Understanding the Polyvocality of Autism Discourse: A Critical Autoethnographic Approach

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Abstract

Currently, much of the autism literature supports the notion that Pervasive Developmental Disorder (PDD) is a deviation from what is considered "normal" and, accordingly, that it is in need of early remediation. This thesis explored alternative constructions of autism and pathology by drawing on theorists from other disciplines, such as cultural studies (Deleuze & Guattari, 1987, 1965, 1972, 1975,1980, 2003), critical psychology (Parker, 1995, 2002, 2005, 2007), disability studies (Danforth,1997, 1999, 2000; Skrtic, 1995, 1996) and anti-psychiatry (Basaglia, 1987).

In an attempt to show how our accounts of the world encompass constructions rooted in language and our own histories of thinking about topics that interest us, this research took an autoethnographic approach to understanding autism discourse. Instead of denying the researcher's existence and personal investment in the research, the author attempted to implicate "the self" in the research by acknowledging her own assumptions, biases and ideologies about autism discourse and practice. Thus, tensions between the self and other, personal and political become woven into the fabric, creating a personal, subjective, and partial account of the phenomenon.

This research was intended to explicate and interrogate some of the taken-for-granted Truths which guide our practices with people with autism. This alternative critical framework focused on understanding autism as a discourse and explored the way these dominant autism constructions *function* in society. Furthermore, positioning "the self" in the research was meant to illustrate the fundamental need for self-reflective practice in the social sciences.

Preface

I looked up the road I was going and back the way I come, and since I wasn't satisfied, I

decided to step off the road and cut me a new path.

– Maya Angelou

An old white guy once said "one person's struggle is another's liberation." This thesis is

written for those who see a piece of themselves in my writing. For those people, like myself, who

did not previously have the language or theoretical framework to articulate their anxieties with

the "power over" techniques used in the psychological sciences, may this thesis offer you an

alternative theoretical framework to evaluate "the self" and the dominant practices and

techniques used in the psychological sciences.

My challenge to you, reader, is to place yourself in a "space of discomfort" by reflecting

on and challenging the taken-for-granted Truths governing your life and to explore how these

Truths function to enhance or restrict capacities for change and collective action.

First Interlude

For as long as I can remember I have wanted to make an impact on the world. Not in the traditional sense of making lots of money, having numerous material possessions and retiring early—which in our current society can been considered the western dream—but rather by positively influencing, affecting, inspiring and supporting children and youth. In keeping with my overarching goal of helping people, I have volunteered in a variety of different settings, particularly gravitating towards organizations supporting children and youth labeled deviant, disordered, or disabled. In the third year of my undergraduate degree, I became involved in a home-based program for two twin boys, Jacob and Joshua,[1] both diagnosed on the Autism Spectrum.

The program was called Intensive Multi-Treatment Intervention (IMTI) and was developed by Jonathan Alderson[2] to treat the multifaceted nature of autism. IMTI incorporates a variety of

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[1] In order to maintain the family's identity these names are pseudonyms

[2] Alderson completed his undergraduate degree in developmental and educational psychology at the University of Western Ontario and went on to receive a Masters of Education in Administration, Planning, and Social Policy at Harvard University. He received a three-year intensive certification training in autism treatment at the Son-Rise

different treatment modalities in order to address the multi-faceted nature of the causes and dysfunctions of autism. The program takes a holistic and individualized approach to address the unique needs of each individual child with autism and incorporates, biological treatments, behavioural and cognitive education and family and therapist attitudinal training (Intensive Multi-Treatment Intervention, 2007).

My own personal involvement in the IMTI program allowed me to receive training as an IMTI volunteer therapist. During my IMTI training I became particularly interested in the concept of "joining,"[3] which was included as one of the many components in the IMTI program[4].

Contrary to traditional behaviourial interventions, joining meant the therapist would join in (i.e., imitate) the child's behaviour even if it was considered socially inappropriate (e.g., rocking). This is true in all cases except where the child was engaging in dangerous behaviours (e.g., the child was causing direct harm to self or others).[5] Through joining it is thought the adult's actions become more predictable, leading the child to become more engaged, socially available and motivated to be with others (Sacks, 2003).

The theoretical underpinning of joining closely parallels the importance assigned to the therapist developing a non-judgmental attitude based on love and acceptance of the child. Since the Son-Rise Program (SRP) philosophy considers emotions to arise from beliefs, it is thought a person can make the choice about how he/she feels in certain situations. The person is therefore able to alter his/her beliefs through what SRP calls an "internal dialogue" and make the choice to be happy with the situation. Choosing to be happy means being accepting and loving of all people for what they are, not for what we want them to be (Jordan & Powell, 1993).

Due to the lack of empirical evidence to support the concept of joining, and owing to its emotionally appealing theoretical orientation which focuses on love and acceptance, SRP has been criticized for providing false hope to parents. Notwithstanding this criticism of the SRP, my

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Program of the Option Institute in Massachusetts, including over 1500 hours of one-to-one floor-time with children with autism. (IMTI, 2007)

[3] The concept of joining was derived from an intervention founded in Massachusetts called Son-Rise (SRP) (see Autism Treatment Center of American 1998-2007 for more details).

[4] Other components of the IMTI program included; biological treatments such as Defeat Autism Now! (DAN!) (see Autism Research Institute, 2005-5006 for more details), Specific Carbohydrate Diet (SCD) (see Gotcshall, 2005 for more details), Auditory Integration Therapy (AIT) (see Berard, 2007 for more details); Cognitive-behavioural treatments beyond Son-Rise, included various recreation programs such as Kindermusic, Brain Gym, PC-based learning, and participation in sports.

[5] When this type of dangerous behaviour occurs the adult is taught to give no reaction, since it is thought if the child is engaging in this behaviour it is because they associate it with a positive outcome. If the behaviour is no longer useful, they will likely turn to alternative behaviours. This explanation closely resembles operant conditioning (i.e., reinforcement and punishment) behaviour therapists utilize. The difference between the two therapies is that behaviourists will utilize these principles when the child is engaging in any behaviour that is considered inappropriate (i.e., repetitive self-stimulatory behaviour, self injurious behaviours, aggression etc). SRP will only utilize this principle if the child is in danger of harming himself or others around him/her: the therapist will "join" in with all other repetitive ritualistic behaviours the child displays.

[6] Some anecdotal examples of the boys progress: the boys went from making grunting noises to get someone's attention, to speaking in full sentences (e.g. "I want puzzle"); the boys went from maintaining no eye contact or initiating social interaction, to looking and speaking the therapist's name, waving hello and good-bye and giving hugs. By the end of the two years the boys were reading at a grade 1 level and were learning simple mathematics.

involvement in the IMTI program, a more comprehensive approach, allowed me to witness two non-verbal and socially withdrawn boys transform into highly verbal and socially responsive children[6].

Having experienced the effectiveness of the IMTI program first-hand, I entered my fourth year of university convinced I could provide scientific support for the SRP concept of "joining". Following the strict guidelines of empiricism and notions surrounding measurement and error, my advisor and I developed a well controlled research project aimed at evaluating the SRP concept of joining against discrete trial training (an already empirically validated strategy used in most Early Intensive Behavioural Interventions [EIBI] programs). Although maintaining a non-judgmental attitude and evaluating therapist beliefs towards autism and autistic behaviours were key components of SRP joining, they were identified by my advisor as being impossible to measure objectively and deemed irrelevant to the overall project. I became quite frustrated during this process, as reducing joining to a series of measurable parts did not seem to adequately capture the essence of this component of the IMTI intervention. This was the first time I began to question whether controlled empirical research did, in fact, mimic the daily experiences we encounter in our everyday lives.

