ADHD AND SELF DISCREPANCY:

THE SOCIAL CONSTRUCTION OF ADHD IN

ADULTHOOD

by

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Abstract

By

JOSHUA JAMES TERCHEK

Once thought only to affect children, ADD/ADHD is increasingly being diagnosed in adults. This qualitative study utilizes grounded theory to describe the process of ADD/ADHD identity construction in a sample of 19 adults diagnosed with ADD/ADHD. An additional 30 unsolicited Internet narratives were collected to add depth to the analysis. This study examines various paradigms for understanding ADD/ADHD, explains how individuals construct and maintain an ADD/ADHD identity, and describes the impact of ADD/ADHD on daily life. It concludes by highlighting the role that social factors play in creating and exacerbating problems so great they are understood as a medical disability.
Chapter 1: Introduction

On the surface, I appear to be a success story. Throughout my life I have done well in school, getting good grades, going to a good university, and even moving on to graduate school. I married my college sweetheart, bought a house, got a dog, and landed a good job at a university doing research that not only paid well but also had excellent benefits. Yet these indicators of success hid difficulties I encountered in everyday life. My graduate student work and exams went well, but I found myself having difficulty writing and conducting independent research. I could verbally articulate what I wanted to study and the methods I planned to use, but getting it down on paper seemed impossible. I often overlooked payment of bills and had difficulties completing home improvement projects. My attention to boring tasks was also an issue. I would rather be keeping up with news and what was going on in the world than focusing on my work. Some of my peers had moved through and completed their degrees more quickly than me. I began to wonder, “What was wrong with me?”

The answer to this question came to me on a snowy day in December 2008. That was the day my sister told me she had been diagnosed with ADHD. When she told me about her diagnosis, she had been on treatment for about a year. Looking back I noticed a difference. My sister who was usually late suddenly began to show up to events on time. She was doing well in her college courses and just seemed to be in better spirits than she had been previously. My sister suggested that I might have ADHD too.
Shortly after my sister’s disclosure, I began researching the disorder on the Internet. After taking several online screening tests, I made an appointment with my family physician. After a brief discussion regarding my history, I was diagnosed with ADHD and began treatment. I noticed a difference almost immediately.

I began to wonder whether my own experiences with ADHD were unique. Was a diagnosis of ADHD in adulthood common? What were other adults’ experiences leading up to and following diagnosis? Like many others who have been diagnosed with a medical problem, I sought additional information and turned to the scientific literature. Most of what I found out about ADHD stemmed from a biomedical perspective and pertained largely to children. I also found considerable debate on ADHD ranging from concerns related to over-diagnosis and/or over-medication to questioning the existence of the disorder entirely. The following section highlights the current state of scientific knowledge pertaining to ADHD.

**Adult Attention Deficit Disorder: A Brief Introduction**

Much of what is known about ADHD stems from a biomedical perspective. This perspective defines ADHD as “neurobehavioral disorder characterized by pervasive inattention and/or hyper-impulsivity and resulting in significant function impairment” (Centers for Disease Control and Prevention, 2005). The *Diagnostic and Statistical Manual* is the handbook listing all mental disorders and criteria for diagnosing them used by the American Psychiatric Association. Now in its fourth
In the fourth edition (DSM IV), the DSM defines ADHD through presence of factors related to inattention, such as inability to complete tasks; hyperactivity, such as always being on the go; and impulsivity, such as talking excessively (American Psychiatric Association, 2000). In order to be diagnosed with ADHD in adulthood, some impairment has to have occurred before the age of 7, it must have occurred in two or more settings, and clear significant impairment has to be occurring currently in at least one setting.

The constellation of behaviors now associated with ADHD has been described by medical professionals since the early 1900s under various labels. These changing labels reflect the shifting etiological explanations of ADHD-like behaviors (Barkley, 2006; Millichap, 2008). For example, “post-encephalitic brain” damage suggested that ADHD-like behavior was due to exposure to encephalitis in childhood (Kahn & Cohen, 1934). However, because not all children with ADHD symptoms had been exposed to encephalitis, this name was eventually dropped. “Minimal brain dysfunction” attributed ADHD-related behaviors to some trauma suffered by the brain that could not be detected (Hammerman & Rostain, 2007). Like “post-encephalitic brain,” this naming convention was also dropped due to lack of evidence and the high levels of stigma associated with that label. It was not until the 1950s that “Hyperkinesia” become classified as a diagnostic category in the DSM (Conrad, 1975, 1976). Eventually “Attention Deficit Disorder” and “Attention Deficit/Hyperactivity
Disorder” became the favored terminology to describe the constellation of behaviors now associated with the disorder.

**Biomedical understandings of ADHD.** A neuropathological theory has informed the biomedical model of ADHD for some time and continues to guide much of the research. The neuropathological theory adopts a disease model to explain ADHD in adults. In this model, the source of impairment or dysfunction is the direct result of some abnormality in the brain (Triolo, 1999). This position assumes that ADHD has been a problem for humans for some time and that it was not until recently that science became sophisticated enough to recognize the disorder (Hallowell & Ratey, 1994). Although there is no specific etiology for ADHD, researchers who use the neuropathological model believe that as science progresses, a specific etiology will be identified. In other words, the neuropathological model of ADHD adopts the doctrine of specific etiology highlighted by Mishler (1981), Dubos (1959), and others (Freund & McGuire, 1991).

**Etiology.** It was hoped that magnetic resonance imagining (MRI) and positron emission tomography (PET) scans would allow researchers to establish a specific etiology, providing a glimpse of what was happening in the brain. However studies have not been replicable and have several methodological problems (Timimi & Taylor, 2004). While neurotransmitters are believed to play a role in ADHD (Shaywitz & Shaywitz, 1992), the lack of agreement on etiology has resulted in a growing emphasis on the role played by genes, with the heritability
of this disorder cited as the main evidence that ADHD is a “real” disorder (Barkley, Cook, & Diamond, 2002; Millichap, 2008). While ADHD appears to be heritable, to date no specific genes have been identified for the disorder nor do any genetic tests exist to establish its presence.

In the past, the success of psycho-stimulant treatment was seen as evidence supporting the neuropathological theory of ADHD (Solanto, 2001). Although ADHD is associated with hyperactivity, stimulant medications appeared to result in better attention and lower hyperactivity. Children given stimulant medication were able to sit still and focus. This “paradoxical effect” was seen as evidence that ADHD was due to pathological abnormalities in the brain.

More recent evidence suggests that stimulant medication increases focus in everyone (Breggin, 2002) and that many people use these medications to gain advantage. For example, a study published in Nature found that approximately 20% of scientists polled were using some form of brain-enhancing drug including Ritalin (Sahakian & Morein-Zamir, 2007). Additionally, 6.9% of college students reported using non-prescribed attention-enhancing drugs to improve their ability to study (McCabe, Knight, Teter, & Wechsler, 2005). These medications are so efficacious in improving attention that some have advocated for the use of stimulant medications in those without disorder (Greely et al., 2008).

**Expansion into adulthood.** For most of its history, the disorder was believed to only affect children, that overtime children would “grow out” of the disorder (Conrad & Potter, 2000; Hallowell & Ratey, 1995). During this early
period which focused on youth, criteria for diagnosis largely had to do with school-related functioning, especially disruptive behavior in the classroom. However, most children were believed to “outgrow” the disorder.

In the 1970s, several longitudinal studies of children diagnosed with ADHD were published showing that ADHD persisted into adulthood. In prospective cohort studies, the persistence of ADHD from childhood into adults is approximately 50%, ranging from 33% to 66% (Davidson, 2008). These studies resulted in a changing understanding of the disorder. Items used to diagnose ADHD became less age specific and more age universal (Conrad & Potter, 2000). For instance, “frequently calls out in class” was changed to “often blurts out answers to questions before they have been completed.” Another important shift in the diagnostic criteria was that no childhood diagnosis was needed. Adults could now be diagnosed in adulthood if they reported symptoms in childhood.

**Epidemiology.** Because ADHD was originally believed to affect only children, much of the prevalence data regarding ADHD has to do with this population (G. Weiss & Hechtman, 1993). Although the Centers for Disease Control (CDC) (Centers for Disease Control and Prevention, 2005) estimates that 7.8% of 4- to 17-year-olds have ADHD, with 4.3% of children currently medicated (Rowland, Lesesne, & Abramowitz, 2002), there is substantial variation in prevalence rates. In the United States, the estimated prevalence of ADHD in children ranges from 2% to 18% in community-based samples (Dwivedi &
Banhatti, 2005). Prevalence rates also vary by country from 1.9% to 16.1% (Fayyad, Graaf, & Kessler, 2007).

There has been little systematic effort to estimate the prevalence of the disorder in the adult population. Current prevalence estimates suggest that ADHD in adults ranges between 1% and 6% (Faraone & Biederman, 2005; Kessler, Lane, Stang, & Van Brunt, 2009). According to the results from the National Co-morbidity Replication (NCS-R) estimates, the prevalence of clinician-assessed adult ADHD is 4.4% (Kessler et al., 2006). However the authors of that study believe this estimate to be conservative given limitations in that study.

A range of risk factors associated with ADHD have been identified. Risk factors associated with ADHD in children include difficulties in childbirth, low birth weight, prenatal exposure to alcohol and nicotine, low social class, marital distress of parents, large family size, and maternal mental disorders (Biederman, Faraone, Keenan, Knee, & Tsuang, 1990; Faraone & Biederman, 1998; Spencer, Biederman, & Mick, 2007). Certain populations appear to be at more risk for ADHD in adulthood, with higher rates occurring in whites, males, those who were divorced, and those with “other employment” status. Faraone & Biederman (2005) also found ADHD in adults to be more prevalent in cities than in rural areas. ADHD in adults is significantly co-morbid with a wide range of other mental disorders including major depressive disorder, bipolar disorder, general anxiety disorder, panic disorder, post traumatic stress disorder, drug dependence, and
intermittent explosive disorders (Biederman 2005; Kessler et al., 2006; Spencer 2006).

**Additional research.** Adult ADHD has garnished increased attention in scientific community. Much of the current research on ADHD in adults utilizes a biomedical perspective, studying the disorder through genetics, MRI, and other "cutting edge" techniques (Conrad & Potter, 2000). While the bulk of literature has focused on the physiological or genetic aspects of the disorder, several studies have expanded their focus to experiences of daily life. For example, one study found that adults recently diagnosed with ADHD reported the diagnosis to be a generally positive event in their lives (Young, Bramham, Gray, & Rose, 2008). Canu, Newman, Morrow, and Pope (2008) found that hypothetical adults with ADHD received negative appraisals in a sample of college students related to group work. Another study of college students found a positive correlation between ADHD symptoms and general distress, affect, activity satisfaction rating, and other concentration problems (Knouse et al., 2008). One of the most prominent self-help books on the subject of adult ADHD, *Driven to Distraction* (Hallowell & Ratey, 1994) builds off the clinical experience the authors have in treating adults with ADHD, relaying many of their patients’ stories.

**Criticisms of ADHD.** Despite being well established in biomedical literature, ADHD (in both children and adults) has come under considerable scrutiny as a form of mental illness with no specific etiology or well established biological basis. Some of this criticism can be traced to general criticisms of
mental illness waged by Thomas Szasz. According to Szasz, mental illness must have some physiological characteristics that can be studied through systematic observation in order to be considered real (Szasz, 1974, 1977). To date, there are no specific cognitive, metabolic, or neurological markers or medical tests for ADHD (Radcliffe & Timimi, 2005). While some have argued that a genetic link proves the reality of ADHD (Biederman & Faraone, 2002), others have noted that it is associated with the normal genetic variation for traits such as height or personality (Timimi et al., 2004) or argued that the evidence establishing a genetic link are weak (Joseph, 2000).

Due to the lack of physiological mechanisms for diagnosing ADHD, the operational definition for the disorder is of critical importance. However, the operational definition has also been criticized for being highly subjective, lacking precision, and for generally being incomplete (Douthit, 2001). As noted above, wide ranges of prevalence have been found across studies in both children and adults. This wide variation in prevalence suggests current measures of ADHD to be unreliable. Additionally, ADHD’s high co-morbidity with other mental health conditions in adults suggests a low level of specificity in measurement. As Horwitz contends, such criterion-related measures of mental health ignore context and in many cases reflect a normal response to stress (Horwitz, 2007). Additionally, the original ADHD criteria were validated in children and may not entirely capture the symptoms of ADHD in adults or be developmentally sensitive (A. S. Bell, 2011; Faraone, Biederman, & Mick, 2006).
The incomplete and subjective nature of ADHD criteria makes over-diagnosis and abuse possible. Although a significant body of literature is aimed at diagnosing ADHD in adults correctly (M. D. Weiss & Weiss, 2004; Wender, Wolf, & Wasserstein, 2001), critics suggest that the ambiguity of ADHD diagnosis has served to benefit pharmaceutical companies (Breggin, 2001; Cohen, 2006). As noted above, stimulant medications work in everyone, and individuals often “fake” symptoms to gain access to these medications (Harrison, 2006; Harrison, Edwards, & Parker, 2007). These drugs also have the potential for abuse and addiction and come with a variety of negative health consequences (Breggin, 2001).

Although the scope and persistence of these criticisms have been an ongoing concern for proponents of the biomedical perspective, they have largely been dismissed. In 2002, more than 100 "experts" signed the International Consensus Statement on ADHD, stating the evidence supporting the reality of ADHD to be clear and overwhelming. Despite such statements, the editor of the special issue on ADHD in adults of the Journal of Attention Disorders felt it necessary to address the ongoing debate regarding ADHD stemming from both lay people and professionals. While acknowledging the debate, the editors squarely dismiss any suggestion that ADHD is anything but a “real” disorder(Reynolds, 2008).

While I find legitimacy in many of the criticisms aimed at ADHD, criticisms of ADHD have been largely dismissed by those utilizing a biomedical
perspective. Criticisms of ADHD largely fail to provide a theoretically driven and empirically supported alternative to the biomedical paradigm that adequately explains (1) the source of suffering and (2) the rise of ADHD as a medical disorder. Specifically, many of the critiques of ADHD (but not all) largely focus on undermining the findings of biomedicine by highlighting problems in method rather than offering a substantive alternative. With few exceptions, the bulk of evidence supporting the social construction of the disorder largely focuses on the large profits of pharmaceutical industries and the social construction of medical knowledge. Other critiques are purely anecdotal. For example, the “hunter-farmer theory of ADHD” suggests that ADHD traits were beneficial for hunters, but because society is now based on a “farming model,” such traits are problematic (Hartmann, 1993).

**Sociology and ADHD.** Sociological literature dealing specifically with ADHD in adults is sparse. Conrad and Potter’s (2000) work tracing the expansion of ADHD from a childhood disorder to one that affects adults represents a crucial first step in applying a critical sociological perspective to current knowledge about ADHD. Using the various versions of the DSM, their work traces how subtle differences in wording combined with studies following children diagnosed with ADHD have allowed for the expansion of a disorder affecting only children to one affecting both children and adults. Conrad and Potter also review popular literature related to ADHD, leading them to the conclusion that ADHD is the “medicalization of underperformance.” They argue
an ADHD diagnosis explains problems of everyday life as resulting from neurobiological disorder rather than from other possible mechanisms such as lack of self-control and societal forces. Once diagnosed, these adults receive benefits from the diagnosis through decreased responsibility and other accommodations.

Although Conrad and Potter provide some social context for the rise in adult ADHD diagnosis including the greater acceptance of pharmaceutical solutions for everyday life, genetic explanations for the disorder, and ADHD treatment for adults becoming “billable,” they exclude any analysis of how other social factors might explain the rise of ADHD in adulthood. Likewise, Conrad and Potter attribute the rise of ADHD with the medicalization of underachievement, basing this conclusion on popular literature written by highly successful people. Their research excludes the lived experiences of the vast majority of individuals who have been diagnosed ADHD.

Leffers examined the lay and professional constructions of ADHD in adults (Leffers, 1997). In her examination of 41 adults with ADHD, she found their conceptualizations of ADHD to be different from those of medical professionals. While adults with ADHD often identified with a biomedical model, they also emphasized social support and continued to seek validation of their diagnosis. Additionally, she found adults would often “try on a diagnosis” (p. 228) before formal help-seeking behavior. While Leffers’ work sheds additional light on the diagnosis, her study had several limitations. Specifically, her sample had largely
bought into the diagnosis, was actively seeking behavioral treatment, and was engaged in support groups or seeking one. Additionally, Leffers’ work is not critical enough of ADHD as a diagnostic category. For example, Leffers contended that ADHD identity is formulated through the experience of “symptoms.” However (and as will be highlighted later), ADHD symptoms are commonly experienced by many in society. In assuming that the symptoms were real, Leffers failed to examine how adults with ADHD came to frame problems as so beyond the scope of normal that they required medical attention.

**Specific Aims of This Dissertation**

My review of the scientific literature revealed that there was little emphasis on the experiences or perspectives of those who had been diagnosed with ADHD in adulthood. As David Karp suggested in his study of the experience of depression, “To really understand human experience, it must be appreciated from the subjective point of view of the person undergoing it” (p.11, Karp, 1996). Current understandings of ADHD often ignore the contextual factors leading up to ADHD diagnosis, the reactions to that diagnosis, the extent to which an ADHD diagnosis changes notions of the self, or the impact of culture and society on our understandings of ADHD. Following several scholars who have studied disability and chronic illness because they were diagnosed with an illness, disability, or disorder (Frank, 1995; Karp, 1996; Zola, 2003), I chose to study the experience of ADHD in adulthood for my dissertation research. The specific aims of my dissertation are to:
AIM 1: Ascertain how some adults "know” they have ADHD

AIM 2: Identify the consequences of an ADHD diagnosis in adulthood.

AIM 3: Describe the impact of social factors on the rise of ADHD.

This study will characterize the process of ADHD identity construction and maintenance in adults, looking beyond individual psychological and biological explanations. The findings will lead to a greater understanding of how adults with ADHD have come to see themselves as sick and how they cope with the disorder.

This study uses the social constructionist perspective and is informed by a wide range of sociological approaches. Social constructionism views all human knowledge, including formal theories and everyday or lay knowledge, as culturally produced (P. Berger & Luckman, 1966). Rather than making statements regarding the truthfulness or accuracy of knowledge claims, the general goal of a constructionist perspective is to illuminate how and why existing knowledge develops in the way it does. Social constructionism has been particularly influential on a range of sociological approaches including medicalization, illness experience, the self and identity, the life course, social models of disability, and the stress paradigm. Each of these overlapping sociological approaches is relevant to this dissertation and the rise of ADHD in adulthood, guiding both the initial formulation of this research as well as the analysis. Further discussion of these approaches is presented in Chapter 2.
The aims of this study were accomplished using a modified version of grounded theory focusing on the lived experiences of adults with ADHD. Nineteen adults self-identified and were interviewed for this study. Along with face-to-face interviews, unsolicited Internet narratives were collected as a complementary data source, adding diversity to the study. Interviews included questions designed to identify issues that lead up to diagnosis, the degree to which ADHD affects daily life, and the beliefs adults have regarding their disorder and the diagnosis. Data were analyzed using the grounded theory method, with data collection and analysis occurring simultaneously to refine the research project, refine the sampling, and to handle emerging themes (Charmaz, 2006, Corbin & Strauss, 1990). Further description of the method, sample, and analysis may be found in Chapter 3.

Although ADHD symptoms are common, very few adults seek a diagnosis. Chapter 4 highlights how some adults “know” ADHD is a reality for them, addressing Aim 1 of this project. It focuses on how formulations of self allow adults to assume an ADHD identity, largely through a sense of self-discrepancy. Chapter 4 also highlights the various paths to diagnosis.

Chapter 5 describes the consequences of an ADHD diagnosis in adulthood. Unlike many other conditions, a diagnosis of ADHD in adulthood was viewed as an extremely positive life event. Along with providing access to formal and informal accommodations, an ADHD diagnosis allowed adults with ADHD to
rewrite their narratives in patterned ways. The role of self-discrepancy in shaping how the diagnosis is interpreted is discussed in detail.

Chapter 6 highlights the structural factors that influence human suffering and help to explain the rise of ADHD in modern life. Specifically, this chapter explores how the rise of the self, increased stimulation, cultural expectations, and lack of personal agency coupled with an increased tendency to explain problems through a medical lens have led to the development of ADHD.

As discussed in Chapter 7, this research represents a reflexive project, influenced by initial understandings of ADHD and my training as a sociologist. In taking this reflexive approach, my own views of ADHD have shifted dramatically over time. Initially, I embraced my own diagnosis of ADHD. Consequently, when I began this study, I was ambivalent regarding the “reality” of ADHD. My goal was to examine illness experience rather than to argue whether ADHD was a “real” disorder. As I highlight throughout my dissertation, it has become clear to me that ADHD in adults is much more social than biological. In other words, I believe social conditions alone are enough to explain many of the problems commonly associated with ADHD. While I do not question that the adults I talked with are suffering, I believe that the suffering we now relate to ADHD is a result of social arrangements rather than physical abnormality.

**A note on terms.** Throughout this dissertation, I refer to adults “knowing” that they have ADHD. As I have shown in this chapter, there is both considerable debate regarding the reality of ADHD and little physiological
evidence that establishes the presence of the disorder. When I say adults “know,” I am referring to adults believing that (1) ADHD is a real thing and (2) they have applied that label to the self. Regardless of whether ADHD is a physiological reality or social construction, the label of ADHD exists and has a range of consequences. As W. I. Thomas stated, “If people define situations as real, they are real in their consequences” (Thomas & Thomas, 1928, p. 572). In other words, because my participants believe ADHD to be real, it has consequences for them forcing them to organize their life around the concept.

Throughout this dissertation, I refer to those adults who have been diagnosed with ADHD in adulthood as “adults with ADHD.” There is some debate in the social sciences regarding how we should refer to those with disability, disorder, or illness (Sass, 2007). Should individuals with disabilities be called “disabled persons” or “persons with disabilities”? Although “adults with ADHD” is commonly used in sociological and psychological literature, I choose to use first person language in an effort to avoid unintentionally dehumanizing those who suffer with problems associated with ADHD (Hall, 2002; Lynch & Thuli, 1994).

While there is considerable debate among sociologists on the degree to which we live in a modern, postmodern, or post-structural society, I choose to use the term modern to describe the period of time in which we now reside. The use of this term is largely influenced by Giddens (1991) and Bauman (2000), who acknowledge the ongoing influence of the Industrial Revolution and suggest that
we have not entered a new, post-modern era. In this dissertation, the term “modern” is used largely to contrast current times with pre-modern or traditional forms of society.
Chapter 2: Guiding Sociological Approaches

The sociologist will be driven time and again, by the very logic of the discipline, to debunk social systems. This unmasking tendency need not necessarily be due to the sociologist's temperament or inclinations. Indeed, it may happen that the sociologist, who as an individual, may be of a conciliatory disposition and quite disinclined to disturb comfortable assumptions, is nevertheless compelled to fly in the face of what is taken for granted (P.L. Berger, 1973, p. 51).

As the quote above suggests, a sociologically informed study of ADHD in adulthood can shed additional light on realities shaping current ADHD knowledge that are commonly taken for granted. For this dissertation, I use a social constructionist perspective to explore ADHD in adults. Social constructionism assumes that reality is constructed through social interaction (P.L. Berger & Luckman, 1966). Specifically, social constructionism views all human knowledge, including formal theories and everyday or lay knowledge, as culturally produced. Rather than making statements regarding the truthfulness or accuracy of knowledge claims, the general goal of the social constructionist is to illuminate how and why existing knowledge develops in the way it does.

Social constructionism has been particularly helpful in informing sociological research on illness experience, medicalization, the self and identity, life course, disability, and stress. Each of these overlapping sociological approaches is relevant to this dissertation and the rise of ADHD in adulthood, guiding both the initial formulation of this research as well as the analysis. A summary of each follows below.
Illness Experience

The focus of this work is primarily on the social construction of illness or the ways in which individuals live with and understand disorder. This is fundamentally different than an examination of disease. Several theorists have distinguished the difference between disease and illness, with disease referring to the biomedical or objective aspect of being sick (Conrad & Schneider, 1980; Kleinman, 1988). The medical enterprise has largely focused on disease, focusing on specific etiology and treatment of physical symptoms (Mishler, 1981). Researchers examining the social construction of medical knowledge have attempted to understand how medicine comes to understand disease and how this process is influenced by culture.

Illness refers to the subjective experiences of those who are sick or suffering. As Kirsten Barker (2010) contends, it is impossible to overstate the importance of the biomedical frameworks in shaping illness experience. While medical knowledge often shapes lay understandings, lay people often perceive illness in a manner different than health professionals (Kleinman, 1988; Prior, 2003) with lay knowledge situated in the larger sociocultural context (Lawton, 2003). “Disease” typically have a clear physiological link and with this link remaining static throughout time and space. However, the experience of “illness” shifts across time, place, and person. Understanding the experience of individuals diagnosed with disorder or disease has become increasingly important within the social sciences, allowing researchers to more deeply
understand a wide range of human experience. As David Karp stated, “to really understand human experience, it must be appreciated from the subjective point of view of the person undergoing it (1996, p. 11).”

The rise in illness experience research within sociology can be attributed to several factors including the shift from acute to chronic illness, the narrative turn in social sciences, and goals in medicine to look at the "whole person" (Bell, 2000). Illness experience research aims to understand how “sick persons and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (Kleinman, 1988, p. 3). As this definition indicates, illness experience research finds the experience of the sick individual central but also acknowledges the importance of the larger social milieu. Studies of illness experience highlight the important role illness plays in changing life, including disrupting both one’s identity and social connections (S. Bell, 2000), changing meanings and understandings (Charmaz, 1991), and highlighting the interplay among biology, psychology, and society (Karp, 1996).

While research focusing on ADHD in adulthood has grown significantly in recent years, much of it stems from the biomedical perspective and aims to enhance medical knowledge. Much of the existing scholarly work examining the lived experience of adults with ADHD is typically written from either a self-help or clinical perspective. Typically, these studies view symptoms as the natural result of physiological disorder and have typically ignored individual society interactions. However, studies that have examined the lived experiences of
those with depression (Karp, 1996), disability (Zola, 2003), chronic fatigue syndrome (Ware, 1999), and other chronic illnesses (Charmaz, 1991) have shown a substantial interplay between the individual and society. This interplay shapes how one experiences problems.

For example, Ware’s (1999) “Social Course of Illness” provides a model for the experience of illness (depicted in Figure 1). The model is based on retrospective narrative accounts of individuals suffering from chronic fatigue syndrome (CFS).

![Figure 1. Ware’s Model of the Social Course of Illness](image.png)

In the model, Ware notes how symptoms of a disorder (qualities of distress) interact with cultural expectations for behavior. In patients with CFS, a person’s lack of stamina clashes with cultural expectations for speed. Through this interaction, individuals begin a process of marginalization, which can include isolation, stigma, or role constriction. Resistance strategies refer to the eventual ways in which individuals come to cope with both illness and society’s norms for expectations. Ware’s model allows us to understand the relationship between individual troubles and societal expectations. Ware’s model also shares some similarities with the stress paradigm (highlighted below). For example, qualities of distress and cultural expectations are similar to models related to person and environment fit. These models posit that when the qualities of a person match
and are well suited to his/her environment, there are positive outcomes for the individual and vice versa (Coulton, 1981). As I highlight in chapter 6, modern society’s emphasis on perfection and efficiency creates an environment where adults who have been diagnosed with ADHD cannot meet these expectations, resulting in distress.

As in other illness experience research, I was driven by three overarching goals. First, I was concerned with the way in which meanings were attached to illness, how adults came to recognize problems in their everyday life as the result of ADHD (AIM 1). Second, I wanted to know how a diagnosis of ADHD changes social interaction (AIM 2). Third, I wanted to learn how ADHD experience is shaped by social structure and culture (AIM 3).

**Medicalization**

Social construction has become a central theme in medical sociology (Brown, 1995) and is particularly powerful in understanding medicalization (Barker, 2010) or the “process whereby more and more of everyday life has come under medical dominion, influence and supervision” (Zola, 1983, p. 295). Medicalization research assesses the role that social factors play in the application of medical labels (Gerhardt, 1989) and how these labels shape health-related action and knowledge (Brown, 1995). Specifically, application of social constructionism to medicalization has shown that medical knowledge is socially and culturally situated, that it is influenced by power and authority, and that medical knowledge changes over time and place. Studies of medicalization
have often been critical of the process, suggesting that medicalization is a problem and results in increased social control.

Is ADHD a medicalized disorder? Phil Brown’s (1995) *Typology of Conditions and Definitions* (Figure 2) is helpful when considering this question.

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<th>Condition not generally accepted, or condition is questionable</th>
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<td></td>
<td>2 Medicalized Definitions (late luteal phase dysphoric disorder, chronic fatigue syndrome, chronic pain syndrome)</td>
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<tr>
<td>Biomedical definition not applied, or there is conflict on making a definition</td>
<td>3 Contested Definitions (occupational diseases, environmentally induced diseases, multiple chemical sensitivity)</td>
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<tr>
<td></td>
<td>4 Potentially Medicalized Definitions (genetic predispositions to diseases)</td>
</tr>
</tbody>
</table>

**Figure 2. Conditions and Definitions (reproduced from Brown, 1995)**

Brown’s typology allows us to consider how diseases and disorders are socially constructed in the ways the conditions are commonly understood and the extent
to which biomedical definitions have been applied. Cell 1 includes routinely defined conditions such as infectious diseases, acute illness, and injuries. In this cell, a biomedical definition has been applied and is generally accepted. The second cell pertains to medicalized conditions or those in which a medical label has been applied, but there is debate regarding the reality of the disorder. In addition to those medicalized conditions listed by Brown, other conditions could include Premenstrual Dysphoric Disorder (PMDD) and female sexual dysfunction (Fishman, 2004; Greenslit, 2005). Cell 3 contains contested definitions in which a biomedical label has not been applied, but lay people believe the disorder is real. In addition to conditions listed in the figure, Cell 3 would also include Gulf War Syndrome (Brown et al., 2001), chronic fatigue syndrome (J. N. Clarke & James, 2003), and environmentally induced diseases (Brown, 2007). The fourth cell includes conditions that could potentially become medicalized and are not understood as disorder by medicine or lay people.

A large body of social science literature argues that ADHD in children is medicalized (Brock, 2010; Conrad, 1976). For example, Conrad’s classic work, *Identifying Hyperactive Children* suggests ADHD to be the medicalization of deviance. By applying the medically recognized label of “hyperactive” to children, children who were once labeled as “bad” could now be labeled as “disabled.” Application of the medically recognized label increases social control through the provision of stimulant medication (which has a decreases deviance), the
Involvement of additional institutions (medicine) to control behavior, and the reinforcement of normative behavior.

In adults, several scholars have suggested that ADHD is a medicalized disorder as well. Conrad and Potter (2000) suggest that ADHD in adults is the medicalization of underachievement. Likewise, Leffers (1997) suggests that the specific behaviors of ADHD in adults are being medicalized.

