

THE MISSED AND DISMISSED DIAGNOSIS:
EXPERIENCES OF PEOPLE DIAGNOSED WITH ATTENTION DEFICIT
HYPERACTIVITY DISORDER (ADHD) BEYOND CHILDHOOD

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Abstract

This study explores people's life experiences when they are diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) as an adult, the impact of this diagnosis and how they experience living with ADHD. ADHD is often missed as a diagnosis in children whom have inattentive type ADHD, as "characteristic" symptoms such as hyperactivity and impulsiveness are not as prominent and therefore the child does not typically stand out in a school setting as having problematic or challenging behaviours. Consequently many children may navigate through their childhood and teen years not receiving a diagnosis until sometime into their adult years. In an attempt to give this group a voice I have created an opportunity for a small group of adults diagnosed with ADHD as adults to share their experiences in this qualitative research study. Discussions and findings from my research include the participants' experiences of feeling relieved after being diagnosed with ADHD as an adult, their resulting responses of thinking about things differently, changing expectations and seeking more information. Participants shared everyday challenges of living with ADHD including physical and cognitive, challenges of daily living and challenges in the school environment. Participants also talked about the emotional impact when relating their experiences of living with ADHD, including having low self esteem, ongoing struggles with feelings of failure, not fitting in and self blame. The purpose of my research was to inform helping professions, and specifically the social work profession, about the experience of receiving a diagnosis of ADHD in adulthood and the realities of living with ADHD. The last area of my findings and discussion fulfills this purpose as it focuses on professional support.

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Table of Contents

Introduction	1
Ontological Reflections	1
My “Ah-Ha” Moment	3
Historical Background	5
Theoretical Perspectives	8
Literature Review	12
Understanding ADHD and Defining the “Subtypes”	12
The Complexities of Diagnosis	15
Factors that Make Diagnosis More Likely	17
Experiences of Living with ADD - Questions of discrimination, marginalization & oppression	18
Methodology	20
Purpose of the Study	20
Study Design	20
Ethical Considerations	21
Recruitment	23
Participants	25
Data Collection	26
Data Analysis	26
Limitations	27
Insider perspective.	28
Findings and Discussion	31

Experience of diagnosis as an Adult	32
Providing an explanation/answering questions.	32
Seeking more information.	35
Thinking about things differently/changing expectations.....	36
Everyday Challenges of Living with ADHD	39
Physical and cognitive challenges.	40
Challenges to daily living.	46
Challenges in the school environment.	50
Emotional Impacts of Living with ADHD	52
Low self-esteem.	53
Ongoing struggles.	54
Fitting in.	56
Professional Supports	58
Stigmatization	66
Strengths and Resilience	67
Self Reflections	71
Implications for Practice and Future Research	76
References	81
Appendixes	87

This thesis reports on a research project completed as part of my Master of Social Work studies. I conducted this research to find out “What are people’s life experiences when diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) beyond childhood and how do they experience living with ADHD?” The diagnosis of ADHD in adulthood is still a new phenomenon and there is little known about the experience of people receiving such a diagnosis. I wanted to provide people diagnosed with ADHD as adults the opportunity to share their experiences related to their ADHD. My assumption was that their voices will help to challenge the dominant discourse and knowledge related to the phenomena of adults having ADHD, including the general dismissal of this diagnosis by professionals and the general public. I hope that my research; by highlighting some of this population’s experiences, will promote social justice by providing professionals with an understanding of the specific day to day challenges and emotional impacts experienced. Ultimately, increasing empathy related to how peoples’ ADHD impacts their life and the provision of ideas for the kinds of help and support that would be most beneficial to adults newly diagnosed will be the outcomes from my study.

Ontological Reflections

Working in a community based mental health service agency I discovered an ingrained culture among the mental health professionals in this agency, including myself, when it came to opinions and considerations about certain mental illnesses. For example, a diagnosis of Attention Deficit Hyperactive Disorder (ADHD) or Attention Deficit Disorder (ADD) meant nothing to these

professionals with respect to being a valid mental illness, despite its' inclusion in the American Psychiatric Association's revised fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders*(DSM-IV-R), (2000).

Typically understood to be a childhood issue, ADHD was completely dismissed as a diagnosis in my work place. It was never considered that this diagnosis could impact/intensify the symptoms of another mental illness should the person have multiple diagnoses; or that it could impact on a person's ability to follow a treatment plan for another mental illness. I do not believe it was our intention to dismiss the actual person and, in our minds, I don't think we were dismissing the idea that the person may in fact need assistance and support. However, the determination was made that people with this disorder "just didn't fit" into our service criteria, without any of us ever really knowing what the disorder was or how the symptoms were experienced.

Because of my own ignorance about ADHD at the time, I was just as guilty as my fellow colleagues in the "dismissal" of this diagnosis. ADHD does seem to be somewhat recognized in certain ways within society and more specifically as a children's issue. However in my office environment, it was usually spoken of in a joking manner. For example, in the work environment when someone was feeling easily distracted or struggling to stay on task with their work they might say, "I must be having an ADHD moment" or "I think I have ADHD"; or a coworker might make this reference and suggest "maybe you have ADHD"? These kinds of conversations indicate that there is some recognition that perhaps ADHD exists in adults and poses some difficulties in life,

however the references and assumptions were still inaccurate. As a result, misconceptions are being reinforced in mainstream informal conversations everyday.

My Ah Ha Moment

The way I viewed ADHD changed dramatically the day I was diagnosed. Still armed with only minimal knowledge about what it is and how it affects people, I responded to the psychiatrist who was assessing me with my usual humour. This was my response as I felt obliged to answer his questions honestly and I was uncomfortable. All of the questions asked focused on my repeated blunders, failures and clumsiness in my every day life. I had learned to laugh at myself and my ‘quirkiness’ a long time ago, never realizing I had developed a coping mechanism to try and prevent myself from constantly beating myself up on the inside for yet another ‘failure in the game of life’.

Charged with this new label called ADHD, I was on a mission to find out as much information as I could about ADHD and what it meant to have it. I believe the title of the first book I bought speaks volumes about the impact of this condition. It is titled *You mean I am not Stupid, Crazy or Lazy?!* and was written by Kate Kelly and Peggy Ramundo (2006). I immediately identified with the title, particularly since I did not find out I had ADHD until I was 35 years old, having lived with this condition for over a third of my life and still not knowing exactly what ADHD was or how it may have impacted my life.

As I learned more and more about what ADHD was and what the associated impairments were, I realized what a grave injustice we had done by

dismissing the clients with ADHD whom we were supposed to be helping. I thought about all of the clients whose cases we closed when they did not follow through on the treatment plan that they had developed in partnership with their worker. I thought about the clients who had a secondary diagnosis of ADHD, a diagnosis that we refused to acknowledge. I realized that quite likely it was not about them choosing to not follow through, but more likely the fact that they could not follow through because of the impact of their ADHD.

Thus, as a result of my own experiences, both personally and professionally I became motivated to create understanding and promote social justice for this group of people.

Historical Background

ADHD has been viewed in many ways over the years. Both Barkley (2006) and Taylor (2010) provide a historical context for the way ADHD has been understood. Taylor (2010) begins by informing us that children in the late 1800's who were described as having symptoms similar to what we currently understand to be ADHD were identified as 'uncontrollable'. Barkley (2006) and Taylor (2010) indicate that the understanding of ADHD morphed over the years. By the early 1900's a group of children were being described as having "defects of moral control" by Still (the founder of pediatrics in England), and the characteristics he identified and attributed to this group at that time mirrored those we understand to be indicative of ADHD today. Taylor (2010) advises the reader of another term adopted in the early twentieth century - minimal brain damage (MBD) - which was a more medically-based term identifying concerns with cognition that were attributed to physical causes. Both Barkley (2006) and Taylor (2010) report that in the mid 1900s the same acronym – MBD - was re-defined as Minimal Brain Dysfunction but was still intended as a way of describing characteristics of ADHD. Taylor (2010) indicates that following an outbreak of encephalitis beginning approximately around 1917 and lasting close to a decade, a better understanding of neuropsychiatric syndromes developed, as well as the realization that behavioural difficulties could be attributed to the brain.

By the late 1960's and early 1970's ADHD was beginning to be viewed as a disorder of attention with links to hyperactivity and hypoactivity (Barkley 2006; Brown, 2009a; Taylor; 2010). A concept of the disorder received inclusion in the

1968 American Psychiatric Association's DSM-II (*Diagnostic and Statistical Manual of Mental Disorders, 2nd Ed*) but was referred to as a diagnosis of Hyperkinetic Reaction of Childhood. Although it was still considered to be organic, it was thought to be based on psychological changes in the individual (Barkley 2006; Taylor, 2010). With further development and research evolved the term Attention Deficit Disorder, with or without Hyperactivity, and in 1980, this version of the disorder received inclusion in the American Psychiatric Association's DSM-III (*Diagnostic and Statistical Manual of Mental Disorders, 3rd Ed*). A revision in 1987 resulted in another name change and Attention Deficit Disorder, with or without Hyperactivity was changed to Attention Deficit Hyperactivity Disorder, which it continues to be known as today (Barkley 2006; Brown, 2009a).

Continued research since the 1980's has progressed the understanding of ADHD, and despite critics who continue to this day to question the validity of ADHD, it is becoming much more widely accepted and understood in the medical and scientific fields (Barkley, 2006, 2002; Brown, 2009b; Faraone, 2005; Remschmidt, 2005; Taylor, 2010). It is this progress, along with technological advances in medical research, that have allowed for tomography studies that show changes in the structure and function of the brains of people diagnosed with ADHD and neuroimaging and neurochemical studies that demonstrate differences in neuronal functions and chemical balances and circuitry in people diagnosed with ADHD (Barkley, 2006, 2002; Faraone, 2005; Remschmidt, 2005; Taylor, 2010). The progress in research in this area has allowed for medical science and

psychiatry to realize that ADHD is not a disorder exclusive to childhood. Much of the current research shows that approximately two thirds of those children diagnosed with ADHD will continue to experience symptoms and have difficulties throughout adulthood (Faraone, 2005; Remschmidt, 2005). Thomas Brown (2009a, 2009b) identifies that recent studies are now revealing that symptoms of ADHD are not being recognized in some people until much later, when they are in adolescence and adulthood. Brown's rationale for this later-in-life recognition of the disorder is attributed to a number of factors: the more complex level of cognition required at later stages in life, certain cognitive functions of the brain being slower to mature and the demands for self management that increase with age and maturity.

Theoretical Perspectives

The theoretical framework for my research draws from a combination of an interpretive social science approach and a critical social science approach. I drew on an interpretive framework so that I could get at the experiences of a group of people who are generally silenced, and try to understand how they construct meaning based on their experiences and interactions with others (Denzin & Lincoln, 2011; Holstein & Gubrium, 2011; Neuman, 1997; Rabinow & Sullivan, 1987). Utilizing this theoretical framework helped to shape my research project as I was seeking to understand people's experiences of being diagnosed with ADHD beyond childhood, as well as how they experience living with ADHD.

I have chosen to draw on a critical framework in addition to an interpretive framework to help identify the structural reasons why the population I am studying has been and, I believe, continues in many quarters to be silenced and dismissed. Fook (2003) emphasizes the importance of using critical social work research to challenge domination and oppression and places value on emancipatory possibilities when approaching research from a critical social science lens. Critical social science is, essentially, a macro level analysis of social structures and constructed systems and serves to uncover conditions and structures that facilitate oppression and to respond by making societal changes (Neuman, 1997). Drawing on the participants' life experiences will help to reveal the larger macro levels at play and my use of this theoretical lens will reveal any oppression experienced by participants and might then be an opportunity to

challenge that oppression by making it visible. I am hopeful that the participants' description of their life experiences will also help to challenge the oppressions they face in having their diagnosis dismissed by dominant discourses that question if their condition even exists.

Likewise, the particular critical lens I am adopting is critical disability theory when considering the challenges faced by this group. Critical disability theory is informed by the social model of disability that identifies a difference between an "impairment" (ADHD in this case) and the "disability", the disabling effects of how the world responds to this impairment. This model stresses changes to the environment (such as physical changes to buildings to ensure accessibility) to address the oppression, as opposed to pathologizing and changing the individual, which is the focus of the medical model of disability. The medical model of disability is an oppressive model in that the medical model serves as a paternalistic hierarchy. It functions by placing blame on the person for their condition, locating disability in the individual, and focusing on treatment of the individual by the medical 'professional' to 'fix' them, forcing the individual into a passive role of receiving treatment (Barnes, 1997; Gilson & DePoy, 2002; Hammell, 2006; Oliver, 1996; Thomas, 2004). In contrast, the focus of the social model is on the conditions a person experiences as a result of being identified as having an impairment. "Disability" is thus understood to be the fault of society (Devlin & Pothier, 2006).

In the critical model, disability is identified as a social construction. Our understanding of disability has varied across time and space. While not always

and in all places understood as a problem, it has often been understood this way and for different reasons. For example, industrialization constructed new roles that were often difficult for people with disabilities to participate in resulting in labeled persons being defined as “unable” and “unproductive”(Barnes, 1997; Davis, 1995; Titchkosky, 2000). Davis (1995) connects disability with the concepts of “normalcy” and “ableism”. He indicates that science and statistics were used to formulate the idea of an “average” person and defines the word “normal” to mean “to conform to” or “not differ from” (p24). Davis further states that “in an ableist society, the ‘normal’ people have constructed the world physically and cognitively to reward those with like abilities and handicap those with unlike abilities” (1995, p 10). Thus “ableism” can be defined as a process of disabling people by imposing restrictions on people’s activities as a result of societal structures and attitudes related to normalcy and differentness (Thomas, 2004). Sophie Freud’s (1999) stance on normality expands on the connection between normalcy and value in that she identifies it as “a value-based concept; that it heavily depends on the sociopolitical economic context including the historical moment; that it is culture specific; and that there in no normality outside a particular context” (p 333).

In the social model, the concept of stigma is also important. Like disability and normalcy, stigma is also socially constructed. Stigma results from perceived differences – for example, those attributed to impairment - which are presumed to be undesirable and result in acts of devaluation and social ostracization (Dovidio, Major & Crocker, 2000; Goffman, 1963; Titchkosky, 2000).

Dovidio et al. informs of stigmatization being a relational process and further highlights the perceived threat posed by those thought to be ‘different’. The authors argue that institutional forms of stigmatization exist for the purposes of maintaining both social control and the status quo (2000). While an examination of the consequences of stigmatization are too vast for the purposes of this paper, Dovidio et al. (2000) do emphasize the significance of the impact of stigmatization on psychological wellbeing. And Vojak (2009), summarizing the overall power of stigmatizing language, speaks to the impact on persons whom are stigmatized and its’ relationship to social justice.

Stigmatizing language not only erodes self-esteem directly, but it also encourages the community to look upon those who are stigmatized with less regard and lowered expectations, which, in turn, impacts the community’s willingness to provide services and resources. The language of exclusion works against social justice by reinforcing the legitimacy of a system that accords unfair advantage to certain members by marginalizing other members. p 944-945

The social constructions of disability, normalcy and stigmatization demonstrate how conditions, systems and structures that facilitate oppression materialize, and this is consistent with the critical social science framework I have chosen. The social model of disability focus on a person’s impairments being the result of our constructed societal structures and systems demonstrates the relevance of critical disability theory. Particularly how it relates to exposing the ongoing domination and oppression of people labeled disabled that stems from resistance to change the environment in ways that will change the meaning of the impairments, and the effects of being labeled with an impairment.

Literature Review

Dr. Russell Barkley describes ADHD as having “status as a chronic disabling condition” (2006, p 40). Although this description does not specify ‘only for children’ I found that there is minimal research regarding adults with ADHD in comparison to the multitude of research reports available on children and adolescents with ADHD. This finding is consistent with the findings of Davidson (2008), Barkley (2006) and Toner, O’Donoghue, and Houghton (2006). Although there was an emerging interest in hyperactivity in adults in the 1970’s and some researchers made the case for the possibility that adults could have ADHD in the 1970’s and 1980’s, it was not until the 1990’s that the adult psychiatry field started to recognize the adult equivalent of ADHD in children (Barkley, 2006; Ramsay & Rostain, 2008).