As I began to voice my concerns and discomforts with reductionism, I was confronted with issues of objectivity. I was told I must distance myself from my own personal experiences with the IMTI program and maintain a neutral status. In order to do this, I was required to operationally define the behaviours I was recording—that is, define them in such detail that another observer would be able to record the behaviour in a similar way. The integrity of the study would then be based on inter-observer reliability. Subjectivity—and hence error and bias—could be masked by the percentage of agreement between two independent objective observers.

The findings of my undergraduate thesis revealed the discrete trial training condition (a primary component of IBI) to be consistently superior to the SRP joining condition in promoting child skill acquisition. Interestingly, in the SRP joining condition the child displayed more positive affect (i.e., smiled, giggled more often) and engaged in less negative behaviour (displayed less aggression, crying, tantruming and repetitive behaviour) than in the discrete trial training condition.

Irrespective of these interesting findings, I started to question the integrity of joining. Was I merely imagining the joining component of the IMTI program to be effectively contributing to the boys' progress? Was I so emotionally caught up in the SRP joining feel-good philosophy of maintaining a non-judgmental attitude and following the child's lead that I only imagined this component was contributing to the significant progress the boys were making in social interaction, language and communication?

Becoming a professional in the "autism industry" but being unable to come to any definitive conclusions about my own subjectivity and bias concerning SRP made the idea of becoming a certified behaviour analyst seem like the only plausible career option for me— that is, if I wanted to work with young children with autism. In line with the increasing awareness of "best practice methods" and "professional accountability", applied behaviour analysis (ABA) provided hard,

unbiased, scientific evidence for treatment effectiveness, and empirical evidence consistently revealed ABA techniques to be successful at teaching children with autism, reducing maladaptive behaviours, including self- injury, and increasing adaptive behaviours, such as language and communication. By becoming a certified behavioural analyst I would be able to fulfill my desire to positively influence, affect and inspire children with autism and other developmental disabilities.

Coming from the traditional discipline of psychology as the "scientific study of human behaviour," it was only in the first year of my masters in Child and Youth Studies that I became exposed to alternative epistemologies—to epistemologies that explicitly problematize taken-for-granted concepts and ideas like objectivity, reality, empiricism and progress. These alternative ways of knowing challenged the assumptions I had otherwise un-self-critically appropriated during my undergraduate training in psychology.

Authors operating within this new paradigm argued that despite the apparent "effectiveness" of behavioural therapy, behavioural intervention can be seen as a form of naïve pragmatism, as it evaluates the functional efficiency and utility of specific behavioural models, practices and techniques in terms of the binary logic of what works and what does not, but unreflectively accepts the assumptions, theories and meta-theories in which these proclamations are manifested (Basaglia 1987; Foucault, 1965, 1872, 1975, 1980; Skrtic, 1995; Parker 1995, 2002; Sailor & Paul, 2004). Put another way, within the behavioural realm, assumptions surrounding the duality of reality, the progressive nature of science and the notion of language as an accurate representation of internal conceptions are left unchallenged. These authors argue that it is only by examining the functions of dominant autism discourse outside the dominant structures of scientism and medical model perspectives of deviance and professional practice that we will begin to see how these discourses currently function in our society.

The purpose of this thesis is two-fold: First, it seeks to provide a descriptive account of modern and postmodern modes of thought and how their associated epistemological frameworks relate to autism discourse[7]. Second, it will describe my history as a white middle-class female in the academy and discuss current anxieties about my future as a becoming academic and practitioner in the autism industry. These two approaches will attempt to explore the specific function that constructions of autism, deviance and pathology serve in various intellectual

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[7] Throughout this thesis the terms Pervasive Developmental Disorder (PDD) or autism will be used to describe all individuals labeled with any 1 of the 5 disorders falling under this category (described below). In doing so, the intention of this paper is not to homogenize autism experience or to suggest that all people labeled with PDD will be exposed to the same constructed realities and discourses surrounding autism diagnosis, assessment, and treatment. Rather, it is to illustrate the problematic nature of allowing uncontested Truths about PDD to guide our practices and treatments (e.g., characterizing autism in terms of how it deviates from normal development). For these reasons, the term PDD will be used to describe all individuals falling under this umbrella term.

frameworks (e.g., traditional psychology, sociology, critical theory, cultural studies, etc.) and

mediums of generating knowledge (i.e., empirical research, anecdotal accounts, personal

narratives etc.).

Thesis Framework

The thesis will be organized according to chapters. Chapter 1 will begin with an overview

of the methodology. Research objectives and questions will be posed. At this time

autoethnography as a method of inquiry will be described, followed by a description of specific

texts selected for personal reflection. In Chapter 2, the reader will be provided with a

comprehensive summary of autism literature to date, including discussions surrounding autism

diagnosis, etiology and treatment. Chapter 3 will describe the modernist discourse, including

notions surrounding truth, progress and language as an accurate representation of reality, and

will seek to show how the dominant autism literature to-date fits neatly into this paradigm.

Chapter 4 will unpack modernist assumptions using postmodern discourse, which will provide a

space for the author/reader to resist dominant autism constructions. Chapter 5 will provide a

theoretical summary of "postulated linguistics" in Deleuze and Guattari's (1987) *A Thousand*

Plateaus: Capitalism and Schizophrenia. A theoretical summary of Franco Basaglia (edited in

1987 by Scheper-Hughes & Lovell) and the anti-psychiatry movement in Italy will be provided

in Chapter 6, followed by a Foucauldian framework for understanding madness and power in

Chapter 7. Theory from Chapters 5, 6 and 7 will be used as tools in Chapters 8 and 9 to further

unpack current constructions of autism and deviance and to investigate the *function* of dominant

techniques used in the autism industry. Chapter 10 will discuss Foucault's insurrection of

subjugated knowledges, which will lead into Chapter 11, which will describe an emerging

discourse within autism, featuring the voices of people with the autistic label. In this chapter

dominant "Truths" about autism that were initially discussed in Chapter 2 will be reinvestigated, in order to see if these dominant constructions coincide with the personal experiences of people with the autism label. Chapters 12, 13 and 14 will identify and unpack a series of themes found throughout the above chapters, including misconceptions with self-reflective writing, challenging existing dichotomies found in the social sciences, and the essential role of the "other" in the understanding the self. The primary aim of these concluding chapters is to provide the reader/author with a space to discuss how this information can be used to conduct research and work *with* people labeled with autism.

Thesis Format

Similar to Kaufmann (2005), I believe every text I read is appropriated and re-appropriated through my own life history and consequently my own life history is rewritten as I come in contact with alternative texts. With this in mind, there is no "real" or "universal" theoretical framework of *Foucault, Basaglia* and *Deleuze and Guattari*, but rather the reciprocal process of writing and re-writing allows each use of theory to be constructed through the autobiography of the researcher and interpreted and rewritten through the autobiography of the reader. Kaufmann (2005) refers to this dynamic exchange between theory and self as an autotheoretical piece of writing.

Throughout this paper, theoretical interpretations will be disrupted with autoethnographic portions (i.e., interludes such as the italicized narrative above), which will include personal accounts of my life and personal reflections on various forms of literature and media, including empirical research, books, movies, websites and personal narratives of individuals with Pervasive Developmental Disorder (PDD). Throughout the remainder of the thesis the font of the text will indicate the source of the piece. Standard, non-italicized text will be used for authors

from peer-reviewed texts (i.e., journal articles) and other literary mediums (i.e., books, anecdotal accounts of people with the autism label and their families, websites, movies etc.). *Italicized* text will serve as a visual cue to the reader that the content has shifted from theory to the author's personal reflections related to the self and other and how exposure to different theoretical paradigms may impact our work with individuals labeled PDD. This dynamic shift from the author's personal experiences to theory (examining these experiences through a wide angle lens by acknowledging the social, political and cultural structures encompassing the personal experience) will attempt to move beyond current representations of the author and again, will expose a self that is moved by these cultural interpretations (Ellis, 1999).

