

Cognitive Difference in a Postmodern World:
Asperger's, Autism, Stigma, and Diagnosis

by

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B.A., Lakehead University, 1979

M.A., McMaster University, 1996

B.S.W., Lakehead University, 2002

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of the Requirements for the Degree of

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Supervisory Committee

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Departmental Member**Abstract**

Asperger's was eliminated as a distinct diagnosis in the DSM-5. While controversy lingers over the assimilation of Asperger's into autism spectrum disorder, my study explores the experience of stigma through interviews with four adults with Asperger's and two with high functioning autism. I examine the phenomenology of autistic stigma, stigma management, and how stigma is impacted by diagnosis. The results provide an understanding of stigma as it is experienced by individuals who, in the words of one participant, suffer from a "relationship disability." The term *ASHFA* evolves during the write-up to become more than an acronym for Asperger's/high functioning autism; it comes to represent a way of being present in the world that transcends diagnosis. A relational methodology derived from Gadamer's hermeneutics and Merleau-Ponty's phenomenology provides a philosophical framework for the project and also guides ethical engagement during the study. Methods used in the data analysis are drawn from constructivist grounded theory. The report itself may contain clues into *ASHFA* because I, the organizing participant, am also diagnosed with Asperger's. I attempt to make sense of the paradoxical conclusion that diagnosis can provide a therapeutic explanation for autistic difference even as medicalization disempowers us as a validating narrative.

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I would also like to acknowledge the people who help build insight into autism by sharing their perspectives online. Some of these publically accessible postings were anonymized and cited in this project. I would be negligent if I did not thank the Asperger's Society of Ontario, Asperger's Ontario, and all those who helped generate interest in this project. Most of all I am grateful to the participants themselves for sharing how they experience the world, their diagnosis, and the stigma they encounter. I have been honoured and inspired by the participation of each one.

Dedication

I would like to dedicate this project to my wife, whose courage, passion, and unwavering support have allowed me to move forward knowing someone believed in me no matter what. Without her I would be a quivering pile of uncertainty lost in some hidden corner of what Goffman calls the “back places.”

Chapter 1: Introduction

Stigma can be defined as the disapproval, degradation, and shame or shaming associated with the possession of any quality, characteristic, or condition designated explicitly or silently by society as a negative “mark of disgrace” (“Stigma,” 2014). Stigmatization is a form of oppression that marginalizes through stereotypes, intolerance, and dominant expectations. Stigma often leads to discrimination and self-diminishment that can “significantly undermine quality of life” (Corrigan, 2007, p.31). The effort to manage stigma can create further confusion and alienation as targeted individuals drain their energy trying to evade, blend, and bluster their way to social acceptance. As a complex cultural construction that undermines relationship, equality, and social justice, “stigma is an issue of major concern to social workers” (Payne, 1980, p.443).

A quick survey of the literature reveals an abundance of research on stigma in relation to such issues as mental illness (Covarrubias & Han, 2011; Sheyette, 2005), suicide (Downs, 2012), gender and sexuality (Kanuha, 1999), HIV (Poindexter & Shippy, 2010), race (Wilton, Sanchez, & Garcia, 2013), and a plethora of other qualities and conditions. Yet although “people with intellectual disabilities have been marginalized throughout history and face negative public attitudes and social exclusion” (Scior, Potts, & Furnham, 2013, p.125), there is little evidence about how stigma operates in the lived world of people who have cognitive impairments and /or negatively perceived differences of mentalization. Mentalization can be defined as “the mind’s innate capacity to make sense of social experiences and implicitly know how to respond to them” (Krugman, 2013, para.1). My research addresses this gap in knowledge by exploring the stigma experienced by adults who are diagnosed in the low severity range of autism spectrum

disorder, a condition that was previously designated by the now eliminated term Asperger's syndrome (AS) and the never officially adopted term high functioning autism (HFS). In this project, the condition will be referred to as *ASHFA*. Individuals with this condition experience stigma from a number of sources, perhaps most poignantly due to deviation from expected norms of mentalization often resulting in frustration, misunderstanding, and dislocation in the area of social interaction. Controversy and confusion surrounding *ASHFA* will be discussed in the following section.

There is a paucity of literature on adults with autism, especially in the low range of severity (Butler & Gillis, 2011; Bruder, Kerins, Mazarella, Sims, & Stein, 2012). It is important to shed light on the stigma experienced by adults located in the high functioning range of the autistic spectrum not simply because of any lack of research in this area, but because such research will help professionals better support and advocate for this population of professionally neglected and often isolated individuals who find themselves struggling to function in an unsympathetic neurodominant environment (Grandin & Panek, 2013). Lack of knowledge can lead to lack of services, which in turn can "lead to unrealized potential, worsened symptom expression, and multiple long-term psychosocial sequelae" (Stoddart et al., 2013, p.11). Autism is "one of the most frequently studied conditions in the field of mental health" (Matson & Kozlowski, 2011, p.418). Depending on whose statistics are cited, the condition has increased in prevalence worldwide between 50 and 2000 per cent in the past ten years (Kopetz & Lee, 2012). This dramatic escalation has been referred to as a public health crisis (Bumiller, 2008) and an epidemic (Grinker, 2007), although some writers feel the reported magnitude of the increase is controversial (Bambury, 2012; Isaksen, Diseth, Schjolberg, & Skjeldal,

2013). Still, society's knowledge about autism has not kept pace with the magnitude of the problem and service availability is typically inadequate. Andre Morin, Ontario's Ombudsman, recently started an investigation into the lack of services for adults with autism (Monsebraaten, 2012). This effort was soon expanded to embrace the dearth of support available to individuals with autism throughout Ontario. According to Kahlia Philips, also with the Ontario Ombudsman's office, the investigations were sparked by over eight hundred complaints, the numbers of which have been increasing steadily (personal communication, October 4, 2013). The Ontario Ombudsman's press release about the initiative states that "several desperate families complained their loved ones risked being sent to homeless shelters or jail because there was nowhere to care for them" (Ombudsman of Ontario, 2012). Lack of knowledge and a shortage of resources for dealing with autism is a worldwide problem that highlights the need for more work in this area (Services criticized on world autism awareness day, 2012; Williams, 2009). There have even been efforts to establish people with autism as an official minority group recognized by the United Nations in order to ensure social justice for this population (Nelson, 2013). Adults with autism have been referred to as a "new minority" that can no longer be ignored or rejected by any society that claims to hold fairness and compassion in high regard (Mandell, 2013, p.751).

The fundamental research question that guided my study is:

1. How do adults diagnosed with autism spectrum disorder experience stigma, and what strategies do they employ to manage it?

Three "second-tier" questions (Smith, Flowers, & Larkin, 2009, p.56), or more specific queries addressing related aspects of interest or conceptual issues, were

addressed through participant recruitment, data generation/analysis, and discussion. It was hoped that addressing these questions would help the study attain more utility as a document of social work knowledge because the questions were seen to bear on unresolved or contentious issues in the literature:

2. How does diagnosis impact stigma? Do the diagnostic changes in the DSM-5 that eliminate Asperger's as a distinct diagnosis and make the condition part of autism spectrum disorder have any impact on stigma?
3. Do different themes emerge about stigma for those who have been diagnosed with the now eliminated diagnosis of Asperger's and those labeled with the never formally adopted diagnosis of high functioning autism? What does this tell us about stigma and diagnosis?
4. Can the exploration of stigma and autism inform the tension between social construction and essentialism in postmodern social work discourse? By this I mean that autism seems part of my core as a person, a perception shared by many of the participants, yet this may be construed as a kind of essentialism that conflicts with central notions of social construction in postmodern social work literature. Interrogating the tension between social construction and essentialism in this study may address a broader issue in postmodern social work, which often refers to essentialism in an "overwhelmingly derogatory" manner, almost rendering essentialism into a "term of abuse" (Sayer, 1997, p.453).

Context of Study

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* was released by the American Psychiatric Association on May 22, 2013. The first major update to the manual since the DSM -IV was released in 1994, the book quickly found its way into the offices of clinicians and diagnosticians. Workshops designed to provide training on the revised diagnostic guidelines began to emerge. In the words of one enthusiastic workshop leader, the new release was considered to be "a real cash cow" (workshop leader, personal communication, May 29 2013). Yet to many critics, the

changes introduced in the diagnostic manual represent organizational shuffling “based on expert consensus” rather than scientific progress (Paris, 2013, p.187). Numerous critical attacks on the DSM-5, most notably by Allen Francis (2013), who headed the task force that developed the DSM -IV, charge that many of the revisions will lead to an increased pathologization of human conduct and character. The controversy over the changes in the DSM-5 have been called “the most intense and widespread challenge to DSM’s legitimacy in its 62-year history” (Wylie, 2014).

This study marks the occasion of these changes in the DSM by using them to help investigate the stigma experienced by autistic individuals and to explore the extent to which stigma is perpetuated by the label imposed by diagnosis. The study looks at the implications of constructing categorical subjectivities through diagnosis in a postmodern world, and seeks to learn from participants’ efforts to manage the stigma and marginalization resulting from their pathologized difference. Insight is also generated from the strategies individuals develop to socially inoculate themselves from the Otherness formalized by their diagnosis. Through this research, it was my intention to provide a voice to a marginalized population to express its needs and challenges. It has been pointed out, after all, that “those with autism are often without any voice at all” (Willey, 1999, p.13). In the course of representing the unique experiences of high functioning adults with autism, the study sheds light on how stigma and mental health nosology together create “formulas of exclusion” that oppress individuals and populations (Foucault, 1963/2003, p.7). In my discussion of the research I interrogate the relationship between modern and postmodern subjectivity, cognitive disability, autistic difference, diagnosis, stigma, and social construction.

Asperger's, autism, and DSM controversy

One of the most contested changes to the DSM-5 is the elimination of Asperger's Disorder as a distinct diagnosis (Ozonoff, 2012). Asperger's, described as a syndrome in 1944 by Hans Asperger and established as a formal diagnosis in the DSM-IV (1994), was one of five "Pervasive Developmental Disorders" listed in the section of the manual enumerating "Disorders Usually Diagnosed in Infancy, Childhood, or Adolescence" (American Psychiatric Association, 2005, p.69). One of these, Rett's Disorder, now has an established biological etiology and no longer appears in the DSM (Buxbaum & Baren-Cohen, 2013, p.1). The other four have been rolled into a multi-dimensional continuum of severity now termed "autism spectrum disorder" (terminology first suggested by Happe and Frithe in 1991).¹ Scientific debate over whether Asperger's should be considered a separate condition from autism has raged for years (for example Frith, 2004; Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995; Macintosh & Dissanayake, 2004; Miller & Ozonoff, 2000; Ozonoff, Rogers, & Pennington, 1991; Tsai & Ghaziuddin, 2014). From the perspective of this study, the most important controversy about the elimination of Asperger's in the DSM-5 is a social one. Parents are worried that their children's eligibility for funding and services will be diminished by the change. Rates of diagnosis may be affected, possibly destabilizing mainstream validation for individuals experiencing mild symptoms and disqualifying them from service. There is also concern that women coping with Asperger's, who typically display milder symptoms than men and often remain undiagnosed, will be overlooked by the medical profession in even greater numbers (Laucius, 2013). Giles (2014) explores the reaction of the online

¹ Specific diagnostic criteria for Asperger's in the DSM-IV TR and autism spectrum disorder in the DSM-5 can be found in Appendix F and G

Asperger's community to the changes in the DSM-5 and identifies responses from acceptance and reassurance to rejection, fear, and suspicion. Uncertainty about losing social supports, fears about losing self-identity, and concerns about increased stigma set off a storm of concerned discussion and internet activity about the changes introduced by DSM-5 (Annear, 2013; Green, 2013; Lutz, 2013; Rosin, 2014; Walton, 2013).

A decisive diagnostic characteristic of Asperger's was lack of language deficits. According to the DSM-IV, if an individual with Asperger-like symptoms experienced language deficits by 3 years of age they were diagnosed with autism. Even if these deficits cleared up later in life they would retain a diagnosis of autism. The DSM-IV did not address this contingency, and the term *high functioning autism* was developed out of "clinical necessity" to designate individuals with no current language impairment previously diagnosed with autism (Stoddart, personal communication, May 17, 2013). Individuals with Asperger's and high functioning autism were not distinguishable based on these designations. They joined the same support groups and shared the same phenomenology of symptoms, so the two terms created confusion. This perplexity is no longer an issue under the DSM-5 because individuals with Asperger's and high functioning autism are no longer distinguished diagnostically from each other. The problem is that individuals with this condition, who share similar challenges and face similar stigma, are no longer recognized as a distinct population at all. Individuals with Asperger's Syndrome, who sometimes refer to themselves as "Apies," have often invested significant aspects of their personal identity around belonging to an Asperger community defined by the characteristics of the condition. Individuals previously diagnosed with Asperger's and high functioning autism, which despite the changes in the

DSM-5 I will continue to recognize as a population with the term ASHFA, often contrast themselves with mainstream “neurotypical” individuals. In this project I will refer to this socially constructed “normal” population as *neurodominant* to reflect the element of social marginalization and stigma experienced by those individuals seen to exist outside of this normalizing group. ASHFA individuals also contrast their condition with degrees of autism involving more profoundly disabling elements, for example linguistic and intellectual impairments. Asperger’s has served as a personal identifier that brings automatic belonging in a strongly defined community with clearly shared and unique challenges. Since the personality characteristics associated with the condition can often result in social exclusion and marginalization, such belonging can create and reinforce a proud sense of uniqueness and affiliation. Having this unifying descriptor ripped away can be experienced as a form of medical oppression.

Kevin Stoddart, in an interview with the researcher May 17 2013, seemed confident that the DSM-5 would not require individuals with a diagnosis of Asperger’s to be re-diagnosed, but the manual clearly states that “individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified [PDD-NOS] should be given a diagnosis of autism spectrum disorder” (American Psychiatric Association, 2013, p.51). Those who do not follow this directive are knowingly or unknowingly engaged in their own small resistance to dominant discourses of medical oppression (Smith, 2011). Yet the current research indicates that doctors are continuing to diagnose Asperger’s; one of the participants was given this diagnosis in December 2013, well after the DSM-5 came into effect. Organizations such as the Asperger’s Society of Ontario have not rushed to change their

names or mandates; the Redpath Center in Toronto continues to “address the social and emotional needs of children, adolescents, and adults with Asperger Syndrome” (2014).

Some experts feel the Asperger community’s strong negative reaction to the diagnostic changes can be explained by their fear of the greater stigma attached to the diagnosis of autism (Anagnostou, 2012). This highlights the need to understand and address the toxic, Othering impact of stigma. Kite, Gullifer, and Tyson (2013) have indeed shown that autism is associated with considerably more stigma than Asperger’s, and the voices of those currently identified with high functioning autism have not been as prominent in the media as those of the Asperger community (at least in my personal experience and after extensive research). How do these individuals experience stigma, and how do they feel about the diagnostic changes in the DSM-5? The current research explores this confusing muddle of stigma and stigma management in the light of the changes in the DSM.

Individuals with Asperger’s/high functioning autism, that is in the now officially undesignated high functioning range of autism spectrum disorder, characteristically lack insight into social rules, often use language literally and pedantically, lack spontaneity and reciprocity, can be self-absorbed,² tend to be dominantly intellectual, often have difficulty maintaining appropriate gaze, and may have trouble mustering interest in what others are saying if not within a tightly delineated area of interest. Such individuals may

² Self-absorption has also been referred to as an “overwhelming sense of local cohesion” (O’Connell, 2010, p.20) that can lead ASHFA individuals to be overly focused on the linear details of insulated personal experience. This can result in an apparently misanthropic disregard for the engaged holism of lived situations. Such behaviour can be framed at least partly as a defensive strategy to manage stigma and anxiety, although it is more often articulated in terms of a perceptual impairment such as “weak central coherence,” which has been theorized to be characteristic of autism (Happé & Frithe, 2006), brain injury and schizophrenia (Martin & McDonald, 2003), and associated with personality and eating disorders (Lopez, Tchanturia, Stahl, & Treasure, 2009). These conditions all involve stigma, the role of which needs to be further researched.

engage in ritualized repetitive movements, often experience sensory over and/or under-sensitivity, experience fine motor control issues and may be clumsy, lack cognitive flexibility, have deficits in attention, executive function, and narrative ability, sometimes lack interest in routine hygiene, and most characteristically experience significant challenges initiating and sustaining relationships (Atwood, 2007; Bashe & Kirby, 2005). The condition is often associated with occupational under-achievement and social failure (Krieger, Kinebanian, Proding, & Heigl, 2012; Portway & Johnson, 2005) as well as co-morbidities such as anxiety, depression, obsessive-compulsive disorder, addiction, and emotional explosiveness. Loneliness and marginalization are frequently a factor in the lives of those with Asperger's and high functioning autism, and such individuals are often considered "perfect victims" because of their lack of social insight combined with their desire to fit in (Klin, Volkmar, & Sparrow, 2000, p.56).

This range of symptomatology combines in unique ways with diverse individuals, and the condition itself certainly pre-existed any formal diagnostic framework. Still, formal diagnosis not only brings medical validation to an existing problem but serves as a rallying point. The diagnosis resonated with the target population and resulted in a peer support movement that grew rapidly and provided a ground for mutual recognition and reinforced agency. Peer groups exist in every major city as well as on the internet. This demonstrates the constructive power of diagnosis, in this case a positive influence leading to social constructions that reduce suffering and support community building.

Eliminating Asperger's from the DSM-5 seems to put the opinion of experts ahead of those of affected individuals, and the needs of clinicians ahead of social responsibility. The "new criteria lend themselves to a more careful and tailored approach to diagnosis,

relying more on clinical judgment and allowing diagnosticians to better capture the nuances of the disorder,” maintains one clinician (Kanne, 2013). Yet uncritical acceptance of the changes in the DSM-5 on the part of social workers has been called “an abandonment of core principles” that violates ethical responsibility and ignores potential harm to vulnerable populations (Carney, 2014). My research is concerned with the impact of eliminating Asperger’s on those whose lives are touched by the condition, a change that amounts to the withdrawal of official recognition for an identifiable population with characteristic challenges. In this study I explore these characteristic challenges, the phenomenology of stigma associated with them, and what they can tell us about ourselves.

Wendell (1996) describes how the “authority of scientific medicine to describe our bodies contributes to our alienation from our bodies and our bodily experiences” (p.119). She talks about how the body is “idealized and objectified” (p.85). Her poignant insights apply equally to the mind, and so does the model of social disability she advocates. Not only is stigma socially constructed, but “culture [itself] makes major contributions to disability” (p.42). Imagining individuals with Asperger’s as potential mass murderers due to their antisocial nature based on isolated incidents is just one example of this (Shah, 2013). While not focused directly on such cultural factors, I hope my research has contributed to what Wendell calls the “social deconstruction of disability” by learning more about the experience of stigma and how dominant medical discourses contribute to it (Wendell, p.45).

Front line workers can hardly avoid being exposed knowingly or unknowingly to autism and its associated social problems. The current study serves a double purpose,

not only exploring the experience of stigma in Asperger's and high functioning autism, but clearing up some of the confusion research has shown professionals often experience in this area (Preece & Jordan, 2007).

Subject Location and Onto-Epistemological Orientation

It is important to further set the stage of this study by making my subject location explicit. Heron (2005) points out that this will involve more than simply announcing the details of my social location, for example my privileged entrenchment in White society, my married hetero-normativity, my status as an MSW candidate, my comfortable socio-economic status as a suburban homeowner, and my position as hospital crisis worker/brief therapist for adults sixteen and older. The "citing of privilege by those in dominance," Heron says, can amount to "a reinscription of marginalization" for the oppressed and disadvantaged (p.344). More relevant to the currently proposed research is that I was diagnosed with Asperger's Syndrome at the age of 44 and that I was raised by an impoverished single mother diagnosed with borderline personality disorder. I am no stranger to the stigma attached to diagnosis. I have personal experience with the way diagnosis constructs subjectivity, and have strong feelings about the changes in the DSM-5. I realize that not everyone with a diagnosis of autism has my level of privilege, but I still identify myself as an insider to the stigma and marginalization associated with the condition.

Ten years ago I submitted an article for publication in the *Journal of Autism and Developmental Disorders*. It masqueraded as an academic article about the concept of

dramaturgy, but it was really a testimonial written shortly after I was diagnosed with Asperger's. It examined Goffman's (1963) insights about impression management and stigma control. I was talking about myself in the article, but it was not exactly an example of "reducing stigma by coming out proud" (Corrigan, 2013). I hid my disclosures behind a front of intellectual neutrality. The reviewers agreed the article was well-written, but it was rejected for publication. They had no way of knowing it was auto-biographical. One reviewer said the paper would have been original if it had described the stigma of Asperger's "from a postmodern perspective," and added that the insights in the article "could lead to a clear proposal for a research agenda." This finally emerged in the form of my current thesis thanks to the University of Victoria. Much has changed, but the lack of literature framing autism in a postmodern context has not.

When my then-new wife said she noticed a similarity between some videos about autism she watched at school and my history of behavior, I was incredulous. I thought "how dare she!" Still, I did some investigation online and had to agree with her. I felt increasingly devastated as I identified with more and more autistic traits. The stigma threatened to overwhelm me; I was almost panic-stricken. It was only when I found out about Asperger's that I allowed myself to cry with the profound consummation of finally realizing *there had always been a reason I was not like everyone else*. Asperger's explained my symptoms without me having to assume the frightening mantle of autism. It was such a relief. I did not have insight into the lateral marginalization I was guilty of as I viscerally positioned myself away from autism. I was intelligent; I was articulate; I could function in society (more or less). I couldn't be autistic!

It took me a while to admit I was upset about having to accept a diagnosis of autism. But why? What's in a word? Stigma. It may be true that stigma only has the power we give it, but it's hard to resist the power of collective, historical, media-entrenched stigmatization. Yet it has to be managed somehow, and my research in this project is designed to shed light on stigma as a marginalizing social construction.

My first reaction to the changes in the DSM-5 was anger. I told myself it was medical oppression. I told myself all the valid, critical things I discuss elsewhere in this paper. Ironically, when I looked closely at the new diagnostic criteria for autism spectrum disorder, I discovered that all my work over the years to find a comfortable place in society has rendered me sub-clinical. Not only is there no more diagnosis of Asperger's, I don't currently rate the lowest specifier of impairment for autism spectrum disorder. I no longer need "minimal support" to "function normally." As such, I feel my diagnosis has been taken away completely. What about all those years of struggle? Where was the medical community then? Where do I stand now? I can't help feeling sad, like my moniker of official recognition for difference has been stripped away. More than that; an integral part of my self-identity feels threatened. I am not alone in my confusion. A recent participant on Wrongplanet, an autism website hosting a long standing discussion group on Asperger's and high functioning autism, asks "does this mean only autistic people who 'require support' can be diagnosed as ASD under the DSM 5?" (Questionhanger, 2014). Others point to confusion about what qualifies as support by commenting that "even though I managed to maintain a specific career for 30 years and live on my own, without the support provided by unemployment insurance and the occasional bailout from my parents, I couldn't have made it alone" (Timebuddy, 2014).

Another notes “if my wife was no longer helping me deal with life, I don't think I would cope well at all” (Superhero, 2014). This last presents a diagnostic dilemma; although the man’s wife provides the support he needs because of his condition, from a DSM 5 perspective the very fact he is able to have a wife at all could be seen to disqualify him from diagnosis on the basis of criteria 3 involving “deficits in developing, maintaining, and understanding relationships” (American Psychiatric Association, 2013, p.50).

Another discussion group participant expresses confusion by commenting that “it's almost as if you can ‘go in and out’ of the diagnosis, based upon your ability to cope at a particular moment in time” (Spacetraveller, 2014). Yet ASHFA can be perceived as more than a diagnostic label; one forum participant points out “it’s who you are” (Hanginthere, 2010). ASHFA is a condition that goes beyond meeting arbitrary requirements for the diagnosis of pathology. It is associated with characteristic challenges functioning in a neurodominant culture, and the stigma associated with the condition happens with or without a diagnosis. All of this comes into play in the findings and will be addressed speculatively in the conclusion of the study. The one thing I am certain of is that I am compelled to do this research for more than academic reasons. I am trying to understand myself and my own situation as well as that of others who share similar challenges.

A thorough statement of subject location must involve an explicit acknowledgement of onto-epistemological orientation. There can little room for “disguised ideologies” in social research (Harrist & Richardson, 2012, p.39). In this regard, most of my life I was firmly steeped in modernist ideals of scientific materialism, rational positivism, and autonomous individualism. These qualities are not only associated with modernist

subjectivity (Bell, 2012; Parton, 2003), but also seem to come naturally to me as an individual with ASFHA. This is not just my own isolated experience; research shows that individuals with this condition tend to be rule based, particularly in social situations (Channon, Crawford, Orłowska, Parikh, & Thoma, 2014). In my tendency to intellectualize, the modernist preoccupation with rules, standards, explicit frameworks, and concrete evidence has a natural baseline affinity for me. In my tendency towards social isolation, the modernist ideal of remaining a neutral observer feels safe. McDonagh (2007) points out that autism was not recognized as a disorder until the modern period, and that autism is an “extreme expression of themes that permeate contemporary society and culture” (p.114). The implications of this observation are fascinating. McDonagh invites speculation when he asks whether autism existed before the modernist paradigm preconditioned the construction of autism as we know it. It would be interesting to explore how individuals in different time periods approached performing autism in unique ways (Glastonbury, 1997; Nadesan, 2005). This exploration would provide little comfort, however, to individuals struggling to cope with what we now call autistic characteristics who were experiencing their time period’s unique forms of stigma, perhaps languishing in poorhouses or locked in asylums. Or is autism a kind of mutation activated by the conditions of our epoch? Some think autism is related to physical toxins associated with increasing pollution and diets heavy in processed foods (Goldberg, 2011).

Notwithstanding the complex intertwining between them, I acknowledge the ways in which both autism and modernism construct me. However, I take these tendencies as possibilities for subversive interrogation and reconstruction. As a social worker, I hope my efforts to challenge the familiar harbor of isolated individualism, rule-based thinking,

and the valorization of concrete positivistic formulations can be helpful to others (with or without autism) who may be struggling with the paradigm shift from modernity to postmodernity. I have found postmodernism's fluid, interpretive orientation towards others and the world not only a fertile ground for my emancipative project, but also a stigma-reducing paradigm capable of healing rigid separation and alienation. If this seems overly intellectual, some of the participants in this study pointed out that a *natural food diet* and *resisting corporatism* can also build stigma resistance, as well as more robust health for both autistic individuals and neurodominants.

Autism has been called "a pilot project for humanity" (Bogdashina, 2010, p.10). To me, this means the condition need not be viewed merely as a cognitive impairment to be tolerated, but a *cognitive difference* to be respected and explored. It conveys the sense in which the investigation of how individuals with this condition cope with its challenges, manage the associated stigma, and move forward against society's resistance to their difference can inform us poignantly of ourselves in the context of our historical epoch. It is hoped the current research can do justice to the crucial task of building emancipative knowledge that will help liberate us from the bondage of dominant expectations and intolerance for difference. It has been pointed out that focusing too narrowly on difference is to reinforce normalcy, or "that from which one is different" (S. Strega, personal communication, Friday May 2, 2014). This is a valid point. To medicalize difference into pathology further reinforces normalcy (for example, homosexuality was not fully removed from the manual of disorders until the DSM-III R in 1987). These ideas will be thoroughly explored in the coming pages. By acknowledging and exploring difference in this project, however, my intention is not to further entrench the dominant

yardstick of normalcy. It is, rather, to honour and scrutinize a certain dimension of diversity, specifically as it relates to ASHFA individuals whose autistic challenges are related primarily to stigma and interfacing with neurodominant culture.

Philosophy, oppression, and liberation

As an undergraduate years ago, I began to challenge the assumptions of modernism when I became aware of alternatives to the dominant paradigm in philosophies like phenomenology and hermeneutics. These schools of thought place embodied human experience before rational systems, engaged interpretation before the neutral pursuit of “objective” truth, and relationality before the preservation of isolated autonomy. What I came to understand as postmodern, poststructural, counter-traditional, or “post-conventional philosophies” (Bell, 2012) held a certain revolutionary fascination for me.³ It was not until I studied social work years later that I began to associate modernist values with colonial systems of oppression, the neoliberal valorization of rugged individualism, the greedy marginalization of equitable social welfare policy, and the reduction of human service to managerial outcome measures. My philosophical assumptions about life, knowledge, and subjectivity remain steeped in still dominant modernist assumptions, even as I strive to position myself within a paradigm of postmodernism. In a spirit of postmodernism I strive to see knowledge as a matter of interpretation and social construction, where truth is seen as a “fluid, multiple, precariously negotiated achievement in interaction” (Parton, 2003, p.5). In relation to this, I see subjectivity to

³ The terms “postmodern” and “poststructural” are often used to describe those philosophies that reject the dominant, totalizing, positivistic, and dualistic paradigm of modernism. The terms are often used interchangeably and not defined precisely, although poststructuralism has been used to refer specifically to linguistic theory (Agger, 1991). Following a social work text I used as an undergraduate (Turner, 1999), I prefer the broader philosophical term postmodernism.

be largely constructed by our interpretations of experience as well as the discourses of knowledge within which we have been acculturated. This makes the “self,” in a spirit of postmodernism, “unavoidably multiple and contradictory” (Heron, 2005, p.347). Along these lines, I see human subjectivity as open to reflective reconstruction rather than something settled and established. I constantly remind myself that I must not simply come to rest in the knowledge of what factors construct my subjectivity, as if they formed some kind of justification of “the way I am.” Self-knowledge is critical in order to identify the unavoidable personal biases through which we involve ourselves in ongoing encounters and projects. It is also important, however, not only to “discover what we are, but to refuse what we are” with subversive non-conformity with those features of our experience that undermine social justice, lead to oppression, and place ourselves and others in various forms of constraint and jeopardy (Foucault, 1982/1994, p.336).

I may betray a certain essentialism in my discussion of autism. I do not, however, mean to propose a Platonic universalism, a Lockean substratum underlying external properties, a Romantic ideal self inescapably corrupted by nature, or an unmitigated naturalism in which the authentic “self” is a given, pre-constructed entity. I am simply hesitant about abandoning efforts to grow more congruent with the evasive “authentic self” I can’t help feeling at the integrative core of my continually “constructed self.” I find that this authenticity, whatever it may be, is not only created or invented as I move through life, I also feel myself more fully discovering it as I get older. This may be an illusion, but it manifests itself in a grounded sense of comfort in my own skin, a growing ability not to internalize stigma, and the realization of my potential both personally and professionally. This dimension of my subject position may not be compatible with the

work of writers like Mansfield (2000), who tells us that "there is no authentic self" (p.63) and that "subjectivity has become a mode of social organization and administration" (p.64); or Weedon (1987), a pioneer in the tradition of poststructuralist feminism who seems to reduce subjectivity to the "effect of an ideology" (p.30); or Davies (2000), who maintains that "agency is fundamentally illusory" (p.60); or Butler, who states that

where there is an "I" who utters or speaks and thereby produces an effect in discourse, there is first a discourse which precedes and enables that "I" and forms in language the constraining trajectory of its will...there is no "I" who stands behind discourse and executes its volition or will through discourse. (1999, p.18)

I don't see a problem with holding powerful insights about social construction and intuitions about the authentic self in non-adversarial tension. I don't see it as more or less reasonable than answering the old "nature/nurture" debate with a higher synthesis that embraces the role of both. Even Foucault, always on the look-out for the "twin dangers of naturalism and essentialism" in order to prevent concretizations of power from becoming naturalized (Whitebook, 2002, p.69), acknowledges the dual sense in which the self is not only "formulated" and "produced" - but also "obeyed" (Foucault, 1980/1993, p.204). Further arguments in defense of an authentic self could be gleaned from Merleau-Ponty in terms of articulating the existence of an embodied self that provides a unifying perspective of the world while it constantly evolves in relationship with the world, and

Charles Taylor who eloquently puts into words how what I tentatively call my authentic self has something to do with the “the space of moral and spiritual orientation within which my most important defining relations are lived out” (1989, p.35). I agree with writers like Bagatell (2007) who despite acknowledging the importance of discourse for social construction and subject formation can’t help feeling that “personal agency plays an important role in the construction of identities” (p.414). This is highly contentious in critical social work debate, but it is part of my emerging onto-epistemological orientation and may be unavoidably reflected in this study.⁴

Chapter Outline

In this introductory chapter I have discussed ASHFA as a phenomenological condition, described how stigma is under-researched, and examined the controversy around the diagnostic changes in the DSM-5 and how these changes may be related to stigma. One principle and three subsidiary research questions were stated that will guide the research. The next chapter, the literature review, looks at current and past research around Asperger’s/high functioning autism, in particular as it relates to stigma, and further notes how the current research fills a gap in knowledge around this issue. A relational methodology (Barton, 2004; Kivinen & Piironen, 2013; Tregaskis & Goodley,

⁴ My rather vague bias towards some kind of essentialism may be committing myself to a philosophical position resembling critical realism. Critical realism is not necessarily inconsistent with postmodernism and constructionism, although it can be seen as a way to avoid the nihilism often thought to be ultimately implied by these positions (Wasserman, 2004). A thorough exploration of these philosophical issues is beyond the scope of this paper, but an excellent discussion of critical realism and postmodernism can be found in Lopez & Potter (2001). Oliver (2012) discusses how critical realism and grounded theory are compatible in terms of research methodology. Vermurlen (2013) creates an interesting onto-epistemological matrix of approaches that inspires a lively online discussion of postmodernism and critical realism in a theological context.

2005) will be developed in the following chapter based on the hermeneutical phenomenology of Hans Georg Gadamer and Maurice Merleau-Ponty. This methodology was designed not only to provide a framework for the research itself but to guide me as the researcher, the organizing participant with my own diagnosis of ASHFA, in the qualitative, relational, and emancipative aspects of the research process. My onto-epistemological position will be discussed at length, ethical considerations will be examined, and the research process will be described in detail. The results will be described and discussed in the penultimate chapter, including opinions about how stigma will be affected by the changes in the DSM-5, an exploration of the phenomenology of stigma, and how stigma is managed. A new term will be coined, *frustigma*, that attempts to capture participants' perceptions of frustration with their inability to fit in, neurodominant frustration with ASHFA, and how these are often indistinguishable from the unpleasant and marginalizing impact of stigma and discrimination. Stigma resilience as well as stigma cloaking strategies including invisibility, helping, extraversion, and substance abuse will be discussed. The concluding chapter will build on theory as it emerges out of the research as well as explore implications for practice, policy, and further research. A central inconsistency in the results will be identified, and an alternative to over-dependence on medical diagnosis will be offered in an attempt to resolve the tension between diagnosis as a helpful validating discourse and the disempowering effects of medicalization.