I found that the research that is available on adults diagnosed with ADHD beyond childhood is, for the most part quantitative; and primarily pertains to the use of medications, the effectiveness of medications, various testing methods relating to overall cognitive functioning and theoretical hypothesis about how ADHD actually impacts the brain and the consequential impairments that result. Likewise, Toner et. al (2006) identifies that literature specific to how this group (diagnosed as adults) deal with their ADHD is almost nonexistent.

Understanding ADHD and Defining the “Subtypes”

The literature shows that both present and past theoretical perspectives consider ADHD to be a developmental impairment of an individual’s executive brain functions. Executive functions are described as functions that manage the

brain's cognitive operations through prioritizing, integrating and regulating cognitive processes, thus providing the means for self-regulation (Barkley, 2011, 2006; Barkley & Murphy, 2006; Brown 2009a, 2009b, 2006; Ramsay & Rostain, 2008). As a result, the core impairment of ADHD is perceived to be an inability to self-regulate. Ironically, there is no inclusion in current diagnostic criteria that identifies problems with emotional regulation and the experiencing of intense emotions, yet many researchers have identified that people with ADHD tend to have ongoing problems in regulating their emotions, often feeling like they are on an emotional roller coaster (Barkley, 2011; Barkley & Murphy, 2006; Brown, 2009a).

Barkley (2011) expands on how the impairments of the executive functions (EF) in someone with ADHD may be observed and indicates that the difficulties they experience are primarily with performance as opposed to knowledge and/or skills. Consequently, Brown (2009a, 2006) and Barkley (2006) argue that the impairments of ADHD cannot be individually tested using standard neuropsychological tests, but instead can be observed much more accurately by evaluating the performance of individuals in their daily management of activities and tasks over a period of time. Barkley tends to draw on the social model approach when discussing the impairments of ADHD as he indicates:

disorders of EF or self-regulation, like ADHD, pose great consternation for the mental health and educational arenas of service. Mental health and education professionals are more expert at conveying knowledge – how to change; far fewer are expert in ways to engineer environments to facilitate performance – where and when to change

2011, p 3

Barkley (2011) further indicates that performance changes will generally only be maintained for as long as the environmental changes or accommodations remain in place, as it is only the changes to the environment that enable the individual to perform, thus reducing the impact of their impairments.

Barkley (2006) and Brown (2006) identify that research conducted over the years has shown that there are actually subtypes of ADHD, and this differentiation was accepted and included in the American Psychiatric Association's 1994 *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition* DSM-IV. The subtypes of ADHD include Inattentive type, Hyperactive-Impulsive type and the Combined type (American Psychiatric Association, 1994, 2000; Barkley, 2006; Barkley & Murphy, 2006; Kelly & Ramundo, 2006).

Characteristics of the Inattentive type of ADHD are described as difficulties focusing and sustaining attention, frequent daydreaming, misinterpretation of and/or missed social cues, lack of attention to details, frequent misplacement and/or loss of items, poor organizational skills (including time management), poor memory and slowness in processing (American Psychiatric Association, 2000; Barkley, 2006, 2011; Barkley & Murphy, 2006; Kelly & Ramundo, 2006; Lamberg, 2003; Ramsay & Rostain, 2005). The Inattentive type of ADHD is the type most likely to be missed in childhood as children identified with this disorder do not generally present with behavioural difficulties or verbal outbursts in school – the more typical indicators of other types of ADHD. In addition, a lot of the areas that impair performance are not expected to be fully developed for a person to draw on independently until in to

late adolescence or early adulthood (Brown, 2009a; 2009b; Hallberg, Klingberg, Setsaa & Moller, 2010; Ramsay & Rostain, 2005).

People with the Hyperactive-Impulsive type of ADHD are seen as exhibiting the more ‘classic’ or ‘well recognized’ features of ADHD (Ramsay & Rostain, 2005): difficulties with hyperactivity, including feelings of restlessness and boredom; feeling or acting like they are driven by a motor and/or have a need to keep busy; impulsiveness in their actions, decision making and speech; the inability to consider long term implications for actions taken in the present; a tendency to blurt things out; difficulty with rule following and engagement in disruptive behaviours (American Psychiatric Association, 2000; Barkley, 2006; Hallberg et al., 2010; Kelly & Ramundo, 2006; Lamberg, 2003). The Combined type of ADHD consists of difficulties experienced from both the Inattentive type and the Hyperactive-Impulsive type and is identified by Barkley (2011) as being the most common type of ADHD.

The Complexities of Diagnosis

ADHD is often undiagnosed in adults (Lamberg, 2003; Rucklidge & Kaplan, 1997). Young, Bramham, Gray, and Esther (2008) identify that it wasn’t until the 1990’s that there was recognition that ADHD can persist into adulthood and Rucklidge and Kaplan (1997) attribute this to being part of the reason why some adults are now being diagnosed.

Research suggests that diagnosis of ADHD in adults can be challenging as there are no comprehensive or consistent methods for determining and measuring symptoms to ensure they meet the current DSM-IV-TR criteria (Brown, 2006,

2009b; Davidson, 2008; Ramsey & Rostain, 2008, 2005; Rucklidge & Kaplan, 1997). Other variables affecting diagnosis include: differences in conceptualizations, definitions, and diagnostic criteria for ADHD used in individual studies; different sources of information used, as well as a lack of longitudinal studies on adults (Barkley & Murphy, 2006; Davidson, 2008). Likewise, there is vast variability in the experience of ADHD - no one experiences it the same way. Different situations and even different times of the day will also impact how the impairments are experienced (Brown, 2009a, 2009b, 2006; Knouse, Mitchell, Brown, Silvia & Kane, 2008; Ramsay & Rostain, 2008, 2005). These concerns can also complicate attempts to develop and define comprehensive diagnostic criteria.

Some of the criteria in the DSM-IV-TR for ADHD that must be met for a diagnosis to occur include the presence of symptoms/impairments prior to the age of seven years old. The symptoms/impairments must continue to be present in adulthood, which proves to be difficult as the symptoms/impairments described in the DSM-IV-TR were developed based on how ADHD presents in children (Barkley, 2006; Brown, 2006, 2009b; Davidson, 2008; Knouse et al., 2008; Lamberg, 2003; Ramsey & Rostain, 2008; Rucklidge and Kaplan, 1997). Lamberg (2003) offers a quote from Barkley that eloquently summarizes the difficulties with the diagnostic criteria included in the current DSM, “People with [ADHD] outgrow the DSM, but they do not outgrow the disorder” (pg 2).

Factors that Make Diagnosis More Likely

There is a strong hereditary/genetic factor associated with ADHD (Barkley and Murphy, 2006; Brown, 2009a; Lamberg, 2003; Ramsay & Rostain, 2008; Toner et. al, 2006). Rucklidge and Kaplan (1997) and Lamberg (2003) indicate that adults are often learning in their 30's and 40's that they have ADHD after their children are diagnosed and they start learning about, and recognizing in themselves, the common symptoms and impairments. Alternatively, their physicians may pick up on some of their symptoms after their children are diagnosed.

Co-occurring mental illnesses are common in people with ADHD, with depression and anxiety being identified as the most common (Barkley and Murphy, 2006; Brown, 2009a; Davidson, 2008; Hallberg et al., 2010; Knouse et al., 2008; Lamberg, 2003; Ramsey & Rostain, 2008, 2005; Rucklidge & Kaplan, 1997; Toner et. al, 2006). Hallberg et al. (2010) and Waite and Tran (2010) indicate that the incidence of a second co-occurring diagnosis is at least 60 percent, with some reports estimating as high as 70 to 75 percent, in people diagnosed with ADHD. It is often when people seek treatment and help for their secondary mental health diagnosis that they actually get their diagnosis of ADHD (Lamberg, 2003; Ramsay & Rostain, 2005).

There appears to be an underlying belief that ADHD is mostly a male disorder which is evidenced by a strong research emphasis on males and stereotypical beliefs that it is young boys who are hyperactive and impulsive (Hallberg et al., 2010; Kelly & Ramundo, 2006; Ramsay & Rostain, 2005;

Rucklidge & Kaplan, 1997; Waite & Tran, 2010). Rucklidge and Kaplan (1997) propose that this focus on males with ADHD in the literature has led to late identification of ADHD in women, particularly those women with the Inattentive type who may not experience many difficulties until late adolescence or early adulthood.

Experiences of Living with ADD – Questions of discrimination, marginalization & oppression

The literature indicates that impaired psychosocial functioning is a difficulty for many people who are not diagnosed with ADHD until they are adults. The psychosocial impairments are characterized by low self esteem, hopelessness, strong feelings of incompetence, ineffectiveness and a chronic sense of underachievement (Barkley & Murphy, 2006; Davidson, 2008; Ramsay & Rostain, 2005; Toner et al., 2006; Waite & Tran, 2010; Young et al., 2008). Further, Young et al. (2008) attribute the primary cause of the impaired psychosocial functioning to be the result of internalized failure. Brown (2009a, 2009b) also refers to undiagnosed people with Inattentive type ADHD experiencing increasing failures, as the demand for self management activities increases in higher grades of school and even after College and University, when structures inherent in school environments are removed. Lundy (2004) identifies that under these conditions, internalized oppression may be present “in [that] we come to believe in our own inferiority, worthlessness and powerlessness, both as individuals and as a group” (p 132).

To compound the internalized oppression of living with ADHD that results from being made to feel as if one is always failing, undiagnosed adults with ADHD are often also labeled in other pejorative ways. They may be described as lazy, lacking motivation or intelligence and not exercising any willpower (Brown, 2009a; Kelly & Ramundo, 2006; Lamberg, 2003; Ramsay & Rostain, 2005). This labeling is generally done by people in positions of power over the individual, for example, by teachers, doctors and parents during childhood or employers, professionals or doctors in adulthood.

The process of labeling exacerbates the already existing power imbalances inherent in our societal structures and systems because of the way these have been constructed, appearing to be fostered from a paternalistic medical model with a focus on pathologizing, blaming, and changing the labeled individual (Gilson & DePoy, 2002; Lundy 2004). These are oppressive systems encompassing multiple forms, where external oppression exists when ideologies of inequality are reinforced by institutions and other social structures (Lundy, 2004).

Methodology

Purpose of Study

As articulated in my introduction, the purpose of my research was to provide people diagnosed with ADHD as adults with the opportunity to share their experiences related to being diagnosed and their life experiences of living with ADHD. My intent was not only to provide this population with an opportunity to have their voices heard but to do so as a means of addressing the gap in our knowledge and thus inform helping professionals, specifically social workers.

Study Design

In my design of this qualitative research study I defined the construct of ‘diagnosis’ to mean a label given by a medical professional, legally licensed to make such a determination, which in Ontario includes physicians, psychiatrists and psychologists. I defined the term ‘beyond childhood’ to mean age 18 years and up because I wanted the people I interview to have lived the majority of their major developmental years without being aware that they had ADHD. In reference to the concept of giving this group ‘a voice’, I am approaching my research from the angle that this group of people do not currently have a voice in comparison to the dominant discourse: a discourse that typically dismisses this diagnosis, and further questions if adults can actually even have such a disorder.

Information gathering was conducted utilizing a brief Demographics Questionnaire (Appendix A) and one-to-one semi-structured, audio recorded interviews (with permission) relying on an Interview Guide (Appendix B) for

both direction and areas of focus during the interviews. The Interview Guide consisted of open-ended questions which were formulated based on the purpose of this study and the literature reviewed.

Ethical Considerations

I received clearance for this study from the McMaster University Ethics' Review Board. The participants were advised that their participation would be anonymous and that their names and any other identifying information would not be used in the write up and that it would be stored separately from their audio-taped interviews. All information about the study – and the potential risks – were explained in the Letter of Information and Consent (Appendix E) provided to participants, and were reviewed verbally at the time of the interview. Participants were also provided with a list of Helpful Resources (Appendix G), should they find themselves becoming upset or in distress at some point during or following the interview as a result of questions asked and/or information discussed during the interview. A professional transcriber was utilized, however no identifying information was provided with the recorded interviews and an *Oath of Confidentiality* (Appendix F) was signed by the transcriber, prior to their receipt of any files. All files were sent via a secure, encrypted email provider.

Researchers are part of the knowledge making process based on the placement of the researcher in the process. In the 'researcher/researched' relationship, researchers have power because of their position as the researcher (Dr. S. Greene, personal communication, September 2010). Therefore as the researcher, I needed to consider my responsibilities in the research process, as

well as my relationship with the participants. With respect to my responsibilities to the research process, I had to ensure I conducted my research within the scope and parameters I specified in my ethics application and in consistency with my intended purpose. My responsibilities to my research participants included keeping their identities confidential and storing their personal information in a locked location. During the interview it meant ensuring they knew that they had the control and choice to not answer a question, to end the interview at any time and/or withdraw from the study at anytime up until the deadline of July 15, 2011. The July 15, 2011 deadline was set as after that time the data would have been analyzed and compiled for my thesis in preparation for submission to my supervisor.

In considering my relationship with my participants, I conducted all of the interviews with my participants in a friendly, informal and non-threatening manner. I had a lot of respect and admiration for my participants and tried to demonstrate this during the interviews by treating them as peers and thanking them for their participation. As well, because I was thankful for the participants' courage and willingness to come forward and share their stories, I held them in high regard which, I hope, was reflected in my interactions with them. The participants seemed to respond favourably to my approach; all of the participants appeared relaxed during the interviews and the interviews felt comfortable.

I took a number of other steps in attending to my responsibilities in the research process as I attempted to manage the inherent power differential. I engaged in a continual process of reflecting on my placement within the research

process, my approach, and my interactions with the participants, through both journaling and thinking about these things throughout, and endeavouring to keep them at the forefront as I proceeded through the research. I also engaged in discussions with peers about my position as the researcher and the potential resulting power differentials.

Recruitment

I initially recruited people for this study through an online internet posting and two listservs (Appendix C) and through distributing a Recruitment Poster (Appendix D) to doctors' offices in the Brantford area. The Hamilton Spectator also contacted me and ran a recruitment posting advertisement (Appendix H) at the end of an article they published on Adult ADHD.

I had over 25 respondents; the majority were over the age of 30. Many were responding to the Hamilton Spectator posting advertisement (as indicated in their email or phone message), however I did not specifically ask or track where the respondents had seen the posting they were responding to. Three people responded for the purposes of seeking information on where they could go for an assessment and diagnosis of ADHD. From the online internet posting I also received 3 responses from people in Alberta and 1 from the United Kingdom, all of whom requested they be permitted to participate in the study. Although I had to decline these requests (because of both time limits pertaining to this research project and ethics approval which was specific to people residing in southern Ontario) this kind of response suggests that there is a demand for further studies in this area encompassing a larger geographical area.

Participants were selected based on the order that that they contacted me. Those participants whom I spoke with on the phone or who contacted me via email; who expressed interest in participating in the study; and who met the criteria for participating (having been given the diagnosis of ADHD as an adult by a licensed professional), were provided with the Letter of Information and Consent for their review. I asked them to contact me again if they were still interested in participating in the study after reviewing the Letter of Information and Consent. I also attempted to respond to all people who responded via telephone and left me a phone message, however the response to my recruitment postings were overwhelming and I was unable to respond to all people who called and left a message due to the time commitment required to do this. Participants who expressed an interest in participating and that I was able to respond to were thanked for their interest and advised that I now had a sufficient number of participants for my study. Timelines with respect to the Master of Social Work program necessitated that I cap the number of my participants at 6 to 10 people.

I learned that I had not thought about one of the characteristics of ADHD, which is a lack of follow through, prior to beginning the recruitment process. I was quickly reminded of this when people initially responded to my posting but then did not respond back, or when I was waiting to hear back from them for confirmation of an interview date and time but did not hear back. Interviews were arranged based on the participants' availability and at a convenient location of their choosing, with the majority of interviews occurring at various branches of the Hamilton Public Library and one occurring at the participants' home.

