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WISTFUL DETERMINATION: ADULTS' PERCEPTIONS OF THEIR LEARNING DISABILITY DIAGNOSES

BY

AVRIL M. RINN

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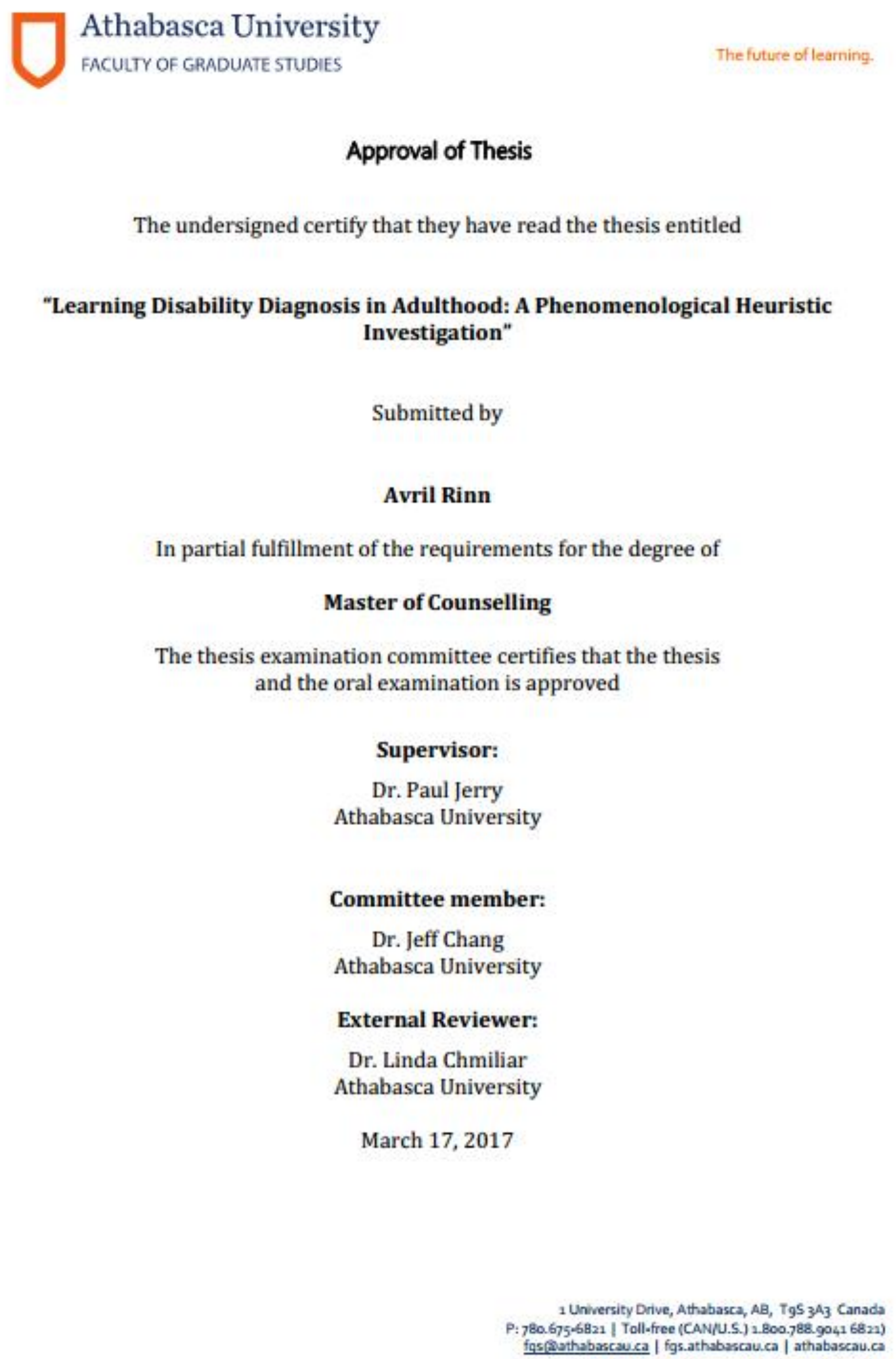

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Approval of Thesis

The undersigned certify that they have read the thesis entitled

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Submitted by

Avril Rinn

In partial fulfillment of the requirements for the degree of

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The thesis examination committee certifies that the thesis
and the oral examination is approved

Supervisor:

Dr. Paul Jerry
Athabasca University

Committee member:

Dr. Jeff Chang
Athabasca University

External Reviewer:

Dr. Linda Chmiliar
Athabasca University

March 17, 2017

1 University Drive, Athabasca, AB, T9S 3A3 Canada
P: 780.675-6821 | Toll-free (CAN/U.S.) 1.800.788.9041 6821)
fgs@athabascau.ca | fgs.athabascau.ca | athabascau.ca

Dedication

For Fred – I owe you much. Without your encouragement, I would never have believed myself capable of completing a thesis. Without those (seemingly) interminable and (only sometimes) undesired discussions about my dreams and goals, I would not have had the courage to apply to graduate school. Who could have guessed that a conversation in the car on the way to Canadian Tire one rainy Saturday afternoon would change the course of my life?

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Abstract

It was once supposed that children "grew out of" learning disabilities (LDs), but it is now known that these are lifelong conditions that can negatively affect many aspects of a person's life. Although the value of receiving a diagnosis is frequently cited as an important step in the process of ameliorating the condition, there is little qualitative research into the experience of being diagnosed in adulthood. This investigation examined the lived experience of receiving an LD diagnosis as an adult with the purpose of developing a deeper understanding of how the process affected subjects. Phenomenological heuristic inquiry was used and data was obtained by interviewing four adults who self-reported as having been diagnosed with LDs. Common themes that emerged included feelings of anger, grief, relief, regret, hope and resilience. All agreed that receiving a formal diagnosis was important to them.

Keywords: heuristic inquiry, learning disability, lived experience, phenomenology, psycho-educational assessment

Table of Contents

Approval Page ii
Dedication iii
Acknowledgements iv
Abstract v
Table of Contents vi

Chapter 1: Introduction 1
  Positioning Myself in the Research 2
  Research Purpose and Question 5
  Definitions 6
    Lived Experience 6
    Learning Disability 7
    Learning Disability Assessment 10

Chapter 2: Literature Review 11
  Qualifying and Quantifying Learning Disability 11
  Labels 14
  A Permanent, All-Encompassing Condition 15
    Education 16
    Employment 17
    Mental Health 18
  Summary 19

Chapter 3: Theoretical Framework 21
  Research Paradigm 22
  Assumptions 22
  Tying it all Together 24

Chapter 4: Methodology 26
  Qualitative Research 26
  Phenomenological Heuristic Inquiry 26
  Phases of Heuristic Inquiry 27
    1) Initial Engagement 27
    2) Immersion 28
    3) Incubation 29
    4) Illumination 30
    5) Explication 30
    6) Creative Synthesis 31
  Research Design 32
    Participant Selection 33
    Interview Structure and Question 34
    Data Collection and Management 35
    Data Analysis 35
    Validation 36

Table of Contents - Continued

Chapter 5: Results 39
    Universal Themes 40
    Regret and Sadness 40
    Anger and Frustration 42
    Relief 44
    Shame and Embarrassment 45
    Hope 47
    Depression and Anxiety 49
    Self-Concept 50
    Wistful Determination 52
    A Complex Interplay of Emotions 54

Chapter 6: Discussion 54
    Implications 55
    Limitations 56
    Future Research 58
    Assumptions Revisited 60
    Definition Revisited 62

Chapter 7: Conclusion 63

References 68

Appendix A: Participant Information Letter 73

Appendix B: Participant Consent Letter 74

Appendix C: Certification of Ethics Approval 76

Chapter 1: Introduction

This thesis represented my desire to combine two things. The first was an intense curiosity about how people with learning disabilities (LDs) make sense of their differences and perceive their labels. The second was the final leg of my much anticipated and long-delayed, educational journey. When I learned the GCAP program had a thesis option, I was immediately interested and knew exactly what I wanted to investigate. At that time a few years ago, merging my interest in learning more about LDs with the final step toward completion of my Master's degree seemed the perfect way to end what has been one of the most exciting and challenging times of my life.

I begin this paper with a discussion of what sparked my curiosity about how adults perceive their LDs, and describe my research purpose and question. The next chapter outlines my foray into the LD-related literature and my attempt to understand a subject about which many unanswered questions and much controversy still remains—the definition of LD. Chapter three explains my theoretical perspective and describes my research paradigm and the assumptions I initially developed as a result of thinking about and researching LDs. It also explains the process that led to the choice of Phenomenological Heuristic Inquiry (PHI) as the methodology for this study. The fourth chapter discusses how I implemented and adapted PHI to this particular investigation and explains how the study was designed and carried out. In chapter five, I share the results of my research. Chapter six examines the implications and limitations of my study and possible future directions for similar research. It also revisits the assumptions I made about a number of things, including the definition of LD. The final chapter summarizes all that I learned in the course of my thesis journey.

Positioning Myself in the Research

In 1994, I met a man who could not read or write—at all. He could not even print his name. I have always been interested in people’s stories, and this gentleman, Jack[1] then in his early 40’s, fascinated me. His math skills were excellent, he was articulate, and he had a prodigious memory. Although he had not finished high school, he had always worked and provided for his family. I did not know it then, but he was probably the first adult I ever knew who had an LD.

Since then I have known, personally and professionally, many people with similar characteristics, including my younger brother. Some of them were functioning well, had completed secondary or post-secondary education, were employed, and had healthy relationships. Others, like my brother, were not. The majority shared a disturbingly similar life trajectory, which included leaving high school before graduation, greater than average reliance on the social service system, numerous short stints of employment, and frequent periods of unemployment. Many also had poor interpersonal skills and problematic relationships. Substance use and mental health problems were not uncommon. Subsequent experience and research confirmed for me that such challenges are often the norm for people with LDs.

Over the past twenty-two years, as a computer instructor, life skills coach, crisis line volunteer, counselling student, and psychotherapist, I have met people who either demonstrated or described symptoms of LD. I observed that these adults struggled to achieve in the societally expected ways: through academic upgrading and retention of steady employment. Some succeeded, many did not. I have spent much time thinking

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[1] Not his real name.

about both the academic and personal characteristics these individuals share, and the institutional and attitudinal barriers with which it seems society burdens them.

My brother was one of the people whose life was irreversibly blighted by his learning problems. Although he was good at math, talented in music and sports, and had an amazing memory, school was an excruciating ordeal for him. As a child, his often spectacular academic failures together with behavioural issues overshadowed everything else. None of his positive traits could compensate for his early educational experiences and the negative self-concept he developed through years of being though lazy, slow, and oppositional. He escaped school as soon as he could, but the things that got him into trouble as a child, including impulsivity and anger-management issues, only got worse when he became an adult. Substance use, mental illness, interactions with the law, and fractured personal relationships followed him throughout his too-short life.

My musings about the myriad of challenges and obstacles faced by adults with LDs led naturally to curiosity about what could be done to more effectively help these people thrive in school, work, and life. Many of those I met over the years mentioned that they had always thought something was wrong with or different about the way they learned, and reported not doing well in school. Most could not articulate why this was. Few had received formal learning assessments even though the symptoms they described suggested that an LD might be present.

There was a time when I believed that receiving a formal diagnosis was the answer. However, a few years ago, I began to question the accuracy of my belief that being tested and diagnosed was the solution for anyone with an LD. One reason for this was that as the years went by, I was meeting more and more people who had been diagnosed as children or adolescents. Most knew their diagnoses and some had copies of the psychoeducational reports. However, in terms of daily functioning—their ability to succeed in school or work—they did not appear to be doing much better than those who had never been diagnosed.

A second reason that contributed my bias toward labelling is rooted in my personal experiences, and understanding from the perspective of someone employed by a social service agency how “the system” works. Myself a person with a disability (legal blindness), over the years my diagnosis brought many positives my way. Some were practical, such as academic accommodations and income tax deductions—things that it is impossible to obtain without first being diagnosed with a disability.

Others were less tangible, such as the societal acceptance derived from having a condition which others can see and understand. My label makes it easier for me to function in society, and for society to understand and accommodate me. Although most disability labels also have inherent negative connotations, they are a place from which to begin to understand ourselves and develop a way of being in the world. Receiving a formal diagnosis seemed to be a much better option than being called stupid, lazy, uncooperative, or unmotivated. Negative terms with which most adults who have had difficulty learning in the typical way are all too familiar.

When I began this research I was unsure about whether being formally diagnosed with an LD was as important as I had once thought. Though I understood that for social institutions to function, diagnoses are necessary I was less sure that a person needed one to live a full and satisfying life. As I continued to research, ponder my findings, dwell on my thoughts, and integrate everything I learned, I found myself growing more and more curious. I recognized the existence of my biases, assumptions and judgments, about this and other things, but did not feel burdened by them. I knew they might in some ways tint my research, but because I was aware of them, I hoped they would not taint it.

I found that as I completed each interview, my mind was opened to new possibilities. I was interested in individuals' stories and the meaning they made of the events of their lives. What my participants shared both enriched my understanding of my research area and created greater appreciation for what it was like to live every day with an LD.

Research Purpose and Question

The purpose of this study was to learn how adults perceived their LD diagnosis. I wanted to begin to understand how receiving the diagnosis as an adult affected study participants. My research question was:

> *"What is the lived experience of individuals who received learning disability diagnoses in adulthood?"*

Prior to conducting interviews, I believed that, for a person with any type of disability, information about their condition could be extremely powerful and even transformative. This assumption grew out of the belief that the better we understand ourselves, the easier it is for us to learn and grow. I thought that people armed with concrete facts would be more likely to develop the self-awareness necessary to thrive in the majority culture through the use of disability-ameliorating strategies and advocacy skills. However, I was unsure whether a formal diagnosis was necessary for all of this to occur.