Chapter 2: Literature Review

The classic and paradigmatic work on stigma is Erving Goffman's *Stigma: Notes on the Management of Spoiled Identity* (1963). Written more than fifty years ago and not having the benefit of all the research and critical thinking his work pioneered, the book remains an insightful and comprehensive phenomenological exploration of stigma. Goffman's writing can seem a bit dated; for example he sometimes employs sexist language that would be unacceptable today. A more serious critical issue is how he establishes a fundamental duality between "we normals" and "discounted" individuals (p.5), thereby essentializing these social polarities and reinforcing the separation of "normal" and "deviant." His use of words like "spoiled" and "tainted" reinforce the stigma overlaid onto difference by society. More of a socio-phenomenological investigation than a research study, his work is nonetheless peppered with first person accounts that make it a rich and important social document. He points to the important role of discourse in perpetuating prejudice, the recognition of which would have us celebrate the overdue removal of the term "retardation" from the DSM-5 and which continues to be a well-researched theme in the field of critical disability (Reaume, 2002; Shapiro, Margolis, & Anderson, 1990). His concept of social dramaturgy, originally explored as a dynamic in the workplace (1956), can be seen as a mechanism through which people generally, and with more urgency in the case of stigmatized individuals, manage self-presentation in order to be accepted and fit in. His description of "passing" and "covering" are insightful phenomenological descriptions of poignant and commonly experienced social strategies that many of the stigmatized individuals participating in this

study employ daily to survive. Goffman examines how stigma can make individuals “suspicious, depressed, hostile, anxious, and bewildered” (1963, p.13). His discussions of visibility, obtrusiveness, ambivalence, back places, the non-person role, and information control appear as themes in the current research. Still, Goffman does not specifically address how stigma impacts individuals with autism and he does not consider the process of diagnosis. The current study shows, however, that Goffman’s work is relevant in the area of stigma as it is experienced by high functioning individuals diagnosed with autism. An interesting discussion about the degree to which Goffman’s thought is compatible with postmodernism can be found in Schwalbe (1993).

Today there are whole journals devoted exclusively to autism research, and the endeavor to understand autism is a multi-disciplinary effort involving not only social work but psychiatry, psychology, sociology, nursing, occupational health, and disability studies. There is writing and research that studies the relationship between autism and related conditions such as intellectual disability (Matson & Shoemaker, 2009) as well as learning disability (O’Brien & Pearson, 2004), and dyslexia (Riddich, 2000). There is copious research into mental health co-morbidities (Mosely, Tong, Brereton, & Einfield, 2011), in particular anxiety (Kerns & Kendall, 2012), depression (Stewart, Bernard, Pearson, Hasan, & O’Brien, 2006), OCD (Russel et al., 2013), and Disruptive Behaviour Disorders (Storch et al. 2012). There is a great deal of current research that explores the experience of autism in specific social contexts, such as college populations (White, Ollendick, & Bray, 2011), criminality (Gunasekaran & Chaplin, 2012), playground interaction (Frankel, Gorospe, Chang, & Sugar, 2011), and intimate relationships (Aston, 2003; Stanford, 2003). There is research examining various social correlates of autism,

for example spirituality (Dubin & Graetz, 2009; Ehrlich Ben-Or et al., 2013), friendship (Calder, Hill, & Pellicano, 2013), reciprocity (Leach & LaRcoque, 2011), humour (Lyons & Fitzgerald, 2004), and creativity (Chilvers, 2007; Fitzgerald, 2004). There is research that explores various psychometric correlates, such as social competence (Minne & Simrud-Clikeman, 2012), decision-making (Luke, Clare, Ring, Redley, & Watson, 2012), central coherence (Aljunied & Frederickson, 2011), and field-independence (Koh & Milne, 2011). There are studies that examine family relationships (Burke, 2010) as well as the intersection of family experiences with autism and ethnic difference (Carr & Lord, 2013). There is research on service needs (Stoddart et al., 2013; Bruder et al., 2012), treatments (Gurkan & Hagarman, 2012; Paxton & Eskay, 2007), and alternative treatments (Hall & Riccio, 2012). Attachment and neurobiological aspects of autism are intensely researched (Barendse et al., 2013; Shore, 2003). All of this research can be of interest to social workers and is often been carried out by social workers whose vocation may be associated with other disciplines. Yet even with all this interest in autism, the stigma experienced by individuals with developmentally mind-involved social impairments has been neglected in the literature (Ditchman et al., 2013). It has been pointed out specifically that “research is needed to explain how stigma plays out in the lives of [these] individuals” (p.207).

Research into stigma is much more plentiful in the area of psychiatric mental illness than in the area of cognitive impairment (Ditchman, et al., 2013). The authors state that the field of mental disabilities “lacks a systematic conceptualization of stigma” (p.207), and suggest that theories of stigma developed in the mental health field based on “psychological paradigms as well as macro-level causes and mediators” be applied to

intellectual and developmental disability in order to facilitate stigma change efforts.

Writing and research done on stigma and self-stigma in mental health includes Corrigan (2007), Feldman and Crandall (2007), Thoits (2011), Elkington et al., (2012), Michaels and Corrigan (2013), Oleniuk, Duncan, and Tempier (2013), and Vogel, Bitman, Hammer, and Wade (2013). Most notably for me, Schmidt (2007) wrote his Master's thesis at the University of Victoria on stigma and borderline personality disorder (BPD). He conducted a qualitative study in which he interviewed six women with BPD about their experiences with stigma and interrogated the data using Critical Feminist Analysis. He found such intense stigmatization and discrimination experienced by the participants from both professionals and the community that he recommended "outright elimination of this diagnostic category" (p.84). A less radical proposal presented in the study was to modify the diagnostic criteria, although this was seen as not going far enough to address the problem. Interestingly, proposals were made to modify the diagnostic criteria for borderline personality disorder in the DSM-5 in order to "diminish problems with underutilization, oversight, and stigma" (Gunderson, 2010). Consistent with Goffman's recognition of the power of language to generate stigma, there have also been proposals to rename borderline personality disorder so the name of the illness doesn't stigmatize people with "a label that is seen as synonymous with [being] untreatable and socially undesirable" (Bernstein, Iscan, & Maser, 2007, p.538). The issue of renaming this disorder has been an active topic of peer discussion on the internet (Haven, 2011; Salthers-Pedneault, 2009). In a poignant example of how dominant discourses do not change without evidence that takes marginalized voices into account, the DSM-5 made no modifications in this stigma-related area.

There is a possible source of confusion for those uninitiated in DSM complexities between intellectual disability and autism spectrum disorder. They are closely related, but they are not the same. Intellectual disability can co-occur with autism and involves “deficits in intellectual functions such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience” that can be identified largely by low scores on intelligence tests (American Psychiatric Association, 2013, p.33). In statistical terms, 70% of autistic individuals also have intellectual disability, whereas 10% of individuals with intellectual disability also demonstrate autistic symptoms (Schwartz & Neri, 2012). Intellectual disability does not appear in Asperger’s or high functioning autism by virtue of the fact that intelligence by definition is not impaired in individuals diagnosed with this condition (the 30% of autistic individuals without intellectual disability). However, the relationship is more complex because developmental disability and intellectual disability can both involve social, communicative, and behavioral challenges. Moreover, some of the cognitive features of intellectual disability (for example problems with abstract thinking, judgment, and executive functioning) can also be present in AS and HFA. In the DSM-5, intellectual disability and autism spectrum disorder, along with social communication disorder, are classified as distinct disorders in the neurodevelopmental category.⁵

Social communication disorder is a new category in the DSM 5 that roughly corresponds with pervasive developmental disorder not otherwise specified (which was eliminated from the DSM IV). It covers atypical cases in which difficulties understanding

⁵ Neurocognitive disorders, on the other hand, refer to acquired rather than developmental conditions including dementia and delirium.

social rules and nonliteral forms of speech, as well as the characteristic use of overly formal language, can be seen in the absence of the “restricted/repetitive patterns of behaviour, interests, or activities” also characteristic of autism spectrum disorder (American Psychiatric Association, 2014, p.49). The DSM IV would have also noted a lack of difficulty in social interaction, but this third criteria was dropped from the DMS 5 and would not have made sense for differential diagnosis because the DSM 5 notes that individuals with social communication disorder do experience “social deficits” as a result of their differences in communicative style. Presumably individuals diagnosed with social communication disorder would experience the same forms of stigma, but no individuals with this diagnosis were included in this study. Future studies may want to broaden the sample of participants to look at the stigma associated with these conditions, the DSM nosology of which is artificially categorical belying the complex interrelationships between them. What I have come to call ASHFA may be less categorical in membership and focus more on the similar stigma experienced by individuals in relation to neurodominants.

I have elected to include a recent study primarily involving intellectual disability in this literature review (Paterson, McKenzie, & Lindsay, 2012). The study came out of the University of Edinburgh and examines stigma, social comparison, and self-esteem in individuals with intellectual disability. The authors conducted a quantitative study, which is still the dominant form of research in the field. They based their data collection on self-report scores obtained with psychometric tests modified for individuals with cognitive impairment. Their sample of 45 participants was drawn from a service organization in Scotland, and 23.8% were noted to have a “genetic disability” of which Down’s

syndrome was named as an example. The sample may or may not have included individuals with autism. The researchers found, logically, that a “greater perception of stigma was related to lower self-esteem,” and that the participants were “more likely to perceive stigma if they feel bad about themselves or vice versa” (p.172). They also found that the degree to which participants harshly compared themselves relative to others was correlated with lower levels of self-esteem. Regarding diagnosis, their discussion of the results led the researchers to conclude that “some individuals may attempt to distance themselves from the label of intellectual disability” (p.174). These results appear to do little more than confirm intuitive assumptions about the negative impact of stigma, but they provide a starting point for further research. It may be that the quantitative methods employed by the researchers led them to superficial results; results which demonstrate nowhere near the phenomenological depth of Goffman’s pioneering work and none of the compassionate insight of Schmidt’s 2007 Master’s Thesis.

Kite et al. (2013) conducted survey-type primarily quantitative research on health and education professionals’ perceptions about the stigma associated with Asperger’s and autism, as well as opinions about the (then upcoming) changes to the DSM-5. The research had a qualitative aspect to it in that the survey included sections inviting answers in the form of free text which were coded manually. The researchers distributed an unspecified number of questionnaires to various professionals and received 547 completed surveys back. Half the participants did not support the changes in the DSM-5 involving the elimination of Asperger’s and merging the condition with autism spectrum disorder. Less than a quarter of participants supported the change (22%) and the rest were uncertain (28%). Their most important finding, however, confirmed “the

assumption that autism is viewed more negatively than the condition of Asperger's Disorder" (p.1699). The same authors had completed an earlier qualitative study (Kite, Tyson, & Gullifer, 2011) involving 51 participants comprised of health and education professionals, community members, and parents of children diagnosed with Asperger's. This study also found that autism is associated with higher levels of stigma than Asperger's (parents reported being relieved when children were diagnosed with Asperger's rather than autism), but also revealed some interesting themes. For example, the key theme in discussions about Asperger children did not involve any of the diagnostic criteria such as lack of social reciprocity, stereotyped movements, or intense obsessive interests, but revolved around challenging behaviours. Frustration with service provision and lack of resources also emerged, as well as confusion about etiology (whether Asperger's is caused by genetics, birth trauma, environmental toxins, or parenting styles). The authors stated that this qualitative research was a preliminary study to help design the questions for the larger quantitative study discussed above. It seems to me, however, that the results of this earlier qualitative study are more richly insightful, revealing, and give the people closely affected by the condition (but not the individuals themselves) more of a voice.

Quantitative measures may be appropriate in some instances, such as surveying opinions or establishing correlations and other statistical relationships. Stigmatization, however, is much more than a social correlate to be operationalized and measured. It is a complex, bodily felt mechanism of oppression and marginalization that has a profound impact on individuals as well as society. To understand this impact, it is necessary to explore the experience rather than reducing it to an operationalized variable to be

instrumentally scrutinized. Qualitative and quantitative approaches can augment and help explain each other. It is not that one is “stronger, weaker, softer, or more sterile than the other,” it is rather that the two approaches are powerful in their own way (O’Day & Killeen, 2002, p.15). Quantitative methods are appropriate for testing and confirming, qualitative methods for understanding and exploring meaning. Each probes the unknown with a different emphasis and both are necessary to construct a balanced knowledge of our world.

Another quantitative study, designed to look at the perception of individuals in the community but not those diagnosed with the condition, revolved around diagnosis, Asperger’s, and stigma (Butler & Gillis, 2011). The study involved 145 psychology students reading vignettes and then completing psychometric measures of social distance. The study found that “the label of Asperger’s syndrome did not significantly impact stigmatization” (p.745). The authors were surprised by this finding because they felt it contradicted “the limited research available that suggests that individuals with AD [Asperger’s Disorder] are stigmatized” (p.744). Butler and Gillis also found that social behaviours were positively correlated with stigma rather than diagnostic labels.

The Butler and Gillis study cites Shtayermman’s (2009) research, which was also quantitative and conducted with questionnaires as well as psychological tests. In a finding not as contrary to their own as Butler and Gillis may have believed, Shtayermman’s study demonstrated clearly and with statistical significance that stigma is experienced by individuals diagnosed with Asperger’s. The study went on to correlate levels of stigma with various other factors. Shtayermman, like Butler and Gillis, was surprised by his results. He found negative correlations between the severity of symptomatology and age,

stigma, victimization, and suicidal ideation. Statistically, he noted that due to the small sample size “apparently meaningful results were not [always] statistically significant” (p.308). Still, he attempted to explain his results by theorizing that teachers are less protective of individuals with less extreme symptoms, leading to higher levels of victimization in high functioning individuals. He also concluded that individuals who experience low symptomatology may experience stigma due to the diagnosis itself rather than their symptomatology. However, this theory contradicts the results of Butler and Gillis who found the label of Asperger’s was not correlated with stigma. Shtayermman may have gleaned a better explanation for his results by asking the participants for their perspectives rather than relying on test scores alone. In the conclusion section we will discuss how the participants in my study generated results that make coherent sense of these seemingly inconsistent findings.

Rosqvist (2012) conducted a qualitative ethnographic study on the impact of diagnosis in a Swedish high school for adults diagnosed with Asperger’s. The researcher, not specifically targeting the experience of stigma, interacted with and observed a group of ten students in a class at the school two days a week for three months. The participants ranged in age from 20 to 50 (seven women and three men, unusual given the preponderance of males who receive the diagnosis). The group also included two female teaching assistants with Asperger’s and two female teachers without Asperger’s. The researcher herself did not have Asperger’s and had not been extensively exposed to the condition before the study. She reported that she had to “learn how to behave in order to fit in,” and said she was treated “in a friendly way” (p.121). She also held voluntary group interviews to discuss her field notes to give the participants a chance to have input

and make corrections. Her data was processed using Critical Discursive Psychological Analysis (Parker, 2002). The participants talked about diagnosis as “a milestone on the path to self-understanding” that became an identifier connecting them with a group to which they could feel belonging (p.122). They also discussed the confusion of “coming out,” emphasizing the importance of openness about the diagnosis as an ideal promoting peace of mind and community education. However, they also raised questions about when or with whom such openness may be appropriate and, in terms relevant to the experience of stigma, acknowledged that “not coming out as a person with an invisible disability affords the individual the opportunity to benefit from those privileges that belong to people with no disability” (p.126). The researcher called this the “ambivalent ideal of openness,” on which further research may help facilitate “the autistic political production of a counter hegemonic discourse of autistic normalcy” (p.127).

The study also touched on a controversial theme. Some participants said they experienced their Asperger’s as a “personality trait” rather than a “disability” (p.125), which the authors point out is consistent with a social model of disability and reflects the distinction between “essentialist” and “constructivist” notions of disability (Baker, 2006, p.175). Other participants were critical of this view, feeling that the impairment should be acknowledged for the developmental disability that it is. In this regard, Baron-Cohen’s (2013) suggestion that the term “autism spectrum disorder” be replaced with “autism spectrum condition” may be an effective compromise. A full and interesting discussion about the medicalization of Asperger Syndrome and whether it should be considered a difference rather than a pathology can be found in Allread (2009). Milton (2012) points out that “differences in neurology may well produce differences in sociality, but not a

‘social deficit’ as compared with an idealized normative view of social reality” (p.886).

This insightful distinction may have valid implications as social theory, but it can be hard for stigmatized individuals who have found themselves repeatedly frustrated, left behind, and unable to fully participate in society to see their biological difference as anything but an impairment. Perhaps the most important thing here is not the effort to determine whether this or that quality is an impairment in itself, as if this were an objectively decidable issue, but to be mindful about whether society, and most importantly we ourselves, will reinforce this impairing impact or direct our efforts into supporting differently abled, differently equipped, differently appearing, and/or differently communicating individuals to move forward in their uniqueness. This issue will be further addressed in relation to the discussion of results below.

The participants in the Rosqvist study contrasted professional outsider knowledge with the insider knowledge of those who actually have the diagnosis. This emphasizes that our understanding of autism has to be negotiated using multiple discourses, as Brownlow concluded in her research investigating online constructions of Asperger’s and neurodominance (2010). Clarke and van Amerom (2007) conducted another study exploring this issue at Wilfred Laurier University in Windsor. Analyzing internet blogs written by individuals with Asperger Syndrome, they found that AS individuals “expressed resistance to the AS organizations, to medicalization, and to what they felt was the public stigma associated with AS.” They further found that the AS Bloggers “spoke of celebrating their differences and of anger at neurotypicals for stigmatizing them” (p.771). In the Rosqvist study, one participant in particular expressed suspicion regarding researchers who are supposed to be “experts” but lack insider understanding of

Asperger's because they don't have the diagnosis themselves. In this regard, my study can be considered true insider research (Heugten, 2004) because I myself have the diagnosis. I believe this positioned me uniquely to relate to the participants and appreciate their experiences and the issues involved. Tregaskis and Goodley refer to this as taking advantage of "ontological research resources" (2005, p.368). As it turned out, I did not disclose my diagnosis to participants because of my own fear of stigma (not from the participants, but from repercussions in the community resulting from the disclosure). This personal research decision to engage in undisclosed insider research will be further discussed in the ethics section. However, my lack of disclosure did not remove me from the genuine insider understanding participants in the Rosqvist study found wanting.

Other studies focus on the stigma experienced by the parents of children with autism. Russell and Norwich (2012) conducted phenomenological interviews with 17 parents in two groups, one in which the parents were actively seeking a diagnosis and one in which their child was already diagnosed. Their research thoroughly explored the complex balance between what makes parents want to have their child remain undiagnosed (such as stigma) and what makes parents seek diagnosis (access to resources, treatment, and resolution, etc.). They also talked about how parents, after the diagnosis is received, first "set about reconstructing their own ideas about ASD to cast it in a more positive light" (p.238), and then move towards "actively destigmatizing ASD" in the community (p.241). Watt and Wagner (2013) employed a questionnaire methodology and found that "parents raising a child with AS self-report greater parental stress, more mental health symptomatology, lower overall job satisfaction/ contentment and less satisfaction with supervisors" (p.34). In addition, they found that the parents of

children with ASD were less likely to work full time. Gill and Liamputtong (2011) conducted a qualitative study with 15 mothers of children with Asperger's employing solicited diaries for data generation and a feminist methodological framework. They found mothers tended to bear the brunt of the stigma in the community associated with their child's condition, often felt blamed for their child's frustrating behaviours, worried about burdening their friends with their struggles, and that their physical health frequently suffered due to their stress. They also found that once their child was diagnosed it brought "a great sense of relief as it validated their concerns about their children" (p.54).

More in line with my research, Punshon, Skirrow, and Murphy (2009) did a qualitative phenomenological study to investigate the experiences of individuals who were diagnosed with Asperger's Syndrome as adults. The authors interviewed ten participants recruited from a service provider in Liverpool, England. The data was analyzed using Interpretive Phenomenological Analysis (Smith et al., 2009). When the research was conducted four years ago, the authors described Asperger's as a "relatively new diagnostic classification" (p.267). It is ironic that just a few years later this "new" diagnosis does not exist anymore; still, the results should be transferable to the low impairment (or high functioning) range of autism spectrum disorder. Punshon et al. employed focus groups to generate a series of open ended, semi-structured interview questions that would allow the participants to "lead the way whilst the interviewer could carefully ask questions that were grounded in the participants' discourse" (p.269). Many of the participants reported they had felt "different" all their lives, and found Asperger's provided a welcomed framework for understand that difference (p.275). They described

attempts to “act normal” in order to minimize the perception that they were different, and said being diagnosed was like a “not guilty” verdict because it meant their difference was fundamental and not like an uncaring choice to keep being offensive (p.277). Other participants reported feeling depressed because it meant there would be “no cure” for their social impairment. Diagnosis was found to be a complex amalgam of positive and negative aspects, and perceptions about society’s reaction to diagnosis were equally mixed. One individual, for example, found his father to be “stand-offish” after his diagnosis (p.279). This study, while noting such confusion and ambivalence, does not fully explore the complexity of participant experiences around diagnosis, stigma, and stigma management. The authors do not speak directly to this, but I suspect they do not have the diagnosis themselves and perhaps this prevented them from fully appreciating the phenomenological complexity involved. In any case, the researchers concluded both that coming to terms with a diagnosis of Asperger’s is not a “singular event but a process that may span months or even years” and that there is a need not only for improved early identification of this developmental condition but also post-diagnostic support for individuals of all ages (p.281).

Another theme that came up in the study was the impact of media on perceptions of Asperger’s Syndrome. The authors noted an increase in the number of movies portraying individuals with Asperger’s and saw this as “a positive step enhancing the profile of the disorder” (p.279). One participant in their study, however, noted that movies depicting individuals with Asperger’s sometimes involve misleading and even disturbing stereotypes. Renwick, Schormans, and Shore (2014) did a recent study focusing on the depiction of intellectual and developmental disability in the media. Their most interesting

conclusion is that media contribute to the “perpetuation of socially devalued social roles” for these individuals and also “reinforce an individual pathology perspective” of disability (p.28). Certainly, the media can be a two-edged sword. Dotter (2002) provides an interesting discussion of the media and how it relates to postmodernism and the social construction of deviance.

Haertl, Callahan, Markoviks, and Sheppard (2013) conducted a two phase phenomenological study in which three women and three men diagnosed with autism spectrum disorder were interviewed in order to identify psychosocial challenges that occupational therapy might be able to address. Their results note the “overwhelming impact” associated with the condition’s lack of social skills (p.37) and replicate the results of previous research in which diagnosis is reported as both the stigmatizing label of a disability for which there is no cure and an “official explanation” that somehow alleviates the struggle to compensate for “not fitting in” by “work[ing] towards being normal” (p.32). Coming at the problem from the other end, Huws and Jones (2010) conducted a phenomenological study investigating non-professional community members’ perceptions of autism. They were struck by the confidence with which people expressed uninformed opinions about how ASD individuals don’t “understand the basic rules of obedience” (p.336) and are “incapable of functioning” (p.338). Their main conclusion was that higher levels of community education about autism are indicated. Both of these studies reinforce the complexity of stigma as it is experienced by and imposed upon individuals with autism.

Ever since the American Psychiatric Association first announced its intention to eliminate Asperger's as a distinct diagnosis in 2009, writers of all kinds have been

exploring the implications of this move by asking questions such as whether individuals exhibiting symptoms of ASD would come forward to seek a diagnosis without the stigma-ameliorating diagnosis of Asperger's to shelter them from the social stereotype of autism (Wallis, 2009). Multi-disciplinary articles continue to emerge exploring variations of the same question, for example whether students experiencing academic and social troubles will come forward to seek assistance if they are faced with being diagnosed with autism (Galligan, Feinstien, Sulkes, Bisagno, & Stein, 2013). Other recent articles examine whether those diagnosed with autism participate fully in society (Wang & Berg, 2014), explore the stigma experienced by parents of young ASD children (Lilley, 2013), and continue to investigate the growing incidence of autism (Russell, Rodgers, Ukoumunne, & Ford, 2014).

Linton, Krcek, Sensui, & Spillers (2014) explore the opinions of individuals diagnosed with or identifying as ASHFA about changes in the DSM-5. The authors maintain it is a phenomenological study, although the exclusive use of internet postings with no interaction with participants makes it seem more like archival opinion research. The authors report that there was 100% consensus on the forum agreeing with the elimination of PDD-NOS, but the mixed perceptions associated with the elimination of Asperger's and underlying perceptions are not explored. Stigma is not discussed despite one post quoted as saying "I don't want to necessarily be called 'autistic' because I don't want to be treated like I have full blown autism" (p.73). Still, this article is one of the relatively few discussed in this project published in a social work journal. For the most part, social work literature continues to be strangely silent when it comes to exploring the voices of those diagnosed with Asperger's/high functioning autism.

Chapter 3: Methodology

This chapter consists of four parts. First, the fundamental methodology underlying the research is developed. Ethical implications are then discussed, including not only how the research was approved by an ethics committee but how emerging ethical decisions were approached as they were encountered during the research process. The research design is then described, including participant recruitment, data generation, and data analysis. The final section describes how the write up was treated as the crowning effort of the methodology. Some of the evaluative attributes that help make the project trustworthy and meaningful as qualitative research are discussed.

The underlying methodology of a study is always important because it establishes the theoretical basis upon which not only the research design but the researcher's assumptions and interpretations are grounded (Taylor & Francis, 2013). The methodology provides a central framework for the research. It not only gives the study direction philosophically and procedurally but can provide guidance in terms of the researcher's conduct. This was particularly important for me as an ASHFA researcher with relational challenges. As qualitative and emancipative research, it was critical to engage with the participants in a nonjudgmental, curious, and collaborative manner. I wanted a postmodern non-positivist methodology that would facilitate and maintain this relational approach. I also wanted a methodology that would encourage the honest exploration of experience in order to address the research questions as fully as possible. A phenomenological methodology seemed like a good basis on which to proceed; a phenomenological approach focusing on deep and fleshy description as well as the exploration of human experience rather than any reductive, dualistic, or objectivity-

seeking perspective. There are, however, many approaches to phenomenology and it can be complex choosing one over another (Dowling & Cooney, 2012). In fact, sorting through the different philosophical approaches to phenomenology can become “a lifelong scholarly activity” (Dewing, 2011, p.70). I considered my research needs as well as philosophical theory and will try to show how the ideas of Merleau-Ponty and Gadamer helped me develop the basis of a suitable methodology.

I originally considered Interpretive Phenomenological Analysis (Smith et al., 2009) as the methodology for this study since the literature indicated previous research into stigma had employed it. However, I decided that the associated philosophical foundation was inconsistent. The authors cited Husserl, Heidegger, Merleau-Ponty, Sartre, and Gadamer as influences, but they failed to reconcile the primary ideas of these diverse thinkers into a unified methodology. For example, Husserl invokes an idealistic but objectivist ontology. His work has been called “the culmination of Cartesian dualism” (Draucker 1999). Merleau-Ponty’s work, on the other hand, involves a holistic ontology of embodied relationality that moves beyond dualism and objectivism. This alone presents contradictions the authors do not resolve. As a way of navigating the endless variety of possible approaches to phenomenology, for this study I settled on an underlying philosophical framework I refer to as *Gad-Pontyan* methodology. It revolves around Gadamer’s hermeneutical insights about interpretation and communicative solidarity as well as Merleau-Ponty’s phenomenological articulation of embodiment and his position that all perception involves interpretation. I was familiar with the work of both thinkers, but it is not only my familiarity that made me focus on the work of these

philosophers. Their ideas provided a coherent philosophical foundation while addressing the communicative and relational demands of the current study.

Turner (2003) discusses the specific elements of Gadamer's thought that provide the foundation for her qualitative study into the experience of hope. She notes in particular Gadamer's rejection of the subject-object dichotomy and the idea of the "hermeneutic circle of part and whole" (Gadamer, 1986, p.292). This means Gadamer acknowledges that the context provided by the whole modifies our perception of the parts, an idea implying that perception is not something objective and context free. This is related to Gadamer's position that historicity, context, and interpretation is central to human understanding, which is important as an underlying assumption of this study in its exploration of human experience. Experience is always historical, contextual, and contingent, a particular construction of truth to be interrogated and explored (Scott, 1991). Gadamer maintains that "prejudices are not false judgments" but rather "conditions of understanding" (Turner, p.9). This grounds my commitment to be as clear as possible about the beliefs and prejudices that condition my involvement in this research and how they contribute to the methodological decisions made in the course of the study. Turner also talks about the importance of *Bildung* or "openness to meaning" for Gadamer. This is crucial for the current study because it sets a tone for the curiosity and openness with which participants were approached. Also crucial in grounding the relationality of this study is Gadamer's idea that the "fusion of horizons," or the sharing of perspectives, takes priority over the advancement of agendas or the defense of established opinion. This idea serves as a model for the way I consistently strove to respect and listen deeply to participants. To these points discussed by Turner I would add

Gadamer's insistence that our human experience of the world is related more powerfully to what we recognize as "significant" than to the "methodological ideal of rational construction" that dominates modern discourse (1986, p.452). This further motivated me to give priority to what participants found significant rather than my own conceptualizations and rationalizations, however strongly held, academically established, or accepted by dominant rationality they may be.

Gadamer maintains that our "relationship with the world is absolutely and fundamentally linguistic" (p.433), which is consistent with central ideas about social construction that characterize current social work. At the same time, however, Gadamer acknowledges a "prelinguistic experience of the world which is no longer language but which looks to an ever-possible verbalization" (p.496). This tentative fragment of thought is consistent with my own prejudice about the importance of something fundamental that grounds who I am and provides the starting point of my growing involvement with others and the world. Gadamer, a former student of Martin Heidegger, endowed a passion for the "truth of play" (p.484) at McMaster University, where I wrote my Master's thesis on Merleau-Ponty and where Gadamer was a visiting professor the year before.

While Gadamer focuses on interpretation and understanding, Merleau-Ponty's early work counters the intellectual structures of modernism by focusing on situated embodiment, which reminds me to stay grounded in my bodily felt responsiveness rather than my rationalizations during the study. This focus in Merleau-Ponty reminds me to be respectful of the bodily felt experiences of the participants even as I question them, and to facilitate the exploration of where they find themselves going during the interview.

Writers like Clare (2001) take embodiment in a Foucauldian direction by reminding us that “without the lived bodily experience of identity and oppression, we won’t be able to reconfigure the world” (p.364). Yet at the same time for Merleau-Ponty, to stop the flow of language would be to “cut off perception” (1982, p.56), since “the human landscape is overrun with words” (1968, p.155). This element of Merleau-Ponty’s thought, also found in Gadamer, is consistent with the importance of discourse in current social work. At the same time, like Gadamer, Merleau-Ponty also acknowledges a prelinguistic mode of being that remains a “comprehensive and inarticulate grasp upon the world” (1945/2006, p.404). This again fits with my feeling as the researcher that there is something fundamental about myself, something fundamental about my autism, something many of the participants alluded to in the context of their own autism.

Merleau-Ponty contrasts authentic, primary, originary, or creative language and rationality with constituted, secondary, deliberately constructed language and rationality. Both have a role to play in human affairs, but constituted language/rationality tends to be associated with the positivistic codes and formulas of modern rationality, while authentic language/rationality tends to be a more proximal expression of the bodily felt carnal flesh of our pervasively intertwined existence in the world. Maybe this is why Weedon (1987) encourages us to “abandon traditional rationality and celebrate irrational forms of discourse and subjectivity” (p.29). Her admonition tends to be ignored, perhaps because it seems paradoxical to abandon rationality for irrationality in any kind of academic context. Still Merleau-Ponty, in line with Weedon, articulates an interpretive, relational, embodied rationality that provides an alternative to traditional modern rationality. I tried to emulate this kind of rationality as I interacted with the participants and in the process

of the write-up, although the content of the research presentation addresses typically dominant academic expectations and formulas. It is difficult to function outside dominant discourses, even with post-conventional intentions.

In her paper about what post-conventional social work might look like, Bell (2012) argues that “the theory underpinning social work needs further articulation” (p.412). She cites Borden (2010), Cameron and McDermott (2007), Gray (2010), and Payne (2010) as she maintains that the profession of social work “needs more attention to ontology” in order for the “very foundations of social work to be strengthened” (p.410). The complementarity of Gadamer and Merleau-Ponty in this sense provides a fruitful, well-articulated methodology for my study and continues to generate valuable thought and research (e.g. Konchak, 2013). Merleau-Ponty’s later works, in particular, go on to develop an ontology of being in the world that moves beyond solipsism to describe “an originary experience of profound relationship that transcends the alienation so typical of...western thought” (Laird, 1995, p.137). With the articulation of concepts such as “reversibility,” which refers to the “intertwining” of subject and object, and the “flesh,” which is the palpable fabric of our living engagement with the world (1968, p.111), Merleau-Ponty develops an embodied, relational ontology with profound ethical implications. He acknowledges “there is ...a wall between us and others,” but adds “it is a wall we build together” (1964, p.19). His work can be seen to provide a context through which we can tear down the walls separating us from each other by grounding ourselves in a situated embodiment that constructs the world as it constructs us. Feminist thought borrows heavily from Merleau-Ponty (Koehn, 1998; Olkowski & Weiss, 2006), and it is in this fertile Gad-Pontyan milieu that the current postmodern research takes place.

Neither Merleau-Ponty nor Gadamer provide specific research methods that correspond with their thought, and in a strict sense their work belongs to philosophy rather than the field of research methodology. However, this is also true for the work of Michel Foucault, whose philosophical ideas have been inspiring social research for the past 30 years (Hammersley & Traianou, 2014). In order to fill the methodology in with appropriate methods, several core strategies of constructivist grounded theory were employed (Charmaz, 2006). This adaptation of grounded theory not only employs established methods for analysis, it is consistent with the postmodern and Gad-Pontyan assumptions about the primacy of interpretation and relationality that underlie this project. Autoethnographic commentary has also been integrated with the data analysis, constituting a mixed approach that takes advantage of my insider position and increases the face validity of the research by making it more personal and penetrating while increasing rigour, nuance, and complexity (Tracey, 2010). The extensive use of autoethnography, as well as a sprinkling of discussion postings from the internet, constitutes a triangulation of data that adds to the study's credibility (Annals, 2006: Cresswell, 1998).

Despite the fact that Glaser, one of the original pioneers of classic grounded theory, dismisses ontological and epistemological positioning as a “rhetorical wrestle that gets wordy and goes nowhere” (as cited in Thornberg, 2012, p.248), the onto-epistemological foundations of this research are explored in detail. This is in accordance with the objectives of the critical social work program at the University of Victoria and in response to literature that charges social work with being “under-theorized” (Bell, 2012, p.410). This attention to underlying philosophy is an important contextualizing

aspect of postmodern research and also an urgent exploration on the part of the researcher for a way to come to terms with the importance of “copresence as a building block of social research” (Campos-Castillo & Hitlin, 2013). This is especially critical because my ability to engage in relationship can be seen to be impaired both by Asperger’s as well as my cultural immersion in modernism, which emphasizes rugged individuality, positivistic logic over creating space for multiple interpretation, and rules over relationality. Gad-Pontyan methodology is a philosophically cohesive attempt to overcome these barriers to collaborative solidarity and interpersonal alliance.