Participants

My participants were from the Hamilton and Burlington areas. I had six participants in this study and this included two men and four women. Participants' ages were 43, 48, 59, 61 years and two were 41 years of age. The time since diagnosis varied from 7 months to 13 years. All but one of the participants were still involved in their first marriage, and the other had been previously married for a period of three years. Two of the participants identified as being Roman Catholic, one identified as being of Portuguese ethnicity, one identified as being of Caribbean ethnicity, one identified as being of Irish heritage, and one identified as third generation Italian and English heritage. The other two participants did not identify as belonging to any specific religion or ethnicity. All participants have or had worked for a period of 9 to 25 years with the same employer and all participants had professional jobs including Physiotherapist, Public Health Nurse, Elementary School Teacher, Sales, IT Manager and Government Service Help Line Operator. All except one participant was involved with working with people, with four specific to professions where they helped other people. Three participants identified as having variety in their jobs and two identified as having ten or more jobs in their lifetime. One participant has two Undergraduate degrees, one has a College Diploma and has taken some university courses, one participant has a High School Diploma, one participant has a College Diploma and two participants have Masters Degrees.

Data Collection

With each of the participants I completed a brief Demographics Questionnaire and then conducted a one to one semi-structured, audio-recorded interview relying on the Interview Guide. The interviews were conducted at various locations in Southern Ontario, based on the locations of the participants. I conducted a total of 6 interviews during May and June 2011. Three separate attempts to meet with my 7th participant (who was 21 years of age) failed. The participant attributed these missed meetings to the challenges experienced as a result of ADHD. The length of the interviews varied between 20 minutes to an hour and a half, with the average interview lasting approximately 50 minutes.

Each interview began with my reviewing the letter of Information and Consent with the participant, answering any questions they may have had, and having them sign the letter if they were still in agreement with participating. Each participant was reminded that they did not have to answer any questions that they did not feel comfortable answering, that they could choose to withdraw from the interview at any time and withdraw from the study up until July 15, 2011 by contacting me and advising me of their wish to withdraw.

Data Analysis

The data from the brief Demographics Questionnaires was categorized with respect to each question with specific answers/information then examined. Those identified as the same were then grouped together allowing for both the commonalities and differences to be identified while also providing information about the research participants (Mason, 2002).

For the taped interviews, to analyze the data I first read and reviewed each transcript prior to working with it. I drew on a constant comparative analysis method, which is a process of examining one transcript at a time, identifying the significant data and then comparing this data to the next (and previous) transcripts, identifying both the similarities and differences. This method involves identifying themes and sub-themes within the transcripts, and then among the transcripts, further refining the themes and sub-themes with each transcript analyzed. At the end of this process the key themes and sub-themes that emerged from the data are identified (Boeije, 2002; Glaser, 1965).

Limitations

Limitations for this study include a small sample size (only six participants) so it cannot be assumed that their experiences of being diagnosed with ADHD as adults, or their experiences of living with ADHD, can be representative of all people diagnosed with ADHD as adults. The participants' ability to recall past events could be considered a limitation in this study based on the differences in the length of time since diagnosis (from 7 months to 13 years), as people's perceptions of their experiences could change over time.

The participants who volunteered and took part in my research were all fairly successful and accomplished, living middle class lives and working or retired from professional occupations. This could be considered unusual given what we know about this population from the literature, as there is a tendency for high rates of employment difficulties and a prevalence of academic problems (Barkley & Murphy, 2006; Davidson, 2008; Knouse et al., 2008; Ramsey &

Rostain, 2005; Toner et al., 2006; Waite & Tran, 2010). Thus, there may be limitations in this study related to the participants and their ability to adapt to and cope with their impairments of ADHD. Particularly if compared with the population with ADHD that is reported in the literature to have a lower socioeconomic status and overall lower global functioning (Barkley & Murphy, 2006; Knouse et al., 2008, Toner et al., 2006), as these factors are in addition to the previously mentioned employment and education difficulties. As well, this population's ability to adapt to and cope with their impairments is not known. Given that the social locations of members of these two (and other) groups would also appear to potentially be quite different, it can be presumed that their experiences in relation to being diagnosed in adulthood and of living with ADHD may also be quite different. Nor was this study large enough to look at differences among adults diagnosed as having ADHD along other parameters: gender, race, ethnicity, etc.

All possible limitations mentioned above were addressed through my transparency in the acknowledgment that these limitations may exist and by recognizing the potential impacts they may have on my research.

Insider perspective.

Central to my research is my own personal identification as a person being diagnosed with ADHD in adulthood. This experience impacted my life in many ways and, thus, I was clearly approaching my research from an insiders' perspective with a potential bias, necessitating my need to attend to this status throughout the research process. As noted earlier, researchers are part of the

knowledge making process based on the placement of the researcher in the process (Dr. S. Greene, personal communication, September, 2010). Research designed and conducted from a critical disability framework demands attention to the researcher's position, status, and experience of the issue being explored. The sharing of similar experiences is considered to be important to our overall understanding and contributes to the researchers' knowledge (Tregaskis & Goodley, 2005; van Heugten, 2004). However, assuming understanding of the research participants' situation and experience can be a problem as an insider because of the potential for over-identification and loss of objectivity. Thus, the importance of self awareness is emphasized (Greene et al., 2009; Kanuha, 2000; LaSala, 2003; van Heugten, 2004).

As a way of addressing the limitations pertaining to my having an insiders' perspective, I chose not to tell participants of my own insider status prior to, or during the interview. When I did share my own status as a person diagnosed with ADHD in adulthood, it was only after completion of the interview and only if the participant, during discussion, asked me directly or asked me about my reasoning for completing this study. Interestingly, this actually only came up in the post-interview discussions with the four female participants; for whatever reason the two male participants did not inquire about this. The reason I consciously chose not to share my status as an insider is because I was concerned that disclosing my own status during the process might have made a difference to the participants' answers. I felt that people might not have gone into as much depth in their answers if they knew I had shared similar experiences, or might not

provide as much detail on the assumption that I would understand what they were talking about.

I believe my disclosure to those participants that asked about my status during discussion after the interviews seemed to provide them with a sense of relief. Their responses were all very similar, such as “Oh, so you get what I mean” and “So you understand what I am talking about”, which all appear to be indicative that they felt that I understood what they were sharing in reference to their experiences. These participants also expressed that they were pleased that I had undertaken this research in an attempt to try and increase understanding of ADHD and the impact of diagnosis in adulthood.

Additionally, as a result of my self-awareness of my position, I consciously worked on setting my own thoughts, beliefs and experiences aside during the research interviews. I also engaged in a process of reflecting on the participants’ responses and shared experiences during the data analysis I did this both to be sure that I was understanding what the participants themselves were saying, and also to recognize where my own experiences might be influencing my analysis – either because their experiences were too similar, or too dissimilar, to my own. I also utilized the support of peers for debriefing and checking in on my interpretations, as I recognized the importance of acknowledging and sorting out my own thoughts, beliefs and experiences as part of this process.

Findings and Discussion

Four main themes were identified as a result of my analysis of the data. The first theme was *Experience of diagnosis as an Adult* and encompassed sub themes of providing an explanation/answering questions; seeking more information; and thinking about things differently/changing expectations. The second theme was *Everyday Challenges of Living with ADHD* and it included sub themes of physical and cognitive challenges (encompassing impulsivity, decision-making, balance, co-ordination, time management, focus and memory); challenges to daily living (in reference to housework and money management) and challenges in the school environment. The third theme, *Emotional Impacts of Living with ADHD* had sub-themes of low self-esteem, ongoing struggles and fitting in. The fourth theme, entitled *Professional Support* encompassed participants identifying the kinds of professional support that was/or would have been helpful.

Some other themes that also emerged included *Controversies of Taking Medications*, where some participants expressed positive benefits of medications and some did not believe in the use of medications. The theme of *Careers* highlighted the kinds of jobs and environments that the participants found to be flexible and structured in such a way that people with ADHD can have successful work experiences. A theme of *Supportive Partners and Parents* focused on the assistance and support provided by partners and parents and *Creative Thinking*, which identified abilities and positive attributes of people with ADHD, was also a theme identified by two of the participants. However, for the purposes of this

thesis I will be presenting the findings from the four main themes previously identified.

Experience of Diagnosis as an Adult

What might appear to be an interesting finding in light of the concerns noted in the literature about the impacts of labeling, is that all of the participants described their experience of being diagnosed with ADHD as a positive experience. The participants explained that there were three reasons for this response: diagnosis provided an *explanation* for their experiences; it led them to seek more *information*; and it meant that they saw things *differently*, which they found useful in understanding their own experiences.

Providing an explanation/answering questions.

All of the participants expressed that diagnosis provided them with an explanation and answered a lot of questions with respect both to the challenges they had experienced in their lives and/or their feelings that they didn't, or couldn't, live up to their potential. One participant described how s/he felt about receiving their diagnosis as:

(E)xcited, because it was like this tiny light at the end of the long dark tunnel. There was finally a reason that I was different, that I could not be quiet; that I could not keep my ideas or my thoughts to myself - that I blurted out things.

A second participant identified that being diagnosed also helped her/him to understand her/his son better, as the child had recently been diagnosed. Another participant's response made clear the idea that diagnosis was interpreted as an explanation:

Knowing that I am ADHD explained a lot, it explained a lot of those mistakes or things that I would do or say impulsively that, you know, not usually anything horribly bad, but it would not always be the best thing to say, you know, or I could not stop talking, I still can't stop talking.

Portway and Johnson (2005) identify that there are risks attributed to later in life diagnosis, such as underachievement, low self-esteem and depression.

Others similarly suggest that diagnosis and labeling creates an identity associated with negativity and oppression that encourages stigmatization (Buckles et al, 2008; Hallberg et al., 2010; Reaume, 2002; Saleebey; 2001; Valeras, 2000). Yet the responses of the participants in my study would seem to be different. Young et al. (2008) and Toner et al. (2006) report findings similar to those found in my study, findings related to the emotional impact of the diagnosis. They report that people feel a sense of relief after being diagnosed and realize that their struggles were not their fault but contributable to their disorder. As stated by one participant in my study:

It gives you a reason for the way you are and so it makes it easier for you to actually understand that the limitations that come with ADD are not like personality faults, they are just realities of the way your condition affects you.

In addition, Young et al. (2008) report that, “Murphy (1995) suggests that being diagnosed reduces an individual's internalized sense of failure and uncertainty because their problems can now be understood and attributed to a specific disorder” (p 494). The following participants' responses seem to support this literature:

I am a fairly introspective person so it gave me a perspective to look back at things that happened in my life and understand them better.

And,

I would say that it [diagnosis] was a positive experience overall because the outcome was that it confirmed what I had known about myself, it is like I know I am smart, I know I can do this so why am I struggling? That is the kind of questions I have always asked. ...

The participants' responses in my study seem to reflect the literature that suggests that, prior to diagnosis, people did not have either the language or the opportunity to talk about and understand their experiences (Barkley, 2006; Ramsay & Rostain, 2008). Receiving a diagnosis has finally provided these participants with an explanation for why they have struggled all their lives with certain issues such as living in chaos, striving to gain and maintain control of their lives, chronic low self esteem, feeling different from others, stigmatization, and co-occurring illnesses such as depression and/or anxiety (Knouse et al., 2008; Ramsay & Rostain, 2005; Rucklidge & Kaplan, 1997; Toner et al., 2006; Young et al, 2008; Waite & Tran, 2010).

Although the participants identified receiving a diagnosis as a positive experience which, as stated previously, is contrary to the literature that indicates that the process of diagnosis and labeling people has negative effects, one of the participants did identify experiencing negativity from being labeled. However the negativity was based on labels given by others based on their beliefs about his behaviours and actions because he had *not yet* been diagnosed, thus there was no “explanation” available for the “deficiencies” as seen by others. This is consistent to Freud's (1999) suggestion that while “some labels pathologize widespread human failings, yet paradoxically, they also normalize them. ... It is possible that diagnostic labels are not only stigmatizing, but also externalize certain problems

of living ...” (p 334). Thus for this participant, the explanation provided by receiving the diagnosis was still perceived as a positive experience:

All my life being labeled, not living up to your potential, lazy, procrastinator, not paying attention etc., etc., lots of negative things - so having an explanation for it was nice.

Levine (1997) argues that “the voices of dominant others, therefore, are an inherent part of the development of self-concept and personal meaning-making” (1997, p 204). From a critical disability perspective it can be conceived that this group has experienced feelings of inadequacies and differentness exemplifying that they do not fit into cultural norms thus contributing to their internalized feelings of not being able to live up to their potential.

Seeking more information.

Participants were asked if they tried to find out more about ADHD after receiving their diagnosis and all of them indicated they did. In the words of one participant: “Everywhere and everything. I have been online, I have tried books; I do not think I have actually finished any single book that I have had.” They all acknowledged engaging in online research and reading books about ADHD. One also utilized their Employee Assistance Program (EAP) through work; another attended an ADHD Support Group and accessed an ADHD life coach; and one garnered a lot of information through the process of their daughter’s diagnosis. One of the participants’ responses to the question of if they sought out information on ADHD after their diagnosis exemplified the mix of emotions they experienced in the process of seeking out and learning more about ADHD, reflecting how important (but also unsettling) the information was:

[reading] *Driven to Distraction* which of course is a classic book and, honestly, I opened the front cover, read the first paragraph and the introduction, and closed it quickly and my heart was racing, going like “Oh my God, this is me” ... so after closing this book and saying “Oh my gosh, I cannot read anymore”, it was like saying “Oh my God, a train crash, I want to look but I don’t want to look.”

Waite and Tran (2010) suggest that self-education is a crucial component of helping oneself and indicate it is important in the process of “getting better”.

Toner et al. (2006) identified how the search and acquirement of knowledge about ADHD allowed adults newly diagnosed to better understand their condition, learn strategies, and get tips on how to implement the strategies into their day-to-day lives. This literature seems relevant to one participants’ response as s/he shares:

The process of my daughter’s diagnosis was actually very educational because they were describing a lot about it, a lot of things that I did not know. The biggest one is the one they describe as “hyper-focused” which is ironic because you would not think that anybody with ADD could focus on anything but, essentially it explains a lot. I can get much focused on a task and put all my energy into it for hours at a time. And it was educational just to get an understanding of how it works and what the weaknesses are.

Similarly, Kelly and Ramundo (2006) indicate that to understand ADHD, its’ impact on one’s life, and to learn ways to gain control over some of the symptoms you need to learn as much as possible about the disorder.

Thinking about things differently/changing expectations.

Participants were asked if, as a result of diagnosis, they changed the way they thought about things, or changed their expectations about themselves or others. The participants’ responses confirmed that they all had done this. This theme proves to be consistent with what Solden (2002) refers to as a “Crisis of Understanding” followed by a “Crisis of Identity” – processes involved in the experience of being diagnosed as an adult. Solden suggests that people have to

learn what ADHD is and its' related symptoms and then move to developing a new sense of self. From there, they are able to learn to accept themselves. Similar ideas evolved from the participants' responses narratives and included "learning to understand myself and my limitations", "learning how to accept my limitations" and "learning how to become more forgiving of myself".

With respect to "learning to understand myself and my limitations", one of the participants shared:

Understanding you are not going to get as much done as you think you are. The other thing that I do is that I tell myself I can get that done in an hour, I can do this many calls today, I can do whatever and then you get to the end of the day and I have done half. You have to understand your limitations. I can go do it but it is not that easy.

On "learning how to accept my limitations" one of the participants explained:

So I wish I knew; if I had known the diagnosis I would know you are not going to be better at that, so you better do this, so that now I do some proactive types of things for myself. I am not great, I know what I am like now and I know this is not going to change. So I can do some things about it.