Chapter 1: Autoethnography as a Method of Inquiry

Closely paralleling the dialogical nature of Basaglia's work[8], this research attempts to use what is typically defined in contemporary literature as a critical theoretical framework, opening dialogue to discuss why dominant techniques in the autism industry have been designed in specific ways, and similarly, deconstructing these practices to make transparent existing contradictions by examining the confining nature of these partial and incomplete descriptions (Cherryholmes, 1988). This critical theoretical framework closely parallels the author's personal journey of her own experiences through dominant autism discourses to alternative postmodern epistemologies which unpack our perceptions of truth, progress, and language and include ideas related to madness and professional power, and finally, to contemporary critical personal narrative accounts of people with the autism label[9]. This multi-perspective piece attempts to transcend the boundaries between and beyond disciplines, incorporating scientific as well as non-scientific accounts of autism.

Research Objectives

The main purpose of this research is to make transparent the underlying unarticulated assumptions surrounding traditional autism discourse. Yet the intention of this piece is not to suggest the alternative discourse of autism is a better or more superior way of thinking about people with autism, as the reality of today will differ from the reality of tomorrow and in trying to freeze it, it either becomes distorted or irrelevant (Basaglia, 1987). This research is not a quest

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[8] Basaglia's collection of readings illustrates controversies surrounding traditional psychology and the limitations of using existing dichotomies (i.e., sane-insane, normal-abnormal, and rational-irrational) as real universal concepts about the world. Yet, he points out that once we call into question these existing dichotomies, we run the risk of falling into the same impasse. Basaglia (1987) argues for "a psychiatry that constantly checks itself against a reality and finds in that reality elements by which it can challenge itself" (p. 75).

[9] It is important for the reader to note that the above critical theoretical framework will not operate as an independent method of inquiry separate from the autoethnography. Rather the theoretical framework is used to elicit critical reflections as it outlines the author's academic trajectory to date, taking the reader on an expedition of the author's own thoughts and critical reflections of the material under investigation.

to find the ultimate Truth of autism, since no universal Truth exists either in language or beyond. Since language is organized to produce specific scientific Truths the aim of this paper is more simply to destabilize these Truths, enabling alternative, local, particular and unstable truths to emerge—truths that will empower instead of marginalize those whose speech, experience and behaviour fall outside the defined norm[10].

Research Questions

With this in mind, the question is not what theory, ideology or research most accurately represents autism "reality," but rather what function do governing autism theories, ideologies and dominant modes of research serve, in relation to maintaining existing structures in society.

More specifically, as I find myself between autism epistemologies, straddling modernist notions of objectivity, duality, and progress on one hand, and postmodern traditions, on the other, which deconstruct the entire modernist enterprise, what are my current beliefs and assumptions about autism? Furthermore, what are some of my anxieties about entering the field of disability research?

What is an Auto-ethnography?

Auto-ethnography is a qualitative method of inquiry that has been in circulation for at least two decades. An array of expressions have been used to describe this methodology, including personal narratives, narratives of the self, self stories, first person accounts, personal essays and auto-observations (Ellis & Bochner, 2000). Denzin and Lincoln (2000) have incorporated this method into the *Handbook of Qualitative Research,* and a variety of scholars are currently using this tradition to explore a variety of different issues (Baker, 2001; Berger,

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[10] The author has intentionally capitalized Truths to refer to common, taken-for-granted, universal, stable Truths that guide our thinking and interpretations of the world. The author uses truths (with a little t) to refer to local and particular truths that are open to mutation and therefore do not have a teleological endpoint.

2001; Ellis, 1999; Kaufmann, 2005; Magnet 2006; Neville-Jan, 2004; Smith, 2001, 2005; Wall, 2006).

This emerging methodology is gaining attention in the academic field as it is founded on postmodern criticisms centered on arguments surrounding the "crisis of representation" which challenges the value of *token reflection* that has often been included as a paragraph (at most) in an otherwise neutral and objective manuscript (Wall, 2006). Questions encompassing this new skepticism include political and cultural representations surrounding not only who should represent whom, "but what should be the forms of representations in relation to specific hegemonic practices of governmentality, including the practices of the social sciences" (Clough, 2000, p. 283). As a result, numerous authors point to the need for "genuine reflectivity" in social science research.

An autoethnography is a layered account of the personal that acknowledges the multiplicity of selves, as the researcher/author draws on as many resources as possible in the writing process, including social theory and lived experience (Magnet, 2006). It can be seen as a genre of writing and research that connects the personal to the cultural. Each of the three components, *auto* (self), *ethno* (culture), *graphy* (research process) vary in emphasis. The goal of reflective research is not to transfer information from one party to another, but rather to move from the traditional monologue of scientism, which typically shuts down different avenues of interpretation, to a dialogical approach that opens up the possibility for alternative meanings (Ellis & Bochner, 2007). Elsewhere Ellis and Bochner (2000) have argued the goal of narrative inquiry is to fuse the literary with the scientific, to create a social scientific art form, thereby revealing the role and expertise of the researcher/author who created the work, rather than constructing his or her absence.

What Determines a Good Autoethnography?

      In a discussion on what establishes a good autoethnography (i.e., the issue of validity), Bochner (2000) suggests narratives should be written in a concrete and detailed fashion that not only relay "facts" but also describe feelings and the intensely driven emotions of people coping with certain life contingencies. Second, the structure of the narrative should be highly complex, modeling the nonlinear process of memory work, shifting from past to present and back to the past. Bochner (2000) cites Kierkegaard (1957) who states, life must be lived forward but can only be understood by reflecting back. Third, the trustworthiness of the author must be made transparent. In other words, the evocative self needs to be displayed on the page, thus, creating a cultural script that resists representations and depicts the contradictory nature of human experience and the various layers of subjectivity. Fourth, good narratives should paint two selves: the historical and present self, and the self re-imagined or transformed by the experienced "crisis." Fifth, the author must hold an ethical standard of self-consciousness, being sensitive to how other people are represented and the kind of person one becomes through the process of storytelling. Lastly, Bochner, (2000) states an excellent autoethnography is one that moves the reader in the heart as well as head.

      In light of the above criteria, I will attempt to give a detailed (yet inescapably partial) account of my journey as a "becoming" academic and my current state "between epistemologies". As the purpose of the autoethnography is to extract meaning from experience rather than to describe experience as it was exactly lived (Bochner, 2000), the self narrative will not be told in a chronological fashion, but rather will move back and forth between the past and present examining images and memories through the lens of the present and the present through the lens of the past.

Conducting Self-Reflective Research

For the most part, reflexivity is now viewed as an accepted method of qualitative research that can be used to explore and expose the politics of representation, to better represent difference and to establish ethnographic authority (Pillow, 2003). Researchers using critical, feminist, race-based, or poststructuralist theories may use reflectivity as a tool to better represent, legitimize or interrogate their data. Although reflectivity is gaining popularity and recognition in the social sciences and humanities, Pillow (2003) contends that most researchers use reflectivity without defining how they are using it, operating under the assumption that reflective research is an accepted methodology with a set of standards put in place for how it should be used when conducting critical qualitative research.