Charmaz (1990) maintains that grounded theory involves “an explicit set of analytic guidelines and procedures” (p.1163). My research design incorporated many of these techniques, including memo writing, concurrent data generation and analysis, constant comparative methods, and the use of progressively analytical coding formats to interpret the data. The use of these techniques helped elevate the research to a level of “rigorous good quality” and, as I discuss later, provided a well-established way to defend ongoing methodological decisions (Hunter, Murphy, Grealish, Casey, & Keady, 2011b, p.11). However, my use of grounded theory in the proposed study could be challenged because a literature review was carried out before the data collection and analysis. Dunne (2011) points out that grounded theory “deliberately avoids imposing a specific theoretical framework on the study from the outset” in an effort to suspend assumptions that might bias the researcher’s analysis of the data (p.119). In this regard, Charmaz (2006) warns researchers against “forcing data” into preconceived categories and “importing preconceived assumptions” (p.181). For this reason, Charmaz recommends that researchers “delay the literature review” in order to better “construct an original theory

that interprets the data” (p.12). Dunne acknowledges that researchers need to keep an open mind to emerging new ideas grounded in the data, but maintains that avoiding a preliminary literature review is a “disproportionate response to an uncertain and unsubstantiated risk” (2012, p.117). A literature review, he contends, ensures the proposed study has not already been done, contextualizes the research, and orients the researcher. Thornberg (2012) adds that not allowing a preliminary literature review because of possible theoretical contamination leads to the absurd conclusion that researchers should not conduct studies in their own area of specialty. He also points out that “ignoring established theories and research findings implies a loss of knowledge” (p.245). These arguments not only justify my decision to conduct a preliminary literature review, but my decision to incorporate some of Goffman’s concepts in order to see if they are still relevant and to build on them. They also address any possible concerns that would disqualify me from coherently employing grounded theory because of my pre-exposure to the research topic due to my diagnosis.

A fundamental aspect of constructivist grounded theory is that it lifts the “cloak of objectivity” that can be seen to obstruct qualitative researchers from fully engaging with participants and intimately “interacting with the data” (p.179). Consistent with Gad-Pontyan methodology, constructivist grounded theory rejects the notion of “value-free” research (Charmaz, 2006, p.132). Various writers point out that “the use of careful reflection can neutralize the influence of pre-existing theories and assumptions to a certain degree (Dunne, 2011; McGhee, Marland, & Atkinson, 2007). It was decided that the current study proceed with an initial literature review in order to put me in a good position to further existing knowledge as well as demonstrate familiarity with the

literature to the ethics committee and my thesis advisor. My intimate experience with the topic of the research put me in a good position to conduct the study because of my elevated familiarity with the issues, and also demanded that I rigorously account for my biases and preconceptions with critical reflection and clear reporting. The autoethnographic element of the study facilitated this clarity as well as contributing relevant insight.

Charmaz (2006) points out researchers must always “see through their armament of methodological techniques and reliance on mechanized procedures” (p.15) in order to engage with participants on a deeply felt level and “enter research participants’ worlds” (p. 19). She maintains that researchers “are not passive receptacles into which data are poured” (p.15), and that it is important to be reflective and honest with participants in order to account for and manage “differences in power and status” (p.27). All of this is entirely compatible with Gad-Pontyan methodology. At the same time, Charmaz is specific about the fact that grounded theory researchers “assume more direct control over the construction of data than most other methods” in order to develop conceptualizations that shape the data into coherent theory (p.28). The primary concern of grounded theory is theory development, whereas a phenomenological orientation is primarily concerned with the exploration of participant experience and meaning-making. I do not see this as a fundamental methodological conflict because both methodologies start with experience. Grounded theory’s technique of moving from a more descriptive level towards higher levels of conceptual interpretation during the research process is in line with Gadamer and Merleau-Ponty’s ideas about the primacy of interpretation.

Autoethnography is used as a supplementary method to augment the data analysis rather than a fundamental methodological orientation.

Although mixed methods research has been defined as the use of both qualitative and quantitative methods (Denscombe, 2007), Salmon and Beutow (2013) define it as the “incorporation of one or more methodological strategies drawn from a second method into a single research study” (p.82). This study incorporates both phenomenological and grounded theory elements in addition to autoethnography. In order to avoid “method slurring,” Baker, Wuest, and Stern (1992, p.1355) maintain it is imperative to show how the methods are compatible with each other as well as with the research question. They try to demonstrate, for example, how phenomenology and grounded theory are incompatible, pointing out how both methodologies are appropriate for qualitative research and focus on the experience of the participants, but differ fundamentally because phenomenology tries to reveal the “essence of experience” while grounded theory is based on symbolic interactionism. Here the importance of specifying which thinker or thinkers the methodology is specifically based on becomes clear. Baker et al. are referring to Husserlian phenomenology, which strives to provide a “rigorous descriptive science of consciousness” (p.1356). Merleau-Ponty, on the other hand, does not subscribe to a theory of essences, focuses on embodiment rather than transcendental reduction, and does not aspire to develop an objective science. Further, the authors are talking about classic grounded theory, which entails an objectivist approach.

Constructivist grounded theory, in the context of which various methods were borrowed for this study, is “unabashedly interpretive” and consistent with postmodern insights about the importance of discourse (Charmaz, 2006, p.128). The fact that Glaser thinks

“constructivist grounded theory is a misnomer” that is “totally irrelevant to GT methodology” (2012, pp. 28, 34) may reflect his opposition to the postmodern paradigm underlying constructivism, but this does not invalidate the utility for the current study of the research strategies he helped pioneer.

Salmon and Buetow (2013) conducted a mixed methods study using transcendental phenomenology and classic grounded theory. Heeding Baker et al.’s warning about “method slurring,” two separate data sets were generated using the two methodologies. However, unlike Baker et al., the authors maintained that the fundamental philosophical assumptions of each method were compatible, both reflecting a “realist ontology and an objectivist epistemology that assumes a correspondence theory of knowledge” (p.e83). The present study, on the other hand, appeals to an underlying philosophy informed by the thought of Gadamer and Merleau-Ponty, what I have called a Gad-Pontyan methodology that rejects realist ontology, objectivist epistemology, and the correspondence theory of knowledge. Rather, it privileges interpretation and relationality, a fundamental orientation shared by constructivist grounded theory.

The interpretations of the researcher came into play in every aspect of the study, and the implications of this for research design and evaluation will be further discussed below. Philosophically, recognizing the centrality of interpretation is crucial for emancipative qualitative research because the dominant positivist paradigm of neutral objectivity, where the researcher assumes the role of the expert, is replaced by more critical perspectives that recognize the centrality of discourse, history, situated experience, interpretation, and social construction (Brown & Strega, 2005). Revealing how my interpretations and biases bear on the research was built into the methodology,

since for both Gadamer and Merleau-Ponty interpretation and individual bias cannot be eliminated but are integral to the process of perception itself (Gadamer, 1986; Merleau-Ponty, 1945/2006). Gadamer tells us that “absolutely no understanding is free of all prejudices, however much the will of our knowledge must be directed toward escaping their thrall” (p.484). To be consistent with Gad-Pontyan methodology, my interpretations and biases are explicitly and consistently revealed throughout the research in a way that is “accessible and open to scrutiny” (Whitehead, 2004, p.518). Uncovering the relevance of my own experience was “an integral part of the research process” (p.517), in a sense already making me a virtual participant in the research (Sandberg & Wallo, 2013). This, coupled with my collaborative approach as well as the fact that my diagnosis of Asperger’s aligns me with the participant recruitment profile, prompted me to expand the acknowledgement of my interpretations and biases into autoethnographic participation in the data analysis. I felt my own experiences enhanced the data, though to prevent the study from becoming self-indulgent (Sparks, 2002) I limited my autoethnographic input to comments that expanded upon, augmented, or countered the data gathered from the other participants. In this way I hoped to “combine the participants’ narratives with my own into a process others may find useful” (Atkinson, 2010, p.33).

Miller (2013) tells us that “social work research may be conceptualized as an advocacy function for social work clients” (p.65). Although postmodern research may focus on various levels of social construction such as discourse, patterns of exchange, or hierarchies of power, Moosa-Mitha (2005) tell us that such research often revolves around people’s experience and the meanings they make of their experience. This, she

points out, is not simply in an effort to comprehend personal subjectivity, but to help make it possible to “deconstruct dominant representations” (p.61). Although the author points out that postmodern research is not necessarily emancipative, she maintains it is well suited to emancipative goals. In my emancipative postmodern research I develop a theory of autistic stigma to help understand this particular form of oppression and show how diagnosis contributes to and perpetuates it. I hope this will assist social workers in advocating for this population and help them provide more effective service. I also hope it will not only help individuals manage stigma but hopefully contribute to eradicating such oppression as far as possible.

Taken together, Gadamer’s and Merleau-Ponty’s philosophies counter the modernist valorization of objectivity and detached neutrality. These characteristics of positivism not only result in a general devaluation of qualitative research, but can lead to an objectification of research participants that makes it dangerously easy to create further oppression. Gadamer and Merleau-Ponty not only provide an appropriate philosophical orientation for social work research and this study in particular, but together they can be seen to articulate a phenomenological and ontological space of deep engagement from which researchers can get involved in the “messy complexities” of unfolding research issues and often complex participant relationships (Brown & Strega, 2005, p.11). For me in particular as a researcher with Asperger’s, finding such a space was critically important in order to proceed with emancipative research.

Ethical Considerations and Emerging Ethical Issues

Constructive grounded theory and phenomenological research are inherently anti-oppressive because of their intention to work collaboratively with participants and their sensitivity to issues of status and “hierarchies of power” (Charmaz, 2006, p.130). My study was carefully designed to create no harm to participants. No one but me (the researcher) had access to the recorded raw data, which was carefully guarded in the researcher’s immediate possession at all times until being secured on the researcher’s computer with password protection and military strength encryption. At that point the raw data on the recording device was destroyed. Everyone involved with the research was informed more than once that they could withdraw at any time for any reason and that their data would be permanently destroyed. No one withdrew from the study, although one participant was a no show twice for her interview and no data was collected. Participants were informed they could decline to answer any question, take a break, or stop the interview at any point for any reason.

Confidentiality was maintained by employing coded identification and anonymization. Full informed consent was obtained from each individual at first contact with the researcher before their participation started. The entire research process, along with the consent form itself, was approved by the Human Research Ethics Board (HREB) at the University of Victoria in accordance with the 2ed edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Interagency Advisory Panel on Research Ethics, 2008). Battacharya (2007), however, has pointed out that “the consent form serves only as a fluid guideline rather than a blueprint” of the

researcher/participant relationship (p.1101). Unforeseen ethical issues emerged at all stages of the study and are outlined below.

I thought I was prepared for one possible emergent ethical issue. Wiles, Crow, Heath, and Charles (2008) have documented how some participants want to be identified in research studies. I armed myself with appropriate waivers and prepared myself to negotiate this eventuality if necessary, feeling that participant identification was too fraught with issues of liability and unforeseen participant consequences to be advisable. No one requested to be explicitly identified in the study, but an issue did come up regarding the degree of anonymization in participant interviews. One participant, for example, was well-known in the HIV community in his area. Since there are not too many HIV positive individuals with Asperger's, especially those active as a facilitator and planner, it seemed like hiding this involvement would provide a secure level of anonymization. On the other hand, not disclosing the participant's intersecting stigma would impoverish the study. Was I being paternal and over-protective? The participant had been given two labels by the HIV community which he had adopted for himself (the "angry PHA" and the "social critic"), and although these seemed very descriptive and paradigmatic as indicators of stigma, they also seemed like possible identifiers. I wrestled with this dilemma intensely before finally approaching the participant by e-mail. He assured me that he was more interested in education than protecting his privacy to that extent. These would only be identifiers within a community in which it was already known he had Asperger's, and increasing understanding of stigma in this community was a primary concern of his. It was decided in collaboration with the participant to relax data anonymization in this case.

A related ethical issue emerged from the use of quotations citing online Asperger's discussion forums. This sort of data collection was employed sparingly as a supplement to the phenomenological interviews. At first I used such quotes routinely as a kind of textual resource, but in the final stages of writing up the project I started to think about the ethics of using these online sources. The HREB advised that the use of such quotes was exempt from the requirements of formal ethical review because they came from publically accessible sites not protected by a password or requiring membership to access. The sites themselves had no evident policy about research or the citation of quotes, and when contacted to enquire about such policies the site administrators did not reply. The HREB decided there was no reasonable expectation of privacy by those posting to the forums and noted that the researcher had not been participating in the discussions, which would have introduced additional ethical concerns. Neither was I secretly observing online interactions as an unannounced observer. Such "lurking," Janzen (2009) points out, would have been consistent with the HREB definition of minimal risk natural observation, but to me would have involved an ethically questionable element of secret surveillance more appropriate, perhaps, to law enforcement than social work research. Rather, I was reading the discussions as an interested party and occasionally reporting relevant opinions and insightful comments relevant to my project. Still, despite the HREB ruling, there were ethical dilemmas involved in my use of these quotes.

The Association of Internet Researchers (2012) provides an excellent list of questions to consider in the context of online research and points out that the use of online sources "requires individuals and institutions alike to confront many irresolvable

contradictions.” The AOIR maintains, like Battacharya (2007), that ethics are not just “regulatory hurdles to be jumped through” but a critical dimension of the research process that tends to destabilize the even the most carefully laid preparations and calls for ongoing resolution according to situational and emerging factors (2012, p.5). The authors of the AOIR report warn that over-reliance on ethical rulings and codes make it “possible to forget that there was ever a person somewhere in the process that could be directly or indirectly impacted by the research” (p.7). It is particularly important to supplement the protocols of regulatory ethics approval in this area because “ethical guidelines and policy to inform research in online contexts is still in its infancy” (Warrell & Jacobsen, 2014, p.24). I decided that informed consent was not necessary since the individuals who made the posts were not active participants. I could have sought consent after the fact for the limited number of quotations used, but felt there was a possibility that seeking such consent might cause distress in its own right, such as perceived violation at receiving unsolicited e-mails that might even cause individuals to stop participating in a forum. On the other hand, to minimize the risk of causing harm, I decided to use pseudonyms for the usernames. Kirsten Faye Linton, a researcher at the university of Hawai’i at Manoa and co-author one of the studies cited in this project (Linton, Krcek, Sensui, & Spillers, 2014), helped me sort this ethical issue out. She said despite her university’s HREB decision that anonymity was not required because of the public nature of the forums she and her colleagues used to generate data, in her opinion “because we cannot guarantee our participants’ intentions, I believe it’s best not to identify them” (personal communication, July 7, 2014). Participation in public online forums might not carry a reasonable expectation of privacy, but there may be a

perception of privacy or a feeling of safety in sharing with the intended audience that should be violated as minimally as possible. At the same time, online forums are a rich source of insight and current opinion as well as archives of interaction and experience. Online methods may constitute the chosen data gathering process for many studies, or as in my study at least add to the richness of the data. Anonymization was deemed to be the best way to protect those whose information was quoted in the research despite the lack of guidelines from the HREB. My thesis advisor agreed. This form of anonymization would not make it impossible to track down a particular quote, but would decrease the possibility that anyone reading the research presentation might recognize someone by their familiar online handle. At the same time I wanted to associate a name with the statements both to help keep their humanity alive and to provide a moniker on the basis of which to provide a reference according to APA standards, a reference pointing towards a sample of online forums for the information of those interested in exploring, or even participating in, ASHFA discussion. Online research and the use of online sources present unique ethical challenges because the familiar boundaries between public and private, text and persons, and even the very concept of what constitutes a human participant are challenged. For those who are interested, the ethical complexity of online research and data collection is further explored, for example, by Lingel (2012), McCleary (2007), and Whiteman (2012).

Moving forward in our discussion of the ethical issues involved with the current research, Charmaz (2006) points to the importance of ensuring accuracy in representing participants' positions. In order to make sure participants' voices were represented correctly, "member-checking" was employed to "confirm accuracy of transcripts and

allow participants to edit responses” (Coniglio, Hancock, & Ellis, 2012, p.155). Cooney (2011) has argued that such checks are not necessary in grounded theory studies because the final goal in such research is theory, not the representation of participants’ voices. However, in order for the theory to be properly grounded in the data, and since participant experiences were cited to support the theory, such checks were considered to be not only respectful but invaluable. As discussed above, representing participants’ voices is not at all inconsistent with constructivist grounded theory, particularly in the context of the Gad-Pontyan methodology developed in this project. Still, there were some emergent ethical issues here as well. First of all, the transcripts were sent via e-mail since the geographic breadth of this study was too large for frequent in-person contact. To make this process more secure, transcripts were sent as encoded Word documents. The code required for decryption was sent in a separate e-mail. This brought up two issues: first, what if this level of technology was too sophisticated for a given participant and how was it possible to ask about their level of computer sophistication without sounding patronizing? Second, was it elitist of me to assume that participants would have an expensive copy of Microsoft Office available to decode the encryption? As with most emergent ethical issues, these were worked out in collaboration with participants, who were asked if it would be permissible to send the transcripts in this way and assured the researcher would work with them if there were any problems. As it turned out, one participant had a problem because his copy of Microsoft Office was a limited version capable of opening the transcript but not making changes that could be saved. He was thanked for his effort to work with the researcher and directed to a free, open-source

program capable of making his desired revisions. Obtaining this program was a benefit to the participant as well as allowing full participation in the research.

Another ethical concern was related to the fact that I am diagnosed with Asperger's myself. This could be seen to impact my ability to conduct qualitative social research. Individuals with Asperger's, after all, are said to have "difficulties with empathy and social skills" (Attwood, 2007, p.22). It is only logical to ask whether this had a negative impact on my ability to relate in a sensitive way to potentially vulnerable participants. It might have led to overlooking or misreading important non-verbal or socially complex information, since a researcher with Asperger's will have to use his or her "intellectual capacity to process social cues" (Attwood, 2007, p.56). This could have a devastating impact on participants, for who can tell "the consequences of errors in interpretation by the researcher if the participants are already stigmatized" (Fortune, Reid, & Miller, 2013, p.xx). The possibility of unintentional harm to participants can only be acknowledged humbly by any social worker, putting them on high alert for the potential to do harm (Blackstock, 2009). It made my immersion in Gad-Pontyan methodology as described above an important ethical dimension of the study.

In my case, intellectualization (of relationality, ideas, and feelings) is a familiar way of navigating the world. It is not the diagnosis of Asperger's or autism itself that constructs me this way, although I hope the current research shows how diagnosis can be socially constructive. The fundamental intellectualization with which I manage my cognitive difference in a social context underlies much of the isolation, awkwardness, anxiety, and under-achievement I have experienced for much of my life. This does not, I contend, prevent me from being a competent researcher. In particular, my identification

with individuals with this diagnosis positioned me to more compassionately engage with the participants. I have always had trouble initiating and maintaining friendships, but being a “friend” is not the same as assuming the role of researcher, which is more of a controlled interaction calling for attention to detail, curiosity, active listening, and being faithful to the narrative constructions of the participant. It is not just that I have learned to “mask symptoms” with age (American Psychiatric Association, 2013, p.31; 50). I have learned, rather, to be more comfortable with myself, to be a supportive husband (though I drive my wife crazy at times), and even to provide service to people as a counselor.

The ability to remain intellectually detached can be useful, allowing me to remain calm and centered in the face of exposure to pain and suffering. I agree that disclosure happens most effectively “when someone feels seen, heard, held, and empowered, not when one is interpreted, held at a distance, and pathologized” (Dietz, 2000, p.337). I do not endeavor to pathologize people (although identifying pathology can be helpful at times as an externalizing tactic), but in my experience as a counselor I find that genuine intellectual curiosity, which can be seen to inherently hold people at a distance, may be as effective as more empathetic approaches. Still, I made an effort to be constantly aware of my tendency towards intellectualization, working hard so that I did not lapse into relational avoidance or separate myself from participants as an “expert.” I also practiced awareness of my tendency to be pompous and pedagogical in my efforts to compensate for social discomfort. Remaining grounded in Gad-Pontyan methodology, which values an orientation of bodily felt reciprocity and mutual understanding rather than objective detachment that valorizes expertise, was very helpful in maintaining this diligently

relational orientation. Frequently checking in with participants to make sure there was an atmosphere of collaboration was also invaluable in this regard.

Basic ethical guidelines were also provided by code of ethics and standards of practice established by the Ontario College of Social Workers and Social Service Workers (2008). Still, especially because of the emergent nature of grounded theory research which develops in response to data analysis and often proceeds in unpredicted directions, it was important to be prepared for “multiple possibilities of ethics” (Battacharya, 2007, p.1112). Asperger’s or not, “ethical judgments cannot be dealt with on the grounds of factual information or professional skill alone” (Holland & Kilpatrick, 1991, p.138). In this sense, Rossiter’s admonition to “refrain from treating the other person as an extension of my categories, my theories, [and] my habitual or learned ways of perceiving others” was adopted as an ethical guide (2011, p.985). She grounds this ethics of encounter in a specifically social work-oriented interpretation of Levinasian thought in which lived encounter is allowed to “overflow” whatever conceptualizations and theoretical orientations are brought to the engagement (p.987). This was particularly important for me to remember because of my tendency to intellectualize relationships to compensate for my “deficits in social-emotional reciprocity” (American Psychiatric Association, 2013, p.50). This made the ethics of encounter especially poignant as an ethical orientation to be mindful of at all times, not only from the point of view of engaging in this research, but from the perspective of an individual diagnosed with Asperger’s struggling to interact socially and emerge from the confining objectivism and individualism of modernity. In practical terms, it is work for me to remember the needs and address the feelings of others. I must reaffirm my commitment to relational ethics

constantly as I interact in order not to lapse into self-absorption. Gad-Pontyan methodology and Rossiter's ethics of encounter provided me with a firm framework to lean on in the study, a framework that is also worth the effort of applying in daily life.

Grounded theory's built-in memo-writing process ensured the full documentation of emerging issues and procedural decisions. In order to be fully prepared to "address the fluid and messy nature of qualitative research" (p.1113), it was also important to ground myself at all times in the spirit of the Gad-Pontyan methodology described in this paper. Although Gadamer and Merleau-Ponty did not develop explicit ethical frameworks, they developed complimentary guiding ethical orientations in their work. Smith (1988) explores the ethical implications of Gadamer's work, which revolves around his commitment to interpersonal communication, fusing horizons of understanding, and privileging the creative play of interpretive possibilities over dogmatic "certainties" and dominant discourses. Fischer (2002) explores the ethical implications of Merleau-Ponty's work in her doctoral dissertation, drawing out the ethical implications of his phenomenological and ontological articulation of embodied engagement with others and the world. She shows how his work leads to an ethics of recognition involving "genuine reciprocity," communicative relationality, respect, and care (pp. 198-200). Others point out that Merleau-Ponty's philosophy "lends itself to an expansive notion of morality such as found in ethics of care that cannot ignore embodiment" (Sanders & Wisnewski, 2012, p.182). Gad-Pontyan methodology's communicative ethics of embodied relationality, along with Rossiter's (2011) ethics of encounter, provided ethical guidance that went far beyond HREB approval and the social work code of conduct.

One ethical dilemma grew in urgency as the study progressed, yet was not at all anticipated by me ahead of time. Nor was it addressed in any code of conduct or ethical guideline provided by the profession or the university. The research involved interviews with individuals who had chosen to be open about their diagnosis with me, and an integral part of the study is my own diagnosis of Asperger's. I had intended to be open about my diagnosis, but when it came down to it I chose not to disclose my diagnosis to the participants. The reason for this was that I have not disclosed the diagnosis to my workplace for fear of stigma that might affect employment. I have no ethical dilemma about not disclosing per se; that is my choice as it is anyone's. I am not required by law to disclose a mental health condition to my workplace, and it is reasonable that I not trust this hidden aspect of myself to strangers who could "out" me. At the same time, I felt like I was violating some kind of silent ethical code by interviewing people who were sharing their diagnosis with me while I was hiding my own from them. This concealment may have had an impact on the research itself and the level of disclosure of the participants. On the other hand, my intimate experience with the symptoms of the condition gave me insight into the individuals involved (in the words of one participant, I did not require a "translator who speaks Aspie"), and this familiarity may have offset my lack of disclosure. I may never know this unless I undertake future research in which I do disclose my diagnosis. It is not the impact on the research that is my real concern, however. It is the concealment itself and lack of mutual disclosure with participants that bothers me ethically. In fact, it makes me anxious, sick to my stomach, and ashamed. I have felt this way before. It is the oppressive necessity of having to keep part of myself hidden as if it were a "discreditable secret failing" (Goffman, 1963, p.65). It is not

because I myself am ashamed of this part of me, although I have struggled with this kind of shame in the past. For me, it has taken growing maturity and self-confidence not to define myself primarily through the prejudices of dominant others. Rather, I keep this part of myself hidden because of consequences in the mainstream world that may befall me (and my family) if the secret is out in certain quarters. Choosing to keep this secret from the participants is a perfect example of what Goffman calls “indeeperism” (p.83), or the inevitable way concealment grows as time goes on. The stigma itself brings shame enough; keeping the secret takes its own toll. In the case of this research, not revealing my diagnosis to the participants amplified the felt weight of stigma exponentially. I am sorry to each and every individual who participated in the study, and apologise for my lack of courage.

Another ethical dilemma emerged around dual relationships. Although I did not reveal myself, I feel my condition allowed me to engage with the participants on a deeper level than I might have otherwise. So much so, in fact, I felt like continuing the engagement in many cases. Would this constitute an unethical dual relationship? One of the participants experienced such loneliness in his life that I felt a responsibility to act upon my genuine feeling of wanting to keep in touch. I identified with his need to help others as a way of fulfilling his own need to build self-esteem. His questions to me during the interview helped me to relate the insights obtained in the research to myself, not only for self-indulgent reasons of personal growth but insofar as locating myself more intimately in relation to the results has allowed me to add additional ethnographic insight to the study. The participant and I agreed to go for coffee at some point when the current research is completed. Countertransference, when participants elicit feelings in the

researcher, unavoidably impacts qualitative research and can become an integral part of the study to be documented and reflected upon (Holmes, 2014).

Another participant battled with extreme anxiety and said she had not been able to find helpful treatment. She said her counsellor, although regarded as an expert on AS, was unable to give her distress management techniques that worked. This brought up a conflict between my role as a counsellor and my role as a researcher. I felt the tension between these two roles coming to a boil. I knew I could not just start giving her treatment, but I wondered if I should contact her after the completion of the study to speak to her further about her anxiety, not only as a fellow individual with Asperger's but also someone who has had to manage his own anxiety. As a trained counsellor I am experienced in the use of CBT, and my positionality as a fellow Aspie, I felt, would give me unique insight into how to apply these techniques in way she might find helpful. My research brought about my knowledge of her and her issues, so (I asked myself) did this not bring a responsibility to be of further service if I felt it was possible? I wrestled with this. I could hear a voice of reasonableness in my head saying "you cannot rescue everyone." I could objectively see that promoting my skills as a therapist from my positionality as a researcher would be blurring boundaries as well as creating potential liabilities. Still, I felt it was only logical to offer my service in this case when the study was over. I also knew, after many bitter life lessons, that logic is not the only yardstick of what is appropriate. This is a theme that emerged clearly in the current study. I decided not to let my habitual dependence on inexorable logic (which is often in defense of ill-considered impulses) run away with me. I gave myself a gentle nudge and shifted my outlook to see the impulse to help not as a call to action but as an indication that my self-

image is bound up inextricably with being a counselor. I should focus, I told myself, on why I felt this need to attempt what other counsellors had yet failed to do. This might be seen as simply letting common sense prevail. I prefer to see it as the tentative resolution of a challenging ethical dilemma, as a certain standing down that something told me may have averted boundary violations, potential liabilities, and professional offense. This kind of standing down from impulse and logic is an all-too familiar challenge for me and is often at the fine line where things either continue to run smoothly or things all start falling apart. What do I defer to at such times? I can't say; certainly it is a quiet, easily ignored knowing within that can be easily trampled by impulse and logic. This inner intuition has become stronger but remains delicate as I grow in age and experience. I think characterizing it as an ethical conflict that demands ongoing mindful resolution captures the spirit of the effort it calls for.

Research Procedures and Field Notes

Participant recruitment

I was looking to recruit eight individuals diagnosed with either Asperger's or autism (in the low or no support required range without language or intellectual impairments, otherwise known as high functioning autism). The only exclusion criteria was that they must be 16 or older in order to be considered adults in the Ontario mental health system capable of signing consent. In line with constructivist grounded theory methods, emergent sampling was to be employed in the study. It was originally proposed that participants would be selected based on qualities the data suggested may be of interest in combination with the characteristics of the potential participants who come forward. This intention, like selective sampling, did not prove possible because of difficulty

getting any participants at all. Those that did participate suggested providing alternatives to face to face interviews. For example, one participant felt that having Skype or online conferencing as an alternative would have resulted in more volunteers. Another participant suggested that mail-in questionnaires would have been an alternative with which more individuals with Asperger's/ high functioning autism would have felt comfortable. These are all lessons for future research in this area.

E-mail was the mode of contact employed in the study because it is immediate and easy and almost universally available. None of the participants expressed having an issue with this mode of communication. Some of them provided their phone number, but none expressed a preference for this mode of communication. A dedicated e-mail address with a robust password was established for the research, but there were not enough resources for a dedicated phone line. Once a participant expressed interest by responding to the study's specially created e-mail, they were sent an immediate reply thanking them for their interest, confirming their age and diagnosis, and asking them if there were any accommodations they might need to more comfortably participate in the study. This e-mail also had a copy of the consent form attached for them to examine. If they expressed further interest, an interview was scheduled.

Participants were initially recruited with a posting on the research page of the Asperger's Society of Ontario website. Volunteers came from a geographic corridor ranging from Toronto to Barrie, an area including millions of people and dozens of cities, towns, and rural areas. No volunteers came forward at first. This surprised me because my own interest in the topic made me assume that everyone with a diagnosis would share my enthusiasm. It not only surprised me, it caused me to panic. I contacted

my thesis advisor, who normalized my anxiety and helped me think of ways to bolster recruitment. I contacted the ASO administrator, who kindly augmented the research posting with a social network blog that generated some interest. E-mails were sent out to various professionals in the field who made further postings. In addition, I attended an Autism Ontario support group meeting in an effort to generate further interest.

Interviews were arranged with the first five participants who responded and agreed to sign the consent form. The sixth participant was obtained through snowball recruitment in the sense that one of the participants had a roommate who was interested in participating. Both these participants were interviewed in their home on the same day, chose to be present during each other's interviews, and were interviewed together briefly (which turned out to be an unforeseen source of knowledge and insight). In accordance with the ethics approval from the university, participants were asked if they had any issues requiring accommodation. None came forward as having such issues. The time and location of the interviews were determined in collaboration with the participants. Three chose to be interviewed in their homes and three were interviewed in private meeting rooms booked at local libraries.

The convenience sample consisted of six adults (five males and one female). Four of the participants had a diagnosis of Asperger's, two of whom were diagnosed as adults, one as a prepubescent, and one as a young child. The two remaining participants were diagnosed with autism as young children after experiencing language delays (the fact that their language skills came back resulting in an unofficial label of high functioning autism). I had all but given up on having individuals diagnosed with Asperger's as well as individuals with high functioning autism in the study. I originally had plans of

generating a large sample pool and having a selective sample consisting of participants with each diagnosis, but lack of response made coming up with any six participants the new goal. I also had plans to include individuals with intersecting stigmas, and luckily this goal was also met by the convenience sample eventually obtained. Two of the participants experienced comorbid mental illness, one was female, one was gay, and one was gay and HIV positive. This variety of participants added to the insights obtained in the research, as the discussion of results will later reveal. Having participants with Asperger's as well as high function autism made it possible to identify differing experiences of stigma related to diagnosis since the underlying condition is the same. The variety of participants also made it possible to get a sense of how various intersecting stigmas are related, thus addressing debate in the literature about whether individuals who have "multiple subordinate group identities" experience more or different levels of oppression (Purdie-Vaughns & Eibach, 2008, p.378).

Data generation

Mills, Bonner, & Francis (2006) propose the term "data generation" rather than "data collection" to emphasize the element of shared participation between researcher and participants. Their term was adopted in this research as part of an effort to democratize the research process. The data for this study was generated primarily through open ended, semi-structured interviews. Such interview formats are typically employed in phenomenological research (Punshon et al., 2009; Rubin & Rubin, 1995). With its reliance on phenomenological interviews to generate data, the study could be charged with focusing too heavily on individual experience. Such a criticism is valid, but no research can pretend to be all-encompassing. Still, an attempt was made to touch

on systemic issues through the experience of the participants. In addition, some critics may charge that phenomenological interviews are incompatible with the grounded theory aspect of the study's mixed methodology. In this regard, Wimpenny and Glass (2000) maintain that "there is no typical grounded theory interview" and that "interviewing...may have a similar construction irrespective of the methodological grounding" (p.1488). Although grounded theory starts with the participant's experience and moves towards higher levels of thematic conceptual interpretation depending on emerging themes in the data, the authors note that "this approach seems just as applicable to phenomenological research" (p.1490). In line with this, the interview questions for this study were developed as the research proceeded in order to pursue emerging knowledge and trends in the data. The final set of baseline questions appears in appendix B, but each interview took place in the context of a unique dyad evolving in responsive collaboration with the participant and took place in a different phase of evolving research (Charmaz, 2006, p.29). Responsive follow up questions ranged from general context-setting ("how did you feel when you were diagnosed") to specific process description ("how do you manage to cope when that happened?"), probing ("what did you do after that?"), and clarifying ("I'm not sure I understand"). Managing and universalizing the interview conditions was not a priority the way it would have been in quantitative research, where variables need to be controlled to achieve generalizability and the goal is to establish strict relationships between variables rather than explore participants' experiences. Still, in practice, I found it challenging at times to let go of the scripted questions in order to follow participants in their phenomenological exploration of experience. I got better at this with practice.

As the research proceeded, I decided in collaboration with my thesis adviser to ask questions directly related to some of Goffman's descriptions of stigma management. I was finding that my questions were not eliciting the depth of insight I was looking for, and I believed his phenomenological descriptions of dramaturgy, back places, passing, covering, and the non-person role were particularly rich sources of insight. As it turned out, the participants identified with these descriptions and the additional questions led to many of the insights described in the discussion of findings below.

Theoretical saturation, a grounded theory technique in which data collection continues until no new coding possibilities emerge, was not employed. This is not only because of the time and resource limitations imposed by the nature of MSW research, but because the notion of theoretical saturation is contentious and imprecise, often leading researchers to "proclaim saturation rather than prove they have achieved it" (Charmaz, 2006, p.114). Another feature of grounded theory is for recruitment, data generation, and data analysis to proceed at the same time in order to pursue emerging trends in the data. However, I did not feel I could hold off interviewing participants until data analysis took place. I could not afford the possible attrition. To be honest, the logistics of arranging interviews and responding to new participants took all my attention and prevented me from starting formal data analysis before the interviews were completed. Participation in the interviews themselves provided the foundation on which future interview questions were modified as I proceeded. Data generation was a flurry of activity that was challenging to keep organized. This might lead to the charge that I was not really employing grounded theory; however, it is Gad-Pontyan methodology underlying the research and I utilized what Grounded Theory methods that proved

helpful and appropriate in order to move towards theory. The Gad-Pontyan methodology made interaction with participants the primary focus rather than commitment to any set of techniques. I found that my grounding in Gad-Pontyan methodology helped me take care of myself as the researcher. The hermeneutical circle, after all, included me as the organizing participant. I felt comfortable with this approach.