In a related vein, participants spoke not only of acceptance but of the need for "learning how to become more forgiving of myself". One of the participants offered a glimpse into her/his progress in this area:

I now accept if I am a little bit impulsive I am a little more forgiving of myself. I think I still have to work on accepting the way I am because I have been such a perfectionist all my life. I have been able to accept more of my imperfections and I let go of what used to drive me crazy, would have put me like into an anxiety attack of making mistakes or doing stuff that other people thought were bad.

And another participant not only speaks of her/his progress with self forgiveness, but also highlights the process s/he has gone through pertaining to her/his own

tendency to blame her/himself, to be harsh with her/himself over what s/he perceived to be personal failures and learning it is okay to say “no”.

I did change my expectations of myself I think. I began to realize that if I go back to that habit where I said I would get very hard on myself and obsess about all the bad things I had done that day, one of my counselors said to me look stop being hard on yourself say “oops, sorry, I will try and do better” and move on, and if people can’t understand that then maybe you need to get away from those people. So, in the end I have not lowered my expectations necessarily of doing things or being successful, I want to live. Things that I have started to do more, and my circle of friends are constantly saying you do too much or my mother saying don’t you ever sleep. I have started to give myself the permission to say “no” more often and I am learning to say “no” more often.

Toner et al. (2006) identify that adults diagnosed with ADHD strive to gain control of their world by becoming aware of their disorder, gaining an understanding of themselves, developing tolerance for themselves and their differences and accepting themselves and their impairments. Young et al. (2008) also indicates that the final part of the adjustment for people diagnosed as an adult is the acceptance of ADHD as a part of who they are.

It is apparent from my participants’ responses that they are working towards a better understanding of themselves, acceptance of their own limitations and self-forgiveness. However, they also identified that this can be a difficult process, one that takes a while to achieve. Participants continued to express frustration in feeling like they were often doing things wrong and talked of “beating themselves up” even after diagnosis because they are unable to meet their own expectations for themselves. It would seem that, although the participants could verbalize that they needed and/or wanted to become more

forgiving of themselves, their responses seem to indicate that it continues to be very difficult for them to change their own expectations.

Levine (1997) discusses the negative impacts attributed to labeling and suggests that the problem is not necessarily the result of labeling but the way in which society responds to disability and anything beyond the identified, socially constructed norms. None of my participants explicitly identified that many of the challenges they experience are a result of, not (just) the impairment, but how people reacted to them, identifying them as different and not fitting in. However, I believe that although they don't use the words they do speak to these experiences. One example can be seen by referring back to the words of one participant who noted her/his concern with other people's reactions to "doing stuff that other people thought were bad". A second example is found in another participant's experiences with how s/he felt others perceived her/him: "All my life being labeled, not living up to your potential, lazy, procrastinator, not paying attention etc., etc., lots of negative things". This second example seems to be identifying the negative way many non-disabled others react towards someone who appears to be different from the norm. The literature also supports the concept that society plays a large role in disabling people by not accepting differences.

Everyday Challenges of Living with ADHD

Thomas (2004) states that for people with impairments, many of their challenges are attributed to societal constructions and impositions but the impairment itself can also create challenges. An example of this kind of impairment would be an impairment directly causing a restriction in activity or

performance, such as someone who experiences ongoing pain from a chronic illness which restricts their participation in an activity; the pain is directly attributable to their condition or impairment and not the result of societal structures or attitudes. However, these ‘impairment effects’ are not then understood to be ‘disabling’ because they are not linked to societal oppression.

Likewise, the participants in this study identified impairments that they felt are inherent to their condition of ADHD. The participants’ sharing of their stories with respect to their everyday challenges not only helps to illustrate their experiences of living with ADHD, but also allows for others to gain a better understanding of the challenges they face on a daily basis.

Physical and cognitive challenges.

Participants identified cognitive challenges including experiencing a lot of difficulty with being able to sustain focus, problems with memory and impulsivity. One participant identified that they “have a hard time keeping on task and remembering stuff”. A second participant described themselves as “a high energy personality but sometimes [with] the attention span of a flea” and identified ongoing difficulty due to “getting side tracked in conversations”. These difficulties are consistent with results from a study by Toner et al. (2006) in that the participants identified chaotic lives attributed to difficulties with inattention, frequently misplacing items and impulsivity. Impulsivity was linked by the participants to a tendency to engage in risk taking activities, frequent talking, blurting things out and interrupting during conversations.

Specific to the ability to sustain focus, one participant explained it as “I digress, like I always digress because I have an opinion on everything”. Another participant shared:

I have difficulties with anything that requires a lot of mental effort, especially if it is something that has not caught my interest. The way I describe it to people it is like holding a small weight at arms length; you can do it for awhile and then it becomes very tiring, then it becomes impossible. I end up cherry picking what I do, or I don't give things the proper attention that they need.

This participant relayed her/his difficulties in sustaining focus and impulsivity through a story about her/his interactions with friends. Her/his story also connects to the earlier findings about forgiving oneself and illustrates the importance of having the acceptance of others:

My really close friends, now they just kind of go with me. We call it quantum leaping, we talk about this and then they will say something, and I will then go onto a different tangent. And all of a sudden we started talking about recipes for chocolate chip cookies, and then all of a sudden we are talking about the Russian Revolution as an example, and all of us will go “how did we get here?” And then we can trace it all back, and then we go back to the cookies sort of thing. So that kind of thinking would drive some people crazy but the people around me think it is kind of fun.

Another participant referred to the opposite challenge some people with ADHD have, which pertains to hyper focusing when they find something they are interested in. S/he shared the following story when talking about an ADHD self help book:

It is written by people with ADD and frankly, I found it really hard to read because I can read novels. I can read novels from start to finish and not get distracted. I found that I don't enjoy books that are quick snippets, I want something that I can dig my teeth into and hyper focus on: I am a hyper focuser.

One of the participants relayed how her/his poor memory affected day to day living with respect to both participating in activities and in social situations:

The swimming lessons did not help because I couldn't remember what they told me to do. Just like I don't like playing card games, I love Scrabble, I love board games like Monopoly but I don't like card games because I can't remember all the rules. I was in a Euchre Club; I don't remember how often we met but kind of like every other Friday night. I don't know why they kept me, they kept me for comic relief because I would always say, "Tell me again what this Jack means" and they would just laugh. Within the evening, if they explained it again I would usually be okay for the evening. I could remember for that long. Two weeks later I would be at somebody else's and we are going to play and I would say, "Tell me again?" I had to laugh.

What can also be seen in this person's account is, again, the importance of being understood and accepted by others, as well as understanding and accepting oneself.

When discussing difficulties with impulsivity, one of the participants identified "I could not stop talking, I still can't stop talking". Another said "when I was quite small, you know, people would describe me as a tornado". And a third participant shared:

I could not be quiet. I always had to have the last word. I just could not be quiet, I could not keep my mouth shut and don't ever tell me a secret. I still swear to this day - don't tell me anything that you don't want somebody else to know because I don't intentionally tell people, but it just pops out.

Another participant explained:

The impulsivity, as far as, yah like, I remember years ago one of my best friends, and we are still friends today, in high school she would say to me, "You never listen to me, can you stop talking?" I worked really hard to do the listening back and forth: that is still hard.

Participants acknowledged decision-making and time management to be problematic areas in their day-to-day lives. Kelly and Ramundo (2006) and Brown (2009b) indicate that many people with ADHD quite often underestimate how much time it will take to do something as they have a distorted sense of time resulting in being late for school, work, meetings and etcetera. Solden (2002) also highlights there is often an inability for people with ADHD to meet their own expectations and “to do” lists, often because they have planned to do much more than what is actually possible within a specific period of time and/or they have taken on too many obligations. One participant identified “typical of ADD, I always thought I would be getting more done than I did”, and another said, “I am notorious for saying ‘yes’ to everybody and ‘yes’ to everything, because we think we can do it but we can’t”. A third participant shared:

My husband ... I would make him late sometimes. He worked for a big company; if they went to a client dinner thing or something, typically I would think I would know what I was wearing but 10 minutes before we are leaving, I would put it on and I would think, “oh God, I can’t wear that” and start over. And he would be down there just pacing and I would feel terrible about this but I could not change it, I kept thinking “Next time I will be better at that”.

One participant also revealed “every time we were going out for dinner with a group of us, they would say “Let’s tell [name] half an hour earlier so s/he will be there. Ha, ha, ha.”

With respect to difficulties making decisions, Kelly and Ramundo (2006) and Ramsay and Rostain (2005) identify that people with ADHD have a flawed filter and so often are overwhelmed by sensory overload. They are taking in everything from all of their senses however they are unable to filter out the

unnecessary stimuli and concentrate and focus on what they need to. In addition, Solden (2002) indicates that people with ADHD often tend to respond impulsively when faced with a decision they need to make, without first finding out all of the important information; and/or they are overwhelmed by everything else that they are already trying to do and find they cannot think clearly; and/or their inability to plan impedes on their ability to make a decision. One participant shared:

I do notice everything; that is the problem. I notice everything and I don't know what is important to you or the situation and what needs to be written down or what needs to be made mention of. I have a really hard time filtering.

Another participant identified difficulties that seemed to be related to an inability to focus and sustain attention, as well as problems with filtering and making decisions:

I can't follow, that is where this ADD comes in. I can't follow certain diets, things, I can't count calories, I can't. And when I say I can't, I think a lot of people think it is just a cop out but I can't, I just do not understand it, there are certain things I just can't do.

Other cognitive difficulties were also identified by some of the participants, including one participant who referred to a common ADHD trait by generalizing, "ADD people, we like quick fixes, all or nothing". And another spoke of their difficulties with procrastination, noting, "It is hard to sit down and really do it". Kelly and Ramundo (2006) and Brown (2009b) identify that people with ADHD tend to function in extremes, switching rapidly from one extreme to another, which often results in "all or nothing" thinking and/or "all or nothing" behaviour and actions. They attribute these rapid switches in extremes to both the brain and nervous system being unbalanced. Kelly and Ramundo (2006), Brown

(2009b) and Ramsay and Rostain (2005) highlight the challenges with getting started on tasks, in part because of anticipated difficulties in completing the task related to their impairments, but mostly because of the major difficulties with focusing attention and the tremendous initial effort required to begin concentration on a task.

When considering attention to details, Kelly and Ramundo (2006) explain that this can be a struggle for people with ADHD. The need to attend to numerous pieces of information at one time requires scanning, processing, and remembering multiple parts, which tends to be incongruent with the way their brains function. Similarly, in relation to the previously discussed extremes in thinking, this aversion to details can be best observed with a tendency to engage in “big picture” or “whole picture” thinking. One participant identified:

I am very good at getting the grand work done and handing it to other people, I am very good at coming up with solutions. I am not necessarily the best person to implement.

Similarly, another participant said “one of the nice things that I kind of enjoy is the brain storming, I can brain storm whenever, but don’t ask me to implement it”. Naturally, although less common because of the way their brain functions, the other extreme for some people with ADHD can be to get so caught up in the details that they are unable to see beyond them (Kelly and Ramundo, 2006).

Toner et al. (2006) reported from their study of adults with ADHD that participants remained hyperactive as adults and felt a need to keep busy, and that they identified having difficulty sitting still at work and in social situations. One of the participants in my study was similarly able to relate their problems

pertaining to hyperactivity, particularly in light of the added challenge of being diagnosed with the inattentive subtype of ADHD, instead of the combined subtype.

Us inattentive types, and they say hyperactivity is not part of that, well it is not obvious but it is inside. I have to sit like this to keep still and I will notice myself ... there was music going and I am the only one tapping, I could see my knees were up and down and up and down, nobody is doing that, I could see the whole place.

Some of the participants expressed difficulties with balance and coordination. Kelly and Ramundo (2006) report that people with ADHD can have spatial distortions, in that they have difficulties determining how their body moves in space in connection to other things. Therefore, they may bump into things or people and have trouble in some sports where there is a requirement for stringent spatial reasoning abilities, or where accurate estimations of how fast and what direction a ball is traveling are required. Spatial reasoning challenges, coupled with a wandering mind (another common trait for people with ADHD) can greatly impede on the person's ability to balance and be coordinated, as can the inability to filter (as was previously discussed). One participant shared "I had the hand coordination problem, I hated playing golf but I would go with people because I would think I was going to get better at this".

Challenges to daily living.

As part of regular daily living tasks, participants reported difficulties related to managing money. Kelly and Ramundo (2006), Brown (2009b) and Ramsay and Rostain (2005) identify that some people with ADHD experience challenges with respect to an inability to plan and an inability to

organize. Add to this the previously identified difficulties many people with ADHD experience pertaining to their memory and impulsivity, it is conceivable that these kinds of challenges could impact on their ability to devise a financial budget including planning for upcoming anticipated expenses, remembering to pay bills on time and then ensuring they stick to their budget and not give in to spontaneous ideas and urges to spend money that has been designated for elsewhere. In reference to financial responsibilities, one participant reported "... and I would miss a bill payment, thank god for automated withdrawal". Another participant shared their thoughts and challenges about money:

I think debit cards are the worst thing they ever came up with. I just don't even think twice about what I am doing. I basically have, like when we went bankrupt we had to pay a certain amount of money and our bankruptcy went on for an extra year because I could not get it together to take care of that.

And a third participant spoke of their attempts in wanting to help with household tasks:

I wanted to make sure I was helping here so I would pay the bills. Big mistake. I did it for a little while when we were in an apartment, I guess we did not have a lot of money, we did not have a lot bills. I handled that but when we got our house though, that was maybe seven years later; I was not even opening the mail. I am not getting the last notice, I paid interest on all kinds of things and then one time, the power went out because I did not pay for the power so we went back to him doing that [the money].

Another participant shared her/his experiences related to money management and how quickly it can get out of control, without them even realizing it:

Financially it has been, thankfully it has never been devastating, but it has been a real challenge to this day. I am still paying the price, I have an excellent credit rating, I have never had to go bankrupt but I have an enormous amount of debt now ... if it had not been for my

parents, I would have declared bankruptcy for sure, there have been a number of times where they have bailed me out over the years. My Mom and Dad have totally enabled me and my brother, they backed off a little bit but just recently I was trying to get another consolidation loan and then looked back and wondered “How the hell did I rack up that Visa again?” I was overspending again, impulsively and just thinking, “I am working, I can afford this”. Well now you can’t; you just like, you overspent again.

Managing household tasks was also identified as problematic for the participants in my study. In considering the multiple impairments that restrict their activities and performance (those which are not constructed or imposed by society) there is little wonder why these routine daily tasks could present as challenging. Thus I have included a few examples of the participants’ stories to help exemplify some of the difficulties they struggle with.

One participant shared, “I would have stuff everywhere, I hired a personal organizer. We never had enough money to do that earlier and we are okay now, but I felt that that was worth the money.” While another identified:

There are some things that are just the simplest things in the world, you know, like housework that I can’t seem to do. I can’t even remember. It does not occur to me to empty the dishwasher, or put a load of laundry in. I can totally daydream a whole day away. I can lose totally track of time.

For one of the participants, clutter and disorganization within her/his home continues to be an ongoing challenge. Even as s/he shared her/his story, the frustration and exasperation were evident in her/his voice:

I was living in my parents’ basement and in a short period of time I could barely walk on the floor without stepping on paper and piles. I would just get all revved up and be avoiding and procrastinating ... I

put strategies in place and sometimes I would let them go and I would not use them, and then I would put them back in place and I am in the process of putting them back again. My den is a mess! I have got piles again: after I separated I had so much crap it was overwhelming. And I had a line of credit and first of all I went to a woman's workshop on how to get organized. And I got Elaine to go over and do an assessment and I hired her and we worked for a number of months and that was huge. She questioned me, "Do you need this or that?" and she explained to me step by step. I was always with her when we did the work, three hours at a time, once every 2-3 weeks and she got me all organized. Now, since then, so last year I moved and I kept most of the organized, but the hot spot has always been papers and books.