Pillow (2003) cites Spivak (1988) who argues "making positions transparent does not make them unproblematic" (p. 183). Reflective research as a means of discovering self-knowledge and truth is difficult to discuss and critique as it is often seen as an attack on the author. Thus, Pillow urges researchers who appropriate reflectivity to ask what these bodies of writing open up and close down in terms of enhanced understanding and questioning after reading the text. A good piece of reflective research should account for multiplicity without making it singular and acknowledge the unknowable without making it familiar. Therefore, "reflectivity of discomfort" incorporates not only the reflective component but a deconstructive element as well. Although reflectivity helps the researcher and his/her audience to understand not what we know but how we think we know, the deconstructive component illuminates that how we think we know is neither transparent nor innocent, and challenges not only the constructs of the author but those of the reader as well. It urges the reader to analyze, question and re-interrogate his/her own knowledges and assumptions throughout the entire reading process.

With this in mind, the present research attempts to use reflectivity of discomfort. The intention of this writing is to continually urge both the author and reader to challenge current representations, by acknowledging that this body of writing incorporates multiple voices, figures and histories. Reflectivity of discomfort pushes the writer and his/her audience toward the uncomfortable and unfamiliar, identifying practices of rupture in language and techniques so that deconstruction is possible. At the same time reflectivity of discomfort acknowledges the political need to represent and find meaning, but simultaneously recognizes this knowledge as always partial and tenuous.

Articles of Reflection

The author will use the discussion of dominant autism discourse (Chapter 2), the alternative postmodern autism framework— including authors such as *Deleuze and Guattari (1987)*, *Basaglia (1987*) and *Foucault* (*1965, 1972, 1980, 2003)* (Chapters 5, 6, 7*)*—and the personal accounts of people with the PDD label (Chapter 11) to reflect on how these three discourses influenced the author's thoughts, perceptions and beliefs about "self as a practitioner" and ideas surrounding autism and pathology. Other articles of reflection include an eclectic array of media, empirical research and theoretical writing. These include the following:

Metz, Mulick & Butter (2005). Autism: A late-20th-century fad magnet. The chapter discusses various modalities used to treat or "cure" autism that are based on faulty logic and that lack a base of empirical evidence. The authors point to the need for more controlled, experimental methodologies and urge consumers and professionals in the industry to be critical of these "miracle cures".

Maurice (1993). Let me hear your voice: A family's triumph over autism. This book is a story of a mother's personal account of her daughter's recovery from autism through exposure to behavioural interventions.

Baggs (2007). In my language. This is a video of a person with autism who discusses contemporary issues related to thought, intelligence, personhood and language.

Herzog (1974). The enigma of Kaspar Hauser (Film). The film follows the real story of Kaspar Hauser, who lived for the first 17 years of his life in a cellar without human contact. Being isolated from society, Kaspar Hauser learns to walk and enters the town of Nuremberg where the unraveling of societal perceptions of madness and abnormality emerge.

Primary Analysis:

A detailed reading of the abovementioned material for reflection will be conducted. A comprehensive electronic notebook of my own personal reflections of the readings will be used as the main article of analysis. The reflections link contemporary issues in dominant autism discourse to my own personal experiences with abnormality, challenging my own assumptions and inconsistencies about the subject matter.

Parker's (2005) Discourse of Analytic Reading:

Parker (2005) summarizes six stages in discourse analysis (spark, ignition, combustion, fuel, flight, landing), the first three of which will be used to foster dialogue and debate within my critical self-reflections[11].

1. *Spark.* What is intriguing about the text? What do you find puzzling, fascinating and/or odd? What questions are you provoked to ask by the text? What kind of a person must you be for this text to make sense?

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[11] Although I am using the first three of Parker's (2005) six stages of discourse analytic reading, it is important to emphasize that I am NOT conducting a discourse analysis, but rather Parker's questions will be used to provoke and challenge my current consciousness and ways of thinking about the texts.

2. *Ignition.* What is suspicious about the text? Elaborate and point out every taken for granted assumption you refuse to accept within the text.

3. *Combustion.* Identify the objects that are described in the text. Who is constructed as an active agent? Who is constructed as passive? What constructed realities must we appropriate for this text to make sense to us? What kind of people does this text attract and what might be said for those who agree with the text versus those people who disagree?

Evaluation of the Autoethnography:

Since the epistemological and ontological assumptions driving the autoethnography are different than those underlying scientific research, Wall (2006) argues that it does not make practical sense to use traditional "scientific" criteria to judge the value of personal text. Based on Wall's contention and taking into consideration the work of Ellis (1999), Kincheloe and McLaren (1998), Jones (2005) and Richardson (2000), it is more practical to evaluate autoethnographic works in terms of the following criteria.

Tests of Validity:

1. *Substantive Contribution.* Does this piece contribute to our understanding of social life? (Richardson, 2000). Does this piece challenge current epistemologies? (Jones, 2005).

2. *Aesthetic merit.* Does this piece succeed aesthetically? Is the text artistically shaped, satisfyingly complex, and not boring? (Richardson, 2000).

3. *Reflectivity.* How did the author come to write this text? How has the author's subjectivity been both a producer and a product of this text? (Richardson, 2000).

4. *Impactfullness* (Richardson, 2000) or *Catalytic Validity* (Jones, 2005). Does this affect me emotionally and/or intellectually? Does it generate new questions, move me to action, or lead to personal transformation?

5. *Express a (subjective) reality* (Richardson, 2000) *or Verisimilitude* (Ellis, 1999). Does this text embody a fleshed out sense of lived experience? Does the piece evoke in the reader a feeling that the experience described is lifelike, believable, and possible?

Tests of Reliability:

1. *Trustworthiness.* Are constructions reasonable to those who constructed them? (Kincheloe & McLaren, 1998).

Tests of Generalizability:

1. *Connectedness* (Ellis, 1999). Does the story speak to the reader's own experiences or the lives of others?

Chapter 2: Dominant Autism Discourses

What is a Discourse?

Language is systematically organized around a series of finite statements where conditions of existence are grouped and defined. This space of meaning making is not ideal or timeless, but rather embodied in a specific period of time arising out of a given social, economic, geographical, and linguistic arena. It is these systems of meaning that define a discourse. Foucault (1972) argues that statements devising a given meaning system become popular representations of lived realities offering positions of power to certain categories of people and disempowering others. From this perspective what is of interest is not what discourse is the most representative of reality, but rather how and why specific discourses emerge during a specific period of time, and what function these discourses serve in relation to society at large (Foucault, 1972).

Brief Historical Review

Infantile autism, pervasive developmental disorder- residual type, childhood schizophrenia and autistic psychoses are terms used over the years to refer to what is currently considered autistic disorder. Leo Kanner (1943) is regarded as the pioneer of autism diagnosis, giving a name to the disorder a little over 50 years ago. His detailed case history account of 11 children between the ages of 2 and 8, illustrated how these children shared unique and previously unreported patterns of behaviour, including social remoteness, obsessiveness, stereotypy, and echolalia. Although there was some debate over whether these characteristics were symptoms of childhood schizophrenia, Kanner (1943) argued that due to the unique and shared symptoms of these 11 children, diagnosis should be seen as something distinctively different from current pathologies. Early descriptions of infantile autism have remained relatively stable since the

Kannerian days, closely paralleling current diagnostics found in the DSM-IV-TR (APA, 2000).

However, understanding the complexities of the disorder continues to be an art and science in

rapid evolution (Filpek et al., 1999).

Characteristics of Pervasive Developmental Disorder

Most professionals working in the field of autism would agree with the following two

notions. First, autism can be described in terms of three different but interdependent pathologies:

a neurological disorder related to abnormal brain development; a psychological disorder linked

to cognitive, emotional and behavioural development; and a relationship disorder resulting from

a failure to acquire normal socialization patterns (Kabot, Masi & Segal, 2003). Second, autism is

a spectrum disorder, meaning that although children share a core deficit in forming relationships

and communicating, expression of these symptoms manifests itself differently in each individual

case, leading children to display a range of symptoms and co-morbid conditions.