Adult ADHD’s appearance in the DSM-IV, its treatment by medical professionals, and the use of prescription drugs suggest that a biomedical definition has been applied. As noted in Chapter 1, there is ongoing debate related to the reality of criticism waged against ADHD. While some critics believe ADHD is over-diagnosed and/or over-treated, others question the reality of the disorder entirely (Breggin, 2001; Cohen, 2006; Timimi & Taylor, 2004). In questioning the reality of such disorders, critics typically state that the disorder is socially constructed. The biomedical response to such criticisms has been to state that ADHD is an objective reality. Because a formal biomedical label has been applied and there is still debate regarding the reality of the disorder, it is clear that ADHD can be considered a medicalized disorder when utilizing Brown’s typology.

A considerable focus of the medicalization literature has been on the medicalization of deviance. Peter Conrad has written extensively on the topic of medicalization of deviance, viewing the process of medicalization as a way to recast deviant behaviors as illness or disease with clear treatments (Conrad,
1976; Conrad & Barker, 2010; Conrad & Leiter, 2004; Conrad & Potter, 2000; Conrad & Schneider, 1980). Conrad and Schneider (1980) proposed the following model to show how deviant behaviors become medical problems:

The behavior must be recognized as a problem.

There has to be medical discovery regarding the problem.

This discovery then has to be accepted by the public.

The medical model gains legitimacy through the passage of laws or sanctions by the state.

A medical definition must become institutionalized through official, medical, or state classifications.

Once the problem has become medicalized, the behavior is recast. The process of medicalization allows the individuals to be viewed as "sick" rather than "bad."

This shift from badness to sickness has several consequences, including increased social control, drawing attention away from structural causes, and a focus on medical solutions by policy makers (Conrad, 2007).

Like Conrad, Foucault sees the medical institution as another form of social control. For example, in _Madness and Civilization_ (1965), Foucault describes how the concept of madness has changed over time, evolving from a special kind of wisdom to a medical problem. Foucault argues that this shift in understanding allows the mad, who are undesirable, to be separated from society and treated. In _The Birth of the Clinic_ (1973), Foucault argues that this rise of medicine is a means of enforcing morality and that medicine has come to
supplant religion as the ultimate conveyer of truth. Due to the authority placed on medicine, physicians and clinics define what is good and bad. However, Foucault views medical authority, in particular the separation of body and identity (the medical gaze) as dehumanizing.

Medicalization is largely concerned with the social construction of medical knowledge or “ways of knowing that are based on biomedical frameworks” (Brown, 1995, p. 37). While physicians were drivers of medicalization in the past (Friedson, 1970), larger corporate interests have taken an increasingly large role in medicalization (A. E. Clarke, Mamo, Fishman, Shim, & Fosket, 2003; Conrad, 2005). These interests include biotech companies, pharmaceutical firms, and health care organizations.

For example, Fishman (2004) explored the role pharmaceutical companies and academic researchers play in the commodification (through medical treatment) of female sexual dysfunction. She argues that collaborations between pharmaceutical companies and academic researchers “created a market” by applying existing treatments for sexual dysfunction (Viagra) in men to women. Others have shown similar processes for disorders such as premenstrual dysphoric disorder (Greenslit, 2005). In both of these examples, the pharmaceutical intervention existed before the problem was understood to be medical. In other words, the cure existed before the disease. By funding scientific research related to the use of specific drug treatments, pharmaceutical companies served to legitimize problems and treatments for these problems.
Direct-to-consumer advertising further exacerbates the problem of medicalization by encouraging individuals to seek help for modest, normal, or benign symptoms (Mintzes et al., 2002).

Critiques of ADHD have tended to emphasize these issues, highlighting the large profits to be gained by pharmaceutical companies and the role of direct-to-consumer advertising in increasing help-seeking behaviors. As highlighted previously, Conrad and Potter’s (2000) work tracing the expansion of ADHD from a childhood disorder to one that affects adults represents a crucial first step in applying a critical sociological perspective to current medical knowledge related to ADHD. The influence of corporations on academic researchers was also highlighted by the large payments received by Joseph Biederman, a key ADHD researcher, and the subsequent ethics investigation by the United States Congress (Harris and Carey, 2008).

Medicalization literature has been especially critical of psychiatry and the DSM (Klienman, 1991). Criticisms of the DSM have typically focused on the increasing degree to which everyday life has been subsumed under a rubric of mental disorder specifically (Scheff, 1999; Szasz, 1961, 1977, 1997) as well as the imprecise nature of diagnostic criteria (Shedler, Mayman, & Manis, 1993, 1994). Allan Horwitz has been especially critical of the vague distinction between diagnostic criteria used by the DSM and normal reactions to stress (Horwitz, 1982, 1990, 2002, 2007). He argues that changes in the DSM have transformed normality in pathology (2007) by emphasizing symptoms, removing assumptions
of etiology, and “treating all symptoms, whether normal or proportionate responses to stressful situations or inappropriate and pathological signs of dysfunctions, as potential signs of mental illness” (p. 215).

As noted above, medicalization consists of defining a problem of everyday life in medical terms. While much of the medicalization literature has focused on negative aspects of medicalization, the application of a medical label can have both positive and negative consequences (Reissman, 1983). For example, application of a medical label can lead to improved well-being of individuals by allowing individuals to make sense of symptoms, validate their troubles, gain access to treatments, and find ways to self-manage (Broom & Woodward, 1996). As noted earlier, it allows individuals to engage in the sick role (Parsons, 1951, 1975) and can remove accountability from the self. Phil Brown has done considerable work examining contested disorders, or those disorders in which lay people struggle to have a medical definition applied to problems. For example, veterans and their family members called for Gulf War Syndrome to be recognized as an official medical diagnosis (Brown et al., 2001) in order to gain access to treatment and accommodations.

Although the focus of this dissertation is on the lived experience of ADHD in adults, viewing ADHD as a medicalized disorder was particularly beneficial in crafting initial questions and informing analysis. Incorporation of this perspective allowed me to remain critical of the diagnosis itself. Additionally, it challenged me to look beyond the experience of specific symptoms that are common to many.
What exactly was being medicalized? As shown in greater detail in later chapters, individuals come to believe they are not successful enough, that they are somehow underachieving based on their understandings of potential. Additionally, these perspectives challenged me to explore both the positive and negative effects of an ADHD diagnosis for individuals.

**The Self and Identity**

The *self* is a central concept in sociology. Traditionally, the *self* is understood as the set of unique characteristics that set us apart from others. Along with the body, the self includes an individual’s identity (Baumeister, 1991), the totality of categories applied to the self (Goffman, 1963) and the meanings attached to those categories (roles) (Stets & Burke, 2000). William James first formalized a theory of the self, describing how human beings viewed themselves as objects (James, 1950). James suggested that a sense of self influenced feelings, attitudes, and behavior of individuals. Cooley further elaborated on this work by emphasizing that the self emerged through communication with others (Cooley, 1968). Cooley’s concept of the *looking glass self* suggests that self-concept or the “set of meanings we hold for ourselves when we look at ourselves (Stets & Burke, 2003, p. 130)” develops by taking the viewpoint of others during interaction.

In *Mind, Self, and Society*, George Herbert Mead (1967) synthesized the work of Cooley and James. Mead stressed that sense of self becomes stabilized over time by a drive to improve responses of other social actors and the
expectations of the larger community. For Mead, institutions are derived from the patterned interactions of diverse actors through the ability to take on roles:

Consciousness of both the self and the other are equally important for the individual's own self-development and for the development of the organized society or social group to which he/she belongs. The individual reads the situation as both him/herself, and as the other, and responds, in action, words, gestures and behavior after placing him/herself in both roles. The immediate effect of such role-taking lies in the control which the individual is able to exercise over his/her own response. And thus it is that social control, as operating in terms of self-criticism, exerts itself so intimately and extensively over individual behavior or conduct, serving to integrate the individual and his/her actions into the social process. Self-criticism is then essentially social criticism (Mead, 1967, pp. 739-740).

Like Mead, Erving Goffman suggests that the self is contingent on the responses of others. In The Presentation of Self in Everyday Life, Goffman (1959) argues that individuals engage in performance to enhance how the self is perceived by others. In these performances, individuals create a front that includes misrepresentations of the self. Goffman argues that individuals wish to present an ideal version of the self that reflects societal values. Unlike Mead, Goffman argued that the self was completely transitory and is situation specific. As Gonos (1977) argues, Goffman's approach to self suggests that structures invisibly govern the presentation of self, rather than developing through social interactions (as suggested by Mead and other Symbolic Interactionists).

With the exception of Goffman, most sociological approaches to self and identity suggest a reflexive relationship between self and society, largely influenced by the work of Mead. In other words, notions of self both emerge in and reflect society (Stryker, 1980). An individual’s identity is constructed through reflexivity, or viewing one’s self as an object, constantly evaluating the self to find
one’s place in the world and find meaning. The meanings attached to identity categories allow individuals to act in predictable and expected patterns as well as to form groups, organizations, and institutions that influence society (Stryker & Burke, 2000). Due to its reflexive nature, identity construction is a lifelong process. A girlfriend may progress to spouse, mother, and widow, all of which shape expectations regarding action and how the person makes sense of the world. Sociological approaches to the self require us to understand not only the self and identity, but also the society in which self and identity emerge. However, identities may not be constructed in a uniform manner, with individuals attaching different meanings to the same identity.

While many adults with ADHD have come to their diagnosis through self-referral, little is known about this process. One of the key goals of this dissertation is to discern how an adult comes to apply the label of ADHD to the self and the social meanings of that label. Specifically, what factors led adults to view their problems as so great that they required medical attention. As I show in Chapter 4, self-appraisals (and criticisms) became central in how adults with ADHD come to see themselves as being disabled. In viewing the self as an object, ADHD adults do not believe they are adhering the values of society.

The Life Course

Although it is most closely associated with sociology, the life course is a multidisciplinary approach to understanding human development (Settersten, 2003a). The life course is viewed as a social construction occurring across
biological, social, and psychological dimensions (Holstein & Gubrium, 2000). Elder (1994) suggests that the life course is a multilevel phenomenon that includes institutions, organizations, and individuals. Life-course approaches tend to look at the entire life span, with the assumption that lived experiences are embedded in history and that development is lifelong. One’s position in the life course, with regard to both age and cohort, can have an impact on the effect of events in one’s life. For example, life-course approaches have looked at how events such as the Great Depression have affected children and adults differently (Elder, 1974).

Age appears to play a particularly powerful role in the presentation of ADHD symptoms. For example, a recent study by Marrow et. al (2012) found that older boys were 30% less likely to be diagnosed with ADHD than younger boys within the same grade. As noted earlier, it is believed that almost 50% of children will “outgrow” ADHD. Although ADHD in adults is now considered by many biomedical experts to be a lifelong chronic disease (Barkley, 1990), as age increases, the prevalence and severity of ADHD symptoms decline. Biomedical literature provides us with two possible explanations for this relationship: (1) as age increases, people do get better, or (2) the instruments used to detect ADHD lose sensitivity as age increases. Biomedical literature tends to emphasize the latter in explaining the negative relationship between age and symptoms, noting that instruments were validated in children (Davidson, 2008) and may lack sensitivity in adults.
Because there is a large degree of uncertainty related to how age itself impacts ADHD, application of the life-course may be particularly fruitful. The life-course offers a considerable amount of theoretical richness to current criticisms of ADHD, providing alternative explanations to the decrease in symptoms due to age. Because much of the prevalence data related to ADHD is cross-sectional in nature, it is possible that differences in prevalence and severity based on age are due to cohort effects rather than increases in age. In other words, adults born in 1940 may not have high prevalence rates because of the time they were born rather than their specific age. To answer these questions, longitudinal approaches to research (including retrospective illness narratives) would be valuable.

The life-course approach has also been particularly beneficial in understanding how normative expectations for the life course can influence mental states. As Neugarten (1969) suggested, our understanding of a “normal predictable life cycle” is shaped by culture. Individuals often divide their life into segments, creating a map of the life cycle (Neugarten and Hagestad, 1976). Settersten and Hagestad (1996) show that “cultural age deadlines” for families as well as educational or work transitions are acutely perceived and largely agreed upon. Although many do not adhere to such normative expectations for the life course, deviation from the expectations regarding life transitions can have consequences (Dannefer, 1988). Several researchers have examined the effects of life events occurring “off time.” While Settersten (2003b) notes that being off
time can have positive effects, most researchers have focused on the negatives of being off time. For example, Hagestad (1988) argues that life-course transitions such as family deaths have become more predictable, making the unexpected death of a loved one particularly devastating. Wheaton suggests that nonevents (or those events that are normative for groups and expected to occur) are a form of chronic stress (Wheaton, 1999). For example, not completing college, having a child, or finding a career by a particular age can all lead to chronic stress.

Because ADHD is commonly understood as a disorder of childhood, the diagnosis of ADHD in adulthood represents an “off-time” event. As discussed in greater detail in Chapter 6, "missed diagnosis" was a particularly powerful theme that emerged early in my analysis. Because adults believed that their ADHD diagnosis should have occurred in childhood, there was considerable distress related to the timing of the diagnosis, with many adults with ADHD wishing they had been diagnosed much earlier. The timing of the diagnosis also had a considerable effect on a person’s perceived life course: they believed their life would have been better had they received a diagnosis earlier. As I will discuss in Chapter 5, role transitions were also particularly powerful in adults recognizing a problem.

The Social Model of Disability

Common models of disability assume that impairments arise from disease or pathology (Bury, 2005). Such models are clearly rooted in biomedical
framework and locate the problem of disability as one originating within the individual. In the case of ADHD, the biomedical model informs the bulk of research associated with disability. As I have stated earlier, the existence of ADHD is determined through the experience of symptoms and impairment. Much of the scientific literature has focused on determining the source of these symptoms through increasingly sophisticated physiological studies. Despite substantial efforts, there is relatively little agreement on specific etiology or pathology related to ADHD, resulting in considerable debate around the disorder.

Although less common in academic research generally, the social model of disability informs this research. Instead of being viewed as a problem within the individual or his/her body, social models of disability suggest disablement “has nothing to do with the body. It is a consequence of social oppression” (Oliver, 1996, p. 35). Like other approaches, the social model of disability is firmly grounded in the constructionist paradigm, viewing the concept of “disability” as firmly rooted in cultural understandings. Such approaches focus on how society is disabling rather than viewing individuals as disabled.

Unlike other approaches highlighted in this section, the social model of disability largely arises from disabled individuals rather than from within the academic community. Consequently, the social models of disability have been emancipatory in nature, with many disability scholars taking on the role of political activist. Rather than addressing problems at the individual level through cures or
treatment as is common in biomedicine, the social model of disability instead focuses on changing the social and built environment to meet individuals’ needs.

The social model of disability has had an important effect on this research project because I myself have been diagnosed with ADHD. In explaining my own illness, I initially employed a biomedical model, asking questions such as “what is wrong with me?” and “why can’t I do this?” As I progressed in my own experience with ADHD and throughout this research, my attention shifted to different questions. Rather than asking what is wrong with me, I began questioning the source of the problems I encountered in daily life. Instead of viewing ADHD as a problem with myself, I wanted to learn those factors in American society that either exacerbated problems of ADHD or created them. As this research project progressed, I began to question the legitimacy of the diagnostic category itself, eventually discontinuing my own use of treatment. As I highlight in Chapters 6 and 7, ADHD as a diagnostic label is a means to increase adherence to the values and beliefs of the larger social system.

The Stress Model

Simply stated, stress refers to any demand that forces an organism to adapt or change its behavior. Stress usually stems from “various stressors or the conditions of threat, demands, and structural constraints that, by their very occurrence or existence, call into question the operating integrity of the organism” (Wheaton, 1996, pp 40). Stressors often include life events (Holmes & Rahe, 1967), daily hassles (Kanner, Coyne, Schaefer, & Lazarus, 1981), role strains
(Pearlin, 1989), nonevents (Gersten, Langner, Eisenberg, Simcha-Fagan, & McCarthy, 1977), lack of person environment fit (Lewin, 1951), and traumas (T. Langner, 1963). All stressors must challenge the integrity of the organism, are problematic, and are identity relevant (Wheaton, 1996).

Social constructionism has increasingly informed the stress model. For example, Jacobson (1989) argues that it is not the strains in themselves that determine mental health consequences of events, but rather the meaning attached to strains. Likewise, Pearlin (1989) stated that culture regulates the meaning and significance attached to both acute and chronic stressors.

Several studies have established a clear link between stressors and physical and mental health. For example, Wilkinson (1997) argues that stress associated with social position have both direct and indirect consequences on health. Likewise, Marmot (Marmot, 2005; Marmot, 2004; Marmot et. al, 2000; Wilkinson & Marmot, 2003), suggests that a low position in the social hierarchy is inherently stressful and leads to increased risk for morbidity and mortality.

Mental health scholars have viewed psychiatric or psychological disorders as the result of stressors or major stress events for some time. Several studies suggest that depressive symptoms are often associated with stressors including lack of educational attainment (Mossakowski, 2008), lack of marriage (Horwitz, 1982; Horwitz, White, & Howell-White, 1996), off-time pregnancy (Mirowsky & Ross, 2002), and unmet expectations (Mossakowski, 2011). Additionally, Goldberg and
Huxley (1980) show that high levels of stress are also powerful predictors of help-seeking behavior.

While the DSM defines disorders through dysfunctions, it attempts to limit the scope of its definitions by noting that disorders:

must not be merely an expectable and culturally sanctioned response to a particular event, for example, the death of a loved one. Whatever its original cause, it must currently be considered a manifestation of a behavioral, psychological, or biological dysfunction in the individual (pp. 21).

However, such boundaries between stress and mental disorders are ambiguous. Horwitz argues convincingly that these criteria often neglect what could be considered normal responses to distress, treating all symptoms as indicators of mental disorders. Horowitz and Wakefield's The Loss of Sadness: How psychiatry transformed normal sorrow into depression (2007) explores this idea more fully, noting that the grief associated with the loss of a loved one is increasingly treated as depression.

Application of the stress model allows this research to examine the types of stressors relevant to an ADHD experience. By focusing on the lived experience of adults with ADHD, this research examines the meanings attached to stressors and the contexts in which they arise. This research also examines how individuals come to cope with stressors and some of the mediating factors.

Summary

This dissertation views ADHD experience as socially constructed and uses several sociological approaches that are informed by this perspective. By using
the various sociological approaches highlighted above, this research adds theoretical richness to current understandings of ADHD, highlighting how ADHD is socially constructed at an individual level. Specifically, this research examines the experience of ADHD, its consequences, and how the acceptance of ADHD in adulthood reinforces societal values. Each of the approaches discussed in this chapter—illness experience, medicalization, identity, the life course, the social model of disability, and the stress model—played a pivotal role in the original framing of research questions as well as subsequent analysis.

While social constructionism has typically focused on determining how and why knowledge develops in the way it does and not aim to determine which view of illness is correct (Barker, 2010). However, questions about truth and reality inevitably arise when examining knowledge from a constructionist perspective. When I began this study, I was ambivalent regarding the “reality” of ADHD. My goal was to examine illness experience rather than to argue whether ADHD was a “real” disorder. As my analysis progressed and evidence mounted, it became clear to me that ADHD in adults was much more social than biological. While I do not question that adults diagnosed with ADHD suffer, I do question the source of that suffering. Drawing on the medicalization and social model of disability literature, I have come to view the source of ADHD problems situated in our social milieu and the diagnostic category a tool of social control and oppression. Ultimately, I hope a sociologically informed critique of ADHD will lead to changes in society that will alleviate the suffering we now relate to ADHD.
Chapter 3: Methods

My goals in this study were to understand the lived experiences of adults who were diagnosed with ADHD. There has been a considerable amount of research examining the experience of ADHD in children, particularly in educational settings (Conrad & Potter, 2000; Hallowell & Ratey, 1995; G. Weiss & Hechtman, 1993). It is clear from this research that children often receive a diagnosis of ADHD as a result of deviant school behavior, usually being referred to medical practitioners by a person in authority (Conrad, 1976).

Rather than being told they have ADHD, most adults who have been diagnosed with ADHD do so through self-referral (Conrad & Potter, 2000). In other words, the path to diagnosis in adults is very different than that for children. What information do adults draw on that makes ADHD a reality for them? How do they know they "have" ADHD? Answering these questions required an examination of the everyday experiences of adults who had been diagnosed with ADHD in adulthood.

As highlighted in Chapter 2, illness experience research informs this dissertation. Illness experience research has examined a wide range of health-related topics including chronic illness in general (Charmaz, 1991; Charmaz & Olesen, 1997), disability (Zola, 2003), as well as specific disorders including depression (Karp, 1996), Parkinson’s disease (Solimeo, 2009), and cancer (Frank, 1995). Illness experience research has typically relied on qualitative data
in the form of narratives (Bell, 2000). Regardless of focus, these approaches have:

Intentionally drawn scholarly attention away from medical settings and medical perspectives on disease and toward the nonmedical settings and nonmedical perspectives of everyday life (Bell, 2000, p. 184)

Like other scholars examining the experience of illness, I was driven by three research objectives as stated earlier. First, I was concerned with the way meanings were attached to illness, that is, how adults came to recognize and attribute factors of everyday life to ADHD (AIM 1). Second, I wanted to know how a diagnosis of ADHD changes social interaction (AIM 2). Third, I wanted to learn how ADHD experience is shaped by social structure (AIM 3). This chapter provides an overview of the method used to address these questions.

Method

This study uses a modified version of grounded theory to ascertain the lived experiences of adults who were diagnosed with ADHD. Originally “discovered” by Glaser and Strauss (1977), grounded theory is a qualitative methodology based on inductive analysis. This methodology is well suited for the aims listed above for several reasons. First, grounded theory has commonly been used to study illness (Thorne et al., 2002) and provides a useful strategy for the study of experience of chronic illness (Charmaz, 1990). Second, grounded theory focuses attention on everyday life rather than medical perspectives. As highlighted in Chapter 2, the majority of what is known about ADHD stems from biomedicine or has focused on the construction of medical knowledge.
Relatively little is known about the lived experience of ADHD in adulthood, how adults come to recognize the disorder, or what they believe regarding the illness. Although medical knowledge shapes everyday knowledge (Barker, 2010), individuals often perceive illness in a manner different from health professionals (Kleinman, 1988; Prior, 2003) with lay knowledge situated in the larger sociocultural context (Lawton, 2003). The approach employed by this dissertation draws attention to knowledge production within individuals. As Strauss and Corbin (1990) suggests, grounded theory is well suited to this goal as it:

…inductively, derived from the study of the phenomenon it represents. That is, discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory should stand in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge. (p. 16)

The use of grounded theory guides the overall process including the generation and analysis of data.

**Generating Qualitative Data**

The primary inclusion criterion for this study was a clinical diagnosis of ADHD in adulthood ascertained through self-report. Only adults (18+ years old) were included in the study. Narratives stemmed from two separate sources, face-to-face interviews and unsolicited Internet narratives. Face-to-face interviews represent the primary source of data and the focus of the study. Because the Internet has become a key means of both gathering and sharing
information and often presents challenges to biomedical perspectives on illness (Conrad and Stults, 2010), unsolicited Internet narratives were collected in an effort to add diversity to the study (Robinson, 2001) (Glaser & Strauss, 1970). Additionally, the use of diverse sources allowed me to ascertain the transferability of concepts across those sources (Corbin & Strauss, 1990). The section below begins with methods related to face-to-face interviews and then goes on to highlight how unsolicited Internet narratives were collected.

**Interview Guide.** A semi-structured interview guide was initially developed in conjunction with my dissertation committee with informal insight from other researchers and health professionals. The interview questions were designed to explore and define processes (Charmaz, 2003). For example, questions included “When did you first notice you had problems with ADHD?” and “What do you tell people about ADHD?” In addition to questions highlighting processes, the interview guide also included descriptive questions (Spradley, 1979). Grand tour questions were included to elicit the general experience of ADHD and orient me to the life-world of the participant. Grand tour questions included “What is it like to have ADHD?” and “What was a typical day like prior to going on treatment?” Additionally, mini-tour questions were included to get at more specific aspects of ADHD experience. These included questions such as “What are some of the tasks you do where you notice your ADHD the most?”

As part of the method used, the guide was iterative and evolving as new themes emerged. For example, an important theme developing early in the study
related to participants’ “to-do lists.” Although respondents had not been asked, several discussed being overwhelmed by uncompleted tasks at about the time of their diagnosis. The interview guide was expanded to include probes related to the concept of “to-do lists” at the time of diagnosis, current “to-do list,” and future “to-do lists.” The final interview guide is included in Appendix A.

Sample composition. A set of basic demographic questions (age, race, ethnicity) were covered at the beginning of each interview. Additionally, several questions related specifically to ADHD were asked. These included age at the time of diagnosis, the type of clinician responsible for diagnosing ADHD, treatment status, and whether anyone else in the participant’s family had ADHD. These questions allowed me to describe my sample more fully. While I tried to recruit individuals from a range of settings, my sample is not representative of the general population or of all adults with ADHD. However, the sample offered a broad age distribution (20s=6, 30s=5, 40s=1, 50s=4, 60s=3), representation from both genders (11 males, 8 females), and a range of occupations (4 students, 4 white-collar, 3 professionals, 6 unemployed persons, and 2 retired persons). All but two of the study participants were white, the racial group with the highest prevalence of ADHD. The non-white participants were African American (1) and Asian (1). All of the participants had some college education, with 9 having completed advanced degrees. Seven of the participants were currently married, 4 were divorced, and 9 had children.
For diagnosis, the median age of participants at diagnosis was 27 (range of 19 to 56), and the median time since diagnosis was 4 years (range 9 days to 28 years). In total, 3 participants were diagnosed by primary-care physicians, 8 by a psychologist, 6 by a psychiatrist, and 2 by a licensed clinical social worker. In total, 10 participants were taking some form of medication to treat their ADHD although nearly all had some experience with pharmaceutical treatment. Seven were engaged in behavioral counseling at the time of the study. Ten participants identified a close family member who had also been diagnosed with ADHD.

**ADHD Screener.** Each interview began with the World Health Organization’s Adult Self Report Scale (ASRS) v1.1. Because the test is used in clinical settings to screen for ADHD, the ASRS was included by request of members of the Dissertation Committee to verify clinical diagnosis and assess the severity of symptom experience. The test included 18 Likert items assessing inattention (9 items) and hyperactivity/impulsivity (9 items). The first 6 questions are those that are most predictive of symptoms of ADHD. The remaining items assess the severity of symptoms and level of impairment. The ASRS is reported to have good psychometric properties. The items are included in Table 1 below along with the number and percentage of participants who met scoring criteria for those items. The median score is also included.

**Table 1. ASRS Item Breakdown**

<table>
<thead>
<tr>
<th>Question</th>
<th>Count</th>
<th>% with Symptom</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you have trouble wrapping up the final details of a project, once the challenging parts have been done?</td>
<td>14</td>
<td>77.8%</td>
<td>4</td>
</tr>
<tr>
<td>How often do you have difficulty getting things in order when you have to do a task that requires organization?</td>
<td>17</td>
<td>94.4%</td>
<td>4</td>
</tr>
</tbody>
</table>
How often do you have problems remembering appointments or obligations? 12 66.7% 3
When you have a task that requires a lot of thought, how often do you avoid or delay getting started? 14 77.8% 4
How often do you fidget or squirm with your hands or feet when you have to sit down for a long time? 14 77.8% 4
How often do you feel overly active and compelled to do things, like you were driven by a motor? 6 33.3% 3
How often do you make careless mistakes when you have to work on a boring or difficult project? 7 38.9% 3
How often do you have difficulty keeping your attention when you are doing boring or repetitive work? 13 72.2% 4
How often do you have difficulty concentrating on what people say to you, even when they are speaking to you directly? 15 83.3% 4
How often do you misplace or have difficulty finding things at home or at work? 9 50.0% 3
How often are you distracted by activity or noise around you? 7 38.9% 3
How often do you leave your seat in meetings or other situations in which you are expected to remain seated? 6 33.3% 2
How often do you feel restless or fidgety? 12 66.7% 4
How often do you have difficulty unwinding and relaxing when you have time to yourself? 9 50.0% 3
How often do you find yourself talking too much when you are in social situations? 6 33.3% 3
When you’re in a conversation, how often do you find yourself finishing the sentences of the people you are talking to, before they can finish them themselves? 15 83.3% 3
How often do you have difficulty waiting your turn in situations when turn taking is required? 7 38.9% 3
How often do you interrupt others when they are busy? 12 66.7% 3

No participants were excluded due to their scores on screening tests. Of the 19 face-to-face interviews included in the study, 15 met ASRS criteria for ADHD. The total number of symptoms ranged from 2 to 16. Three patients reported 11 symptoms (mode). Of the 18 items, 17 of the 19 participants indicated they had problems getting things in order when they had to do a task that requires organization. Only 2 reported difficulty remaining in their seats during meetings or other situations where they were expected to remain seated. The range of symptom experience reported by participants also suggests the diversity of the sample. While some participants had experienced quite a number...
of symptoms, several had managed their ADHD well. These participants were not excluded in an effort to capture a wide range of ADHD experience. Low scores could be indicative of successful coping and management and these participants provided additional insight to the study of ADHD experience.

**Sample Site (Face-to-Face Interviews)**

Face-to-face interview participants in this study became involved through a variety of means including snowball sampling and advertisements. Initially, participants were identified through personal acquaintances. Personal contacts accounted for four of the study participants. These individuals referred one additional participant to the study. The majority of face-to-face participants were recruited through advertisements on websites (www.cleveland.craigslist.org, www.forum.case.edu, www.cleveland.backpage.com) and the classified section in a local newspaper. These advertisements appeared in the Help Wanted and/or general Classified sections. Twelve participants were recruited through print or electronic advertisements, with www.craigslist.com being the most effective. For example, when I first posted the advertisement on craigslist, I received a phone call less than a half-hour following the post. Last, flyers were placed in several locations including libraries, in a health clinic serving low-income individuals, and around two college campuses. Only three participants were recruited through flyers, all of whom were college students. As noted above, all participants self-identified as being diagnosed with ADHD in adulthood. Their
diagnosis was verified both during initial contact and additionally before the start of the interview.

By not recruiting through physicians’ offices, I was able to include individuals who were not currently receiving treatment for ADHD. Likewise, several participants were diagnosed by licensed social workers, through encounters with marriage counselors, or through college counseling services. My recruitment technique increased the diversity of my sample, providing a wider range of ADHD experience.