With respect to parenting, one participant identified:

The children of an ADD person become resilient, I showed them how to do the wash and all that, but I was not going to keep on top of this, some other mothers might be hovering over, "Do you have your homework?" I could not.

And another participant alluded to the resulting social implications because of the challenges h/she faces when trying to entertain. Within a critical disability framework, this is illustrative of how constructed norms in society can result in disabling a person and negatively impact on social relations.

This is reflected in this example because of the participant's perceived inability to meet societal expectations around entertaining:

[I did] not like having people for dinner, that has dogged me my whole life because I can't stand somebody watching me, because I am distracted by that. I think I have to talk to them ... everybody wanted to come into the kitchen, I don't want them in my kitchen because I would realize that I am going to talk with them and everybody is standing around having something or other, and of course I am forgetting what is in the oven, it came so that I did not want to invite people over. That became a problem because other people would be inviting us.

Challenges in the school environment.

Experiences and struggles with school came up as a recurring topic among all of the participants, although there wasn't a question in the interview guide that specifically asked about school experiences. It would thus seem from the participants' responses that experiences in school must have been significant.

This is consistent with the literature that identifies that there is a prevalence of academic problems for persons with ADHD (Barkley & Murphy, 2006; Davidson, 2008; Knouse et al., 2008; Ramsey & Rostain, 2005; Toner et al., 2006; Waite & Tran, 2010).

Pertaining to difficulties with examinations and tests, one of the participants identified "I have never finished a written exam in my life." Another shared "I could only take courses that had essays because I would just forget at a test, my mind was blank, no matter if I knew the stuff before I got there – I just blanked." Reid and Katsiyannis (1995) identify the need for modifications to tests and exams for children with ADHD, including providing both verbal and visual instructions, providing a classroom aid to assist with scribing, and adjustments to seating arrangements. As my participants were not diagnosed with ADHD until they were adults, they would not have been eligible for any accommodations. Interestingly however, one participant identified how s/he essentially developed and provided her/his own accommodations:

In high school, when I was 15-16, I would help some of my fellow classmates to get through the material and they would say what did you get on the exam and I would tell that and they would go "Your kidding me, that is all you got!" I would see this puzzled look on his face and then be really surprised that I did not get a high mark. In University I would help my fellow classmates to get through and

teach them – you see, the teaching aspect, if I could take the information and explain it to somebody else I definitely understood it and this was one of my strategies without realizing it, this was one of my strategies to grasp the information and being able to enhance my working memory because I am working with it more, right, I am sort of listening, touching it, re-hashing it, it makes it mine and I have to spit it out because I have to explain it to somebody else, you know.

In considering the executive functioning impairments that impact cognitive processing (as were discussed earlier in this paper), it is not surprising that tasks required for academic success in school would prove to be challenging for this group. One participant revealed, “I had to work harder to get good marks because I was not a good student. I did not write notes well”. While another participant shared:

In school I was not interested in studying, it was kind of something that I had a very hard time doing. I had a very hard time staying on task, so I would say I went through school on the seat of my pants.

A third participant identified difficulties with trying to stay on task and having her/his mind always wandering and shared how s/he just wanted to pretend the homework didn’t exist:

My mind would wander all the time if it was not an interesting topic – and lots of high school was not – and I would go home with the homework and ignore it, ignore that it was in the bag, thinking, “if I don’t think about this ...”

And another participant disclosed, “I have always been a horrible homework person for example and the thing that drives my classmates – the ones that I see – crazy, is that I do not take notes.”

What I found ironic about this theme was that all six of the participants in this study completed high school, with five of the six participants also going on to

complete postsecondary studies. Two participants completed more than one program or degree, while another is in the process of completing their second program. Two participants have Masters degrees. This is quite contrary to what the literature says about school experiences and school performance for children and adults with ADHD. This suggests to me that, despite all of the participants relaying the impact of having ADHD on their experiences at school, they all must have picked up some valuable coping abilities and/or had really good support systems (through family and/or friends) during their school careers to enable the majority of them to continue on into postsecondary studies. However, this is purely my speculation, as I did not pursue this with them during the interviews.

Emotional Impacts of Living with ADHD

It was clear when analyzing the data that there was a strong theme related to the psychosocial impact on participants of living with ADHD both before and after diagnosis. The emotional impacts of living with ADHD are attributable to several factors, including the participants' experiences prior to diagnosis related to feeling different, feeling unable to fit into constructed societal norms and feeling inferior. Another factor is the participants' ongoing struggles with accepting their own limitations, feeling like they are often doing things wrong and "beating themselves up" when they don't meet their own expectations, despite having been diagnosed and feeling relief at having an explanation or reason for their impairments. Lastly, in considering the critical disability perspective, there is the fact that these participants have been socially oppressed through the process of society disabling them. Lundy identifies that "we come to believe in our own

inferiority, worthlessness and powerlessness” (2004, p 132) as a result of being oppressed.

What was most notable in this study was that participants spoke to how, even after diagnosis, they battled low self-esteem and how most continued to struggle with feelings of inferiority and fitting in. Several identified not feeling good about themselves or not feeling confident in their ability to do things. All of these experiences and feelings are consistent with what the literature reports.

Low self-esteem.

The literature identifies there are negative impacts on self-esteem for people with ADHD including those not diagnosed with ADHD until adulthood. It further identifies feelings of hopelessness, feelings of incompetence, feelings of ineffectiveness and a chronic sense of underachievement as common (Barkley & Murphy, 2006; Davidson, 2008; Ramsay & Rostain, 2005; Toner et al., 2006; Waite & Tran, 2010; Young et al., 2008). One of the participants, in response to her/his struggles with self-esteem, revealed. “You give up, so you accept mediocrity.” Another participant identified their frustration with their ADHD by explaining that it is “(a) problem that does not show: you just do something really crazy and it bothers you.”

While demonstrating a sense of humour about her/his situation, one participant shared:

When I learned that the frontal cortex is smaller, I said to the instructor “Do we have something bigger?” So, I have to laugh about this, but I did always, my whole life, have that underachieving feeling.

Whereas another participant could only address the ongoing exasperation s/he experiences, related to her/his self-perception, as well as to the perceptions of others. In the quotation below is exemplified the social model's emphasis on the disabling effects of the expectations within society that are based on normalcy and people being 'able' to do things:

I am frustrated that I don't understand myself. When I tell people that "I can't" and I really can't and I think that people think that I just won't, that I won't try, and it is not that I have not tried, it is that I can't.

Ongoing struggles to be "normal".

Toner et al. (2006) refers to the concept of pretending to be "Okay" in that adults with ADHD want to hide their diagnosis and differences from others so that they can present as "normal" to the outside world. Likewise, Hallberg et al. (2010) reported similar findings in their study in that their study participants identified a fear of being regarded as different and feeling like they weren't "normal". Goffman (1963) speaks to a skill of 'impression management' that people with disabilities will sometimes develop in an effort to hide their true self from society and try to control what others see.

Pertaining to low self-esteem, an internalized sense of failure and self-blame, my study participants identified ongoing struggles with trying to conform to what is considered "normal" and conceal their impairments from others. Davis indicates "the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (1995, p 24). The participants' expression of wanting to conform to the concept of "normal" is indicative of the impact of societal constructions of what is acceptable

and exemplifies Davis' notion that normalcy, as currently constructed, creates the disabled person as the problem. Naturally with these cultural norms and beliefs, and consistent with the disability literature, "being the problem" is then internalized, ultimately impacting the disabled person's attitudes and behaviours when others perceive them as not meeting these standards and contributes to them wanting to hide their impairments.

One participant discussed how they have had to force themselves to change/conceal her/his own personality characteristics because of her/his fear of doing something inappropriate:

When I was younger I was much more impulsive, much more bubbly and like "Let's go have a blast" and I am sure I was lots of fun for my friends 'cause I would just go off and do anything with them but, as I got older, I realized that I had to have much more control of the way I was and, if anything, I actually pushed the other way so I am actually probably a lot more serious than I would like to be because I have a big fear of doing something inappropriate.

Another participant shared their ongoing struggle with repeatedly hoping and trying to "do better":

I always thought I will do better next time so that if I had the diagnosis it would have been nice to know this is the way my brain works, let's figure out a different thing to do, but I did not: I kept doing the same things and thinking, "Why can't I get this, I will try again and this will work."

Two participants spoke of similar struggles with meeting their own standards and expectations, which can be considered to be a function of internalized ableism in the sense that they have adopted and internalized societal attitudes and beliefs related to normalcy in forming their expectations for themselves. Having imposed these unrealistic expectations on themselves, they have indicated ongoing concerns of only being able to focus on their perceived mistakes:

I get the reminder from my life coach that, you know, I could have an entire room, I could have every room in my house organized, and I will focus on that one room and totally beat myself up and she said that is a real ADHD thing. Instead of seeing all the successes I have had, I am focusing on the one thing that I have not done, the one mistake that I have made that I could have done better on that.

And the second stated:

I was really getting down and part of my stress pattern that really being hard on myself and being my absolutely worst enemy and my worst critic and obsessing. You asked if there were any other diagnoses: well, no, I was not diagnosed with obsessive compulsive but the active obsessing about having made a mistake, not being able to be the dog that dropped the bone, and sometimes I would get into that bad pattern and that would just, I would get this little thing in my head, “I should have just tried this, I can’t believe I did this, I am so embarrassed” over and over and over again – it is like “Stop it”.

Fitting in.

Being regarded by others as “normal” and conforming to societal standards, were identified by the participants as necessary to “fitting in” and belonging. With respect to this idea of normalcy and fitting in, Davis indicates that, “Everyone has to work hard to make it seem that they conform, and so the person with disabilities is singled out as a dramatic case of not belonging” (2009, p 363). One participant identified:

Life has not been easy and not in such a big way: it is not like I am in a wheelchair, so people think “What are you complaining for?”; it just caused sadness for me because I spent too much time not being able to do things that other people can do.

Another participant shared their ongoing struggles with trying to “fit in” within their own family by doing things only as a means of living up to others’ expectations:

I took tennis lessons over and over again because my Dad and brothers loved tennis and he thought I needed to learn this. I hated that. Finally, as an adult, I could give that up.

Another spoke of his/her attempts to measure up to her/his perception of accepted societal standards demonstrating how internalized the cultural norms and attitudes are:

I think you compare yourself to others quite a bit, right? I guess the other people with similar jobs, similar age and they will appear to you that they are doing more, they are more successful, more happy, making more money – whatever it is – and you are like “Oh, you know, I would love to be that person but I can’t.” ... I feel inferior to others to the point where, if someone actually pays me a compliment, I actually have a hard time accepting that; I have a hard time accepting compliments.

The social model of disability highlights the disabling of people with impairments as a result of our societal structures, attitudes and cultural norms and the construction of these in ways that prevent people with impairments’ ability to fit in, conform to and/or meet these defined standards. This would appear to be apparent in this participant’s experience and perception.

Although there is some suggestion in the literature that receiving the diagnosis will help to reduce the impact on self-esteem and feelings of inadequacy as it provides an explanation for the problems (Murphy as cited in Young et al., 2008), it would appear from the participants’ experiences that they continue to struggle in these areas, despite knowing and understanding the reason for their difficulties. At times, however, this appears to contradict their stories around the impact of diagnosis, those pertaining to feeling a sense of relief and finally having an explanation for their experiences.

I recognize some of the participants' experiences may be related to their actual impairment, to how the impairment itself contributes to some restrictions in activity or performance. However, based on the stories participants told and language they used to describe their experiences, I believe most of their identified ongoing struggles with self-esteem and internalized blame can be attributed to the marginalization and oppression they have experienced from our constructed societal structures and systems throughout their lives. A lifetime of this kind of exposure can be presumed to have some long-term effects, as can their continued struggles with trying to "fit in" a society constructed around ableist norms and values and be accepted, despite their differences. Lundy (2004) summarizes the process of this oppression and its resulting consequences on people:

... the attitudes and beliefs that are dominant in society reflect the experiences of those who are privileged and in positions of decision-making ... Those who live in the margins and who encounter racism, sexism, homophobia, and stereotypes of mental and physical disability on a daily basis can begin to internalize these messages. If they internalize society's view of them as "other" or "less than", it can be easy to begin to believe that there is something wrong with them, resulting in feelings of inadequacy and/or self blame (p 86)

Professional Supports

One of my purposes for engaging in this study was to educate professionals, and particularly social workers, about the realities of living with ADHD. My goal was to increase their understanding of how having ADHD impacts people's lives in various ways and to provide some ideas for the kinds of help and support that would be most beneficial to adults newly diagnosed.

Consequently, one of the areas I chose to explore in my interviews related to whether participants sought professional help or counseling after diagnosis; to describe the type of help they were looking for, and what they believed a professional support person could have said or done that would have been helpful.

Four of the participants indicated they sought professional help and one spoke of success in finding a good social worker whose support s/he found to be very beneficial. That participant discussed her/his experience with respect to her/his involvement in this helping relationship:

I was introduced to the most wonderful and fantastic social worker, counselor who is also ADD herself and she is now in her late 50's early 60's, and having her guide me was most helpful because I could certainly recognize certain aspects of her personality that, in mine, were very similar. I thought, "Hey, she can get through this and sort herself out, and she has given herself permission to be ADD when she needs to be and just be nice to yourself". ... again, probably because she also had ADD or ADHD, she was quite forthcoming in telling me that and explaining her experiences, and I think having her as an example as how she dealt with her symptoms – albeit that her profile was a little bit different from mine – she demonstrated that she understood it.

Elements that appear to have made this experience a positive support for this participant include a focus on giving yourself "permission to be ADD" and encouragement to "be nice to yourself". As well, the participant identified that they found it very helpful that the person understood ADHD, in this case it was because the support person themselves had ADHD, and the examples of her experiences and how she dealt with her symptoms were also identified by this participant to be particularly helpful.

As noted previously, two participants relied on benefits provided to them through their employment to access supports. One participant paid privately for an

ADHD Life Coach and also attended an ADHD Support Group. The participant shared her/his experience pertaining to the support received from the Life Coach and the ADHD Support Group:

Getting help - part of the role about my life coach is to keep educating me. So she is very good at reminding me, this is what it is like to have ADHD, the meds can take you so far, it is like putting glasses on. But like they say in the group, I need the skills and tools and I need to implement those to really feel better and feel successful with that and feel like things are in control.

Interestingly, with respect to the previous two quotes, the participants did not speak to the larger societal factors at play when they spoke of their experiences around support, despite having identified the impact of these forces (larger societal structures, responses, attitudes, etc.) throughout their interviews in relation to their experiences of being adults with ADHD. Both of these participants, and the support persons they worked with, kept the focus on individual supports, individual interventions, and in this context, it does not seem to move beyond this individual level. From a critical disability lens, this raises the question as to what this will mean for real change to occur. There is no mention of work towards either consciousness raising about the disabling effects of society or strategies for working towards larger systemic or societal change, as would be consistent with the social model of disability. And in fact, although the focus on the individual is important, the focus being entirely on the individual is actually more demonstrative of a medical model approach.

Although some participants had success finding and accessing good professional support, some were not as fortunate. One in particular is still hoping to find appropriate supports in the community that are available at no cost, as s/he

identified that the costs for private support and services were prohibitive. This participant's experience clearly illustrates that while the impairment creates some challenges on its own, it is the larger systemic barriers that exacerbate this. The lack of available, accessible and affordable support clearly demonstrates the disabling societal barriers which exist when one views this situation from a critical disability lens. With respect to her/his continued search for help, s/he identified:

I thought there would be help, I do not know quite what I expected you know, I know there should be some work to it but I thought that there would be something, like basically, about the most I've come up to that I probably should get a life coach, but again it is going to cost money.

Five of the six participants effortlessly provided lots of ideas about what they believe would have been helpful support from a counselor or social worker. With respect to assistance with managing the psychosocial impact of being diagnosed with ADHD as an adult, one participant indicated that they believed the following would be helpful:

I think around some of the grieving and maybe going that little bit deeper ... and I guess the reasons behind my behavior throughout my life. Because there has been behavior that has been different from most people I know who are normal.