The information contained in the preceding paragraph was what I thought, not what I knew based on evidence. In addition to learning more about how people perceived an LD diagnosis, through this study I also hoped to learn what my participants wanted or needed to know about themselves and their conditions. Some of the questions I hoped to have more insight into at the conclusion of the research were: Do people with LDs need a diagnostic label? Do they need to understand that they learn differently? Do they want to know how they learn best? Is the label valuable for them, or for others? Does having a diagnosis legitimize their differences in some way? Do they feel better or worse after receiving a diagnosis? Does it have practical or symbolic meaning to them?

While I realized that this study would not answer these or any other questions definitively, I hoped that it would assist me to understand the needs of individuals with LDs more fully as I embarked on a career in counselling. At the conclusion of my graduate studies I intend to become more involved in adult literacy and the promotion of mental health awareness, and I am sure that my participation in this research will improve the quality of assistance I am able to provide to my clients. I also hope that my research will be read by physical and mental health professionals and educators, and that it will broaden their understanding of LD and the ramifications, both positive and negative, of receiving a diagnosis in adulthood.

Definitions

Lived experience.

In qualitative research literature in general, and phenomenological methodology in particular, the term “lived experience” is often used. Although the words seem self-explanatory, it is worth noting that this phrase has a deeper meaning than simply to learn the details of what it is like having experienced a particular phenomenon (Moustakas, 1994). When researching lived experience, investigators are not only interested in learning how an individual describes the phenomenon, but also how that person experiences it within the context of their own life. It is through delving deeply into lived experience that a researcher “may gain understanding of the meanings and perceptions of another person’s world” (Pascal, Johnson, Dore, & Trainor, 2011, p. 175).

Learning disability.

Variations in the ability to learn have undoubtedly been present ever since humans began imparting knowledge to each other. However, the word learning disability as used to describe children and youth having difficulty acquiring academic skills, such as reading and mathematics, was only coined in the US in 1963 (Grunke & Cavendish, 2016). The first federal definition in the US was written in 1975. Since that then it has been amended several times. This definition was influenced by the medical model of LD which was formulated long before LDs were recognized and researched as they are today. Prior to the 1960’s, parents and teachers, lacking any other specialists to consult, first brought concerns about a child’s ability to learn to physicians and psychologists. These professional often labeled the children as brain damaged or neurologically dysfunctional (Grunke & Cavendish, 2016).

In Canada, the first LD-related organization, the Learning Disabilities Association of Canada, was incorporated in 1971. Since then it has established branches in every province and territory with the mission of helping people with LDs achieve equality, and promoting public awareness of LD. As LDs are often first noticed and most noticeable in school, over the past five decades, the education system has evolved to accommodate students with LDs (LDAC, n.d.).

Prior to the 1970's, children with disabilities, including those with learning issues, were generally segregated into special schools or classrooms. During the 1970's and 1980's, children with disabilities were often placed in regular classrooms but removed to receive specialized accommodations. Over the next few decades a growing movement of inclusion saw these children more frequently staying in their regular classrooms while receiving the assistance they needed alongside their same-age peers (Historica Canada, n.d.).

Unlike other conditions considered to be disabilities, such as deafness, blindness or quadriplegia, there is no universally accepted definition of LD (Grunke & Cavendish, 2016). In many countries, an LD is defined as any disability that interferes with a person's ability to learn. For the purposes of accommodating learning needs, individuals with specific LDs, such as dyslexia or an auditory processing disorder, are categorized by governments and or educators, with those who have other conditions for which problems acquiring and processing information are symptoms, such as Down Syndrome, dementia, and autism.

Although all of these conditions have learning difficulties as symptoms, in Canada and the United States (US), they are distinct from learning disabilities. In other countries this is not the case. The website of the Foundation for People with Learning Disabilities in the United Kingdom (UK) states: "In the USA and Canada they use the term 'intellectual disability' for what we in the UK would describe as a 'learning disability'" (Foundation for People with Learning Disabilities, n.d.).

Although in Canada and the US, provincial and state governments and social service agencies all use somewhat different definitions, for the most part, organizations in both countries agree that LDs are distinct from global intellectual disabilities, and a defining feature of LD is that “people with learning disabilities have average to above average intellect and reasoning and are fully able to learn given the right interventions (Burk, 2008, p. 2).

Given that an agreed-upon definition of LD does not exist, in order to decide upon a working definition of LD for the purpose of this paper, I examined and compared definitions from a number of Canadian and US sources. These included: national and provincial websites, advocacy organizations, and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Although length and wording varied considerably, most sources were consistent about what distinguished a specific learning disability from other conditions.

The one that eventually resonated most powerfully with me was that of DSM-5. There were two aspects clearly articulated within this definition which I thought were fundamental to separating LDs from other conditions also characterized by learning problems. These were firstly, that an individual had otherwise at least average intelligence, but unexpectedly underperformed in one or more specific areas of learning or academic skills acquisition. Secondly, the issue could not be attributable to other internal or external factors, such as the existence of another disability, or that the individual lived (or was raised in) an impoverished environment unconducive to learning (American Psychiatric Association, 2013). Where I writing my own definition, these would be its fundamental characteristics.

Learning disability assessment.

Learning disabilities are diagnosed using a number of different tools and criteria that vary from one jurisdiction or institution to another. While both the LDAC, and its US equivalent, the Learning Disabilities Association of America (LDA), agree that the process of LD diagnosis (variously referred to as testing, assessment, or evaluation) is crucial for adults and children, both are vague on the details of who is qualified to perform an LD assessment and what specific diagnostic techniques and instruments should be used (LDA, 2014; LDAC n.d.).

The LDAC's website says nothing about the diagnostic process other than that if a person is suspected of having an LD, information should be gathered from various sources, including family, teachers, and doctors. If a pattern is discerned, an evaluation should be sought from school administration or someone who specializes in LD evaluation (LDAC, n.d.). The LDA's website offers information about how individuals qualify for various LD-related supports and what information the assessment should include (LDAC, 2014).

Although exactly what the assessment process will entail may vary, it usually includes specific norm-referenced tests to identify functioning in areas such as general intelligence, language, memory, attention and concentration, measures of adaptive behaviour, and hand-eye coordination. Academic skills are evaluated, including literacy, numeracy, oral expression and listening comprehension. Individuals (or their parents) are also interviewed to learn details of their medical and family histories. If the person is a student, teachers may be asked to contribute details of academic performance or issues that have been noticed with learning or in the classroom. Most reports conclude with a summary of the results and recommendations (Bell, 2002, LDAC 2014).

Chapter 2: Literature Review

This chapter examines research about adults with LDs. It begins with an examination the occurrence and definition of LD. Some understanding of these topics is helpful in developing a “big picture” of the condition and contextualizing the challenges faced by people with LDs and those who work in the field.

The next section examines what the research says about having an LD label. Labels matter for two reasons. Firstly, they are necessary for people to be eligible for various types of support and assistance, such as disability payments, educational and employment accommodations, and protection from discrimination afforded by legislation in Canada and the US (Reynolds, Johnson, & Salzman, 2012). Secondly, they are important because people use them to create identities and define themselves (Savaria, Underwood, & Sinclair, 2011).

Until recently, LDs were considered problems of childhood that effected education only, and eventually disappeared. The last section examines research that dispels this myth. Not only are LDs permanent, they affect all aspects of life including interpersonal relationships, education, employment, and mental health.

Qualifying and Quantifying Learning Disability

Although a large number of articles discuss LD, the process of searching for literature was complicated by the fact the term *learning disability* has no universal definition. As noted in the Definitions section of the previous chapter, unlike physical and sensorial disabilities, there is no standard, quantifiable measure for LD.

Consequently, the term means different things to different people, organizations, and governments in different geographic locations (Taymans, Swanson, Schwarz, Gregg, Hock, & Gerber, 2009).

For example, in the UK, the Foundation for People with Learning Disabilities definition of LD focuses only on how the issue manifests itself; a problem that, no matter what its cause, results in “significantly reduced ability to understand new or complex information, to learn new skills as well as reduced ability to cope independently which starts before adulthood with lasting effects on development” ((Foundation for People with Learning Disabilities, n.d.) That organization’s website explains that other countries use the terms intellectual disability or developmental delay to describe what, in the UK, would be considered an LD (Foundation for People with Learning Disabilities, n.d.).

Both the LDAC in Canada and the National Center for Learning Disabilities (NCLD) in the US emphasize the difference between LDs and intellectual disabilities. The LDAC’s definition states that a distinguishing feature of LD is that an individual demonstrates at least average abilities necessary for thinking and reasoning but has significantly lower performance in one or more particular areas related to acquiring, retaining, or understanding verbal or non-verbal information (LDAC, n.d.).

The NCLD describes LD as “unexpected, significant difficulties in academic achievement and related areas of learning and behaviour.” Its definition goes on to specify that the individual must have received “high quality” instruction and that the learning issues cannot be attributable to “medical, educational, environmental, or psychiatric causes” (Cortiella, & Horowitz, 2014, p. 3).”

The DSM-5 referred to LDs and specific learning disorders and provided a highly detailed explanation of symptoms and diagnostic criteria. It stated that for LD to be diagnosed, learning issues must last at least six months and persist "despite the provision of interventions that target these difficulties" (American Psychiatric Association, 2013, p. 69). It listed problems that could be attributed to the existence of an LD and went on to discuss the key diagnostic features. These included that: the disability was not as a result of some other cause, such as intellectual disability, hearing loss, or neurological disorder; the individual must have normal intellectual functioning in other areas as defined by an IQ test, and; the issue was not caused by social or economic factors.

Because there is no consistent definition of LD, locating accurate statistics about the incidence of its occurrence was challenging. This is a discussion which is affected by geography. Kasler and Fawcett (2009) estimated that LDs effect between 5-20% of the adult population, but concede that arriving at a definite number is problematic due to differing definitions (these authors are from Israel and the UK where LD is assessed differently than in Canada) and because the "cut-off points used to interpret scores on diagnostic tests" vary (Kasler, & Fawcett, 2009, p. 201).

Burk (2008), a Canadian source, suggests that 10% would be a conservative estimate and the number is likely much higher. Taymans et al. (2009) reported that LD is the largest disability group, and that between 15-20% of Americans may have LDs. The LDAC puts the Canadian figure at 4.9% for school age children and notes that it fluctuates depending on the age range (LDAC, 2007).

Confusingly, although it is now agreed that LDs are permanent conditions, some sources make a distinction between the occurrence of LDs in children, adolescents, young adults and older adults. The number is higher among the younger age groups. For example, the DSM-5 estimated the prevalence of LDs that affect reading, writing, math at 5-15% for school-aged children, but only 4% for adults (American Psychiatric Association, 2013).

Confusion around defining LD is part of the challenge faced by people for whom the condition is suspected or has been diagnosed, and for those who educate and employ them. Unfortunately, misinformation seems to be very common. In a 2012 nation-wide study conducted by the NCLD, 31% of those surveyed thought poor diet caused LDs. Twenty-four percent attributed LDs to childhood vaccinations, and 22% believed watching too much television was the cause. All of these suppositions are false (Cortiella & Horowitz, 2014).

Labels

Only one investigation was found that specifically discusses LD and labels (Savaria et al. 2011). In this Ontario study, young adults who had been diagnosed with LDs as children were interviewed. The researchers found that although there may be negative consequences to receiving an LD label, those who had had their diagnosis for several years were able to find positive aspects as well. Interviewees who perceived that they had been able to participate in the construction of their label through assessment or involvement in the design of their education plans felt these experiences improved how they felt about themselves.

Savaria et al. (2011) also noted that identity is not static and that interviewee’s feelings about the diagnostic process and bearing the LD label changed over time. Their research found that study participants’ perceptions of the label were likely to improve as they grew older if they had been able to identify strengths and coping strategies that promoted success in specific areas. Orr and Goodman (2010) similarly found that while the LD label can be detrimental, participants in their study also reported resilience brought about by focusing on strengths and positive interpersonal relationships. Although participants in the latter study were post-secondary students, it is reasonable to postulate that all adults with LDs, whether they attended college or university or not, would have similar experiences with their diagnostic labels.

A Permanent, All-Encompassing Condition

Although it was once thought that LDs were disorders of childhood, it is now well-established in the scientific community that they are intrinsic to each individual and persist across the lifespan (Reynolds et al. 2012). Despite this knowledge, in a 2012 study, Gerber (2012) noted that there is a scarcity of evidence-based research to guide further research or adult education practices.

Further evidence for the permanence of LDs was provided by Reynalds et al. (2012). These authors suggested that one reason it was not until relatively recently that LDs were recognized as lifelong conditions was that once someone left school, many of the overt symptoms seemed to disappear. However, if these students later attended adult basic training programs, decided to obtain a GED, or pursued post-secondary education, the symptoms of LD would reappear. The all-encompassing, life-long nature of LDs is best articulated by Burk (2008, p. 1):

> Learning disabilities are lifelong. They affect each person differently. The needs of every person with learning disabilities also change or evolve throughout their

lifetime. The educational, social, economic and health impacts of learning disabilities are far reaching and infiltrate every aspect of our modern society. Learning disability experts concur. Both academics and advocacy organizations are expanding their efforts to educate the public about the permanence of LDs (Cortiella & Horowitz, 2014; Gerber, 2011; Kasler, & Fawcett, 2009; LDA, 2014; LDAC, n.d. Reynolds et al. 2012).

Education.