Sampling continued until the point of theoretical saturation was met. Theoretical saturation means the point at which no new codes, dimensions, or concepts emerged from narratives (Charmaz, 2006). Saturation is considered to be essential for producing rigorous qualitative research. The point of theoretical saturation is one of ongoing debate within qualitative research methods. Several researchers have argued that approximately 20 to 30 cases are needed to reach theoretical saturation (Esterberg, 2002; Morse, 2000). More recently, Guest, Bunce, and Johnson (2006) have showed that theoretical saturation could be met (with some stipulations) with as few as 12 using an experimental design. In this project, the majority of codes emerged after analyzing the first 12 face-to-face interviews. Code definitions also changed throughout the project and were revised with a static coding dictionary developed at about the 14th interview. I was confident I reached theoretical saturation at about the 17th interview, but I
chose to continue with data collection to be sure. In the last 2 interviews, no new codes emerged. In total, I interviewed 19 adults diagnosed with ADHD.

**Interview Procedure**

Most interviews took place at small private study rooms located in public libraries. Several interviews took place at the participant’s home, the participant’s place of work, or my office on campus. Face-to-face interviews were between 44 minutes and 2 hours and 22 minutes, with the typical interview lasting about 1 hour and 30 minutes. For participation, each individual received a $15 gift card as compensation.

Following informed consent, each participant was asked basic demographic information. Additionally, an ADHD screening tool was used to assess the severity of ADHD in this population, the ASRS v1.1. As mentioned earlier, the data garnished from this test was used to supplement qualitative interview data by suggesting the severity of problems experienced by adults with ADHD. It was not used to exclude individuals from the study.

My goal was to treat each participant as an expert to draw out his or her ADHD experiences as fully as possible. The manner in which people shared their stories varied. While some respondents talked in depth and at length, others were quite short in their responses and required significant probing. Occasionally, I would include my own experiences and those of others, verifying the experiences of participants and further establishing rapport (L. Berger, 2001). Immediately following interviews, field notes were taken, initially by writing then
by recording thoughts into the audio recorder. These field notes/recordings supplemented the unspoken aspects of the interview. I would record gestures and the tone of the interview as well as my overall impressions. If interviews took place in more personal places (homes or offices), I would also record the aspects of the environment. Field notes added additional richness to data by capturing the unspoken aspects of the interview.

Generally, participants viewed the interview process as a positive experience. Several respondents stayed well after the formal interview concluded to ascertain the nature of the study and to learn about my own views on ADHD. Several respondents also emailed me after the interview, sharing additional thoughts on their experiences with ADHD.

**Unsolicited Internet Narratives**

In addition to face-to-face interviews, unsolicited Internet narratives were collected and analyzed to add additional diversity to the sample and to test the transferability of codes. Websites with ADHD narratives were identified using the Google search engine. The following search terms were used:

- Adult Attention Deficit Disorder Story
- Adult Attention Deficit Disorder Personal Story
- Adult Attention Deficit Disorder My Story
- Adult Attention Deficit Disorder Narrative
- Adult Attention Deficit Disorder Personal Narrative
- Adult Attention Deficit Disorder My Narrative
Only those stories were included that explicitly stated that an ADHD diagnosis had occurred during adulthood. While many of the unsolicited Internet narratives were informal, others were professionally written articles. I did not include forum discussions or posts. In all, 54 unsolicited narratives were collected from 7 websites. Due to the anonymity of the Internet, adhering to inclusion criteria was more difficult for unsolicited Internet narratives. Each Internet narrative had to be reviewed carefully to discern the personal characteristics of the author. Twenty were eliminated because they did not meet inclusion criteria, with 34 included in final analysis.

The use of unsolicited Internet narratives added diversity to the study. First, by their nature, unsolicited Internet narratives are not researcher driven (O’Brien & Clark, 2011). Instead, these narratives reflect what is important to sufferers themselves. The narratives did not adhere to a semi-structured interview guide or probes that I deemed to be important. Due to their anonymity, unsolicited Internet narratives tended to reveal things normally not discussed in face-to-face interactions (Fleitas, 1998, Rier, 2007). The unsolicited narratives often talked much more frankly about substance abuse and difficulty with relationships than did participants in face-to-face interviews.

Beyond these substantive considerations were some practical ones. Unsolicited Internet narratives were both easier and less expensive to obtain. In addition to the interview time, each face-to-face interview took an estimated 1.5 hours for scheduling, commuting, preparing, and taking field notes. Every
hour of recorded interview took an additional 3-4 hours to transcribe. The collection of unsolicited Internet narratives took only minutes to copy, paste, and import into Nvivo qualitative software analysis program (highlighted below). Furthermore, for unsolicited Internet narratives, no incentive or compensation was required.

While unsolicited Internet narratives had several benefits, they also had several downsides. As noted above, ensuring that the Internet narratives met inclusion criteria was more difficult. Data stemming from unsolicited Internet narratives was not as rich as face-to-face interviews, generating fewer codes than face-to-face interviews and being generally shorter. While potential research bias was minimized in unsolicited Internet narratives, lack of control was also an issue. There was no way to follow up for clarification or expansion on poignant topics. Instead of having the structure imposed by the researcher, many of these narratives followed patterns of Internet communicating. Specifically, many were aimed at providing advice and helping others through shared experiences.

As with face-to-face interviews, I could not verify a clinical diagnosis of ADHD. Unlike face-to-face interviews, I could not assess the severity of ADHD using screening instruments. While some explicitly mentioned age and age of diagnosis, others described their time of diagnosis in general terms. Additionally, many other demographic indicators (race, profession, geographic region) were completely absent from many of the Internet narratives.
Shadowed Data

As Morse (2001) highlights, participants in qualitative interviews often talk about the experiences of others. Morse defines shadowed data as “information that participants gives us about the types, characteristics, and dimensions of concepts, perceptions, behaviors and opinions of others” (pp. 291). While obtaining “shadowed data” was not originally a goal of the initial interview guide, it was clear that the experience of others was important early in the coding process. In face-to-face interviews and unsolicited Internet narratives, adults with ADHD would often reflect on the experience of others, both those with and without ADHD.

These reflections were essential in contrasting participants’ notions of “normal” and “sick.” As will be discussed in future chapters, comparisons to reference groups were a key mechanism that allowed adults with ADHD to perceive problems. Adults with ADHD were often amazed at what “normal” people appeared to accomplish. The experience of others with ADHD serves to validate an ADHD adult’s own experiences. This was particularly relevant to individuals whose children had been diagnosed with ADHD. The “lack of attention in others” was also commonly discussed, with individuals noting aspects of ADHD in their peers, especially other family members.

Data Analysis

All data were analyzed on an ongoing basis and represent an incremental and iterative process (Charmaz, 2006). All interviews were transcribed in their
entirety (Poland, 1995), with all narratives imported into Nvivo to facilitate analysis. Specifically, Nvivo allows researchers to manage complex data, conduct searches, generate memos, and create coding maps. Nvivo does not determine which themes to focus on or conceptual decisions (Tesch, 1990). Each document was read two to three times before initial coding at which time I noted my initial thoughts. In the case of unsolicited Internet narratives, these initial read-throughs also allowed me to eliminate those narratives that did not meet inclusion criteria.

Following initial reading of narratives, I began open coding (Glaser, 1978). As prescribed by Charmaz (2006), these codes were immediate and defined action. Coding is the process by which “data are broken down, conceptualized, and put back together in new ways. It is the central process by which theories are built from data.” (Strauss and Corbin, 1990, p. 16) As highlighted above, this process was iterative. As new codes were generated, data were constantly being reexamined, requiring me to go back to interviews that were previously coded to search for specific codes.

Once initial categories had been developed, axial coding was used to match themes to specific research questions for this dissertation. Axial coding refers to exploring how codes relate to one another and looking for how they may influence or be influenced by the phenomena in question. These axial codes represent a more abstract level of coding than the immediate categories generated by line by line coding (Strauss and Corbin, 1990). Specifically, I was
interested in discerning how people ‘knew’ they had ADHD, the consequences of
diagnosis, and how cultural factors had an impact on the experience of suffering.

Throughout this work, I present representative quotations of the categories
and themes derived from analysis. These quotations serve two purposes 1) to
further illustrate the meaning of the category and 2) to speak to the credibility of
the analytic process (Agren, 1998). By presenting quotations, readers are able to
make their own judgments about the accuracy of the analysis (Corden and
Sainsbury, 2006). As highlighted above, the inclusion of unsolicited internet
narratives and face-to-face interviews within this project allowed me to triangulate
my data, assuring that my findings were not the result of a single source of data
or my own biases (Rubin and Rubin, 1995).

Limitations

Grounded theory approaches suggest that the researcher enter the
process as a tabula rasa (Glaser and Strauss, 1967) and that a literature review
should be done following the development of pertinent codes (Charmaz, 1990;
Glaser, 1999; Glaser & Holton, 2004). However, several scholars have argued
that entering the field as a tabula rasa to be impossible (Bulmer, 1979; Henwood
& Pidgeon, 1995; Pidgeon, 1996). The framing of research questions,
development of themes, and presentation of data all reflect my own training as a
sociologist and my experience as an adult diagnosed with ADHD. Additionally, to
defend my prospectus, I had done a significant literature review on this topic,
which further shaped my views on ADHD in adulthood. Of course, the fact that
little research had explored the lives of adults with ADHD was a central rationale for this study. Nevertheless, I continued to review literature throughout my analysis and write-up, revising codes with relevant insights from existing literature. For example, I noted a sense of self-discrepancy across ADHD narratives early in the coding process. By turning to the literature, I later enhanced my own understanding of that code by including Rogers’ (1957) concept of incongruence and later Higgins’ (Higgins, 1987, 1989) self-discrepancy theory.

My own experiences with ADHD in adulthood and my training as a sociologist also both supplement and shape the interpretation of data. As Corbin and Strauss (1990) suggest, my personal experiences with ADHD provide me with theoretical sensitivity. This work represents both an "insider" and "outsider" perspective. As someone who was diagnosed with ADHD in adulthood, I found myself personally relating to many of the narratives included in this research. At the start of the interview, I would disclose my own diagnosis to participants. I believe that this assisted in both establishing rapport and improving the quality of data by allowing the interviews to take place in a "safe, nonjudgmental" environment (L. Berger, 2001). My training as a medical sociologist also allowed me to step back and view ADHD in adults from an outside perspective, allowing me to look past the taken-for-granted realities of daily life. However, throughout this study, I tried to acknowledge how these perspectives could provide me with both new insight and additional hurdles for analysis (Russell & Kelly, 2002).
In this research, I used several techniques to overcome potential sources of bias. First, I was highly engaged with the research for a substantial time. In doing this research, I was solely responsible for all the data collection. As highlighted above, I also transcribed many of the narratives, which facilitated my own immersion with the data and improved the rigor of the study (Poland, 1995). Second, I engaged in peer debriefing on several occasions through presentations and collaborative work. These sessions allowed me to further refine my analysis and rethink my work. For example, in one such debriefing session, it was clear that participants were portrayed as overly narcissistic. While this was not my intention, the debriefing highlighted this issue and was rectified in subsequent write-ups. Triangulation was also employed to increase the trustworthiness of this analysis. For example, I explored several theoretical perspectives to examine data related to the discrepant self (highlighted in Chapter 5). As noted above, qualitative data were generated from two sources, face-to-face interviews and unsolicited Internet narratives. The emergence of codes that spanned both types of data speaks to the dependability of findings.

Despite my potential biases, I attempted to remain as open as possible. I believe this openness is clear in the evolution of my own understanding of ADHD. As discussed in previous chapters, the main goal of this study was to investigate the experience of ADHD as an illness. The extent that ADHD is a real disorder caused by physiological abnormality is still up for debate. As someone who had embraced the diagnostic category, my initial goals for this project were not to
undermine the diagnostic category. I was interested in how some adults “know” they have the disorder. As my research progressed, I became much more critical of the diagnostic category, eventually abandoning my own treatment. While this research cannot definitely prove ADHD is not the result of a physical abnormality in the brain, the findings presented in this dissertation add weight to arguments that ADHD is socially constructed.

Additionally, at the start of this study, I was particularly critical of Conrad and Potter’s position that adult ADHD is the “medicalization of underachievement.” I felt this position to be problematic due to their reliance on secondary data and cultural artifacts. As this study progressed, I came to a similar conclusion, that an ADHD diagnosis is the result of perceived under-performance. At the same time, my methods allowed me to explore this concept more fully, examining why people felt they were underachieving, the consequences of diagnosis and how ADHD identity reinforces societal values.

As highlighted elsewhere, the narratives collected for this study are not representative of all adults with ADHD in the United States. Face-to-face interviews were limited geographically. Additionally, clinical diagnosis of ADHD could not be verified. In the early phases of study design, it was hoped that primary care physicians, psychologists, or psychiatrists could refer face-to-face participants to the study. This approach had several merits, most importantly a verified diagnosis of ADHD in adulthood. However, given the competing demands on physicians’ time (Jaén, Stange, & Nutting, 1994), restrictions
imposed by HIPAA (Ness, 2007), and insight from a psychiatrist familiar with recruiting ADHD patients in clinical settings (Findling, 2008), this approach was abandoned.
Chapter 4: The Discrepant Self and ADHD

In routinely defined conditions such as injury or the flu, individuals come to know something is wrong when their bodily sensations change from those they normally experience (Brown, 1995). ADHD is anything but routine. Because ADHD is thought of (by the biomedical model) as a lifelong chronic condition, individuals cannot rely on a sudden change of functioning nor feelings that would alert them to ADHD’s presence. The lack of physiological tests also makes it difficult to “know” whether an individual has ADHD. Instead of a “brain scan,” blood draw, or genetic test, ADHD is diagnosed using screening instruments and patient interviews, both which rely on self-report of symptoms. This chapter explores the sources of suffering and help-seeking behaviors in adults who have been diagnosed with ADHD.

Like other chronic conditions, “symptoms” associated with ADHD are subtle, making it difficult for individuals to recognize them (Bury, 1991). The detection of ADHD is further complicated through the considerable overlap between items on ADHD screening instruments and problems common to many in American society. For instance, many can relate to the following symptoms:

- Unable to wrap up or finish projects
- Inability to get things done in order on complicated tasks
- Forgetting appointments
- Avoiding tasks that require a lot of thought
- Being compelled to do things
Making careless mistakes on boring or difficult work

Misplacing things

Interrupting others when they are busy

(Modified Checklist from the ASRS v1.1)

Indeed, one study of ADHD in adults found that 40% of adults felt “on the go” and
23% felt “restless” (Murphy & Barkley, 1996).

As Mechanic (1980) and others have suggested (Green, Fryer, Yawn, Lanier, & Dovey, 2001; White, Williams, & Greenberg, 1961), common symptoms are often regarded as trivial and ignored by most people who experience them. Instead of being viewed as symptoms per se, these problems are viewed as part of the normal fluctuations of life and are ignored. Consequently, most people who feel “on the go” or “restless” do not seek medical attention. The majority of adults meeting clinical criteria for ADHD ignore their symptoms and remain undiagnosed or untreated (Barkley, Cook, & Diamond, 2002; Kessler et al., 2006). At the same time, most adult diagnoses of ADHD are through been self-referral by adults who have actively sought their diagnosis (Conrad & Potter, 2000). ADHD in adults stands in stark contrast to ADHD in children who are often initially identified by adults in positions of authority, usually by schoolteachers, guidance counselors, or parents (Conrad, 1976).

Given the lack of clear physiological indicators for ADHD along with the overlap of ADHD symptoms with common problems, how do some adults "know" they have ADHD? Answering this question is essential in understanding both
help seeking behavior and the acceptance of diagnostic categories for adults who have been diagnosed with ADHD.

Medical sociologists and anthropologists have provided some insight into this process. For example, help-seeking behavior is, in part, determined by the extent that individuals interpret some problems as separate (Charmaz, 1991) and so far beyond the scope of normal that they require medical intervention (Karp, 1996). The interpretations of problems rely on experience, general knowledge, and the experience of others (Mechanic, 1980). Because ADHD lacks a clear biological mechanism, interpretations of problems draw on the subjective understandings of social cues.

As Kleinman (1988) has suggested, clinicians must interpret the subjective experiences of patients and apply medically recognized categories to explain them. However, subjective experiences also influence the degree to which a diagnosis is accepted by the patient. Haug and Lavin (Haug & Lavin, 1983; Haug & B. Lavin, 1981) argue that patients have taken a consumerist stance where they actively make health decisions. When a diagnosis fits with experience or knowledge, it is often accepted. This was clear in several of the narratives. As Mary (female student, age 20) stated, “They start telling you ‘You have a little bit of an attention problem’; I thought that that fits. That fits my experience and what I’ve been experiencing I guess all since I ever started school, so…” However, when diagnosis or treatments do not match the patients’ experience or desired outcome, they may seek a second opinion. When I asked Joseph (male student,
age 21), who actively sought an ADHD diagnosis, what he would have done if he was not diagnosed with ADHD, he said he wouldn't have believed the physician and would have sought a second opinion. The majority of adults with ADHD included in this study actively sought an ADHD diagnosis, with a small number of them visiting several clinicians until the desired outcome was achieved. Seeking multiple opinions until receiving the desired outcome was more common in Internet narratives.

What experiences drove Mary to seek help in the first place? Why do some adults like Joseph actively seek an ADHD diagnosis? How do some adults “know” they have ADHD, often before being labeled by medical experts? As stated elsewhere in this dissertation, I have come to view those problems associated with ADHD as stemming largely from social factors rather than biological abnormalities.

**Self-Discrepancy and ADHD**

The adults in this study experienced a variety of discrete symptoms they related to ADHD. Many of these symptoms were similar to those items included in the ASRS screening instrument. While many ADHD narratives discussed having difficulty with boring tasks, staying organized, and getting things done, no single symptom or set of symptoms was a clear indication that something was “wrong.”

Instead, a sense of wrongness stemmed from an ADHD adult’s view of the self. As Moses (IN) stated in his narrative:
Somehow I knew that there was something different about how I was. I knew that I was intelligent but my scholastic achievements were not showing it. I know that I am intelligent, athletic, and handsome but I have nothing to show for it. Sometimes I just feel hopeless. So I know that something isn’t right. I don’t want to feel sorry for myself and mope around because I know that people just don’t get as lucky as me. I just want to get the problem fixed and move on. — Moses (IN)

As the quote above suggests, Moses comes to know that there is a problem based on an assessment of his own current reality against his expectations of what his life should be. Based on his self-appraisal, Moses believes his life should be better than it is. The disconnection between how life is and how it ought to be was apparent across all ADHD narratives. It was both the major source of suffering and central in indicating that there was a something “wrong.”

This finding (a perceived disconnection between actual self and potential self) emerged early in the data analytic process and bears similarity to several concepts in the scientific literature. For example, Carl Rogers (1957) used the term “incongruence” to describe a perceived gap between an ideal self and real self. Rogers defined the “ideal self” as the self one thinks one should be. The “real self” is defined as what one currently is or is realistically capable of becoming. To Rogers, the “ideal self” was always out of reach. In Rogers’ formulation, incongruence results in psychopathology. Similarly, Thoits (1985) describes how norm-state discrepancy or a gap between an individual’s understandings of normative expectations and his/her perception of current reality facilitates the self-labeling process for emotional problems. Like Rogers, Thoits believes that the normative expectations for feelings are often unattainable for a variety of reasons. Building on the work of Rogers and several others,
Higgins’ (1987, 1989) “self-discrepancy theory” highlights how perceptions of the self can be problematic for individuals. Higgins’ theory postulates that the quality of distress in individuals is based on the type of discrepancy they experience. In stating that adult ADHD is the medicalization of underachievement, Conrad and Potter (2000) also touch on this notion of a discrepant self. Lastly, and ironically, the authors of the ASRS v1.1 state that ADHD as a problem of not living up to potential, suggesting that:

Because this disorder is often misunderstood, many people who have it do not receive appropriate treatment and, as a result, may never reach their full potential. Part of the problem is that it can be difficult to diagnose, particularly in adults (Adler, Kessler, & Spencer, 2004, p. 3).

While there is considerable overlap in each of the concepts highlighted above, perhaps the most beneficial in understanding ADHD in adults is the self-discrepancy theory as formulated by Higgins, largely due to its predictive value. As stated above, Higgins’ theory postulates that the type of distress experienced by individuals is contingent upon the type of disconnection they experience.

Higgins defines three domains of self, the actual self, the ideal self, and the ought self. The definition of each is provided below:

The actual self is the “representation of the attributes that someone (yourself or another) believes you actually possess”
The ideal self is the “self that is your representation of the attributes that someone (yourself and another) would like you ideally to possess.
The ought self is the “representations of the attributes that someone (yourself or another) believes you should or ought to possess” (Higgins, 1987, pp. 320-321)

In addition to three domains of self, Higgins defines two standpoints of the self, the actor’s “own” standpoint and the standpoint of a significant “other.” Lastly,
combinations of domains of self with standpoints of self yield six types of self-representations. Self-concept is made up of actual/own (and to a lesser degree other/own). The remaining four combinations make up self-guides (ought/own, ideal/own, ideal/other, ought/other). Higgins speculates that individuals vary as to which self-guide they adhere to and that discrepancies between self-concept and self-guides will influence the types of discomfort experienced by individuals.

As highlighted in Moses’ quote above, Moses believes something is wrong based on his own appraisals of where he is (actual/own) versus what he believes he should be able to accomplish based on his own attributes (ought/own). In Higgins’ theory, this type of self discrepancy (actual/own versus ought/own) is associated with agitation from self-criticism, feeling guilty, feeling irritated all the time, feeling no interest in things, and feeling that everything is an effort. These types of feelings are commonly reported by adults with ADHD, both in this study and the literature generally (Gadow & Weiss, 2001; Hallowell & Ratey, 1995; M. D. Weiss & Weiss, 2004).

This specific type of self-discrepancy (actual/own versus ought/own) was common across nearly all the ADHD narratives. For example, the discrepancy between actual/own and ought/own was clear in the following quote from Chester (male consultant, age 68).

I think it’s sort of like the way I look at my life. Before I got diagnosed is I managed to accomplish a lot of stuff that other people might feel you know just fine about. I don’t think I felt like I was living up to my own potential…So no, most people looking on would say ‘Gee, that’s pretty decent,’ and but it doesn’t matter. None of it matters. It’s all what you feel inside…There’s nothing more challenging than having a high potential, you know like learning
Like Moses, Chester feels like his life should be better than it is. However, Chester’s life could be considered good by many measures. He lives in a large suburban home, has a comfortable income, completed his doctorate, and runs a successful business. Despite these apparent successes, Chester experiences a high degree of self-discrepancy. As is clear in the quote, Chester’s assessments of the self are based on his own views rather than those of others. Because he views himself as having a high potential, he believes he is obligated to live up to it, to use it to his “best advantage.” As with Moses, it is not the experience of symptoms that leads Chester to seek answers. Instead, Chester’s belief that he should be doing better (coupled with ADHD knowledge) leads him to seek and accept an ADHD diagnosis in adulthood.

Most participants in face-to-face interviews were individuals who had achieved some degree of success. Most had at least a college degree, with many seeking or having already obtained advanced degrees. When probed on grades, most reported getting good grades in school; one respondent was a high school valedictorian. It was also common for adults with ADHD to note how they were particularly good in subjects that interested them. Additionally, adults with ADHD were often identified by authority figures (e.g., teachers or bosses) as exceptional.

For example, when she was in college, Maureen (female teacher, age 36) was having particular difficulty with course work in one of her classes. She noted
how hard she had to work on assignments and how she had difficulties with the material. When she talked to her instructor about dropping the course due to these troubles, he identified her as his “best student” and encouraged her to continue. Despite her instructor’s advice, she dropped the course. To Maureen, she never should have had the problems she did. Likewise, Maureen also talked about difficulty writing papers in college, noting she often gave her papers to others for editing. At the same time, she was employed as a writing tutor at her university. For Maureen, these indicators of success or ability were inconsequential. She always held the belief that she ought to be doing better, that things should be easier for her.

Across the narratives, adults with ADHD experienced a high degree of self-discrepancy between their actual self and the self they thought they ought to be. As I highlight below, these adults with ADHD developed a sense of self-discrepancy through a patterned set of social cues. Specifically, self-discrepancy was shaped by high perceived potential and comparisons to reference groups.

High Perceived Potential and the Ought Self

As was clear in Chester’s and Moses’ stories above, perceived potential played a significant role in establishing what the self should be capable of. They both believe they have the potential to do better. In the coding process, I coded “potential” as the belief that some attribute of the self should lead to success. Nearly all the adults with ADHD included in this study believed they had the potential to do better. While indicators of potential included good looks or ability
(as with Moses’ story), the most important indicator of potential across narratives was intelligence. This should not be surprising given the central role intelligence plays in modern society and the view that it is predictive of both current ability and future success. Nearly every ADHD adult talked explicitly about his or her high intelligence.

Assessments of self increasingly rely on numbers, with several scholars describing the quantification of the self (Robbins, 2012; Wolf, 2010). It should not be surprising that many assessments of intelligence among the adults studied relied on standardized test scores. Below are some examples of how adults with ADHD utilized standardized test scores:

In the first grade I was testing beyond what is college level yet bored with everything. Throughout my years I found it difficult to concentrate and it was addled by parents who for the sake of saying, lets say they could not deal. -- Liz (IN)

And I looked at my test scores and like it’s interesting, I didn’t know then, except I fought my way through college. I graduated from college in my 30s, late 30s and these statistics said that…I think teachers, I heard all my life ‘You can do better than this. You’re capable of much better.’ I never knew what that meant until I saw these scores and what they meant, and you know I mean it’s not like it’s super genius stuff, but it’s like 130. — Stan, (unemployed male, age 56)

Both my sister and I were IQ tested at young age. I had no idea of this until near the middle of high school when my father told me about it, saying that we had both tested out at genius level. Even with these remarkable results, our grades were poor and we brought home report cards with comments about not living up to our potential or not focusing enough in class. Both of us read at a level well beyond our school placement; indeed I was reading and comprehending at a grade twelve level in grade six. Two obviously bright children, so what happened to the results? ADD. Pure and simple. — Brian (IN)
Adults with ADHD considered standardized test scores as objective assessments of intelligence and potential, whose legitimacy was established by science. Based on their understanding of these tests, adults with ADHD believed they should have done better in the past, particularly with grades. This belief was clear in Wayne (male teacher, age 61):

So there’s this gap, you know, and that’s what led her to think ‘Well maybe it’s ADD.’ And the other thing was my, I don’t know what they call it, aptitude or whatever. I had this real high line that I was supposed to be achieving in school and I was way below. I scored high on the aptitude tests all the time, but my grades were never anywhere near what I should’ve scored. — Wayne (male teacher, age 61)

In our talk, Wayne did not make it clear what his grades and aptitude test scores actually were. Regardless of the scores, his perception of these two factors is what matters. Based on what he perceived his aptitude scores to be, he feels he should have done better in school. In other words, for Wayne and other adults with ADHD, IQ and aptitude scores help to establish the ought self. When they compare their low grades (or other indicators) to what they think tests told them they should be able to do, they see the actual self coming up short. Self-discrepancy is the result of such comparisons.

While low grades could be used to ascertain the actual self and indicated that one should have been able to do better, high grades were indicators of high intelligence and potential. For example, Stephen (male student, age 21) used graduating as valedictorian as indicative of his high level of intelligence. In the quote below, Mary (female student, age 20) believes that her past grades show her current potential, what she ought to be capable of achieving in college.
Like all through high school I had a 4.0 grade point average and my grades just started dropping off a little bit and I thought "This coursework isn’t any more difficult, but I’m having trouble with it.” So I went to the Counseling Services and asked them you know… — Mary (female student, age 20)

Considering their past high grades in school, Stephen and Mary believe that they should be able to do well in college. When Stephen and Mary do worse than they expected based on their perceived potential, it becomes clear that something is wrong with them and they seek help.

Perceptions of high potential were also reinforced through interactions with others. Many respondents discussed being labeled by teachers and others as “not living up to potential,” “not applying themselves,” or “underachieving.” Like Stan, Ken (male lawyer, age 32) described his teacher’s views of him this way: “‘Well he’s really smart and gifted, but you know he doesn’t apply himself,’ or whatever or something to that effect, ‘doesn’t apply himself.’” Rather than viewing these statements as forms of encouragement used by many teachers to entice all students to work harder and accomplish more, adults with ADHD viewed such statements as assessments of potential, further inflating the ought self.

While great weight was often put on “objective” indicators of intelligence, some adults with ADHD relied on their own assessment of intelligence. For example, Kendra (unemployed female, age 35) assessed her own intelligence this way:

Oh I’ve always been smart, and then my good friends would be like ‘She’s always been that smart. She’s probably not looked that consistent, but she’s always been that smart,’ you know and I’ve missed out on a career in the way
that I should’ve, which is unfortunate for me, so... — Kendra (unemployed female, age 35)

As with “objective” indicators of intelligence, these self-assessments indicated to adults with ADHD that they should be able to achieve more and do so with greater ease. Regardless of the source, the perception of a high intelligence was viewed as some way predictive of the amount of success a person should have. When their perceived success (actual) did not match up with their perceived intelligence (ought), adults with ADHD knew something was wrong.

As suggested above, when information regarding potential was positive, it was generally accepted and served to inflate the ought self. However, when information could indicate lower potential, it was (a) indicative of a problem (undiagnosed ADHD) or (b) due to other factors beyond the control of individuals.

In other words, adults with ADHD often employed the self-serving bias to maintain the ought self when notions of the self were threatened (Campbell & Sedikides, 1999). This phenomenon is clear in the two quotes below.

I was diagnosed a year and a half ago with ADD. I was 22 years old. I am now 24. I never had it easy in elementary school or high school I new I had a problem but I was put with more of a disability. I was known to be one of the people that belong in a category. They just said I had a learning disability. I was never given much of a chance. I was to learn at the same level as the other students even though I new I was way much smarter then that. — Denelle (IN)

I was a special ed student all of my life and never did well in school. I an an IQ that would be concerened border line of rearted. But i kow i am not. — Mary (IN)

Denelle (IN) and Mary (IN) dismiss information that may indicate their potential is lower than they thought. They “know” they are smart and capable of more.
Denelle believes she is unfairly labeled as having a learning disability despite her intelligence. In Mary’s case, she later goes on to question the validity of the IQ test, speculating that the low score is because she is a “visual person.”

As this section has shown, adults with ADHD viewed themselves as having high potential. Based on their perceived potential, in particular their intelligence, adults with ADHD believed they should be doing better in life regardless of their current levels of success. Because they were not living up to their perceived potential or their ought self, adults with ADHD knew something was wrong with them. When information regarding potential was positive, it was generally accepted and served to further inflate what the self ought to be able to do. When information was negative and could indicate lower potential, adults with ADHD engaged in self-serving bias, or the willingness to attribute positive indicators to internal disposition and negative outcomes to external factors (ultimately ADHD), especially when these indicators threatened the self (Campbell & Sedikides, 1999).

**Reference Groups and Self-Discrepancy**

As sociologists have noted for some time, reference groups play a pivotal role in defining both achievement and success of individuals. Kemper (1968) defines reference groups as:

...a group, collectivity, or person which the actor takes into account in some manner in the course of selecting a behavior from among a set of alternatives, or in making a judgment about a problematic issue. A reference group helps to orient the actor in a certain course whether of action or attitude (Kemper, 1968, p. 32).
Comparisons to reference groups played a central role in adults with ADHD recognizing that there was a problem. As I will show throughout this section, comparisons to reference groups served to exacerbate self-discrepancy by lowering self-concept and set the standard of what the ought self should be able to accomplish. This section also highlights how perceptions of reference groups are often inaccurate.