The one-on-one interviews were scheduled two per week whenever possible. I had planned to schedule both on the same day to save traveling time, but found that one a day helped me keep the appointments straight (the exception to this was when I interviewed both roommates consecutively in their home). More importantly, a less hectic schedule allowed me to maintain a full and energetic focus on each participant not only as I worked with them but (and I found this was critical) in reflection afterwards.

Hunter et al. (2011b) point out that grounded theory's ideal of "equal partnership in research [can be] extremely challenging to apply" (p.9). In this regard, I always collaborated with participants to select the time and place of the interview as far as possible. Participant questions and concerns were invited and addressed throughout the process. I engaged in a genuine and appropriate degree of reciprocity and mutual disclosure with the research volunteers in order to help build a collaborative spirit between myself as the researcher and the participants (Mills et al., 2006, p.9). In this way, my own contributions to the research were developed and explored, and the give and take of mutual discussion helped to ripen the data. Participants were always approached with respect and curiosity. A strong effort was made to "emphasize eliciting the participant's definition of terms, situations, and events and to tap his or her assumptions, implicit meanings, and tacit rules" (Charmaz, 2006, p.32). In line with

Gad-Pontyan methodology, I approached each participant as a human being in openness for a unique encounter rather than an expert with an inflexible agenda. In line with Rossiter's social work interpretation of Levinasian ethics, my approach to participants was molded as far as possible by the participants themselves rather than my concepts and presumptions. This proved particularly important because the wide range of thinking styles, communication skills, and levels of conceptual sophistication among the participants.

Data analysis

Data analysis begins with reflection on the movement of ideas initiated in the course of each interview. At this phase of data analysis it is not just the spoken words that are important; the very encounter with the participant resonates and leaves a certain imprint that imbues the research with its emerging character. Transcription, a process challenging in its tedium, continues analysis as a phase of intense exposure to the data along with further reflection. Ideas generated at these early stages become initial impressions that lead into the formal phase of data analysis, which involves a process of "constant comparison" between the different data sets, emerging conceptualizations, and the researcher's thoughts about the data and the research process. All through this process I wrote "preliminary analytic notes called memos" (Charmaz, 2006, p.3) that helped crystallize my thinking, allowed ongoing research decisions to be worked through for later examination, generated new ideas, developed intuitions, and identified issues as they come up. Such memo-writing can be an integral part of the grounded theory process and often initiates dimensions of data analysis whose importance may not become clear until later. Charmaz, for example, describes a personal experience with how a certain memo

became the basis of a keynote address and a published paper (2006, p.89). Charmaz emphasizes the importance of memo-writing throughout the whole process, describing how memos can reveal how “sensitizing concepts, long left silent, may murmur during coding” (p.76). Memos or field-notes also contribute to research validity as they add to the research’s level of transparency and create what Tracey (2010) calls an “audit trail” that allows readers to understand why research decisions were made the way they were and what the researcher was thinking (p.842). I have tried to incorporate the content of relevant field notes into this research presentation.

With the participants’ permission, interviews were taped on a digital tape recorder. I had intended to take notes about contextual information, gestures, expressions, reactions, and ideas, but found this distracted me too much from the encounter. The encounter itself, according to Gad-Pontyan methodology, is the priority. Other researchers may not have found note-taking such a distraction. I had planned to transcribe the recordings using computer software (Dragon Naturally Speaking), but found listening and typing and re-listening and typing brought me into closer proximity to the data than constant “echoing” of the recorded data (the program only recognizes the owner’s voice, so to use Dragon all interviews have to be repeated in the software owner’s voice as the recordings are listened to on a headset). The use of powerful CAQDAS (Computer Assisted Qualitative Data Analysis Software) was considered and could be obtained quite cheaply at student rates (for example NVivo 10 was \$120.00 at the time of this writing: http://www.qsrinternational.com/quick-order_listing.aspx). However, online comments like this one from David Seaman at Kent State University made me decide to do things the old-fashioned way:

The heart of phenomenological interpretation is "staying with the phenomenon" thus I would recommend that one NEVER use software programs to identify underlying themes. The hard work of reading, rereading, and rereading many times more leads to an engagement with the phenomenon that is absolutely essential for accurate, comprehensive discovery. For meaning to arise, one must be present and that presence is lost when software programs are introduced.

(Seaman, 2014)

All of the participants signed additional consent to have the transcript sent to them for approval and amendment, although one did not answer the e-mail sent to him when the transcription was finished. Since he had signed consent to participate and had not revoked it, I took this to indicate that he was no longer interested in reading over the transcript and proceeded to analyze the participant's data after a two week interval had passed. All the other participants were sent their transcripts as encrypted Word documents to be read, corrected, clarified, and amended in any way they saw fit. Formal data analysis began as each participant returned their approved transcript. Only one of the participants made extensive additions to the transcript. At each stage of the data analysis, autoethnographic commentary was inserted into the growing data tree, enhancing connections, amplifying certain points, and providing an additional perspective. This commentary is an inherent part of the discussion of findings presented below, and

hopefully contributes additional insight into the phenomenon of stigma and stigma management.

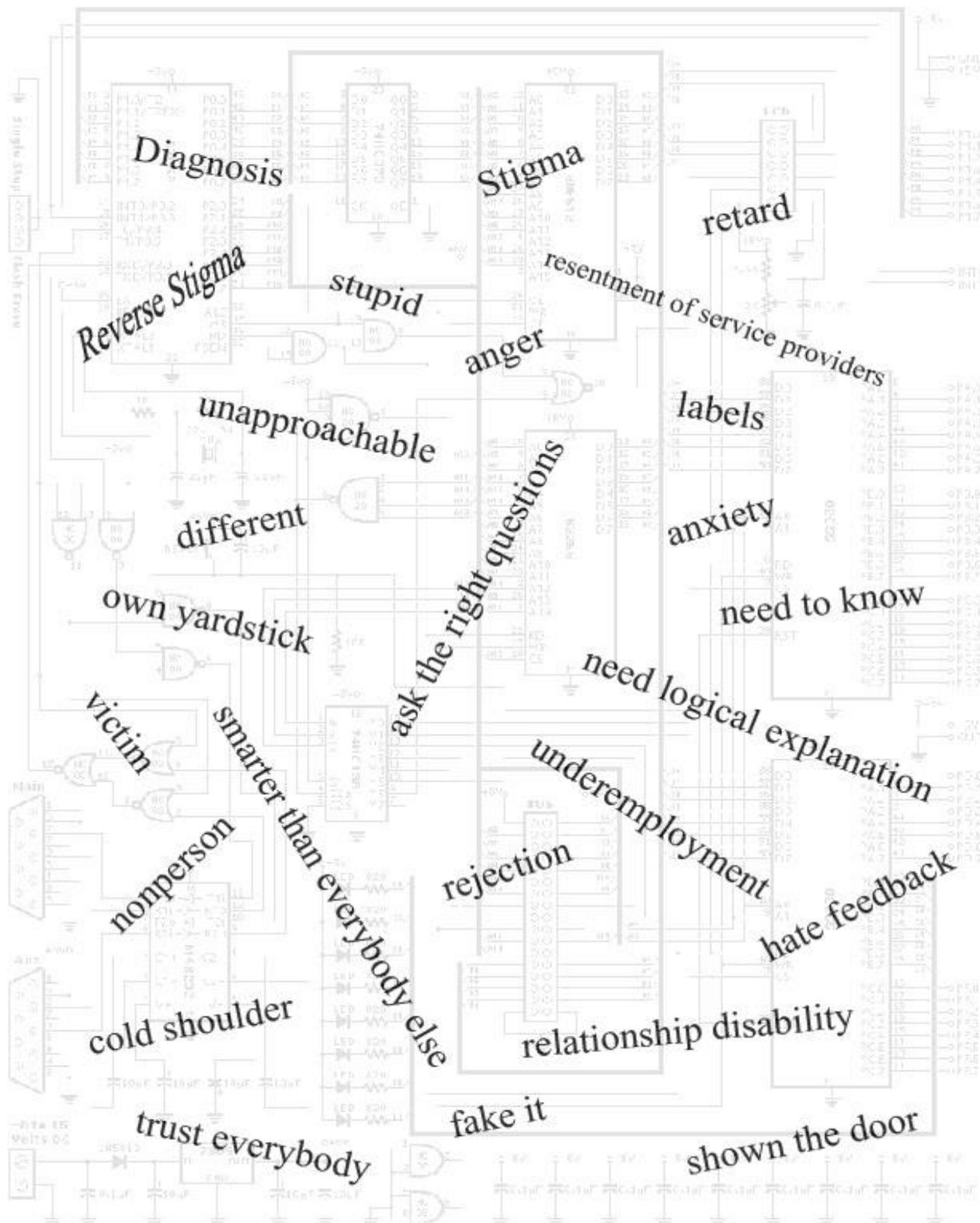
The data was interpreted using a technique called *coding*. According to Kendell (1999), Glaser described two types of coding (substantive and theoretical), while Strauss and Corbin described three (open, axial, and selective). In line with Charmaz (2006), four levels of coding were considered, each involving progressively higher levels of conceptualization. Initial coding (open coding), involved line by line analysis in which themes and categories of participants' experience were identified. This basic coding followed the original data closely and helped me "refrain from imputing motives, fears, or unresolved personal issues to... [the] collected data" (p.54). At the same time, initial coding also encouraged me "to think about the material in new ways that may differ from research participants' interpretations" (p.55). At this level of coding the participants' unique terminologies were retained whenever possible in the form of "in vivo" codes (p.55). For example, one of the participants coined the term "reverse stigma" to describe the experience of being told nothing was wrong with him when he was trying desperately to find out what was preventing him from connecting with others. This term was retained and made into a coding category that applied to the experience of other participants who were not able to articulate the experience so clearly. Chenail (2012) warned that if codes repeatedly equal lines of text it might be a sign the researcher is becoming "overly organized by lines of words" rather than emerging themes and ideas (p.267), so if I found my codes corresponding with lines of text too frequently I would take a break and try to look at the data more creatively. Gibbs (2010), whose lectures about coding were very helpful, stated that it would be important to dimensionalize the codes with descriptive

detail, which I found helped crystalize emerging ideas and led to the next phase of coding. One way I deviated significantly from grounded theory techniques was in using some of Goffman's previously established concepts as codes. The themes he described were clearly present and I felt using his terms would provide continuity with the literature as well as provide colourful codes for clearly emerging themes. Grounded theory usually discourages the use of established concepts for codes so that the emerging theory is grounded in the data rather than the old theories.

The next level of coding (focused coding) was "more directed, selective, and conceptual" (Charmaz, 2006, p.57). This level of coding moved beyond line by line analysis and involved relating the initial coding themes and categories to each other in a coherent way. "Focused codes" were generated which reflected this higher level of conceptualization. A third form of coding (Charmaz retains Strauss and Corbin's term *axial coding*) can be used to further conceptualize the relationship of themes and "specifies the properties and dimensions" of the various categories to each other (Charmaz, p.60). This level of coding is supposed to involve the use of conceptual diagrams and flow charts (Morrow & Smith, 1990, as cited in Gibbs, 2010). Some researchers find this level of coding unnecessary (for example Hunter, Murphy, Grealish, Casey, & Keady, 2011a). Charmaz herself notes that axial coding can help "extend the analytic power of emerging ideas," but can also be "cumbersome" and "technical" (2006, p.63). I did find it necessary to engage in additional work at this level to make sense of the data, but I found axial coding to be vague as a procedure. In turning to the literature for help, I re-discovered Clarke's (2003) technique of situational mapping, which the author says she developed as way of "regenerating and updating" constructivist grounded

theory (p.553). Charmaz (2006) briefly mentions Clarke's technique and describes it as a method of developing "sophisticated situational analyses" (p.118), which strikes me as overly technical and not the kind of inspiration I was looking for to move forward. To me, Clarke's method provides a way to generate creativity and explore "messy complexities" (p.559) and "sites of silence" (p.561) in the data. The technique involves randomly placing various combinations of codes on a page as if they were inkblots. The idea is to engage with the map in creative ways, linking the terms to each other with differently coloured lines and writing memos about what comes up. I found I had a tendency to get stuck on categorical logic until I engaged in this process, which I found to be an experience in which the "art of research" could really come into play (Clarke, 2003, p.563). To make the technique work for me in this study, I constructed creative data maps as needed (Clarke calls them "messy situational maps"). I sprinkled the maps with initial codes I felt needed more meaningful conceptual inclusion as well as focused codes I felt needed further development. I placed a circuit board in the background because I found this inspired me more than a blank white canvas. The technique helped me incorporate my initial codes more creatively and to further develop my focused codes towards coherent theory. An example of one of these originative connection-focused research palettes is provided in figure 1 below:

Figure 1: Creative Data Map



The final level of coding (Charmaz retains Glaser's term *theoretical* coding), is the most sophisticated and provides theoretical structure to the emerging relationships amongst the focused codes. Charmaz describes how "theoretical codes may hone your work with a sharp analytic edge... [and] can add precision and clarity as long as they fit your data and substantive analysis" (p.63). It was at this level of analysis that grounded theory began to emerge. Care was taken to ensure the theoretical codes "earned their way" into the grounded theory by being rooted in the original data through constant comparison with previous levels of analysis (p.64). It should be stated that the resulting theory of stigma for Asperger's/high functioning autism does not pretend to be an explanatory theory with predictive value or a concise hypothesis as might be verified by quantitative research. The theory emerging from this study, rather, is a conceptual level of systematizing interpretation that makes sense of the data and sites of deconstruction within the data. In the current study, a theory will emerge about Autistic stigma grounded in the experience of individuals with this personality type. As Charmaz points out, this emergent theory may provide "a new twist to old theoretical clothes" (p.134), especially insofar as it expands on the phenomenological themes found in Goffman's seminal work on human interaction, Foucault's description of power relations, and Merleau-Ponty's phenomenology of human presence. I had thought the "theory" would emerge as a discrete level of codes and a separate level of presentation, but it merged with the presentation of findings and grew from there. It is hoped that this level of theory will provide insight at various levels to create further understanding of the phenomenon of social stigma and facilitate greater social inclusion, minimize exclusion, and result in better service provision for this population. It is also hoped the emerging theory will

provide a postmodern validating discourse that will be of assistance to those individuals struggling with the characteristics of autism and struggling even harder with the resulting stigma.

Write-up and Evaluation

Charmaz (1990) points out that writing up grounded theory research is not just a matter of representing already final results. Rather, she maintains the researcher “gains further insights and creates more ideas about the data while writing (p.1169). Creating the research report is yet another opportunity to work the theory out, since “writing is a method of enquiry” (Mills et al., 2006, p.12). In my experience, this certainly proved to be the case. For me, writing up the research brought the study to its culmination and ramped it up to fever pitch in a frenzy of expression. I found unforeseen connections and insights emerging on their own during the write up when I allowed the process to be as freely creative as possible rather than limiting it to a mechanical exercise of putting into words. Attending to each step of the research carefully and striving for methodological rigour throughout the project, of course, made this flourishing outpour possible in the final stretch. Although it was rewarding to see the project coming to life “in an organism of words” (Merleau-Ponty, 1945/2006, p.212), unfortunately this did not make attending to minute details of accuracy, organization, and finding better formulas of expression obsolete. All this work, rather than afterthoughts and technicalities, was part of how “writing and re-writing [became] crucial phases of the analytic process” (Charmaz, 1990, p.1169). In the rest of this section I will address how methodological rigour was built into the whole research process and how this can provide criteria to evaluate the project as high quality research.

Even though enthusiastic interpretive researchers have talked about a “qualitative revolution” that values the exploration of meaning and significance, in particular by honoring the voices of marginalized people (Denzin & Lincoln, 1994 as cited in Marshall & Rossman, 2011, p.2), others have pointed to a “positivistic resurgence” characterized by quantitative research that valorizes causation, prediction, statistical confirmation, outcome measures, and evidence-based practice (Brown & Strega, 2005, p.5). Trafimow (2014) points out that both qualitative and quantitative researchers “have been guilty of narrow mindsets” in not recognizing the value of both approaches (p.22). He recommends researchers have an orientation in both fundamental methodologies in order to further knowledge through each rather, thus maximizing the contribution of both rather than regarding each other as adversaries. For me, this operationalizes as the first criteria of high quality research; that is to develop a context that establishes in rational terms why a quantitative or qualitative methodology is the best way to address the gap in knowledge being examined by the researcher. Throughout this project I have tried to articulate why my study of ASHFA and stigma was most appropriately carried out with a qualitative methodology, specifically because it deepens and clarifies current understanding of a neglected area of research by developing insight through the experience of individuals who live daily with the phenomenon being studied. Quantitative studies may be better at confirming specific hypotheses about this phenomenon and establishing statistical tendencies in the data, but I decided that more insight grounded in the phenomenology of the condition was required to contextualize further research. Having determined qualitative methodology as the most appropriate way to address the phenomenon being studied, I then used Tracey’s (2010) eight criteria for high quality interpretive research.

Whether universal standards of evaluation can be applied to diverse approaches to qualitative research and what they should be has long been a subject of controversy (Gordon & Patterson, 2013). Tracey's criteria seemed applicable because they helped me address the research questions more poignantly.

Everything in rigorous qualitative research is connected; attention to ethics is related to research quality as is the use of sound, established methods that address the dimension of knowledge being sought in the study (Fossey, Harvey, McDermott, & Davidson, 2002). Throughout this report I strived to maintain and carefully articulate this kind of *meaningful coherence* between the different dimensions of the project, which I think is one of Tracey's (2010) most important criteria. I also attempted to build transparency into the project so my decisions, motivations, and rationalizations would be honestly and clearly conveyed. Such transparency underlies two of Tracey's criteria, which are the use of *rich rigour*, also evidenced by theoretical cohesiveness, and the effort to maintain *sincerity*. Her other criteria include the selection of a timely, significant *worthy research topic* (p.840), establishing *credibility*, for example by giving participants a chance to confirm the accuracy of the data (p.842), increasing the *resonance* of the project with readers, for example through evocative description (p.844), attending to *ethical issues* and attempting to make a *significant contribution* that builds substantially on existing knowledge in the area of research (p.846). I leave it to readers to determine if I have been successful in these areas.

In the interests of rigour and high research quality, enough detail was provided so the study could be replicated as far as possible (Moon et al., 2013). This report describes how memos have left an audit trail for others to assess research decisions, how the theory

can be seen to apply outside of the limited sample of participants, how participants have been consulted to check accuracy, and how the researcher's own location and critical reflections have shaped the study (Cooney, 2011). If another characteristic of high quality interpretive inquiry is that the researcher experiences some degree of personal transformation (Cresswell, 1998), then the insights and deepening of awareness I experienced as I worked on the project may also be evidence of quality research. It remains to be seen if social transformation will result from the study, even if only a few seeds of change are planted. I tried to constantly be mindful of one of the original criteria for assessing grounded theory research, namely that "it fits the situation and that it works, helping the people involved in the situation to make sense of their experiences and manage the situation better" (Glaser & Strauss, 1967, as cited in Cooney, 2011, p.18).

Chapter 4: Findings and Discussion

This research makes one thing perfectly clear. Stigma is a real experience that individuals diagnosed with Asperger's/high functioning autism must contend with on a regular basis. Butler and Gillis (2011) found "the label of Asperger's Syndrome [does] not significantly impact stigmatization" (p.745), which they found confusing in light of research like mine indicating that individuals with Asperger's experience stigma. The participants in my study, however, clear this confusion up by showing that stigma is overwhelmingly associated with the symptoms of their condition rather than the label. This result colludes with the Butler and Gillis finding that stigma is correlated with symptomatology rather than diagnosis, but as a quantitative study not exploring participant experiences the significance of this finding did not sufficiently emerge. Stigmatization due to symptoms rather than diagnosis was reported by individuals in my study who had high functioning autism as well as Asperger's, even though participants agreed that higher levels of stigma are associated with autism than Asperger's (a finding confirmed by Kite et al., 2013).

The current study also generated findings consistent with the position that early diagnosis can improve outcomes (Stoddart, Burke, & King, 2012; Goldstein & Reynolds, 2011; Attwood, 2007). Participants in the study who were diagnosed early in their lives reported high levels of comfort with themselves and described a hard-won equanimity for "working with and around" the symptoms of their diagnosis. Most of the individuals who were diagnosed later in life wished they had been diagnosed earlier because they felt it might have helped them understand the stigma they were experiencing. Participants

from families with sufficient resources to access private counsellors, occupational therapists, and nutritional supplements were diagnosed earlier and reported better self-esteem as well as significant symptom reduction through the years. Such findings stimulate reflection about social justice since they associate low income with poor outcomes. Initial impressions, however, only go so far. In this chapter the full complexity of the research findings are presented in terms of the themes and concepts that emerged. These themes will be grounded in the raw data and frequent quotations from the interviews will be provided for evidence. In the final chapter I will attempt to formulate theory around the findings as well as the silence at the heart of the findings.

Table 1: Organization of Research Findings

<u>Focused/Theoretical Codes</u> <i>(Emerging Themes/Ideas)</i>	<u>Representative Initial Codes</u> <i>(Designated snatches of data)</i>
Phenomenology of Stigma	exclusion; feeling stupid; loneliness; made fun of; rejection; desperation
Stigma Resilience	self-acceptance; right questions; supportive family; doctor knows me; importance of parents/teachers
Diagnosis and Reverse Stigma	told nothing's wrong; not believed; medical explanation; validation; search for explanation;

Frustigma	neurodominant frustration; stigma acts; need for logic; confusion
Diffability	difference or disability
Interacting Stigmas	Asperger's the worst; hard to explain; not knowing what's wrong hierarchy of stigma
Stigma Cloaking (Goffman's dramaturgy)	
Cloak of Invisibility (Goffman's passing and covering)	pretending to be normal; keeping secrets learning what doesn't come naturally
Cloak of Intelligence	smarter than everybody else; jealousy
Cloak of Helping	pride from helping; being of service
Cloak of Humour	laugh with everybody else
Cloak of Outrage	anger towards neurodominants
Cloak of Labels	refuge of labels; re-labeling
Cloak of Safety (back places)	island of misfits; blend in
Service Resentment	no services; ineffective services; patronizing; conflict of interest; lack of knowledge; barriers

An additional ethical issue associated specifically with the presentation of findings should be discussed at this point. I had to be very careful not to use language with an underlying tone of stigmatizing diminishment. I would catch myself using judgemental language sanctioned by society that could be potentially hurtful. My test was to imagine whether I would verbally repeat written statements to individual participants if we were face to face in a Gad-Pontyan spirit of communicative solidarity. Descriptions such as “lower functioning” and “lack of insight,” for example, were never acceptable when used in association with participants. An attempt was made not to privilege dominant discourses, for example avoiding the deceptive “objectivity” of medicalization, and by not employing language that would only make sense from an “elevated” position relative to those diagnosed or struggling with autistic symptoms. Formal ethical guidelines and codes of conduct could not help me with this emerging ethical issue. Kittelsaa (2014) encountered the same challenge in her research on intellectual disability and stated “it is important that people who are perceived as belonging to marginalised groups should not be described in ways that increase their burdens or position them in an unfavourable light” (p.34). The care taken with this issue in research can be seen as a microcosm of the effort called for in everyday life not to further stigmatize or re-victimize already disadvantaged and oppressed individuals. Few of us would kick a person with a broken leg or dump a paraplegic out of their wheelchair. Part of the problem with Asperger’s and high functioning autism is that the stigmatizing condition may not be as immediately apparent as the discomfort felt in the presence of these individuals as a result of their impairment or difference. The violence of stigmatization can occur without awareness.

Phenomenology of Autistic Stigma

Perhaps the most logical place to start reporting the findings of the current study is with the phenomenology of stigma. Participants gave poignant descriptions of the bodily felt shame and rejection resulting from their condition. One participant described an experience of being ostracized for no known reason:

When I went to a bar the first time, I talked to them and said hello to people. Then when I turned around they complained about me and I was shown the door. I was asked to leave...they complained behind my back. They didn't talk to me, they just didn't feel comfortable with me around them. They made complaints behind my back and club security said it was time for me to go.

The same participant said he had heard himself being called "retard" on a number of occasions. One participant graduated from college on the dean's list but never got a call back from a job interview. Another reported that he had responded to more than 200 profiles on a dating website yet only went on 3 dates. Participants reported extreme difficulty making friends, not being heard, and not being included. "Most people just don't bother talking to me," said one participant. Another stated that he got "the cold shoulder" from people regularly and voiced a common theme when he said "I just don't seem to fit in." Another said "people don't want to include me; they make false and

misleading assumptions about me.” Another said “people show utter contempt towards me for no reason.” One participant said he was worried about his long term health because of all the rejection he had experienced through the years.

The phenomenology of stigma in Asperger’s/high functioning autism is not a simple litany of exclusion, however. The point of discussing these experiences is not to invoke sympathy or to portray people with this condition as victims. The research had only six participants but generated a long list of enacted stigma, or examples of how stigma is manifested towards ASHFA individuals. The study tried to get beneath and between these examples in order to explore the fundamental margins of personally felt stigma. Data analysis indicates that much of the stigma ASHFA individuals experience may not be a direct result of visible differences, but rather a consequence of not meeting deeply ingrained social expectations. Participants consistently reported their stigma to have roots in the space between symptomatology and social interaction.

Sociologists point out that “cultural scripts” involving unwritten social rules are integral to society and are “learnt through continual processes of engagement and interaction” (Scott, 2006, p.186). When these unwritten social rules are broken, not only do the perpetrators themselves feel uncomfortable but “habitable reality shrinks until everyone feels small or out of place” (Goffman, 1967, p.108). The resulting discomfort can lead to enacted stigma as well as felt stigma. Social rule theory is not just an established sociological field of knowledge (Calhoun, Gerteis, Moody, Pfaff, & Virk, 2012), but a recognized dynamic to be managed, for example, in politics as well as local and global business transactions (Chinomona, 2013). Goffman, whose insightful phenomenology of stigma does not directly address Asperger’s/high functioning autism,

writes primarily about the interplay of these social rules. He points out that “the penalty for breaking the rules is harsh” (1966, p.248). Individuals with Asperger’s/high functioning autism pay this penalty all their lives.

There are continuously variable levels of what Goffman calls the “visibility” of a stigmatizing condition (1963, p.48). For individuals with Asperger’s/high functioning autism, their stigmatizing condition is often invisible and may be sensed rather than explicitly seen. Not as explicitly apparent as, for example, a facial birth mark, there may be perceptible signs of difference such as lack of eye contact, inappropriate eye contact, overly pedantic speech patterns, or cognitive rigidity and self-absorption. These symptoms exist along a continuum and can blend indistinguishably with mainstream expectations, but when they become clear markers of difference some dominant others may seize on these visible signs of difference and take them as an excuse for enacted stigma such as bullying and discrimination. There may be other qualities possessed by a person with Asperger’s/high functioning autism that make them appear vulnerable to manipulation (Attwood, 2007). One participant spoke of the naïve trust for others he experienced when he was younger. Others spoke about obsessive interests they find difficult to put aside when interacting with others. One participant said he “tries to find common ground in conversation,” but admits “it’s difficult to do unless it’s about topics that interest me.” Depending on the person and the situation, some people may see these qualities as positive traits. Others may feel they call for compassion (or rescuing); some dismiss the person exhibiting these qualities as lesser than themselves; others take outright advantage. Between the participants and myself, the individuals in this study have experienced all these reactions.

More fundamentally, all the participants in the study spoke about how they often find themselves at a loss in social situations. One participant said she often felt “stupid” and found herself “in tears a lot of the time trying to understand what I was supposed to do” in social situations. Another participant talked about the challenge of trying to logically construct how he was supposed to act in social situations. “I just find myself telling myself in my head things like ‘OK, now listen for a bit, add something now, don’t rebuttal here,’” he said. This experience of constituting social behaviour was most apparent in the complex area of dating. One participant described how “there are a lot of non-verbal cues and expectations going into dating. Do we kiss? Do we hold hands? I never quite know what do.” Phenomenologically, individuals with Asperger’s/high functioning autism seem to experience a kind of social blindness regarding conventions others take for granted and have come to expect. ASHFA has been characterized as a condition involving “difficulties in the spontaneous processing of social information” (Channon, et al., 2014, p.161). Again, dating provides a poignant example. One participant described being in an intimate situation with a member of the opposite sex. He says he was just starting to like her, but got confused at one point because she was standing before him with her eyes closed as if expecting a surprise. He had no idea what was happening, but closed his eyes to play along. The moment passed and he could not figure out why she never acted the same towards him again. It wasn’t until years later he realized he had rejected a woman expecting to be kissed. Another participant told how he once bought tickets to a special event long in advance hoping to get a date. Strategically, he asked one of the plainest girls he could think of hoping that she, at least, would go out with him. He did not interact with girls and had not engaged with this girl at all in the

past. Understandably, she refused him. The participant said he was sad when he went to his next class, where one of the most popular girls in the school sat next to him. He asked her if she would like to go to the upcoming dance and remembers how she said “yes” enthusiastically. Did he smile happily? Did he feel lucky? No, he handed her his tickets and told her to have fun. The participant said he thought about this incident for years and could never understand why the girl seemed to want nothing to do with him after that. He said he did not realize until years later that he had unwittingly asked her on a date only to reject her. After “getting it,” he said he mourned the lost opportunity and felt colossally stupid, although he never mentioned being sorry for hurting her.

Dating complexities notwithstanding, such misunderstandings were a commonly reported theme with participants. A relationship seems to be going reasonably well until something happens and from that point on others are not the same towards you. At such times interaction assumes an air of “wrongness” and befuddlement. Discomfiture floods the relational space; a transgression of neurodominant social convention has occurred. The degree of awareness that a transgression has taken place on the part of the ASHFA individual, however, varies.

Individuals with Asperger’s/high functioning autism receive feedback about transgressions of conventional social expectation in various ways. The other person may become angry that they have been treated in a way that seems impolite or disrespectful. They may begin to regard the ASHFie (individual with Asperger’s/high functioning autism) as odd or strange and distance themselves accordingly. Feedback can be immediate or delayed, but it may be years later if at all that the ASHFA individual understands the implications of the episode. Regardless of the other person’s reactions,

social transgressions are perpetrated in four ways. Some are *hapless* violations, in which the individual is not only unaware of the nature of the transgression but the fact that there has been a transgression at all. One participant spoke about having absolutely no clue about the reason for the “allegations” of social impropriety often made against him or why he finds it hard to make friends. ASHFie’s experience this frequently, sometimes due to lack of insight into the rules being transgressed and other times due to lack of reflection. Once I had a neighbor who I spoke to from time to time when we met in the driveway. I often feel proud of myself for engaging in small talk, as if it were some kind of small victory, because it is so uncomfortable for me. Perhaps this is because of my younger days, when anxiety made speaking to others for anything other than need-fulfillment almost impossibly difficult. Even at 56, when my anxiety is much less and I have learned to manage it effectively, the simple nicety of small talk with a neighbor presents a barrier to be overcome. I thought I had a decent casual relationship with this neighbor until my wife asked me one day why I was being so mean to him. I was shocked. I asked her to explain what she meant. She said I didn’t ask him how he was, I didn’t seem interested in what was going on in his life, and I was always abrupt. I had no idea. She had spoken to the neighbor that day and he had told her a story about one time when he offered to have a beer with me and I just said goodnight and went in the house. He said he was quite hurt and offended. I could remember that time. He hadn’t come right out and said “do you want a beer?” In hindsight, I could see how he had alluded to having a beer with me because he was having one and said he had more. I had not broken a rule of social conduct intentionally, but I had affronted someone by ignoring their invitation when I did not recognize the double meaning in his approach. I had also not

been on the lookout for his invitation because it was not even on my radar. This is ironic given all the times in my life when I was dying to get a social invitation and felt passed over. The next time I saw the neighbor I apologised profusely. This is when I told him about my Asperger's. He understood and we had a laugh. This could be termed a late catch discovered through third party intervention, and it makes me wonder how often this kind of thing must go by without my knowledge. The only evidence of such hapless violations of social conduct are people who don't seem to like me, who avoid me, or as one participant put it, act as if I'm "not worth bothering with at all."

Channon, et al., (2014) cite multiple studies demonstrating that individuals diagnosed with Asperger's/high functioning autism score consistently lower on tests eliciting an explanation of what makes certain social situations awkward, identifying inappropriate social conduct, and working out the significance of human behaviour. The authors point out that such findings may be associated with "inappropriate responses in everyday social situations, but little experimental work has explored this directly" (p.152). My research, let alone my whole life, tends to confirm this pragmatic leap. Difficulty processing complex linguistic constructions such as double entendres, irony, and sarcasm are characteristic, but the difficulty extends beyond the use of language and causes frequent misadventure in lived social situations. Not all social blunders leading to stigma, however, are totally hapless on the part of individuals diagnosed with, identifying as, or struggling to function in a neurodominant world with characteristics of ASHFA.

There are also *willful* violations of social conduct. Whereas hapless violations usually take place in the minefield of subtleties involved with social interaction, willful violations more often occur with clearly identifiable patterns of behaviour. One

participant said he often refuses to participate in conventions such as greetings and celebrating birthdays. He reports he has taken flack for this but has resigned himself willfully to the situation. “I’m now at the point where I can say ‘that’s a neurotypical ritual and I’m not participating in that’, most importantly the sorry rituals and the greeting rituals,” he said. Another participant asked “why would you ask how I am when you don’t care, and why would I ask when it makes no difference to me?” Sometimes this involves avoidance of uncomfortable situations. Sometimes it is due to a genuine feeling that the social conduct in question is “illogical.” Sometimes, like with birthdays and anniversaries, it is hard to remember events that are important to others and we just don’t bother making the effort. At other times, willful violation is to make a point, for example to challenge stigma. One participant said he often “sticks my neck out to challenge stigma” by calling attention to questions no one seems to be addressing, identifying populations that are being neglected, or pointing out patterns no one seems to want to acknowledge. In this participant’s volunteer work with the HIV community, for example, he has come to believe there are “unwritten rules about asking big questions.” Bravely, though, he continues to ask them. He says he chooses to ignore the advice he was given when he graduated college to “keep my mouth shut:”

There are countless studies that I think are all connected together but they can’t see the connections and they choose to ignore it. I have to ask why, and this gives me my reputation as ‘the social critic’ ...there are a whole set of false rules, social rules, and social paradigms we have

to live under. It's very easy to say I don't subscribe to those paradigms, but then I leave myself open to stigma and discrimination.