Predominant Pervasive Developmental Framework

To date the most frequently cited definition of autism is found in the DSM-IV-TR (APA,

2000). Five disorders are described under the broad term Pervasive Developmental Disorder,

which include Autistic Disorder, Retts Disorder, Childhood Disintegrative Disorder, Aspergers

Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (APA,

2000). Although these five disorders differ in relation to age of onset, etiology, epidemiology,

and associated conditions, similarities exist, as all children falling under the autism spectrum

deviate significantly from their predicted developmental level, displaying qualitative

impairments in at least one of the three following areas: reciprocal social interaction,

communication skills, and behaviour variability.

Although it is argued that each disorder on the spectrum is distinctly different, in practice these similarities commonly result in definitional and diagnostic confusion. The three disorders most frequently subjected to diagnostic uncertainty include Autistic disorder, Aspergers and PDD-NOS (Kabot et al., 2003). Professionals will commonly use the vague term autism to describe the most prevalent disorders on the autism spectrum: Autistic Disorder, Aspergers Syndrome, and PDD-NOS. Similarly, some professionals do not see PDD-NOS as a separate disorder but rather place children in this category when they fall within the spectrum, but do not meet full criteria for autistic disorder (Kabot et al., 2003). In practice, PDD-NOS and Aspergers, and Aspergers and High Functioning Autism are used interchangeably, adding confusion regarding the implications of a specific diagnosis on the autism spectrum. This further contributes to perplexities surrounding epidemiology, etiology, and treatment (Kabot et al., 2003).

Prevalence of Pervasive Developmental Disorder

The earliest autism epidemiology studies displayed an infantile autism prevalence rate of 4-5 cases per 10,000 (Lotter, 1966, as cited by Filpek et al., 1999). To date, autism is more prevalent in the population than childhood cancer, diabetes, spina bifida, and Down syndrome. In a recent prevalence study conducted by Chakrabarti and Fombonne (2005), a rate of 58.7 per 10,000 (95% CI=45.2-74.9) was found for all autism spectrum disorders. Yet, it is still unclear whether the upward trend in prevalence rates (the proportion of people in a population identified with the disorder) can be attributed to an increase in incidence (the number of new cases occurring in a population over a period of time) (Fombonne, 2003) or to other reasons, such as broader clinical phenotype, improvements in case ascertainment, and an increased awareness of pervasive developmental disorders in both the general public and professional community. These

factors may partially account for the artificial impression autism spectrum disorders are on the rise. Regardless of whether autism incidence rates are also increasing, most professionals agree this increase in numbers affirms the need for improved early screening and diagnosis, so that these children can be provided with intervention as early as possible (Filpek et al., 1999).

Additional characteristics in identified samples of autism indicate 70% of identified cases also have an intellectual impairment, 30% have a mild-moderate intellectual impairment, and 40% are labeled with a severe/profound intellectual disability (Fombonne, 2003). Furthermore, sex also seems to influence autism trends, as the overall ratio of males to females with a diagnosis is approximately 3:1 to 4:1. Interestingly, this ratio appears to vary according to IQ, ranging from 2:1 in those individuals identified with a severe intellectual impairment to more than 4:1 in those children with average or near average IQ (Bryson, 1997; Ehlers & Gillberg, 1993; Filpek et al., 1999). Some author's postulate fewer females with average IQ are diagnosed with PDD because they are more socially adept than males with similar IQ scores (Filpek et al., 1999; Volkmar, Szatmari & Sparrow, 1993).

Etiology of Pervasive Developmental Disorder

Current literature suggests PDD results from a dysfunction in the central nervous system that most likely has a genetic basis (Blaxill, 2004; Kabot et al., 2003; Piven, 1997). The consensus in the literature suggests that unidentified factors within the prenatal and postnatal environment may trigger the onset of autistic symptoms. Although studies examining brain functions and structures exist (Courchesne et al., 2001; Iverson, 2001), explanations about behavioural symptoms in relation to the neurobiology of autistic disorder remain unclear (Kabot et al., 2003; Piven, 1997).

Genetic research using linkage analysis implicates Chromosomes 7 and 15 as possible defective genes related to autism. In a study by Ingram (as reported by the National Institute of Child Health and Human development), 40% of people with autism displayed a change in one of the two copies of the HOXA1 gene, located on chromosome 7. This was compared to 22% of people without autism, who did not have a family member with an autism diagnosis, but showed the same change. Furthermore, 33% of family members of people with autism who did not have a diagnosis themselves also displayed a change in this gene. From these results, researchers postulate the HOXA1 gene may not be a causal gene for autism, but may in fact be an autism susceptibility gene. This suggests that individuals with a HOXA1 abnormality may make a person more susceptible to developing the condition (Kabot et al., 2003).

Treatments for Pervasive Developmental Disorder

In the past autism has been viewed as a severe, lifelong, developmental disorder as those affected with the condition will require unending support and guidance throughout their entire life (Roger, 1998). Recently, this assumption has been put into question as a result of research indicating the progress young children with autism can make in certain early intervention programs. As a result, a new nation-wide movement highlighting the importance of providing more systematic and focused interventions for these children has occurred. Although a variety of strategies have been used to treat children with autism, including medication (Fein et al., 2001), gluetin-free casein-free diet (GFCF) (Panksepp, 1979), auditory integration therapy (Bernard, 1993, as cited by Metz et al., 2005), facilitated communication (Biklen, 1997, 2003), Floortime (Greenspan, 2000, as cited by Metz et al., 2005), and TEACCH (Schoper, 1970, as cited by Metz et al., 2005), Lovaas' (1987) Early Autism Project, based on the provision of intensive behavioural treatment was the early intervention method associated with the strongest supporting

scientific evidence (Metz et al., 2005). Lovaas (1987) study initiated the rise of behavioural interventions in the autism industry and motivated other researchers in this area to replicate his promising results.

Lovaas (1987) conducted a non-randomized control study consisting of children diagnosed with autism, between the ages of two and three. Children were assigned to three different conditions depending on the number of staff available in the area to render treatment. The conditions consisted of an experimental group (n=19) receiving more than 40 hours of intensive behavioural treatment per week, a minimal control group (n=19) who received less than 10 hours a week of intensive behavioural treatment and a second control group (n=21) who were also receiving minimal treatment, but were not treated by the Early Autism Project. All treatment methods lasted for at least two years (Lovaas, 1987). Pre-treatment measures revealed no significant differences between the three groups of children; at two year follow-up, 47% (9 of 19) of children in the experimental group achieved normal intellect and educational functioning and were mainstreamed into grade one classrooms, compared to only 2% of the controls (Lovaas, 1987). Furthermore, McEachin, Smith and Lovaas (1993) conducted a follow-up study of the same children several years after the last assessment (mean age =13) and found the participants in the experimental group with "best outcome" had maintained their previous level of intellectual functioning, which was on average 30 points higher than that of the control groups.