This participants' response demonstrates the societal devaluation and stigmatization that exists. The participant seems to be grieving the loss of the 'normal' self and wanting support around grieving however if society didn't make people with ADHD feel 'not normal' then the participant wouldn't be experiencing this grief in the first place. From a critical disability perspective it is imperative that support also focus on assisting the person to recognize why they feel they

must grieve this loss as opposed to challenging the normative assumptions that created her/his experience in the first place. The participants' feelings of grief are real and validation of her/his feelings is necessary however it is also important for the participant to understand the grief and recognize the factors that are causing them or influencing them to feel a particular way. Societal attitudes related to 'normalcy' contribute to the participants' beliefs around not fitting in and not being 'normal'.

I have listed three participants' responses below pertaining to the supports that they identified would have been, or would be helpful in regards to learning about their ADHD and how to better accommodate it and manage their impairments and challenges. However again, the participants are clearly focusing on support from an individualized perspective – the emphasis is consistently on helping them to understand the impairment effects of ADHD and the focus never moves from the individual to the larger structural forces involved in disability:

More coaching, so like coaching you through what your issues are, and your coping strategies and organizational skills, and things like that. I had to really seek that that out on my own.

Number 1: I would like a professional that could oversee, like in the books they talk about like the three things, the counseling, the medication and structure I guess. So I guess if you had the right counselor, the right person that could take care of that.

I would have loved to have somebody to talk about to just say if it is my ADD that is making this happen, and "Have you got some ideas on this?" and it would have stopped me from, I just felt so bad about not being able to do things and kept thinking it was going to get better, it would have been nice to talk to somebody who would say, "Okay, this is the way your brain works and let's just figure out some other way for you to do that", and I do not know if that would have made me feel better because it still makes me feel bad that I wasted a lot of time in my years not enjoying a lot of things other

people can do. I do not know if that would have helped, well, it would have because if I knew I could not do whatever it was maybe I would start focusing on something else instead of beating my head against a brick wall.

This individual focus is interesting from a critical lens. Their experiences have been so difficult and they have lost so much time as a result of not having been diagnosed sooner – which is, itself, a function of societal misinformation and myths around adulthood and ADHD - that they are anxious for as much information and support as possible as a means of not only being more successful, but also of understanding and coming to accept who they are.

One participant shared her/his thoughts about what s/he believes would be important for a professional to do, both with respect to them gaining an understanding of the experience of living with ADHD, and also to learning about the kind of support that would be helpful. Although again very much focused on the individual, I found this participants' perspective particularly interesting as her/his partner is a social worker, which s/he refers to in her/his response:

For me, for getting inside the head of what it is like to live with this is important for somebody who actually understands how to help someone. Because I would say that [my partner], even though s/he is a social worker, s/he does this for a living and I frustrate her/him regularly. S/he has a very good understanding of how to help adults with a variety of mental health issues and s/he knows about it. If you are trying to help somebody else you have to kind of take that into account because, I am sure, for a therapist who is like you know, “I gave you this coping strategy and you did not do any of it right” and for an ADD person that is just what happens. You have to have a tremendous amount of patience. It is not curable so you are trying to coach and teach people how to a) understand it, b) understand the personal limitations and what are the coping strategies and how to take little bites out of chunks. You cannot give an ADD person a list of ten things, you can give an ADD person one thing to do, they do

everything in a linear fashion and that is the way I do it. You have to give them one thing to try, and the next time it is just like “How did you do?”, “Now I am going to give you another thing to try” because the interesting thing is that once it becomes routine then they don’t have to think about it anymore; but you are creating a whole new routine.

This participant’s perspective helps to exemplify the importance for social workers and other helping professionals to have knowledge of ADHD to really provide effective support for people with ADHD. Further, s/he identifies that it is really not enough to have experience in the helping profession – it is important to have a good foundational understanding of ADHD, and the ways this particular impairment can pose challenges – not only for the person with ADHD, but also challenges to social work’s reliance on particular ways of helping. As outlined by this participant, the social work practice of working with clients to develop tasks or goals, and the expectations that they will follow through with these may be problematic if the client has ADHD. As well, if social workers lack an understanding of the cognitive challenges posed by ADHD they may, inadvertently, end up blaming the client for what is, in effect, the social workers’ failure and not the clients.

I want to highlight the participant’s assertion from the preceding quotation that ADHD is not curable. We live in a society that operates from a medical model of disability with respect to how illnesses and conditions are viewed, described, diagnosed, and treated. As ADHD is not curable, an ongoing challenge for social workers, as well as other mental health professionals, will be how to provide appropriate beneficial supports to adults with ADHD while remaining cognizant of the need to work from a social model of disability. Otherwise, as is

indicated by both the literature reviewed and the theoretical perspective adopted for this study, we risk falling into practices that will continue to be oppressive and stigmatizing for the individuals we are trying to support.

This is further apparent in contemporary social work when one looks at the language used by social work. What I have come to understand, from my own practice is experience, is that, for the most part, what is used is language that continues to be reflective of the bio medical framework. There is a move to some other less pathological social work models such as Saleebey's "strengths based" approach (which emphasizes the persons' strengths and attempts to build on these (Saleebey, 2001) and "client centered" social work (where the client identifies the areas they want assistance with and directs the kind of support they want (Elliott & Freire, 2007; Green 2000). However, for the most part, the terminology utilized still lends itself to the idea of a "problem" which can be "fixed". This is not restricted to disability. Social work language such as "case", "therapy", "solution focused therapy", "presenting problem", "intervention", "therapeutic intervention", "psychosocial assessment" – right down to how we refer to our jobs as our social work "practice" – continue to permeate the idea that professionals, in this case social workers, know what is best for the ("damaged", "broken") person and will engage in activities that will attempt to "fix" them. This is in direct contrast to the social model's inclusive, empowering and action oriented approach to addressing the oppression.

Stigmatization

One of the commonalities I noticed among the participants' responses, particularly when they spoke of the impacts of living with ADHD, their ongoing struggles with low self esteem, feelings of inadequacy and trying to fit in, was their desire to be understood and for some, even a desire to understand themselves. From hearing the participants' voices during their interviews and the language that they used to describe their experiences, it was apparent to me that many of them feel different compared to other people, believe that they do things differently from others and believe that they must hide their "true self" if they want to be accepted by the dominant "normal" society. This quote by Sari Solden (2002) further explains this sense of "differentness":

... between the AD/HD and non AD/HD worlds, there is a gulf of communication and understanding that adults with AD/HD often find difficult and frustrating to bridge. People with AD/HD act, think, talk, and process information differently from those without AD/HD. ... For adults who have grown up with the experience of being different, their core vulnerability and their greatest hurts have resulted from being different. ... It is painful to contemplate being seen as different since you've spent your whole life hiding your differences or have been ridiculed for them. (p 21)

Research by Hallberg et al. (2010), Knouse et al. (2008), Toner et al. (2006), Valeras (2000) and Young et al. (2008) all show similar findings with respect to people wanting to hide themselves – or the fact that they have ADHD – from others. I believe these kind of responses and many of the feelings and beliefs expressed by the participants can all be attributed to the stigmatization that results from their differences because they are presumed by non-disabled others to be

‘undesirable’ which results in devaluation and social ostracization (Dovidio et al, 2000; Goffman, 1963; Titchkosky, 2000). Goffman defines stigma as:

... an undesired differentness from what we had anticipated. ... By definition ... we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination. ... We create a stigma-theory, an ideology to explain [the] inferiority and account for the danger [represented]. (1963, p5)

Similar to the way Davis (1995) defines the word “normal” to mean “to conform to” or “not differ from” (p24), this process of discrimination and stigmatization reveal the larger macro level forces at play and makes their oppressive structures visible.

I wish to conclude this discussion by including a final story shared by one of the participants, a story which exemplifies the social model perspective of disability and which relates to the discrimination, stigmatization and oppression this group of people have experienced in their lives:

I would say, like any mental health issue, my challenges are exponentially more difficult than the average person, so I would say it is hard for people to understand what that means. I do not tell people I am ADD. I have only told my mother and my brothers. It is one of those things, because I don’t want to tell people because I know I will be judged. I do not want people to think of me as “[name], the ADD guy”. I just want them to think of me as “[name]”.

Strengths and Resilience

As previously mentioned, there is a move towards the use of some less pathologizing social work models which focus on client strengths and the client directing their own support. It is important from a critical disability perspective to ensure social workers are not continuing the cycle of oppression by pathologizing

the individuals they are supposed to be supporting. Working from a strengths-based perspective achieves this goal.

Saleebey (2001) focuses on the concept that the individual is the main component of the social order within the dominant culture and that individuals are responsible for their own meaning and identity making, albeit influenced by others, as well as cultural, societal and historical influences. He identifies however, that people who are oppressed are more vulnerable and less likely to have the skills, responsibilities, or privileges to make their own meaning, thus they essentially lose their voice, adopt the views of their oppressors, and see themselves as not worthy, inferior, and at fault. In an effort to confront this now ingrained vulnerability and oppression, Saleebey champions the idea of giving the voice back to those who are oppressed and encouraging autonomy by recognizing them for who they are and identifying their positive attributes, strengths and resiliencies, expanding their capacities, assisting them to rise above their situations and, ultimately, attending to their hopes, and possibly even their dreams. Saleebey describes this process as “stimulating the heroic in clients” (2001, p 36) and identifies it as powerful in that it produces new ideas and possibilities. Saleebey states that:

Tapping into the energy, imagination, and will of clients to be heroic is to help people recover or command the power to change, using old skills and resources, and discovering or developing new ones. We don't know what people are capable of and, sometimes, they don't either” (2001, p 37)

As a way of demonstrating the merit of this anti-oppressive approach, one that gears towards a social model understanding by taking the focus off of pathologizing the individual, I want to attend to the moments of strength and

resilience that my participants revealed in their quotations. This focus on a strengths perspective and my attention to these moments provides for a different discourse, and a more complex discourse than the deficit-focused dominant discourse of ADHD and people so labeled.

To begin with, some of the quotations from my participants that were included in the theme of *Everyday Challenges of Living with ADHD* actually identified some participant strengths, even though the quotations were presented as examples of the participants' physical and cognitive challenges. For instance, a tendency to engage in "big picture" or "whole picture" thinking and the ability to effectively "brainstorm" can actually all be viewed as strengths. Helping both the person with ADHD and non-disabled others to recognize it as such would move our understanding beyond a deficit-based one. Likewise, another participant identified:

I am very good at getting the grand work done and handing it to other people, I am very good at coming up with solutions. I am not necessarily the best person to implement.

Although this participant identified their inability to implement plans, the fact that s/he is able to come up with the larger picture plan and the solutions are great strengths and very necessary skills for many occupations. The fact that the focus typically seems to be on what the person can't do undermines recognition of strengths. If however, social workers actively sought out strengths, a different understanding, assessment and interaction are possible.

The participant who spoke of their university experience and how they came up with their own, very creative solution to help them in

managing the work and assist in their own learning also exemplified

numerous strengths:

I would help my fellow classmates to get through and teach them – you see, the teaching aspect, if I could take the information and explain it to somebody else I definitely understood it and this was one of my strategies without realizing it, this was one of my strategies to grasp the information and being able to enhance my working memory because I am working with it more, right, I am sort of listening, touching it, re-hashing it, it makes it mine and I have to spit it out because I have to explain it to somebody else, you know.

Other examples of my participants' strengths, specific to their careers, demonstrated their ability to incorporate their strengths into a job that appeared to be a good match for them. These are listed below:

I would be able to do stuff, like, if we did not have a song for Remembrance Day I would make it up. I made up one everybody liked. I would hear it sung in other rooms and I would think, "I made that up". But that is what I was good at doing, but it is a good thing. I couldn't remember, I would use this as part of the reading program, if I did not have the kids writing it down I would not have a copy of it.

It is an interesting thing, if you read you find there are a lot of careers that work well for ADD people. Sales orientated stuff ... you need an energy level to be able to do that. I think the thing in sales though there are a lot of sales jobs that are very instant. It is very, very quick.

And,

The good trait of being distracted by everything and noticing everything and not focusing on one thing, that was great. I knew what everybody was doing and I was the teacher on the playground that was walking and seeing where everyone was, not one of those who stand there.

Another participant identified:

I am someone who is very, I want to say self-sufficient, but I am more self-reliant in a lot of ways, so I try and seek out solutions on my own. I do not always like to be told what I should be doing.

And lastly, one of my participants spoke of their childhood, identifying strengths s/he demonstrated at that time:

As a kid I bounced off the walls but maybe because I was a girl and it was not noticed so much, I was a very happy go lucky girl, I was always smiling, I was a clown. In kindergarten, we were in line for vaccines and I was helping the kids to be happy about getting vaccinated.

In these examples, social work intervention could not only attend to the participant's needs related to being successful as a student or employee with ADHD, but also focus on the strengths this person has and the positive impact of these strengths on her/his own ability to be successful and, in many cases, on the success of others. Such a recognition of strength works to both identify and to reframe devaluing and stigmatizing understandings of the person with ADHD into more valued and respectful understandings.

Self Reflections

As previously identified, I locate myself as an insider in this research. This was an interesting experience which, in some ways proved to be validating for me in the sense that there were some similarities between the participants' experiences and my own. I think my extensive review of the existing research, in conjunction with the participants' stories, also helped to confirm and 'normalize' some of my own experiences. I found on occasion that listening to the participants' experiences was somewhat painful as some of their experiences resonated strongly with my own experiences. I recognize, too, that I may have been over-identifying with participants at times because of experiencing feelings of emotional pain, however I do not think it negatively influenced how I

conducted my interviews as I continued to follow my interview guide. In hindsight, I think I may have asked clarifying questions at certain times because of identifying with the participants, however, I think this had a twofold effect: it meant that I explored the participants' experience further but, being conscious of the potential for over-identifying, I was concerned to do so from the participants' perspectives, as opposed to jumping to assumptions based on my own similar experience.

During the interviews, whenever I found myself identifying with my participants, I ensured that I acknowledged and addressed these feelings and that I considered the participants' positioning, as well as my own, from all angles. I was careful not to subject participants to a difficult or uncomfortable situation as a result of counter-transference or bias, both of which could easily have compromised my research. After acknowledging and initially addressing my own feelings, and considering both the participants' and my own positioning, I then consciously worked on setting my own thoughts, beliefs and experiences aside during the actual research interviews. After each interview, as well as after the interviewing segment of my research project was completed, I engaged in a process of reflection and evaluation of the research process, from the relationship and interactions with the participants to the analysis. I also drew on peer support to assist me in challenging my own beliefs, values and interpretations as a part of this process in an effort to prevent – or at least to minimize – insider bias.

I have thought a lot about how my status influenced my interpretation of the data and I know from discussion with my research supervisor and colleagues

that I, at times, perceived some of the participants' stories differently than how my research supervisor and colleagues did. Or perhaps, instead of perceiving the stories differently, I picked up on, or gave meaning to words or ideas that perhaps seemed minuscule, in comparison to the larger story shared. I gave a lot of credence to the participant's stories about the psychological impact of being diagnosed with ADHD in adulthood and their experiences of living with ADHD; both prior to and after diagnosis. I do not know for sure if this is a result of my having an insider perspective and my relating it to my own experiences; if it is because this was the main theme that resonated throughout much of the participants' stories; or if it was a combination of both. I have reflected on this often and believe that perhaps it was a combination of both however I do not feel this overly biased my analysis of the data and focus of my study, as the literature also very consistently identified the psychological impact as significant.

During the course of my research and writing the thesis my passion for wanting ADHD to be identified in childhood remained unchanged and hearing the participants' stories only proved to reinforce this desire. While acknowledging the importance of the macro level oppression at play that disables people because they are different and do not fit with societal and cultural norms, I do believe that, at a micro level, having an explanation and understanding of this condition and associated impairments while growing up is also important. From what the participants shared, this knowledge could assist somewhat in decreasing some of the feelings of inferiority and internalized blame so intrinsic in the population who are not diagnosed until adulthood. However, I do recognize that this is

primarily an individualized approach, and I know that a diagnosis alone does not even come close to addressing the larger societal structures and forces that are at play which contribute to ongoing oppression and stigmatization of this group.