Generally speaking, adults with LDs leave school earlier than average young people. Often childhood education was not a pleasant experience and those who were able, left school as soon as they could (LDA Canada, 2007). As an example, one study found that people with LDs were half as likely to have graduated as people without LDs (Wilson et al. 2009). Possibly, due to early identification and accommodation, more young people with LDs are entering college and university than in the past, but a much greater number do not make it that far. Those who do attend a post-secondary institution drop out more frequently and may take longer to graduate than their non-disabled peers (Orr & Goodman, 2010; Winn, 2010).

For many of these people, returning to formal adult education to upgrade or acquire new skills can be an extremely stressful experience. Often, their return to formal education is further complicated if they have not been officially diagnosed. This is because eligibility for government programs and academic supports almost always requires proof of the diagnosis. In the US, those without it are not eligible for academic accommodations when writing the GED (Reynolds et al. 2012).

In the province of Ontario, the rules are somewhat less stringent, although still problematic for individuals who have been away from formal education for any length of time. Students who need academic accommodations for writing the GED must provide a copy of an individual education plan (IEP) or a psychoeducational report written within the last five years. If they do not possess either document, a letter provided by a medical doctor, psychologist, or school administrator outlining learning needs and the accommodations requested will suffice (Ontario Educational Communications Authority, 2016).

Low literacy is also a pervasive problem. The Canadian Council on Learning cited a 1999 study that estimated that 77% of people with LDs have low literacy. However, since this organization defines LDs as "Cognitive disabilities related to learning or memory" (Canadian Council on Learning, 2009, p. 2) it can be assumed that disabilities other than specific LDs were included. Consequently, the percentage of people with LDs may be lower. However, when this statistic is combined with the higher incidence of early school leaving, it is likely that literacy in adults with LDs is substantially lower than in the general population.

Employment.

It is probable that lack of success in school is correlated with employment issues. Adults with LDs are more likely to be unemployed, under-employed, and reliant on government assistance (Cortiella & Horowitz, 2014; Lancaster & Mellard, 2005; Winn, 2010). Often people with LDs are able to find jobs but are terminated or quit after a relatively short time. Reasons for job loss include: low literacy, inability to follow written or verbal instructions or keep pace with other employees, lack of organizational skills, and employee stress and anxiety.

Frequently employees were reluctant to disclose their LDs to employers, so that, even if the employer were willing to make accommodations, they were never requested. Although there is little quantitative data available in this area for the adults with LDs who did not attend post-secondary education, one study found that university and college graduates with LDs were unlikely to disclose their disabilities or request workplace accommodations. Instead, most stated that they relied on personal strategies such as arriving early, or seeking assistance from family and friends. More overt approaches, such as self-advocacy were seldom employed by those who responded to this survey. (Holmes, Silvestri, & Harrison, 2011).

The same study, that described the lack of disclosure among post-secondary graduates, also noted that this group was more likely than their non-disabled peers to be under-employed or working in jobs considered less demanding than the careers for which they had been trained (Holmes et al. 2011). As a consequence, they earned less money than their comparably educated peers. This statistic was supported for the general population of adults with LDs by sources which also found that people with LDs were more likely to have low socioeconomic status and receive social assistance (Burk, 2008; LDAC, 2007).

Mental health.

Another indicator of the pervasive nature of LDs is their negative effects on mental health. Several studies found that people with LDs had a higher than average incidence of mental health disorders, including depression, anxiety, stress, and suicidal ideation, and rated their perception of their mental health as low. These individuals were also more likely to seek help from a mental health professional than those who did not have LDs (Burke 2008; Klassen, Tze, & Hannok, 2013; Wilson, Armstrong, Furrie, & Walcott, 2009;). Klassen et al. (2013) emphasized that just as LDs remain present across the lifespan, so too do the mental health issues that often first developed in childhood. Burk (2008) noted that individuals with LDs were more likely than people without LDs to abuse substances, have addiction issues, and be involved with the criminal justice system.

Summary

Although the topic of LDs in adults has been receiving more attention from academics in recent years, there is still dearth of research on this subject. Much of what was available focused on some facet of LD and education. The majority of peer-reviewed studies I found that related to my research question involved children, post-secondary students, or people in adult education programs. Relatively little was mentioned in these papers about how LD affects adults outside of educational settings (Gerber, 2011; Taymans et al. 2009). There was even less about what having a diagnosis meant to them.

While many sources asserted the need for early diagnosis so that students with LDs could receive appropriate accommodations, none provided evidence of a strong connection between these interventions and subsequent success in education, employment or relationships. However, one positive byproduct of more and earlier diagnosis may be the increasing number of people with LDs who are now enrolling in colleges and universities (Holmes et al., 2011; Orr & Goodman, 2010).

A number of sources suggested that identification has value for an individual's psychological health and overall self-concept. Burk stated "Identification of learning disabilities can be of vital importance in providing an individual with self-knowledge and insight into why they may struggle or find particular tasks difficult" (Burk, 2008, p.7). Savaria et al (2011) found that the young adults they interviewed thought that understanding their LD was important, and that acceptance took several years to develop. Adults with undiagnosed LDs have often had negative experiences in the educational system and as a result leave it early and do not wish to return. Providing these individuals with a way of understanding their poor academic performance while also offering accommodations and coping strategies could help them achieve their full potential in school and work (Kasler & Fawcett, 2009).

The lack of agreement around LD between professionals, government departments, educational institutions, and non-profit agencies is significant because these entities are involved in diagnosing LDs and providing LD-related supports and services. Although organizations exist to help people with LDs understand their disabilities and navigate systems, many aspects of the topic remain confusing and contradictory. One of the conclusions reached by the PACFOLD[2] investigators in a study commissioned by the by the LDAC several years ago was that "all Canadians with learning disabilities are at a disadvantage" in virtually every aspect of life (LDAC, 2007). The fact that these individuals are confronted with so many barriers and challenges would be frustrating for

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[2] After the study was completed, the LDAC made PACFOLD publicly available on a separate website. Data was procured primarily from studies conducted by Statistics Canada and from one international study that was sponsored by the Organization for Economic Co-operation and Development. PACFOLD began with an extensive literature review, and the study was conducted and written by five Canadian researchers. More information about the authors and the study can be found at www.pacfold.ca

anyone, and must be especially discouraging for adults with LDs, many of whom have literacy limitations and information processing difficulties.

Due to this lack of consensus about what constitutes an LD, the number of people estimated to have these conditions varies widely. How best to help these individuals overcome the many personal and societal barriers they face is also in dispute. What most authors do appear to agree upon, is that the present resources available for identifying and treating LDs are inadequate and that government, society, and individuals pay a high price for this deficit (Coriella, 2014; Lancaster & Mellard, 2005; LDAC, 2007; Reynolds et al, 2012).

Although one consistent definition of LD was not found, all of those examined had some common features. Specifically, for a condition to be considered an LD, there were two important considerations. The first was that other causes had to be ruled out. The learning difficulty or difficulties could not be attributed to some other disability or environmental factor such as, intellectual disability, hearing impairment, socio-economic status, or absenteeism from school. The second was that the individual had to be functioning at an average or above average level in areas other than those presenting challenges.

Chapter 3: Theoretical Framework

After completing the literature review, it was necessary for me to choose a methodology. I investigated a number of different options before eventually settling on Phenomenology, which I thought would be the best fit for my proposed study.

Research Paradigm

All qualitative research is informed by higher-level theory. Investigators may not realize this because the theoretical framework upon which they based their work is so "embedded in their assumptions about the nature of reality and knowledge" (Glesne, 2011, p. 5). These assumptions, when taken together with the purpose and question of the research, describe the research paradigm. All are important factors in the choice of research method. There are several research paradigms common to qualitative investigation. The one that guided and informed this investigation was interpretivism.

Interpretivism assumes that reality is socially constructed and ever changing; each individual creates their own truth which is unique from that of others. This reality reflects a rich and complex interplay of factors, such as each person's family of origin, culture, socio-economic status, life experiences, geographical location, and many other aspects. Through the use of an interpretivist framework an investigator is able to contextualize and understand (to some degree) an event, object, perception, or behaviour from the perspectives of those who have experienced it (Glesne, 2011).

Assumptions

After completion of my literature review and reflection on my perception of LD and the experiences and anecdotes of people I knew who had LDs, I realized that I held a number of assumptions about LDs and the people who have them. Identifying these assumptions was necessary to ensure that they did not affect how I interpreted my research.

The first was that LD is socially constructed. It seemed to me that we as a society employ only a few educational methods and impose them on all learners. Those who do not achieve in the expected way are said (for lack of a better term) to have a disability which affects how they learn. This assumption fit very neatly within the interpretivist framework that was my research paradigm.

As I spoke about in the introduction to this thesis, something I began to ask myself several years ago was whether or not adults with LDs even needed a diagnosis. Instead, I wondered if an individual's time would be more productively spent identifying strengths and learning to compensate for weaknesses. As an (at the time) adult educator, the symptoms of LD were usually readily apparent in the classroom. Working to improve performance in weak areas, while at the same time identifying and building upon strong areas, seemed like a sensible and practical approach.

Another closely held belief of mine was that with effort, self-awareness, appropriate accommodations, and realistic expectations, people with LDs could attain whatever personal and professional goals they set for themselves. I thought that if someone just worked hard enough and wanted something badly enough, they could accomplish it. I believed that a determined person could overcome any barrier.

Being aware of these assumptions was crucially important during the research phase of the investigation. This was true because, as much as I tried to remove myself and my own biases from the research, I knew that bracketing out these deeply-held thoughts was not completely possible (Moustakas, 1990). Articulating my underlying preconceived notions about people with LDs was a way for me to keep these ideas in my conscious awareness and protect my research process, as much as possible, from being tainted by them.

Tying it all Together

One of the most challenging aspects of this project was creating harmony (in my own mind) between my worldview, research paradigm, choice of methodology, and research question. Achieving the desired level of genuine understanding and synchronicity was an evolving and elusive goal. My worldview told me that knowledge is valuable, but not necessarily powerful unless we know how to us it. I also believe that each of us inhabits our own unique reality, distinct from that of any other person.

These ideas fit well with the interpretivist paradigm, which is frequently used in phenomenological investigations. Interpretivism holds that reality, in addition to being socially constructed, is also multifaceted and dynamic (Glesne, 2011). The idea that, although certain facts in our stories may be indisputable, we humans create our own interpretations of them—our own reality—was extremely appealing to me.

This particular ontological viewpoint also worked well for my research question, since it could be argued that the phenomenon of LD is socially constructed. LD, like any other identity in modern society depends on “the complex interaction of people, places, activities” (Dudley-Marling, 2004, p. 485). Without an individual or institution making judgements about a person’s behaviour or intellect based on what seems normal or appropriate for someone who exists within a particular context (age, gender, culture, point in history, etc.) LD would not exist.

To receive an LD diagnosis, an individual is usually administered a number of tests which measure such executive functions as memory, attention, and problems-solving, as well as academic achievement in areas such as mathematics and reading. The assessment may also include interviews with informants who know the person well, such as parents, teachers, partners, and medical professionals (Roche, 2012). After collecting all the data, the assessor examines it as a whole and makes a determination of LD based her or his interpretations.

The tests that are used as part of a psychoeducational assessment are standardized. They have been norm-referenced and are considered to be valid and reliable at testing a particular skill with a particular population (Erford, 2013). However, receiving the label also relies on subjective answers to questions provided by the individual who is suspected of having an LD, and others who are familiar with various aspects of the person's life. Everyone who receives an LD diagnosis experiences it in a way that is unique to themselves and cannot be known to anyone else. Her or his personal reality is forever changed to include the understanding of what it means to possess the LD label.

Thus, heuristic inquiry, a variant of phenomenology, seemed an appropriate methodology for exploring this question. Although the philosophical underpinnings of phenomenology were not easy for me to grasp, I found Moustakas' approach extremely attractive. Creswell (2013) noted that phenomenology might be too highly structured for more experienced investigators, but as a novice, I was glad to find a research method that was sequentially organized and explained in a linear fashion. Understanding the philosophy that informed Moustakas' work was challenging for me, but his well-articulated processes provided much needed guidance. I especially appreciated his explanation of concepts and phases, which offered me a sturdy framework upon which to build. Although I allowed Moustakas to guide me, as the next chapter demonstrates, I also personalized his approach to fit my research question and timeline.

Chapter 4: Methodology

Once I had chosen a methodology, Phenomenological Heuristic Phenomenology (PHI), it was necessary to further explain it. Doing this helped me understand it more clearly and allowed me to begin to organize my thoughts about how best to operationalize it for my study. This chapter describes that process.

Qualitative Research

All types of qualitative research have two things in common: investigations are focused on phenomena that occur in natural settings, and the particular phenomenon that is being examined is never simplified, but rather studied in all its complexity (Leedy & Ormond, 2010). A qualitative approach is an appropriate choice when the purpose of the research is to describe the nature of processes, relationships, people, or systems. It is also well-suited to interpretations, as when a researcher wishes to gain insight into a particular phenomenon or discover problems that exist within it (Leedy & Ormond (2010).

Phenomenological Heuristic Inquiry

Phenomenological heuristic inquiry (PHI), the methodology chosen for this study, combines elements of phenomenology and processes of heuristic inquiry. As its name suggests, phenomenological research is interested in understanding phenomena. Its purpose is to "reduce individual experiences with a phenomenon to a description of the universal essence" (Creswell, 2013, p. 76).

Heuristic inquiry is a type of phenomenology used to guide how an investigator conducts a study. Essential component of heuristic inquire are that the researcher and the research are not distinct entities, and the researcher makes no effort to separate her or himself from the process, except where personal biases and assumptions must be identified and set aside so that she or he is open to new learning from the material acquired in the course of the research.