Effectiveness of Early Intensive Behavioural Interventions

Lovaas' (1987) groundbreaking research was the first empirical study to suggest the prognosis of autism may be significantly more optimistic than once thought (Eikeseth, 2001; Klinger & Dawson, 1997). A variety of assumptions surrounding autism treatment surfaced as a result of Lovaas' (1987) work. These assumptions or "Truths about autism" continue to influence

professionals, service providers, and families' perceptions of autism, often guiding their practices and treatment selections. First, as 47% of the children in the treatment group attained normal functioning and were considered indistinguishable from their peers at follow-up, the Lovaas (1987) study provided strong evidence to support the use of behavioural interventions for children with autism, which has recently been supported by various other authors (Anderson, Avery, & DiPietro, 1987; Birnbrauer & Leach, 1993; Cohen, Amerine-Dickens & Smith 2006; Eikeseth, Smith, Jahr & Eldevik, 2002; Ozonoff & Cathcart, 1998; Sheinkopf & Siegal, 1998; Smith, Groen & Wynn, 2000). Second, as the study indicated the experimental group (receiving 40+ hours a week of behaviour therapy) outperformed control group 1 (receiving behaviour therapy less than 10 hours a week), Lovaas' (1987) research also suggests the more intensive the intervention the better the outcome. Again further research appears to support this assumption (Cohen et al., 2006; Smith et al., 2000). Furthermore, when examining the children in Lovaas' (1987) experimental group, he noted the children were more likely to achieve "best outcome" if they were younger and/or had higher IQ scores prior to treatment administration.

What Happened After Lovaas' (1987) Study?

Even though Lovaas' (1987) study was conducted 20 years ago, his research is still used as a benchmark to measure treatment success. Following his study a variety of researchers have attempted to replicate his findings (as mentioned above). Studies slightly modifying Lovaas' (1987) treatment strategies, yet still falling under the broad rubric of behavioural interventions, have consistently demonstrated a positive relationship between behaviour therapy and child outcome (specifically in relation to IQ and adaptive functioning) (Anderson et al., 1987; Birnbrauer & Leach, 1993; Cohen et al., 2006; Howard et al., 2005; Ozonoff & Cathcart, 1998: Sheinkopf & Siegal, 1998; Sallows & Graupner, 2005; Smith et al., 2000).

Anderson et al. (1987), Birnbrauer and Leach (1993), Ozonoff and Cathcart (1998) and Sheinkopf and Siegal (1998) conducted partial replication of Lovaas' (1987) study; however, children in these replication studies received fewer hours of treatment (18 to 25 hours versus 40 hours) and typically had less experienced trainers conducting the therapy (Smith et al., 2000). The children in these studies displayed significant increases in non-verbal IQ (22 to 29 points), but all other gains made by these children during treatment were smaller than those reported in the Lovaas (1987) study.

To address some of the issues mentioned above, as well as concerns about the lack of methodological rigor of the Lovaas (1987) study (i.e., selection bias, instrumentation [refer to Gresham and MacMillan, 1997 for details]), Smith et al., (2000) conducted a replication study. Children were matched based on diagnosis (PDD-NOS versus Autistic Disorder) and IQ, each pair being randomly assigned to either an intensive treatment group, receiving 30 hours a week of intervention for 2-3 years, or to a parent training group where the parents were taught behavioural principles to help their child acquire skills. Parent training occurred approximately 5 hours a week for 3-9 months. In both the treatment and the parent training groups the children received intervention based on the Lovaas et al. (1980) treatment manual.

Pre-treatment measures revealed the children to be closely matched on all variables with no statistically significant between-group differences. At follow-up the intensive treatment group outperformed children in the parent training group on measures of intellect, visual-spatial ability, language and academic achievement. However, intensively treated children did not differ from children in the parent training group on standardized tests of behaviour problems and adaptive functioning in every day settings. Interestingly, although various studies have confirmed the significant gains children with autism can make in behavioural programs, none of the above

existing studies have been able to replicate the outstanding treatment outcomes achieved by the

children in Lovaas' (1987) original experimental group (Anderson et al., 1987; Birnbrauer &

Leach, 1993; Ozonoff & Cathcart, 1998: Sheinkopf & Siegal, 1998).

Truths within Dominant Autism Discourse

The abovementioned contemporary autism literature is used to drive parents',

practitioners', policymakers' and society's perceptions of what it means to have a diagnosis of

autism. These current modes of thinking are summarized below:

- PDD is considered a mental disorder; a deviation from what is considered "normal".

    Diagnosis is premised on the person meeting a specific number of behavioural criteria

    found in the DSM-IV-TR (APA, 2000).

- PDD is most commonly seen as a neurological deficit that has a genetic and biological

    basis.

- Diagnosis of PDD is currently on the rise. Prevalence rates are increasing at a greater

    than expected frequency.

- PDD is in need of intervention. Currently, empirical evidence suggests Early Intensive

    Behavioural Intervention (EIBI) is the most successful approach to reducing autism

    symptoms.

- A window of opportunity exists for children with PDD, meaning that exposing young

    children (before the age of 7) to treatment can make the difference between a child who is

    severely disabled and one who has some degree of normal functioning.

Second Interlude

It has been almost a year since I decided to alter my academic trajectory, abandoning everything I had come to know as "true" and diverge into unknown territory. Since this time, although I have given my subject position a great deal of self-reflection and critical thought, I have been unable, on paper, to clearly articulate my subjective status.

The idea of sharing my most personal and intimate experiences, tracing the series of events that have ultimately led me here, currently writing this autoethnography about children with autism, has been a constant struggle for me. I feel as though I cannot sufficiently deconstruct the external and internal structures influencing my thought process, in order to clearly articulate why I have this desire and drive to "help people."

I could attribute this difficulty in self-reflective writing to my inability to clearly explain anything in terms that others will understand. I frequently experience the "tip of the tongue phenomenon" where I can't seem to find the "perfect" word to adequately explain any feeling, personal life event or experience.

I could also attribute this difficulty to my poor writing skills and the series of run-on sentences and awkward phrases that I only become aware of once I have distanced myself from a piece of writing; reviewing something I have written several months prior, in which the dreaded personal criticisms emerge "did I actually write that?" "I can't believe someone else had to read this crap!"

Although the above do contribute to my anxieties about this reflective writing piece, my main issue with this autoethnography is the idea of writing for an audience. It becomes easy to distance myself from the subject matter, to study a group of people in which you pretend to have no invested interest, and then talk about that group as if you are "the expert"; knowing the subject matter better than the subject can ever know and describe him or her self—after all you are the objective and unbiased researcher! Yet, it becomes quite difficult when the subject of study is, in fact, your self. Everything immediately becomes so personal; the designated researcher role becomes blurred. Now I am not only the researcher, but also the "object of study" as my life, and most intricate thoughts and experiences become judged, condemned and critiqued, not only by myself but by the reader as well!

* * *

The thought of stating my subject position as a white middle class female is absolutely horrifying. I know my femaleness has become an inherent part of my identity (and I use this term very loosely). I have either conditioned myself to take on traditional female qualities or they are indeed innate. Yet the nature-nurture debate is not of interest to me; what is of importance, however, is why I do not want to discuss my position as a female. It seems that as soon as I acknowledge my femaleness I am judged, or as soon as I identify myself as being female, my female qualities surface and I become this over-emotional basket case. Yes, it is a struggle to find my own voice as a female in a predominately male dominated hegemonic society, yet for myself, coming from a discipline encompassing 98% of its students as female, it does not seem to

be an issue of finding my voice in a male dominated society, but rather finding my voice at all. I find myself silencing my own knowledge, beliefs, desires and questions, in fear of not only being identified as an imposter, but also offending and displeasing others by being critical of their work and practices.

<div align="center">*   *   **</div>

Public speaking has never been my strength. Throughout my undergraduate and graduate degree, I continue to feel like an "imposter", always thinking everyone else has something more valuable and intelligible to say than myself; thus, rendering me mute for the most part of my educational experience. Anxieties surrounding my competence as an academic continue to escalate as I climb my way up the academic ladder. Although I feel as though I can save face and pretend to be insightful and intelligent, I continue to fear that someone will one day uncover the truth; that I am merely an expert at playing the academic game and have no real, unique thoughts of my own.

<div align="center">*   *   **</div>

Notions of being female, femaleness, and womanhood in Western society carry with them a variety of different assumptions. For myself, ideas surrounding "womanness" encompass thoughts related to external beauty, selflessness, responsibility, emotionality, nurturance and extreme sensitivity towards others.