Comparisons to reference group members were common across ADHD narratives. What was striking about many of these comparisons was that adults with ADHD often reported outcomes similar to their reference groups for grades or other indicators of achievement. However, instead of focusing on the similarity of their own outcomes to those of the reference group, adults with ADHD felt they had to work harder for the same result. For example, Stephen (male student, age 21) reported doing well in both college and high school, maintaining a high GPA. Despite reporting outcomes similar to his peers, Stephen perceives other college students as completing tasks with relative ease. To achieve at a high level, Stephen describes his efforts as “Herculean,” a term he used throughout our interview to describe his efforts in comparison to others. Cathy (female lawyer, age 30) made a similar comparison when I asked how she knew she had ADHD:

I think when you know that there’s something wrong with you like that, and then also you know you see if everyone is doing the same task and let’s say I get an A on the project and my friend gets an A, right? It took her less work to get that A, whereas you know I was tearing my hair out and you know there’s juice everywhere. Do you see what I’m saying? — (Cathy, female lawyer, age 30)
For Stephen, Cathy, and other adults diagnosed with ADHD, it was not the appearance of success, nor the outcome, but rather the processes they had to go through to achieve at a high level. As Cathy’s story indicates, she still got an A. However, her friend appears to have had an easier time getting the A. Because she has to work harder than her friend, Cathy "knows" something is wrong. Likewise, Stephen has to put in extra effort for the same outcomes as peers, suggesting something is wrong with him. Such comparisons were common across narratives.

As Cathy’s quote above suggests, it was very rare for adults to make downward comparisons or to look to others who were not doing as well. For example, Cathy does not compare herself to students who got Bs, Cs, Ds, or even Fs. Although such downward comparisons often improve self-concept (Wills, 1981) and could serve to lower the self-discrepancy experienced by adults with ADHD, it was rare for adults with ADHD to make such comparisons, instead focusing on reference groups.

Although comparisons to a reference group consisting of classmates were most common, they were not limited to school situations. Comparisons could relate to ability to sit through meetings, communicating with others, and getting specific job- or home-related tasks done. Examples are quoted below:

I mean like my behavior was not like most people, you know, you can look around you can see you are an hour and half in some meeting and everybody is just calm and relaxed, and I’m sitting here like, “Oh my gosh. Are you people serious!” — William (unemployed male, age 37)

I always felt like my classmates knew something I didn't. I'd see people who were two and three years older than me and think they looked so much more
mature and confident than I felt. It never happened to me though. I always thought when I reached the older age, I would feel the same way. I didn’t. I still felt small and insecure. — Kim (IN)

Comparisons to a reference group highlights some of the difficulties in human interaction. This difficulty was clear in both William’s and Kim’s quotations. As Goffman (2004) has highlighted, social actors engage in a process of impression management where they attempt to influence others’ perceptions of the self, usually in positive ways. In these interactions, actors present an idealized version of the situation, often through the use of deception. What remains hidden to others is the actual processes people go through to present that idealized version of the self. Goffman described the idealized presentations as the “front stage” and the hidden preparation the “backstage.”

As members of the audience, adults with ADHD examine the front stage of others and compare these idealized presentations with their own messy back stage processes. The degree to which an individual’s thoughts are apparent to others is unclear. Similarly, the degree to which others can guess one’s feelings is also unclear. William does not know for sure whether everyone is calm or finds value in the meetings he struggles to sit through. Instead, he relies on social cues that suggest they are calm and relaxed or that they feel the meeting has value. Like William, Kim compares the external presentation of others to what she feels inside. However, it is likely that both are putting on successful fronts, and others would not be aware of the inner turmoil William and Kim are experiencing.
The problem with comparing front stage presentations to backstage processes was very clear in my interview with Victor (service professional, age 29). When Victor and I were talking about the ease with which others appeared to accomplish tasks, he relayed the following:

**Victor:** You know I think about other people that don’t have it and I wonder ‘Are these people able to get everything done that they want to do?’ and it’s then that I feel like I have this obstacle or this disorder that doesn’t allow me to get everything done that I want to do…

**Interviewer:** Do you think other people tend to get the things done that they want that don’t have ADD?

**Victor:** I think they do. I have no way of knowing really. It’s just something I think about to myself. — Victor (service professional, age 29)

While Victor believes others are able to accomplish everything they want, he also acknowledges that he has no way of really knowing. What he does know is that he has difficulty completing everything he wants. Similarly, Juliet (IN) relayed the following:

As an adult, I ambled along and felt like a fraud. I was considered mysterious by everyone who knew me because I’d reveal nothing about myself, nothing that could incur judgement at least. I was hiding all the problems I was having: losing shoes and other important items, all the forgetting and the ability to be even remotely organized. I was terrified someone would find out and then I’d be exposed. I didn't have opinions on things or really any hobbies; all my energy was spent trying to figure out my environment. After diagnosis I felt relieved but also felt there was nothing wrong with me and still feel that way now. — Juliet (IN)

While Juliet describes how she is actively engaged in impression management, hiding her problems from others, she takes others’ presentation self at face value.
In explaining his heroic efforts to accomplish tasks, Stephen noted that other students talked about how easy an assignment was. Stephen took these boasts at face value, never questioning their truthfulness. It is also very likely that other students who had difficulty with assignments said nothing or also presented idealized versions. Taking these idealized performance as reality, Stephen then looked at his own difficulties, noting that he had taken significantly longer than others to accomplish the same tasks. Indeed, when he began treatment, Stephen was told by his psychiatrist that he needed to realize that everyone had difficulties in getting things done. Even if Stephen accepts this fact, the back stage of other actors will remain illusive, resulting in problematic comparisons that lower self-concept while maintaining understandings of what the self should be capable of.

Help Seeking

As highlighted above, help-seeking behavior is in part influenced by individuals experiencing problems so great that they require medical attention. While adults with ADHD acknowledged that their problems were common, they believed they never should have encountered the problems they found themselves facing. Sandy (female schoolteacher, age 52) put it this way:

And you know, now I know we are all different, we all learn at different paces and it has made me a better teacher. But going through it as a child and not having any diagnosis that was what was wrong. That's why again, I think it has made me a better teacher due to the fact I look at the kids and I say, you know we're all different, let's learn how we can function, how we can figure out what is the best the way you are learning, so I have learned to cope with it. — Sandy (female schoolteacher, age 52)
Sandy acknowledges that everyone learns differently and that as a teacher she must adjust her style to meet the needs of her students. At the same time, her difficulties in school are a clear indication that something is wrong with her. Similarly, Maureen (female teacher, age 36) did not believe that students who came for writing tutoring had a mental disorder. However, her need to have papers edited by someone is used as evidence that something is medically wrong with her.

Although self-discrepancy is the main problem that leads to an ADHD diagnosis, at what point do adults seek help for this problem? This section highlights how self-discrepancy can lead ADHD adults to seek help for their problems.

As with other mental health conditions (Karp, 1996) and chronic conditions (Charmaz, 1991), crisis played a particularly powerful role in influencing adults to seek help. Many adults with ADHD described a precise time when a personal crisis led them to seek medical help. For example, Anthony (male lawyer, age 56) described the following:

Work-related stuff. I was practicing in a firm in Cleveland and I was on the road a lot and I would come in real early in the morning so that I could get home at a reasonable hour in the afternoon, and so I went in. I’d been out of the office for about a week and came in about 6:30 in the morning. I was in the office by 6:30 there that morning and my desk was just stacked with stuff and I melted down right there on the spot. I just could not cope anymore, and I remember sitting at my desk and just staring at it ‘til 8:00 when I knew my Family Physician’s office was going to be open and I called him up and I said, ‘You’ve got to get…’ I told him, ‘You’ve got to get me to talk to somebody right away.’ I said ‘I’ve got to talk to somebody to figure out what the hell is going on.’ I’ve always been, I’ve always felt or looked at myself as the go-to
guy, and <wife> will tell you, she gets mad at me sometimes because I will do anything for anyone. — Anthony (male lawyer, age 56)

Anthony’s high work load pushes him to the crisis point, getting him to seek help.

In many cases, crisis followed an identity transition, usually to a more demanding role. For example, many of the college students interviewed for this project noticed something was really wrong with them in college. While they had acknowledged some problems related to self-discrepancy in the past, it was not until college that these problems became so great that they sought medical help. Maureen really noticed problems when she transitioned to a new, more demanding position (female teacher, age 36). Similarly, during Rachel’s (female retiree, age 61) retirement, she began taking on new tasks at home. In her new role, she found the tasks so difficult that she eventually sought help. Rachel had not noticed her problems so acutely in previous roles. Inability to live up to the expectations of a new role further exacerbated self-discrepancy.

In addition, role transitions often changed the reference groups of individuals. For example, Stephen (male student, age 21) did not really notice his problems in high school where he was valedictorian. However, at his selective university, his peers appeared to achieve things with greater ease. The change in reference created a high degree of self-discrepancy for Stephen.

In many cases, the ought self led some individuals to experience crisis. Based on their idealized versions of self, many individuals took on tasks that were difficult, or they ignored evidence that they may not be well suited to the tasks at hand. For example, Cathy (female lawyer, age 30) had failed her bar
exam several times. Rather than believing her difficulties may indicate she
should choose another path in life, Cathy continues to work toward her goal of
becoming a lawyer. Because she believes she should be able to pass the bar
exam, Cathy seeks other answers, eventually learning about ADHD through an
online support group for the bar exam. Similarly, Marie (IN) described the
following:

Let me take you back a little bit and describe my academic experience. I am
very creative, and majored in art. In any given class I would have 5 or so
projects going on at the same time, then when finals came around I either
didn't finish them (because I got bored and moved on) or, did such a sloppy
finish that my potential couldn't be seen. My professors (most of them in the
department) were VERY frustrated with me. Some of them lost their temper
with me, some just threw in the towel. At one point during those seven years it
was suggested that I change my major completely, but I refused. Keep in
mind that no one knew what ADD was in '93'94 etc... I knew that something
was up with me; whereas, I knew that I was as smart as my peers but I was
different, I couldn't put a finger on it. — Marie (IN)

Rather than viewing her professors’ suggestions and ongoing difficulties as an
indication that art was not the best subject for her, Marie continued to work
toward her goals based on the belief that she had the potential to do well in that
subject. She felt she had the potential to succeed in art. Following school, Marie
continued to have problems and eventually followed a different career path.

Ultimately, crises and self-discrepancy were closely linked. In some
cases, crisis exacerbated self discrepancy, increasing suffering. In other cases,
self-discrepancy itself was the source of crisis. Higgins (1989) and others
(Mossakowski, 2011; Rogers, 1957; Wheaton, 1999) have suggested that high
levels of self-discrepancy can lead to increased distress and suffering. As other
studies have shown, those experiencing high levels of distress are significantly
more likely to seek medical help, with distress scores one of the most important predictors of help-seeking behaviors (Goldberg & Huxley, 1980; Mechanic, 1995; Mechanic & Greenley, 1976). Similarly, Burke (1991) suggests that those experiencing high levels of self-discrepancy are also motivated to remediate discrepancy. Once they decide to get help, ADHD adults do so in two ways. First, there are those who actively seek an ADHD diagnosis. Second, there are those who seek clinical help for other problems and are eventually diagnosed with ADHD.

**Seeking an ADHD diagnosis.** In this study, those adults with ADHD who actively sought an ADHD diagnosis usually did so following a crisis period or as a means to explain ongoing distress. Clearly, those who actively sought an ADHD diagnosis were those who had prior ADHD knowledge, usually applying the diagnostic category to the self prior to an “official” diagnosis.

While several scholars have suggested that ADHD diagnosis is in part influenced by direct-to-consumer advertising and media attention (Conrad & Leiter, 2004; Conrad & Potter, 2000; Strawn, 2003), I found the diagnosis of a peer or close family member to be a key source of ADHD knowledge. Nine of the 19 face-to-face interviews reported a close family member was diagnosed with the disorder, most commonly a son. Due to the dominance of the biomedical model and its emphasis on the heredity of ADHD, a child being diagnosed with ADHD played a particularly powerful role in help-seeking behavior. For example, Trudy’s (IN) five children were “all diagnosed right brained and ADD to different
degrees.” Following the diagnosis of her children, Trudy began to understand her problems as resulting from ADHD and sought help. Like Trudy, Darlene was diagnosed at the same time as her grandson.

Well, we got diagnosed at the same time. Put on meds. Ritalin cocktails in the AM. It was like WHOA! SO THIS IS WHAT IT'S LIKE TO BE NORMAL!!! WHO KNEW??? My grandson stopped having detention and daily principal appointments and actually learned how to read, never mind that it was in 3rd grade. I got myself a bona fide college degree. I would have felt guilty about waiting so long seeing about treatment, but memory is only as good as recall which i still struggled with. Eventually the ritalin made me sleep more hours than I was awake and I got switched to Adderol. That lasted a year. — Darlene (IN)

As Mechanic (1972) has argued, comparisons between others who have become sick or disabled and who are like ourselves increases the likelihood of perceiving risk.

Adults with ADHD who had a child diagnosed with ADHD now gained new insight into their past. Many of the inexplicable difficulties they met with throughout their lives were now quite clear. What was shrugged off in the past and viewed as difficulties common to life were now reframed as problems caused by undiagnosed ADHD. For example, following the diagnosis of their sons, Anthony (male lawyer, age 56) and Chester (male consultant, age 68) described the following:

I don’t know. I suppose it depends on what you mean by “notice it.” I mean I realized that, I remember especially in high school and stuff you know working on big projects and whatnot that I would be distracted at times, but I never really understood what was going on until my son was diagnosed really and then things that I had noticed before started to make sense. — Anthony (male lawyer, age 56)

So it was one of those things where, and I knew so much by then having had to learn about it for <my son> that I was able to rattle off why I thought I had it
and did he think I have it, and ‘Yes. That certainly sounds about right, and I have it too, so I know what you’re talking about from the inside as well because I’m a professional in this field,’ and it’s so long ago I can’t even for sure tell you. I’m sure I must’ve done some kind of inventory with him, but it was just, it just was, there was never much question. I mean it was really it just made too many things of a lifetime make sense.--Chester (male consultant, age 68)

In some cases, following the diagnosis of a child, adults with ADHD “tried” their children’s medication (discussed in Chapter 5), reinforcing the idea that they might have ADHD.

While comparisons to children were important, adults with ADHD also referred to other members of their social circles. In writing up an individualized education plan (IEP) for a child with ADHD, Maureen (female teacher, age 36) reflected on her own troubles, noting the similarities she had with this child who had recently been diagnosed with ADHD.

The day I was writing an IEP…and the parents for the boy said he needs an accommodation, you know they were like my son misspells words all the time, so you know I was like, I misspell words all the time and I was like I don’t need an IEP.-- Maureen (female teacher, age 36)

Through this new knowledge, she was able to see similarities between others diagnosed with ADHD and her own experiences. Such comparisons were significant in validating experience, influencing help-seeking behavior, and accepting an ADHD diagnosis in adulthood. In other words, comparisons to others with ADHD allowed adults with ADHD to understand and frame their problems in medical terms.

While the diagnosis of a family member or personal contact was particularly important for framing problems, media and popular literature on
ADHD were also influential in helping adults frame their problems and seek help.

Those who read information on adult ADHD often talked about how it perfectly described their own experiences or how narratives of other adults with ADHD resonated with their own. For example:

In 1996 I was yet in another relationship, coincidentally she had ADD, She was nice enough to explain to me and then she mentioned a book. Well, I being the crazed learner, “if stimulated”, I went straight to the library, Got the book “Driven to Distraction” and went through it like a hot knife through butter. My self-talk kept telling me, wow; this is I, with the various short stories in the book of how people are with ADD. — Peter (IN)

Oh my goodness. I read this book and felt as if someone was in my house watching my every move. It was really spooky. I went back to see her again, to talk about the book and my findings. Her conclusion... I have attention deficit hyperactivity disorder — Kim (IN)

Well, I am a 34 year old man, currently single after a Seven year relationship with someone who didn't wish to believe I had ADD, I self diagnosed myself originally when I was 32 years old...with the help of several books on ADD (Driven to Distraction, and You Mean I'm Not Lazy, Crazy or Stupid), later on I got a therapist to diagnose me legitimately (like any of us really need to tell us once we suspect). — Blair (IN)

As Peter's and Blair's quotes indicate, sometimes these stories were used in conjunction with the diagnosis of another person.

As the above quotes suggest, adults with ADHD were often quite certain of their own status before an official diagnosis. Most adults who actively sought a diagnosis were quickly able to get them. For example, after he read *Driven to Distraction* (Hallowell & Ratey, 1995), Peter took the following steps:

I started calling around and found a Therapist who would test me for ADD, that was in 1996. I went through some extensive testing, and what he found was I have various symptoms of ADD, leaning towards inattentive type. He told me I would do well with therapy and medication. He recommended a doctor who I was anxious to see. So I started to see this doctor and was prescribed Ritalin. — Peter (IN)
Nearly all the participants in face-to-face interviews who actively sought an ADHD diagnosis were able to get the diagnosis without having to seek an additional opinion. For example, William (unemployed male, age 37) took an ADHD screening test on the Internet following initial suspicions regarding ADHD. He is able to get a diagnosis on his first visit to his physician. As with others, William already “knew” he had ADHD and was not shocked by the diagnosis, relaying the following, “Pretty much, I pretty much knew, OK, it wasn’t that big of a shock.”

While most adults had little problem receiving a diagnosis after their first visit, it was not entirely uncommon for adults with ADHD to seek several opinions, pushing for their diagnosis. For example, Birdie (IN) relayed the following:

> Read some literature on ADD, and remember thinking of how it described my life. I was seeing this female Psychologist at the time, and mentioned my suspicions to her, only to be blown off as if to say "what makes you think you are smarter than me, or can diagnose yourself". Once again I went away from her office feeling hopeless. Then in 1996, the bottom was starting to fall out. I was about to lose my job, I didn't have a social life to speak of, my life was a mess. In desperation, I sought the help of yet another Psychologist, one that I picked from a group out of the Yellow Pages. I sat in this caring man's office for a whole month, never telling him of my suspicions, going over my whole life, from school to the present time. After the fourth visit, he asked me to do some homework. He asked me to read the book "Driven To Distraction" and come back the next week and tell him what I thought. I can remember reading, and crying at the same time. My name was written at the top of every page. It was all so clear, I had ADD. — Birdie (IN)

As Birdie’s quote suggests, she not only pushes for a diagnosis, but leaves her clinician because the clinician won’t diagnose her. As highlighted in Chapter 1,
Joseph (male student, age 21) described how he would have sought a second opinion if his family physician did not diagnose him with ADHD.

Many adults with ADHD described being “tested” for ADHD during their visit with the physician. While the exact nature of tests was unclear in many of the narratives, several adults with ADHD described screening instruments similar to the ASRS v1.1. Others described simply telling their physicians about their suspicions regarding ADHD and receiving a diagnosis. For example, once she seeks a diagnosis, Maureen’s (female teacher, age 36) family physician quickly gives her one:

So then I told the story to my doctor, and she has been my doctor now for…um…12, 11 years. “Now that I think about it,” she is like, “you fit every single characteristic for ADHD.” — Maureen (female teacher, age 36)

As this interaction suggests, Maureen’s physician never suspects ADHD until Maureen pushes for the diagnosis. She ends up receiving the diagnosis with no screening tests.

**General help seeking.** Not everyone diagnosed with ADHD specifically sought that diagnosis. Several respondents engaged in help-seeking behavior due to ongoing struggles in daily life and a significant amount of distress. For example, Missy (female research assistant, age 29) and Wayne (male teacher, age 61) were both diagnosed through previous engagement with mental health specialists. As Missy described:

I was officially diagnosed when I was 26; actually I was seeing a therapist because I was having marital, umhum, actually was seeing a therapist on and off for depression issues. I was seeing a therapist. I mentioned that my dad made this off the cuff comment to me about being ADD, and everyone in my generation is ADD. I made that comment to her, well actually you know, I just
recently started seeing her, and she pulled out a questionnaire and you rate high on the recklessness stuff and some of the questions that are on the longer questionnaire were the ones you just asked me. That might mean, you have ADD, she gave me this...she recommended this book, I wish I could remember what it is called off the top of my head, but I can't, and it talks about having ADD and depression, and a lot of people that have ADD and depression think they are bipolar which I did, because I think my mom is. I didn't have so much of the highs and lows, but that probably makes sense to you, that someone would say that, that having ADD and being depressed would look on the surface like being bipolar, so I read the book; yes, this is me...exactly. —Missy (female research assistant, age 29)

Wayne described a similar experience. Through his engagement with a marriage counselor, he initially receives a depression diagnosis. After his first clinician gets another position, he is diagnosed with ADHD by another psychiatrist. As with Missy and those who actively sought the diagnosis, once the ADHD label is applied to self, it matches Wayne’s experiences to a high degree. As he explained,

That, it made so much sense, and even just when I was describing how I performed in school, for the subjects that I liked, I was all As and Bs. By college my Masters... or Masters, majors, I got all As, but the required courses mostly Ds. So there’s this gap, you know, and that’s what led her to think “Well, maybe it’s ADD.” — Wayne (male teacher, age 61)

Usually, those seeking help for general distress received more thorough psychological testing than those who actively sought a diagnosis. For example, Kendra (unemployed female, age 35) was facing ongoing problems with her life while at college:

Well, I’d had trouble finding and keeping jobs in college, and my doctor recommended, “Just go, get it checked out and find out what’s wrong,” and so I did. They made me do the battery of tests, including like performance. I think that’s the best way to go, because then people who are not don’t end up on medication, because I really do believe unless you’ve got it, you shouldn’t be. I’m not a fan of giving Ritalin to kids to quiet them down. If you’ve got it, you need it, whether it’s Strattera or what have you, but if you don’t, you have
no business around it. So and I’d had a professor the semester before pull me aside and say “I think you have a learning disability. You show up. You do the work. You’re here every day. You always have everything I recommend done and you’re always doing your best to pay attention,” but my performance on tests was abysmal, so no kidding. It was a statistics course, and college-level stats. That’s no joke, so yeah, I was getting somewhere between 20 and 30%. Yeah, not so good. So I’m like “Why, now I’ll get tested.” — Kendra (unemployed female, age 35)

Similarly, Mary (female student, age 20) described her diagnosis this way:

Mary: Probably about my second semester at <university>. I’m a junior now, so I just, my grades started dropping off. Like all through high school I had a 4.0 grade point average and my grades just started dropping off a little bit and I thought, “This coursework isn’t any more difficult, but I’m having trouble with it.” So I went to the Counseling Services and asked them you know, “Can you see if I have some sort of disability?” So they, I don’t want to say analyzed—what’s the word?—they tested me for a disability and then they said “You have at least some…” They didn’t do a very comprehensive, but at least some form of ADD, whether it’s a more, I can’t think of the word, sort of exaggerated or...

Interviewer: Inattentive type?

Mary: Yeah.

Interviewer: Impulsive type?

Mary: Yeah, it’s definitely inattentive. Yeah. I don’t remember exactly what the words they used were, but, and then once they gave me accommodations where I just get extra time and a reduced distractions environment, I’ve been doing better in my classes.

Interviewer: So how did they come up with that diagnosis?

Mary: I took, there were several just basic either reading or math tests or puzzles, a little bit of interview, and just what they found was that I did much better on tasks when I was given more time, that I usually failed the task when I was given the normal amount of time, but when they extended it I did very well on it.

Interviewer: What did you think when they first told you about having ADD?

Mary: It was something I hadn’t really considered. I thought you know maybe I have some borderline dyslexia or something like that, but once I found out what dyslexia really was and they started telling me “You have a
little bit of an attention problem,” I thought that that fits. That fits my experience and what I’ve been experiencing I guess all since I ever started school, so… — Mary (female student, age 20)

Additionally, many who did not seek an ADHD diagnosis usually had problems receiving the “correct” diagnosis. Like Missy and Wayne, it was not uncommon for adults with ADHD to receive a depression or anxiety diagnosis before being diagnosed with ADHD. As Edward (male counselor, age 57) described, he was initially diagnosed with depression:

I’m trying to…I came in to talk to them about mood changing, mood changes and maybe some depression, and I talked to them from a point of view as I thought I’d relate it to my vision loss and you know grappling with new business, and so that’s where I first came to talk to them about it. So they talked about the Wellbutrin as being a way of like leveling off the highs and lows, and it was just something I wanted to do. I felt they were certainly not manic depressive, but the highs were a little higher than they needed to be, the lows were a little lower than they needed to be, and I didn’t want that affecting my performance. So that’s where we started was more of that situation, and the Wellbutrin certainly helped with some things. — Edward (male counselor, age 57)

However, after this diagnosis does not result in significant improvement, Edward eventually switches psychiatrists in the hopes of a better outcome:

So I went and saw someone and he recommended we try Wellbutrin. I tried it for about a year and a half and I really didn’t feel that much was going on, so I stopped and then I tried a different psychiatrist, the one that was recommended, and we talked about it and then he asked me about it, then I mentioned Ritalin somehow for the first time in the conversation and that’s when he decided to try this, and I’ve been on this now for about 11, 13, 14 months. — Edward (male counselor, age 57)

As with those who actively sought their ADHD diagnosis, those who were eventually diagnosed due to contact with clinicians came to describe how the diagnosis seemed to fit their lives better and explain their subjective experiences more than other mental health conditions.
Summary

The considerable overlap between common problems and symptoms of ADHD and absence of physiological measures make it difficult for an individual to “know” whether they have ADHD. Rather than relying on the experience of discrete symptoms, adults with ADHD came to “know” something was wrong with them through the experience of self-discrepancy between perceptions of an actual self and the self they thought they should be (actual/own versus ought/own). While adults with ADHD acknowledged that their problems were common, their sense of self-discrepancy allowed them to frame their problems as special and their successes as inadequate. Based on perceptions of their ought self, they always believed that they should be doing better in life. In adults with ADHD, this type of self-discrepancy developed from a patterned set of social cues, including perceived potential and comparisons to reference groups. Ongoing distress stemming from self-discrepancy and/or crisis eventually spurred help-seeking behaviors. While many adults sought an ADHD diagnosis specifically, others engaged in general help-seeking behavior. Regardless of their path to diagnosis, adults with ADHD came to accept the diagnosis because it fit with their past experiences.
Chapter 5: The Consequences of Diagnosis

For the adults with ADHD in this study, an official diagnosis had profound consequences on formulations of the self. A clinical diagnosis represents an identity turning point (Strauss, 1992) resulting in new formulations of the self. By linking lay experiences to institutionally authorized and sanctioned knowledge (Fuller, 2011), a diagnosis provides individuals with a means to make sense of their problems and a set of actions to correct them (Bury, 1991). A clinical diagnosis also allows individuals to fully engage in the sick role providing individuals with an “out” with regard to social responsibilities (Parsons, 1951). At the same time, an ADHD diagnosis represents a potential source of stigma and distress (Canu, Newman, Morrow, & Pope, 2008). This chapter describes the consequences of an ADHD diagnosis in adulthood (Aim 2). Specifically, the following topics are addressed: response to the diagnosis, the role of medication, disclosure decisions, and rewritten narratives. The chapter concludes by highlighting the role self-discrepancy plays in influencing how adults with ADHD respond to their diagnosis.

Response to Diagnosis

In ADHD narratives, the reaction to being diagnosed with ADHD in adulthood differed greatly from other chronic and mental health conditions. In the scientific literature, being diagnosed with a chronic illness/disorder typically entails coping and eventual acceptance. Many are likely familiar with Kübler-
Ross’s (1969) stages of grief where, following the diagnosis of a disease, individuals move through discrete stages including denial, anger, bargaining, depression, and acceptance. While individuals may not move through each stage, the final and goal stage in this model is acceptance, where individuals eventually learn to live with their diagnosis. Like Kübler-Ross, Charmaz (1991) describes four ways in which people respond to chronic illness, including ignoring illness, struggling against it, reconciliation, and “accepting” the chronic illness.

Unlike other chronic conditions, most adults who were diagnosed with ADHD found the diagnosis to be a positive event in their lives. Some reported being simply relieved by the diagnosis. For example, Victor (male service representative, age 29) described the following:

> It was kind of a relief, ‘cause at least now I knew like what it was and that it could possibly be treated, but then I also felt like it was the first time I had, you know, an actual disorder that I had to like work with, so that was kind of… Didn’t really change the way I looked at it, but it was that it gave me some kind of, I don’t know if closure is the right word, but like I said, at least I knew that it was something that could, you know, that there was medication for. — Victor (male service representative, age 29)

While a sense of relief sometimes went with an ADHD diagnosis, it was more common for adults with ADHD to feel elated following a diagnosis. When I asked Rachel (retired female, age 61) how she felt when she was diagnosed with ADHD, she described her reaction this way: “Oh I was thrilled. Are you kidding? I was absolutely thrilled.” Throughout the interview, she described the diagnosis as a “godsend,” a “blessing,” and “wonderful.” Near the end of the interview, Rachel described being diagnosed this way:
It’s not like a curse, like “Oh my god, I have ADD.” So what? It’s not a… And if you’d say “Oh my god, I have cancer,” I would go ”Oh yeah, you poor thing,” but it’s a blessing to know because it’s fixable and doable and your life will be better once you get a handle on this. Understand it. Work with it. Your life will just blossom and take off. That’s my opinion. — Rachel (retired female, age 61)

Like Rachel, ADHD adults felt their diagnosis of ADHD was different from other chronic conditions or disorders. An ADHD diagnosis allowed Rachel and others to put a name to their unexplained troubles, alleviating some of the uncertainty in life. For Victor, Rachel, and other adults with ADHD, the diagnosis provided a clear solution to the problems and chaos they had experienced throughout their lives and a means to “fixing” them.

While I was not surprised that an ADHD diagnosis would eventually be accepted by adults who were diagnosed, I was initially shocked by the scope of the positive response and the speed at which the diagnosis was accepted. As stated above, many adults with ADHD were elated at being diagnosed with ADHD. I could not think of nor find another disorder within the academic literature where individuals responded so positively to the diagnosis. The elation following an ADHD diagnosis found in this study is similar to the findings of Young, Bramham, Gray, & Rose (2008), who also found adults diagnosed with ADHD to be elated following the diagnosis.