A third category of social code transgression might be termed *precarious* violations. These seem to be closely related to willful violations but their intentionality differs; in particular, they don't involve an element of conscious defiance. Rather, they involve a blurring out which often has unpleasant social consequences. Here I am not referring to the blurring out that happens in Tourette's syndrome, with which one of the participants was diagnosed in addition to Asperger's. This participant talked about his frustration when socially frowned upon terms and statements seem to "slip out like a sneaky fart." Such involuntary social violations are independent of the complexity of social interaction. Still, the participant's tendency to experience such social transgressions exacerbates the kind of stigmatizing violations inherent with his Asperger's and may lead to greater experiences of stigma. The quantification of stigma, however, was not pursued in this project.

Precaious violations occur when ASHFA individuals blurt, rant, tattle, or pontificate about issues that seem perfectly logical to them but violate codes of polite restraint or expected conduct. One participant talked about how careful he has to be to "think about what I'm going to say before I just blurt out an inappropriate statement or something." The need for this kind of restraint is not particular to ASHFA individuals; I'm sure everyone is familiar with this experience. As is often the case, however, ASHFA provides an extreme example of the familiar. Rather than occasional blunders associated

with carelessness, personal agendas, misunderstanding, or isolated lapses of impulse control, ASHFie's regularly get themselves in trouble with their habitual incapacity, or seeming incapacity, to recognize what is supposed to be socially appropriate. One participant talked about how he would always get himself into conflict with teachers, for example:

Sometimes you can listen to people and they'll say things that are wrong or incorrect or just kind of dumb. Some people can sit there and kind of politely nod. I just have to go out and call them on it.

Sometimes this kind of violation involves throwing caution to the wind in order to make a point. In such cases they become willful violations. Reflection on the consequences of previous experiences with this kind of blurting can prevent social incidents, regardless of the logic involved. Precarious violations involve an impulsive carelessness in favour of making things more logical, orderly, and correct in the individual's eyes. These violations often involve a certain pomposity or self-righteousness that immediately brings on the kind of stigma characteristic of ASHFA (which I will describe below as *frustigma*). I suspect I was guilty of such a violation on one of my first days of class in postgraduate social work. The professor had just explained a certain categorization of social paradigms or some such thing. I thought about it carefully and came up with what I thought was a much better way of doing it. I went up to her after class and critiqued her system as if I were an expert. I thought this would

improve her system and show her I was listening. Instead, I felt this professor never regarded me in quite the same way again. I could not put my finger on it exactly, and I'm not sure she was aware of it, but I felt somehow disliked by her after that incident. It is not that being liked by her was particularly important to me, but years of stigma have sensitized me to the feeling of being disliked, regarded negatively, or disregarded entirely. Another kind of precarious violation occurs when an ASHFie discovers a fact or statistic they find intriguing. They may blurt it out inappropriately when an unsuspecting readily available person is busy doing something else or when a conversation is totally unrelated. In these cases, it is not initially dislike but a sense of detaching confusion and sometimes demeaning judgement that emanates from other people. I completely identify with the participant who said he restrains himself with internal narrative such as "don't say anything, don't say anything, don't come off like a smart ass again." ASHFA individuals often work hard at self-presentation in order to manage stigma, but it inevitably seems like a losing battle based on faulty intelligence.

One final category of stigma-producing social code transgressions reported by participants are *telegraphic* violations. These seem to involve the most intense source of bodily felt stigma aside from bullying and outright victimization. These violations involve being flustered due to the sense that something incongruent has happened, although the individual cannot say what. It involves a feeling that something is wrong, that "I've screwed up again." One participant says "anything where I have to interact with others is hard for me" and involves "feeling stupid." The individual can tell they've made a comment, or not responded when they should have, or don't know how to respond, or perhaps made a gesture that has not gone over well. They feel "threatened"

and sometimes “overwhelmed” with a feeling of being “put in the spotlight” for their inability to grasp the unsaid that others take for granted. Their inability to fit in, or the incomprehensible barrier to fitting in before them, is accentuated and dramatized. They may feel like “disappearing into the floor.” It is not the violation of social conduct in itself that is distressing; it is the feeling of being exposed for “not getting it.” In this case ignorance would be bliss. Hapless violations are much less painful. Another participant describes telegraphic violations in existential terms that evoke a feeling of crisis:

Although we don't have the ability to know what someone is thinking, we are acutely aware when people are waiting and judging. Their being can actually put us into a meltdown. There's a disconnect between what's being said and what we're sensing, although we can't articulate it. If somebody is saying something that has a double meaning, for example, and I'm taking it in the literal form while they're meaning it in a non-literal form, I'm going to sense they're intending something else than what I'm hearing. I'm not able to clue into the intended or implied version, so that will send me into meltdown because I know I'm not getting it because their being is telling me I'm not getting it. It's an emotional reaction that I sense in other people. I just know something's not right and I get overwhelmed.

This experience may be related to the “all powerful glance...from behind each eye [that] can be said to eat away at the flesh” (Foucault, 1963/1998, p.81). Here again, at any

rate, exploring the sources of stigma in autism can inform us of ourselves. The experience of flustering that accompanies telegraphic violations resembles the experience of embarrassment explored in phenomenological detail by Goffman (1967):

a completely flustered individual is one who cannot for the time being mobilize his muscular and intellectual resources for the task at hand, although he would like to; he cannot volunteer a response to those around him that will allow them to sustain the conversation smoothly. He and his flustered actions block the line of activity the others have been pursuing. He is present with them, but he is not "in play." The others may be forced to stop and turn their attention to the impediment; the topic of conversation is neglected, and energies are directed to the task of re-establishing the flustered individual, of studiously ignoring him, or of withdrawing from his presence.

(pp.100-101).

It has been noted that Goffman's insightful descriptions of experience are "as true now as when they were written" (Ewing, 2013). Yet his discussion of social flustering, however apt, is not directed towards ASHFA. Goffman goes on to say that an embarrassed person will "sense what sort of conduct *ought* to be maintained as the appropriate thing" (p.105). Imagine how much worse the experience must be for

someone who is completely lost and has no sense of what is supposed to be appropriate. This “disqualifying attribute” of differently constituted social apprehension was not considered by Goffman, although it sounds like he might be describing the experience of Asperger’s when he adds that

The person who falls short may everywhere find himself inadvertently trapped into making implicit identity-claims which he cannot fulfil. Compromised in every encounter which he enters, he truly wears the leper's bell. The individual who most isolates himself from social contacts may then be the least insulated from the demands of society. (p.107)

It is an autistic catch 22. In regard to telegraphic social code violations at least, the more invisible the condition, the more intensely stigma may be experienced. Shtayermman (2009) found a strong negative correlation between AS symptomatology and stigma. As discussed in the literature review above, he tried to account for this by saying the experience of stigma in Asperger’s/ high functioning autism must come from the diagnosis and not the symptoms. However, all the participants in this study felt the stigma they experience comes from the symptoms rather than the diagnosis. Another explanation for Shtayermman’s finding may be that the invisibility of their difference/condition sets up incongruent expectations with others. The more hidden the difference/condition of ASHFA, the higher other’s expectations may be (in Goffman’s terms, the more the individual makes “implicit identity claims”) that make telegraphic

violations all the more pronounced. The experience of stigma may go up as the visibility of the stigmatizing condition goes down. This was a trend in the data of the current study, and the opposite of stigma in the case of epilepsy, for example, where more intense and frequent seizures (higher visibility) result in higher stigma (Bandstra, Camfield, & Camfield, 2008).

I have had this experience all my life. No matter where I go, at first I seem to fit in normally. Then there are a combination of hapless, wilful, precarious, and telegraphic social incidents that lead to a growing sense of stigma and exclusion. Willful and precarious violations can be minimized with a certain amount of effort, for example at work where the consequences of social blunders can be high. Hapless and telegraphic incidents, however, are inevitable. In addition, the stigma of these violations can be exacerbated by other, sometimes more visible characteristics of ASHFA, not only like eye contact but issues with sensory processing (Shankar, 2013) and emotional regulation (Laurent & Ruben, 2004; Samson, Huber, & Gross 2012).

Stigma can accrue from repeated errors, oversights, and apparent clumsiness resulting from impairments in “executive function” (Cumine, Dunlop, & Stevenson, 2010, p.31). Not all the participants reported this, but I know I tend to make little mistakes in my administrative duties frequently, such as reversing numbers, filing things in the wrong place, looking at the wrong date on the calendar, and confusing appointment times. This is part of the reason I found the data gathering stage so challenging; I had to take careful steps to make sure I kept everything straight. The people at work are too polite to say anything, but I know I have a reputation for these lapses. People may blame this tendency on laziness, sloppiness, not caring, or even insubordination. I put all kinds

of backup plans in place, such as double checks and cross checks, often taking on extra tasks to prove I'm not lazy and that I take my job seriously. In doing so, I am attempting to avoid as much stigma as possible. It's as if overcompensation buys additional tolerance for unavoidable lapses.

Hyper or hypo sensitivity to sensory stimuli is one of the hallmarks that may be present with autism spectrum disorder. Not all ASHFA individuals have sensory episodes, but more than one participant in this study reported having sensory "meltdowns." One participant describes these episodes graphically:

I mean if I'm having a bad day, or on a very sensitive day, the floor and the lights are...I mean you can almost feel them pulsing in your skin after a while and it just drives me insane and I can't do it. I just have to go back to my room and before I know it I'm lying on the floor in my underwear clutching myself in the dark listening to something on the stereo trying to de-stress...it's the worst when I obviously need to leave the room and can't really leave the room that I start to panic and I just absolutely crash.

Again, not everyone ASHFA has this, but difficulty with emotional regulation can be another embarrassing source of stigma. This can lead to other kinds of meltdowns. Whenever I feel challenged or unexpectedly put on the spot, for example, I get flustered.

I can't seem to think clearly, as if the power to my brain has been cut. One participant said "think of it as the main command and control computer being locked out of all the peripherals." My head shakes involuntarily. I may get defensive and stammer. It takes a real effort to counter this, but no matter how herculean an effort I make, I am acutely aware of my ineffectiveness. I would like to think no one notices, and no one usually talks about it afterwards, but I can usually tell people are wondering what's going on. In one such encounter recently (about nothing particularly important) I remember taking shaky sips of coffee in rapid succession well after the cup was empty in an effort to hide my discomfort. This could be described as a *defensive* meltdown, and it may be exacerbated by anticipatory fear of a stigma episode. Participants also described meltdowns when they felt overwhelmed with information, demands, or lack of personal space. As one participant said, it can be an "absolute tailspin panic." These could be described as urgent meltdowns because they involve a desperate impulse of fight or flight. One participant described a time when he was being bullied as a youngster and experienced "one of those Berserker rages." This was a particularly dramatic meltdown, and friends later told him he beat the bully off with uncharacteristic aggression (although he says he has no memory of what happened). These episodes may or may not be visible, but they can escalate to the point where they can be stigmatizing as an observable event comparable to an epileptic seizure. In these cases stigma and symptomatology would have a positive correlation.

If an ASHFie is lucky, they find an environment where they are accepted despite their lapses and diverse episodes. Even then there may be stigma. It can come up as a glass ceiling at work, a tendency to get the raw end of the stick, not be consulted in

matters that concern them, or the observation that other people's opinions are being taken more seriously. There seems to be a silent agreement to not talk about these phenomena.

Stigma: Where Resilience meets Oppression

The participants discussed various ways they build resilience to stigma. Some involve learning strategies and behaviours that make relational interaction flow more smoothly with less social transgressions. One participant, for example, said "over the years I have learned that people like it if you let them talk more." Another said "I usually find another good thing is to ask people to talk about themselves." Others talked about learning to make better eye contact and not stimming (self-stimulating) in public. Learning neurodominant conventions of social interaction, however, can be unnatural and self-defeating, not unlike forcing a left handed person to use their right hand. The participants talked about having to "fake it" all the time, which takes a lot of energy. One lamented "I have grown up being someone I'm not." These kinds of strategies, which might be called "performing normality" (Lester & Paulus, 2012, p.267) can make life easier all around, but they can also be adopted as a protective shield against stigma that makes neurodominants feel more comfortable while it drains the energy of the ASHFA individual. One participant made me think here of a video game in which a certain number of positive rewards must be accumulated to keep the shields from dropping. Such behavioural strategies, which are often seen as a helpful learning of skills to improve communication, insidiously merge with protective self-defence measures. When employed as bulwark against stigma, such strategies can become efforts of negative assimilation, attempts at self-camouflage, and even auto-annihilating acts of self-denial.

Foucauldians might refer to such acts as examples of self-managing bio power, a kind of “relational power that sustains itself through its own mechanisms” (Foucault, 1975/1995, p.177), a “synaptic” or “capillary form of power” (1980/1993, p.39). In his later work, Foucault came to refer to such strategies as “practices of the self” (Foucault, 1984/1994, p.282) and “techniques of the self” (Foucault, 1980/1993, p.203). The efforts to “blend in” reported by participants in this study can be associated with a will to conformity that is disciplined by stigma. Further strategies of this kind reported by participants will be discussed in the section on *stigma cloaking*.

Participants generally agreed that the use of such stigma cloaking becomes less urgent with age. One participant said “I allow myself to do more, I guess, autistic things as a get older. I have come to know that for me it’s normal, so I don’t really care anymore.” Another participant said “I’ve just come to the understanding that I’m weird and that’s O.K.” A third participant emphasized that “it’s really important to know where your boundaries are and when, where, and how to push them.” Such self-acceptance was reported by participants as building a core of fundamental stigma resilience that grows with experience and maturity. The only exception to this was one participant who reported intense anxiety that made her experience of stigma seem to worsen with age. Her experience will be discussed in the section on intersecting stigmas.

The importance of “getting out and talking to people, especially around events that are based on food” was discussed enthusiastically by another participant. He advised that “when you want to go and do something, just do it.” This participant was very active in the community, participating in sports and other events. He also described how stigma can be encountered in the community, so getting out takes a certain amount of courage as

well as equanimity. He says “some people don’t want to talk to me and some people ignore me...I just try to talk to the people who want to talk to me, and the ones who are not willing to talk to me I just ignore.” This may sound like nothing more than common sense, but for someone who deals with stigma regularly it is hard-won wisdom. I find attending social events an anxiety-provoking invitation to rejection and stigma, and many of the participants stay home for the most part, only going out when necessary.

Developing an attitude in which you focus on positive interactions and not stigma and rejection necessitates drawing on inner strength and takes practice. Another stigma resilience factor discussed by participants in this regard is spirituality. The above individual participates in a spiritual healing community on a monthly basis. Others attend church, and others talked about the importance of developing a sense of “purpose and meaning.” For some this involved social interaction, for others it was intensely personal in nature. Every ASHFA individual is unique.

The importance of caring, supportive adults during childhood was also specifically mentioned by participants. Parents, in particular, were described as either setting up stigma resilience or stigma sensitivity depending on whether they were able to foster secure attachments. This is not to say that parenting styles can cause autism, which was debated for years and originally suggested Leo Kanner, an early pioneer in the identification of autism as a disorder (Lambrechts, Leeuwen, Boonen, Maes, & Noens, 2011). Supportive parents can make a positive difference in anyone’s life, but parenting a child with autism is fraught with challenges that can make it difficult to be consistently available and supportive. Research has shown that parents of autistic children report higher levels of stress, more mental health issues, and lower satisfaction with work (Watt

& Wagner, 2013). One participant reported that the parents of many of his autistic friends separated “because they couldn’t handle the stress.” He added that “I’m lucky because my parents just kind of rallied around the fort.” His parents were also privileged and had access to resources none of the other participants in this study had access to. Building stigma resilience is not only a matter of individual tolerance and well-being, but systemic factors such as access to resources influenced by socio-economic standing and government policy. This will be discussed in more detail below.

Teachers were also mentioned by participants as either building stigma resilience or making stigma worse. Specifically, one participant said “everything changed” when he got a teacher who encouraged him to pursue his obsessions and directed his energy into special projects that boosted his self-esteem as well as his prestige among peers. Another participant described how the principal of his school added to his experience of stigma by unintentionally colluding with the bullies at school by not recognizing his victimization:

I remember once being out on the playground and these kids grabbed my book and then they literally held me down and beat me up. We got sent to the principal’s office and the other kids are just sitting there while I’ve got blood coming down my nose and the principal says ‘well, fighting is a very serious thing.’ So I’m thinking like, do you know what’s going on at all?

Developing friendships is notoriously difficult for this population, yet one participant talked about how lucky he felt to be supported by friends throughout his life. He specified, however, that “I’ve been very lucky that a lot of my friends haven’t been neurotypical, so we’ve just been a little slow with each other.” His mother used to refer to him and his friends as “the island of misfit toys,” and used to joke with the participant that “you could line up a hundred people and I would find the weirdest one in the group.” Having friends who are also diagnosed or struggling with symptoms of autism provided this participant with a common ground of understanding as well as a social arena without the stigma and incongruent social expectations of mainstream others. The participant described it as “a weird comrade in arms thing.” Here the theme of telegraphic perception emerges again; how do individuals diagnosed with autism or struggling with the symptoms of autism recognize each other? In the absence of visible symptomatology, how do victimizers recognize the vulnerability of high functioning autistic individuals? It would be interesting to explore these questions further.

I was fortunate in this study that one of the participants had a room-mate who expressed an interest in being interviewed. One was diagnosed with Asperger’s and one with autism. They not only agreed to be interviewed together, but chose to be present during each other’s interview. It was inspiring to watch them support each other, stimulate each other’s ideas, and provide each other with a safe, caring environment. When one was asked about whether he felt he could contribute his strengths as a person to the community, he could not think of his strengths. His roommate immediately piped in and suggested “you should tell him that you’re a Special Olympics athlete.” When one told about an experience with stigma and how upset he was that no one would tell him

why they were upset with him, his roommate jumped in with “maybe it was because they were jealous of something you had that they didn’t.” When one of them was talking during the other’s interview, the other picked up the recorder and held it closer to his roommate to make sure his voice would be heard. Love relationships involving ASHFA have been explored (Aston, 2003; Stanford, 2003); long term relationships with non-romantic peers have not. Klin et al. (2000) note that long-term relationships with peers can be a source of stigma resilience, although they acknowledge they are only drawing on anecdotal evidence. The authors suggest “peers do not make explicit demands, but they also make few allowances” (p.397). The two roommates I interviewed seemed to make allowances for each other’s uniqueness out of familiarity and mutual understanding. When asked the advantages of having an ASHFA roommate, they both immediately agreed that “finding a roommate that won’t lie, cheat, or steal from you is worth more than their weight in gold.” They each described instances of being taken advantage of and outright robbed by neurodominant roommates. I suspect an ethnographic study of roommates on the spectrum would probably be an insightful source of information about an under-documented area of stigma resilience. Both were on income assistance, and because of low assistance levels, finding a roommate in such instances can be almost as fundamental as the need to pick up groceries.

One of the participants in this study had been married to an individual of the opposite sex also diagnosed with Asperger’s for ten years. Another had been with a neurodominant same-sex partner for about ten years. Each described different challenges. The intimacy involves complications and issues that roommates, obviously, do not have to deal with. The participant with an autistic partner reported that “we have tons of

communication issues and there are many misunderstandings. We each have problems with getting frustrated when the other interrupts what we are focused on because we get so intense we can't switch to something else and then switch back." The participant with a neurodominant partner enumerated several issues over which his partner gets frustrated with him. He said "I can't validate," meaning he did not feel able to provide his partner with emotional validation. He said his partner gets angry because the participant is on the computer too much and "can't see obvious little things," such as items on the floor that need to be picked up. He also spoke about frequent conflict resulting from his routines being broken. My own neurodominant wife often says she feels like she's the one who has to live with Asperger's because I am so oblivious to the frustration and emotional isolation she experiences because of my condition. Yet no matter how intense or challenging, no participant reported their relationship to be a source of stigma. Rather, the intimate relationships discussed in this study were reported as a refuge from stigma where, as one participant said, "someone can accept me no matter what." Again, an ethnographic study of these various combinations of autistic relationship would probably provide a great deal of insight into how autistic and neurodominant human beings differ, touch, and inform each other. It would be interesting to explore how this insight could shed light on how stigma is generated and sustained.

Diagnosis, Reverse Stigma, and Dominant Discourses

One participant said his relationship was particularly challenging at the beginning because "there was a lot of expectation for me to be able to perform at his level." Since

being diagnosed with Asperger's, however, he says his relationship has improved because his neurodominant partner is "able to compensate since he knows the name of the condition." Now, says the participant, his partner can "play the autism game." Knowing the symptoms of Asperger's, his partner can make allowances and understand the participant's behavioural differences. This is true even though the participant and his partner struggled for ten years in the relationship without a diagnosis. Couples continue to struggle after a diagnosis, I can attest, but with more understanding and access to a community of peers for support. These validating, explanatory, and unifying functions of diagnosis were reported on an individual level as well. One participant lamented how difficult it was to function in his life before getting a diagnosis of Asperger's at age 42 because he always knew there was "something different or strange about me but I did not know what." Participants diagnosed later in life agreed the label had a powerful therapeutic impact because it provided an explanation for their history of living on the "margins of normality" (Portway & Johnson, 2005, p.73). One participant said "I think I would have been more successful in the past if I had had that word" (meaning autism). Along with gratitude for this explanatory function of diagnosis, however, goes resentment towards professionals for not helping facilitate a diagnosis sooner. Described by one participant as an experience of *reverse stigma*, he reported that in hindsight it was "the same intensely wrong feeling" as stigma when he was told over and over that nothing was wrong with him when he was seeking an explanation for his difference:

Is it reverse stigma, you know, when you're told
you're fine and you know inherently you're not? That is,

when I'm different and I can't communicate how I'm different and no one can help me? When I don't know how to move forward and all I can do is put one foot in front of the other and professionals keep telling me I'm fine? Is that reverse stigma?

Another participant talked about how “people who don't know much about autism sometimes disbelieve my diagnosis and think I'm just being silly.” Unfortunately, often helping professionals that “don't know much about autism” cause stigma as well as reverse stigma. If a person doesn't have a diagnosis but is struggling with symptoms, it is doubly important to be like a Gad-Pontyan researcher in practice by being curious, asking lots of questions, being interested in the answers, listening to the individual's experience on their own terms, and collaborating to find meaning that works with them. The neurodominant tendency to dismiss autistic struggling is not only unhelpful but disrespectful, a kind of violence against the person's integrity. I identified with this experience immediately. I had not articulated it as reverse stigma before this research, but I remember how I used to tell doctors, social workers, and teachers about my isolation and relational challenges and was always assured nothing was wrong with me. I was told to stop being so anxious. I was told to relax and accept myself, and that not everyone could be popular or spontaneous. I remember I told a friend who was an occupational therapist once that I felt I had some kind of relationship disability. I was encouraged to focus on my strengths. I spoke to a number of therapists through the years. None pointed me towards a diagnosis or any other form of explanation that made sense of

my experience. This reverse stigma was ironic, because all the while I experienced social isolation, rejection, unexplained stigma, and trouble at school. Apparently people could tell there was something different, strange, and irritating about me, but there was no discourse to talk about it in terms of until I self-diagnosed. Once self-diagnosed, I sought appropriate specialists to confirm the diagnosis. Is reverse stigma an artifact of bygone days when autism wasn't talked about, is it related to the low visibility of the condition, or is it a sign of the superficial relationships so typical of our times? This might be another interesting topic for further research.

The participants in the study talked about using discretion revealing their diagnosis, not in the sense of keeping it hidden in principal but in the sense of not revealing it to individuals or groups they had not developed trust with. One participant said "I've never had someone react negatively when I tell them I have Asperger's." Another participant claimed he was "happy to say I have high functioning autism." He added, however, that he worried about revealing his diagnosis too quickly because people may "run for the exits." Both of the individuals identifying with high functioning autism in this study were diagnosed at a young age because of speech deficits they later grew out of. Two of the participants diagnosed with Asperger's were diagnosed at a young age. Of those diagnosed with Asperger's later in life, I seem to be the only one involved with the study who had initial issues with their diagnosis. This may be because I was initially exposed (as an adult) to the possibility of a diagnosis of autism. Autism, as discussed previously, has higher levels of stigma associated with it than Asperger's. It's as if when you mention autism, neurodominant people immediately think of classic autism (also known as Kanner's Syndrome), or non-verbal individuals with intellectual impairment isolated by

self-absorption cut off from the rest of the world (Kite et.al., 2013). The incongruity of this image with my sense of self caused immense distress and resistance to diagnosis. I was spared my fear of being stigmatized with autism by finding I could pursue a diagnosis of Asperger's. One of the participants described how a friend had a similar experience. When he first began seeking a diagnosis, this friend "very much had to deal with 'I'm a freak because I'm autistic,' but when he looked at it from the perspective of Asperger's he didn't feel like a freak." The participant himself did not agree with this perspective and said he was comfortable with his location on the autistic spectrum. Even before the DSM-5, research on the internet would quickly reveal that Asperger's is seen as a being on the high functioning end of the autistic spectrum. The idea of a spectrum, and being on the high functioning end of it, was enough to allay my fears when I considered diagnosis. As one participant pointed out, however, "who's to say what functioning looks like? Are you functioning well if you cut yourself off from people, or cut other people off?" This participant was saying that people who stigmatize others or even themselves because of impairments, who dismiss those they deem "lower functioning," should look carefully at the low level of social functioning represented by the act of making such stigmatizing judgements.

Although diagnosis was not seen as an issue by the participants, and even welcomed by some (at least once they were able to integrate it with their self-image), deconstructing the narratives in this study uncovered an inconsistency that shed light on an unspoken but fundamental objection to diagnosis. Although all participants acknowledged an element of social disability in their condition, most of them believed the disability was not inherent in themselves but due to having mainstream neurodominant expectations

imposed on them. One participant said “it’s only a disability relative to society. If I’m measured by society’s yardstick, then yes I have a disability. If I’m measured by my own yardstick, as I’m requesting, then I don’t have a disability, only a difference.” Another said “I don’t like to call it a disability. I just say ‘condition,’ something that has to be worked with. I don’t like doctors calling it a disease. I prefer to go towards wellness.” Yet another said “I am quite comfortable with my uniqueness.” At the same time, he acknowledged there may be some element of disability involved with his condition because “it has been very difficult to make friends.” Most participants seemed to align themselves with a neurodiversity perspective that does not see autism as pathology but as a difference to be accepted as part of individual uniqueness. There is a huge debate around this issue which the participants seemed to resolve by holding the tension of both difference and disability. I tried to capture this interwoven duality with the code “*diffability*” (the belief that their condition is both a difference and disability). The aspect of disability involved with the condition, as reported above by participants, can be attributed to the social context of autistic relationality with neurodominants. However, there is a fundamental conflict between taking the perspective that one’s condition is part of one’s uniqueness on the one hand and accepting a diagnosis from the medical community on the other. The categorization of autism as a deficit or impairment is implicit in the pathologizing discourse of diagnostic nosology. As revealed in this and other studies, individuals struggling with the isolating and confusing social aspects of autism are relieved to get the validation of a diagnosis. At the same time, the pathologizing account of their condition imposed by the dominant discourse of medicalization is not consistent with the autistic values of difference and individuality

reported by the participants. This incongruity between diagnosis as a welcomed explanatory validation and an oppressive dominant discourse will be further discussed in the concluding chapter.

DSM-5

Participants were asked their opinion about the diagnostic changes in the DSM-5. Of the six participants, two said it didn't matter because it wouldn't change anything for them. One (diagnosed with autism) said "high functioning autism and Asperger's are pretty much the same thing anyway. There are people who are lower functioning and people who are higher functioning whether they have autism or not." The other participant (diagnosed with Asperger's) said "I call myself autistic anyway, so it doesn't matter to me whether they call it Asperger's or autism." She added that "maybe it's a good thing it's all autism if it helps people get services." Of the remaining participants, two agreed and two disagreed with the decision to eliminate Asperger's as a term and a distinct diagnosis.

One participant with Asperger's was vehement in his disagreement about the changes insofar as he felt eliminating the term Asperger's would lose the flavour and uniqueness of the condition. When asked if he also disagreed with merging the condition with autism, he did not object to this because both he and his roommate would share the same diagnosis. However, he honestly admitted "I don't react well to change. I loathe change. I'd rather things stay the same." The participant's roommate, who had a diagnosis of autism, said he agreed with the changes. "I like to say autism is one big spectrum," he affirmed. At the same time, he acknowledged that "sometimes it's

important to keep each individual classification and to treat each person differently.”

Another participant, diagnosed with Asperger’s, agreed with the change because he said he felt separating people with autism from people with Asperger’s was divisive and stigma producing. The final participant, diagnosed with Asperger’s, disagreed with the change because “people with Asperger’s function a lot better than someone with full blown autism, and getting rid of the term Asperger’s and calling it all autism is a bit misleading.”

All this seems to suggest that individuals with high functioning autism do not necessarily differ from individuals with Asperger’s about the changes in the DSM-5. I had wondered about this because with all the controversy on the internet about this issue, the voices of those with high functioning autism did not seem to be represented. None of the participants in this study seemed to have an issue with the actual diagnostic change eliminating Asperger’s as a distinct diagnosis. The idea of autism being a unified spectrum appealed to most of the participants. The participant who most strongly disagreed with the change took issue with the elimination of the term Asperger’s rather than modifications in the actual diagnostic criteria. The participant who most strongly agreed with the changes maintained his identification with Asperger’s despite the official elimination of the term. Merging Asperger’s with autism spectrum disorder removes the distinction between high functioning autism and Asperger’s, which was a confusing distinction based on vague criteria. People with both diagnoses join the same peer groups and share the same stigma associated with social blindness and other symptomatology. No one seems to dispute the existence of an autistic spectrum or that the spectrum has a “high end” that involves no intellectual or language impairment. Indications are that the

term Asperger's is not going to go away. No organization I am aware of has dropped it, individuals continue to identify with it, doctors continue to use the term to make diagnoses, and new books published by experts continue to employ the term (McPartland, Klin, & Volmar, 2014). It is certainly easier to refer to "Asperger's" than "autism spectrum disorder without language or intellectual impairment." Considering Asperger's as part of the autistic spectrum did not seem to cause distress for any of the participants, whereas the elimination of the term did seem to be controversial and upsetting for some. Asperger's is a colourful identifier with long history. Keeping the term while acknowledging it is not a distinct condition from autism does not seem contrary to any of the diverse opinions expressed in the study. Keeping the term Asperger's may help address the concern that less individuals will seek diagnosis if autism is the only available label. Whether medical diagnosis should carry the weight that it does as a narrative of autism, however, is a separate question that will be considered in the final chapter. As we will see, this is where the term *ASHFA* begins to take on new meaning.

Borderline, Autism, and Frustigma

It is interesting that Schmidt's (2007) thesis on stigma and borderline personality disorder did not mention the symptoms of the condition as a source of stigma, especially since most of the participants in the current study located the source of stigma (as one participant said) "not in the diagnosis, but in the autism itself." Schmidt notes the "particularly pejorative connotation" of BPD (p.1), which results in stigma not unlike that associated with autism. His participants noted "having a negative reaction when first hearing the diagnosis of BPD" (p.49), which is similar to my own negative reaction when

I first thought I may be diagnosed with autism. Schmidt notes how borderline personality disorder is often used synonymously with the term “difficult” (p.2). Those with Asperger’s/high functioning autism, as we have seen, often get the same reputation. Still, Schmidt’s participants with BPD seemed to attribute the stigma they experience entirely to their diagnosis, while the participants with autism in the current study attributed their stigma to behaviours associated with autism. What accounts for this interesting difference in findings? It could be the questions that were asked. Schmidt focused on a few questions exclusively about diagnosis, whereas the current study asked a variety of questions revolving around the experience of stigma. It could also be that individuals diagnosed with borderline find their stigma increases after getting diagnosed because of the stigma associated with the label. When adults get a diagnosis of Asperger’s, the current study shows their experience of stigma may decrease because of the explanation it provides for their behaviour. It would be interesting to see if this continues to be true if individuals start getting diagnosed with autism rather than Asperger’s. Before the DSM-5, autism was usually diagnosed in young children rather than adults. At any rate, this phenomenon would not explain why individuals diagnosed with Asperger’s at a young age also attributed their stigma to behaviours associated with their condition rather than the diagnosis itself. Could this difference in results be due to the fact that borderline is a mental health diagnosis seldom given before adolescence, while autism is a developmental condition intertwined with the individual’s personality since a young age whether or not it is actually diagnosed? Could it be because BPD is a treatable condition overlaid on a person’s personality that usually diminishes with age (Linehan, 1993), while ASFHA is a lifelong characteristic deeply integrated with an individual’s

personhood? This study explores the phenomenology of mentalization as it is associated with autistic stigma and the resulting challenges of interaction with neurodominant culture. BPD is seen by a growing number of mental health professionals to be characterized by impairments of mentalization (Choi-Kain & Gunderson, 2008; Potthoff & Moini-Afchari, 2014). If mentalization “lies at the very core of our humanity” (Anna Freud Center, 2013), what can ASFHA and BPD tell us about our humanity? These are fascinating questions that deserve further study.

In my experience as a working clinician as well as having a family member diagnosed with borderline, it is the actual behavioural patterns of someone struggling with the symptoms of borderline (whether or not they are diagnosed) that cause frustration. The diagnosis comes to represent these patterns and the label can be abused (as in “oh my God, another borderline client”). However, speaking for myself, it is the patterns of behaviour leading to frustration rather than the label itself that leads to negative reactions. I have to carefully manage these reactions in order to avoid further stigmatizing someone diagnosed with borderline. Persons demonstrating the patterns of behaviour typical of borderline personality disorder can be challenging to interact with. These frustrating behavioural patterns, according to the DSM-5, might include “unstable and intense interpersonal relationships characterized by alternating extremes of idealization and devaluation...affective instability...inappropriate intense anger... [and] paranoid ideation” (American Psychiatric Association, 2013, p.663). This list could be supplemented by unpredictable and explosive reactivity in relationship, excessive dependence on the opinion of others, easily triggered defensiveness, unexplained withholding, and a frequent need for emotional support that meets rigid but unspecified

demands. In the case of Asperger's/high functioning autism, behaviours that could be frustrating to others could include "deficits in social – emotional reciprocity...absence of interest in peers...adherence to routines...rigid thinking patterns...extreme distress at small changes... [and] fixated interests that are abnormal in intensity and focus" (American Psychiatric Association, 2013, p.50). This symptomatic list of possibly frustrating characteristics could be augmented with exasperating relational experiences that include being ignored, interrupted, resisted for no apparent reason, presented with rationalizations, and being confronted with self-absorbed obsession (most frustratingly, when empathetic validation might be a more helpful and welcome response). Of course every individual is unique, but those who tend to demonstrate such behavioural patterns may find themselves facing frustration in others not because of stigma associated with their diagnosis, but because of these patterns of behaviour. This experience may be indistinguishable from stigma and experienced as or mixed with stigmatization based on prejudice associated with labels. Such confusion in relational dynamics is consistent with the experience reported by participants diagnosed with autism in the current study. I developed a code called *frustigma* to reflect this dual, sometimes indistinguishable experience of stigma and frustration. Not only does it indicate the complexity of stigma, it also indicates an element of volitional practice that can provide a way to manage stigma. Stigmatized individuals can make an effort to identify, be mindful of, and learn strategies to address the behaviours others find frustrating to the extent consistent with their personality and capacity for insight. At the same time, dominant others in a position to inflict stigma can be mindful of their frustration and try to address it in ways that are not further stigmatizing. Both these positions call for good will and committed effort.