It is interesting that prior to this quest of self-exploration; I have come to accept many of my female qualities as an innate part of my existence. I am female. The additional X chromosome is the explanation for many of the traditional feminine qualities I encompass, which are thought to be a static and internal part of my female existence.

I have a malleable personality that allows me to easily adapt to various situations so that I am able to fulfill my role of "pleasing others." I have a tendency to want to help others; an over-active theory of mind (continuously ensuring that my actions do not in any way, shape or form upset others); an ability to listen, instead of speak up; I have a self-sacrificing personality (going to any extreme to make the people I love happy); and a habitual ability to assume responsibility for my actions even when others are involved. These qualities, put together, structure my internal personality or unique self, which has been left seemingly unquestioned up until this point of my life.

If I was to examine the social structures that have influenced the above, traditionally female qualities I have appropriated throughout the last 25 years of my life, it would be difficult, or rather nearly impossible to peel away the layers of social influence in order to get to the "substance" that lies beneath (if there is some existence that does, in fact, lie beneath these layers). Yet, when I reminisce about my personal experiences, some aspects of my life provide an incomplete and partial explanation of the emergence of these female qualities.

<div align="center">*   *   **</div>

If I were to trace the emergence of my "selflessness", it would likely stem from observing my mother. Throughout my childhood she has always put her family first; her own personal

ambitions, desires, passions being neatly tucked away from our view. She gave up her aspirations, largely ignoring her own intellect and capabilities, to live vicariously through my father, whose intellect and capabilities were never interrogated or even questioned. Giving up everything for my father's success, moving across the country, isolating herself from her own family and friends, she raised my sister and me, for the most part, alone, while my father brought home the "bread". Watching my mother go above and beyond her duties and obligations of motherhood, I became consciously aware of my responsibilities as a female; to care, to be compassionate, to be self-sacrificing and to covertly hide one's own emotions, desires, passions and ambitions.

Chapter 3: Autism through the Modernist Lens

Rationalism, Objectivity and Language as a Medium for Generating Knowledge

Psychology as a science can be seen as a by-product of cultural modernism (Gergen, 2001). Modernism can be traced back to the age of Enlightenment, which encompassed notions about the transcendental self, that is, about a timeless and universal human nature. From this Enlightenment standpoint and the program of science it supported, reality is measurable and an ultimate, stable, ahistorical framework can be established to determine what counts as reason, Truth, knowledge and correct action.

Gergen (2001) identifies three broad assumptions—reflective of this modern cultural heritage—which are pivotal to modern practices in the psychological sciences.

1. *Individual knowledge exists*. Within this paradigm it is believed that inside each citizen lies the sacred sanctuary of the mind. The mind, in this instance, is portrayed as a closed, bounded system operating independently of external influences. Unearthing these homogenous mental capacities, which may include cognitive schemas, information processing mechanisms, and storage and retrieval structures, provides a gateway into the world around us. Through the discovery of fundamental mental processes, a degree of prediction and control of human behaviour can be established. It is thought that this incremental understanding of the stable structures of human thought move us progressively towards a more "ideal society" as it

produces techniques used to cure mental illness, improve education, reduce crime and create a life filled with increasing satisfaction (Gergen, 2001).

2. *The belief in an objective and knowable world*. Descartes' dualism suggests a distinction can be made between the interior world of the mind and the exterior world of material objects. Although this separation exists, it is thought these two domains work together simultaneously providing information to each other. In other words inquiry into the mind is essential to understanding one's actions in the world, and behaviours exhibited by an individual are fundamental to understanding one's mental processes. This bi-directional relation between mental processes and environmental events is guided by three principles: 1) mental events are biological processes at a higher level of abstraction and are therefore available for objective study; 2) internal processes are causally related to environmental inputs on one hand, and behaviour consequences on the other; 3) controlled empirical analysis is superior to all other methods when attempting to capture whether these causal relations exist in reality (Gergen, 2001).

3. *Language is the bearer of truth*. Words signify internal conceptions, as they stand as external markers for ideas within the individual mind. It is only through language that these internal conceptions can be made known to others and that thoughts within the mind can be conveyed in the outer word (Gergen, 2001).

Understanding Autism through a Modernist Lens

Much of the autism literature to date is guided by the abovementioned modernist assumptions articulated by Gergen (2001). Empirical evidence supports the notion that autism is a neurological disorder. Current research in the area suggests children with autism display deficits in their ability to process information. Impairments in executive functioning associated

with frontal lobe dysfunction are hypothesized to contribute to this information processing impairment (Bebko & Ricciuti, 2000). Dominant autism neurological literature consistency operates under the modernist assumption that within every individual lies the sacred sanctuary of the mind. By stating *children with autism have frontal lobe impairments* homogenous structures of the autism mind are targeted and identified. Strategies and techniques are then developed to enhance brain stimulation in the frontal area. In this instance, empirical research provides a window into the unknown, better equipping society with the skills needed to predict and control the autism population's behaviour.

Second, contemporary autism literature operates under the assumption that autism is a real phenomenon and controlled experimental methodologies will enhance our understanding of the unique characteristics specific to autism, providing insight into the best way to treat the disorder. Current research indicates signs of autism become apparent in the first two years of a child's life. Early screening measures such as the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter & Le Couteur, 1994), the Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore Risi, 1999), the Checklist for Autism in Toddlers (CHAT) (Baron-Cohen et al., 2000), the Screening Test for Autism in Toddlers (STAT) (Stone, Coonrod & Ousley, 2004), the Pervasive Developmental Disorders Screening Test-II (PDDST-II) (Siegal, 2001) and the Behaviour Observation Scale for Autism (Freeman et al., 1978) are currently used to detect autistic symptoms. Although these screening measures exist and are utilized, Bryson, Rogers and Fombonne (2003) argue that problems with measurement sensitivity may result in higher rates of false negatives (versus false positives). Most of the literature in this area points for the need to develop reliable and valid assessment instruments so children with autism can be identified early and appropriate intervention can be provided. Furthermore, the National Institute of Health

(NIH) report identified several methodological and statistical issues needing to be addressed in future autism research. All six suggestions articulate the dire need for more well-controlled experimental research designs where participants are randomly assigned to various conditions in a controlled, objective fashion (see Gresham & Macmillan, 1997, p. 185). The abovementioned literature takes a realist position towards the world suggesting PDD exists "out there" and is available for observation though the use of controlled empirical analysis. It assumes that by utilizing controlled experimental methodologies we will be able to objectively capture what lies beyond our own subjectivities.

People labeled with PDD are in constant mutation both definitionally and temporally as characteristics of the disorder continue to evolve and be fine tuned. Within the dominant autism literature these mutations are portrayed as extensions of previous scientific discoveries adding onto existing frameworks in an incremental fashion. The improved understanding and explanation of PDD diagnostics, etiology and effective procedures used to treat labeled individuals, suggest that our enhanced knowledge of the disorder will continue to improve the lives of people with PDD and their families. Again this points to the assumption of progress; as time moves forward our understanding of the disorder also enhances. It is through this enhanced understanding that we are able to develop appropriate assessment instruments and individualized treatment packages that are effective and efficient.

The third assumption of modernism, that language is the bearer of truth, also exists within contemporary autism research. Children with a diagnosis of autism typically display impairments in language, communication and social interaction. Standardized tests used to assess a person's cognitive capacity are heavily reliant on the use of language (both expressive and receptive). As the ability to understand and produce dominant language patterns is a key component to

evaluating intellectual development, individuals who display a developmental lag in language are also commonly diagnosed with an intellectual impairment. Alternative techniques have been developed to help children with PDD that lack skills necessary to communicate verbally. These include PECS (Picture Exchange Communication System), sign language, facilitated communication and augmentative communication systems. Yet all of these instruments fall within the dominant regimes of language (refer to p. 40-41 for details).