Throughout the writing of the thesis it became apparent that I struggled with staying within a critical disability perspective – I found I moved back and forth between a critical disability perspective and a medical, individual-focus model. I attributed this, at least in part, to working in a mental health setting where I am immersed in a medical model approach in my day-to-day work. This seems to speak to the power of an institutional culture, the embeddedness of a medical model perspective in mental health settings and the difficulties in resisting this model for people working in these systems. Another challenge for me with respect to staying within a critical disability perspective, which may well be similar for others was not having the language to speak about things from a different perspective which for me, resulted in my resorting to the language I know. This perhaps demonstrates how the use of a medical, pathology, deficit-based language to talk about disability is still predominant in the larger society.

Lastly, I acknowledge that I, at times struggled with a critical disability framework in general, as the approach in the society that we live in is still very much fostered after the medical model and I believe treatments (individual or otherwise) for some conditions are necessary, required and/or helpful. I recognize that my recognition and identification of this belief is not consistent with the scope of this thesis with respect to using a critical disability lens however, I acknowledge that I am just beginning to learn about critical disability theory.

Although I know some theorists do attend to both the medical and social aspects of impairment and disability (Thomas, 2004), I do not yet have a strong understanding of how the social and medical approaches might fit together. This perhaps further highlights the amount of work that is necessary for society as a whole to move towards a social model of disability, which at times even for me seems very idealistic.

Implications for Practice and Future Research

It is apparent from both the available literature and the results of this study that the experiences of living with ADHD can have a negative impact on people's lives, particularly if it is not diagnosed until adulthood. The psychosocial impact on people is significant and demonstrates that ADHD continues to present challenges even after diagnosis.

As the concept of adults having ADHD is still a fairly new phenomenon there is still limited research, particularly of a qualitative nature, so our understanding of this population's experiences, including the factors that can enhance or worsen their experiences, is still quite narrow. The fact that I received an overwhelming response from people in the local area wanting to participate in my study, coupled with the fact that I also had responses from 3 people living in Alberta and one in Great Britain, suggests that this an area of research requiring further attention, including expanded geographical boundaries.

The importance of early identification and treatment for people with ADHD is stressed by the majority of researchers whose work I examined (Rucklidge & Kaplan, 1997; Toner et al., 2006). Rucklidge and Kaplan (1997) also identify risks associated with not being diagnosed with ADHD until adulthood, including secondary mental health concerns such as depression and anxiety, low self esteem, inadequate coping skills and an external locus of control. Ramsey and Rostain (2008) identify the need for future research on ADHD and menopausal women and ADHD and geriatric populations where some cognitive

decline is typically anticipated, as neither of these areas have received attention in the past.

Additionally, there is also a need for research from a critical disability perspective – one that provides information about the societal structures and factors involved in people’s experiences of marginalization and oppression and which provides direction for social change efforts. There needs to be attention to moving things beyond the important and necessary focus on the well-being of the individual to also include a focus on research and practice that addresses the larger societal structures and forces that are at play in the lives of people with ADHD.

Pertaining to the social worker’s role in providing supports to this population, an understanding of this population and their unique life experiences needs to be acquired so that empathetic and genuine supports can be provided. As has been demonstrated by the participants in this study, the value of such cannot be underestimated. But, to do so, the social worker needs also to be aware of their own position in the helping relationship. The role of “mental health professional” positions social workers in a social location that grants them the privilege of power, and thus their knowledge becomes the authority regardless of its accuracy. The predominant barriers to achieving social justice that are identified in the literature are tied to the proposition that social work, in and of itself, is socially unjust. This is understood to be due to social workers’ failure to acknowledge their own social location or to recognize the power differentials between themselves and their clients. This is attributed to the ways that social workers

frequently deny their clients a voice and instead, act as a mechanism of social control (Noble 2004; Rossiter, 2007; Sakamoto & Pitner, 2005; Sellick, Delaney & Brownlee, 2002). In moving towards a more anti-oppressive practice, critical consciousness can be used to assist in addressing some of these injustices, as it emphasizes the need for social workers to be conscious and aware of their own positioning and its impact on clients, the need to focus on listening to the client and the imperativeness of starting the dialogue based on where they (the clients) are ‘at’ (Baines, 2007; Lundy, 2004; Rountree and Pomeroy, 2010; Sakamoto and Pitner, 2005).

Thus, to ensure we are taking the initial steps towards achieving social justice for this population, social workers and other mental health professionals need to do a number of things. They need to learn about ADHD so that they are able to recognize it, be aware of its impact on peoples’ lives and its impact on other illnesses. But this individual-focused knowledge and intervention, while important and necessary to the process of supporting adults with ADHD, encompasses only the initial steps towards social justice, and is not sufficient on its own for the actualization of social justice and change. The individual experience must be addressed as the starting point but it is then necessary to move beyond the individual to address the larger factors. It is not just about increasing social work knowledge about ADHD – social workers also need to recognize their own assumptions, the dominant institutional and societal attitudes and discourses of disability and the role social work plays in the oppression of people with

disabilities. The knowledge I gained about my own assumptions through this research project makes this plain.

Rountree and Pomeroy (2010) inform us that “social workers must analyze current structural institutions to identify power imbalances and actions that could be taken to dismantle oppressive structures” (p 293). Lundy (2004) quotes Staples and offers “the capacity for effective action is an essential component of any meaningful conceptualization of empowerment” (p 134). What is required for the development of a more appropriate and helpful social work response is a social worker who is informed about ADHD (both the individual and social aspects), who is able to critically reflect on her/his own position and power and work towards more empowering practice, who has an understanding of both micro and macro level influences on the lives of social work clients and can target intervention towards these different influences.

Likewise, in sharing information with other professionals in the field, another focus for social work practice will need to be making people aware of the potential to become immersed in oppressive structures and the need for critical reflection to ensure one does not reproduce the oppression. This will become part of my own dissemination strategy. Not only will I share the results of my research with other professionals to facilitate their own knowledge about adults with ADHD, but I will also share my own experiences of doing this research: the lessons I have learned through my own critical reflection on social work practice, understandings of disability and the power of institutionalized knowledge. Only with this understanding can appropriate, beneficial and responsive supports be

developed that will ultimately help lessen the effects of ADHD; both those that are a function of the impairment itself (i.e., staying on task) and those that are constructed or imposed by society.

In closing, to exemplify the degree of oppression experienced by those with disabilities and illustrate why ongoing research and work are so necessary in this area to address this oppression and marginalization, I turn to Lennard Davis who eloquently summarizes this ongoing phenomena:

... People with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group.

Davis, as cited in Titchkosky, 2000, p 200

And in final summary, the quote from one of my participants from the section on impacts of diagnosis exemplifies the importance of what I have been emphasizing in this entire thesis – what is required is that we attend very carefully to questions about disability and to how we understand it and how, if we start to understand it differently, then it can work to change what Davis and my participants have identified as the oppressive treatment of people with disabilities – what we need to do is to “look back at things” and to “understand them better”.

I am a fairly introspective person so it gave me a perspective to look back at things that happened in my life and understand them better.

References

- American Psychiatric Association. (1968). *Diagnostic and Statistical Manual of Mental Disorders, Second Edition*. Washington, DC: Author.
- American Psychiatric Association. (1980). *Diagnostic and Statistical Manual of Mental Disorders, Third Edition*. Washington, DC: Author.
- American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Washington, DC: Author.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*. Washington, DC: Author.
- Baines, D. (2007). Bridging the practice-activism divide in mainstream social work. In D. Baines, (Ed), *Doing Anti-Oppressive Practice*, (Chapter 3). Halifax: Fernwood.
- Barkley, R. (2011). *The Important Role of Executive Functioning and Self-Regulation in ADHD*. Available at http://www.russellbarkley.org/content/ADHD_EF_and_SR.pdf . Guest Column, 1-7.
- Barkley, R. (2006). *Attention-Deficit Hyperactivity Disorder, Third Edition: A Handbook for Diagnosis and Treatment*. New York: Guilford Publications.
- Barkley, R. (2002). International consensus statement on adhd. *Clinical Child and Family Psychology Review*, Vol. 5 (2), 1-23.
- Barkley, R. & Murphy, K. (2006). ADHD factsheet. Adapted from *Attention deficit hyperactivity disorder: A clinical workbook (3rd ed.)*. Available at <http://www.russellbarkley.org/content/adhd-facts.pdf>
- Barnes, C. (1997). A legacy of oppression: A history of disability in western culture. In Barton, L. & Oliver, M., (Eds), *Disability Studies: Past Present and Future*, (Chapter 1). Leeds: The Disability Press.
- Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity*, Vol. 36(4), p 391-409.
- Brown, T. (2009a). *ADHD Comorbidities: Handbook for ADHD Complications in Children and Adults*. Available at <http://www.drthomasebrown.com/pdfs/tb01.pdf>

- Brown, T. (2009b). Add/adhd and impaired executive function in clinical practice. *Current Attention Disorder Reports*, Vol. 1, 37-41.
- Brown, T. (2006). Executive functions and attention deficit hyperactivity disorder: Implications of two conflicting views. *International Journal of Disability, Development and Education*, Vol. 53, No. 1, p. 35–46.
- Buckles, B., Brewer, E., Kerecman, J., Mildred, L., Ellis, A. & Ryan, J. (2008). Beyond stigma and discrimination: Challenges for social work practice in psychiatric rehabilitation and recovery. *Journal of Social Work in Disability & Rehabilitation*, 7(3), 232-283.
- Davidson, M. (2008). Literature review: Adhd in adults: A review of the literature. *Journal of Attention Disorders*, Vol. 11(6).
<http://online.sagepub.com> :Sage Publications.
- Davis, L. (2009). The rule of normalcy: Politics and disability in the USA (united states of ability). In Radway, J. et al. (Eds), *American Studies: Anthology*, (Chapter 36). Wiley-Blackwell.
- Davis, L. (1995). *Enforcing Normalcy: Disability, deafness, and the body*, Verso, London, New York.
- Denzin, N & Lincoln, Y. (2011). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y.S. Lincoln, (Eds), *The Sage Handbook of Qualitative Research*, (Chapter 1). USA: Sage Publications Inc.
- Devlin, R. & Pothier, D. (2006). Introduction: Toward a critical theory of dis-citizenship. *Critical Disability Theory: Essays in philosophy, politics, policy, and law*, UBC Press, Vancouver, Toronto, 1-22.
- Dovidio, J, Major, B & Crocker, J. (2000). Stigma: Introduction and overview. In Heatherton et al. (Eds), *The Social Psychology of Stigma*, (Chapter 1). New York: Guilford Press.
- Elliott, R. & Freire, E. (2007). Classical person-centered and experiential perspectives on Rogers (1957). *Psychotherapy: Theory/Research/Practice/Training*, Vol. 44, (3), 285-288.
- Faraone, S. (2005). The scientific foundation for understanding attention-deficit/hyperactivity disorder as a valid psychiatric disorder. *European Child & Adolescent Psychiatry*, Vol. 14(1).
- Fook, J. (2003). Critical social work: The current issues. *Qualitative Social Work*, Vol. 2 (2), 123-130.

- Freud, S. (1999). The social construction of normalcy. *Families in Society: The Journal of Contemporary Science*, Vol. 80(4), 333-339.
- Gilson, S. F. & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education*, Vol. 38(1), 153-165.
- Glaser, B. (1965). The Constant Comparative Method of Qualitative Analysis. *Social Problems*, Vol. 12(4), 436-445.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster Inc., New York.
- Green, C. (2000). Classics in the history of psychology: Significant aspects of client-centered therapy. *Internet Resource* by York University, Toronto, Ontario. Available at <http://psychclassics.yorku.ca/Rogers/therapy.htm>.
- Greene, S., Ahluwalia, A., Watson, J., Tucker, R., Rourke, S., Koornstra, J., ... Byers, S. (2009). Between skepticism and empowerment: The experiences of peer research assistants in HIV/AIDs, housing and homelessness community based research. *International Journal of Social Research Methodology*, Vol. 1(12), 1-12.
- Hallberg, U., Klingberg, G., Setsaa, W., Moller, A. (2010). Hiding parts of one's self from others – a grounded theory study on teenagers diagnosed with Adhd. *Scandinavian Journal of Disability Research*, Vol. 12(3), 211-220.
- Hammell, K. (2006). Theoretical models of disability. *Perspectives on Disability and Rehabilitation: Contesting assumptions, challenging practice*, Churchill Livingstone, Edinburgh, 55-70.
- Holstein, J & Gubrium, J. (2011). The constructionist analytics of interpretive practice. In N. K. Denzin & Y.S. Lincoln, (Eds), *The Sage Handbook of Qualitative Research*, (Chapter 20). USA: Sage Publications Inc.
- Kanuha, V. (2000). "Being" native versus "going native": Conducting social work research as an insider. *Social Work*, Vol. 45(5), 439-447.
- Kelly, K & Ramundo, P. (2006). *You mean I am not Stupid, Crazy or Lazy?!: The Classic Self-Help Book for Adults with Attention Deficit Disorder*. New York: Scribner.
- Knouse, L., Mitchell, J., Brown, L., Silvia., P & Kane, M. (2008). The expression of adult adhd symptoms in daily life: An application of experience sampling methodology. *Journal of Attention Disorders*, Vol. 11(6), 652-663.

- Lamberg, L. (2003). ADHD often undiagnosed in adults: Appropriate treatment may benefit work, family, social life. *Journal of the American Medical Association*, Vol. 290, (12), 1565-1567.
- LaSala, M. (2003). When interviewing “family”: Maximizing the insider advantage in the qualitative study of lesbians and gay men. *Journal of Gay and Lesbian Social Services*, Vol. 15(1/2), 15-30.
- Levine, J. (1997). Re-visioning attention deficit hyperactivity disorder (adhd). *Clinical Social Work Journal*, 25(2), 197-209.
- Lundy, C. (2004). *Social Work and Social Justice: A Structural Approach to Practice*. Canada: Broadview Press Inc.
- Mason, J. (2002). *Qualitative Researching, 2nd Edition*. London: Sage Publications.
- Neuman, W.L. (1997). The Meanings of Methodology. *Social Research Methods: Qualitative and Quantitative Approaches, 3rd Ed*, Chapter 4. Allyn and Bacon – Pearson Education.
- Noble, C. (2004). Postmodern thinking: Where is it taking social work? *Journal of Social Work*, Vol. 4(3), 289-303.
- Oliver, M. (1996). Defining impairment and disability: Issues at stake. In Barnes, C. & Mercers, G., (Eds), *Exploring the Divide*, (Chapter 3). The Disability Press, Leeds, 29-54.
- Portway, S. & Johnson, B. (2005). Do you know I have asperger’s syndrome? Risks of non-obvious disability. *Health, Risk & Society*, 7(1), 73-83.
- Rabinow, P. & Sullivan, W. (1987). The interpretive turn: A second look. In P. Rabinow & W. Sullivan (Eds), *Interpretive Social Science: A Second Look*(p 1-30). California: University of California Press.
- Ramsay, J. & Rostain, A. (2008). Adult adhd research: Current status and future directions. *Journal of Attention Disorders*, Vol. 11 (6), 624-627.
- Ramsay, J. & Rostain, A. (2005). Girl, repeatedly interrupted: the case of a young adult woman with adhd. *Clinical Case Studies*, Vol. 4(4), 329-346.
- Reid, R. & Katsiyannis, A. (1995). Attention-deficit disorder and section 504. *Remedial and Special Education*, 16(1), p 44-52.

- Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in north america. *International Journal of Law and Psychiatry*, 25, 405-426.
- Remschmidt, H. (2005). Global consensus on adhd/hkd. *European Child & Adolescent Psychiatry*, Vol. 14(3).
- Rossiter, A. (2007). Self as subjectivity: Toward a use of self as respectful of recognition. In Mandell, (Ed), *Revisiting the Use of Self: Questioning Professional Identities*, (Chapter 2). Toronto: Canadian Scholars Press.
- Rountree, M. & Pomeroy, E. (2010). Bridging the gaps among social justice, research, and practice. *National Association of Social Workers*, Vol. 55(4), 293-295.
- Rucklidge, J. & Kaplan, B. (1997). Psychological functioning of women identified in adulthood with attention-deficit/ hyperactivity disorder. *Journal of Attention Disorders*, Vol. 2(3), 167-175.
- Sakamoto, I. & Pitner, R. (2005). Use of critical consciousness in anti-oppressive social work practice: Disentangling power dynamics at personal and structural levels. *British Journal of Social Work*, Vol. 35, 435-452.
- Saleebey, D. (2001). Vulnerability and strength: Giving voice to the voiceless. *Bioethics Forum*, 17(3/4), 31-38.
- Sellick, M., Delaney, R., & Brownlee, K. (2002). The deconstruction of professional knowledge: Accountability without authority. *Family in Society: The Journal of Contemporary Human Services*, Families International, Inc.
- Solden, S. (2002). *Journeys through ADDulthood*. Walker & Company, New York.
- Taylor, E. (2010). Antecedents of adhd: a historical account of diagnostic concepts. *ADHD Attention Deficit Hyperactive Disorder*, (Springer-Verlag 2011), published online January 11, 2011.
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, 19(6), 569-583. Retrieved from <http://dx.doi.org/10.1080/0968759042000252506> .
- Toner, M., O'Donoghue, T. & Houghton, S. (2006). Living in chaos and striving for control: How adults with attention deficit hyperactivity disorder deal with their disorder. *International Journal of Disability, Development and Education*, Vol. 53(2), 247-261.

- Tregaskis, C. & Goodley, D. (2005). Disability research by disabled and non-disabled people: Towards a relational methodology of research production. *International Journal of Social Research Methodology*, Vol. 8(5), 363-374.
- Titchkosky, T. (2000). Disability studies: The old and the new. *Canadian Journal of Sociology*, 25(2), 197-224.
- Valeras, A. (2000). “We don’t have a box”: Understanding hidden disability identity using narrative research methodology. *Disability Studies Quarterly*, 30(3/4), 1-19. Available at <http://www.dsqsds.org/article/view/1267> .
- van Heugten, Kate. (2004). Managing insider research. *Qualitative Social Work*, Vol. 3(2): 203-219.
- Vojak, C. (2009). Choosing language: Social service framing and social justice. *British Journal of Social Work*, 39, 936-949.
- Waite, R. & Tran, M. (2010). Explanatory models and help-seeking behavior for attention-deficit/hyperactivity disorder among a cohort of postsecondary students. *Archives of Psychiatric Nursing*, Vol. 24(4), p 247-259.
- Young, S., Bramham, J., Gray, K., & Esther, R. (2008). The experience of receiving a diagnosis and treatment of ADHD in adulthood: A qualitative study of clinically referred patients using interpretative phenomenological analysis. *Journal of Attention Disorders*, Vol. 11(4), 493-503.

Appendix A

Demographics Questionnaire

The Missed and Dismissed Diagnosis: Experiences of People Diagnosed with Attention Deficit Disorder (ADD) Beyond Childhood

Lynn Wardell, (Master of Social Work student)

(Department of Social Work – McMaster University)

Information about these interview questions: These questions are seeking non identifying demographical information. Interviews will be one-to-one and will be primarily “yes or no” and short answer.

1) Your age now?

2) Your age at the time of your diagnosis?

3) What is your relationship status now? Have you previously been in a cohabitating relationship? (i.e. GLBT relationship/married/common law/divorced?)

4) Do you have children and how old are they?

5) Do you have an ethnic or cultural group with whom you identify? If so, which group?

6)What is your socio economic status?

___ under \$20 000 ___ between \$20,000-30,000 ___ between
\$30,000-50 000

___ between \$ 50 000 - \$75 000 ___ between \$ 75 000 - \$ 100 000 ___ over
\$ 100 000

7) Do you work presently? If yes, what kind of work do you do?

8) How many jobs have you had in your lifetime?

9) What is your longest period of time at the same employer?

10) What is your highest level of education?

some high school high school graduate some College College graduate

some University Undergraduate degree Masters degree Ph degree

Other (please specify)

11) Besides your diagnosis of ADD, have you been diagnosed with any other mental health problem?

Depression Anxiety Bipolar Schizophrenia PTSD
(post-traumatic stress disorder)

Other (please specify what)

12) If you have had other mental health diagnosis, for each diagnosis above, were these diagnosis before or after you were diagnosed with ADD?

13) For each diagnosis, if it was before your ADD diagnosis, do you believe it was an accurate diagnosis for that time period in your life? If no, why?

Appendix B

Interview Guide

The Missed and Dismissed Diagnosis: Experiences of People Diagnosed with Attention Deficit Disorder (ADD) Beyond Childhood

Lynn Wardell, (Master of Social Work student)

(Department of Social Work – McMaster University)

Information about these interview questions: This gives you an idea what I would like to learn about your experience of being diagnosed with ADD as an adult. Interviews will be one-to-one and will be open-ended (not just “yes or no” answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: “*So, you are saying that ...?*”), to get more information (“*Please tell me more?*”), or to learn what you think or feel about something (“*Why do you think that is...?*”). This is the portion of the interview that I am going to audio record.

- 1) Can you tell me how old you were when you were diagnosed with ADD and describe for me what being diagnosed with ADD was like for you?**

- 2) Did you find being diagnosed to be a positive or negative experience? Please tell me more about why you think that?**

- 3) Did you try medication as a course of treatment for your ADD? If you did, can you please describe this experience and indicate if you still take medication.**

- 4) After you received your diagnosis did you try to find out more about ADD and its associated symptoms? How did you try to find out this information?**

- 5) Would you consider being diagnosed with ADD to be life changing for you in any way? If yes please explain.**

- 6) Did you think about things differently and/or change your expectations about yourself or others after you were diagnosed?**

- 7) Can you tell me about some of your symptoms of ADD and/or areas of your life that you believe are impacted by your disorder and how they are impacted?**

8) Do you think your life would have/could have been different if you had known you had ADD when you were a child and can you explain how?

9) Did you seek out professional help/counseling after you were diagnosed and can you explain what kind of help you were looking for?

10) Regardless of if you sought help or not, is there anything that you think a counselor or social worker could have said or done that would have been helpful for you?

11) Is there something important we forgot? Is there anything else you think I need to know about your experience?

Appendix C

Online Recruitment Posting

The Missed and Dismissed Diagnosis: Experiences of People Diagnosed with Attention Deficit Disorder (ADD) Beyond Childhood

Lynn Wardell, BA, BSW, RSW
Masters Candidate in Social Work

We are looking for volunteers to take part in a study **about the experiences of people diagnosed with Attention Deficit Disorder (ADD) as adults**

Purpose of the Study

You are invited to take part in this study on people's experiences of being diagnosed with Attention Deficit Disorder (ADD) as adults. I am hoping to learn what it is like for people who are diagnosed with ADD as adults; including their life experiences, what it is like for them living with ADD and their opinions of the impact of not knowing they had ADD while growing up, if any. The purpose of this research is to inform helping professions, and specifically the social work profession about the implications on life experiences associated with not receiving a diagnosis of ADD during childhood and the realities of living with ADD.

As part of the Master of Social Work program at McMaster University, I am doing this research for my thesis.

What will I have to do?

You would be asked to take part in a one-on-one audio taped interview. The interview will take approximately an hour to an hour and a half. The interview would be scheduled for a mutually convenient date and time and in a mutually agreed upon quiet and comfortable location.

Your participation in this study would be confidential. Your name or any information that would allow you to be identified would not be used.

This study has been reviewed by, and received ethics clearance through, McMaster Research Ethics Board.

For more information about this study, or to volunteer for this study, please contact:

Lynn Wardell

Masters Candidate in Social Work

School of Social Work

McMaster University

Hamilton, Ontario

519-771-5823 or by Email: wardelle@mcmaster.ca

Appendix D – Recruitment Poster



Department of Social Work

PARTICIPANTS NEEDED FOR RESEARCH ABOUT ATTENTION DEFICIT DISORDER IN ADULTS

We are looking for volunteers to take part in a study **about the experiences of people diagnosed with Attention Deficit Disorder (ADD) as adults**

You would be asked to take part in a one-on-one audio taped interview. The interview will take approximately an hour to an hour and a half. The interview would be scheduled for a mutually convenient date and time and in a mutually agreed upon quiet and comfortable location.

For more information about this study, or to volunteer for this study,
please contact:

Lynn Wardell
School of Social Work
McMaster University
Hamilton, Ontario, Canada
519-771-5823

Email: wardelle@mcmaster.ca

This study has been reviewed by, and received ethics clearance through, McMaster Research Ethics Board.

Appendix E – Letter of Information and Consent



DATE: May 2011

LETTER OF INFORMATION /CONSENT

A Study about the experiences of people diagnosed with Attention Deficit Disorder (ADD) as adults

Principal Investigator: Lynn Wardell
School of Social Work
McMaster University
Hamilton, Ontario, Canada
519-771-5823
Email: wardelle@mcmaster.ca

Faculty Supervisor: Dr. Ann Fudge Schormans
School of Social Work
McMaster University
Hamilton, Ontario, Canada
905 525 9140 ext. 23790
Email: fschorm@mcmaster.ca

Purpose of the Study

You are invited to take part in this study on people's experiences of being diagnosed with Attention Deficit Disorder (ADD) as adults. I am hoping to learn what it is like for people who are diagnosed with ADD as adults; including their life experiences, what it is like for them living with ADD and their opinions of the impact of not knowing they had ADD while growing up, if any. The purpose of this research is to inform helping professions, and specifically the social work profession about the implications on life experiences associated with not receiving a diagnosis of ADD during childhood and the realities of living with ADD. I am doing this research for my Master of Social Work thesis.

What will happen during the study?

You will be asked to take part in a one-on-one audio taped interview with myself. This one time interview will be in person and approximately an hour to an hour and a half in length. You will choose the location for the interview (i.e. private room at a public library, etc.) based on what is most convenient for you. The date and time will be determined based on when we are both available.

There are two parts to the interview. The first part will be approximately 5 to 10 minutes and will consist of my asking you some non-identifying demographic/background information like your age and education. The answers for these questions will be primarily "yes or no" and short answer. With your permission, as you answer each question I will write your answers on the questionnaire.

The second part of the interview, with your permission, will be audio recorded and will consist of questions about your experience of being diagnosed with ADD, how not being diagnosed until you were an adult impacted your life and what it is like for you living with ADD. The actual interview guide (Appendix B) has been included for you so that you can review the types of questions that I will be asking you.

With your permission I may contact you a second time to clarify any of the information I have collected from you, particularly after transcription to ensure I understand what you were communicating and to ensure I have captured it accurately in the transcription.

Are there any risks to doing this study?

The risks involved in participating in this study are minimal. You may feel uneasy about sharing your personal experiences or you may become upset when thinking about things that happened in your past. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. And you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Are there any benefits to doing this study?

The research will not benefit you directly. I hope that what is learned as a result of this study will help us to better understand life experiences associated with not receiving a diagnosis of ADD until adulthood and the realities of living with ADD. It is my hope that this will help social workers to better understand their clients with ADD, and what it has been like for them if they were not diagnosed until they were adults.

Confidentiality

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me will know whether you participated unless you choose to tell them.

The information/data you provide will be kept in a locked desk/cabinet where only I will have access to it. Any information kept on a computer will be protected by a password. The information will continue to be stored in a locked file and on a password protected computer for a 2 year period after completion of this study. After this time period (August 2013) any data on paper will be shredded and electronic files deleted.

What if I change my mind about being in the study?

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), even after signing the consent form or part-way through the study up until July 15th, 2011. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results

I expect to have this study completed by approximately late fall 2011. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me, Lynn Wardell at 519-771-5823 or by email at wardelle@mcmaster.ca.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Lynn Wardell of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time.

I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

1. I agree that the interview can be audio recorded.

... Yes.

... No.

2. ... Yes, I would like to receive a summary of the study's results.

Please send them to this email address _____

or to this mailing address: _____

... No, I do not want to receive a summary of the study's results.

3. I agree to be contacted about a follow-up interview, and understand that I can always decline the request.

... Yes. Please contact me at: _____

... No.

Oath of Confidentiality

This is to confirm that I, _____ as a professional
(print name)
Transcriber will keep confidential, any and all information that I may be privy to
during the course of providing transcribing services to Lynn Wardell, for the
purposes of her Master of Social Work Thesis Research at McMaster University.
This includes any and all personal information and/or identifying information
regarding specific research participants.

SIGNATURE

WITNESS

DATED THIS ____ DAY OF _____, 2011.

Appendix G – Helpful Resources List

Hamilton

Distress Centre of Hamilton - 24 hour Crisis Line: (905) 525-8611

Hamilton Suicide Crisis Line, Education and Resource Centre, Crisis Line 905-522-1477

Catholic Family Services - Walk In Counselling Clinic for individuals, couples and families.

Tuesdays from 12 noon until 6:30 p.m. at Catholic Family Services offices at 447 Main Street East, Unit 201

Mondays from 1:00 until 3:30 at Wesley Neighbourhood Centre at 93 Delena Avenue North.

A small fee is charged to counselling clients based on income. No one is turned away due to inability to pay.

For more information about the Walk-in Counselling Clinic please call 905-527-3823 Ext. 279.

Burlington

Telecare Burlington Distress Line- Mon-Sun 24 hrs: 905-681-1488 (does not accept collect calls)

Burlington Counselling & Family Services- Personal, Couple & Family Counselling

Appointments are available during the day, evenings, and Saturdays. Fees are geared to income.

460 Brant St. Ste. 200, Burlington

Phone: 905-637-5256

TOLL FREE 1-866-457-0234

Halton Family Services - individual, couple and family counselling

Available to any resident of Halton, day and evening appointments are available at their offices in Burlington, Georgetown, Milton and Oakville. Fees are geared to family size and ability to pay.

Counselling available in French, Italian, Portuguese, and Spanish, as well as English.

To Make An Appointment please book through the Oakville office at (905) 845-3811.

Other - Distress Centre of Niagara - 905 688-3711

eCounselling/Coaching through Catholic Family Services of Hamilton - eCounselling is a method of counselling that research has shown to be highly effective. It works like traditional counselling except the counsellor and client exchange emails instead of meeting for a face-to-face appointment. Many people prefer eCounselling because it is more convenient and offers greater anonymity.

Because you will be exchanging emails, what you share in your counselling can be worded by you thoughtfully and at your own pace, without having to think off the top of your head or having to type quickly. When you are ready, you send your email and the e-counsellor responds in two business days. The emails you send and receive are stored on our secure email service so that you can revisit them and consider your counsellors responses carefully

Family/Individual eCounselling sessions are conducted over the internet similar to email. All online sessions are private and secure* through www.cfshw.privacemail.com

Appendix H – Hamilton Spectator Recruitment posting advertisement

Saturday May 7, 2011 The Hamilton Spectator Weekend Reader, page WR2

McMaster study looking for volunteers

Lynn Wardell, a masters of social work candidate at McMaster University is looking for volunteers for a study into people's experiences when diagnosed with attention-deficit hyperactive disorder in adulthood.

The study will look at how people's lives change after diagnosis and how they then view their behaviours and symptoms.

Wardell needs six to 10 adults who have been diagnosed with ADHD. Her goal is to raise awareness of the disorders and their symptoms among social workers, mental health agencies, family counsellors and community based nurses.

Study participants will be asked to fill out a questionnaire and talk about their experiences with ADHD for a taped interview.

Contact Wardell at 519-539-8055, ext. 226 or at wardelle@mcmaster.ca if you are interested in participating.