Social workers need to find ways to facilitate these efforts even as they work simultaneously in the area of advocacy and policy to create environments in which stigma is less likely to flourish.

Challenges of Stigma Management

More than one participant in this study talked about needing logical explanations for why people often get so frustrated with them. The participant discussed above who was thrown out of a bar because people were uncomfortable with him said “no one explained why.” Another participant talked about how he was asked to leave a meet-up group after there were complaints about him. He was angry and confused because the group leader would not tell him what the complaints were or what led to them. This was not the first time:

The organizer claimed on more than one occasion she had gotten complaints about me. She wouldn't tell me, but I persisted because I wanted to know. I'm tired of taking B.S. like that about complaints about me and nobody tells what.

Participants described how they are frequently excluded or ousted from a group or decision-making process without being part of the proceedings. One participant described this as “a lynching about my attitude.” This frustrating lack of explanation can infiltrate

the social life of individuals with autism in less dramatic but equally stigmatizing ways. When asked why he thought it was hard for him to make friends, one participant said “I guess I communicate a bit differently than most people. How, I don’t know. The people who have a hard time communicating with me don’t say why.” Another participant said “it’s possible that I give people the wrong impression but I don’t know because they don’t give me that feedback.” Yet another participant agreed that people (especially his spouse) get frustrated frequently with him because of his need for logical explanations:

People get frustrated with me because I need a lot of explanation for things that come naturally to others. Especially when they want to express things emotionally and I just don’t get it. At other times they may just ignore what I want an explanation for. Why is it there’s a barrier when I have an issue I’m trying to understand and everyone else takes it for granted or doesn’t want to hear about it? I feel shut down. It’s frustrating.

The participant says this has become a running joke with his friends. He says:

I’ll tease people when I clue in they’re having a feeling. I’ll go ‘ohhh, you’re having a feeling.’ It becomes a joke between us, like ‘oh-oh, there’s feelings involved here, there’s going to be trouble’.

This would suggest that one thing neurodominants can do to help manage stigma is to provide individuals with autism who don't understand the subtleties of communication and feeling a logical explanation they can understand. More than one participant talked about the importance of patience and "asking the right questions" to help facilitate understanding. However, a participant described how he was once given feedback that a certain response of his "included too much detail, was unexpected by the other person, could make the other person feel overwhelmed, and could sound like bragging." The participant could not process this and spent part of his interview defending himself from the feedback he was given. Another participant specified that the explanations given must be simple and step by step:

I think something neurotypicals don't understand is how hard the interpersonal relationship things are [for those of us with high functioning autism spectrum disorder]. I mean hard level stuff, things like making eye contact, like understanding someone else's point of view. I mean, it's easy enough to say something like "you've just got to put yourself in their shoes," but I literally don't...I mean, I have the empathy of a bowling ball. I don't understand how other people feel. You've got to baby steps this with me. I'm very brutally honest with my friends. When one of my friends says "you've just got to see it from the other side" I'm like "you've

got to baby steps me, you've got to help me put on the training wheels.”

Another participant said he does not like the way neurodominants often seem to provide feedback in the form of admonishment and accusation:

If they knew anything about autism, they'd know we don't like feedback. We don't get the idea of feedback. Why would you just come up to me and scold me? Why can't you come up to me and ask intelligent questions to help me understand the situation better?

This participant says he has asked for “accommodation in the form of a translator” from his organization. “Someone who speaks autism,” he said, someone who could help him pick up on subtle and non-verbal messages, double entendres, and interactions involving feelings he can't relate to his own experience. Someone who could help the neurodominants in the room understand what he is trying to convey in his own way. My wife often tells me, for example, that I don't set the context of what I'm trying to say or that I jump from one thing to the other and that it is “too much work” for her to interpret or figure out what I'm talking about. A translator would be helpful to say hello for me when I walk into a room. I'm often told I just pick up where I left off without saying hello. I don't do it to be impolite; I just don't see the need for it unless I'm meeting the

person for the first time. Even then I may be so focused on my own agenda that I brush by people with perfunctory or no acknowledgment as if I have urgent business elsewhere.

Negotiation is another model that could provide an alternative to abrupt dismissal. Sometimes I need to slow myself down and take in the social reality of the moment. It's as hard for me to switch tracks to consider the presence of other people at times as it is for neurodominants to slow down and provide an explanation for what's obvious to them. Curiosity about each other's perspective, even if it has to be reduced to logical terms, could lead to discussion and finding common ground in the spaces between difference. Again, this takes good will, effort, and commitment. A mediator familiar with the communication patterns of autism may be helpful in some critical interactions, but a mediator can't be there all the time. The more social workers and other professional helpers understand the phenomenology of autism the better positioned they will be to help negotiate in such situations and to provide a validating discourse for the marginalized autistic. This could include helping to facilitate diagnosis or simply referral to an online autism discussion. One doesn't have to be diagnosed to be struggling with an autistic personality in a world seemingly full of neurodominants.

Intersecting Stigmas

Intersecting stigmas are experienced when an individual possesses more than one characteristic and/or belongs to more than one group that is stigmatized by society. Several intersecting stigmas in addition to a diagnosis of ASHFA were represented by the participants in this study. All participants were white. One was female, suggesting she may experience stigma attached to the marginalization of women. This participant did not

talk about gender-based oppression, however. In fact, even the stigma attached to her diagnosis of autism was eclipsed by the stigma she attributed to her anxiety. The participant was formally diagnosed with general and social anxiety three years ago, but reported she has suffered from anxiety her whole life. She has also been subject to stigma attached to Asperger's her whole life since this is developmental, but still she said "the problem is more my anxiety...I don't mind having Asperger's, it's the anxiety that's bad. That's the only thing I would get rid of." She acknowledges her Asperger's and says "I don't function as well as people think and that's why I experience such high anxiety." However, when she is uncomfortable in social situations it is anxiety she tries to cover up, it is anxiety that makes her experience stigma. "I hide my anxiety," she says, "when I don't understand something." As with the other participants, it is behavioural symptoms she associates with stigma rather than the diagnosis itself. However, for her, the stigma associated with Asperger's is minimal compared to the symptoms of anxiety. "I get judged because of my anxiety," she says, "I don't think it's the Asperger's." She adds that she knows "Asperger's does cause some of the anxiety with the communication problems and stuff like that, but it's the anxiety that's the main problem." In this sense, anxiety for this participant is the primary source of the stigma she experiences because it is most associated with her discomfort and the behavioural awkwardness she is so conscious of.

This tends to go against the "double jeopardy" model of intersecting oppression that says individuals who experience more than one form of oppression or stigma experience it cumulatively (Purdie-Vaughns & Eibach, 2008, p.378). According to this theory, the above participant would feel both the stigma of Asperger's and the stigma of anxiety and

hence a resulting increase in stigma. This theory could still apply; perhaps the participant does feel increased stigma, but this may be difficult and of questionable utility to measure. More importantly, she does not feel stigma from two qualitatively distinct sources. Rather, she only reports experiencing stigma from a single source, the overpowering source, and for her this is anxiety. This may be because the stigma of anxiety and the stigma of ASHFA merge into each other and are hard to distinguish. Both can be related to social flustering, awkwardness, averted gaze, and social avoidance. The participant diagnosed with Tourette's syndrome spoke of the frustration of blurting out in public, but did not speak of the stigma he experienced as coming from two sources. Other stigmas may be experienced as more distinct. This would be an interesting topic for further research.

Another participant who reported intersecting stigma was gay and diagnosed HIV positive. This participant clearly distinguished different sources of stigma. There is much more literature on stigma experienced by this population than autism (Kanuha, 1999; Poindexter & Shippy, 2010). Still, this participant stated clearly that "although living with HIV is considered a disability, I would say it's been less debilitating than autism." He went on to say that "even above HIV, I would say Asperger's makes me feel more different":

There seems to be a hierarchy. Being gay is a little bit more acceptable than being HIV positive, and Asperger's, well autism is probably at the bottom of the pile. Being gay was no problem for me; I came out when I was 16. I

told everybody and had no regrets. I knew the skinheads were going to spit at me every time I went out but I didn't care. Becoming HIV positive, well I've always been out about it. I've always advocated for condom use and people knowing my story. But Asperger's is really hard to explain.

The participant said autism is the most pervasive and intense source of stigma for him. He went on to say that part of the reason for this is that he finds it hard to explain this source of difference even to himself:

I can't articulate it, and that's the nature of the disorder. I can't articulate what it is that's different. Yet people see it and judge me for it, and they judge me across all of those communities. The gay community judges me as being HIV positive and autistic, and the HIV community judges me for being autistic and gay. There is that judgment in there. In the '80's across Canada the ASO's [AIDS service organizations] were 'de-gayed,' trying to remove the image of HIV being a gay disease. Yet more than 50% of us are gay; more than 50% of us are gay and only 25% of funding goes towards gay programming.

The participant says he is active as an organizer in the PHA community (persons living with HIV/Aids), but says “I feel that in the HIV community my every word is judged...they’re always trying to put me in a box and figure out what’s wrong with me.” He says he has been referred to as “challenging,” the “social critic,” and the “angry PHA.” He reports that “people don’t answer my e-mails.” He says “when I want to talk about stigma and discrimination they shut me down.” This is the participant that said he could use a “translator who speaks autism.” His experience of intersecting stigma seems to match the “double jeopardy” model in that his “multiple subordinate group identities” seem to result in additive and more intense experiences of stigma (Purdie-Vaughns & Eibach, 2008, p.378). These authors, however, offer an even more intriguing model of intersecting stigma that has more explanatory power in terms of the social dynamics involved. They describe a model called *intersectional invisibility* in which group members belonging to other marginalized groups do not fit the “prototype” of the main group and are not “fully recognized” as such, all of which “relegates them into an acute position of social invisibility” (p.381). This situation would only be aggravated by the socially disabling nature of the participant’s autism, and the authors’ description of how the personhood of such group members tends to be distorted to fit the prototype of the main group seems to fit very well with the participant’s discouraging experiences in the HIV community. His reports provide first hand evidence for the process of intersectional invisibility Purdie-Vaughns and Eibach (2008) describe in their theoretical article.

Stigma Cloaking

Intersectional invisibility can be seen as a group variation of what I have termed *stigma cloaking* in the current research. Stigma cloaking is a focused code I devised to thematize the different ways participants attempt to manage stigma with various behavioural strategies. One such strategy the participants reported, a maneuver they often observed and felt targeted by but did not report engaging in themselves, was *offloading stigma*. Goffman (1963) referred to this as “ambivalence,” a process through which the stigmatized individual offloads stigma by “taking up in regard to those who are more evidently stigmatized than himself the attitudes the normals take to him” (p.107). Two participants talked about the “irony” of being bullied by other kids in school who also had autism, which may or may not be an example of this. The participant identifying himself as PHA said “the thing that bothers me the most is when oppressed people oppress other oppressed people. I just don’t get it. My mind literally shuts down.” He talked about how he sees this happen “not just in the HIV community, but everywhere.” People experience stigma, for example HIV, and they offload it where they can:

They turn around and they stigmatize people who have wrongful behaviours, or that are inappropriate by normal standards. They will shut you right out, they will shut you right out. Because ‘you’re the angry PHA and we’re going to shut out the angry PHA.’ They make you follow these rules of engagement, and if you don’t follow them they shut you out for that too.

The DSM-5 move to eliminate Asperger's as a distinct diagnosis and merge it with autistic spectrum disorder has shone a spotlight on stigma offloading. The participant quoted above remembers "I had a friend in Australia who ended up not talking to me for a while because I disagreed with his perspective on this. To me we're one big family." He adds that "even the low functioning Aspie's don't want to be further stigmatized as autistic." None of the participants reported having this attitude, although one started the interview by saying he had been diagnosed with infantile autism as a baby and had "grown out of it." He initially maintained that his condition had "resolved itself into a severe learning disability." It wasn't until later in the interview that he acknowledged his high functioning autism. The initial resistance to merging Asperger's with autism may be more apparent online because most ASHFA individuals "perceive the internet as liberating" (Benford, 2008, p.15). As one of the participants acknowledged, "people tend to hide their prejudice when they know it's socially unacceptable." This tension between acknowledging one's autistic personality and distancing oneself from the diagnosis could be considered an aspect what Rosqvist calls the "ambivalent ideal" autistic openness (2012, p.127). Of course, autistic openness transcends issues of medical diagnosis.

Several mechanisms of stigma cloaking were identified by participants. The most fundamental of these is the *cloak of invisibility*. One form of this stigma management strategy was described by Goffman as "passing" (1963, p.73), which involves what participants described as "faking it" and what Willey (1999) described as "pretending to be normal" in the title of her autobiographical book about life with Asperger's. It means attempting to pass as normal by controlling information, isolating, denial, and concealing

the condition by whatever means necessary in order to avoid stigma. It may also involve adopting what Goffman calls the *nonperson role* (1963, p.18). Goffman gives the example of a servant who is present in the room but as invisibly as possible (1956, p.95). All the participants seemed to identify with this strategy on some level. One participant said “I learned when I was younger just don’t say anything and you won’t get in trouble.” She added “I don’t want to stand out or anything.” Another participant said “when I’m overloaded I just say to myself ‘that’s enough, they’re not interested in understanding so I’m just going to withdraw and see how things are going to play out’.” In alignment with their cloak of invisibility, ASHFA individuals sometimes find roles they can play, like the servant, that allow them to take on a function they can manage without having to engage in excessive social interaction. One participant takes on the role of group facilitator for this reason, saying he is much more comfortable doing this than being a group member. Others take on the role of mediator, photographer, or camera man. Some ASHFA get jobs in their area of obsession; others turn their nonperson roles into productive careers that may not have been foreseen as appropriate or even possible.

The cloak of invisibility can also involve what Goffman described as “covering” (1963, p.102), which is adopting neurodominant behaviours to camouflage the condition. It can also involve unlearning what one of the participants in the current study called “spectrumy” behaviours:

I have asked for 25 years to be measured by my own yardstick, not to be measured by everybody else's yardstick, and nobody's ever even acknowledged that statement. They ignore that state-

ment, they don't understand that statement, they can't see how someone else could have a different yardstick, and I understand that because I don't look Autistic. I can look at people in the eye. I don't have to stim. But that comes from years of abuse. Being abused not to do these things. Having your head turned - "look at me!" Not just from parents and teachers but from society as a whole.

This participant's narrative shows how neurodominants can sometimes exercise what Foucault would call a "relationship of violence" (1976/1994, p.340) or "disciplinary power" (1975/1995, p.170) over autism. Most stigma cloaking is the result of what Foucault would call "the productive aspect of power" (1982/1994, p.120), more insidious "transverse" dynamics of power related to expectation, conformity, homogeneity, and hierarchy. These subtle pressures are often what lead individuals with autism to either isolate, blend, or "dumb down," as one participant put it, or alternatively find some way to feel superior.

One participant spoke about a *cloak of intelligence*. Asked if he could identify a behaviour or characteristic neurodominants might find frustrating about him, this participant said "that I'm more intelligent and mature than them." He added "I was always smarter than everybody else and I wasn't modest about showing it." Another participant talked about how "everyone else was reading like the Cat in the Hat and I was miles ahead of them." It is not unusual for individuals with Asperger's have high levels of intelligence. Even into adulthood, ASHFA individuals can sound pedantic and

pompous at times. ASHFA children sometimes give the impression of being “little professors” (Attwood, 2007, p.86). However, this intelligence can also become a cloaking device that marginalized individuals use to shield themselves from stigma. My uncle used to call me “Einstein.” I remember how I would conceal my anxiety and social detachment with intense, intelligent expressions as if I were trying to solve a serious world problem. In a perfect example of Goffman’s dramaturgy, when I was older I would stroke my beard for effect. Sometimes stigma cloaking strategies appear in unique combinations, like invisibility and intelligence.

The issue of intelligence and ASHFA brings up another consideration. One participant remembers doing a project in public school about how gas contributes to the explosive nature of volcanoes. The teacher, probably expecting that at his grade level he must mean gasoline, failed him and said gas had nothing to do with volcanoes. The participant remembers going to the school next morning with his father and “dropping about fifty pages of United States geological survey documents on her desk.” With the support of his dad (who the family has informally diagnosed with Asperger’s), the participant was able to demonstrate that he actually knew what he was talking about. Without his dad, the participant may have been left feeling invalidated and ashamed. Although they may have a command of logic and facts, ASHFA individuals may not have the presence of mind to defend themselves or the language to engage others.

I remember having a similar experience. My teacher in grade two once asked the class what parachutes were made of. I had seen a documentary that said nylon was a good material for this purpose. I shot up my hand and proudly gave my answer. The whole class erupted in laughter, probably thinking I meant women’s nylons. The teacher, rather

than coming to my defense, agreed with the class and told me I was wrong. I felt embarrassed and stupid. I have often wondered if it would have made a difference if the teacher had known I had Asperger's. She might have been more prepared for answers out of her usual context of expectation. After doing this research, however, I now think this question betrays an over-reliance on the discourse of diagnosis. Rather than needing medical validation in order to be prepared for alternate contexts, it would be better to be prepared for diversity as a general rule.

The *cloak of helping* can be very effective as a stigma management strategy. One participant in particular said "I take enormous pride in volunteering." It is common practice wisdom that helping others can take one's mind off one's own troubles and help build a sense of mastery. However, sometimes ASHFA individuals intensify things to the next level and helping takes on a sense of urgency. The above participant said he does not understand why neurodominants tend to marginalize him. He compensates by trying to be of service. He puts up posters offering to be of help. Yet still he runs into brick walls:

Participant: I've tried to help people because I understand what it's like to need help. If they could understand what I intend, they would come to me and say "I could use some help." Instead, I get the cold shoulder.

Researcher: Do you think you're doing something wrong?

Participant: I don't know, they don't tell me. This means I have to try multiple avenues to get the message out that I'm willing to help.

Researcher: What else would you like neurotypical people to know?

Participant: I just wish they would tell to me what's allegedly so upsetting about what I'm doing. I feel that what I'm doing is inoffensive, yet they feel I'm bragging or whatever. I'm not. I just want to help other people. Helping people gives me an enormous sense of pride. I would love to help anyone.

Researcher: So if people would just accept you and see you as a human being, maybe be more patient with the different way you communicate, things would be a lot better for you.

Participant: They sure would! There wouldn't be such a need to put up these [holds up a handful of his "help" posters].

I identified with this participant. I have always been eager to be of help. It is often easy to discern when help is needed, when something "nice" will please someone. It's as if building up nice-guy credits could help offset the times I seem to frustrate people without even knowing why. I never thought about it explicitly when I was younger, but for me this calculus of helping has always been a desperate strategy of impression management and stigma control. For those who adopt this strategy, the frequency and urgency of helping behavior may be correlated with the amount of stigma an individual experiences, and perhaps negatively correlated with the degree of control an individual feels in their ability to manage personal relationships. More research on helping behaviour is called for.

For me, helping was a way to take on the cloak of invisibility. I had to be a crisis counsellor from an early age because of a family member with borderline, and this

generalized to my whole social life. I learned that adopting a helping stance with others gave me a controlled, well-defined social role without having to interact spontaneously. There is a story here about how this stigma cloaking strategy, along with philosophical exploration, life experience, tenacity, and an emerging therapeutic style based on curiosity rather than empathy led me as an anxious, socially awkward boy with a relationship disability into a career as a counsellor. It is a long story beyond the scope of this project, but it shows how stigma cloaking strategies can turn into productive work.

Like many social workers, I originally went into the profession largely out of a desire to be of help. Critiques of helping as a motive for social work (De Montigny, 1995; Heron, 2004) made me fiercely defensive at first, but enabled me to disengage my need to help from my social work practice. Such critiques have also enabled me to reflect on the implications of the helping motive, which is deeply ingrained in western social work but has not stopped social workers from doing harm. On a personal level, the helping motive may lead me to “construct a damaged ‘other’ to justify my own interventionist impulses” (Dozema, 2001, p.16). An unreflective rationale of helping may lead me to assume I can “improve other people” when I am actually guilty of “arrogance and oppression” (Blackstock, 2009, p.31). At its worst, the helping motive can rationalize a “civilizing framework” that can justify the use of force, torture, and even genocide in the interests of protecting what I, my organization, or my government judge to be “depleted and helpless populations” (O’Connell, 2009, p.188). As a “white liberal subject,” honest reflection on uncritical helping motives can “call into question the desirable identity of oneself as a good person, a good and altruistic helping professional” (Jeffery, 2005,

p.411). The strategy of stigma cloaking one adopts can construct one's subjectivity in many ways and lead to unpredictable avenues of insight, expression, and reflection.

ASHFA individuals may also don a *cloak of humour* to protect themselves from stigma. One participant said she “pretends to get jokes when someone tells one by laughing when other people laugh.” Sometimes humour is unintentional but still acts as stigma protection. I don't know how many times I've made comments that made people laugh, possibly because of a twisted connection to the topic at hand, when I was trying to be serious and make a thoughtful contribution. Sometimes my answer comes off as deadpan humour when it really reflects ignorance of the social context at play. Like the above participant, I have learned to laugh along with the others, often at myself, as I wonder what was so funny. Another participant refers to himself as “goofy.” I have known ASHFA who don't take anything seriously, as well as those who take everything too seriously. One participant tended to laugh frequently during his narratives, almost as a form of punctuation as if it gave him a chance to assess whether he should keep talking. Sometimes the cloak of humour can turn into the mask of the clown; this is when constant and overt attempts at humour give people a reason to never take you seriously and your “muff-ups” can be taken painlessly as another joke. This strategy can help neurodominants feel at ease and relieve social pressure, but it can also involve hidden resentment.

If humour is a response to stigma that attempts to blend and camouflage, anger is another, perhaps more congruent response to the oppression of stigma. When anger goes from being an appropriate response in specific situations to being a protective barrier, it can become another stigma cloaking strategy. *The cloak of outrage* was well-worn by

one participant in particular. He made frequent comments like “most of the people out there are superficial, judgemental, and hypocritical.” When asked what he thought of neurotypicals, he said “you mean all the people whose only function is to breathe and expend resources? The ones who just make life harder for the rest of us? You mean the ones who are only alive because it’s against the law to shoot them?” It is easy to see the source of such anger; years of stigma, oppression, bullying, and rejection. Sometimes it can’t be contained nicely. Sometimes the anger that comes up helps us protect ourselves from more abuse. A related stigma protection device none of the participants talked about or demonstrated but which I have observed is the *cloak of the jerk*. Like the other stigma reduction strategies, this stance may be adopted by anyone for a number of reasons and can merge with one’s personality. Whereas some individuals seem to hide their social awkwardness behind anger or humour, those adopting the cloak of the jerk adopt the stance of an uncaring, selfish curmudgeon. The reason this came to mind is I remember thinking at times growing up that this would be an easy stance to take if I didn’t care so much about what people thought of me. I also remember a friend complaining once about such an individual. She said he was a “real asshole.” I said enviously “at least he’s a real something.” I meant that I was so busy with impression management and dramaturgical stigma cloaking strategies that I didn’t feel like an authentic person, especially in public. This theme came up in another conversation when a neurodominant spouse once wondered aloud if their spouse’s rude, irritating, and selfish behaviour was “Asperger’s or asshole.”

To protect against stigma it is also possible to wear the *cloak of labels*. Most of the participants had engaged in some kind of self-labelling to normalize their condition. One

referred to herself as “shy.” Another called himself “odd.” I have often thought of myself as “eccentric.” We have already discussed “the social critic,” which was a label imputed to the participant by his community that he adopted proudly. Accepting a diagnosis could be seen as a medically validated form of stigma cloaking, unless the stigma associated with the label itself becomes more stigmatizing than the condition, which seems to be the case for borderline personality disorder. This might also be true for the label of autism, although Asperger’s has mediated the stigma of autism for higher functioning individuals with this condition. Perhaps the community building and pride in neurodiversity that has coalesced around Asperger’s (what one participant called the “Aspie” movement”) has bled back into autism. If this is the case, the changes in the DSM-5 may be helping the distigmatizing process generalize itself further across the spectrum.

The *cloak of safety* involves finding a safe environment in which one’s stigmatizing condition will blend in naturally or be accepted as normal. One participant’s tendency to make friends that are “as goofy as me” could be seen as strategy of stigma management. This has already been described in the section on stigma resilience. The way the participant described his group of friends with like personality and eccentricity sounded like a strategy of empowerment rather than cloaking, although the two shades of self-practice are intertwined and merge into each other persistently and often imperceptibly. Goffman’s description of “back places” inspired my exploration of this positionality with participants; places where individuals with “the same or similar stigma stand exposed and find they need not try to conceal their stigma, nor be overly concerned with cooperatively trying to disattend it” (p.81). Goffman used the example of a carnival as a back place where various stigmatized individuals can find an environment safe from stigma. Some

of the participants identified their online chat rooms as such places, including Facebook. Sometimes ASHFA go to great lengths to find such back places. I spent ten years in a small community in the rainforest with artists, hippies, environmentalists, and nature-oriented survivalists. There were few expectations and it seemed the more eccentric you were the more you were accepted. This is a perfect example of how some ASHFA function in fringe subcultures where their deviance does not draw attention to itself. This was a place where what paraded as “cool choices” were really desperate efforts to deflect as much stigma as possible and secure a much needed sense of belonging. I look back on those days now and I feel I was living in a cult. Me of all people; my grade 13 history teacher gave me an award as the “student least likely to belong to a cult” because of my rigid intelligence and the social isolation I worked hard to disguise as rugged independence.

Another participant had worked as a hairdresser, where the stigma associated with being gay could be rendered acceptable through choice of profession. He had also worked as a bar manager (he worked in the back office and had a partner who mingled with the patrons). In both of these work environments, the stigma of Asperger’s may have been disguised by the unique social characteristics of the environment. For the participant, however, both had more to do with stigma cloaking related to substance abuse, which is another stigma cloaking device.

This brings us to the *cloak of extraversion*. Although ASHFA involves “an awareness of personal inadequacy in social situations and repeated experiences of failure to make and/or maintain relationships,” still most individuals with this diagnosis are “not loners by choice” (Klin et al., 2000, p.350). Especially with a cloak of safety

successfully in place, such individuals may be outgoing and even gregarious. One of the common misperceptions about ASHFA, even among professionals, is when people think “he’s so social he cannot have AS” (Ducharme & Gullota, 2013, p.27). When I lived in my hippie back place, I become more and more extraverted. I learned to celebrate my difference because I was accepted. I attended coffee houses, even volunteering to help run them. I did comedy onstage, led drum circles, and ran the bar at dances. I had never been so social in my life. I even learned to flirt with women. When I removed my cloak of safety to go back to school, I quickly learned to be silent again. My difference began to stand out once more as a stigmatizing condition. Some of the habits I had learned, however, came to haunt me. It was at this point I met the woman who eventually became my wife. Some blessed combination of vulnerability and compatibility conspired to bring us close despite my social impairments. As one of the participants said, it was like “winning the lottery.” Unfortunately, I had learned to relate to women by flirting with them. I kept giving women unintended messages about my availability and giving them the power to intrude on the one relationship that was really important to me. All I knew was that I had finally learned a way to talk to women and was having fun doing it. When the method I learned became inappropriate, I could neither sense the nature of the problem nor how to change. I thought it was profoundly ironic. The first woman with whom I ever had what I considered to be a real relationship was being assaulted by women who meant nothing to me and with whom I would not know how to have a relationship even if I wanted to. It was a precarious and painful situation for us as a couple. Professionals were no help. As I described the problem as best I could they would normalize my behaviour or blame my wife for being jealous. Couples counsellors who

are not familiar with autism sometimes take sides with the ASHFA individual because they sound so reasonable (Aston, 2003, p.169). One doctor gave us both a lecture about how men were conditioned by their caveman history to seek trophies of the opposite sex. I now think of this as a poignant example of reverse stigma. At any rate, the cloak of extraversion can easily get out of control because ASHFA individuals may not comprehend the implications of their behaviour in a practical way.

Finally we come to the *cloak of addiction*. When an ASHFA individual wants to express their sociality and can't find a way to do so successfully, they may turn to drugs for help. Alternately, they may start to abuse substances to mask the pain of their stigmatization. One of the participants in the current study did both:

I never fit into the community. I found I could fit in where everyone knew me at the bars growing up. I wasn't totally ousted. I had people who would look out for me, but I didn't have a lot of friends. I did a lot of drugs instead. Because of being undiagnosed through my childhood I turned to drugs for self-medication starting with pot and moving up to crystal meth.

The participant reported that drugs helped at first. He described how they didn't help with his ability to make real friends or to socialize effectively, but they did decrease his anxiety, boost his energy, and give him the sense that he could "be in the same headspace with other people." Towards the end, he said that substance abuse became more about managing sensory issues:

The acceptable thing to do was to go to the bars Friday, Saturday, and Sunday nights and I wanted to do the acceptable thing. We did that doing drugs, but I did get wasted, I mean really wasted, because of the flashing lights, the people touching me, and drugs would help me cope with that. I didn't like it, it was "what the hell is going on with me," but it was the only way I could get on. Towards the end it was very sensory oriented.

The participant went on to report that drugs were "an acceptable way of coping in the hairdressing industry" but that "towards the end I knew drugs weren't good for me." The participant says he had been active in the HIV community for years in an effort to prevent being diagnosed HIV positive before he realized his drug use was not helping him towards that goal. By that time, his substance abuse had progressed from stigma cloaking to a disorder in its own right. Regretfully, I did not explore this participant's experience with co-occurring substance abuse in further detail. At the time it did not seem relevant to the topic of stigma, although after analyzing the data and writing up the research the participant indicates that substance abuse can serve both symptom and stigma management functions. Current research tends to confirm the participant's experience that drugs may "positively influence the subjective perception of their social skills, or cause a reduced awareness of social awkwardness, without actually improving their social functioning" (Sizoo et al., 2009a, p.1294). In terms of using drugs as stigma cloaking, Hull (2012) reports anecdotally that he often hears comments from clients such

as “if I am high and my friends are also, they don’t care if I do something stupid” (slide 8). Clinicians working in the field acknowledge that the stress of not getting a diagnosis can lead to addiction, and also report they often see clients whose substance abuse is their primary presenting symptom even though they also have ASHFA:

The abuse of drugs or alcohol is sometimes a means of self-medication without proper pharmacological, behavioral, or psychotherapeutic treatment for anxiety, mood, or sleep disorders. It is probable that adults with AS are at risk of substance use because of lack of other coping mechanisms, the presence of addictions in their families (Miles, Takahashi, Haber, & Hadden, 2003), their repetitive thought patterns, their difficulty with regulating mood, the effect of environmental stressors, and the absence of other socially protective influences. (Stoddart, et al., 2012, p.121)

There is very little in the literature about autism and substance abuse. A quantitative study in 2010 based on a sample of 123 patients with autism spectrum disorder (ASD) and attention deficit disorder (ADHD) reported that substance abuse disorder (SUD) is almost twice as common in ADHD than ASD and that early onset tobacco smoking is the most important risk factor in the development of substance abuse disorder, followed by parental SUD and “adverse family history” (Sizoo et al., 2010, p.47). Another

quantitative study based on 128 patients with ASD and ADHD (Sizoo, van der Brink, van Eegie & van der Gaag, 2009b) found that 22% of their participants had current substance abuse issues, 19% had past substance abuse issues, and 59% had no history of substance abuse. They also found that their participants with ASD as well as ADHD got higher scores for harm avoidance than the general population, that alcohol and marijuana were the most popular substances of choice, that participants with SUD got higher novelty seeking scores than those without SUD, that participants with past and current SUD got higher self-transcendence as well as higher social engagement scores, and that those participants with high persistence scores were more likely to overcome substance abuse issues. All of this is very interesting, but it begs for qualitative research to explore the experiences of participants more deeply in order to give meaning to the statistical results. I am thinking, for example, of how the current study can be seen to give meaning to Shtayermman's (2009) quantitative findings about the inverse relationship of AS symptomatology and stigma.

Since only one of my participants reported having had issues with substance abuse, I searched publically accessible online Asperger's forums in an effort to glean more insight. I found two discussion groups in particular where individuals diagnosed with Asperger's/high functioning autism and substance abuse issues interact. Their narratives add to the lone voice of the participant in this study. One person posted that:

I was diagnosed as an adult. I was almost 35yo at the time.

It was then I decided to go drug free because the condition

I'd been aware of having my entire life was suddenly given

a name. This gave me the confidence to try and confront life without numbing the pain artificially... Life is hard sober. I find it a struggle. It is, however, better than life on drugs. There are many effects of drugs that can make the autistic person feel better for a time. They can help relax and increase social potential, or at least seem to... My AS has certainly caused me major problems throughout my life. The prognosis is far more positive for people with sufficient support at the right times. I drifted through early adulthood homeless, sofa-surfing and abusing any and every chemical I could get my hands on. Anything to blot out reality. However, it never worked. The drugs don't work, eventually. (Countryboy, 2010)

Stoddart, et al. (2012) point out that the social aspect of substance abuse treatment is crucial, which poses a particular challenge for ASHFA. On another online discussion group, a female with autism posted that:

I'm an Aspie as well. It sucks, but recovery from the substance itself (heroin) has been really easy...I can't do any of the steps, though because I'm too literal and powerless to me means powerless. I find myself insisting that I wasn't powerless or I wouldn't have been able to stop on my own before finding NA. Don't get me started on the higher power stuff... it's

not always so fab being of above average intelligence ~
(especially when you have dyslexia as well and people think you're stupid because you can't spell). Relationships are very difficult (I'm a girl Aspie so its expected of me even more to be empathic but i don't have such noticeably odd behaviours)
I found that I can't really make any decent friends in recovery because no one is on the same level as me, they all believe in some kind of higher power and I can't have those conversations..
I can only talk about things I know about which are things I believe to be true. I found it much better not to waste my time with recovery 'friends' go and find people that have the same special interest as you... join a club, a forum, work within the field of it - who needs the pub? (Bluesky, 2010)

All of this is important as it relates to stigma and ASHFA not only because of the predisposing factors that lead individuals with the condition to use drugs, but because of the “demoralizing attitudes towards individuals living with a serious addiction and culturally ingrained views on moral responsibility” (Buchman and Reiner, 2014, p.19). These attitudes come into play as intersecting stigmas when ASHFA become embroiled in substance abuse. The symptoms and stigma associated with ASHFA can contribute to an individual with this condition becoming involved with drugs from an early age, initiating an escalating stigma cycle:

Illicit use of drugs and alcohol pose problems and risks for all kids. However, for persons with AS, these risks are multiplied. The social disability makes our kids easy marks for those who would take advantage of them by asking them to 'hold' or sell drugs or steal beer from a store, for example. Peer groups that are heavily involved in such illicit activities tend not to be as picky as some groups you might prefer your child associate with. Our children with AS may be more readily be accepted by them. We are well aware of the role of peer pressure in teenage drinking and drugging. However, peer pressure takes on a whole new meaning and a lot more force when directed at a young person with AS who may be even more desperate to fit in and lack the social savvy to fully appreciate all aspects of a situation. (Bashe & Kirby, 2005, p.461)

Service Resentment

Reverse stigma has already been discussed as a type of service resentment mentioned by participants. One participant went to therapy for two years and was then told "nothing's wrong with you," even when the isolation and difference of his undiagnosed Asperger's had not been addressed. The participant said that on one level, at least, this was "easy to accept." On the other hand, he said "something prevented me

from saying ‘no, you’re wrong, something’s wrong.’” Was it anxiety that stopped him, respect for the authoritative power bestowed on the therapist by the discourse of professionalism, intimidation instilled by the inherent power imbalance of therapy, or habitual deference to neurodominants conditioned by stigma and rejection? This is another example of when more responsive and creative follow up exploration deviating from the scripted questions during data collection might have resulted in richer narratives.