It was rare for ADHD adults to describe life as being any worse following their diagnosis. If any negative impact was reported, it was usually relatively small. For example, Cathy (female lawyer, age 30) described only being embarrassed by the diagnosis:
Several adults with ADHD reported difficulty with managing medication (discussed further below). For example, Wayne (male teacher, age 61) stated:

And the other thing is, after the meds, there were certain tasks that were “This is too easy,” and I’d set them aside, and once I got on the meds I was um, I would get organized or mild, slowed it down or whatever so that I could deal with you know the mundane aspects of my job. — Wayne (male teacher, age 61)

Even those who said having ADHD was a problem later described how it wasn’t really the diagnosis itself, but the ongoing problems that might be attributed to ADHD. As Mark (unemployed male, age 25) described:

Well I mean I don’t think it’s totally related to the diagnosis. It’s more related to me being dismissed from (professional) school and the bad situation. So it’s just hard to say whether it has anything to do with the diagnosis. — Mark (unemployed male, age 25)

With these few exceptions, a diagnosis of ADHD in adulthood was viewed as a positive event with few negative consequences.

**The Role of Medication**

For many adults with ADHD included in this study, an “official” diagnosis of ADHD in adulthood provided access to medication. Prescription medications, in particular stimulant medications such as Ritalin and Adderall, have become the most common form of treatment for ADHD in both children and adults (Solanto, Arnsten, & Castellanos, 2001). In face-to-face interviews, nearly all participants had some experience with ADHD medication, with most respondents currently taking some form of prescription medication. As discussed in Chapter 1, there is
a large body of evidence to suggest that medications are efficacious for improving functioning (Faraone & Biederman, 1998; Jensen, Kettle, Roper, & Sloan, 1999). As Conrad and Potter (2000) describe, ADHD medication has been credited with “saving marriages, rebuilding altering careers, and transforming problematic personalities” (pp. 574). Likewise, Young et al. (2008) found that adults with ADHD reported feeling normal and better able to function due to medication. Consequently, these positive effects have created a huge demand for ADHD medication, a demand so great that there has been concern over potential shortages of stimulant medication (Knox, 2011). This section highlights the perceived effects of medication in ADHD adults. It should be noted that the extent to which these changes can be attributed to medications themselves or to beliefs regarding medications (placebo effects) cannot be determined in this study.

Throughout narratives, it was clear that adults with ADHD believed medication to be largely helpful. Adults with ADHD noted improvements in general functioning and in performing specific tasks. For example, Wayne (male teacher, age 61) described:

And the other thing is, after the meds, there were certain tasks that were “This is too easy,” and I’d set them aside, and once I got on the meds I was um, I would get organized or mild, slowed it down or whatever so that I could deal with you know the mundane aspects of my job. — Wayne (male teacher, age 61)

While Wayne saw improvements in work, the range of improvements attributed to medication in narratives was wide and included improvements in school, work, and emotional functioning, and an overall improvement in life. For example,
Kendra (unemployed female, age 35) attributed improvements in her grades directly to medication. Edward (male counselor, age 57) described how medication allows him to keep better track of his work. Rachel (retired female, age 61) described how she is much better able to handle life at home.

For some, the medication itself was a revelation. Following his son’s diagnosis, Stan (unemployed male, age 56) took some of his son’s prescription prior to being diagnosed himself. He described the impact below:

It was, that was very revelatory and I was, for the first time in my life I think getting a sense of what it felt like, what other people called like normal, that are functional and productive and well adjusted and just that common neuroses of you know, ‘cause I’ve gone through as many of my neuroses as I can. — Stan (unemployed male, age 56)

Similarly, Chester (male consultant, age 68) took his son’s medication, noting its effects on improving his view of the self and feeling normal:

That blew my mind to have something that I had carried with me most of my life, to have that just disappear was the biggest tip-off to me it was something chemical. You know that it wasn’t just, you know there at least was a heavy biological component to it that I wouldn’t have never described all those years. — Chester (male consultant, age 68)

As Chester’s quote indicates, for some adults with ADHD, the efficacy of medication and the so-called paradoxical effect (described in Chapter 1) were used to re-enforce the accuracy of the diagnosis.

While Chester and Stan took medication prior to being diagnosed, it was not uncommon for adults with ADHD to describe how medications allowed them to feel like a "normal" person following a diagnosis. As Darlene (IN) described “Put on meds. Ritalin cocktails in the AM. It was like WHOA IS THIS WHAT IT'S
LIKE TO BE NORMAL!!! WHO KNEW???” Like Darlene (IN), many adults with ADHD described how medication made them feel like a “normal” person.

In many ADHD narratives, ADHD medication was viewed as the single most important factor in improving life. For example, when I asked Sandy (female teacher, age 52) how her life had gotten better following a diagnosis, she explained:

I have more patience. I’m patient with myself. I am patient with the children more so. And I understand the needs of all. It’s kind of annoying at times that I do have to take medicine to help myself focus, especially when I am on an extremely heavier busy, busy load and I notice to myself that is when I seem the worse, when I am going, going, going and I don’t have time to take a break. I just get worse, my rehearsals get worse, my writing gets worse. I just have to stop and slow down every once in a while. I know that with myself, without the medication, I don’t think I could have done it. — Sandy (female teacher, age 52)

Likewise, Paul (IN) described medication this way:

I am now on 30mg of Paxil and 40mg of Adderall and I have never been happier in my life! I can think before blurting something out, read a book (even a novel now, something I could not do before). I am finding new interests since I have more patience as well. Life is good, and I just wish I did this 20 years ago, but I guess I should be happy where I am now! — Paul (IN)

The importance of medication was also reflected in the advice that adults with ADHD would give to others. When I asked Maureen (female teacher, age 36) what piece of advice she would give to someone who was diagnosed with ADHD, it was this:

Take medicine, take medicines, and like that’s usually like a lot of times parents come in and they’re like “we don’t want to medicate our child, we don’t want to medicate our child,” but ya know sometime I look at it if they’re not medicated, you do worse. — Maureen (female teacher, age 36)
To Maureen and others, medication was the best route to doing better and ultimately to success.

When adults with ADHD went off medications, they noted negative results. Adults with ADHD often stated that there was a decline in performance related to missing their medications, and that they would do worse at school, at work, or at home. It also was common for many adults with ADHD to “forget” to fill their prescriptions resulting in time periods when they were not taking medications.

For example, Maureen (female teacher, age 36) described the following interaction with her physician:

‘Cause one time I went off of it for 3 months and she's like "How's that going?" and I’m like I just paid $4000 for my PhD class and I only wrote three pages. And she's like, “When are you going to realize, you're the type of person that has ADHD so bad, you need your meds everyday.” Ya know she’s like, “There's different variations of it. Some people can have ADHD; they'll make it through life without medication. You are one that with what's going on in your life right now, you need meds to get through.” That’s what she said. So she's pretty blunt with me. — Maureen (female teacher, age 36)

Several adults described how others would “know” whether they were off their medications. As Maureen went on to describe:

Well yeah, like at work one week, the problem with medication is, it is the controlled substance so you can't just go and get a refill; you have to keep those papers. And for someone who’s not perfectly organized don't always remember to get 'em filled when you are supposed to. So I was off my meds for I think for 2 weeks. And within that 2 weeks, I started cleaning out my file cabinets, and they were all over the floor in my room and stayed that way for like 3 days. My desk was a mess. None of my grades were done, and two of the teachers actually came in and were like "We're going to help you. I am taking your prescription and getting it filled," and the other one helped me clean my room. — Maureen (female teacher, age 36)

Like Maureen, Cathy (female lawyer, age 30) describes how both her boss and husband “know” when she is off her medication, largely through her own
perceived decrease in functioning. Similarly, Kendra (unemployed female, age 35), saw declines in performance when off medications and expressed concern that others would be able to tell.

While medications were largely viewed as efficacious, adults with ADHD also reported some side effects including increased anxiety, loss of sleep, feeling jittery, weight gain, loss of social skills, and decreased creativity. For example, Greta (unemployed female, age 45) described:

Exercise period, which when I got out of college I started exercising a ton, and I mean like way too much and like for hours and ‘cause I have a high anxiety level, ever since I took the ADD medication. — Greta (unemployed female, age 45)

Along with specific side effects, there was also some concern regarding the long-term health effects of medication. Greta also described her concerns this way:

‘Cause stimulants are really kind of hard on your system, especially when you get older, but this happens to work a lot better. And you know, it was kind of hard, too, at the beginning to say, "Oh, I’m going to be on medication my whole life," you know, and nobody really wants to hear that either, but it was easier after the first couple of years once I saw… You know if I’m going to go off of this. And I had an aunt who was manic depressive, and I saw, and not that I wanted to have that diagnosis, but I saw what it did to my family and her when she went off, and other people, and I saw what the medication did for me and it changed my life and I thought, "You know, I went all the way through my life with tutors and everything else. This medication, I’m getting to my appointments on time. I could keep a job. I could do these things. You know do I want to not have that? No," you know, and so I never really...You know it’s really up to me. It’s my life. This is what I want to do. —Greta (unemployed female, age 45)

Greta continues to take medications despite the experience of side effects and concerns over the long-term health effects. For Greta, the marked improvement she attributes to the medications far outweighs her concerns:
Nobody was shoving anything down my throat. I’m not a little kid, and when I’m off of it, I don’t feel clear and I like feeling clear and connecting my own thoughts, and that’s more important to me. — Greta (unemployed female, age 45)

Despite their efficacy, some adults with ADHD chose to go off their medications. For example, Joseph (male student, age 21) chose to stop taking medications due to the negative side effects he experienced and cost associated with them. As he described:

Well first of all because they’re expensive, and secondly because I didn’t like the way they made me feel. I mean it was easier to pay attention, but at the same time I gained like 30 pounds in those few months and I just felt tired all the time and I decided it wasn’t worth it — Joseph (male student, age 21)

In narratives, adults with ADHD weighed the negative side effects of medication against their ability to cope without medication. As Joseph went on to say, “I’ve been able to cope at least well enough here. In medical school...I don’t know. It might be worth the weight gain. I don’t know. I’ll have to figure it out.” Chester (male consultant, age 68) chose to go off his medication due to enjoyment in his current work.

Yeah, yeah, yeah, and even though I get tested, it was like you know we both decided together. I can’t even remember who took the lead on it, but we decided together: ”Maybe I should just try doing without,” because the risk-benefit didn’t seem to be worth it anymore. It was like if it isn’t doing that much for me and I’m now in the middle of this life I mentioned to you at the outset that’s really high stim, I mean it’s so exciting and so challenging, it’s not like I lack for you know things that turn me on in a day. — Chester (male consultant, age 68)

Anthony (male lawyer, age 56) had been off medication for some time due to declining demands in his daily life. However, a recent increase in demands made him examine going back on medications with his physicians.
I’m finding that I’m just…and that’s what prompted me to talk to my counselor this past, like I said, just this past week and you know explain to him that you know the procrastination has started again, the little irritability, especially when a lot of things are going on all at once, and you know just kind of feeling overwhelmed with the to-do list, and so he’s getting with my family physician. I’m going to be going in and they’ll probably put me back on. — Anthony (male lawyer, age 56)

As Anthony’s story suggests, many of those who were not currently taking medication still noted the efficacy of drugs and would resume treatment should things become difficult. Similarly, Chester kept an emergency reserve of medication in the medicine cabinet just in case.

While Chester and Anthony’s current ability to go off medication due to decreased demands was somewhat unique, several adults with ADHD described their desire to go off medications when demands declined or their ability to cope improved. For example, when I asked her how long she would need treatment, Maureen (female teacher, age 36) described:

Umm, it depends, I’m at least gonna need it until I am done with my PhD program and then depending on what job I have. So if I keep the job that I have now I think I might actually be able to do my job without taking medication every single day. — Maureen (female teacher, age 36)

For many, going off medications was a long-term goal. Edward (male counselor, age 57) described:

And then what’s happened in the last couple of months is I’ve actually started implementing some of the changes that I think the Adderall is giving me a chance to implement. My goal is to get off it. This is the first time…I’m really very homeopathic. I had kidney stones and I dealt with it homeopathically. So I just don’t…I don’t like doctors. I don’t like hospitals, so I’ve been so far, and I know this is going to be a problem at my age. It’s probably going to be a problem, but so my own bent about that has made it difficult for me sometimes to participate in some solutions that might’ve been more helpful. So now I feel I’m implementing some things that I didn’t think I could before, and I’m also accepting that you know one of my barriers to change is my
stubbornness that I can do everything as well as anyone else. — Edward (male counselor, age 57)

While some expressed a desire to or actively chose to go off medications, others such as Stan (unemployed male, age 56) and William (unemployed male, age 37) lost access to medication due to job loss and lack of health insurance. Despite losing access to medications, adults with ADHD maintained a reserve for when they thought medications would be helpful. William kept a reserve for situations in which he had to perform as he described in the exchange below:

**Interviewer:** When did you stop treatment?

**William:** Um, right around the time I left my job. Well, I didn’t have any insurance anymore, so I went to the (employer) and their being nonprofit, they don’t, um, their insurance, you know it’s not under that COBRA act or anything.

**Interviewer:** Right, it’s gone, Yeah, it’s gone. Are you planning—if you get a new job—are you going to go back on the treatment or…

**William:** Yes.

**Interviewer:** OK. So the main reason you went off treatment wasn’t because of Ritalin—it’s more because of the insurance issue you think?

**William:** Right, because he didn’t push me to take the medication. Um, actually to tell you the truth, um, I will take it in certain situations. Like my daughter at Christmas had a play and I knew it was going to be long and I took it then (laughs).

**Interviewer:** If you had a job, or would you take it if you had a job interview or…

**William:** Yeah, something like that, yeah. — William (unemployed male, age 37)

Like William, Stan (unemployed male, age 56) had lost access to medication due to insurance. Throughout our interview, he expressed his desire to go back on medication, but was unable to do so due to the cost.
Despite its efficacy, not all adults with ADHD started taking medication immediately following an ADHD diagnosis. Adults chose not to start medications for two reasons: Some believed there were too many negatives associated with the medication; others believed they did not need their medication at that time, that they were coping well enough without it. Mark (unemployed male, age 25) decided to delay medicating, “’Cause it’s kind of expensive and my parents are against it, ’cause they don’t…they don’t believe in this stuff at all.” Stephen (male student, age 21), who wanted to join the military, knew that by taking stimulant medication, he would be excluded from military service.

Other adults with ADHD who had no experience with medications believed they were doing well enough without them. For example, Missy (female research assistant, age 29) described her decision to stay off medication this way:

> She is a big fan of cognitive behavioral therapy. We…I guess we would just talk about it, I would see her once a month, we would talk about it in the sessions, and I would bring up…uh…reckless behavior, she didn’t think it warranted medication. “If you want to try it you can talk to your primary care doctor about it.” But I don’t think she warrants it; I tend to think that she is right. Every once in a while I have kinda thought about it, but I think it is fine, it is just a matter of me talking about it, it is something that comes up. She will ask me a lot, on updates on my dissertation and things, keep me on tasks, in a way that doesn’t make me feel guilty. — Missy (female research assistant, age 29)

Likewise, Ken (unemployed male, age 32) described why he hadn’t gone on medications this way:

> I haven’t started on any medications yet ‘cause I’m still deciding whether I want to do that. She said you know it’s not the kind of thing where I can’t live a happy life without medications, but it might help or it might not. She you know didn’t… It was basically my choice if I wanted to try that or not, and but I’ve gotten better just through counseling and recognizing the problem and
dealing with things through counseling and you know changing my thought processes a little bit. — Ken (unemployed male, age 32)

For Missy and Ken, the diagnosis itself has provided them with additional understanding and ability to cope with stressors. Both their therapists had suggested trying behavioral accommodations first. Many of those who never started taking medications were much more engaged with ongoing therapy and reported seeing a therapist somewhat regularly.

With few exceptions, ADHD medication was viewed as immensely helpful in dealing with problems associated with ADHD. Specifically, many adults with ADHD believed that medications allowed them to adhere to performance norms as well as allowing them to feel normal. For those who actively chose or expressed a desire to go off their medications, it was largely due to a decline in demands. Those who chose not to start medications did so because they believed they were doing well enough without them, believed there were too many negatives associated with them, or a combination of these two factors.

Disclosure

Because ADHD status can remain hidden to others, the decision to disclose the diagnosis to others is one that takes careful consideration and represents a strategic decision (Omarzu, 2000). Although some argue that ADHD is a highly visible disorder and is detected quickly in social interaction (Canu, Newman, Morrow, & Pope, 2008), this position is counter to the bulk of scientific literature related to adults with ADHD. As noted previously, there is a substantial body of literature dealing specifically with accurate diagnosis of ADHD.
in adults (Harrison, 2006; Harrison, Edwards, & Parker, 2007; M. D. Weiss & Weiss, 2004). This literature suggests that accurate diagnosis of ADHD can be difficult for trained medical professionals. As highlighted in Chapter 4 and consistent with other literature (Conrad & Potter, 2000; Faraone et al., 2000), most adults who receive an ADHD diagnosis do so through a process of self-referral. Very few adults with ADHD are encouraged to seek help by others.

In ADHD narratives, it was clear that ADHD and its symptoms were not easily detected by others, including clinicians. As Maureen (female teacher, age 36) stated in our talk, her physician of 11 years never raised the possibility of her ADHD until Maureen brought it up during a visit. Given the scope of her suffering and what she believes to be obvious now, Maureen is surprised her ADHD was not detected earlier. As others have found (Dias et al., 2008), Maureen also notes discrepancy between her own recall of ADHD symptoms and those of her parents, noting that her parents don’t believe she has the disorder.

Disclosure decisions were in part driven by the potential downsides associated with the label. In the literature, ADHD is associated with a range of negative social consequences. Generally, adults with ADHD report fewer friends and greater marital distress and are more likely to be divorced (Faraone & Biederman, 2005; Kessler et al., 2006). It is unclear in the literature whether the label itself is driving these negative outcomes, or whether they are due to the symptoms/attributes associated with ADHD. One study by Knouse et al. (2008) found that ADHD-like behaviors affected appraisals, with those exhibiting ADHD
traits being viewed more negatively by peers. Another study by Canu et al. (Canu et al., 2008) found that the label itself can lower social appraisals.

While there is certainly some stigma associated with ADHD and its symptoms, disclosure of an ADHD diagnosis can also have benefits. Disclosure may minimize the risk of social rejection by allowing individuals to explain problematic behavior (Jastrowski, Berlin, Sato, & Davies, 2007). Additionally, because ADHD is recognized as a disability, adults with ADHD have many of the rights guaranteed by the Americans with Disabilities and Rehabilitation Act (ADA). Although ADHD is not mentioned specifically in the ADA, adults with ADHD are entitled to reasonable accommodations in education and the workplace (Conrad & Potter, 2000). These accommodations can include additional time to take tests, extra clerical support, checklists, protection from discrimination, use of tape recorders and laptops, special considerations in the hiring process, along with other mechanisms to help adults with ADHD manage their disorder (Perritt, 2003; Stefan, 2001).

Most of the adults with ADHD interviewed for this project were quite open about disclosing their disorder to family members, coworkers, and peers. While most adults with ADHD were clear that they did not “announce it to the world,” many reported not going out of their way to hide their disorder. For example, Cathy (female lawyer, age 30) explained “I just don’t want people in general knowing, I think. It’s embarrassing. No offense.” Despite being embarrassed by the disorder, she does disclose her status:
My husband. My boss knows. My parents know, and people who I think would benefit from knowing, obviously you. I’ve been told by some people I know who have children that their children have it, and I share my experiences with, especially with the diet issue, like because that helps so much. — Cathy (female lawyer, age 30)

While Cathy feels embarrassed, she is still open about her diagnosis to those who would “benefit” from this knowledge. However, for Cathy and adults with ADHD, disclosure of ADHD benefits the self more than others. For example, when I asked Cathy why she let her boss know she had ADHD, she explained it this way:

Well I told my first boss obviously because I needed some time off and he was not one for giving me any kind of time off. Again, nutty. And my boss had shared some personal stuff about him. We were just in that kind of sharing space and we talked about my experiences at the Bar, and also I just figured it would lead him to a greater understanding how I process information and why the train of my thought goes the way it does, so he wouldn’t think that I’m, you know sometimes when I’m showing him something that he wouldn’t think my train was an Amtrak train of thought, that there is logic to it. — Cathy (female lawyer, age 30)

As her quote indicates, Cathy discloses her ADHD to her boss to gain additional accommodation along with feeling comfortable with him. Like Cathy, Mary’s (female student, age 20) disclosure of her ADHD status also results in significant benefit. As she describes below:

Yeah, it’s definitely inattentive. Yeah. I don’t remember exactly what the words they used were, but and then once they gave me accommodations where I just get extra time and a reduced distractions environment, I’ve been doing better in my classes. — Mary (female student, age 20)

In being open with her university and professors, Mary was able to receive formal accommodations, which she believes allow her to do better in her classes.
Mary’s disclosures result in additional informal accommodations as well, allowing
others to understand her behavior. As she described below:

Anybody that I have to, you know anybody that I work with like in my
department…But when I talk to people in (my department) they just think “Oh,
ADD is you’re just not paying attention and there’s nothing else to it,” but I
mean there are other little things to it, but they think “Oh yeah, that’s okay.
It’s cool.” I’m not sure if it’s…There I go losing my train of thought. People
that I talk to in the department. Other people that I talk to, my family. My
family, they’re like “Cool. Now we have a name for this. Now we know why
you’re not paying attention so we can tell you, ‘Hey, you’re not paying
attention,’ and then you listen.” — Mary (female student, age 20)

In disclosing their statuses, Cathy, Mary, and other adults with ADHD provide a
mechanism to explain their behavior. In so doing, they receive both formal and
informal accommodations that allow them both additional avenues to success
and an ‘out’ for potential deviant behavior.

While adults with ADHD often disclosed their status when there was a
direct benefit to them, others viewed it as their duty to be vocal about their status.
It was not uncommon to engage in activist/spokesperson roles similar to those
highlighted by Anspach (1979), Goffman (1961), and Zola (1991). As described
by Anthony (male lawyer, age 56), “I know some folks feel stigmatized by it. I
don’t at all. I tell people about it.” To Anthony, there is no shame in needing and
getting help for ADHD. Similarly, Stan (unemployed male, age 56) described the
disclosure of his ADHD this way:

I tell people. I’m not ashamed of it. I think initially I’d hear folks say, “Well oh I
get like that too,” and yet they’re highly organized, and then well everybody
has some of that, but it’s just like a monkey wrench in your transmission, you
know. So I think I would try to educate folks that I knew, and then over time I
realized some people are receptive to understanding and some people
already have a judgment about it. — (Stan, unemployed male, age 56)
Anthony, Stan, and several others became advocates for others with ADHD, viewing it as their responsibility to make it better for others and increase awareness.

As others have found, the role of spokesperson was especially prominent in unsolicited Internet narratives (Hardey, 2002). For example, Gerard (IN) advocated for a changing view of ADHD this way:

I would like to conclude with a story from my youth. I remember that when I was a child a boy from my neighbourhood who was left handed was punished and yelled at for being left handed. In fact his teachers would tie his left hand to the back of his chair in order to force him to use his right hand (and I mean right in both senses of the word). Now when I think back to that story I feel like I can relate in fact feel that it is great metaphor for my experience of ADD. That boy was viewed as having a problem/deficient and was forced to change. Looking at that situation today most people probably think that what those teachers and parents did to that child was ridiculous and wrong because we all know that there is no such thing as RHDS (Right Hand Deficiency Syndrome) and some thing tells me that in the not so distant future we will begin to recognize and hopefully appreciate that ADD is more about Difference than Deficit. — Gerard (IN)

Likewise, Jason (IN) described:

The point of the story? It's never too late to get help and to live your life. ADHD doesn't make you dumb, although there is a lot of past conditioning to undo if you've felt dumb. Society had set it's cookie cutter notion of "normal". ADHD brains work differently thats all! Less dopamine to the frontal brain. The pros of an ADHD brain? I am creative 24/7, and at wierd late night hours when it sometimes wakes me up. This is the very brain that I struggled with. — Jason (IN)

In taking on the role of advocate, adults with ADHD often reframed their disorder as a positive aspect of the self.

Adults with ADHD also reported disclosing their status to others when peers disclosed their own diagnosis or disclosed that their children had ADHD or
were exhibiting ADHD-like behaviors. For example, Rachel (retired female, age 61) described:

Well if…I mean I don’t go around…I have friends who, if they’re frustrated with something, we you know share information and I tell them, you know. Not everybody. Close friends know, and if their kids have issues and they’ll tell me, you know we talk about the kids and I said, “Do you think maybe there’s this?” And you know some of my girlfriends, some of the kids have it, but they don’t want to do anything. They don’t want to take medication. I understand that, and they don’t take the time to go through therapy, but they’re still, they’re functioning and they’re doing great, so you know they might be doing their own self-therapy understanding what the issues are. — Rachel (retired female, age 61)

While most adults with ADHD were relatively open with their diagnosis, several were cautious over disclosure, especially for fear of being stigmatized.

For example, Victor (service professional, age 29) talked about the disclosure of his diagnosis this way:

Very few people…I would say like my family. Like one of the women that I work with, and just the lady that sits next to me, but you know I told her, “You know keep it between us.” I told her and nobody else at work knows really, just because like I’m not ashamed of it. I just know that if you know somebody that has something unusual or a disorder or something, then like you see that when you look at them…and it might change the way that they act around me, like especially at work when like if someone’s giving me something to do. I don’t want to be treated like somebody who might not get it done. — Victor (service professional, age 29)

While Víctor doesn’t disclose his ADHD status due to potential stigma, others had experienced stigma related to ADHD through past experiences. For example, after Kendra (unemployed female, age 35) disclosed her ADHD to a boss, she reported:

I was treated differently. I was seen as less competent, so and I think that’s probably common, probably more the norm than anything, ‘cause there are so many people who are convinced it’s not real and on and on and on. So rather
than deal with people’s misunderstanding and prejudice, it’s my job to manage my condition. — Kendra (unemployed female, age 35)

The fear of potential stigma and the experience of stigma associated with ADHD were important factors in disclosure decisions.

Although only some adults with ADHD took on a spokesperson role trying to educate others, most were open with their diagnosis, largely due to the formal and informal benefits they received. However, this was not true for the entire sample, with some being cautious of disclosure. When adults with ADHD chose not to disclose their status, it was usually from fear of stigma or fear of being treated differently based on their disability status.

Rewritten Narrative

As Pennebaker and Segal state, “constructing stories is a natural human process that helps individuals to understand their experiences and themselves (1999, p. 1243).” Similarly, Gergen and Gergen (1984) see self-narratives as allowing individuals to make sense of critical events in their lives. As Strauss (1992) contends, the diagnosis of a chronic condition represents an identity turning point requiring new interpretations of the self, others, events, behaviors, and objects. Once the identity changes, it can never go back, with all interpretation of the self influenced by the new status. As with other chronic conditions, personal narratives are often rewritten reflecting new status following a diagnosis (Bury, 2005; K. Charmaz, 1991; Frank, 1995). Leffers (1997) suggests that adults with ADHD revise their histories following an ADHD diagnosis. In her study, adults came to view their problems not as personal
failures, but the result of their undiagnosed disorder. Like Leffers, I also found that adults with ADHD would rewrite their narratives and came to understand problems of the past, present, and future from their new status.

**Past self prior to diagnosis.** Prior to being diagnosed with ADHD, respondents experienced a wide range of problems they often attributed to personal weakness. As I highlight in Chapter 4, there is considerable overlap between symptoms of ADHD and common problems. Based on their experience with these problems, adults with ADHD described a period of time when they "knew" something was wrong with their life, but were unable to describe it in words. This period of inchoate feelings for adults with ADHD is similar to those described in depression (Karp, 1996). As Sandy (female teacher, age 52) described:

> Oh, I knew as a child but again as growing up in the 50s, 60s and the early 70s you didn’t know, I knew that something was wrong. I didn’t know exactly what was wrong, because I kept thinking why wasn’t I as smart as they are, why couldn’t I write, my spelling was horrible. So I am going to say at an early age but I didn’t get any help with any of it. — Sandy (female teacher, age 52)

The time prior to being diagnosed represented the largest portion of illness experience, in part due to the nature of the study and current conceptualizations of the disorder.

Adults with ADHD attributed problems to ADHD in early childhood, usually in elementary school. Despite doing well in school, many sufferers described problems in school related to specific activities including taking tests, completing homework, spelling, solving math problems, reading, writing, and following
directions. Missy (female research assistant, age 29) described problems sitting still.

Like you know, class. I never had problems doing well in school, it was this sitting still and behaving myself in class, even in graduate school. It was always that, that could create challenges, what would be challenging for me in terms of you know, maybe my professors thought I was an asshole or something, because maybe that is what I was acting like, even though its because...It's not like I am making excuses, like I really just couldn't sit still, I really just couldn't, but I wanted to be there, but I was bored, or they would think I thought their class was boring because I was falling asleep, because it was really they were lecturing and not engaging us. So that's why, so perception problems, again. Misperceiving me? — Missy (female research assistant, age 29)

As Missy’s story suggests, she has done well in school. However, due to her perceived actions, she believes her teachers view her negatively. As with others, Missy initially internalizes these problems. Following the diagnosis, Missy comes to explain her problems through a lens of ADHD. However, she also hints that the environment (un-engaging lectures) may have played some role in her problems.

As Missy described in the quote above, being perceived negatively by a person in authority was a concern for those with ADHD. Some sufferers described themselves as being labeled as lazy, stupid, or dumb by teachers or parents. A sample of these statements is included below.

It has been 26 years in the making. I, like most people's stories I have heard, grew up being labeled as lazy, bad, troublemaker, or even worse. After a while I started to believe that. That will be something I will have to overcome but sometimes it seems like I can't or won't ever be able. — Jessica (IN)

Throughout my years I found it difficult to concentrate an it was addled by parents who for the sake of saying, lets say they could not deal. At times I was called stupid and I was hit, if I could have only made it through a paragraph or a book. My father, who was teaching advanced college
mathematics would often become frustrated at the way I would not get things as fast as he wanted to see it. My mother helpfully pitched in when it came to hitting me. — Liz (IN)

I can remember in third grade, again I didn’t know what was wrong. I can remember, actually I can remember actually all the way in first grade and I would be pulled out to go to the reading trailer and I kept thinking “why can’t I read, what’s wrong with me, why am I so stupid, why can my friends read and I -- a story could be read to me and I could tell you about the story and I could retain it, but I could not stand and read the words for you or I could not spell for you and the teacher would say, “Oh she’s lazy”, and my mom would say “She’s not lazy. You don’t see what she does when she comes home.” I would work and I would work and I would work, until I made myself do it. So my stick-to-it-ness, in fact that is what the woman said when I was diagnosed, she said “Stop thinking of yourself as stupid, think of yourself that you have a lot of will power. — Sandy (female teacher, age 52)

Clearly, these negative labels have long-term negative effects. Despite being diagnosed with ADHD in adulthood, Jessica (IN) and other adults with ADHD are still haunted by the negative labels. However, they view these labels as the direct result of their undiagnosed ADHD.