Because the investigator is so involved in the research process, she or he is considered to be a research participant (Moustakas, 1994). As the stages of the research unfold, the investigator develops a deeper understanding of the topic and experiences personal growth through the acquisition of increased self-awareness and self-knowledge (Moustakas, 1994).

Phases of Heuristic Inquiry

Heuristic inquiry as described by Moustakas (1990) consists of six phases. Although Moustakas described the phases as discrete from each other, for me they were not completely so. Instead, they ebbed and flowed and overlapped as I engaged with various aspects of the research at different times throughout the investigating and writing stages or my research. I wondered if this might have occurred due to the length of time it took to complete my work. Although Moustakas did not specifically discuss timelines, I had the feeling, when reading of his research and methods, that the time between beginning the investigation of a phenomenon and when he completed his write-ups was fairly short. Although somewhat of a departure from Moustakas' method, I do not think the intermingling of the stages was detrimental to my research, and may have even enhanced it.

1) Initial engagement.

Moustakas wrote of this first phase of heuristic inquiry that: "The task of the initial engagement is to discover an intense interest, a passionate concern that calls out to the researcher, one that holds important social meanings and personal, compelling implications” (Moustakas, 1990, p. 27).

Moustakas (1990) describes one of the most basic elements of PHI as tacit knowing; an awareness of something without understanding how or why. As a person with a disability myself, I believed I possessed the ability to tacitly know certain things about my participants, and thus had a way of relating to them that would be different for a non-disabled individual doing the same research. Since I did not think of this as either a bias or assumption, I saw no need to attempt to bracket it out. It was more an essence or a way of connecting that was unspoken and but may have helped me understand the internal frame of reference of my participants.

On a more practical note, as an educator and a future counsellor, the struggles and triumphs of adults with LDs have been ongoing topics of thought and study for me. My initial engagement began many years ago when I met the first person I ever knew who had an LD. Subsequently, and much more personally, I realized my brother, who throughout his life struggled in various ways, likely had an LD. His illness and death last year prompted even more and deeper engagement with this topic. As I conclude my master’s degree and embark on my counselling career, my engagement with LD is sure to continue.

2) Immersion.

This phase begins after initial engagement guides the choice of a question and the development of other aspects of the research project. During immersion, the researcher “lives the question in waking, sleeping, and even dreaming” (Moustakas, 1990, p. 28).

Although I never dreamed about my research, it was uppermost in my thoughts many times each day for weeks at a time. It was often on my mind when I woke up in the morning and some related thought was frequently the last that I was aware of before falling asleep. While walking to work I found myself having some random (but crucial to my research) idea, and recording a voice memo on my phone so it would not be lost. As I tried to make sense of the philosophical aspects of PHI and relate them to my research, I frequently tried to entice friends and colleagues into discussing whatever concept or question I happened to be grappling with at the time.

I also began seeing LD everywhere. There seemed to be almost daily news stories about it. I began to feel as though everyone I knew, including myself, must have an LD. At one point, I seriously thought about finding a way to get myself tested because I was sure my math difficulties were the result of dyscalculia!

3) Incubation.

During incubation, the researcher is said to withdraw from her or his "intense, concentrated focus on the question" (Moustakas, 1990, p. 28). At this time, the researcher may become detached from the question and involved in things not directly related to the investigation (Moustakas, 1990). However, below the surface on a subconscious level, thoughts are percolating.

Due to the exigencies of my work schedule, my brother's long illness and death, and the time that passed between interviews, I was often away from my academic pursuits for days or weeks at a time. Although I still found myself thinking about my research, or more precisely, my research topic, when I was otherwise occupied, these short breaks when I was doing things unrelated to my topic and question were very useful to my own heuristic processes. I often found that I viewed my writing and even my thinking with a renewed enthusiasm when I return to them after a break. Time away often resulted in things that I had been puzzling over being clarified.

4) Illumination.

Moustakas (1990) stated that the understanding revealed during the illumination phase is a process that naturally flowed from the information gleaned from research participants during interviews, and all that the investigator previously learned and intuited. He positioned this phase after the time when much knowledge has been obtained from gathering primary source data, and when themes and qualities of the phenomenon had begun to emerge.

However, I think for me illumination began soon after I decided on my topic and is likely to continue long past the completion of my degree as I deepen my experience of LD through meeting more people with various learning issues. I say this because illumination seemed to be an ongoing process. Although there were no real “ah-ha” moments for me, I did have many small flashes of insight. This phase was the most recognizable for me during initial examination of the data as a whole. That is, after I had completed all interviews and had a body of data to work with. As I began to identify themes, I realized somewhat to my surprise, that my research participants, although quite varied in the details of their lives, had many similar experiences and feelings around the process of being diagnosed with an LD.

5) Explication.

During illumination, important themes, qualities, and components of the experience under investigation begin to emerge more clearly (Moustakas, 1990).

Explication marks the beginning of a deeper examining of the subject, during which the investigator engages fully in the processes of heuristic inquiry, including, focusing, indwelling, self-searching, and self-disclosure (Moustakas, 1990). These are crucial processes as this phase is marked by the need for researcher to "attend to their own awareness, feelings, thoughts, beliefs, and judgements as a prelude to the understanding that is derived from conversations and dialogues with others" (Moustakas, 1990, p. 31).

As I completed and transcribed each interview, I found that I became increasingly preoccupied with examining the ways that my preconceptions about what I would learn were similar and different from the reality of what I did learn. I spent a significant amount of time thinking about the experiences of my participants and the narrative each had constructed around being diagnosed with an LD.

There were times when indwelling felt like obsession and I just could not stop thinking about my interviewees and their experiences. Although I approached the actual interviews with a degree of objective detachment, while listening to the recordings and then reading and rereading transcripts, the themes and qualities touched on by participants began to come to life. I began self-searching during this phase as I found myself wondering, based on things participants had said, how many times over the years I may have inadvertently overlooked an LD, or made assumptions or judgements that were hurtful or harmful to an adult with an undiagnosed LD.

6) Creative Synthesis.

In the final phase of heuristic inquiry, the researcher, now thoroughly familiar with all the core themes, qualities, and components of the research process, develops a creative synthesis of the material (Djuraskovic, & Arthur, 2011; Moustakas, 1990).

Although the final product can take a variety of forms, including a piece of visual art, a poem, or some other creative artifact, the usual product of heuristic inquiry is a narrative containing direct quotes and examples taken from participant interviews (Moustakas, 1990).

I created the latter type of narrative. I enjoyed this part of my research for two reasons. Firstly, because it meant that the end was in sight. A long, and at times exhausting and frustration process was finally drawing near. Secondly, because it allowed me to combine all I had learned into a (hopefully) coherent document and gave me the opportunity to distill a vast amount of information into a narrative that was carefully constructed but also captured the essential elements of participants' experiences.

This phase is aptly named. Due to only asking one question and following in whatever direction participants' thoughts took us, the interviews tended to meander from one topic to another and back again. While this conversational style seemed the ideal way to capture the essence of the experience of being diagnosed with an LD, it was probably not ideal for a first-time qualitative researcher.

Having said that, I really did feel as though I was involved in a creative synthesize as I took the information which had been transmitted to me in disjointed and often ungrammatical dialogue, and organized it thematically. Although time-consuming, this process was also highly rewarding. Despite frequent frustration and self-doubt, this became the part of the research that I enjoyed most. The more time I spent with the transcripts, the better I thought I understood the meaning of what participants were sharing with me.

Research Design

Participant selection.

Purposive criterion-based sampling was used to select four participants for this investigation. This type of sampling is used when participants are chosen with a specific purpose in mind (Leedy & Ormond, 2010). In the case of my study, participants were selected for the purpose of informing my research on LD assessment in adulthood. The inclusion criteria for this study was that participants had to be: eighteen years or older, report receiving their first and only psych-educational (LD) assessment during adulthood, and that assessment resulted in the diagnoses of an LD.

Although I assumed I would locate the necessary number of interviewees from the client base of ATN Access Inc., in London, Ontario, the organization for which I was working, finding willing participants from this agencies client base was much more difficult than anticipated. As a result, I had to expand my search and utilize other methods of soliciting volunteers. I contacted several community agencies, including the Learning Disabilities Association—London Region as well as Western University and Fanshawe College. I also used snowball sampling, which allowed me to obtain “knowledge of potential cases from people who know people who meet research interests” (Glesne, 2010, p. 45). Via email, I shared my invitation (see Appendix A) with friends, colleagues, and other contacts suggested by colleagues.

Of the resulting four participants, one was a client of ATN Access Inc., and one was located through an acquaintance. The last two contacted me after hearing of my study from staff at their universities. Although I did not specifically collect demographic information, in the course of the interviews I learned many personal details about participants that provided context. This information is summarized in Table 1.

Table 1

Participant Information

Pseudonym	Age Range	Occupation
Princess	Late 20’s	Student
Ella	Early 20’s	Student
Navi	Early 20’s	Student
Deborah	Early 50’s	Professor

Interview structure and question.

Data was collected using the extended interview method suggested by Moutakas (1990). Utilizing this technique, I initiated a dialogue with each participant. These conversations were not highly structured. Instead, they were allowed to unfold spontaneously, with me encouraging the expression of whatever thoughts, feelings or ideas participants chose to share. As the model suggested, I did not adhere to firm time limits (Moutakas, 1990). Instead, the dialogue flowed unconstrainedly to a natural conclusion, which was reached when the individual had the opportunity to fully share her or his story (Moustakas, 1990).

Each interview began with me asking one question: “Tell me what getting a learning disability diagnosis was like for you?” I then followed up with open-ended questions and declarative probes chosen in the moment but carefully worded to reflect meaning and encourage further exploration and sharing. To affirm the accuracy of what I thought I was hearing, throughout each interview I checked my assumptions frequently. I did this using reflections and summaries. The four interviews were conducted between May and October of 2015. They lasted from 45 minutes to 1:45 minutes.

Data collection and management.

Contact with each participant was made via email or telephone, and each was given the opportunity to review the consent document prior to signing it. Each aspect of the research and the process was explained before signed consent was obtained. All of this occurred before recording began. Two of the interviews took place in person and two via telephone. Participants received twenty dollars to compensate them for their time and/or any expenses associated with participating in the research. On the consent form interviewees were asked to select a pseudonym to protect their identities. This was used to identify them in my reflexive journal, data analysis, and in this paper.

The consent forms were stored in a locked filing cabinet at my home. Interviews were recorded using a password protected smart phone. I transcribed the audio files myself using Microsoft Word. As indicated in the letter of consent (see Appendix B) each audio file was deleted within one month of being transcribed. All other primary source data will be destroyed within five years, or no later than December 31, 2020. Electronic information will be deleted, and physical data will be shredded.

Data analysis.

Data was analyzed following the guidelines outlined by Moutakas (1990). After completing each interview, I spent significant time immersed in the data, first, as I transcribed it, then by re-reading it. After these processes were completed, I left each interview for a length of time ranging from several days to a few weeks before returning to it. This break gave me time to develop fresh perspective (Moustakas, 1990).

Upon revisiting the data, I felt reenergized and reengaged. New thoughts and ideas were identified after each hiatus. As I explored each transcript, a more and more complete depiction of each individual's experience with the phenomenon was identified.

I frequently returned to my primary source material to determine if my representation of the experience aligned with the data from which it was derived. Once I had ascertained that the image I was creating was accurate, and made revisions where necessary, I moved on to the next participant's data (Moustakas, 1990).

After the above process was completed for each interview, I began to develop a composite description of the phenomenon which contained elements of all participants' experience (Moustakas, 1990). Frequent use of their own language allowed me to create an honest, accurate, vibrant depiction. This phase was challenging as I worked on constructing an interpretation, which accurately portrayed a collective experience but also contains elements of its individual constituents.

It was at this stage that I began to truly feel like a "scientist-artist" (Moustakas, 1994, p. 52) as I utilized all that I had learned to develop a narrative that embodied the essence of the experience of receiving a LD diagnosis as an adult. This was an exciting time because it gave me the opportunity to creatively explicate all that I had learned about the phenomenon, the people who live with it, and myself. It also marked the beginning of the end of a very long journey.

Validation.

As a qualitative researcher, I knew that validation was not something that I could achieve through the analysis of statistics and correlations (Moustakas, 1994). In phenomenological heuristic inquiry, validity is achieved when the researcher is confident she or he has distilled accurate meaning from data—that her or his interpretation was the right one. In my case, this was done in a number of ways. I frequently revisited audio files and interview transcripts. I also kept a reflexive journal, and sought advice from my supervisor.

Another method I used to determine that my interpretations of what I heard was accurate, was saturation. Although this is a term more closely associated with grounded theory research, which typically involves many more interviews then I conducted (Creswell, 2016), it seemed to be a suitable validation strategy for my study. By the second interview I was able to identify many similarities between participants' experiences, even though the two individuals' life experiences were very different. By the end of the fourth interview, I felt as though I could accurately describe the essence of what it means to be diagnosed with an LD. As well, I noticed that my interviewees were echoing issues and sentiments that I had read about during my literature review.

I also discovered during my research that some qualitative researchers questioned whether concepts such as internal validity, external validity, reliability and objectivity, terms associated with validity of quantitative research, should be applied to qualitative research. Guba and Lincoln, in their landmark treatise, *Naturalistic Inquiry*, suggested that instead, qualitative researchers would do better to rely on credibility, transferability, dependability and confirmability as determinants of the trustworthiness of qualitative research (Lincoln & Guba, 1985).