A general lack of current knowledge was also mentioned by participants as a source of service resentment. One participant complained that

Well, here you have all these people that have University and college degrees and supposedly know their jobs, but even when I was a kid I was able to tell them stuff about my condition they didn't know. You think they know best and because they think they know best, you trust them. Then it turns out later that they didn't know their ass from a hole in the ground, you know? They were just parroting old obsolete data or whatever, either because they were naïve, stupid, or just – what’s the word – apathetic?

ASHFA is not a condition that is amenable to treatment, although comorbid conditions such as depression, anxiety, and OCD are. When I was first diagnosed, the psychiatrist told my wife that “there is no treatment.” She was told I would never change

and that living with me would be a “life sentence” of frustration. The psychiatrist was technically correct. “There is no medical treatment for autism” (Frith, 2008, p.118), and there is no “substantial body of literature that speaks to therapeutic interventions” (Ducharme & Gullota, 2013, p.40). For this reason, health care professionals sometimes seem to feel they can do nothing at all. Before I was diagnosed, no professional ever helped me understand my difference, nor did any of them collaborate with me on making sense of my experience. After self-diagnosing and getting medical confirmation of my Asperger’s, more than one mental health professional added to my sense of social rejection by refusing to provide treatment because of professed lack of expertise or their belief my condition was intractable. There may be no medication for our difference or the stigma that accrues from it, but what we are often looking for from treatment is guidance, compassion, validation, and support in simply making sense of our lives. Basic familiarity with the phenomenology of the condition would allow professionals to engage compassionately. Simple curiosity would allow for valuable therapeutic interaction. It is not always “expertise” that is needed. An over-reliance on expertise, as opposed to basic familiarity with the condition and a willingness to relate precariously, may be the biggest barrier to helpful therapeutic interaction with individual service providers. A referral can always be made to someone with greater expertise for specific purposes. However, as one participant pointed out, “we don’t want to be cured.” He added that the need for

support is “more about acceptance.” In her autobiographical account of living with Asperger’s, Willey (1999) said “I don’t want a cure for Asperger’s.” Instead, she said she would like to see a cure for “the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards” (p.122).

Participants reported having resentment towards service providers on different levels. The two participants who were roommates were both on ODSP (the Ontario Disability Support Program). They complained of low assistance rates, but also intrusive surveillance programs related to financial claw backs they felt “prevent you from getting ahead.” One participant said he likes to save his money and resented that if he saves up \$5,000, while his friends are purchasing video games or junk food, that “my benefits can be suspended until I consume that money.” He says “they call it overpayment.” This participant also complained that if he gets a job and makes more than \$100.00, ODSP keeps 50% of every additional dollar. His roommate said “it’s like they put up barriers to getting off support when you think they’d want you to get off support.” When I asked them if they were given trouble by ODSP because of the “spouse in the house” rule in which co-habiting sexual partners get diminished assistance, they said “not unless we get married – and that’s not about to happen!” Still, this rule discourages people who could be remotely construed as sexual partners from moving in together, which can become a barrier to wellness for many people. Living with someone is not only cheaper but, as these roommates reveal, can be therapeutic and provide a space of safety and support rather than further isolation. One of the participants compared such “neo-liberal” policies (Mahon, 2008, p.343) with self-interested profit-making of corporations “that don’t seem

to care what's good for people as long as they save money and make money.” The participant spoke passionately about “organizations that pursue their own motives and don't give a screeching monkey about who gets hurt.” Consistent with this participant's commitment to healthy food, he compared it to “nutritionists being funded by pop and snack companies.” His roommate concurred. “I say conflict of interest,” he declared, and likened the situation to “sports venues that promote pop and sports drinks loaded with sugar when the best thing to have is water.” Both participants lamented the tendency of society to engage in “self-destructive activities all in the name of money.”

The participants not only made charges of corporatism and putting agendas before people against provincial service programs, but also pointed a critical finger at local service agencies. One of the participants declined case management due to what Foucault has called “hierarchized surveillance” targeting individuals deemed to have a disability (Foucault, 1975/1995, p.177):

I tried to get a worker, but I just didn't like the whole program.

They want me to do an intake interview with a bunch of questions, then you get your worker, then they want you to do another intake interview after you get into the program, then you have to meet with your worker one hour every week and then do a life planning meeting either at your house or a coffee shop. Then you have to go into the office once a year. The other thing I wasn't happy about is that they want to know that I'm going to the doctor, going to the dentist, and getting my eyes checked every year As soon as I found out about

all this I withdrew.

Not only did the participants not trust this “power exercised discretely through surveillance and documentation” (Rouse, 2005, p.109), they did not appreciate the way they had been treated by many of their past workers. One participant said he did not always feel listened to and often felt like a “pet project or summer job.” His roommate complained that past workers would not drive him places, such as the supermarket to get groceries. He says the workers blamed this on insurance policies and organizational mandates, providing evidence of Green’s (2009) charge that growing managerialism can impede service provision. Both participants agreed “they have their own political agendas, these places. They’re supposed to help people out, and they do everything but”:

If you’re a worker, you should be able to drive your clients. If they need to go to the grocery store, they should be driven to the grocery store and help out with their grocery shopping, help them pick out what food they need and what food they don’t need. It’s all politics.

Finally, the participants complained about high bus fares. At \$3.00 a ride, they find it prohibitive to use public transit on their limited income. One of the ways to build stigma resilience is to go out and interact, which is restricted by high bus fares. All of

this points to the need for assessing the impact of systemic factors when determining the best interests of any population of marginalized individuals.

Another participant described how services are not always well-integrated with the specific needs of the autistic population. When applying for a new service, the participant said she had an autism worker with her along with the intake worker for the program (this reminds me of another participant's call for "a translator that speaks autism"). She said the intake worker talked to her in a patronizing way, which made her feel resentful and stupid. Probably not knowing how to address her client's need for explicit, direct formulations without double meaning, the intake worker precipitated a crisis for the participant. When the intake worker asked if the participant needed support with self-injurious behaviours (SIB's), the participant became confused. This did not seem like something the organization could support her to do. In a classic telegraphic episode involving communication failure, the participant could tell there was a social incongruence making her appear out of line which she could not articulate. The stress overwhelmed her and, donning her stigma cloak of invisibility, she engaged in a carefully disguised act of self-injurious behaviour right in front of both workers (which neither noticed). This demonstrates the importance of being familiar with the phenomenology of the conditions we may have to deal with as social workers. More fundamentally, it shows how important it is to be ready to manage diversity whether it is clearly labeled or invisible and sensed marginally. Considering the growing incidence of autism, this is an increasingly important population to be prepared for in life as well as practice.

Chapter 5: Concluding Theory and Remarks

In this chapter, consistent with the element of grounded theory in the study's methodology, I build on and further explore the theory that can be seen to emerge from the current research. As discussed previously, this theory will not pretend to represent objective reality. Such grand narrative would be contrary to the element of social construction, multiple interpretation, and democratizing communication embraced by postmodernism and hermeneutical phenomenology. It will not attempt to be any kind of "final and complete understanding" or what Foucault rejects as "totalitarian theory" (Mansfield, 2000, p.52). In the spirit of postmodernism, the theory will consist of a tentatively constructed narrative emerging from and rooted in the data that attempts to address autistic stigma and social oppression. The following initial part of the theory emerges from the data itself through constant comparison and growing levels of conceptualization that can be traced through the previous section. This will be followed by more conjectural theory addressing a silent contradiction at the heart of the findings. The paper will conclude with final words about dissemination, implications, and recommendations.

ASHFA stigma arises partially in response to visible differences, but it is the confusion and unexplained rejection arising from felt incongruences and neurodominant social code violations that are most poignant. The resulting stigma arises as a combination of neurodominant intolerance of difference along with frustration associated with behaviours related to the condition. Communicative blunders from a neurodominant point of view are the main source of this combination of stigma and frustration. Individuals with an autistic personality not complicated with intellectual or

communicative impairment (ASHFA), whether diagnosed or not, are socially constructed by the *frustigma* they experience as well as the cloaking strategies they adopt to manage the stigmatization they encounter. ASHFA frustigma is exacerbated by the invisibility of the condition. Neurodominant expectations are reinforced and heightened by this invisibility and unexpected social code violations are felt all the more intensely.

Familiarity with the phenomenology of ASHFA may allow neurodominants to better understand and negotiate such uncomfortable moments without provoking stigma. This is the case with those ASHFA individuals lucky enough to have found themselves in long term relationships, either sexual or nonsexual. Service providers familiar with the phenomenology of ASHFA would be able to better recognize camouflaged autistic personalities and provide appropriate support. Especially when such individuals have not yet identified themselves with ASHFA through diagnosis or other forms of validating discourse, appropriate support includes helping the autistic individual understand their difficulties functioning in a neurodominant world. This understanding can be very therapeutic and transformative. Medical and psychiatric expertise is less important at this delicate stage of initial contextualization than a helper's compassionate presence and willingness to engage in precarious therapeutic relationship. Diagnosis is the validating discourse that typically serves this contextualizing function, although relying on the level of expertise needed for diagnosis may leave those without the resources to access such services in the margins. Many overworked doctors and other service providers do not realize the importance of familiarizing themselves with autistic phenomenology in order to act as efficient educators, stigma resilience facilitators, and service gatekeepers for this population. What one participant called "reverse stigma" results when service providers

do not recognize autistic difference and assure clients nothing is wrong when understanding their difference and what is causing chronic and unpredictable stigma in their lives is what clients need desperately.

ASHFA, Modernism, and Diagnosis

The current project began with a discussion of stigma and the controversy surrounding the diagnostic changes in the DSM-5 as they pertain to Asperger's and autism. Research questions were presented, pertinent literature was reviewed, and my own onto-epistemological location as organizing participant was discussed. A postmodern methodology appropriate for research with possibly vulnerable and marginalized individuals was developed, not only as a framework for emancipative research but in order to provide a strong relational orientation to compensate ethically for my own "disability on relationships" (as one participant referred to his Asperger's). The postmodern roots of the research were rigorously explored in an effort to move beyond the "sterile environment of traditional epistemology" associated with modernism, a philosophical orientation that tends to keep society both constrained and oppressive (Wagner-Lawlor, 2013, p.193). I couldn't help noting that the challenges I face in the neurodominant world because of my Asperger's are exacerbated by the modernist paradigm within and around me because of its valorization of individualism, objectivism, explicit logic, and positivistic rules (making me wonder whether it is modernism or ASHFA that is more of a social disability). Findings were then presented and discussed, the most pronounced and surprising for me being that participants overwhelmingly reported the symptoms of the condition rather than the diagnosis as the source of their

stigma. I don't know why I found this so surprising since I suffered stigma for years before I was diagnosed, but it went counter to my research expectations for some reason. I think I was on my high horse about an issue, in this case stigma associated with diagnosis, rather than minding my own reflective position. I will be more careful about this in future work. At any rate, this result may indicate that what I have called the frustigma associated with ASHFA is more painful for participants than the stigma associated with the diagnostic label. It may also indicate that the condition from which the stigma arises is rooted at a profound existential level, that the condition is experienced as deeply interwoven with personality and being in the world. In this regard, one participant said his symptoms of ASHFA are "just parts of me." Another said "it's just the way I am." Still another said "if you call it [ASHFA] a condition people might think it's a disease and there are people out there who think these are diseases. They're incredibly short-minded, stupid, gullible people."

Uta Frith is a developmental psychologist who was prominent in bringing the work of Hans Asperger to North American attention. In 2008 she wrote a volume for Oxford's "Very Short Introduction" series about autism. She acknowledged the neurodiversity movement, although she seemed a bit out of touch with current trends when she referred to Aspies as all being self-diagnosed and well-adjusted. In the ASHFA community generally, *Aspie* is simply a short form of the phrase *individual with Asperger's* whether formally diagnosed or not ("Aspie," 2014). The neurodiversity movement celebrates difference rather than focusing on pathology. It developed around ASHFA, which by definition does not involve gross intellectual or communication impairment. However, such individuals are not always well-adjusted. As we have seen, this population, despite

various degrees of invisibility associated with their difference, still deviates from neurodominant convention which often results in stigma, confusion, rejection, and marginalization. Frith, as a psychologist who frequently deals with “classic autism,” or autism associated with clear intellectual and communication impairments as well as significant support needs, noted that “it is not surprising” that high functioning ASHFA individuals and groups tend to maintain their condition is not a disorder (p.37). At the same time, she points to the suffering experienced by those individuals with severe autism and maintains it would be “perverse” not to talk about pathology and the search for a cure in such cases (p.38). A study to hear the voices of these individuals is certainly called for, although it might be challenging because many of them may not be legally able to consent, able to comprehend the purpose of the study, or have the language to respond. I pause here to be grateful because *there but for the grace of God go I*. This is not meant to elevate me fundamentally above others or make judgements upon those I perceive as less fortunate than me, but rather because I could not do the work I do, would not be able to sustain my privileged lifestyle, would not be the person I am if my intellect or my linguistic abilities were not what they are. These two perspectives, to celebrate difference or search for a cure, are not two necessarily different camps about the same issue. This study does not pretend to speak to cases in which autism is associated with morbid losses of human capacity or the need for significant supports in order to survive. These conditions are no longer ASHFA, and issues around impairment and disability take on new meaning in such cases. There may be no clear dividing line here, but there are different perspectives understandably associated with these populations.

The qualitative difference between ASHFA and severe autism may count against the fact that both are now on the same spectrum. Before the changes in the DSM-5, individuals with Asperger's were not on the spectrum while those diagnosed with autism were, even if they had been lucky enough to outgrow the language deficits that led to their label of autism. There has been research interrogating whether ADHD is related to ASHFA; should this condition also be part of autism spectrum disorder? The "considerable diagnostic confusion" and controversy around this issue has not been cleared up (Klin et al., 2000, p.386; Ducharme & Gullota, 2013). For example, it seems lacking in discrimination to have only three specifiers indicating need for support across the whole autistic spectrum. Compared to those with severe autism, ASHFA may have little need for support. Put in a relative context, an ASHFA individual who is trying to make a relationship work or start a new job may require high levels of support associated with their condition. Service providers should be able to respond to this kind of need. There is a huge lack of services for this population and no formal way to mobilize support based on individually felt need rather than presumed level of pathology.

In terms of diagnosis, the DSM-5 states that one of the criteria for autistic spectrum disorder is that "symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning" (American Psychiatric Association, 2013, p.50). If diagnosis provides the validating discourse for autistic stigma, and according to participants this stigma is associated with their personality and who they perceive themselves to be in relation to others, what happens if an ASHFA individual does not get a diagnosis because they lack "clinically significant impairment in current functioning?" Too many ASHFA individuals fall through the cracks due to

reverse stigma often relative to identifiable pathology. Should such individuals be denied a validating discourse because their functioning is deemed too high? By what yardstick is “impairment” assessed? Does the distress of stigma qualify as impairment? Diagnosis may be necessary in the neurodominant world to qualify for services, but it is based on a medicalized perspective that can change with the newly released edition of a manual. Struggling ASHFA sense it by the phenomenology of the stigma they experience, not through a screening list of objective criteria. They see the condition as part of their personality, part of themselves, not just in terms of a label they may or may not get (Gray, 2013, p.2). Relying on the dominant discourse of medicalization for ASHFA identification, rather than self-identification with a culture of being in the world, is reminiscent of the social injustice involved when governments reserve the “authority to define Indian status” (Furniss, 1999, p.120).

Frith (2008) hopes to glean “rich rewards” from research in the areas of neuroscience, cell biology, and genetics both about neurodominant as well as autistic personalities (p.121). Baron-Cohen (2008) hopes the diagnosis of autism will someday be related to specific biological markers rather than subjective assessments of client history, self-report, and symptomatology. Does the presence of biological correlates in autism make a pathology model inevitable? It has been reported that brain injuries can result in social difficulties resembling those in high functioning autism (Channon, et al., 2014). This is not surprising; everything about human beings has biological correlates. On a fundamental level, we are biological organisms. This does not lead logically to the conclusion that everything about human beings can be reduced to biology. Biological bodies have neuroreceptors that respond to a certain range of light frequencies, whereas

phenomenal bodies see rainbows. This emergence and irreducibility is as true for neurodominant personalities as autistic ones, and Merleau-Ponty emphasizes the importance of distinguishing the lived body of experience from the “body as set forth in works on physiology” (1945/2006, p.409). The distinction between deaf, the biological condition of hearing loss, and Deaf, belonging to a community of Deaf people who do not see their condition as an impairment, comes to mind (Tremain, 2005).⁶ I found this distinction best articulated on the internet by someone identifying themselves as a sociologist and a “native ASL signer for 30 years” (Best Answer, 2011). The comments after the post seemed to reveal that not everyone appreciates this distinction. Most of those who posted felt “deaf” should only be capitalized at the beginning of a sentence. In terms of this project, deaf with a small ‘d’ corresponds with someone diagnosed with autism spectrum disorder who passively accepts the condition as pathology, avoids acknowledging the condition in order to avoid pathology (such individuals clearly need an alternative to diagnosis as a validating discourse), or struggle in marginalized isolation with the stigma of the condition. Deaf with a capital ‘D’ corresponds with someone who may or may not be diagnosed who identifies with the ASHFA community through recognizing in themselves the phenomenology of the condition and the associated frustigma. Identifying with ASHFA culture (online, in principle, actively, or in theory as a fundamental personality type) can provide a way to offset the stigma and marginalization felt in relation to neurodominant culture. Current support groups tend to revolve primarily around diagnosis.

⁶ Hindhede (2011) conducted a study of hearing disabled identities that includes an interesting discussion of stigma and hearing impairment

Deconstructing Diagnosis

This leads us to a more complex and highly conceptual leap of theorization based on the outcome of the research. It is rooted in a silent contradiction contained in participant narratives and points to the deconstruction of diagnosis as a dominant validating discourse. I use Derrida's term "deconstruction" here not to denote a device of literary criticism (Kates, 2008), but as a rigorous process of challenging established concepts and practices by exposing contradictions and taken-for-granted processes of privileging (Balkan, 1995). In this transformative sense, "deconstruction is not opposed to reconstruction" (Derrida, 2002, p.77). Such critical analysis leads to possibilities of re-imagination and "unheard of, undreamt of possibilities" (Caputo, 1997, p.31). Insofar as this movement of deconstruction points towards positive social change it "calls for an increase in responsibility" for realization (Derrida, 1989, p.20).

This silent contradiction in the data has already been discussed in the section above on diagnosis. Participants acknowledged a socially disabling aspect to their condition, but also maintained they did not feel inherently impaired. They described their condition as "part of myself I have to work with and around." At the same time, participants expressed feeling relief when they were diagnosed. The participants confirmed previous research in this area by reporting their diagnosis provided a validating discourse that brought healing and positive change. Self-confidence grew, relationships became easier, and others became more empathetic and patient, all because of the contextualizing discourse diagnosis provided. The individual quoted above from an online internet discussion posted that he quit drugs after he was diagnosed because the

validating discourse gave him “the confidence to try and confront life without numbing the pain artificially” (Countryboy, 2010). Yet paradoxically, diagnosis represents a paradigm that characterizes autism as an inherent disability, a position the participants did not endorse. Murray (2012) points out that “the idea of autism as a ‘problem’ or ‘deficit’ is in fact built in during diagnostic evaluation” (p.13). In other words, when medical diagnosis provides the main validating discourse for autistic personality, it imposes at the same time a pathologizing model that implies ASHFA individuals are diminished, impaired, afflicted, and disabled. In accepting diagnosis as the resolution to a search for validation, ASHFA individuals paradoxically undermine their “autistic integrity” (Barnbaum, 2008, p.204). This is only logical since “to be situated in a discourse of pathology is to be delegitimized” (Tremain, 2005, p.83).

Butler (2002) was referring to gay marriage but could have been writing about ASHFA when she maintained that practices departing from cultural norms are seen by society as “perilous to the putative natural laws said to sustain human intelligibility” (p.16). The manner in which ASHFA individuals constantly break codes of neurodominant social conduct has been discussed extensively. These social code violations are what lead to much of the stigma ASHFA individuals’ experience. An individual who cannot make friends, experiences rejection, and seems to be a “perfect victim” for bullying and manipulation may be crying out for some kind of validating discourse (Klin et al., 1995, p. 58). Butler describes how a “crisis of legitimation” can ensue because one’s “sense of personhood is fundamentally dependent on the lexicon of that legitimation” (p.17). For ASHFA individuals, accepting a diagnosis means accepting a socially constructed mantle of disability even if they simply prefer to see

themselves as differently oriented towards the world through their style of communication, as many of the participants reported.

One alternate validating discourse involves the theory that ASHFA represents an exaggeration of male characteristics. Hans Asperger himself noted typically male characteristics such as logic, abstraction, precise thinking, and explicit formulation, maintaining that “in the autistic individual the male pattern is exaggerated to the extreme” (Asperger, 1944, p.85). I would extend this pattern of exaggeration further to embrace characteristics of the modernist paradigm and add “the male-dominated normative perception of the individual as independent and autonomous” (Gray, 2010, p.1805). What if ASHFA is being diagnosed more and more frequently because of the biological, evolutionary impact of the modernist paradigm (the valorization of the aforesaid male characteristics) on the human species? It would be paradoxical, then, that predominantly patriarchal, modernist discourses impute impairment and disability to the condition. This is an interesting scenario, but it is hard to see how research could explore the possibility further or why such a condition would be associated with so much stigma and marginalization if the characteristics associated with the condition are so highly valued by society (unless the condition, seen in this way, represents an ironic backlash).

One participant who was diagnosed with Asperger’s at a young age, after acknowledging a socially disabling aspect to his condition, stated he did not feel inherently disabled and cited an article (the title and author of which he could not remember) that talked about how ASHFA may represent an individual’s location on a broader spectrum representing a general human orientation towards EQ (emotional orientation) and IQ (intellectual orientation). This position seems to be an adaptation of

Daniel Goleman's work on Emotional IQ (Goleman, 1996/2009). The participant said "I just think that I've got more on the intellectual side and less on the social side." That many ASHFA find this notion helpful as a validating narrative can be seen on various discussion groups (e.g. <http://www.wrongplanet.net/postt70229.html> and <http://www.wrongplanet.net/postt171255.html>). This can be seen as a part of a larger attempt to "normalize autism through an association with general human variation" (Murray, 2012, p.35). If widely adopted, such a narrative might decrease the stigma experienced by ASHFA individuals because it could provide an explanation for their difference without imputing diminishment or pathology relative to neurodominants. Such an explanation might not in itself reduce frustigma when neurodominant and ASHFA interact, but similar to the acceptance and understanding developed through familiarity in long term relationships, such equalizing discourses may condition stigma resilience on a systemic level. Yet such explanations have been criticized because they generalize the definition of ASHFA to the point where it becomes "meaningless" and also "removes much of the specificity about what the condition actually is" (p.35). Retaining specificity is an important part of embracing diversity, although specificity can revolve around a prominent phenomenological feature.

I would like to briefly present a related theory, the beginnings of a theory at least requiring further research and investigation, which provides a validating discourse for autism without imputing disability. This theory is based on the philosophy of Maurice Merleau-Ponty, on whose work the methodology of this study is partly based.

Authentic Presence, Constituted Presence, and Autistic Presence

I wrote my Master's thesis in philosophy on Merleau-Ponty's phenomenological distinction between authentic and constituted presence. As an individual struggling with the frustigma of ASHFA, this was the initial validating discourse that had a therapeutic impact for me. I was not diagnosed until years later, and the distinction helped me make sense of my life and the stigmatizing difference I felt around others. I laboured for years on that project, intellectually recognizing it was more than an academic thesis but not fully appreciating its urgency as an effort to understand myself. The relevance of those ideas on my current research did not occur to me until I reflected on the participants' narratives, recalled my own need for a validating narrative, and in the silence at the heart of the data saw the discrepancy involved with filling that need using medical diagnosis.

These concluding remarks bring the whole process full circle.

In his later work, Merleau-Ponty wrote "our first truth, which prejudices nothing and cannot be contested, is that there is presence" (1968, p.160). From the outset, Merleau-Ponty rejected subject-object duality and foreshadowed postmodernism not only by opening up rationality to relationality and embodiment, but by specifying that humans do not relate themselves to an objective in-itself world:

What is given is not the thing on its own, but the experience of the thing, or something transcendent standing in the wake of one's subjectivity, some kind of natural entity of which a glimpse is afforded through a personal history. (1945/2006, p.379)

This had a therapeutic impact on me. I often found myself feeling like an isolated subject relating awkwardly to a cold objective world. The passage helped me appreciate how the world in which I live is intimately constructed by my own perception and history, how closely intertwined I am with the environment in which I live, and that I am an active participant in my world. This was comforting. The environment around me could feel like a detached, separate, cold, objective, scary place in which I experienced mostly rejection. I did not seem able to function in and relate to the world the way other people seemed to. Merleau-Ponty helped me to start feeling the depth of my connection with the world through his elegant phenomenological articulation. It is a typically ASHFA characteristic to arrive at personal awareness if not through formal logic, at least through careful formulation. Yet this was just the beginning. In the course of his effort to ground human presence in the phenomenal body, Merleau-Ponty described a living spontaneity that transcends subject/object duality through the “fusion of soul and body in the act” (1945/2006, p.84). He described how we “project ourselves” into the world (1945/2006, p.159). For example, a person bitten by a mosquito:

does not need to look for the place where he has been stung.
 He finds it straight away, because for him there is no question
 of locating it in relation to axes of co-ordinates in objective space
 but of reaching with his phenomenal hand a certain painful spot
 on his phenomenal body, and because between the hand as a
 scratching potentiality and the place stung as a spot to be scratched
 a directly experienced relationship is presented in the natural system

of one's own body. The whole operation takes place in the domain of the phenomenal; it does not run through the objective world... Similarly, the subject when put in front of his scissors, needle and familiar tasks, does not need to look for his hands or his fingers, because they are not objects to be discovered in objective space: bones, muscles and nerves, but potentialities already mobilized by the perception of scissors or needle, the central end of those 'intentional threads' which link him to the objects given. It is never our objective body that we move, but our phenomenal body, and there is no mystery in that, since our body, as the potentiality of this or that part of the world, surges towards objects to be grasped. (Merleau-Ponty, 1945/2006, p.121)

Merleau-Ponty extends this kind of spontaneity not only to physical reflexes and familiar learned tasks, which he uses for illustration, but to our very engagement with the world and each other. He calls the phenomenal world "a *whole* already pregnant with irreducible meaning" and describes how authentic presence places us in "spontaneous accord with the intentions of the moment" (1945/2006, p.25). This world fits, so to speak, like a hand in a glove; we dwell there in responsive oneness. Interaction proceeds "without any calculation on my part" (1945/2006, p.122). He compares such being in the world to the experience of a musician where, during engaged performance, "the performer is no longer producing or reproducing the sonata: he feels himself, and the others feel him to be, at the service of the sonata; the sonata sings through him or cries

out so suddenly that he must ‘dash on his bow’ to follow it” (1968, p.151). Leonard Angel at UBC described this kind of spontaneity as “the infusion of grace in agency” (1987, p.60). I found all this beautiful to contemplate, and these authors made it seem like a human birthright to experience such engaged spontaneity. Yet I so often seemed, unless in a flow of self-absorbed activity, to find myself clumsily navigating the world through deliberation and uncertain calculation, blundering repeatedly and experiencing stigma in the process. I was a perpetual awkward beginner in the school of life. This is constituted presence; living in the world, particularly the social world, as if it were an objective setting, a task zone, a matrix of possible calculations that do not come naturally.

Merleau-Ponty embraced this natural responsive fluency of being not only in relation to the natural world, but in relation to language. He distinguished what he variously referred to as authentic, originating, transcendent, active, fertile, true speech from constituted, secondary, empirical, stereotypic speech. Constituted speech draws on a system of already-established explicit meanings from which concrete messages are constructed logically by stringing together discrete elements in a mechanical, additive fashion. Many people are technically proficient at this use of language and can convey complex ideas quite articulately in this way. This use of language tends to put pre-existing thought into words, as if words were labels to be applied externally. Merleau-Ponty maintains that speech can be much more:

To speak is not [always] to put a word under each thought. If it were, nothing would ever be really be said. We would not have the feeling of living in language and we would remain silent...we sometimes have, on the contrary, the feeling that a thought has been spoken – not

just replaced by verbal counters but incorporated in words and made available in them. (1964, p.44)

Merleau-Ponty described how authentic speech does not call for the kind of deliberate mechanical control exerted in constituted speech, an effort which can sometimes appear as visible strain. In authentic presence, as in play for Gadamer, the effort of work and the effort of speech are “felt subjectively as relaxation” (1986, p.94). Authentic speech, Merleau-Ponty says, “streams forth” from us (1968, p.152) and “instantaneously emerges” from our intention to communicate. In authentic speech we “speak as we sing when we are happy” (1945/2006, p.404). We do not have to strain to put things into words. Meaning blossoms to life in an “organism of words” (1945/2006, p.212). In constituted presence we flatten the world to an objective setting where it is necessary to proceed through a series of deliberate decisions. In authentic presence we function responsively through a field of phenomenal intentionality:

I do not need to visualize external space and my own body in order to move one within the other. It is enough that they exist for me, and that they form a certain field of action spread around me. In the same way I do not need to visualize the word in order to know and pronounce it. It is enough that I possess its articulatory and acoustic style as one of the modulations, one of the possible uses of my body. I reach back for the word as my hand reaches towards the part of my body which is being pricked; the word has a certain location in my linguistic world,

and is part of my equipment. (1945/2006, p.210)

Most poignantly for me, Merleau-Ponty extended this distinction to the social world. When it is authentic, for example, “a friend’s speech over the telephone brings us the friend himself, as if he were wholly present” (1964, p.43). On the other hand:

When I have the feeling of dealing only with words, it is because expression has failed... We no more think of the words that we are saying or that are being said to us than of the very hand we are shaking. The hand is not a bundle of flesh and bone, it is the palpable presence of the other person. (1973, pp.116-117)

I often find the telephone a challenging instrument. I have to work myself up to present myself on the phone in a friendly manner. Rather than talking to the other person as if they were “wholly present,” I tend to feel I am reducing myself to a disembodied voice and talking to another disembodied voice over objective space. My wife tells me I forget to be pleasant, that I can be impolite and cold. I often forget what I meant to say. One thing is certain, after a social phone call I feel exhausted and relieved to be off the hook. As for shaking hands, it sometimes does feel like I am holding “a bundle of flesh and bone.” I wonder how long to hold it for. As described by participants, the social world often becomes an objective task zone where nothing comes naturally. I can attest to the fact that “analytic thought interrupts perceptual transition from moment to moment, from place to place, from one perspective to the next” (1964/2007, p.268). Maybe this is

part of the reason why ASHFA individuals, at least the participants and I, have so much trouble with change and having habitual routines broken. I know that my life is full of such analytic interruptions.

Merleau-Ponty's project is not to attribute constituted presence to pathology. He is encouraging us to seize our capacity for spontaneous embodiment in the experienced world. He tells us that because of modernism, scientism, positivism, and objectivism, "most of the time we remain within the bounds of constituted language" (1945/2006, 218). He wants us to remember that we are "as sentient subjects, a repository stocked with natural powers at which I am the first to be filled with wonder" (1945/2006, p.249). He tells us "the mistake lies in treating the social as an object," and maintains "we must return to the social with which we are in contact by the mere fact of existing and which we carry about in us before any objectification" (1945/2006, p.421). In contrast to this, ASHFA often manage their interactions in the neurodominant social world, where they can be like fish out of water, through a logical process of deliberate strategic planning in a context of objectification. At least part of this is due to anxiety associated with stigma.

Merleau-Ponty often appealed to Gelb and Goldstein's (1920) brain damaged patient Johann Schneider in order to demonstrate constituted presence. Marotta and Behrmann (2004) call this patient history "one of the most thoroughly discussed and controversial cases in the history of neuropsychology" (p.633). The authors agree with a reviewer at the time who noted the "the wealth of clinical, objective description of symptoms" in this case history (C.P.S., 1922). Employed by Gelb and Goldstein to develop Gestalt theories of perception, the case is usually taken as a description of visual agnosia, an impairment of "accessing meaning from visual input" (2004, p. 635).

Merleau-Ponty's philosophical presentation of the case in relation to constituted presence is unique as far as I know. Schneider was injured in a World War I accident and sustained shrapnel injuries to his brain, yet I found it easier to relate to Schneider and his constituted presence than to what Merleau-Ponty described as the authentic presence characterizing the majority of healthy people (at least, those who manage to overcome the objectivism of modernity):

The thought of others will never be present to him, since he has no immediate experience of it. The words of others are for him signs which have to be severally deciphered, instead of being, as with the normal subject, the transparent envelope of a meaning within which he might live. Like events, words are for the patient not the theme of an act of drawing together or projecting, but merely the occasion for a methodical interpretation. Like the object, other people 'tell' him nothing, and the phantoms which present themselves to him are devoid, not, it is true, of that intellectual meaning arrived at through analysis, but that primary meaning reached through co-existence. (1945/2006, pp.153-154)

One doesn't have to have shrapnel in their brain to experience constituted presence. Merleau-Ponty used Schneider as an illustration, the way he used reflexes and familiar tasks to illustrate engaged spontaneity. Schneider, after all, was physically injured and emotionally traumatized. From Merleau-Ponty's descriptions, he had more profound

trouble functioning in the world than I or any of the participants in this study. He could not form political or religious opinions; when he went for a walk it could only be to complete an errand; he would not recognize a familiar house if he did not go out with the intention of finding it (1945/2006, p.155). It was his qualitative orientation of constituted presence, not his injury or the biological correlates, that were of interest to me. His level of disability, location on a spectrum of pathology, and need for support is another matter:

He speaks practically only when he is questioned, or, if he himself takes the initiative in asking a question, it is never other than of a stereotyped kind, such as he asks daily of his children when they come home from school. He never uses language to convey a merely possible situation, and false statements (e.g. the sky is black) are meaningless to him. He can speak only if he has prepared his sentences. It cannot be held that language in his case has become automatic; there is no sign of a decline of general intelligence, and it is still the case that words are organized through their meaning. But the meaning is, as it were, ossified. Schneider never feels the need to speak; his experience never tends towards speech, it never suggests a question to him, it never ceases to have that kind of self-evidence and self-sufficiency of reality which stifles any interrogation, any reference to the possible, any wonder, any improvisation. (1945/2006, p.228)

Merleau-Ponty was not highlighting biological pathology or the physical condition behind constituted presence. He was attempting to show how modern western culture has been “obsessed with objective thought” (1945/2006, p.393), how modernity tends to “idolize objectivity” (1948/1991, p.91), and how the “objectivist illusion is firmly implanted in us” (1973, p.148). For ASHFA, the degree to which constituted presence sets us apart is in an important sense integral to our personality and our constitution. It becomes an uncomfortable “disorder” because of stigma. If it was a matter of adopting a new philosophy, I would clearly be getting over my Asperger’s by now. Constituted presence may be associated with modernism as well as variations in brain structure, but how can it be characterized as a pathological condition for ASHFA if the only suffering associated with it comes from stigma in neurodominant contexts? Constituted presence is fundamentally part of my “personal core” and a certain “power of existing” (1945/2006, p.155). For me, constituted presence is a manner of being so integrated with my personality that seems to reflect the structures of my insertion in the world as an organism. Future research may be able to define and differentiate that part of autistic presence currently defined as “impairment” that is associated with distress caused by frustigma, neurodominant intolerance, and systemic factors such as those pointed out by participants ranging from barrier-generating policies around financial assistance to high bus fares, gaps in service, and current models of service provider training.