Prior to the diagnosis, many adults with ADHD attributed their problems to personal weakness. Rachel (retired female, age 61) described it this way:

I just had that feeling that there was something you know missing. Things weren’t clicking. So I went and I was tested. I mean I wouldn’t have been oblivious my whole life thinking that...First of all, I mean when I found out about the depression part of it, I mean who knew from you know years ago, I just figure that “This is just the way I am,” you know and “That’s just my makeup” and you just do what you do. You know you just muddle through and you know plow ahead and all those clichés, but you do it, ’cause I just figured that’s just me. — Rachel (retired female, age 61)

Like Rachel, Chester (male consultant, age 68) initially believed his problems were due to not being "disciplined” and to being “anxious,” beliefs supported by his father.
I didn’t know I had it, I mean that’s a big huge chunk of life when I didn’t know, I felt all the usual things that people feel about themselves in terms of feeling like I wasn’t disciplined enough, like I was…My father had a lovely term called “being a weak sister” ‘cause I had a lot of anxiety. — Chester (male consultant, age 68)

As Rachel and Chester suggest, the problems they encountered throughout their life could be considered common. However, based on perceptions of their ought self (described in Chapter 4), they believed they shouldn’t have encountered these difficulties. To adults with ADHD, these early difficulties often resulted in long-term feelings of inadequacy and viewing the self as a failure.

**Past self following diagnosis.** After the diagnosis, nearly every past problem imaginable could be explained through the lens of ADHD. For example, when I interviewed Maureen (female teacher, age 36), she owned several rental properties, which were causing a significant amount of stress in her life. Instead of attributing this difficulty to external factors (the recent real estate crisis), Maureen explained the problems through a lens of ADHD. She believed that the impulsivity caused by her ADHD allowed her to rush into these purchases without considering the consequences.

Although more prominent in Internet narratives, adults with ADHD often talked about drug, alcohol, and other risk behaviors as being the result of their yet to be diagnosed ADHD. Cathy (female lawyer, age 30) explained her lack of friends and past risky behaviors as the result of her undiagnosed ADHD. In many cases, adults with ADHD viewed their past substance use as a form of self-medication. Past and current substance abuse is consistent with much of the biomedical literature pertaining to ADHD (e.g., Hallowell and Ratey, 1995).
Following a diagnosis, many adults with ADHD attempted to verify their diagnosis by examining their past. Several went back to their school records in search of evidence of their new status. Stan (unemployed male, age 56):

So I went to my high school and I got my transcripts and it wasn’t just grades. They would give all of the standardized testing scores. Iowa test and Thorndike…And I looked at my test scores and like it’s interesting, I didn’t know then, except I fought my way through college. I graduated from college in my 30s, late 30s and these statistics said that…you know all this punishment for not paying attention to what he thought was important and he should’ve, too bad he couldn’t pay attention to how important my own intellect was or the teachers. I think teachers, I heard all my life “You can do better than this. You’re capable of much better.” I never knew what that meant until I saw these scores and what they meant, and you know I mean it’s not like it’s super genius stuff, but it’s like 130. — Stan (unemployed male, age 56)

These school documents served as documentation that ADHD was present in the past. For example, spelling tests, report cards, and teacher notes were all used to show that ADHD was present throughout the lives of adults with ADHD.

Following a diagnosis, adults with ADHD reinterpreted their past problems in light of their new status. Problems that adults with ADHD had acknowledged as common were now understood to be the result of ADHD. Consequently, many of the common struggles encountered by adults with ADHD throughout life were now viewed as unnecessary or avoidable.

**Missed diagnosis.** The biomedical model played a significant role in shaping how narratives were rewritten. Currently, ADHD is understood by biomedicine to be a lifelong disorder, usually diagnosed in childhood. Consequently, adults with ADHD believed they had ADHD most of their lives, and the “missed diagnosis” was a common theme in many of the ADHD narratives. Adults with ADHD developed particular stories to explain how and why their case
of ADHD was overlooked. Some respondents felt that the scientific understanding of ADHD during their childhood was inadequate or underdeveloped, resulting in their case of ADHD being missed. As Chuck (IN) and Bunny (IN) put it:

I'm 36. When I was younger, ADD didn't exist. Or, more accurately, it hadn't been discovered yet. — Chuck (IN)

Unfortunately when I was a child in the 50's and 60's they did not know what ADD was. I went through my school years as a daydreamer, a person who was always on the outside looking in at everyone else have a good time, hearing the same message over and over again of how lazy, stupid and crazy I was. — Bunny (IN)

As highlighted in Chapter 1, ADHD-like diagnoses have existed for some time, even in the 1950s.

Several women in the study felt that ADHD was poorly understood in girls and women. Kendra, whose brother was diagnosed in childhood, explained her missed diagnosis this way: “So I mean they’d heard the stereotypically ADHD kid you know and that generally boys get diagnosed as kids. Girls tend to be looking out the window, like I did, so…” Kendra believes (based on the biomedical model) that boys and girls exhibit ADHD symptoms differently, with boys exhibiting more overt behavioral problems in class that tend to get noticed. Cathy (female lawyer, age 30) described the difference between boys and girls this way:

Females growing up in middle class homes tend to have less behavioral problems in the sense that I’m not going to go out and set anything on fire like a boy would, or hit someone or act out in a physical manner like that, but you’re more likely to make poor decisions, be promiscuous, be messy. — Cathy (female lawyer, age 30)
As Cathy’s story indicates, she believes boys are much more likely to have behavioral problems making them more likely to be recognized. Biomedical literature is likely influencing views such as these by suggesting ADHD in girls and women as being less disruptive and more likely to be overlooked (Mikami & Hinshaw, 2008; Quinn, 2005).

Although they believed they had ADHD all of their lives, both men and women indicated that their past behaviors were not problematic enough to gain the attention of authority figures who would refer them for diagnosis. Ken (male lawyer, age 32) and Kendra (unemployed female, age 35) recalled:

“I was in school I think because I was getting Bs, Cs whatever, you know I wasn’t flunking out, probably the teachers and guidance counselors or whoever in the system didn’t feel the need to...You know “Yeah, we’re worried about kids that are flunking. We’re not worried about kids that are passing that could be doing better.” — Ken (male lawyer, age 32)

In my case it showed up in the job world, as opposed to in school. I have a tendency when I read something to remember very, very well what I’ve read, so that worked for me and against me. If I hadn’t been able to do that so well, I would’ve gotten noticed and helped sooner, but it’s because of that that I actually managed to do well enough in school to go to college, and so it’s a two-edged sword, but I would’ve probably been found out sooner, like I don’t know, 10, 15, instead of 21. — Kendra (unemployed females, age 35)

Ken feels his problems were never addressed because his school had bigger problems to deal with. Kendra’s abilities allowed her to compensate enough to go unnoticed at school. However, while ADHD was believed to be missed because it was not problematic for institutions to notice, adults with ADHD reported suffering through most of their lives.

Despite the reasons given for the missed diagnosis, once an adult had been diagnosed, the presence of ADHD in his/her past was obvious and should
have been to others. Past struggles were now viewed as unnecessary or avoidable; it was not uncommon for respondents to report feeling angry that their ADHD was “missed.” As articulated by Denelle (IN), “They never tested me to see if I had ADD they just assumed that I belonged there. I never got the chance I missed out on a lot of things and I blame the schools here…” While nearly all adults with ADHD described their diagnosis as a positive event, there was some anger regarding the timing of the diagnosis. For example, Maureen (female teacher, age 36) describes:

Well sometimes I get mad because I don’t know if it was ya know, my mom or dad but we were just in denial, well she’s still in denial, my mom is still in denial, like not accepting that I have it. Ya know, and I wonder if teachers at school ever said anything to them ya know like do you think she has attention deficit disorder, this is how we can help. Because all along the way, I think I would have failed school if I didn’t have my mom and dad there. Because somebody had to say something…ya know so I mean I just wish that it was addressed at a younger age and ya know like being medicated younger, like where would I today. Ya know? — Maureen (female teacher, age 36)

Like Maureen, Sandy (female teacher, age 52) described how it was “wrong” she had to go through this for most of her life without a diagnosis. To adults with ADHD who experienced anger or regret, the presence of ADHD was clear when reinterpreting their past. In their view, ADHD should have been obvious to others throughout their lives. Consequently, adults with ADHD viewed the struggles they went through earlier in life as unnecessary, resulting in their anger.

**Current and future self.** Before their diagnosis, adults with ADHD described their lives as one of suffering and failure. Adults with ADHD often talked about what they were unable to do. Following a diagnosis, narratives generally turned to tales of success. Adults with ADHD often described what
they were now able to accomplish. For example, Wayne (male teacher, age 61) stated:

So I remember trying to memorize stuff and trying to understand things, and it didn’t make sense, and once I got...Well it was funny because once the medication kicked in it was so easy and I understood it, but the function, the essence of whatever it was...I can read philosophy like crazy now and I know “Okay, this guy’s talking about...” you know “This makes sense.” Well let me go back. So back then it was just you know I just accepted it back then that “Okay, I’m not good at school.” Yeah. — Wayne (male teacher, age 61)

Like many other adults with ADHD, Wayne notices an improvement in functioning following an ADHD diagnosis (largely due to access to medication). Some like Loraine (IN) described how the diagnosis “saved” her:

I sought out the Learning Disabled Counselor who had given me the photocopying to do, and I kept saying, "This is me, this is me." I'll never forget her expression. Compassion. My whole life made sense now, it was like finding a piece of myself that I never knew existed. I was given several tests, including TOVA, and they determined that I had gotten this far without meds, I was in college after all, why not try behavioral modification and see how that goes. Six years later, with a Bachelor of Arts, I am working towards my goal of becoming a writer for television, I recently married, and I have just purchased my first home. There are some days I wish I had opted for medication, but other times I am so glad that the behavioral modification helped me organize my life. Finding out I had ADD saved me. — Loraine (IN)

In her view, life without the diagnosis was one of suffering. With the diagnosis, she is optimistic about her current and future self.

Most adults with ADHD described how an ADHD diagnosis allowed them to make better sense of themselves. As highlighted earlier in Chapter 4, it was common for adults with ADHD to talk about how their diagnosis fit their experiences. For example, Mary (female student, age 20) describes:

They started telling me, “You have a little bit of an attention problem”; I thought that that fits. That fits my experience and what I’ve been
experiencing I guess all since I ever started school... — Mary (female student, age 20)

Like Mary, Missy (female research assistant, age 29) described how reading *Driven to Distraction* allowed her to make better sense of her difficulties:

I read the book, it was one of those things, I couldn't put it down, like I thought it was such a well written book, it made so many things that I had experienced make so much sense. — Missy (female research assistant, age 29)

Many adults with ADHD described how the diagnosis fit them perfectly, that they related strongly to the symptoms and stories of others.

While some literature suggests ADHD is over-diagnosed (Sciutto & Eisenberg, 2007), adults with ADHD believing their diagnosis was appropriate and correct was largely due to the degree to which ADHD fit with experience. However, some questioned the validity of the diagnosis in others. For example, Cathy (female lawyer, age 30) and Joseph (male student, age 21) stated the following:

I still think it’s over-diagnosed in general. I think that any time that there is you know some kind of behavioral problem, that it’s diagnosed as that. I think that some kids are just bad. — Cathy (female lawyer, age 30)

I definitely think it is. I think that there are people who say they have it, and I’ve seen them, like we study together and I don’t think they do. They were diagnosed with it as children and I think the doctors tend...When people go to doctors, they don’t want to hear that “Your kid’s fine.” They want a diagnosis and a pill, so I think that a lot of people, they’re like ”My kid’s not behaving,” and instead of the doctor saying, “Well, parent them,” they say, “Here’s a pill that will make them sluggish. You’ll like that,” and there you go. — Joseph (male student, age 21)

Cathy and Joseph view themselves as good people who work hard, yet perceive (as discussed in Chapter 4) their success to be lacking. To Cathy and Joseph, it was likely that others had been inappropriately diagnosed by overzealous
doctors—those who were bad, lazy, or prone to misbehaving and not really disabled. It is worth noting that many adults with ADHD engaged in some behaviors that could be considered bad, including risky behaviors such as drinking and drug use.

While many adults with ADHD believed they would have the disorder for the rest of their lives, they were also very hopeful for the future, largely due to the gains they had seen following the diagnosis. Many adults with ADHD believe they will now be able to accomplish long-term goals. For example, Sandy (female teacher, age 52) believes she would finish her doctorate, while Victor (male service representative, age 29) believes he will finish a novel. Following his diagnosis, Joseph (male student, age 21) believes he will get into medical school. Others believed they would just continue to experience positive personal growth. As Jessica (IN) described: “I know that I have a lot more room to grow and expand as a person and a person with ADD but it doesn’t feel so impossible as it did before the diagnosis.” As highlighted above, following a diagnosis, many adults with ADHD believed that life would continue to get better. Although many acknowledged that ADHD was a lifelong disorder, many believed they would not need treatment for their entire lives.

Alternate trajectory. Almost all respondents felt that if they had been diagnosed earlier, their lives would be better. When I asked study participants about how their lives would be different if they had been diagnosed earlier, most believed they would be more successful in life and able to accomplish long-term
goals more easily. For example, Rachel (retired female, age 61) believed she would have lived in New York and been a singer. If she had been diagnosed earlier, Maureen (female teacher, age 36) believes she would have been able to work through difficult college courses in computer science and able to work in that field instead of teaching. Kendra (unemployed female, age 35) put it this way:

I just wished I’d been diagnosed earlier. That’s my reaction. I wish I’d been diagnosed earlier, much earlier, and treated, because then I could’ve accomplished more in my life and not been held back by what had happened. Results matter. Potential. Potential, yeah, potential doesn’t pay the bills. — Kendra (unemployed female, age 35)

To Kendra, an earlier diagnosis meant she would now be working as a librarian rather than being unemployed and living at home.

Conclusion

Most adults with ADHD viewed their diagnosis as a positive event. In addition to gaining access to medication, a diagnosis also led to other accommodations. Such accommodations were viewed as central in improving success. Disclosure decisions were largely made because of the extent to which they would result in accommodations, allowing for additional avenues to success and an out for potentially deviant behaviors. Following a diagnosis, adults with ADHD were able to rewrite their narratives in light of their new status. An ADHD diagnosis allowed adults with ADHD to explain the vague and common problems of the past due to their undiagnosed ADHD. The benefits of diagnosis were so great, many adults with ADHD were angry that they had not been diagnosed
earlier in life. If they had been, they believe their lives would have been significantly better, and they would have had vastly different and more successful lives.
Chapter 6: Attention Deficit Disorder and Society

As C. Wright Mills states in *The Sociological Imagination*, “Neither the life of an individual nor the history of a society can be understood without understanding both (Mills, 1959, p. 2).” Mills believed that personal troubles resulted from and were shaped by problems of the society in which that individual lived. Until this point, this dissertation has focused on the personal troubles encountered by adults with ADHD, how they come to see themselves as sick, and the consequences of the diagnosis. While the lived experience of adults with ADHD is important in understanding how adults come to “know” they have the disorder, the goal of this chapter is to provide a more complete understanding of ADHD by placing the source of suffering and problems related to ADHD within their socio-historical context.

Clearly, the narratives collected for this study reflect this context and are consequently used to support statements related to the socio-historical context in which ADHD occurs. However, the effects of culture, structure, and history on daily life are often illusive and taken for granted. With several exceptions, most ADHD narratives explained the presence of suffering and disorder in the subjects’ lives through local terms.

As stated in previous chapters, the biomedical model minimizes the role that culture and history play in shaping disorder. In this orientation, ADHD becomes a problem that is relevant to all humans in all cultures throughout all of human history. For example, *The International Consensus Statement* on ADHD
implies that culture plays no role in shaping ADHD (Barkley et al., 2002). Similarly, Hallowell and Ratey (1995) speculate that children with ADHD were beaten and mistreated throughout all of human history. In this view, it is only through advances in scientific understanding that we are able to determine the source of these deviant behaviors. In conceptualizing ADHD as a neurobiological problem with a strong genetic component, the biomedical model places the source of suffering as being internal to the individual. Accordingly, alleviating that suffering has to do with interventions at the individual level.

Given the power of the biomedical perspective in shaping illness experience and knowledge (Barker, 2010), adults with ADHD usually framed their suffering and problems as resulting from abnormalities in their own biology. For example, when I asked adults with ADHD what caused the problems related to ADHD, most used biomedical explanations related to neurobiology, biology, or genetics. When environment was mentioned, it was usually related to environmental toxins that could ultimately affect physiology.

While I was certain that social factors play a role in how ADHD is experienced (as an illness), I was unsure of the degree to which ADHD itself is the result of modern existence. Despite the claims of biomedicine, I found it unlikely that the Yanomami Indians famously described by Napoleon Chagnon (1968), hunter-gatherers, or agrarian farmers would experience problems or suffer ways we now relate to ADHD. In thinking sociologically about ADHD, my goal was to move beyond local or individual explanations and to examine the
interplay of culture, society, and history on the experience of ADHD. This chapter examines the role these factors play in shaping understandings of ADHD. Specifically, this chapter highlights how the rise of self, increased stimulation, cultural expectations, and lack of personal agency can create suffering through exacerbating self-discrepancy. Our increased tendency as a society to explain problems through medicine allows for the development something we have come to call ADHD. Ultimately, it is my position that ADHD is not due to physiological abnormality.

**Rise of the Self**

As I highlighted in Chapter 4, much of the personal troubles encountered by adults with ADHD are the result of self-discrepancy, or a belief that the self should be able to do more than it has. However, the scope of problems associated with self-discrepancy is contingent on the increasingly prominent role the self plays as a source of value and meaning in modern society. It is my position that such problems would not have occurred in the past because the self has not always played such a prominent role.

As several sociologists have noted, the self has not always played a central role. In *The Division of Labor in Society* (Durkheim, 1984), Durkheim describes how an increasingly complex division of labor results in people relating to one another through interdependence (organic solidarity) rather than shared values or similarities (mechanical solidarity). In these advanced societies, individuals are driven by their own self-interests rather than the interests of the
group. Similarly, Tönnies (2001) describes differences between *gemeinschaft* (or community) and *gesellchaft* (or society). In *gemeinschaft*, the simpler social arrangement, Tönnies contends that there is a moderate division of labor, statuses are largely ascribed, values are shared, and individuals are more oriented to the collective good. Conversely, *gesellchaft*, the more complex social arrangement, is characterized by a complex division of labor with individuals acting in their own self-interests and an emphasis on achieved status.

Over time, increases in the complexity of divisions of labor and improvements in social mobility have led to more freedom, but they have also posed new challenges for the self. Rather than being told by society what to be, individuals must now search for their proper place in life (Turner, 1969). In simpler forms of society, questions such as “Who am I?” are unlikely to arise, with status largely determined by birth (P. Berger & Luckman, 1966). The means to answering that question and a central source of value in fulfillment is through the cultivation of self in modern society (Baumeister, 1991). The emphasis on answering that particular question is clearly reflected in the hundreds of self-help groups and books that have sprung up in the United States and across the world.

Today, to be a good/successful person, one must know the self, discover its potential and work toward unlocking it. As Abraham Maslow (n.d.) stated, “One’s only rival is one’s own potentialities. One’s only failure is failing to live up to one’s own possibilities”. The author Thomas Wolfe (n.d.) echoed those sentiments in the following quote: “If a man has talent and cannot use it, he has
failed. If he has a talent and uses only half of it, he has partly failed. If he has a talent and learns somehow to use the whole of it, he has gloriously succeeded and has a satisfaction and a triumph few men ever know.” In this context, the self becomes a project, one that should be constantly worked and improved upon. As Lash (1979) suggests, we now live in a “culture of narcissism” where individuals increasingly seek validation of the self. Due to the decline in traditional types of authority, we increasingly rely on the self to determine what that proper place is, largely through employment.

Narratives of study participants often described efforts to improve the self and to live up to perceived potential. Adults with ADHD were often enrolled in school, were in the process of writing books, or were engaging in other activities to improve the self and live up to expectations. Several examples are included below.

To try and combat the chaos of myself in general I started keeping a list of things to do at home, a system which has saved me from myself to certain extent. It's a lined A4 notepad with four columns of things to do (that should say 'things that need doing' I suppose). I eagerly cross things off all week and then every Monday morning (well, nearly) I copy all the things I haven't done onto the next page and fill up the remaining space with new things to do. There are things in the first column which I've been copying over each week for over five years. Some may sound familiar.......learn to play the guitar (yes, that guitar, the one I bought six years ago), varnish the shed door, clear out the cupboard under the stairs, finish writing book, finish writing other book, plan overland trip to South America, learn to drive (the world may be a better place if I don't), give up smoking, get new office keys cut (we've actually moved offices in the last five years but I've lost the spare set of office keys to the new place so there didn't seem much point crossing that off). The next column along, remnants of far more recent times, is more worrying, it's peppered with items of the abandoned dry cleaning and tax return variety — Doug (IN)
I have a great library of about 1,000 books and they're all the right ones. :) The classics, reference books, biographies, mysteries, business books, etc. Really good stuff, and they look great in the nice bookcases I've had built for the house too. I've only read maybe a dozen of them. When people ask me if I've read them all, I say "most of them." HA! Right now, I have 8 books on my nightstand that I've started (some I started years ago) and not finished. HA! — Andrew (IN)

To these adults, their inability to accomplish everything they desire indicates a problem. As Andrew says, he hasn’t read all the "right" books, although he has them on his bookshelf and feels as if he should have already read them.

Despite viewing themselves as failures due to their inability to live up to their potential, many adults with ADHD could be considered successful by many measures, as I and others have suggested (Conrad & Potter, 2000). However, due to the centrality of the self in modern life, these external evaluations of success are inconsequential. As Chester stated:

It’s like I’ve been able to do things, you know create things that didn’t exist before. So no, most people looking on would say “Gee, that’s pretty decent,” and but it doesn’t matter. None of it matters. It’s all what you feel inside. — Chester (male consultant, age 68)

As I highlighted extensively in Chapter 4, adults with ADHD believed they had the potential to do well, but found success lacking, largely through their own perceptions of the self.

Many of the adults with ADHD “knew” what they should do with their lives based on their own perceptions of what seemed right to them. These perceptions of what the self should do were often in direct conflict with forms of authority that might suggest otherwise. For example, Cathy (female lawyer, age 31) feels she should be a lawyer despite her repeated difficulty passing the bar
exam. Other examples of individuals’ efforts to self-determine are described below.

Let me take you back a little bit and describe my academic experience. I am very creative, and majored in art. In any given class I would have 5 or so projects going on at the same time, then when finals came around I either didn't finish them (because I got bored and moved on) or, did such a sloppy finish that my potential couldn't be seen. My professors (most of them in the department) were VERY frustrated with me. Some of them lost their temper with me, some just threw in the towel. At one point during those seven years it was suggested that I change my major completely, but I refused. Keep in mind that no one knew what ADD was in '93'94 etc... I knew that something was up with me; whereas, I knew that I was as smart as my peers but I was different, I couldn't put a finger on it. I had great difficulty paying attention in art history classes which consist of sitting still in a dimly lighted room looking at slides and listening to a lecture. Its no wonder that during my undergraduate history I went through THREE art history professors. — Marie (IN)

I'm 27 years old now and I'm in the process of changing careers. I graduated in Parks and Recreation Management, as it was the only thing I could stay focused in long enough to complete. But Parks and Recreation is not what I wish to do with my life. — Lance (IN)

As is clear in the quotes above, adults with ADHD would often rely on their own self-evaluations of where they should be in the world rather than the evaluations of others, even those in authority. As Higgins’ posits in self-discrepancy, this form of self evaluation leads to unique types of distress.

An emphasis on achieved status and choice coupled with changing economic realities also pose additional problems for the self relevant to ADHD. In America, we often assume that there is equality of opportunity and that hard work will result in a desired outcome. Lack of success in such societies has consequences related to how we come to see ourselves and cope with difficulties in achieving. As Dannefer (2000) suggests, “where ideology celebrates
individual mobility on the basis of individual merit, a behavioral response of working harder and faster is accompanied by a subjective tendency for self-blame” (p 285). It was typical for ADHD adults to work harder when they found success was lacking. For example, in trying to be successful, Stephen (male student, age 21) describes his efforts in school as “Herculean.” Sandy (female teacher, age 52) described her efforts to be successful in school this way:

I would work and I would work and I would work, until I made myself do it. So my stick-to-ittiveness, in fact that is what the woman said when I was diagnosed, she said, “Stop thinking of yourself as stupid, think of yourself that you have a lot of will power and you stick to projects once they’re started.” Well, because I don’t take “no,” I don’t take failure as an option. — Sandy (female teacher, age 52)

Like Sandy, when adults with ADHD were unable to succeed despite their hard work and potential, they came to believe something was wrong. It was common for adults with ADHD to blame themselves initially for their lack of success.

Recent historical changes and economic shifts have served to further exacerbate the potential for self-discrepancy. In the past, a college education was a ticket to the “middle class.” Although greater proportions of the population are educated, the value of education has recently come into question (Stoops, 2004). A college degree is no longer a guarantee into the middle class nor meaningful employment. In addition, social mobility as a whole has declined (citations). Consequently, problems associated with ADHD will only grow if these problems continue to get worse.

Multiple roles. Due to complex divisions of labor, individuals now often occupy a number of social positions or and have multiple identities (Gergen,
The high number of social positions brought about by modernity require individuals to self-consciously employ their positions as they cross various domains of daily life (Coser, 1991). As Thoits (1985) suggests, in occupying multiple roles, additional problems like role strain and inter-role conflict can lead to discrepancy in the self.

**Role strain.** Increased demands within roles can lead to additional stress and feeling like one is not living up to expectations. Adults with ADHD highlighted the considerable amount of role strain they encountered. Role strain was apparent near the time of diagnosis for many ADHD adults. For example, Anthony (male lawyer, age 56) described role strain as a driver for seeking help:

> Work-related stuff. I was practicing in a firm in Cleveland and I was on the road a lot and I would come in real early in the morning so that I could get home at a reasonable hour in the afternoon, and so I went in. I’d been out of the office for about a week and came in about 6:30 in the morning. I was in the office by 6:30 there that morning, and my desk was just stacked with stuff and I melted down right there on the spot. I just could not cope anymore, and I remember sitting at my desk and just staring at it ‘til 8:00 when I knew my family physician’s office was going to be open and I called him up and I said, "You’ve got to get..." I told him, “You’ve got to get me to talk to somebody right away.” I said “I’ve got to talk to somebody to figure out what the hell is going on.” — Anthony (male lawyer, age 56)

Anthony felt that the demands of travel and increasing office work were too much to cope with, leading him to seek help. Throughout our interview, William (unemployed male, age 37) described how he had become increasingly agitated at work, noting how he had to juggle his high case load with clients and attend staff meetings. As described below, William’s clients wanted to take the time to talk through their problems, but he felt pressure to see them as quickly as
possible. Many of the ADHD narratives collected indicated role strain near the
time of diagnosis.

**Inter-role conflict.** Occupation of multiple roles can lead to competing
demands across roles. For example, Maureen (female teacher, age 36) was in
the process of completing her PhD, raising children, and managing rental
properties, while at the same time working a full-time job. Like Maureen, Sandy
(female teacher, age 52) also occupied multiple positions, working full time while
completing her PhD and raising a family as a single mother. Both reported how
competing demands brought on by these roles inhibited their ability to complete
tasks. Maureen described how she was often preoccupied with tasks stemming
from these roles:

**Maureen:** I’m day dreaming about anything that’s not finished in my life or
what’s causing me stress. It’s usually not about my kids, it’s always about
tasks

**Interviewer:** Like what?

**Maureen:** Like for example, right now I need to sign a lease with one of my
tenants so I think about that. Umm, I have to umm, fax some documents to
our bank which again I gotta take my medication for a week so, I’ve been
putting it off putting it off putting it off and I keep thinking oh my gosh I gotta
do that today, I gotta do that today, I gotta do that today. But then yet I don’t
do that today so the tasks that I focus on not so much like people, ya know
like, I don’t worry about the kids or (my husband) or more of what needs to get
finished and how it’s going to get finished. — Maureen (female teacher, age
36)

**Roles and “to-do” lists.** Regardless of whether demands were
stemming from within a single role or from multiple roles, it was clear that adults
with ADHD felt more distress when they had a lot on their to-do list. The to-do list
emerged early in coding as a key driver for help seeking. Adults with ADHD felt
overwhelmed with tasks they felt they had to complete. As highlighted in Chapter 4, adults believed they should be able to complete these tasks based on their own appraisals of potential and comparisons to their reference groups. It is likely that adults who were diagnosed with ADHD took on additional tasks because they believed they had the potential to complete them. Then they would often encounter significant distress as tasks piled up.

More distractions and stimuli. Human beings are innately curious and drawn to novel information throughout our lives (Montagu, 1981). Put simply, human beings are drawn to interesting things. Today, there is much more access to novel information and stimuli than in the past. Scientists from a variety of fields have suggested that the amount of information in modern life has had an impact on how the mind works. As Georg Simmel suggested in *The Metropolis and Mental Life*, “the psychological basis of the metropolitan type of individual consists of an intensification of nervous stimulation which results from the swift and uninterrupted change of outer and inner stimuli” (Simmel, 1985, pp. 409-410). According to Simmel, this intense stimulation associated with modern life “agitates the nerves to their strongest reactivity for such a long time that they finally cease to react at all,” resulting in what he calls the *blasé attitude*. The advent of televisions, computers, smart phones, the Internet, and video games and a growing emphasis on multi-tasking have only increased the potential sources of information/stimulation since Simmel’s writing (Castells, 2000).
Much of what is known regarding the effect of increased stimulation on problems associated with ADHD has focused on children. For example, in *Ritalin Nation*, DeGrandpre (2000) argues that increased levels of stimulation in society have resulted in more stimulation-seeking behavior in children. According to DeGrandpre, ADHD is the result of children gravitating toward stimulating tasks instead of those boring tasks that are often deemed important by authority figures. Children would rather be playing or drawing than reading or doing math problems. Like Conrad’s (1976) examination of hyperactive children, DeGrandpre’s arguments largely view ADHD as a means of social control used by authority figures in schools. However, statements regarding the effect of increased stimulation on ADHD have largely been dismissed by the biomedical model. For example, Shaywitz’s (1999) review of DeGrandpre’s work tacitly acknowledges that there might be a cultural effect related to ADHD. Despite the lack of specific etiology and physiological evidence provided by biomedicine, Shaywitz ironically falls back to the biomedical perspective, arguing that DeGrandpre does not provide sufficient evidence to link culture and increased stimulation to ADHD.

Yet a clear association between exposure to various sources of stimulation and ADHD symptoms (not the disorder itself) in children has been established. For example, ADHD symptoms are linked to television watching (Christakis, Zimmerman, DiGiuseppe, & McCarty, 2004) and playing video games (Chan & Rabinowitz, 2006). Several recent articles suggest that
exposure to forms of digital stimulation can result in a brain that is more easily habituated and less able to sustain attention (Dworak, Schierl, Bruns, & Strüder, 2007; Richtel, 2010). Similarly, multitasking has also lowered one’s ability to pay attention (Grafman & Krueger, 2009; Rosen, 2008). High levels of stress have also been associated with a lowered ability to focus on tasks (Knouse et al., 2008).