To assess credibility, these authors suggested a number of methods, including prolonged engagement, referential adequacy, and member checks (Lincoln & Guba, 1985). I utilized prolonged engagement as I worked with my audiotapes and transcripts extensively and over a long period of time. Referential adequacy was achieved because I frequently checked my transcripts against the audiotapes to be sure that they were correct, that I had not omitted or added anything, and that my interpretation of what I was hearing or reading was accurate. Although I did not engage in formal member checks after the interviews were completed, I frequently reflected and summarized during the interviews.

The concept of transferability refers to whether or not the results of the research could be applied to other settings and contexts (Lincoln & Guba, 1985). I think my research results would be easily transferrable to a study that asks the same question about a different disability diagnosis, although not just any disability. My results would be most transferrable to studies investigating the diagnosis of a non-visible disabling condition, symptoms of which had been affecting sufferers for a prolonged period and that was either misdiagnosed or disregarded by experts or others in positions of authority.

One way of establishing dependability is to create a study that has been explained carefully enough that it could be replicated by another researcher (Lincoln & Guba, 1985). I think my study meets that criteria. Although the study design was simple and the sample size small, this methodology gleaned a very large volume of data. This study could easily be replicated using more or fewer participants and I am confident similar results would be obtained.

Confirmability is the degree to which study results could be confirmed or corroborated by others (Lincoln & Guba, 1985). A technique for establishing confirmability is the keeping of a reflexive journal. I journaled extensively throughout all phases of this research. That process reminded me to be aware of my biases and assumptions and cautious about allowing them to influence my interpretations of what I learned and how I explicated it.

Since every qualitative research study is unique, there is not one single way to establish validity. Instead, this type of research relies on a series of different techniques which, taken together create trustworthiness. I am confident that my interpretation of the data I collected accurately reflects the experience of being diagnosed with a learning disability as an adult.

Chapter 5: Results

The four participants[3] interviewed for this study were all female. They ranged in age from early twenties to mid-fifties. Each reported receiving their first LD diagnosis as an adult. Princess was a native woman living on reserve with her mother and siblings. She left high school before graduation and, at the time of her interview, was preparing to complete the General Equivalency Diploma exam. Her long-term goal was to attend "beauty school."

Ella was a student completing her last year of a Master's degree in Kinesiology. She was considering further study but was not sure in which field. Navi was also a student. She was born in India, where her parents were still living, and English was not her first language. She was in her third year of a Bachelor's degree in economics. She was taking longer to complete her degree due to failing some courses prior to being diagnosed. Navi explained that her goal was to "get through" and graduate, then change fields to something more suited to her skills and personality. Parental pressure and the

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[3] All names used were pseudonym chosen by research participants.

desire to prepare for a good job and justify the expense of her education were motivating her to complete her economics degree.

Deborah, a psychology professor working at a Canadian university was married with grown children. After struggling through high school, she chose not to go on to post-secondary education because she was afraid of failing. She married early, worked for many years as a foster parent, and did not begin university until her children were in elementary school.

Universal Themes

All participants reported that their feelings after learning of their diagnoses followed a somewhat similar trajectory: They experienced, to varying degrees, regret, sadness or grief as they imagined what might have been different for them if they had known sooner. These emotions were intermingled with, or followed by, a sense of relief at finally having an explanation for their differentness. Anger and frustration were common emotions around the time of the diagnosis. Shame was something they all experienced at some time in their lives. Finally, and for me a little surprisingly, all expressed hope for the future. Receiving a diagnosis was both a vindication of something they had always known but never been able to fully articulate, and a catalyst for positive growth and change.

Regret and Sadness

Upon learning of their diagnoses, all participants reported experiencing regret. This emotion was compellingly expressed by Ella who always struggled in school and never understood why. After she was diagnosed (in university) and began utilizing accommodations, her grades improved:

> If I had, like, known earlier I would have been able to do better in school. I used to want to be a doctor, but, like, I could never get my grades that high. I could have done all of these things if I knew how to handle it.

This was also the case for Navi, who reported having no social life and not being able to enjoy her first three years of university because she studied constantly just to maintain mediocre grades. She said: “I was not the typical student. I was studying from morning until night because it took me that much time to understand material.” She frequently compared herself to friends and peers and began to question her intelligence:

> Other people I was hanging out with, they were really smart. They were doing so much better and I felt like maybe, you know, I just don’t belong here and then I started getting embarrassed of myself in a way because, what am I doing? I’m putting in the same effort, I’m actually studying all the time. I’m missing everything to do. Basically, I’m not spending time with my friends or partying or anything. I would just not go.

Once her issues were identified and accommodations provided, she was able to earn higher grades with much less effort.

Participants in Duquette & Fullarton’s (2009) study also experienced regret that they had not been diagnosed sooner. Among their specific beliefs on this subject, one person thought she would not have left high school without graduating had she been aware of her LD. Others believed they would have been more successful at finding and keeping jobs if they had known about their LDs.

Everyone expressed some degree of sadness or grief. It was very intense for Navi: “Oh it was horrible. I feel like crying. I would cry every day. I broke down a couple of times. I actually broke down once when my counsellor told me that I needed to actually go to a psychologist and test myself….”

Deborah described being identified as gifted and attending an enrichment program one semester, and being placed in a remedial classroom with intellectually disabled students, the next. She remembered hearing a teacher tell her mother: “we just want to shake her up because she’s being careless.”

When she was given her diagnosis, Deborah felt an upwelling of emotions for “that little girl:”

> So all these years that I have been told that I was lazy and careless, which is what I was told as a little girl, and that I wasn’t trying hard enough actually was me struggling with something my brain was having trouble with and I was angry and mournful for that little girl, that she was made to feel like a loser instead of challenged with, okay you need to do these things differently. So that’s kind of why I was mournful, why I was so sad for that little girl…

Deborah was profoundly effected by the judgements made by the adults in her life over this and similar incidents. These assumptions about her underlying personal characteristics led directly to the internalized belief that she “wasn’t smart enough for university” and her very conscious decision to take a “different path.”

Anger and Frustration

Anger and frustration were common emotions. For Princess, frustration manifested itself in feelings of not being able to do “what everyone else did” so easily. She said she was also angry because, after struggling in high school, she left before graduating because she believed “that’s what I was like and there was nothing I can do about it.”

Ella was angry for two reasons. First, because during her childhood her mother (a teacher) long suspected, and even joked that she might have an LD. Ella said that the psychologist who tested her told her that it was common for children who were “able to cope” not to be diagnosed. The second reason was because of the negative connotations of the label:

> Part of me really hates being considered disabled, or like having a mental illness. I function pretty well. I think I’m doing pretty good overall. So whenever negative labels are associated with you, it’s like, no, just because there’s this thing that I’ve experienced doesn’t mean that there’s anything wrong with me. It actually bothers me on an emotional level.

Deborah remembers the judgements made about the effort she expended as a child in math and spelling, subjects that were particularly difficult for her. More than thirty years later, she vehemently believes adults should be cautious about assuming that when children are doing very well in some things and not so well in others it is because they are not trying hard enough.

> This has to stop. This assuming… Making assumptions of kids’ efforts. I used to hate… I still hate that about school report cards when they give a letter grade for effort. Or, you know, they ask the teachers to assess effort. How do they know? They don’t know.

Relief

All four participants reported that their diagnosis was a great relief to them. Each had known in some hitherto inexplicable way that something about how they experienced learning was different from how they knew other people learned. Being diagnosed was a vindication because it proved to them they were not stupid, lazy, disorganized, careless, not working hard enough, or any of the other negative characteristics that had been attributed to them during their educational experiences.

Princess said: "It felt good to know there was something really wrong… that it wasn't my fault… Over all I'd say it's [the LD assessment] been a good experience for me and I'm glad to have gone through it…"

Ella also felt relieved as she thought the depression caused by her, previously undiagnosed, LD detrimentally affected her life and relationships:

> So… in a way, it's a good thing knowing because I'm able to try and, like, understand myself better. And, when, like, you get angry and frustrated in situations you really don't think you should be, and it's nice to know why. Because, like, there's not something wrong with you it's just the way you are and you have to cope or do things slightly differently in order to do that. As opposed to, you're just moody and horrible, which is worse.

Navi was relieved because having an LD was the explanation for why she had to work so hard in school and yet never got grades that were high enough in relation to the time and energy she was expending on her studies.

> I was actually kind of relieved to find out because I wasn't sure if I had… like LD or something else… And then that's why I said I felt relieved when I found out

> because I was like, OK now I know why I did all this work and still my grades are lower.

She felt as though her life completely changed for the better after the diagnosis:

> Well the diagnosis has actually… before I even got diagnosed, it had affected me so much, you know? It put me into depression. It put me into anxiety. And now I feel like, yeah, honestly I feel like this year after summer, I'm basically, I'm getting answers about things in my life now I'm taking medication for anxiety and I'm getting tutors and I'm getting things to help me get through school. I think… I don't know, it's pretty much, like, been a pretty good year for me so far.

Deborah was also relieved. Although, until being diagnosed, she could not have articulated it, she had always known something was not right about the way she learned. For her, relief was mixed with other, less positive emotions. She mentioned relief several times during her interview, but could not speak about it in isolation. Instead, she mentioned relief coupled with feeling justified, mournful, sad, and angry.

Relief appeared to be a common emotion experienced by people diagnosed with LDs. Most participants in a study of those recently diagnosed stated that, similar to the feelings of individuals in my study, knowing helped them understand themselves better in terms of strengths, weaknesses and frustrations (Duquette & Fullarton, 2009).

Shame and Embarrassment

Every participant spoke directly about, or alluded to, often in many ways, feeling some degree of shame. Princess said: "When I was in grade four I think… we had to read, um, novels, so we had to read, like paragraphs, and then I had trouble reading, so…

and then kids would make fun of me too. That was hard." Being ashamed of her inability keep up with her peers ultimately lead to her dropping out of high school.

Deborah reported intense embarrassment and shared and an experience that she said eventually informed her decision not to apply to university directly after high school because she decided she wasn't smart enough. In grade six she was identified as gifted, but the next year she was placed in a special needs class to work on math and spelling:

> It's embarrassing not to be able to do basic arithmetic and I was humiliated going to this remedial class with kids who were intellectually disabled for a semester. …Yeah, so it was humiliating, it was humiliating. Because, of course I'd made friends with many of the gifted kids and all my friends went to university, every single one of them. …I remember thinking this actually, was that if you were really working at your hardest and you're not doing well according to the information, and people are telling you you're careless and you know you're not. The other option is, then I'm just stupid because my best isn't good enough.

Navi felt very embarrassed when she compared herself to friends and classmates. She eventually concluded that she didn't belong in university.

> …The thing is when I was working I was putting way more in then other people. I just started realizing that, maybe I shouldn't be here. Maybe I'm dumb and that's why I'm not understanding things, you know? Maybe that's why my grades are always lower and that kind of thing… and that started making me embarrassed of myself.

Similar results were found by Orr and Goodman (2005) in their investigation of the lasting impact of LD on post-secondary students. Thirteen of the 14 individuals they interviewed mentioned feeling ashamed or embarrassed.

Hope

Although it seemed unlikely given the many negative themes which emerged during the interviews, all four participants expressed feeling extremely hopeful about their futures. After being diagnosed, Princess approached her adult education classes with renewed energy. She was working toward writing the General Equivalency Diploma exam and planned to become an esthetician. Prior to being diagnosed, post-secondary education was a dream she could never imagine coming true. Since being diagnosed she described feeling optimistic about her ability to achieve in school and for her future prospects. She also thought it was a message of optimism she could share with future generations:

> Yeah… because you can tell your grandchildren, or grandkids or whatever, that you have a learning disability and if also they have a learning disability… you can tell them that maybe its genetics and its not their fault, and, yeah… then they know it’s not something they did or nothing, it’s the way they are.

Navi’s diagnosis engendered hope because it helped her realize she was not stupid and did belong at university. It also gave her the strength to continue and the confidence to recognize that even though her current major, economics, is not a good fit for her, there are many other options available. Getting answers to questions that she had about herself for as long as she could remember was also valuable to her: “That answered my questions about why I was struggling so much when I was putting the same work into it as others. So it was pretty shocking but it kind of helped me in a way to understand what I need to do further."

Ella was glad to be diagnosed because she thought it helped her understand herself, specifically her brain, more fully. She said that knowing she had an LD made her think about learning differently: "There's not something wrong with you it's just the way you are and you have to cope or do things slightly differently." Both Ella and Navi experienced improvements in their academic performance after being diagnosed and utilizing various LD-related accommodations. Both saw these improvements as evidence that they were fully capable of succeeding at whatever they chose to do.

Deborah described her diagnosis as "wonderful." Renewed hope in her own abilities led her to pursue graduate studies and attain a PhD, something she likely would not have done had it not been for her LD diagnosis. Learning she had a "hole in your brain" where the math and spelling processes were supposed to be [as her LD was explained to her by a psychologist] although initially an upsetting depiction, eventually allowed her to understand her differences from a scientific perspective and demonstrated to her that having an LD just meant she had to approach things differently.

In contrast to my finding that study participants appeared hopeful about their futures, those in a similar investigation (Duquette and Fullarton 2009) were not. These authors found that "participants' comments did not offer much hope that a diagnosis at this time would make much difference in the course of their lives" (Duquette & Fullarton, 2009, p. 67). The reason for this finding may lie in life experience. Three out of 4 of my participants were still engaged in formal education, which appeared to be a generally positive experience for them. The fourth had a satisfying career. Whereas, most of

Duquette and Fullarton's participants reported limited success in school and work and had been receiving social assistance.