As I reconsider my thesis on Merleau-Ponty, I come to realize that authentic and constituted presence are not discrete types, like another binary dualism such as subject and object. All humans function within a range of authentic spontaneity and constituted deliberation. For human beings, “everything is both manufactured and natural”

(1945/2006, p.220). It strikes me that I operate along a different range of the spontaneity continuum than mainstream others, that I have a need for explicit clarity and formulation, that my action and behaviour are often more “manufactured,” particularly in the social world. As a lived, phenomenological characteristic of my being, the most poignant time this becomes an impairment or stigma issue is when I interact with neurodominants in social settings. This does not make me any less than anyone else, just differently oriented in the world and towards others in a way I can articulate as a phenomenological continuum underlying the autistic/normal spectrum. I wonder if mentalization researchers are moving towards the existential significance of discriminating authentic and constituted character when they note the “profound difference between abstract self-understanding and the kind of insight that is mediated by live affective experience” (Fonagy, Gergely, Jurist, & Target, 2002, p.430).

Metaphysically, presence does not imply a naïve essentialism; absolute presence in itself is a romantic oversimplification. For Merleau-Ponty, as for Derrida, presence involves powerful depths of silence, invisibility, and “ir-reducible absence” (Derrida, 1967/1997, p.47). Phenomenologically, at the felt crest of the wave that is *being*, the discourse of presence becomes my validating discourse. It is a great relief to realize I am not stupid or worthless, but my manner of presence is different. This way of thinking might not change the level of stigmatization others direct towards me, but it has the effect of building stigma resilience because, without the medicalization and pathologization of diagnosis, it gives me a way to contextualize my difference. I have come to see myself as ASHFA, involving an existential style or manner of being present in the world that is deeply integrated with my personality. What started at the beginning of this project as

my diagnosis of Asperger's/high functioning autism has evolved into what Murray (2012) has called my "autistic presence," which need not be considered in terms of pathology. It is part of who I am, an integrated part of my personhood. I have many brothers and sisters whose presence in the world is akin to mine, including the participants of this study; a community and more, a culture of presence that gives me strength since it locates me as more than an outsider on the margins of neurodominant culture. Pride in the character of my presence powerfully "renegotiates the terms" of being human to embrace a more comprehensive vision of what it means to be normal (Murray, 2012, p.104). I have internalized the stigma and marginalization associated with my difference from neurodominant culture for long enough.

Negotiating difference with ASHFA from a neurodominant perspective can be seen from this point of view not as having to make "accommodations" but as a form of cultural competence with differently present human beings. As discussed in the findings, there are various levels of systemic oppression that need to be addressed in order to create a social environment in which stigma will not flourish. Still, there may always be stigma associated with deviation from the dominant norm. Stigma resilience resulting from self-understanding, confidence, and community can provide a powerful position from which to start deconstructing the marginalization resulting from this difference.

Lester and Paulus (2012) make a good point about the socially constructed nature of normality/ deviance. They tell us that attempting to fit into the neurodominant world may be fruitless because "to achieve typicality or normality is impossible, as it too [like deviance] is a discursive construction always shifting across time and place" (p.267). If by this they mean "normality is not an essential thing in itself that can be determined

independent of a social context," it is easy to agree with her. Interacting in a lived social environment, however, it often seems that everyone else achieves "normality" very well compared to me. Failure to achieve "normality" is a source of very real (even if socially constructed) stigma. If ASHFA is seen in terms of cultural diversity involving differently oriented human presence, it becomes more than a "condition" associated with pathology. Seen as a manner of being in the world rather than a deficit, ASHFA situates itself proudly at the dynamic frontiers of so-called normality. The "condition" becomes a deeply rooted style of human presence in the world empowered by the integrity of its own unique quality of relationship and being.

Final Words: Dissemination and Recommendations

The current research will be written up three times in an attempt to engage readers of different types. The first version is the full research report, the current thesis, in which the focus is on a full description of the research process and the underlying onto-epistemological foundation. In addition to the full research report, a condensed version will be written for academic publication. A third write up will be intended for general distribution and provided to the general public as well as individuals diagnosed with, identifying as, or struggling with the characteristics of ASHFA. This copy will be designed to put the insights gleaned in my study to work in the community. The insights generated in the research will be presented in a way that will hopefully be of assistance to those whose lives are touched by ASHFA. In an effort to address the "emancipatory commitment" of the research (Brown & Strega, 2005, p.9), this user-friendly write-up will be distributed to service organizations including hospitals, which are supposed to

work with people in distress but have been called “instruments of domination” grounded in positivism and neoliberal managerialism (Wilson, 1992, p.7). I hope my study will provide “evidence of a new style suggesting a shift to a new paradigm” that involves, like postmodernism, constructivist grounded theory, and Gad-Pontyan methodology, a non-hierarchical co-constructing partnership that puts encounter and genuine concern for the needs, experiences, and voices of people on an equitable footing with quantitative evidence, political agendas, bureaucracies, rules, and normalized expectations.

The most important practice recommendation emerging from this research is that front line workers familiarize themselves with the phenomenology of ASHFA in order to provide more effective service to this population. This is not only true for workers providing direct service to these individuals, but all professional helpers since the prevalence rate of this condition is growing rapidly. Any service provider, including social workers, teachers, doctors, nurses, and therapists, if they are familiar with the phenomenology of ASHFA, will inevitably find themselves in the position of being able to guide individuals struggling with frustigma who may be suffering because they don't know what is happening to them. It is crucial to recognize such individuals and be able to direct them not only towards possible diagnosis but supportive peer communities. This study indicates that the suffering caused by ASHFA stigma is much more manageable when the individual is aware of a validating discourse that explains their difficulty fitting in, whether this takes the form of diagnosis, identifying with a group having similar experiences, or the empowerment of recognizing in oneself a certain manner of being present in the world even if it is not the dominant way. One of the most poignant sources of suffering reported by participants is reverse stigma, in which their difference becomes

a more powerful source of alienation when it is dismissed and left unaddressed.

Increasing not only professional but community level familiarity with the phenomenology of ASHFA would decrease stigma as well as reverse stigma and promote a less painful interface between ASHFA and neurodominant culture. Policy recommendations emerging from this study are related to facilitating this increased level of awareness and stepping up the resources allocated to this marginalized population. The lack of services available to these individuals has already been discussed. Resources are understandably targeted towards supporting individuals at the severe end of the spectrum where pathology is clearly identifiable, especially in children, yet the suffering of high functioning youth and adults struggling to function in a neurodominant culture must not be overlooked.

A proposal for the DSM-6 committee emerging from the findings of this study would be to reinstate the term *Asperger's* as a descriptive term for the high functioning range of the autistic spectrum. The findings of my study agree with Linton et al. (2014) that specific diagnostic changes in the DSM-5, such as eliminating the pervasive developmental disorder category and merging Asperger's into the autistic spectrum, are not highly controversial among ASHFA individuals. The elimination of the term Asperger's, however, is problematic for many and ignores the widespread peer affiliation based on this descriptive moniker for the condition. Eliminating the term from the DSM may not stop individuals and organizations from continuing to employ the designation (which could be seen to undermine the authority of the American Psychiatric Association), but it may cause ASHFA individuals to become less acknowledged by dominant medical and political institutions as a population needing support and

recognition. My research agrees with Kite et al. (2013) that indicates Asperger's has less stigma associated with it than autism, thus providing a safer diagnostic affiliation than the more general term autism which seems to be associated in people's minds with classic or full blown autism clearly demonstrating organic pathology. Retaining the term Asperger's as the high functioning range of autism spectrum disorder (rather than a distinct diagnostic entity) would not compromise the DSM committee's effort to streamline diagnosis. Asperger's is much easier to refer to than autism spectrum disorder not associated with language or intellectual impairment. Retaining the term would address the need for this population to retain its cohesiveness as a peer group facing similar stigma and sharing identifiable characteristics of social functioning and mentalization (the ability to apprehend the mental states underlying behaviour).⁷

When the DSM-III stopped categorizing homosexuality as a disorder, there were concerns about access to service reminiscent of those resulting from the current elimination of the term Asperger's. It's not the need for official validation that is in question here, but lack of a formal avenue for addressing service needs. The DSM-5 avoids pathologizing fundamental ways of being in the world such as homosexuality and transgenderism with the recognition of "Gender Dysphoria" (American Psychiatric Association, 2014, p.451). This effectively recognizes the distress that can be associated with these unconventional ways of being; a kind of distress similar to that experienced by ASHFA in the sense that the associated suffering is not a function of some condition in itself but rather stigma, fear of stigma, and the process of negotiating conventional

⁷ In the context of ASHFA, mentalization has often been referred to as "theory of mind." I always hated that term because when I am told I have no "theory of mind" it conflicts with the pride I take in my ability to have a strong theory of just about anything. Mentalization is a more comprehensive concept (Fonagy et al., 2002).

expectations. Perhaps the DSM-6 can find a way to give ASHFA a similar kind of recognition, thus mobilizing resources to respond on the basis of felt need rather than imputed pathology or the degree of conventional or unconventional functioning.

Most studies examining autism through the lens of social functioning and stigma have focused on children at the more disabling range of the spectrum, while “relatively few studies have addressed this concern in adults who are high functioning” (Channon, et al., 2014, p.161). I hope my study stimulates further interest into ASHFA as a fertile ground for future research. My study makes sense of quantitative findings like Butler and Gillis (2011) that indicate the term Asperger’s is not associated with stigma, which they took to conflict with findings like Shtayermman’s (2009) indicating that individuals with Asperger’s indeed experience stigma. Once the social behaviour of ASHFA in relation to neurodominants is seen as a primary source of stigma rather than the diagnostic label, which this study indicates, the findings of both studies become consistent and more meaningful. Future research that explores the phenomenology of ASHFA can take this as a starting point and build on social work’s knowledge of this population and how it interacts with neurodominant culture. Such research may well increase our knowledge about ourselves as it builds on our professional insight into the dynamics of social dominance, exclusion, and marginalization. This project has been concerned primarily with the exploration of *felt* stigma. It is hoped that others may be inspired by this project to extend the exploration to forms of *enacted* stigma such as bullying and discrimination and how these can become inscribed by policy and social convention.

One final consideration for further research is in the area of mentalization.

Weinberg (2006) wrote “mentalization theory appears to be a genuinely new model of psychoanalytic development and clinical theory” (p.251). Over the past 20 years, mentalization has been the subject of growing (mostly quantitative) research and has been applied, for example, in the areas of disordered attachment (Morken, Karterud, & Arefjord, 2014), child abuse related to substance disorder (Fewell, 2013), body awareness (Ekerholt, Schau, Mathismoen, & Bergland, 2014), and eating disorders (Robinson, et al., 2014). It has also been developed into a treatment modality (mentalization based treatment or MBT) that research has shown to be as effective as dialectical behaviour therapy (DBT), which is the current treatment of choice for borderline personality disorder (Bliss & McCardle, 2014). An important distinguishing characteristic of social work research is that it “promotes justice, social change, and social inclusion” (Shaw, 2007, p.665). Social work research, then, has a unique role to play in this burgeoning field because, like my current study, it can explore how differences in mentalization can be associated with stigma and marginalization. “Autism-like” impairments of mentalization have been noted in other conditions, including borderline personality disorder (Fonagy, Luyten, & Strathearn, 2011) and schizophrenia (Sasamoto et al., 2011). It would be interesting to explore the phenomenology of mentalization and stigma in these other conditions. It was not very long ago that individuals with autism were routinely institutionalized, and this population, among others with differently equipped mentalization, continues to suffer from silent as well as overt oppression. As a social work contribution to the emerging field of critical autism studies (Davidson & Orsini,

2013), I sincerely hope my efforts to develop this project will inspire further research that will help lead to mutual understanding and acceptance along this dimension of diversity.

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Appendix A: Recruitment Posting

Volunteers Wanted For Study

My name is Gord and I am a Master's social work student doing a study through the University of Victoria called "Asperger's, Autism, and the Impact of Diagnosis on Stigma." The diagnostic changes in the DSM-5 prompted the research, and I am very interested in the experience of youth and adults 16 and over who have Asperger's or high functioning autism. I am particularly interested in the experience of stigma (social prejudice, difficulty fitting in, lack of understanding, and related challenges). Exploring this issue will help people appreciate the unique challenges individuals with this condition experience. This could facilitate not only a better understanding of stigma, but more appropriate and well-directed advocacy, more effective services and supports, and combined with other studies that work towards social justice, eventually a more inclusive society.

This study is not designed to prove or establish any particular theory or point, but is designed to explore the experience of individuals who have Asperger's. It seeks to give such individuals a voice from which a greater understanding of stigma may emerge.

I would like to do some individual interviews that will last an hour or so. All expressions of interest are very welcome. The only conditions are that you must be 16 or over and have a diagnosis of Asperger's or high functioning autism. Any extraordinary needs or accommodations needed by potential participants will also be discussed in order to determine how and whether such needs can be accommodated. This will be discussed further with those who respond as potential participants.

Participants will be able to select the location of their interview so they will feel most comfortable. They can expect to be asked questions about the various areas of their lives in which they may have experienced prejudice, exclusion, lack of understanding, stereotyping, judgement, or other forms of stigma. In addition to the benefits outlined above, individuals who participate may learn more about the recent changes to the dsm-5, may appreciate the chance to discuss their experiences of stigma, and will have the satisfaction of knowing they have helped increase society's knowledge

of Asperger's. They will be given the opportunity to check the accuracy of their transcribed interview and make subsequent additions to their narrative. The final study will be made available to the Asperger's society of Ontario and may be published in a future article and/or book, a copy of which will also be provided to the society.

Every participant's identity will be anonymous and privacy will be maintained as a priority.

Appendix B: Interview Questions

The interviews proceeded along emergent lines depending on the presentation of each participant, how their narratives unfolded, and the themes emerging from previous data generation. The following is the baseline set of questions that emerged by the final interview:

- a) What exactly is your diagnosis?
 - b) At what age were you diagnosed?
 - c) How old are you now?
 - d) What is your occupation?
 - e) What is your living situation?
 - f) Where did you hear about this research?
-
1. Stigma is when people experience judgment, negative attitudes, or injustice because of some quality or condition they have that is misunderstood by society. Would you say you experience stigma because of your condition?
 2. Do you feel mistreated or misunderstood by others?
 3. Do you feel people treat you fairly?
 4. Did you experience stigma from other kids when you were growing up that looking back may have been due to your Asperger's? For example, did you feel excluded, bullied, or taken advantage of?
 5. Would you say you experienced stigma in your relationships with your family growing up?

6. How do you manage the challenge of being in relationships? Do you feel your condition and/or people's perception of it has an impact on this area of your life?
7. Do you experience challenges in your current household because of Asperger's?
8. Do you think your condition affects the kind of work you can do?
9. How would your experiences of looking for work? Have you experienced stigma in this area of your life?
10. Has your diagnosis ever become an obstacle at work or at school?
11. What kind of things related to your diagnosis do you think neurotypical people find frustrating?
12. Do you think it's possible to separate the experience of stigma, such as unfair judgments, prejudice, stereotypes, and that kind of thing from people's frustration with the way you interact socially because of your Asperger's? How much of your social difficulty do you suppose is due to people's frustration and how much is due to stigma and prejudice? Do you ever think about this?

Remember you can skip any question you are not comfortable with and take a break at any time.

13. Have you or do you experience much anxiety, depression, or any other mental health issues?
14. How did you cope with this?
15. Have you ever experienced stigma from medical or mental health professionals?
16. How did you come to be diagnosed? Do you remember how your diagnosis came about?
17. How did you feel when you were first diagnosed?
18. How long did it take you to become used to your diagnosis?
19. Did your life change in any way after being diagnosed?
20. How do you feel about your diagnosis now?
21. How open with others are you about your diagnosis?
22. How do you find other people react to you and your diagnosis?
23. How do you decide when to tell people about your diagnosis?
24. Do you feel more comfortable in groups or one and one and why do you think this is so?
25. Has the way you cope with the world changed over the years?
26. Have you become more comfortable with yourself?
27. A sociologist named Irving Goffman in the 50's and 60's talked about different strategies people use to lessen the experience of stigma in their lives. He called it "impression management" or

“dramaturgy,” that is playing a role or “faking it” in order to fit in or minimize stigma. Although he did not talk specifically about Asperger’s, I am going to give you a list of some of the strategies he described and would like you to tell me if you identify with any them: As we go through the list, could you please describe, if applicable, how this strategy or technique has come into play in your life?

27 a. Main Strategies

passing: Trying to pass as normal by concealing the condition, which may involve tightly controlling information about yourself that may result in exposure.

covering: minimizing the condition, such as looking directly at people even though it isn’t natural or comfortable because it is “normal” and consistent with known social rules

27 b. Have you adopted other strategies to manage life given the challenges of your condition and people’s reaction to it?

27 c. Do you think you have gotten better at such strategies as “faking it” over the years or do you feel less need for these strategies as time goes by?

27 d. According to the theory of dramaturgy, there are three main roles in social interaction: the actor, the audience, and the outsider. One of the supplemental roles Goffman describes, however, is the “non-person,” or one who does not participate in the interaction and may not be recognized as a person who is present in the room. Goffman gives servants as an example, but from what I have learned in my research so far, people with Asperger’s often take this role during social interaction because they don’t know what to say or how to be appropriate. Have you experienced this?

27 e. Sometimes people with Asperger's take on formal "non-person" roles, such as photographer, cameraman, or note-taker so they can be more comfortable in social settings. Have you done this or know others with Asperger's who have?

27 f. Goffman separates dramaturgy into "front places" (that is, in front of the audience) and "backstage places" (where the performer can relax). Do you have "front places" and "backstage places"? Where are they?

27 g. Back places: finding a place away from the mainstream world of "normal" expectations where a stigmatized individual need not hide and can find acceptance among a community of different others. Have you found any good "back places" over the years?

27 h. Ambivalence towards others with the same condition because we may accept them more because of our insider understanding or reject them because we are trying to be normal to minimize stigma and fit in. This often involves offloading stigma to others with different stigmatizing conditions, and even those who have the same condition as us in more visible ways. Have you seen this happen?

Thank you. The rest of the questions are a new section of the interview:

28. Do you feel your condition is a disability?

29. Do you feel your self-esteem is affected by your Asperger's?
Do you judge yourself?

30. Do you feel comfortable with your uniqueness as a person?

31. Do you feel you are able to contribute your skills and strengths?

32. How do you feel about the American Psychiatric Association's decision to stop using the term Asperger's and make the condition part of autism spectrum disorder?
33. Some writers think people may be less likely to seek a diagnosis if autism is the only diagnosis available since the term autism may have more stigma attached to it. Do you think this may be the case?
34. Would these changes in the DSM-5 have had an impact on you back when you were seeking a diagnosis?
35. Have the changes in the DSM-5 had any impact on you, or do you think they will affect you in any way?
36. Are you aware of all the controversy and dissension on the internet for the last year or so about the elimination of Asperger's and how it has been rolled into autism spectrum disorder?
37. Why do you think there was so much concern about it?
38. Is there anything else you want to say about Asperger's, autism, or stigma?
39. Do you have any suggestions about questions I may have left out or anything else I might do differently to explore the social experience of people who are diagnosed with Asperger's?
40. Do you have any questions?

Thank you for participating in my research.

Appendix C: Consent Form

You have expressed interest in being interviewed as part of a study entitled “Cognitive Difference in a Postmodern World: Asperger’s, Autism, and the Impact of Diagnosis on Stigma.” My name is Gordon Gates and I am the researcher.

As a Master of social work student at the University of Victoria, I am required to conduct research as part of the requirements for a degree in social work. It is being conducted under the supervision of Susan Strega.

Purpose and Objectives

The main purpose of this research is to explore the experience of stigma in individuals diagnosed with Asperger’s or high functioning autism. Stigma can be defined as the disapproval, degradation, and shame or shaming associated with the possession of any quality, characteristic, or condition designated explicitly or silently by society as negative and undesirable. Stigmatization is a form of oppression that marginalizes through stereotypes and dominant expectations. It often leads to discrimination and self-diminishment. The effort to manage stigma can create confusion and alienation as the targeted individuals drain their energy trying to conceal, blend, or bluster their way to social acceptance. As a complex cultural phenomenon that undermines relationship and equality, stigma is an important problem for any society that values social justice. The study will also explore how individuals with this condition feel about the American Psychiatric Association’s recent decision to stop using the term Asperger’s and make the condition part of autism spectrum disorder. Participants will be asked if they think this will have an impact on the stigma associated with their condition.

Importance of this Research

Research of this type is important because although there is a lot of research on stigma and mental illness, there is very little on the experience of stigma and Asperger’s and high functioning autism. More knowledge in this area will lead to higher levels of sensitivity around this condition, better advocacy, and perhaps even better service provision.

Participants Selection

You are being asked to participate in this study because of your diagnosis of Asperger’s or high functioning autism.

What is Involved

If you consent to voluntarily participate in this research, you will be interviewed one on one with the researcher about your experiences with stigma in the community. You will be given a list of available times and places and be allowed to choose both the time and the place of the interview. The interview will last an hour to an hour and a half. It will be taped digitally (audio only) and notes will be taken by the researcher. You will also be asked to read a short passage in order to calibrate an electronic program to transcribe the

interview, but this will be voluntary. You will be sent a transcript of the interview (if you so choose) and have an opportunity to correct or amend your contribution.

Inconvenience

Participation in this study may cause some inconvenience to you, primarily by having to take time for the interview.

Risks

There are no known or anticipated risks to you by participating in this research. If you are uncomfortable with any question during the interview please feel free to skip the question. The interview can be stopped by you, or just feel free to ask for a break at any time.

Benefits

The potential benefits of your participation in this research include the opportunity to discuss your experiences with stigma. You may also learn more about Asperger's, autism, and the changes in the DSM-5 (the latest version of Psychiatry's Diagnostic and Statistical Manual).

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be destroyed irretrievably and permanently.

Anonymity and Confidentiality

Your anonymity will be protected throughout this study. Your data will be identified by code only, and only the researcher will know the code. The code will be password protected and encrypted, along with all the data gathered in the study. Any identifying details will be disguised. The researcher will not discuss your information with anyone. The only limits to confidentiality are if you divulge that you or someone else, especially a child, is at risk. In that case, keeping everyone safe becomes a priority and whether another professional needs to be told will be discussed at that point.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways. First, a final report will be written in the form of a thesis for the university. This thesis will be posted on the university's website and will be available to the public. Second, an article will be written and hopefully published. Third, the researcher plans to write a book someday and if so the current study may be cited therein. The interviews themselves (the "raw data") will be destroyed at the conclusion of the current study.

Commercial Use of Results

The results of this research will be used not only for the researcher to graduate, but an article will be written that will hopefully be published and increase the knowledge base of social work. The results may also be cited in a future publication.

Disposal of Data

All data not appearing in the final report/article will be permanently and irretrievably destroyed at the conclusion of the study. Some of the researcher's notes about the research process will be retained, but these will contain no data provided by the participants.

Contacts

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria.

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

Name of Participant _____ **Signature** _____
Date _____

Appendix D: Ongoing Consent to Review Transcript

If you would like the opportunity to review and make changes or additions to the transcript of your interview, please check the box and provide your signature:

I would like to review the transcript of my interview: yes no
If you, I agree to be sent a copy of the transcript when it is ready:

NAME _____ DATE _____ SIGNATURE _____

Appendix E: The Autism Spectrum Quotient Test

This test may help if you are seeking an explanation for why you find it so difficult to connect with others. Do you feel different from other people? There are lots of possible reasons for such an experience. This test can help indicate if you are “on the spectrum.” No matter what the results say, talk to your doctor and be honest.

For each question, circle the response that it seems best describes you:

1. I prefer to do things with others rather than on my own.

definitely agree slightly agree slightly disagree definitely disagree

2. I prefer to do things the same way over and over again.

definitely agree slightly agree slightly disagree definitely disagree

3. If I try to imagine something, I find it very easy to create a picture in my mind.

definitely agree slightly agree slightly disagree definitely disagree

4. I frequently get so strongly absorbed in one thing that I lose sight of other things.

definitely agree slightly agree slightly disagree definitely disagree

5. I often notice small sounds when others do not.

definitely agree slightly agree slightly disagree definitely disagree

6. I usually notice car number plates or similar strings of information.

definitely agree slightly agree slightly disagree definitely disagree

7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.

definitely agree slightly agree slightly disagree definitely disagree

8. When I'm reading a story, I can easily imagine what the characters might look like.

definitely agree slightly agree slightly disagree definitely disagree

9. I am fascinated by dates.

definitely agree slightly agree slightly disagree definitely disagree

10. In a social group, I can easily keep track of several different people's conversations.

definitely agree slightly agree slightly disagree definitely disagree

11. I find social situations easy.

definitely agree slightly agree slightly disagree definitely disagree

12. I tend to notice details that others do not.

definitely agree slightly agree slightly disagree definitely disagree

13. I would rather go to a library than a party.
definitely agree slightly agree slightly disagree definitely disagree
14. I find making up stories easy.
definitely agree slightly agree slightly disagree definitely disagree
15. I find myself drawn more strongly to people than to things.
definitely agree slightly agree slightly disagree definitely disagree
16. I tend to have very strong interests, which I get upset about if I can't pursue.
definitely agree slightly agree slightly disagree definitely disagree
17. I enjoy social chit-chat.
definitely agree slightly agree slightly disagree definitely disagree
18. When I talk, it isn't always easy for others to get a word in edgeways.
definitely agree slightly agree slightly disagree definitely disagree
19. I am fascinated by numbers.
definitely agree slightly agree slightly disagree definitely disagree
20. When I'm reading a story, I find it difficult to work out the characters' intentions.
definitely agree slightly agree slightly disagree definitely disagree
21. I don't particularly enjoy reading fiction.
definitely agree slightly agree slightly disagree definitely disagree
22. I find it hard to make new friends.
definitely agree slightly agree slightly disagree definitely disagree
23. I notice patterns in things all the time.
definitely agree slightly agree slightly disagree definitely disagree
24. I would rather go to the theatre than a museum.
definitely agree slightly agree slightly disagree definitely disagree
25. It does not upset me if my daily routine is disturbed.
definitely agree slightly agree slightly disagree definitely disagree
26. I frequently find that I don't know how to keep a conversation going.
definitely agree slightly agree slightly disagree definitely disagree
27. I find it easy to "read between the lines" when someone is talking to me.
definitely agree slightly agree slightly disagree definitely disagree

28. I usually concentrate more on the whole picture rather than the small details.
definitely agree slightly agree slightly disagree definitely disagree
29. I am not very good at remembering phone numbers.
definitely agree slightly agree slightly disagree definitely disagree
30. I don't usually notice small changes in a situation or a person's appearance.
definitely agree slightly agree slightly disagree definitely disagree
31. I know how to tell if someone listening to me or is getting bored.
definitely agree slightly agree slightly disagree definitely disagree
32. I find it easy to do more than one thing at once.
definitely agree slightly agree slightly disagree definitely disagree
33. When I talk on the phone, I'm not sure when it's my turn to speak.
definitely agree slightly agree slightly disagree definitely disagree
34. I enjoy doing things spontaneously.
definitely agree slightly agree slightly disagree definitely disagree
35. I am often the last to understand the point of a joke.
definitely agree slightly agree slightly disagree definitely disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.
definitely agree slightly agree slightly disagree definitely disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.
definitely agree slightly agree slightly disagree definitely disagree
38. I am good at social chit-chat.
definitely agree slightly agree slightly disagree definitely disagree
39. People often tell me that I keep going on and on about the same thing.
definitely agree slightly agree slightly disagree definitely disagree
40. When I was young, I used to enjoy playing games involving pretending with other children.
definitely agree slightly agree slightly disagree definitely disagree
41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).
definitely agree slightly agree slightly disagree definitely disagree

42. I find it difficult to imagine what it would be like to be someone else.
definitely agree slightly agree slightly disagree definitely disagree
43. I like to plan any activities I participate in carefully.
definitely agree slightly agree slightly disagree definitely disagree
44. I enjoy social occasions.
definitely agree slightly agree slightly disagree definitely disagree
45. I find it difficult to work out people's intentions.
definitely agree slightly agree slightly disagree definitely disagree
46. New situations make me anxious.
definitely agree slightly agree slightly disagree definitely disagree
47. I enjoy meeting new people.
definitely agree slightly agree slightly disagree definitely disagree
48. I am a good diplomat.
definitely agree slightly agree slightly disagree definitely disagree
49. I am not very good at remembering people's date of birth.
definitely agree slightly agree slightly disagree definitely disagree
50. I find it very easy to play games with children that involve pretending.
definitely agree slightly agree slightly disagree definitely disagree

Scoring the AQ

“Definitely agree” or “slightly agree” responses score 1 point on the following items: 1, 2, 4, 5, 6, 7, 9, 12, 13, 16, 18, 19, 20, 21, 22, 23, 26, 33, 35, 39, 41, 42, 43, 45, 46.

“Definitely disagree” or “slightly dis-agree” responses scored 1 point, on the following items: 3, 8, 10, 11, 14, 15, 17, 24, 25, 27, 28, 29, 30, 31, 32, 34, 36, 37, 38, 40, 44, 47, 48, 49, 50.

Add up your score. Eighty percent of those diagnosed with autism or a related disorder scored 32 or higher. This test cannot give you a diagnosis, but it can provide insight into your personality and/or give you an indication that you may want to investigate a diagnosis further. Even very high scores do not indicate that you will not be able to function well in society. The test can be seen as a measure of difference rather than disability.

The test was designed by Simon Baron-Cohen and his colleagues. It was presented and validated in this article:

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., and Clubley, E. (2001). The Autism Spectrum Quotient: Evidence from Asperger Syndrome/high functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders* 31 (1), 5-17.

Appendix F: Diagnostic Criteria Asperger's in DSM IV TR

Diagnostic criteria for 299.80 Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) failure to develop peer relationships appropriate to developmental level
 - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (4) lack of social or emotional reciprocity
 - B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (4) persistent preoccupation with parts of objects
 - C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
 - D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
 - E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
 - F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.
-

Appendix G: Diagnostic Criteria Autism Spectrum Disorder DSM-5

Autism Spectrum Disorder

Autism Spectrum Disorder

Diagnostic Criteria

299.00 (F84.0)

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- Specify current severity:*
Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- Specify current severity:*
Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

Appendix G continued: Diagnostic Criteria Autism Spectrum Disorder DSM-5

Autism Spectrum Disorder

Autism Spectrum Disorder

Diagnostic Criteria

299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

Appendix G continued: Diagnostic Criteria Autism Spectrum Disorder DSM-5

Autism Spectrum Disorder

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- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor
(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder
(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119–120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Appendix G continued: Diagnostic Criteria Autism Spectrum Disorder DSM-5 (Severity Specifiers)

Severity Level for ASD	Social Communication	Restricted interests & repetitive behaviours
Level 3 - 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others	Preoccupations, fixated rituals and/or repetitive behaviours markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 - 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest
Level 1 - 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions	Rituals and repetitive behaviours (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

Post-Script

When I was writing my thesis on Merleau-Ponty at McMaster University in 1986, no one gave Foucault more than passing mention. While working on my degree in social work at the University of Victoria in 2012, Merleau-Ponty's name was hardly uttered. Merleau-Ponty gave his inaugural lecture at the College de France in 1953 (In Praise of Philosophy). Foucault delivered his in 1970 (Orders of Discourse). I recently came across a thirty year old essay that speaks about the relationship of these two thinkers, and I include it here as evidence of an attempt to bridge Foucault's historical ontology with Merleau-Ponty's ontology of the flesh:

Foucault clarifies what he means by the anthropological epoch. It is the epoch in which "man appears in his ambiguous position as an object of knowledge and as a subject that knows." This epoch began when Descartes split mind and matter, the subjective and the objective, and it has been dominated by this opposition ever since... [Merleau-Ponty and Foucault] see that all the unresolved dualisms of modernity arise from an erroneous abstraction, one which divides a single flesh... The difference separating Foucault and Merleau-Ponty is really one of degree, a difference of tone, rather than anything more fundamental. Foucault's style, especially in the later works, is more militant, hyperbolic, more explicitly influenced by Nietzsche than Merleau-Ponty's... While both are radically critical post-anthropological thinkers, Merleau-Ponty belongs to what Gary Madison, in his excellent book on Merleau-Ponty, calls the "counter tradition" of philosophy, and Foucault, like Nietzsche, belongs to the "anti-philosophical" tradition... Both demand a shift in paradigm... but Merleau-Ponty's approach is more moderate... I would like to suggest that the difference stems from Foucault's closeness to more specific fields of the flesh, that it is attributable to his commitment to discerning the reservoirs and flows of meaning not in a global conception, such as "the flesh itself," but in its local and specific forms, in the history of madness, in the development of the clinic, in the rise of the medical profession, in the transformations of discipline and punishment, in the history of sexuality. This is not to say that Merleau-Ponty was "lost in abstractions," for surely he did specific work in the areas of art, perception and politics, and his notion of style can only lead to concrete studies. Rather it is to suggest that Foucault was able to reap the rewards of his turn to flesh without having to justify the flesh itself. It is this concrete turn, I think, that accounts for the more militant tone of Foucault's later work, for he, too, in his early work, spoke in the "calm Platonic form of language and dialogue." The distinction between anti-philosophy and counter-philosophy, then, must be tempered with Foucault's distinction between "the specific intellectual as opposed to the universal intellectual."

Cohen, 1984, p.329.