While this study cannot determine whether brains were rewired, the sheer amount of stimulating information in modern life did pose problems for adults with ADHD included in this study. For example, Stan describes his curiosity about novel information this way:

What I like to do, or what I would like to do, 'cause they’re two different things? Well I guess what I like to do is I…See I think my like ADD contributes to me being bored with norms or fixed forms, and so I have a natural desire to seek out anomalies, so I'm curious. I spend time. I may even have a news addiction, political and social commentary, and it’s been a hell of a last nine years. There’s been a lot of stuff. — Stan (unemployed male, age 56)

Similarly, Mark described how the Internet and information stemming from it were particularly interesting and often distracted him from other tasks.

Mark: It’s kind of I think I use the Internet as a way to escape, because I don’t want to do anything that I don’t want to do. Does that make sense?

Interviewer: Yeah.

Mark: Yeah. I mean and the more you read online, the more, you know the more you are hooked onto it, you know? I mean I don’t play games. I don’t watch pornography or anything like that. I don’t gamble, but it’s just a, you know sometimes you do a message word. You know you’re just reading all kinds of stuff. I think the stuff that interests me most are sports and culture I think, pop culture. I would occasionally talk online, but not frequently. — Mark (unemployed male, age 25)
A number of adults with ADHD described enjoying and being good at highly stimulating tasks. The biomedical literature also highlights how individuals with ADHD may hyper-focus on tasks they deem enjoyable or stimulating. As I highlight below, the tendency to hyper-focus is viewed as a problem only when the task is not related to productivity.

**Cultural Expectations**

In her examination of chronic fatigue syndrome (CFS), Ware (1999) suggests that specific cultural expectations make it difficult for individuals with CFS to conform. Specifically, individuals with CFS cannot keep up with expectations for constant activity, speed, and “scheduledness” that are expected by modern societies. Similarly, much of the medicalization literature views medicalization as a process of recasting deviant behaviors as medical problems (Conrad & Schneider, 1980). As Thoits (1985) suggests, perceived deviance from expected norms plays a central role in those who self-label with mental health problems. Based on Thoits’ work, I would assume that an ADHD adult is:

A well-socialized actor who, by sharing the cultural perspectives of the larger society, can recognize rule breaking or the violation of normative expectations. Second, there are known categories of norms whose violations carry cultural labels that can be applied to persons who perform such behaviors...The third assumption is that the actor is motivated to conform to social expectations (pp. 223).

In examining ADHD, it is important to consider those cultural expectations to which adults with ADHD have difficulty conforming. In other words, what expectations for behavior are adults with ADHD violating?
In many ADHD narratives, individuals had difficulty adhering to standards related to perfection and efficiency. In reviewing problems of adults with ADHD, I was reminded of a quote by Georg Simmel (Simmel, 1950), who said in *Metropolis and Mental Life*:

Punctuality, calculability, exactness, are forced upon life by the complexity and extension of metropolitan existence...these traits must also color the contents of life and favor the exclusion of those irrational, instinctive, sovereign traits and impulses which aim at determining the mode of life from within, instead of receiving the general and precisely schematized form of life from without (p. 413).

As Simmel's quote suggests, the emphasis on perfection and efficiency is symptomatic of a modern existence. Rather than developing within the individual, these expectations stem from external sources, usually institutions. The difficulty that ADHD adults in this study had in adhering to these cultural expectations played a central role in them labeling themselves as deviant.

**Perfection.** “Perfection” (and related terms such as exactness, faultlessness, flawlessness) has long been an ideal that humans beings have sought. In modern American life, perfection has taken on profound meaning. Perfection regarding objects in daily life has become so common that marketplaces have sprung up for imperfect objects. As the author Chuck Palahniuk joked in his novel *Fight Club*: “I had it all. Even the glass dishes with tiny bubbles and imperfections, proof they were crafted by the honest, simple, hardworking indigenous peoples of wherever” (Palahniuk, 1996, p. 15). With few exceptions, objects that come close to perfection are those that are highly valued in modern American life. As highlighted above, Simmel suggests that the values
of exactness or perfection have been forced upon daily life by a modern existence. In rural life, we can assume that such an emphasis on these values did not exist to such a great extent if at all.

The notion of perfection in modern life extends well beyond objects. In *The Protestant Ethic and the Spirit of Capitalism*, Weber (1958) argues that Protestant teachings lead to the rational struggle for perfection as a reflection of God’s providence. Consequently, the appearance of perfection is central to perceptions of the self. Today, being “perfect” is important in establishing whether a person is “good” or not. We often hear about a “perfect family,” “perfect partners,” or “perfect students.” Attaching the label of “perfect” to a status implies success in that role. Inability to live up to that expectation suggests inferiority.

The value of perfection has permeated all institutions. In bureaucratic organizations, being perfect typically involves the extent to which individuals adhere or perceive themselves to adhere to formal regulations (Weber, Gerth, & Turner, 1991). Most institutions have clear formal systems of ranking individual performance, through grades, reviews, raises, promotions, pay, etc. Anything produced in work or school that is less than perfect is often seen as inferior. When individuals adhere to standards, there are usually positive outcomes. If an employee or student is less than perfect, there can be negative consequences, usually in the forms of poor grades, evaluations, labels, and a variety of other sanctions.
In this study, difficulty in adhering to ideals of perfection was especially common in educational domains. Several ADHD adults described difficulty in paying attention to small details in writing, spelling, or math. Such difficulties were commonly understood as symptoms of ADHD rather than the unrealistic standards of perfection in modern life. Others described problems adhering to standards of perfection in more complicated tasks. Sandy (female teacher, age 52), who was attending school for singing, described her difficulty in adhering to expectations for perfection below:

There are several events that stand out. Of course when I was diagnosed when I was 24, I was singing in the opera and I had already had my first degree. My first degree was in music and performance, and so I was singing an opera and I kept singing certain arias in French backwards…I kept singing them backwards and the professor at the time was an off-and-on drinker and so he was off the wagon at that time and...throws down this script and he is screaming at me, “What’s wrong with you? Are you so stupid?” and again my whole life I would always say, people would say “You’re stupid, you are just stupid,” and for years I would believe I’m stupid. Again you believe what people tell you forever. But anyway, he threw the paper down and said “I want you tested, you must be so stupid there is something wrong with you.” And I’m thinking, “Oh my God, in front of all these people he was saying this.” I can see it as plain as day. It’s like it happened yesterday but obviously that was over 25 - 20 years ago. — Sandy (female teacher, age 52)

To Sandy, her inability to sing arias in French, a language she does not speak, during a rehearsal in front of others is indicative of a problem. Based on her own ascertains of self, Sandy believes should be able to do this. Sandy and her professor frame her problems as internal—something is wrong with her because she cannot sing perfectly.

Many of the difficulties in adhering to perfection were related to maintaining perfect grades. As with several others, Mary (female student, age
20) was worried about not maintaining a perfect GPA in college, seeking a diagnosis after a slight drop in grades. As she described:

Probably about my second semester at <university>. I’m a junior now, so I just, my grades started dropping off. Like all through high school I had a 4.0 grade point average and my grades just started dropping off a little bit and I thought “This coursework isn’t any more difficult, but I’m having trouble with it.” — Mary (female student, age 20)

Similarly, Mark (unemployed male, age 25) described his grades this way:

**Interviewer:** And how’d you do in high school and college?

**Mark:** High school I got maybe a 3.7 or 3.8, maybe a 3.6. College, I graduated with a 3.7.

**Interviewer:** So pretty good.

**Mark:** Well I mean could be better. Could be a lot better. — Mark (unemployed male, age 25)

Joe (male student, age 21) and his peers were clear on the meaning of grades in determining future outcomes, particularly in getting into medical school.

Like the pre-meds all talk to each other ‘cause you know grades are like everything, so we would talk and you know they’d be like “Yeah, OChem was such a bitch. I spent like nine hours yesterday reading all the chapters,” and I’m just thinking, “Wow, I had to spend four days to get through all those chapters, and that’s all I did for four days.” — Joe (male student, age 21)

As I have stated above, perfection as a value often stems from external stakeholders rather than internal sources. In the cases highlighted above, these external stakeholders include graduate and professional schools as well as employers. To Joe and other pre-med students, the drive for perfect grades has meaning because they will enable entrance into medical school and future success. Mark is especially concerned that his “poor” grades may make it difficult for him to get into graduate school. Consequently, anything less than
perfect represents a problem. Like Joe, Mary, and Mark, others also noted the importance of grades in determining both current value and future success.

ADHD narratives also described difficulty with perfection in the domains of work. As Maureen (female teacher, age 36) described:

At that time I was getting my Master’s degree online; work was…I really was getting in trouble for my paperwork, like I couldn’t, an Individual Education Plan involves a lot of documentation, a lot paperwork that has to be, it is a legal document, so everything has to be done a specific way, if not done that specific way, our school can get in trouble. So…my boss had to come to every single one of my meetings to make sure, just for my paperwork, she had to sit next to me to make sure my paperwork was done, and then I started, I was the first one in the district to use a computer, so I wouldn’t lose the paperwork, so like all those things I was thinking I gotta do something because I can’t be the only one in the district that misplaces things, stuff like that. but at least my boss was understanding and like pulling for me, like I never got written up for anything, like I never did anything egregiously wrong, but, I don’t know but it helped. — Maureen (female teacher, age 36)

When filling out an “Individual Education Plan,” Maureen believes there will be negative consequences for any mistake, both for herself and for her employer. Despite having an understanding boss, she still feels the pressure to adhere to the standards related to perfection quite acutely. If she doesn’t adhere to these high levels of perfection, she may be viewed poorly.

Difficulty adhering to standards of perfection was also related to home and family life. Rachel (retired female, age 61) talked about difficulty in doing taxes, noting that any mistakes could result in negative consequences. She also believed she needed to maintain a perfectly clean house:

I thought I was doing what I was supposed to be doing, but I wasn’t; it’s like I wasn’t seeing things. It’s a very weird feeling. I know that the pictures were crooked, I guess, because I had dusted, but it didn’t register in my brain. So you know I’ll tell you, so after this all, after this medicine, after a while it was like I was sitting in the kitchen one day and "Wow, did the bottom of the
refrigerator always look like that?” I’m tearing stuff apart and I’m cleaning, and I have to tell you the funniest thing is that in closet I’m just, you know it was like what a disaster. Nothing was organized. Now I mean and it’s so easy now. I have things that are organized by colors, just my choice to do it that way, I mean and it makes sense for me. — Rachel (retired female, age 61)

To Rachel, pictures being crooked and the presence of dust deviate from these standards of perfection.

Similarly, Trudy (IN) compared her imperfect family life to the idealized portrayals of family life in Leave it to Beaver and The Brady Bunch in the following quotation:

Life was one big drama for us. My husband and I divorced after 27 years of fighting and frustration and one child ran away, another chose to turn lesbian, one got pregnant and one was doing drugs and drinking. I was devastated. All I have ever wanted since I was a young girl in the 1950’s was to marry and have a family. Of course I believed in "Leave it to Beaver" and the "Brady Bunch" and just knew that MY family would be happy, healthy and functional...yeah right! — Trudy(IN)

Difficulty in adhering to norms related to perfection was common across ADHD narratives. Adults with ADHD believed that they should be able to adhere to those standards based on their high ascertains of the self. Deviation from these standards resulted in ADHD adults feeling like something was wrong. However, perfection is often unreachable. As Pacht (1984) argues, the drive to perfectionism results in a “no-win” scenario for individuals, leaving individuals constantly frustrated and unable to enjoy success.

The value of efficiency and timeliness. In the United States, efficiency and timeliness have long been core values. As Benjamin Franklin said, “You may delay, but time will not.” American workers are often lauded for their
efficiency, with much of this country’s success being attributed to it. The federal
government is criticized because it is inefficient. Companies that can produce
products efficiently are the ones that are successful. Individuals who can achieve
tasks efficiently are those who achieve long-term goals. “Wasting time” has also
become a common problem. Efficiency and timeliness were an ongoing issue for
many with ADHD.

Not being able to do things on time results in negative consequences.
Continued employment is contingent upon performing activities by a certain time.
Homework and papers have due dates. Bills need to be paid on time, or one
risks having services cut off or penalties added. Leisure and social activities are
also scheduled, often well ahead of time. Clearly, timelines and deadlines must
be met, or negative consequences can result.

As with perfection, those who able to meet deadlines are those who are
deemed “good” by society. In the DSM IV and on many ADHD screening
instruments, frequently missing appointments or difficulty meeting deadlines are
symptoms of ADHD. It should not be surprising that adults with ADHD reported
difficulties keeping up with the scheduled nature of life. However, biomedical
approaches assume that the value of time is shared across cultures and times.
As highlighted above, Simmel (1950) suggests that punctuality has been forced
upon daily life through existence in modern life. Similarly, Hagestad (1988)
suggests that our sense of timing stems from the social milieus in which we live.
Neugarten (1969) argues that schedules provide us with expectations for a
normal day, informing us how life should unfold. Consequently, the timing of an event can have consequences for meaning making. Likewise, Ware describes “scheduledness” as a cultural expectation, one that has increasingly penetrated everyday life. A wide range of sociological research has suggested that our perception of the pace of daily life is that it is accelerating (Hochschild, 1997; Schor, 1993), resulting in individuals feeling more harried (Southerton, 2003).

Adults with ADHD were acutely aware of the difficulties they had in performing tasks in a timely fashion. They often noted how they perceived themselves as behind or how they procrastinated. Many adults with ADHD noted the external pressures to achieve tasks efficiently. For example, while completing his PhD, Chester had gained real world experience working for a college. However, this work got in the way of completing his dissertation, requiring him to ask for an extension as he described below:

You know dramatic way it happened with my dissertation for my doctorate, which itself is advanced, ‘cause I got involved with a non-traditional college and worked with it for a bunch of years and put my dissertation on, sort of like on the side and then only came back and finished it when the Statute of Limitations came knocking on the door and I had to…put up or shut up, right. Right. So I got a year’s extension because I had been working for this college. They figured that was the best excuse they’d heard in a while, so they let me have like ten years instead of nine, but meanwhile I had to do it in that year or else, and I did. — Chester (male consultant, age 68)

Others noted their inefficiency in school-related tasks. While Joseph is clear about the importance of perfect grades above, his quote also suggests that he believes he is not as efficient as his peers and that he has to put in more time and energy to receive the same outcome.
Efficiency as a value has also created other problems. Due to the expansion of technologies and ongoing efforts to make workplaces and services more efficient, an increasing number of tasks have fallen to individuals. As Juliet Schor (1993) has argued in *The Overworked American*, employers are asking more and more from workers both in terms of time and productivity while simultaneously providing less and less support.

Adults with ADHD were acutely aware of difficulties associated with efficiency, as is clear in the following quote by Greg:

> Unfortunately, the environment I have allowed to evolve is killing me anyways. Work is a disaster due to corporate changes and people who only know how to say YES to those who have no idea how to run a business. You have to do much much more in less and less time. Then as I come home I get hit with MORE and GREATER stress. — Greg (IN)

Ken, (unemployed male, age 32), who was running a fledgling law practice, was forced to become more efficient due to financial difficulties. He described his difficulties when he lost his assistant this way:

> At that time you know financially I couldn’t afford to maintain an assistant anymore, and he was a friend of mine and we mutually decided that he should go find employment elsewhere, which he did. He found a better job, and so it worked out for everybody as far as that goes, but when I didn’t have an assistant anymore taking my phone calls, organizing my files, and when I was in a position where I had to do all the things that an assistant used to do on my own, it wasn't getting done, and it wasn't for a lack of time on my part. It was just a lack of focus, and I never really realized what all the assistant was doing for me and I didn’t realize how dependent I was on that for getting the basic details of my practice done basically. So that’s really what happened is when I didn’t have an assistant anymore, that’s when it really got bad and I really started noticing. — Ken, (unemployed male, age 32)
After he loses his office assistant, the demands at work increase dramatically for Ken. He believes he should be able to accomplish all of the tasks on his own, but he is unable to. Shortly after losing his assistant, he seeks help.

Like Ken, William also felt the pressures to be efficient given the demands at work:

When it started affecting my work. I actually put a lot of effort toward listening to the people I work with because, you know, I have to talk. I had a case load of 35 people and I had to listen to them and sometimes I’d get—you know, I wanted them to come right to the point and also we had a lot of staff meetings that over the years, the six years I was there, the staff meetings just got to the point I was “Oh my gosh.” — William (unemployed male, age 37)

For William, clients who wouldn’t get to their problems quickly and many staff meetings were getting in the way of doing his job quickly, leading to stress.

While many adults with ADHD described difficulty in completing specific tasks in a timely fashion, ADHD narratives often described being “off time” in their lives. As a wide range of life-course research indicates (Neugarten, 1969; Settersten & Hagestad, 1996), there are negative consequences to perceiving one’s self as “off-time” or not adhering to scheduled patterns in the life course.

In our interview, Stan (unemployed male, age 56) described how he often took a long winding path in completing goals rather than taking a more direct route. To Stan, those who were able to stay on that direct line were the ones who were successful. Consequently, his inability to stay on this direct line is why he finished college at the age of 31. For Stan, finishing college so late was a source of stress and evidence of a problem.
Difficulty with long-term goals including completing a degree or securing meaningful employment was common across ADHD narratives and became a key indicator that something was wrong. ADHD adults wanted to adhere to norms and felt they should be able to, but for some reason they continually came up short.

Several researchers have suggested that regardless of how closely individuals adhere to cultural ideals, they typically feel like they are not meeting these standards. For example, in his study of thinness norms, Dornbucsh et al. (1984) argues that it is the high status and already thinner than average females to be most at risk for anorexia nervosa. Likewise, Lawrence (1984) suggests that office managers often see themselves as “behind time” even when these perceptions are inaccurate. Despite doing well in many ways, adults with ADHD felt they were not able to live up to the standards of perfection and efficiency that are commonly expected in society.

**Lack of Personal Agency**

In sociology, there is an ongoing debate regarding the primacy of agency over structure in shaping human behavior. Agency is defined as the capacity of an individual to act independently in the world, to make his/her own choices. Structure refers to the patterned set of rules and resources associated with groups that constrain behavior. Those who recognize the primacy of agency suggest that actors are able to choose their behavior and minimize the influence that structure has on these choices. For example, Giddens (1991) has argued
that the decline of traditional forms of authority have created more opportunities for individuals to self-determine. Those who favor structure emphasize how structural conditions influence behavior and limit agency. Simmel argues that structures in modern life emphasize the “exclusion of those irrational, instinctive, sovereign traits and impulses which aim at determining the mode of life from within, instead of the general and precisely schematized form of life from without” (Simmel, 1950, p. 413).

While I do not expect to end this debate within sociology, throughout their narratives, adults with ADHD described difficulty in self-determining. Adults with ADHD often described difficulty completing those tasks that they “had to do” instead of those they wanted to do. These “had-to-do” tasks were typically established by institutions rather than stemming from within individuals and included taking certain classes in school, doing taxes, or any other tasks they found difficult, boring, or unenjoyable. Examples are included below:

Finally when I got to high school and you choose your own classes, and I would choose things in the arts. I would excel at like drama, music, but everything else was Cs, Ds, and Fs, and I could never do homework. You know I got Cs, Ds, and Fs and never doing any homework. — Stan (unemployed male, age 56)

I ended up in a special math class where I was able to begin to learn well and then that was cut short and I was thrown back into regular math class and you could guess what happened from there, I just didn't get it and still cannot, I can add and do very minor multiplication but anything other than that I have severe difficulty, this includes money counting as well. I recently graduated from Medical Assistant school, even though I passed at 92%, I almost dropped out when medication administration started because "math" was necessary to calculate dosages. — Dwanna (IN)

I do good one-on-one or even group client work, but I’m horrible at writing the closure report. I mean I am trying right now to do closure reports. If I don’t
get done by the end of this week, I’m going to lose $5000 to $10,000 of income, and I’m still having a horrible time of getting the focus of what I’m doing. So and I do think some of that’s habit, but you know some of it is habit of 30 plus years, so I’m having a hard time breaking it. So what I want to do is get myself in a situation where these reports aren’t necessary, and I had that situation for a while and then I had to change the focus of my business. — Edward (male counselor, age 57)

While many adults described how they had difficulty with tasks they “had to do,” they described few problems with tasks that they enjoyed doing. As we can expect, some tasks included things like watching TV, going on the Internet, or other stimulating activities. When engaging in these enjoyable tasks, many adults would often feel guilty because they believed they were not living up to expectations related to efficiency and productivity.

However, when they found work or a task to be both enjoyable and productive, it was viewed positively. Chester described how he didn’t have many problems in the job that he found highly rewarding. He described it this way:

Well no, I mean I think that part of what’s going on in my life at the moment is I’ve managed to be involved in things that are all high stim…There’s highly stimulating in the sense that very engaging, things I really believe in, where the stakes are high personally and in terms of the impact, and so that it’s almost like a good substitute for Adderall. And then I don’t seem to get easily bored. I always know, you know I’ve got a list of things ahead that I want to do and it’s a question of, the hardest part is deciding which one to do, not…I can’t even remember the last time I ever felt bored in my life. And then I’m blessed with the ability to be able to relax when I need to and want to, and then I have a wife with whom you know we can do that together really well, and so I’m lucky about that. — Chester (male consultant, age 68)

Similarly, Wayne described:

Oh man, let’s see, like sociology, psychology, the education courses. I liked the English courses, depending on the authors, but in general it was just I enjoyed that. It’s just something with the creativity of it, it just kind of takes you away. And then after I got, well I’ll say I got in the business world, I discovered I had an aptitude for computers and I mean that was like taking
heroin, working on computer stuff again. I’d get lost in the accounting and the system stuff, the whole thing, and I took accounting and I hated it, but something would, this huge process of balancing numbers you know and having something start here and it’s supposed to come out this way, it triggered whatever, you know, my brain. — Wayne (male teacher, age 61)

Lack of personal agency was also clear in job-related tasks. William described how exerting agency in his job got him into trouble below:

Interviewer: Well, how did they want you to do things? Just out of curiosity?

William: I would move around a lot. Like I’d, I’d never call my guys up to the front desk because there is a warehouse and they worked in the back. They live in the building, but they also work in the back helping them sort the clothes. Um, I would go in the back and get ‘em. I would walk in the back and actually get ‘em and bring them up and that’s what I’d do in between each session, each change session. I’d go back and get ‘em and bring them up and I, um, that gave me a little time outside of the office to move around. You know, cause I hated sittin’ still in that office. Um, they didn’t want me to do that. They wanted me to sit still in the office all day.

Interviewer: Did they give you a reason why they wanted you to do that?

William: Honestly, between you and me, I think it was just a control. Um, they wanted to let everybody know, I mean it wasn’t just with me, they wanted everybody to know that they were in charge and this is how they wanted things but I just couldn’t, I couldn’t do it and their staff meetings were 4 hours, 4 hours long. I thought that was the most fucking stupid thing in the world. Four hours long, and I did it for like a month and a half and I couldn’t take it any more. Even with the Ritalin. I was just done. So, yeah, that had, that played a big part of it. — William (unemployed male, age 37)

William believes his bosses are just trying to exert control. His inability to act in self-directed ways eventually causes him to leave his position.

Medicalization

As Mills states, “many great public issues as well as private troubles are described as ‘the psychiatric’—often it seems, in an attempt to avoid the large issues and problems of modern society” (Mills, 1961, p.12). Since Mills’ writing,
the process of medicalization or “the process by which non-medical problems become defined and treated as medical problems has become a central interest for medical sociologists. As several have noted, medicalization has changed and continues to expand (Clarke, Mamo, Fishman, Shim, & Fosket, 2003; Conrad, 2005). Societies are increasingly coming to explain a range of problems through a medical terminology with medical treatments.

As discussed in Chapter 2, medicine has increasingly focused on deviant behaviors or emphasizing normalcy. As Foucault (1973) has suggested, physicians increasingly employ the "medical gaze" to explain deviant behavior. Likewise, Conrad and Schneider (Conrad & Schneider, 1980) suggest that medicalization has increasingly focused on deviant behavior. In these approaches, medicalization results in increased social control. Foucault also provides insight into the process of self-labeling, arguing that social control has become consensual (Foucault, 1977). In other words, individuals become the source of their own social control, acknowledging their own deviance in trying to do something about it. As Barker (2010) contends, patients are increasingly active participants in medicalization, attempting to resolve and legitimate their own suffering.

As highlighted above, adults with ADHD often felt guilty when doing things they “wanted to do” as opposed to things they “had to do” or “should be doing.” Additionally, they often felt guilty that they were not doing things perfectly, efficiently, or on time. In deviating from these norms, adults felt they were not
living up to their “ought self.” Consequently, the process of self-labeling with ADHD increases social control by reinforcing these expected behaviors. As highlighted in Chapter 5, adults with ADHD often believed that medication allows them to adhere more fully to standards for behavior.

Despite sweeping statements by biomedicine, social scientists have noted for some time that culture plays a central role in shaping the experience of illness. In understanding illness as a social construction, social scientists have noted that something can be both real and socially constructed (Barker, 2010). The experience of widely recognized “real” disorders varies widely across space and time. For example, the experience of HIV/AIDS, cancer, and epilepsy differs greatly across cultures and time periods. Social scientists have been particularly interested in examining the ways in which cultures come to define both health and illness (Brown, 1995).

Even in the DSM, a wide range of cultural bound illnesses are acknowledged (disease within a specific culture or society) (Hughes, 1998; Prince & Tcheng-Laroche, 1987). For example, “susto” and “dhat” are considered culturally bound syndromes. Although some argue that all illnesses are in some way culturally bound (Kleinman, 1991), there is growing concern regarding westernization of mental illness, that is, the concern that the dominance of western biomedicine is shaping the expression of illnesses in other cultures (Lee, 1996; Watters, 2010). However, culturally bound disorders are usually limited to conditions in nonwestern cultures. Although several have
argued convincingly that anorexia nervosa is a culturally bound system in the West, influenced by mass media and an emphasis on thinness (Lee, 1996; Swartz, 1985), it is not listed as a culturally bound syndrome in the DSM IV.

As W. I. Thomas’s (192) definition of the situation suggests, strongly held cultural beliefs can and do have consequences on health. One of the best examples of this fact is Walter Cannon’s study of “Voodoo” death (Cannon, 1942). In his study, Cannon argued that belief in curses was deeply rooted in cultural understandings of native peoples from around the world. If a man believed he was cursed, he would begin to withdraw from society out of fear, denying himself both food and water. Other social actors who avoided the cursed individual would reinforce the belief in the curse. The resulting terror would cause the individual to go into shock and ultimately die. Although Cannon’s work was largely based as on second-hand accounts, his work has largely been accepted by the medical community (Lex, 1974; Sternberg, 2002).

As highlighted in Chapter 2, cultural context plays a particularly powerful role in mental health with stress being determined by the meanings and significance attached to an event rather than the event itself (Jacobson, 1989; Pearlin, 1989).

Throughout this chapter, I have highlighted some of the cultural factors that lead to the problem of ADHD. In framing these problems as internal to the individual and related to one’s biology, the medical model draws attention away from the structural causes. When these problems are treated pharmaceutically, the status quo is maintained and existing societal values are reinforced.
Conclusion

Despite the lack of consensus on specific etiology and considerable debate associated with ADHD, the biomedical model assumes that ADHD is the sole result of physiological abnormalities in the brain. As others have suggested, the role of culture has been downplayed by the biomedical models, particularly in mental health problems (Karp, 1996; Kleinman, 1991). In this chapter, I have highlighted the central role culture has played in shaping problems and suffering associated with ADHD. Rather than viewing ADHD as a problem with physiology, I believe social factors are sufficient in themselves to explain the rise of suffering we now relate to adult ADHD. In this chapter I have provided an overview of cultural and societal issues that help to explain the rise of ADHD in modern life. Specifically, I have highlighted how the rise of self, increased stimulation, and cultural expectations coupled with limited personal agency has led to suffering. The expansion of medicalization allows us to explain that suffering through a medical lens. In so doing, current values and expectations are reinforced. As society continues to change through increasing standards and decreased social mobility, the problems associated with ADHD will only continue to get worse.
Chapter 7: Conclusion and Epilogue

As I have highlighted throughout this dissertation, especially in Chapter 1, there is considerable debate regarding the reality of ADHD. Is ADHD the result of a physiological abnormality in the brain as suggested by the biomedical perspective? Or is ADHD the result of social conditions? Much of the biomedical literature has focused on determining the specific etiology of ADHD, the effects abnormalities have on behavior, and development of more efficacious treatments. With a few notable exceptions (Breggin, 2001; DeGrandpre, 2000), those who argue that ADHD is the result of social conditions have typically focused on the power of medicine to define behavior, the large profits of pharmaceutical companies, and the lack of a widely accepted specific etiology for the disorder. In other words, much of the criticism of adults with ADHD has focused on the social construction of medical knowledge. Both orientations have largely centered on the “disease” component of ADHD or the “abnormalities of the structure and function of body organs and systems” (Helman, 1981, p. 548).

When I began this dissertation, my position in this debate was one of ambivalence. Initially, I had embraced the biomedical understanding of ADHD, seeking a diagnosis and using medications. However, I felt that the biomedical paradigm was understating the influence of culture and social factors on the experience of ADHD. Consequently, my initial concern was to focus on how ADHD was constructed by adults who had been diagnosed with the disorder. Eric Cassell’s (1976) distinction between “disease” and “illness” was particularly
helpful in framing my initial research questions, noting that “disease is something an organ has; illness is something a man has.” Rather than looking at “disease,” I wanted to look at “illness,” or how adults with ADHD came to understand and cope with the problems they associated with disease/disorder. For some time, social scientists have viewed this distinction as important, noting that “illness” is largely influenced by social and cultural contexts and personality traits (Fox, 1968). Even the responses to “real” disease and physical symptoms are influenced by social and cultural factors (e.g., Zbrowski, 1952). Because so little research has been directed at understanding the illness experience of adults with ADHD, I thought this approach would provide additional insight into the disorder and suffering related to ADHD.

As Helman (1981) has noted, there is some overlap between disease and illness. It is usually presumed by biomedical perspective that disease is the underlying source of those problems associated with illness, suffering being the result of physiological abnormality. Application of this causal order is often true for many conditions. However, applying similar reasoning to mental health conditions is often more complicated. For example, the biomedical perspective views depression as the result of physiological abnormality in the brain. As Kleinman argues, depression cannot be understood to be the result of biological causes alone (Kleinman, 1991). Similarly, based on the work of Kleinman and others, Karp (1996) suggests that the abnormalities that develop in the brain are, at least in part, due to life events and social factors.
By employing a social constructionist perspective, I inadvertently entered this debate, suggesting the truthfulness of one perspective over another (Barker, 2010). While I have provided a compelling case for understanding ADHD in adulthood as a social problem, I cannot prove that ADHD does not exist in a biological sense. Clearly (and as I suggest in earlier in this work), proponents of the biomedical paradigm who contend that ADHD has no cultural basis are overstating the strength of their findings. However, based on my own research and general weaknesses of the biomedical paradigm in explaining problems, I argue that ADHD in adults is more social than it is biological. Framing ADHD in this way has several benefits over the current biomedical paradigm (as highlighted in chapter 7). However, as a scientist, I do not want to fall into that same type of dogma as proponents of the biomedical paradigm and am open to the evidence as it arises. Sociologists can (and have) acknowledged that something is both socially constructed and real (Barker, 2010).