Depression and Anxiety

Two participants reported formal diagnoses of depression and/or anxiety before receiving their LD diagnoses. Navi had both, and believed they were directly attributable to her learning issues. She reported that:

> …I started going into depression and I was like why, like why am I doing this because I'd be sitting down for all day and studying, and it's not fun, you know? I gave up going out and everything because I didn't understand why am I spending all my time studying and I would actually get nervous every time if I had to do something else because I was like, oh no, because if I do something else, if I spend my time with something else, I'm not going to do good on my exams.

She got to the point that she felt nervous whenever she had to do anything other than school work and often missed out on activities because she studied constantly. When family and friends asked her why she studied so much, she reported being too embarrassed to try to explain. She eventually became so anxious she needed medication.

Ella also experienced both anxiety and depression, although she thought the depression had the most profound effect on her. She believed that if her LD had been identified when she was younger, she would not have depression. Years of bullying in elementary school, always having to work harder than other students to achieve good grades, and feeling inferior to others took their toll on her mental health:

> I dealt with major depression and some anxiety but mostly depression while I was in my undergrad… So, for me, exam periods and everything… Like it just killed me and I would just go… I would be an emotional wreck, I wouldn't be able to eat properly and I would be so stressed and have a huge emotional breakdown every single exam period…

Although Princess and Deborah did not share information about depression or anxiety, both identified times when they felt emotional pain. Princess remembered a time in grade four when she really noticed that she was unable to read as well as the other children. She sometimes felt nervous because "I had trouble reading so… the kids would make fun of me…" Deborah remembered getting into trouble as a child in math class because she used "social support to deal with… to managing stress." "My desire to be with others was really me trying to deal with the fact that this was very stressful and I was putting out so much effort."

Other authors concurred that having an LD pre-disposes a person to mental health issues. Wilson et al. (2009) found that an LD diagnoses increased the risk of depression, anxiety, and suicide among youth and adults. Burke (2008) cited poorer than average mental health as a long-term consequence of having a learning disability. Klassen et al. (2013) found that rates of anxiety for both youth and adults were higher than for those without disabilities.

Self-Concept

Every participant reported that their learning issues had adversely affected their views of themselves, and that the process of being diagnosed with an LD had a positive effect on their sense of who they were and how they related to the world.

Princess, reported feeling “happy” and “relieved” as the psychologist explained the findings of her psychoeducational assessment because it proved to her that there really was something different about the way she learned. “It felt good to know there was something… something really wrong with me… that it wasn’t my fault.”

For Deborah, diagnosis represented a justification that she was something other than lazy or careless:

> I’m actually very hardworking. I’m actually quite clever. The fact that I’ve been able to accomplish what I’ve been able to accomplish is amazing. But it [the diagnosis] helps me understand where I need to put the supports. So I don’t trust me adding and subtracting my taxes, no one should.

Although Navi initially found her diagnosis “pretty shocking” she was glad to have it. “Because now I know what’s the problem because all my life I’ve been thinking I’ve been so sad and confused about why, why it’s always been like that. And it’s not like I’m being, like, lazy or procrastinating.” She explained that throughout her life she was often “sad and confused” about her inability to learn in the same way that she thought others did. Being diagnosed answered questions about why she had struggled so much and what she would need to do to improve academically. Knowing she had an LD and that there were things she could do about it lessened her symptoms of anxiety and depression.

Ella also reported feeling better about herself after being diagnosed:

> Growing up with an [undiagnosed] LD, I think you automatically put yourself on a lower tier than other people and there’s a good chance that you think, ‘I can’t do that, I can’t do this.’ So…In a way it’s, it’s a good thing knowing because I’m

> able to try and, like, understand myself better. And, when like you get angry and frustrated in situations you really don’t think you should be… It’s nice to know why.

The concept of knowing intrinsically that something was different about how they learned compared to peers, was a sentiment echoed by participants in a study that also asked adults about their perceptions of their LD diagnoses. The investigators reported that “all of the adults were aware of differences between them and their peers” (Duquette & Fullarton, 2009, p. 56).

Wistful Determination

An over-arching theme woven throughout all four conversations was something that, after much reflection, I decided to call wistful determination. It was characterized by the feeling of sorrow for what might have been, coupled with a resolve not to allow LD to limit potential. Each person expressed it in a unique way. Princess said: “I work harder now… now that I know. Like I know It’s not me, it’s something about me… and I can do what I want, I can finish school now… now that I know.”

For Ella, it helped with deeper understanding and putting things into perspective:

> I wanted to be a doctor and I know I won’t be that now, but because I know that I, like, learn differently, I can, like, do what I need to do… and when I feel, like, discouraged, I just think this is this thing with your brain and you can learn… you really are smart… you just have this difference and it doesn’t really matter.

Navi expressed it in this way:

> Honestly, I don’t want to ever take it as an excuse, you know. Like, oh, you know, the reason I can’t do this is because I have this. I think I can do everything. You

> just have to see things in a very different way. Yes, I might have to struggle a little bit, but you know, who doesn't? Everyone does. Everyone has to.

Wistful determination was most poignantly and passionately expressed by Deborah. After struggling through high school and barely graduating, she decided she was done with formal education. However, after much life experience, including raising biological and foster children, and "very suddenly" becoming divorced, and realizing she wanted to accomplish more, she decided to apply to university:

> "I realized after I started having some success in my first year… I had ninety-eight in some of my courses. Ninety-eight out of a hundred in my undergraduate courses in my first year. And I remember thinking, 'okay, I shot myself in the foot, I decided not to go on to university because and I was afraid.' I will never do that again. I am going to keep going until somebody says, 'Deborah get off this train' and I get to the end… I was nearing the end of one track… and you know somebody said, have you thought about grad school? And I said, 'I'm not going to say no, I'm going to try it and see how far I can go.' And when I got my PhD I did a postdoc and then I got a professorship and in professorships, as you probably are aware, there's tenure, you have to get tenure. That's a painful process and then… Oh, I want to advance to an associate level professor, and I've done that, and so my next goal is, the next stop on the train is full professor. So I'm going to go for it, not because I care. It doesn't mean more money, obviously. But because I started my career late I'll never be on the rungs of academia where I get paid, where I hit the top of my salary wrung. So it's not for money, it's just because I have promised myself never to let… to shoot myself

> down until I am shot down by someone. Until I can't make the bar. Don't assume you can't make the bar…

A Complex Interplay of Emotions

It was clear during the interviews, and became clearer the more time I spent with my data, that the entire process of knowing they were in some inexplicable way different from their peers, and then having that knowledge validated by a formal diagnosis of LD elicited a complicated combination of emotions for participants. Princess said she felt "happy… and relieved" after being informed of her LD. Ella spoke of certain situations causing her to feel both anger and frustration. Navi talked of spending a great deal of time prior to her diagnosis feeling a mix of sadness and confusion and after she found out feeling relieved and hopeful. This mix of emotions was compellingly expressed by Deborah who, after she received her diagnosis said: "It was actually, it was a little bit of justification, a little bit of relief, and a little bit of a mourning period."

Although no other studies were found that articulated participants' feelings in exactly the way I did, others noted significant levels of resilience in the face of the daunting challenges posed by having an LD while pursuing post-secondary education (Orr and Goodman, 2010). These researchers attributed this to a number of factors including, positive social connections and finding other things, such as social and recreational pursuits, with which to identify.

Chapter 6: Discussion

To say I learned a lot from the process of researching and writing this thesis would be an incredible understatement. I continue to be astounded by the fact that the learning never seemed to end. Even though I spent hundreds of hours over the past two years writing, rewriting, interviewing, transcribing, explicating and distilling, each time I returned to this paper, I felt as though I learned something new, or at least thought of some aspect of the subject in a novel way. In the paragraphs that follow, I share what I learned and what I think it means to me and the world.

Implications

Something I found fascinating about the interviews and that initially did not occur to me to question, was that none of the research participants had to think too much about their answers to my questions. Based on their responses, it seemed apparent that all of them had thought about their LDs, or more precisely, their learning issues—a lot. Unfortunately, most of this thinking was musing on short-comings and negative traits attributed to them by adults when they were children, or reinforced by lower-than expected academic performance. The diagnosis, even though it came late, appeared to have helped them put their feelings into perspective. All seemed able to speak more positively about themselves after learning there was a plausible, organic reason for why they were the way they were.

After I noticed that participants had thought so much about their LDs, I spent significant time deciding how that was important and what I could learn from knowing it. Something else that did not occur to me until I was immersed in transcription and meaning-making was my own reactions to what I was hearing. I consider myself to be a very matter-of-fact person who is able to absorb things that are sad or disturbing without too much emotional upset. At some point near the end of the process, interacting with the data became quite emotional for me. I found myself experiencing the range of emotions my participants had described. I am immensely privileged to have spent time with these four people who so willing shared their feelings about a process that, to say the least, was fraught with a complicated mix of emotions. It became very important to me to do justice to what I had learned.

Limitations

This study had a number of limitations common to qualitative research. They included: the small number of participants (four) that I interviewed, the use of purposive sampling, and the open-ended structure of the interviews. For these reasons, this research cannot be used to make general assertions. It also cannot, and should not, be used to definitively describe the experiences of the average adult who has received an LD diagnoses.

Another limitation was the use of PHI, which requires bracketing. Using this technique, I tried, as much as is possible, to set aside my own values, beliefs and assumptions. However, because I arrived at this research with my own personality traits and life experiences, the process of bracketing was, as Moustakas (1990) explained, more aspirational than attainable. I attempted, as much as possible, to maintain constant awareness of my thoughts and feelings during interviews and data analysis, because I knew if I did not these might creep into the narratives I was creating. Although I am sure I was not able completely prevent this from happening, I tried diligently to mitigate its effects by staying close to my raw data and repeatedly checking my perceptions with my research participants during each interview.

Although heuristic inquiry has many strengths, it also has limitations. As noted by Frick (1990) one of the most fundamental is that PHI affords the investigator much freedom in the creation and application of procedures. Although this presents many opportunities for flexibility and creativity, it may also contribute to irresponsibility on the part of the researcher and to work that is not well-developed. As I completed my interviews, the freedom that PHI allowed me sometimes felt like a double-edged sword. While I appreciated the unstructured approach, there were times when I felt uncertain about the direction the discourse was taking and wished that I had a more structured set of questions to rely upon.

Another potential limitation is that PHI methodology requires the investigator to have a thorough knowledge and solid understanding of its philosophical underpinnings. These abstract concepts can be difficult for some to understand (Creswell, 2013). So it proved for me. Understanding the theory underlying PHI and then creating a solid foundation upon which to build the rest of my work was by far the most challenging part of this entire project.

A major limitation of this study was that I (neophyte researcher that was) I disregarded everything I had read about the problems associated with conducting research with participants associated with the organization for which I worked. Although the pitfalls of so-called “backyard” research (Glesne, 2011, p. 41) were compellingly articulated by this author and others, I chose to ignore them. Instead, convincing myself that the selection of my workplace had more advantages the drawbacks and what disadvantages there were would be relatively easy to overcome.

Looking back over my journal, I realize that, due to my enthusiasm for this project, I over-estimated both clients’ interest in talking to me about their LDs and the amount of energy my colleagues would be willing to invest in helping me seek potential participants. This issue undoubtedly lengthened the time it took me to complete the required number of interviews as I spent several months hopefully awaiting a stampede of eager potential participants that never materialized.

Future Research

Based on my literature review and interviews, it is clear that there still exist myriad opportunities for future investigations that could enrich what is known and understood about LD diagnosis in adulthood. A mixed methods study which targets a large population of individuals diagnosed as adults and which gathers both qualitative and quantitative data would create a more accurate picture of the issues as they exist today. Although something similar was done by the Learning Disabilities Association of Canada's PACFOLD report, it was released almost ten years ago and most of its components, including the literature review and focus groups, were written and conducted much earlier.

An interesting and informative study would be one that looks at what happens after adults who are not connected with the education system in some way are diagnosed with LDs. School boards, colleges, and universities all have policies in place to assist newly-diagnosed students, and supports for which they automatically become eligible. However, this is not the case for those who are not formally associated with an educational entity. Having more information about how (or even if) these individuals use their diagnoses to obtain practical assistance, such as social services or employment accommodations, would be valuable.

Evidence from my literature review suggested that many adults do not disclose their LDs to employers and as a result are disadvantaged in the workforce in various ways. Learning whether adults, once diagnosed, were more likely to return to school would be a validation of the assessment process. It would also be a justification for directing more resources toward identification in adult education programs and by government and social service agencies.

Passage of the Access to Ontarians with Disabilities Act (AODA) may be helping to change the hitherto rather bleak employment outlook for adults with LDs in the province of Ontario. This 2005 legislation included a serious of standards designed to make all segments of society accessible for people with disabilities by the year 2025. By January 1, 2017, employers with more than fifty employees had to ensure their employment practices, including recruitment, retention, and career development, were fully accessible (Oncario.ca, 2015).

Many employers, especially those with parent companies in the US, where the American's with Disabilities Act (ADA) has been federal law since 1990 (Information and Technical Assistance on the Americans with Disabilities Act, 2010), already have accessible employment policies and procedures. Their websites promote commitment to equitable, barrier free employment, and the development of diverse and inclusive corporate cultures (Home Depot of Canada, n.d.)

While all of this sounds very promising, it is too early to know how these measure will affect employment statistics for people with LDs in Ontario. A study that gages the effectiveness of the AODA employment standard and whether it is helping adults with LDs find and maintain employment would be useful for secondary school and community-based employment counsellors.

Another potential avenue for research is how (or if) an individual's perceptions of her or his LD diagnosis changes over time. My study did not ask participants when they had been diagnosed, if their feelings about the diagnosis had changed, and if so, what was different. One of my sources (Savaria et al. 2011) mentioned that over time the perspective of young people who had been diagnosed as children altered as they got older. It would be interesting and informative to examine how adults feel at various points in time after their diagnoses.

