: relationships with family and peers; experiences at school

3. What was life like after your diagnosis?

➤ Potential prompt areas: relationships with family and peers; experiences at school; treatment experiences (e.g. with mental health professionals, in-school services, medications)

4. In what ways did you share or talk about your diagnosis with the people in your life?

➤ Potential prompt areas: experiences talking with peers, siblings, parents, teachers

III. INSIGHTS INTO MANAGING DIAGNOSES IN CHILDHOOD:

5. If there was a child who was being diagnosed today, what are your thoughts about the best ways for that child to learn about their diagnosis?

➤ Potential prompt areas: who should explain; how and when should it be explained

IV. CLOSING QUESTIONS:

6. How did it feel talking to me about your experiences during this interview?

7. Is there anything else that you would like to tell me about?

• Do you have any questions for me before we end the interview?

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