Of the social factors highlighted in this work, the rise of the self in modern life is of central importance in the ADHD debate. Without the highly central role of the self, I do not believe the suffering we now attribute to ADHD would be possible. Specifically, the problems associated with ADHD arise from culturally situated interpretations of the self. Once the self has been established as the central source of value, self-discrepancy becomes a major problem for individuals to cope with.
Figure 3 highlights how self-discrepancy related to ADHD is exacerbated by social factors. Specifically, through an increasingly quantified self and the perceived value of intelligence in modern society, adults with ADHD expected their outcomes to be better based on their perceptions and interpretations of intelligence and potential. Comparisons to reference groups served to exacerbate self-discrepancy by highlighting what the ought self should be capable of and where the actual self was. Such comparison’s were often based on inaccurate information, with adults with ADHD examining their own messy back stage processes of the self and comparing these to the idealized front stage presentations of others (Goffman, 1959).

Lastly, culturally situated understandings of perfection, timeliness, and efficiency allow adults to understand what the normative expectations are for
behavior. ADHD adults find themselves deviant for not living up to these high standards. Suffering is the result of the increased sense of self-discrepancy. The rise of ADHD is also contingent on society’s increasing tendency to explain problems through a medical lens (medicalization). As highlighted in Chapter 5, adults with ADHD embraced a diagnosis due to its ability to describe past problems of self. In essence, ADHD is the application of a medical explanation being to describe problems of self-discrepancy.

This research shows that identification of ADHD in adulthood is somewhat distinct from factors the childhood disorder. As Conrad (Conrad, 1976) suggests, children are often identified by others, usually those in positions of authority, as having ADHD. These children are often identified in an effort to address overt forms of deviance and thus improve social control in the school or home setting. Rather than being identified by those in position of authority, adults with ADHD largely self-label with ADHD. Adults arrive at an ADHD self-diagnosis through self-appraisals, perceiving a discrepancy between the ought self and actual self. Understanding the importance of these self-appraisals of suffering gives us insight into why “successful” adults could view themselves as failures. In addition, this research suggests that a lack of agreement between individual and parental recall of ADHD symptoms (Dias et al., 2008) may be due to self-perceptions of failure. When ADHD is viewed as a problem of self-discrepancy, new insights are provided, particularly in the reaction to being
diagnosed. This research also has implications for ADHD research, adults with ADHD, and policy. These implications are discussed below.

The Impact of Diagnosis and Self-Discrepancy

Why is an ADHD diagnosis and the medication associated with it viewed so positively by adults who have been diagnosed? What drives some adults to disclose their diagnosis status? Why do rewritten narratives take the shape and form they do following an ADHD diagnosis? As highlighted above, before diagnosis, problems were initially viewed as a result of personal weakness for many of the respondents. Rachel (retired female, age 61) described it this way:

I just had that feeling that there was something you know missing. Things weren’t clicking. So I went and I was tested. I mean I wouldn’t have been oblivious my whole life thinking that…First of all, I mean when I found out about the depression part of it, I mean who knew from you know years ago, I just figure that “This is just the way I am,” you know and ”That’s just my makeup” and you just do what you do. You know you just muddle through and you know plow ahead and all those clichés, but you do it, ‘cause I just figured that’s just me. — Rachel (retired female, age 61)

Like many others, Rachel viewed her early difficulties as part of normal life, something that had to be dealt with.

This view had negative consequences on perceptions of the self. Several narratives explicitly discussed how self-esteem was lowered due to these early problems. Other participants talked about how others had labeled them in negative ways. For example, Chester (male consultant, age 68) described:

So like first for a big part of my life, before we diagnosed <son> and I didn’t know I had it (I mean that’s a big huge chunk of life when I didn’t know), I felt all the usual things that people feel about themselves in terms of feeling like I wasn’t disciplined enough, like I was…My father had a lovely term called
“being a weak sister” ’cause I had a lot of anxiety. — Chester (male consultant, age 68)

These early difficulties often resulted in long-term feelings of inadequacy, sometimes to the point of depression.

As highlighted in Chapter 4, many of the problems experienced by adults with ADHD are the result of self-discrepancy, or a belief that they should be doing better than they are. Understanding ADHD as a problem with self-discrepancy allows us to understand why adults reacted so positively to ADHD diagnosis. For Rachel, Chester, and others, a diagnosis of ADHD in adulthood had three consequences for their sense of self-discrepancy. First, it allowed them to explain the gap between actual and ought self. Second, it allowed them to maintain or inflate the ought self. Third, it decreased the gap by bringing the actual self closer to the ought self. These effects on the self are indicated in Figure 4.

Figure 4. ADHD and Self-Discrepancy
Explaining the gap. Before an ADHD diagnosis, adults with ADHD experienced discrepancy between the actual and ought self, which caused suffering. As highlighted in Chapter 4, adults with ADHD believed they were smart and doing many of the things expected of them. When comparing themselves to their peers and their own expectations, they saw themselves coming up short. While they perceived this discrepancy, they were unable to understand why they were not able to achieve at the level they thought they should be. In Figure 4, this lack of clarity is indicated by the dashed line. In many cases, inability to live up to the ought self were explained through a perceived weakness in the self with most adults lacking the words to name their problem. Instead, they described a general sense of “wrongness,” noting that they should have been doing better than they were.

Following a diagnosis, adults with ADHD were able to explain the gap between actual and ought self in clear terms. Rather than having a general notion of wrongness or weakness in the self, adults now used medical terminology to understand the gap. Consequently, the gap between actual and ought self following a diagnosis is represented by a solid line in Figure 4.

The ability to explain the gap had several benefits. By embracing an ADHD diagnosis, adults with ADHD engaged in the sick role. In doing so, adults with ADHD removed accountability from the self (Parsons, 1951). As Conrad and Schneider (1980) suggest, by engaging in the sick role through an official diagnosis, “one is absolved of responsibilities for one’s behavior” (1980:246).
Past failures that had previously been understood as a problem of the self could now be explained as problems due to untreated ADHD. The main benefit of an ADHD diagnosis is the ability to explain past problems in a “more positive and realistic light” and remove responsibility from the self (Murphy and Levert, 1995). As Ken (male lawyer, age 32) described, “I was diagnosed kind of they say “You know these things aren’t your fault. Your behaviors aren’t your fault,” so then I kind of started justifying some of the things.”

**Maintaining or inflating the ought self.** Despite its status and wide recognition as disability, a diagnosis of ADHD in adulthood served to maintain or inflate the ought self. With most disabilities or medical diagnoses, it would seem that the ought self would be lowered as expectations need to be re-examined in light of one’s new status. However, ADHD allowed individuals to maintain or inflate their ought self in several ways. Before the diagnosis, it was common for adults to begin questioning whether they were indeed able to live up to the ought self. They believed they should be able to do those things, but began to question whether achieving their goals was realistic. Many adults believed they just “couldn’t do it” but lacked the reasons why.

Following a diagnosis, adults reconstructed their self-identity in light of their new status. In removing accountability from the self, questions about what one should be able to accomplish were answered. It was no longer that ascertains of the ought self may be unrealistic. Instead, inability to live up to the ought self was explained through ADHD. Maintenance of the ought self was
particularly clear when I asked adults with ADHD how their lives would be
different had they been diagnosed earlier. Many adults with ADHD believed they
would have been able to live up to their ought self had they been diagnosed
earlier (as highlighted in Chapter 5). Maureen (female teacher, age 36) believed
she would have been working with computers; Rachel (retired female, age 61)
believed she would have become a singer. In addition, a diagnosis of ADHD
allowed adults with ADHD to deflect any criticisms that could lower or undermine
the ought self.

In addition, several adults with ADHD would recast their diagnosis in a
positive light. Instead of viewing it as a disability, ADHD adults viewed it as a
different way of being. In my interview with Chester (male consultant, age 68),
he described his dismay in my referring to ADHD as an illness/disability. In his
view, he was neither “sick” nor “disabled.” Likewise Stan (unemployed male, age
56) believed it was the environment and society’s values that pathologized him:

I love chaos. I fit right in. I understand, or I’m seeking patterns inside chaos,
so things that are loosely structured I enjoy. Then I feel like I can flourish and
I do and I enjoy, but if I’m in highly structured environments and I’m expected
to perform, then it’s just very, it’s frustrating. — Stan (unemployed male, age
56)

Like Stan, Gerard (IN) perceived his problem as follows:

To me ADD means Attention Difference Disorder not Attention Deficit
Disorder It is not something I have but the way I am. I am not inherently
flawed or disordered but different then the majority of other people and that in
my opinion is where the bulk of the problem lies. — Gerard (IN)

Others recast their disorder as a positive trait, providing them with advantage:

I’m trying to…I’m more aware of the positive side. I always get, I’ve got all
kinds of awards at work and everything, and I always thought “Oh it’s just
some quirk in my brain. I don't know what it is,” but now I’m starting to realize that I process stuff faster when I’m locked in. — Wayne (male teacher, age 61)

I remember that I do not live my life like the others around me. I will never plan, save, organize, think-through or finalize things the way they will. Instead I must do things in a way which feels right and natural to ME. I live my life FOR THE MOMENT in a way that they never will. I am not designed to be the long-term planner - instead I'm the one designed to see the new thing and be the first one to discover how it works, how to use it. I'm the one designed to measure up in a crisis, to come up with the solution from somewhere 'way out of the box'. — Megan (IN)

I have been blessed with lots of talents, many as a result of ADD, some not. I'm very intelligent (most ADDers are). I learn so damn quick it looks like I know what I'm doing. I was always a good test-taker in school, largely because I was fortunate enough to be able to remember enough of the classwork to make a wild guess at the answer. I'm a very positive person, fun to be around, have what has been described as a great sense of humor. — Chuck (IN)

In addition, some respondents attributed ADHD to famous historical figures including Albert Einstein, Thomas Edison, and Benjamin Franklin. This recasting of diagnosis allows ADHD to maintain the ought-self following a diagnosis, allowing them to maintain a positive self-identity.

**Improving the actual self.** An ADHD diagnosis allowed for improvements in the actual self, accomplished largely by accommodations such as medication. As highlighted above, it was clear that these accommodations resulted in individuals perceiving themselves in a more positive light. Following a diagnosis, adults with ADHD reported a range of improvements, including doing better across multiple domains—school, work, and home. Consequently, the perceived gap between actual self and ought self was lessened, decreasing the amount of stress or sense of wrongness perceived.
Self-discrepancy provides a mechanism for understanding the positive reactions to an ADHD diagnosis as well as disclosure decisions. The main benefit of an ADHD diagnosis in adulthood was that it served to lower the discrepancy between the actual self and the ought self. Although an ADHD diagnosis allowed individuals to maintain or slightly improve their ought self, the marked improvements perceived by adults with ADHD related to their actual self served to lower discrepancy. By lowering self-discrepancy, feelings of inadequacy and stress were also minimized. In other words, following an ADHD diagnosis, adults with ADHD were more likely to adhere to their “ought” versions of the self.

The model proposed above may also have benefit in understanding the potential impacts of other diagnoses. When a diagnosis lowers self-discrepancy and maintains the ought self, we could expect that it would be viewed as a positive life event. When a diagnosis increases self-discrepancy and lowers the ought self, we could expect negative reactions to the diagnosis.

Implications for ADHD research. This dissertation challenges the existing biomedical perspective on ADHD and shows that factors driving the suffering associated with ADHD are social rather than biological. Throughout this dissertation, I have presented evidence that ADHD in adulthood is the result of perceived self-discrepancy and largely occurs within a particular socio-historical context. Viewing ADHD as a problem with self-discrepancy provides more explanatory power than the current explanations offered by the biomedical
model. Specifically, the biomedical model is unable to explain variations in prevalence rates of adult ADHD across geographic regions and specific groups. As I stated in Chapter 6, ADHD in adults is more commonly found in developed countries and urban areas (Faraone & Biederman, 2005; Faraone, Sergeant, Gillberg, & Biederman, 2003). To my knowledge, no studies indicate that the prevalence of ADHD is higher in rural settings or under-developed countries. In other words, when a significant difference is found, environments that would be considered less stimulating always have lower prevalence rates of ADHD and related symptoms. Biomedicine offers two perspectives to explain variation. The first is that adults with ADHD move out of these areas, seeking additional stimulation. The second is that ADHD is poorly understood in these settings, resulting in lower self-report.

Based on my findings, I would argue that simpler forms of social arrangements are protective of the problems we commonly associate with ADHD. As discussed in Chapter 6, the self does not play as central a role in these groups. Individuals tend to act in ways that are less related to self-interests, and their actions reflect more communal ties. Traditional forms of authority also still have considerable power in determining status in these communities. Cultural expectations related to perfection and efficiency are also not as highly valued in simpler social arrangements. Additionally, there are fewer distractions and fewer more new stimuli in simpler societies. This research suggests that as
communities become more complex, the problems we now associate with ADHD will only increase.

Although relatively rare, the effect of simpler social arrangements was sometimes acknowledged by adults with ADHD. These adults typically focused on how life in the United States made things more difficult.

**Interviewer:** Do you think people in Italy have less ADD than here?

**Anthony:** Shoot, I couldn’t begin to tell you. I don’t know. That’s a good question. I mean you know you’d be in these little towns and it’s like the people there, it was like there’s no pressure whatsoever, and you know that that’s not true, but still I mean I don’t know if it’s you know just wishful thinking or whether it’s true, but those folks, they just seem to have a very, at least in the rural areas, a far more relaxed lifestyle, and everybody is far more social than they are over here and I think that that’s part of it. Do they have ADD? Sure, I’m sure there’s people over there with ADD, but you know do they notice it as much? Maybe not. It doesn’t seem like there’s much pressure, at least like I said in the rural areas. Everybody was far more casual and far more personable than folks are over here. So that’s a good question. I don’t know the answer to that. — Anthony (male lawyer, age 56)

**Mark:** Okay, and actually when I went to the psychiatrist, he is an immigrant like me and he definitely believes there’s a link, because there’s a clash of cultures here. That’s what I think. I can’t really explain it. I think you would have to think yourself. For me it’s definitely a factor. — Mark (unemployed male, age 25)

To Anthony, although ADHD probably exists in the rural areas of Italy, it is not as much of a problem. Mark sees a link between culture and his ADHD but is unable to describe what this link is.

As noted previously, white middle class males are the most likely to be diagnosed with ADHD in adulthood (Kessler & al., 2006). As Diller (2011) suggests, ADHD is largely a white, suburban phenomenon. The biomedical models suggest that high intelligence allows adults with ADHD to cope enough
and not be detected. However, current biomedical models are unable to explain why white males are most at risk for ADHD in adulthood. I would contend that white males suffer the most acutely from self-discrepancy due to their privileged position in society. As Annette Lareau suggests, middle class families’ child rearing patterns result in a growing sense of entitlement as opposed to restraint (Lareau, 2011). Sociological research has emphasized that the aspirations of white men are typically higher than other groups (Kao & Thompson, 2003; Kao & Tienda, 1998). Consequently, the ought self is likely the highest in this group. Additionally, this group lacks other reasons to explain why success is lacking. For example, they cannot rely on discrimination or structural inequality to blame for their problems. I believe these factors make self-discrepancy and problems associated with ADHD particularly “real” for white middle class men. This research also suggests that as expectations for success increase while opportunities decrease, problems now associated with ADHD (as well as diagnoses) will only get worse.

Viewing ADHD as a problem with self-discrepancy also allows us to predict help seeking and reaction to the disorder. When self-discrepancy increases, we would expect individuals to seek help due to increased suffering. Increased self-discrepancy could occur through a variety of mechanisms including crisis, life transitions that result in new and more demands and new reference groups, and long-term feelings of not living up to potential. As highlighted above, when individuals moved to a more demanding position with
reference groups that achieved more, they noticed their ADHD much more acutely and sought help. Some sought a diagnosis following a crisis. Others sought a diagnosis following the diagnosis of a child due to years of feeling like a failure.

In many ways, ADHD is unique in that the response to diagnosis is incredibly positive. As I have shown above, one of the main reasons ADHD is viewed so positively is its effect on perceptions of the self. Specifically, ADHD allows self-discrepancy to be lowered by improving perceptions of the actual self. At the same time, it is one of the few illnesses I am aware of that allows individuals to maintain their ought self or the self they should be. In other words, adults with ADHD do not have to adjust their goals, aspirations, and dreams following a diagnosis. They still receive considerable benefit and notice marked improvement.

Implications for ADHD adults. To many of my participants, the answer to their problems was ADHD diagnosis (and to myself at the start of this project). To them, ADHD represents a real biological disorder firmly understood by neuropathology and genetics. In doing this qualitative project, it is not my intention to minimize the suffering encountered by participants or those who suffer from ADHD nor to diminish their understandings of how the world works. In no way is this research meant to “blame” adults with ADHD nor their upbringing or parents as the source of suffering. I have attempted to provide an accurate description of the lived experiences of adults with ADHD. Those adults
who have sought an ADHD diagnosis in adulthood encountered suffering in their daily lives, suffering so great it required them to seek answers.

However, as a sociologist, my role is to look beyond common sense taken for granted knowledge and to understand how realities are socially constructed (Berger and Luckman, 1973). In completing this dissertation, I have provided a framework to understand ADHD (and those difficulties associated with it) as a social issue stemming from problems and dilemmas stemming from a modern existence. Specifically, much the suffering encountered by adults with ADHD stems from their interpretations of social cues and expectations pertaining to what one ought to be able achieve in life compared to an individual’s assessment of where they are at.

Clearly, this position stands in contrast to the views of many of my participants. Throughout this work, I have highlighted why this difference occurs. Specifically, the biomedical paradigm has a profound impact in influencing how we come to understand human suffering (Barker, 2010). That impact is clear in how adults with ADHD come to understand the source of their problems and explanations for them, often relying on the biomedical framework to understand the source of their problems. Additionally, the benefits of the diagnosis would increase the likelihood of the ADHD being embraced. As highlighted above, access to accommodations and medications lead to tangible improvements in the lives of adults diagnosed with ADHD. Additionally, by embracing the sick role,
ADHD adults remove accountability from the self and are able to explain past problems through their illness.

While this work stands in contrast to the current understandings of participants, there may be benefits for ADHD adults to understand the social factors on their suffering. Specifically, this work has suggestions for decreasing suffering in daily life of adults with ADHD. On an individual level, strategies that would lower perceived self-discrepancy would likely lower the sense of wrongness and suffering those individuals now relate to their ADHD. Related to perceived potential, acknowledging that both standard and subjective measures of intelligence may not translate directly into success would be important in decreasing perceptions of the ought self and decreasing suffering. Downward comparisons would also likely improve one’s sense of accomplishment and serve to improve views of the actual self. Acknowledging the role of deception in the presentation of self would also decrease the amount of self-discrepancy in daily life. Lastly, acknowledging the role of structure and specifically declining opportunity and increasing demands on the individual provide a mechanism to explain the source of problems we now attribute to ADHD and provide a framework for changing society in ways which would minimize suffering.

Implications for society. When considering ADHD as a sociologist, I found myself thinking about who benefited the most from ADHD as a label or status. In the course of this project, it was clear that adults with ADHD believed they had benefited from their diagnosis in many ways. They reported marked
improvements in their lives, generally reported being happier following the
diagnosis, and also saw themselves as being able to understand themselves
more fully and better able to handle life’s problems.

In addition to individuals benefiting, ADHD diagnosis also serves to benefit
the pharmaceutical industry. ADHD treatment represents a significant amount of
revenue for various pharmaceutical companies. Many of the current critiques of
ADHD largely focus on these large profits (Breggin, 2001; Conrad & Potter, 2000).

Ultimately, I believe ADHD serves the interest of the already powerful by
reinforcing cultural expectations and beliefs. As Conrad argued, childhood ADHD
served to increase social control in classroom settings. Like childhood diagnosis,
I believe ADHD in adults is a form of social control. By continuing to explain
problems associated with ADHD as the result of biological abnormalities,
attention is drawn away from the structural/cultural roots of many of the problems
we now associate with ADHD. Embracing an ADHD diagnosis in adulthood
serves to reinforce widely held beliefs that we live in a meritocracy. The label
serves to explain lack of success through medical abnormality rather than
decreasing opportunity structures. Further, cultural expectations related to
perfection and efficiency are reinforced by embracing an ADHD diagnosis. The
label of ADHD draws attention away from these unrealistic demands and places
the blame squarely on the individual for not meeting them.

ADHD in adults coupled with stimulant medication creates better, more
efficient workers, those who feel guilty for pursuing their own interests rather than
engaging in constant productive activities. While increased efficiency in itself is not negative, the economic gains in worker efficiency in the United States have largely served to benefit the top levels of society and resulted in greater income inequality (Domhoff, 2010). The label of ADHD allows more and more to be thrust onto the individual, attributing lack of success to medical disorder. ADHD also allows cultural scripts related to hard work and individual merit to be reinforced. At the same time, opportunity structures are decreasing. Ultimately, ADHD as a medical diagnosis limits social change by explaining the source of problems internal to the individual with individual-level solutions (-pills) rather than drawing attention to structural arrangements that may increase suffering.

**Limitations**

This study has several limitations that should be considered when evaluating its findings. The largest limitation is the lack of verified clinical diagnosis of adult ADHD in the participants. In the early phases of study design, it was hoped that primary care physicians, psychologists, or psychiatrists could refer face-to-face participants to the study. This approach had several merits, most importantly a verified diagnosis of ADHD in adulthood. However, based on the competing demands on physicians’ time (Jaén et al., 1994), the restrictions imposed by HIPAA (Ness, 2007), and insight provided by a psychiatrist familiar with recruiting ADHD patients in clinical settings (Findling, personal communication December 15th, 2008), this approach was abandoned. However, many studies of illness experience rely on self-identification of participants. In
talking face-to-face to participants, it was clear that many had in-depth experience with the diagnosis of ADHD. I am confident that no face-to-face participants were dishonest in this regard.

As highlighted elsewhere, the narratives collected for this study are not representative of all the adults with ADHD in the United States. Face-to-face interviews were limited geographically to Northeast Ohio. However, the sample is reflective of the composition of adults with ADHD; namely, the sample is comprised primarily of white middle class males. As highlighted in Chapter 2, the sample is also diverse, drawing on a range of experiences.

Additionally, there may have been selection bias in the sample. As highlighted in chapter 5, most narratives (but not all) in this study found their diagnosis as an extremely positive life event, one that was freely discussed in this research. Those who may not have had such a positive experience were not well represented in this study. Although rare, several adults in this study did not view their diagnosis as positively. However, there was still overlap. For example, Mark was still grappling with acceptance of his diagnosis. However, self-discrepancy was readily apparent in his narrative, where he would often compare himself to his classmates, rely on his sense of potential to indicate what he was capable of, and dismay in not living up to expectations for perfection. He also used ADHD to explain past problems and remove some of the accountability from the self (although not as much as others).
While there were no formal member checks (participants who had ADHD who verified the interpretation) for this project, they were informally done following some of the later interviews. In these cases, some of the initial findings were shared with participants and their feedback was noted in field notes. For the most part, individuals were positive in their feedback when learning about my perspective on self-discrepancy as the cause of suffering.

**Final Thoughts and Epilogue**

The primary goals of this research were to explore ADHD from an academic perspective. My own experiences with ADHD in adulthood and my training as a sociologist also both supplement and shape the interpretation of data with this work representing both an "insider" and "outsider" perspective. As Corbin and Strauss (1990) suggest, my personal experiences with ADHD provide me with theoretical sensitivity. As someone who was diagnosed with ADHD in adulthood, I found myself personally relating to many of the narratives included in this research. My training as a medical sociologist also allowed me to step back and view ADHD in adults from an outside perspective, allowing me to look past the taken-for-granted realities of daily life. This training not only influenced the goals of this project, but also the findings. Of particular note is the emphasis on social causes of suffering. While this research cannot definitely prove ADHD is not the result of a physical abnormality in the brain, the findings presented in this dissertation add weight to arguments that ADHD is socially constructed.
Despite my potential biases, I have remained as open as possible. I believe this openness is clear in the evolution of my own understanding of ADHD. As discussed in previous chapters, the main goal of this study was to investigate the experience of ADHD as an illness. Due to the reflexive nature of this project, as my work progressed it became clear to me on a personal level that an ADHD diagnosis and the accompanying medication were not for me on a variety of levels. I became much more critical of my own diagnosis. At my most critical points, I felt that I was cheating, using my diagnosis and the medication that came along with it to get ahead. At the same time, I felt like I was just reinforcing those often-unrealistic expectations for production and success so common in our modern existence. In attempting to cope with ongoing problems I encounter in daily life, I often tried to come up with alternate explanations, contextualizing my problems and the behaviors of others, and in some cases lowering expectations,

Clearly, my understandings of ADHD have shifted substantially in completing this project. I am currently off medication and have found that being more realistic in my expectations have decreased the amount of suffering I encounter in daily life. This is not to say there is none, however, by being more realistic about what I am capable of, I am happier. Ultimately, this is a personal decision, one that I would not advocate for everyone with ADHD. However, I do believe that by discontinuing medication, I am engaging in a form of resistance to larger structural factors that I view as limiting personal agency and increasing
suffering. In a world of socially constructed realities, I have made statements of truth that reflect my own training as a sociologist, a person diagnosed with ADHD. I too still remain open on the causes of ADHD. While I feel I have presented a compelling case, I would leave it up to the individuals, especially to other adults diagnosed with ADHD to judge the merits of my findings.
Appendix A: Interview Guide

Semi-Structured interview Guide.

Aim 1

1. When did you first notice you had problems with attention? What did you think then?

2. As you look back on your AD/HD, are there events that stand out in your mind?
   a. Can you describe them?

3. At what point did you decide you needed to seek medical help for AD/HD?
   a. What lead you to seek medical treatment?
   b. Who if anyone influenced your actions? How did they influence you?
   c. What was going on with your life then?

4. What was on your “to do list” when you were diagnosed with AD/HD

5. How did you feel when you were first diagnosed with AD/HD?
   a. What did you do next?

6. How have your feelings changed since you were diagnosed?

7. What was your life like prior to diagnosis?
   a. What kind of problems were you having?
   b. How would you describe yourself as a person then?

8. What is your life like now? Are you still having problems?

9. What is on your “to do list” now?
10. When you have less things on your “to do list” do you notice your ADD less?

11. When you went to the doctor, what did he recommend?

12. How would you describe yourself now? What most contributed to this change?

13. How would your life have been different if you had been diagnosed as a child?

14. How would your life have been different if you had been diagnosed earlier in adulthood?

15. How has your life gotten better since being diagnosed?

16. How has your life gotten worse since being diagnosed?

17. What is it like to have AD/HD?

18. Walk me through a typical day prior to your treatment

19. When you had difficulty paying attention, what were you doing?
   a. What were you thinking about instead?

20. When you think about your ADD or your difficulties, how do you feel?

21. What are some of the tasks you do where you notice your AD/HD the most?

22. How have things changed since beginning treatment (or stopping treatment)?
   a. Are your days different if you skip medicine?
23. When do you notice your AD/HD the most?
   a. What are you doing?
   b. How do you feel about these tasks?
24. When is your ADD not a problem?
   a. Do you notice it much when doing leisure activities.
25. How does ADD effect you at work?
26. How does add effect you at home?
27. When do you think your AD/HD is not a problem?
   a. What are you doing when it isn’t a problem?
28. How does AD/HD effect your interaction with others?
29. How would your life be different if you didn’t have AD/HD?
30. What positive things have happened since your diagnosis?
31. What negative things have happened since your diagnosis?

32. What do you know about AD/HD?
   a. What has your doctor told you about AD/HD?
   b. What else have you learned about AD/HD?
   c. About what % of people do you think have AD/HD
33. What causes someone to get AD/HD?
   a. What caused you to have AD/HD
34. How do you manage your AD/HD?
   a. What are you doing to get better?
   b. Where did you learn how to manage your AD/HD?

35. How long do you think you’ll need treatment for AD/HD?

36. Where do you think you’ll be in 5 years?

37. Who do you tell about your AD/HD?

38. Who has helped you the most since your diagnosis?
   a. How have they helped?

39. Has anything else been helpful since your diagnosis, like an organization, book, or technology?

40. What advice would you give someone who was diagnosed with AD/HD?

41. Is there anything you have thought about that you might not have before since this interview?

42. Is there anything else you think we should know about AD/HD?

43. Is there anything you would like to ask me?
Appendix B: Recruitment Material

Recruitment Materials:

Newspaper Advertisement
Diagnosed with Attention Deficit Disorder as an Adult?
The CWRU sociology department is doing a study on Attention Deficit Disorder. If you have been diagnosed with Attention Deficit Hyper Activity Disorder after high school, I would like to hear your story. For more information, please contact Joshua Terchek at 216-702-614 or ADD.Study@gmail.com.

Internet Advertisement
Subject: Were you diagnosed with Attention Deficit Disorder as an adult?
Were you diagnosed with Attention Deficit Disorder as an adult? The CWRU sociology department is doing a study on Attention Deficit Disorder in adults. If you have been diagnosed with Attention Deficit Hyperactivity after high school, I would like to hear your story. For more information, please contact Joshua Terchek at 216-702-6146 or ADD.Study@gmail.com.
The CWRU Sociology department is conducting a study on Attention Deficit Disorder in adults. If you have been diagnosed with Attention Deficit Hyperactivity after high school, I would like to hear your story. For more information, please contact Joshua Terchek at 216-702-6146 or ADD.Study@case.edu.
Attention Deficit Disorder in Adults

The CWRU Sociology Department is conducting a study on Attention Deficit Disorder/Hyper Activity Disorder in Adults. If you are above the age of 18 and were diagnosed with AD/HD following high school, we would like to talk to you.

The purpose of this research is to understand how adults like you come to see themselves as having attention deficit order and the effect of the diagnosis on their daily life. We would like to hear your story in your own words; the circumstances surrounding your illness, and your thoughts and feelings regarding your diagnosis.

This study will characterize how adults came to see themselves as having the disorder, looking beyond the contextual factors associated with the disorder. The findings will lead to a greater understanding of how adults with AD/HD have come to see themselves as sick and cope with the disorder. It may inform future research efforts regarding AD/HD in adults.

If you participate in this research project, you will be interviewed for approximately 1 to 3 hours. The length of the interview is approximate because it will depend on how you respond to questions in the interview. A brief AD/HD screening test will be given at the time of the interview. The interview will be audio recorded. You will be compensated for your time.

For more information, please contact Joshua Terchek at 216-702-6146 or add.study@gmail.com.
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