I have made suggestions for future research that would undoubtedly enhance the existing body of literature on LD in adulthood, but the argument could also be made that further research of the types I suggest may not be necessary. Although we do not know the cause of LDs, we do have compelling evidence demonstrating that having an LD, no matter when it is diagnosed, creates life-long challenges related to education, employment, relationships, and mental health.

Perhaps research time and money would be better utilized in developing interventions that support adults in education. Investigators would also do well to develop new approaches that address LD symptoms as they relate to other areas of life, such as maintaining employment and managing relationships. Such investigations might involve new or newly emerging technology, such brain imaging or computer-assisted learning to identify and ameliorate deficits. Or, since a defining feature of LD is a deficit in one area of learning with average or above average performance in others, they might focus on identifying and helping people capitalize on strengths.

Assumptions Revisited

I previously wrote about three assumptions I held going into the study. It was important for me to articulate these so I remained aware of them during interviews and later as I wrote about my results. These assumptions were that: the LD label is a social construct, diagnosis may not be necessary, and success (for people with LDs) is always possible. At the near-completion of this project, I have the following to say about these assumptions.

Firstly, I realized that it probably does not matter in the big scheme of individual lives if LDs are socially constructed or not. Whichever side of the philosophical fence upon which a researcher positions her or himself, the most important thing is that we never forget that everyone with whom we interact is an individual. Although that person may have a neurological issue that affects learning, they are also the product of complex and interwoven genetic traits, personal characteristics, and environmental factors. What I now think is most important is that assistance in a variety of forms be available and that this help does not cease when formal education does.

Secondly, based on what I learned from the adults I interviewed who had known life before and after LD diagnosis, having a name for what caused their learning difficulties was important. That validation of being different was crucial to their self-concept. It also had implications for their futures. Initially, I think I wanted to believe diagnosis might not be unnecessary because I thought that any well-trained, observant, empathetic professional could help any individual overcome (or work around) whatever learning difficulties they presented. What I learned from my research was that the label gave my participants the energy they needed to engage in the process of exploring new ways of learning. It gave them hope and optimism. Without the diagnosis, long-held negative beliefs would persist and impede progress.

There were three flaws inherent in my third assumption, that success is always possible. The first was that I did not define success. As I learned from participants, it could take many forms and was a very personal concept. The second was regarding making judgements about effort. I posited, without really thinking about it critically, that the people who expend the most energy get the most in return. As I learned from my research, effort does not always equate with results, and judging effort can have lasting negative effects. My third erroneous belief was that success could be guaranteed. For any number of interconnected reasons success, however we choose to measure it, may not always be possible.

It became very clear as I reflected on these assumptions both during the research and writing phases, and as I neared the end of this project, that explicating my inherent biases and assumptions was vitally important to the veracity of my work. Becoming aware of these things allowed me to interpret interviews and transcripts in a way that was most genuine and true to what participants were sharing.

Definition Revisited

As mentioned in Chapter One, the definition of LD which seemed to me to be the most complete was that of the DSM-5. Although I initially dismissed this one, thinking it too clinical and the text too lengthy and dense to be useful, I have come to realized that LD is an extremely complex topic. Not only from the scientific perspective, but also from the viewpoint of the children and adults who spend their lives dealing the effects of having an LD. I think that such a thorough discussion as is provided by the DSM-5 is necessary to guide the decisions of those professionals tasked with diagnosing and treating people with learning difficulties. While I remain somewhat disturbed by how closely this definition aligned with the medical model of disability (something being wrong with or broken about a person that needs to be cured or fixed) I also believe that those who accept the label must also, for the sake of pragmatism, accept the paradigm.

Chapter 7: Conclusion

As I write my concluding paragraphs, I am reminded of the many people I have met over the years whom I suspected of having LDs. It is difficult to think about this topic generally without remembering Leo[4] specifically. His arrival in the introductory computer class I taught was preceded by a telephone call from an adult literacy instructor. She apologized for referring him to my agency, saying she knew he was not a good fit, but his time with her organization had expired, and she wanted to refer him "somewhere."

Leo was a well-spoken forty-three-year-old man. A year before, he had quit his job as a courier. He did the job well for fifteen years without his employer or co-workers ever knowing he could barely read. He quit abruptly when the company implemented a real-time computerized delivery system. Previous to this change, he had received the following day's deliveries on paper the evening before. Each night, his wife would read them to him. His excellent memory and knowledge of the city helped him map out his route and complete his assigned tasks. When he learned of the imminent deployment of the computers, he chose to leave the job rather than disclose his reading difficulties.

Leo arrived in my class angry, and stayed that way throughout the course. This otherwise calm and quiet man was easily frustrated in the academic setting and vented his rage by shouting and physically intimidating me and other students. He was profoundly aware of, and embarrassed by, his learning issues. He had never been diagnosed with an

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[4] Not his real name

LD, but the symptoms were there. His previous adult literacy program had recommended he be assessed for an LD, and he was open to the idea, but at that time there was no program in our community that funded them and he could not afford to pay for it himself.

Because he did not have a diagnosis, he was ineligible for services that might have helped him. Without any better labels to use, he persisted in referring to himself as “stupid,” and “retarded.” Months of unemployment and dwelling on his inability to find a new job had adversely affected his self-esteem and caused him to become depressed to the point of needing medication. His sense of self-loathing was palpable and he sometimes mused that his wife would be better off if he were dead.

As my research has shown, for Leo and Jack, who first sparked my curiosity about LDs, and all the others like them, including my brother, having an accurate label to explain their differentness would have been extremely valuable. An LD diagnosis could have been a way for them to conceptualize their learning issues differently and would have provided a less demeaning vocabulary for them to use to describe themselves. An LD diagnosis could also have been something they *had*, not something they *were*. For me and other educators, knowing of an LD would have provided important clues about how best to accommodate their learning needs.

As my brother and so many others like him so aptly and sadly demonstrated, learning disabilities are not outgrown as people mature. Although individuals may develop compensatory strategies and learn to use assistive technologies to help them manage their symptoms, they will never, in the traditional sense of the word, be cured. Despite statistics that demonstrate that LDs are among the most common disabling conditions, many adults remain undiagnosed for reasons related to issues of identification, access to assessment, and funding.

The absence of a diagnosis leaves many ineligible for services that could help them. Their challenges are compounded by the lack of a consistent definition and public misinformation. As was revealed in my literature review, outside of the educational context, there has been relatively little qualitative research into the effects of LDs on adults, and even less on the lived experiences of these individuals once they have received a diagnosis.

The idea for this study developed out of personal frustration and discouragement as I continued to encounter people who, like Leo, Jack and my brother, did not learn in the traditional way and were, as a result, not able to achieve their educational or employment goals despite great desire and effort. These were individuals in whom much latent talent seemed to exist, but for whom the ability to utilize it remained elusive. Some had received LD diagnoses, others had not. That fact, learned long before I began this thesis, led me to conclude that assessment was not a defining feature of success for a person with an LD. My conversations with research participants forced me to rethink this conclusion.

In the introduction to this paper I posed a number of questions about which I wanted to gain insight. Although I realized it was beyond the scope of both qualitative research in general and this study in particular, I still hoped to be closer to having answers after I finished than before I started. What I learned was that, for the people I interviewed, receiving a diagnosis was extremely important. There were a number of reasons for this and, as Chapter Five illustrated, all were unique to the individual.

Of all the questions I posed earlier in this paper, the one that was most significant to me was: “Do people with LDs need a diagnosis?” Prior to my research, had someone asked me this question, I would likely have answered it by listing the pros and cons of the diagnostic process and its aftermath. Going forward, I will still do this, but I will feel much more confident in stating that, based on what I learned when conducting this research, having the diagnosis is valuable. The fact that it is the key that unlocks the door to academic accommodations and social services is a compelling reasons to be tested, but not the most important one.

What I discovered through my interviews was that receiving a diagnosis led participants to greater personal understanding. It provided each one with the opportunity to rethink long-held (and almost always negative) biases and assumptions about themselves. The reasons my participants gave for valuing their diagnoses transcended the practical. Prior to being diagnosed, they described themselves as often feeling “less than” peers, needing to work harder, frequently feeling shame, and questioning their intellect and abilities. Having a diagnosis, a reason for why they were the way they were, provided an explanation for their differences.

Although receiving an LD diagnosis in adulthood made them sad and angry about what might have been, they also felt happy and relieved. What they finally knew was that their learning difficulties were not, as they had been led to believe by others or learned to believe about themselves, flaws of character such as laziness or carelessness, but real, organic issues. In the words of Ella, “I found the personal value is huge [because] it’s not something that’s wrong with you as a person.” Having a diagnosis allowed each to reflect on their lives and see the past in a new way. They were able to rewrite their personal narratives and re-reconceptualise their identities in ways they previously could not have imagined.

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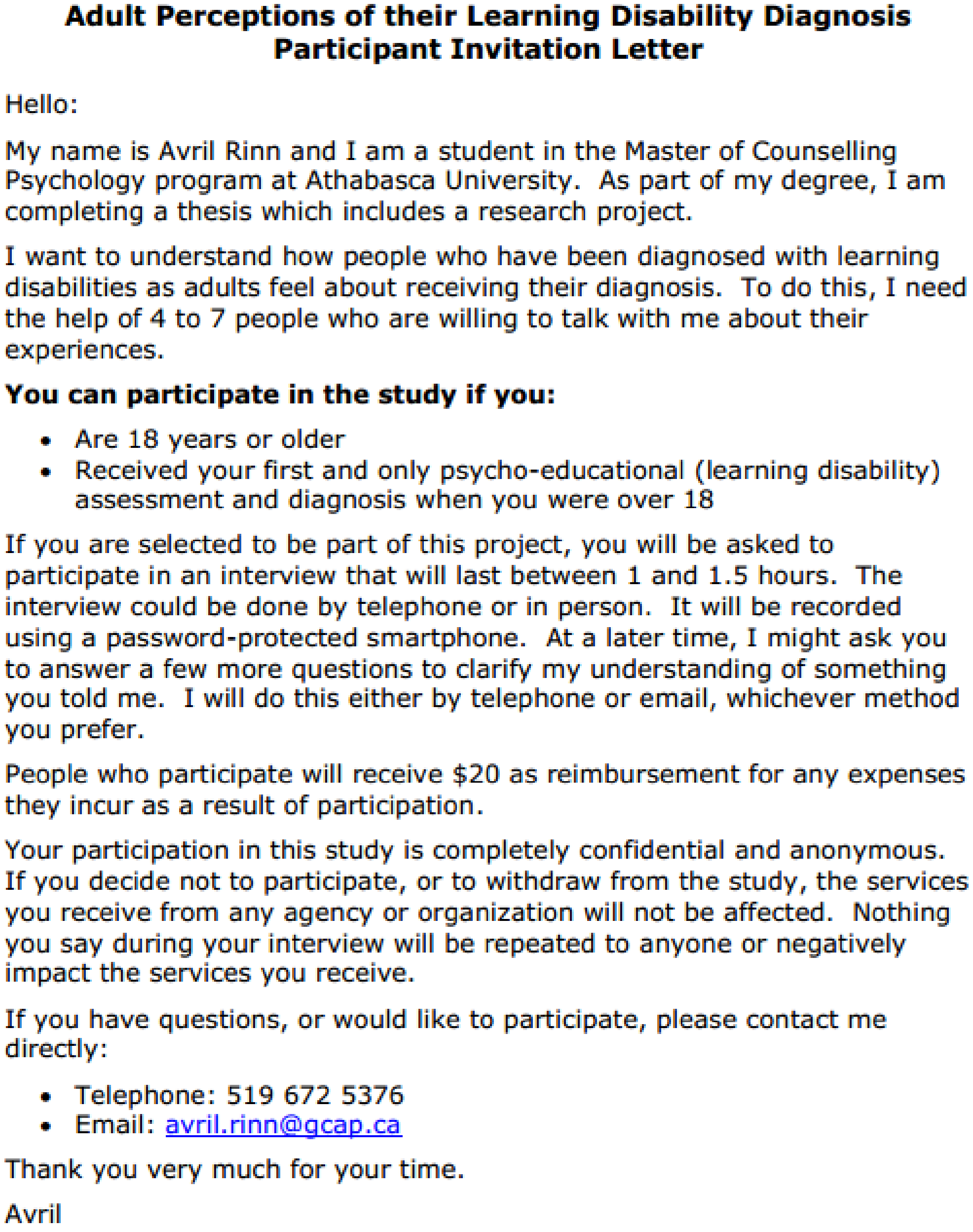
Appendix A: Participant Information Letter



Adult Perceptions of their Learning Disability Diagnosis
Participant Invitation Letter

Hello:

My name is Avril Rinn and I am a student in the Master of Counselling Psychology program at Athabasca University. As part of my degree, I am completing a thesis which includes a research project.

I want to understand how people who have been diagnosed with learning disabilities as adults feel about receiving their diagnosis. To do this, I need the help of 4 to 7 people who are willing to talk with me about their experiences.

You can participate in the study if you:

- Are 18 years or older
- Received your first and only psycho-educational (learning disability) assessment and diagnosis when you were over 18

If you are selected to be part of this project, you will be asked to participate in an interview that will last between 1 and 1.5 hours. The interview could be done by telephone or in person. It will be recorded using a password-protected smartphone. At a later time, I might ask you to answer a few more questions to clarify my understanding of something you told me. I will do this either by telephone or email, whichever method you prefer.

People who participate will receive $20 as reimbursement for any expenses they incur as a result of participation.

Your participation in this study is completely confidential and anonymous. If you decide not to participate, or to withdraw from the study, the services you receive from any agency or organization will not be affected. Nothing you say during your interview will be repeated to anyone or negatively impact the services you receive.

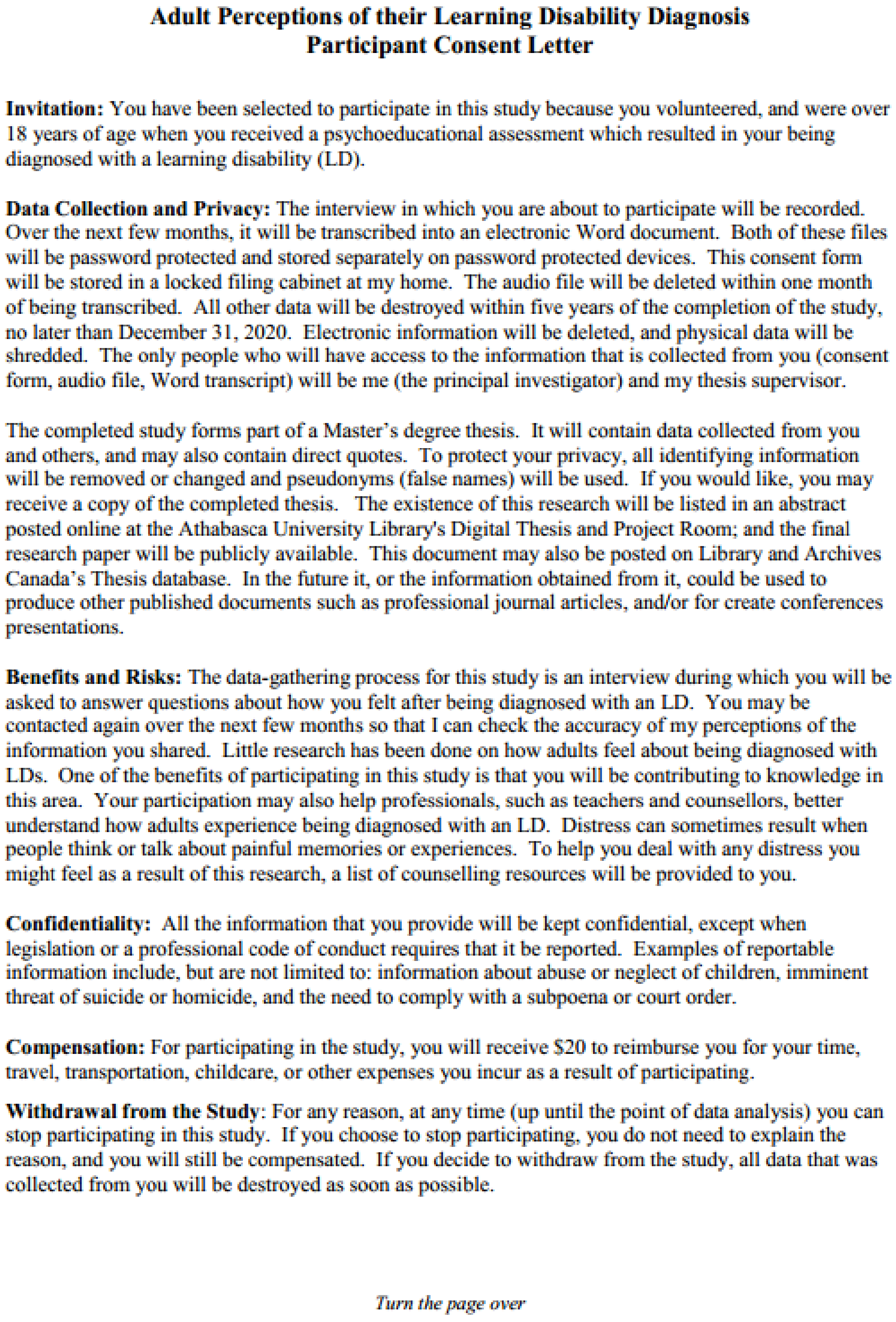
If you have questions, or would like to participate, please contact me directly:

- Telephone: 519 672 5376
- Email: avril.rinn@gcap.ca

Thank you very much for your time.

Avril

Appendix B: Participant Consent Letter



Adult Perceptions of their Learning Disability Diagnosis
Participant Consent Letter

Invitation: You have been selected to participate in this study because you volunteered, and were over 18 years of age when you received a psychoeducational assessment which resulted in your being diagnosed with a learning disability (LD).

Data Collection and Privacy: The interview in which you are about to participate will be recorded. Over the next few months, it will be transcribed into an electronic Word document. Both of these files will be password protected and stored separately on password protected devices. This consent form will be stored in a locked filing cabinet at my home. The audio file will be deleted within one month of being transcribed. All other data will be destroyed within five years of the completion of the study, no later than December 31, 2020. Electronic information will be deleted, and physical data will be shredded. The only people who will have access to the information that is collected from you (consent form, audio file, Word transcript) will be me (the principal investigator) and my thesis supervisor.

The completed study forms part of a Master's degree thesis. It will contain data collected from you and others, and may also contain direct quotes. To protect your privacy, all identifying information will be removed or changed and pseudonyms (false names) will be used. If you would like, you may receive a copy of the completed thesis. The existence of this research will be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Project Room; and the final research paper will be publicly available. This document may also be posted on Library and Archives Canada's Thesis database. In the future it, or the information obtained from it, could be used to produce other published documents such as professional journal articles, and/or for create conferences presentations.

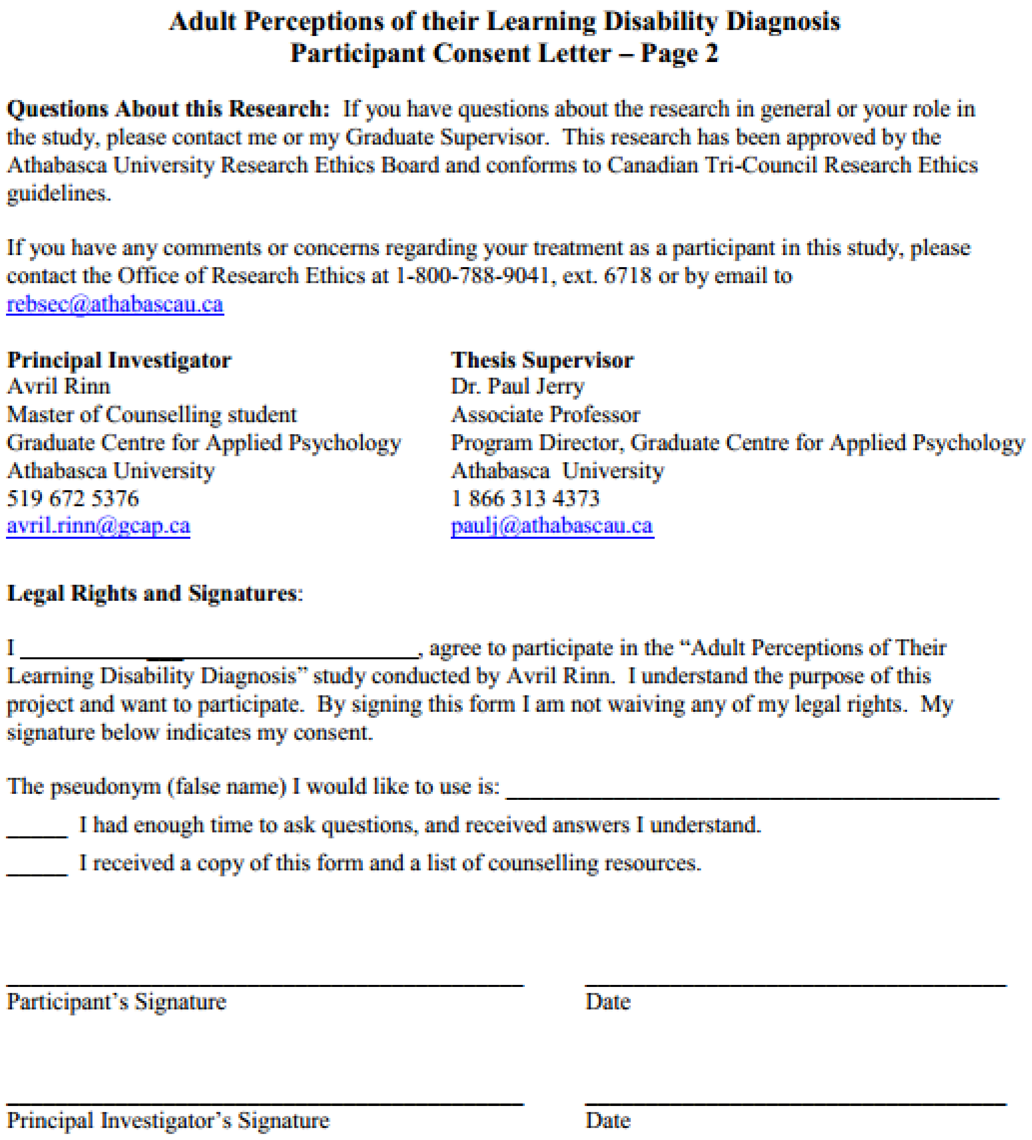
Benefits and Risks: The data-gathering process for this study is an interview during which you will be asked to answer questions about how you felt after being diagnosed with an LD. You may be contacted again over the next few months so that I can check the accuracy of my perceptions of the information you shared. Little research has been done on how adults feel about being diagnosed with LDs. One of the benefits of participating in this study is that you will be contributing to knowledge in this area. Your participation may also help professionals, such as teachers and counsellors, better understand how adults experience being diagnosed with an LD. Distress can sometimes result when people think or talk about painful memories or experiences. To help you deal with any distress you might feel as a result of this research, a list of counselling resources will be provided to you.

Confidentiality: All the information that you provide will be kept confidential, except when legislation or a professional code of conduct requires that it be reported. Examples of reportable information include, but are not limited to: information about abuse or neglect of children, imminent threat of suicide or homicide, and the need to comply with a subpoena or court order.

Compensation: For participating in the study, you will receive $20 to reimburse you for your time, travel, transportation, childcare, or other expenses you incur as a result of participating.

Withdrawal from the Study: For any reason, at any time (up until the point of data analysis) you can stop participating in this study. If you choose to stop participating, you do not need to explain the reason, and you will still be compensated. If you decide to withdraw from the study, all data that was collected from you will be destroyed as soon as possible.

Turn the page over



Adult Perceptions of their Learning Disability Diagnosis
Participant Consent Letter – Page 2

Questions About this Research: If you have questions about the research in general or your role in the study, please contact me or my Graduate Supervisor. This research has been approved by the Athabasca University Research Ethics Board and conforms to Canadian Tri-Council Research Ethics guidelines.

If you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or by email to rebsec@athabascau.ca

Principal Investigator	**Thesis Supervisor**
Avril Rinn	Dr. Paul Jerry
Master of Counselling student	Associate Professor
Graduate Centre for Applied Psychology	Program Director, Graduate Centre for Applied Psychology
Athabasca University	Athabasca University
519 672 5376	1 866 313 4373
avril.rinn@gcap.ca	paulj@athabascau.ca

Legal Rights and Signatures:

I ______________________________, agree to participate in the "Adult Perceptions of Their Learning Disability Diagnosis" study conducted by Avril Rinn. I understand the purpose of this project and want to participate. By signing this form I am not waiving any of my legal rights. My signature below indicates my consent.

The pseudonym (false name) I would like to use is: ____

_____ I had enough time to ask questions, and received answers I understand.

_____ I received a copy of this form and a list of counselling resources.

____ __________________________________
Participant's Signature Date

____ __________________________________
Principal Investigator's Signature Date

Athabasca University
RESEARCH CENTRE

February 17, 2015

Ms. Avril Rinn
Faculty of Health Disciplines
Athabasca University

File No: 21658

Ethics Expiry Date: February 16, 2016

Dear Ms. Avril Rinn,

Thank you for your recent resubmission to the Faculty of Health Disciplines (GCAP) Departmental Ethics Review Committee, addressing the clarifications and revisions as requested for your research entitled, 'Learning Disability Diagnosis in Adulthood: A Phenomenological Heuristic Investigation'.

Your application has been **Approved** and this memorandum constitutes a ***Certification of Ethics Approval***. You may begin the research immediately. Please note there were several 'typos' in your invitation letter. Please review this document and correct any errors before sending out ('chose' should be 'chosen'; 'y our' should be 'your'; 'effected' should be 'affected')

This REB approval, dated February 17, 2015, is valid for one year less a day.

Throughout the duration of this REB approval, all requests for modifications, ethics approval renewals and serious adverse event reports must be submitted via the Research Portal.

To continue your proposed research beyond February 16, 2016, you must apply for renewal by completing and submitting an Ethics Renewal Request form before January 30, 2016. Failure to apply for **annual renewal** before the expiry date of the current certification of ethics approval may result in the discontinuation of the ethics approval and formal closure of the REB ethics file. Reactivation of the project will normally require a new Application for Ethical Approval and internal and external funding administrators in the Office of Research Services will be advised that ethical approval has expired and the REB file closed.

When your research is concluded, you must submit a Project Completion (Final) Report to close out REB approval monitoring efforts. Failure to submit the required final report may mean that a future application for ethical approval will not be reviewed by the Research Ethics Board until such time as the outstanding reporting has been submitted.

At any time, you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator at research_portal@athabascau.ca.

Sincerely,

Simon Nuttgens
Chair, Faculty of Health Disciplines (GCAP) Departmental Ethics Review Committee
Research Ethics Board