Third Interlude

I recently attended a 2-day PECS training workshop. PECS is a unique augmentative/alternative communication training protocol that is predominately based on Skinnerian philosophy of verbal behaviour. The manualized training program is based on the principles of applied behaviour analysis and offers an intensive, objective, detailed procedural account of how to teach communication to people who are currently non-verbal.

The audience, predominately made up of behaviour therapists, support workers, educational assistants and graduate students, were highly enthusiastic about the idea of teaching clients a rudimentary form of communication, since many of the people these audience members support did not have an intelligible medium for articulating their wants, needs and desires. However, some skepticism was present in the audience, particularly pertaining to anxieties about the intrusiveness of the method (e.g., the two person prompt) as well as feasibility issues including availability of staff, maintaining consistency, the generalizability of the skill to other settings and people, and the overall maintenance of the communication system.

Uncertainty, again, was met with traditional notions of scientism, as the PECS trainers stressed the need to be objective through data collection. If the data displayed the training to be ineffective, the audience was encouraged to act logically and rationally by conducting a functional analysis, in order to identify the antecedents and consequences that may be maintaining the inappropriate behaviour.

The PECS training focused on universal administration; it is the techniques of applied behaviour analysis that are effective, leading any member of the audience who is fluent in behaviour principles to carry out the training.

Chapter 4: The Postmodern Discourse as a Space of Resistance

Approaching the Age of Uncertainty: The Death of Man

Today we have entered what some call *the age of uncertainty* as disputes concerning absolutivism versus relativism and foundationalism versus fragmentation have emerged in broader discussions surrounding the formation of knowledge and what can be considered True representations of external reality (Falzon, 1998). This emerging skepticism has led to the re-theorization of many taken-for-granted assumptions of the social sciences, including the belief in an objective reality, ideas surrounding the subject as a stable, coherent, rational and timeless being, and language as a medium for shared understanding. This intellectual enterprise interrogates the existence of ultimate foundations of knowledge which allow us to organize and comprehend the totality of things.

Currently, intellectuals such as Gergen (2001) and others (Basaglia, 1987; Danforth, 1997; Foucault, 1965; Parker, 1995; Skrtic, 1995) articulate their concern with appropriating the beliefs, values and opinions of the dominant society. Scheper-Huges and Lovell (1987) eloquently illustrate this apprehension by stating, "psychology is the phantom of objectivity; a mask that conceals more than it reveals" (p. xxiii). Foucault (1972) also nicely illustrates this concern in his book *The Archaeology of Knowledge* when he states,

> True discourses, liberated by the nature of its form from desire and power, is incapable of recognizing the will to truth which pervades it; and the will to truth, having imposed itself upon us for so long, is such that the truth it seeks to reveal cannot fail to mask it (p. 219).

What the above authors are alluding to is that without maintaining a critical stance, without deconstructing unquestioned Truths within a given society, we may maintain the existing societal structures and power hierarchies we wish to eradicate.

Traditionally, the psychological sciences attempt to mimic the models and methods of the natural sciences to explain human affairs, providing rational explanations for social action, with the intention of predicting and controlling human behaviour. Falling within a functionalist framework this position assumes all events and structures within a society are productive and essential; if they were not they would not exist. This cornerstone idea leads one to assume that all current aspects of society are indispensable to the larger system, and the existence of all structures is absolutely necessary for the system to function (Skrtic, 1995). This taken-for-granted truth is being questioned by many authors (e.g., Basaglia 1987; Danforth, 2000; Foucault, 1965, 1972, 1980; Parker, 1995; Skrtic, 1995) who currently describe the psychological sciences as being historically frozen in the empiricism tradition, isolated from radical theorists and critical thinkers of the past half century, which offer new directions for radical social change. This proliferation of apprehension with the current techniques and procedures used in the psychological sciences suggests we are in the midst of a paradigmatic shift. Skrtic (1995) argues we remain relatively unaware of the dominant discourses we are currently operating under, as these discourses only tend to surface when they are in the process of changing.
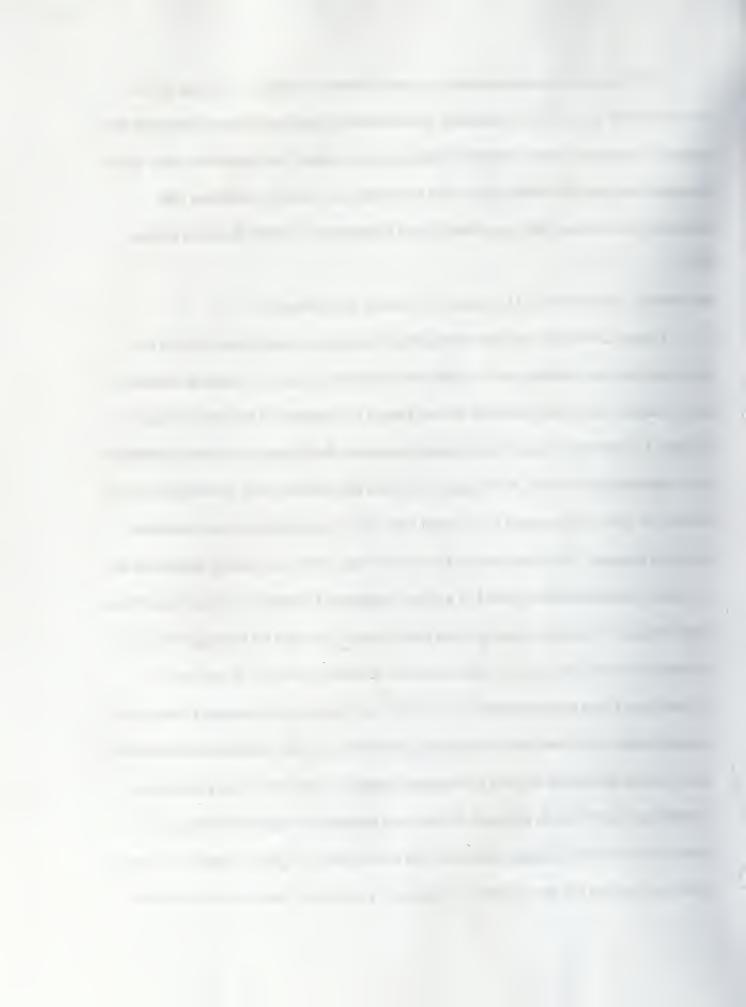
What is Postmodernism?

Postmodernism can be seen as a space between historical periods. It does not describe the movement out of modernity into a postmodern world, but rather the term is used to describe a period of radical indeterminacy (Skott-Myhre, 2007). This space can offer fundamental new ways to interpret and understand that both resist and exceed our current grasp of the world. It offers new and exciting opportunities for understanding diversity, otherness and other forms of life (Falzon, 1998).

Unlike modernists, understanding the totality of human experience and what can be considered "real" is not of direct interest to postmodernists; rather what becomes important is the pragmatic capacities of these constructed realities. In other words, postmodernism offers space to investigate how specific constructions of the world function in society, examining what organizational structures they support and silence through their existence in society (Gergen 2001).

Irrationality, Subjectivism and Language as a Form of Representation

Gergen (2001) offers an alternative postmodern epistemological framework for the abovementioned assumptions used to guide modern practices in the psychological sciences. He argues that the belief in the individual rational subject is problematic if not oppressive in its function. For example, consider the modernist assumption that language is a direct expression of one's reasoning of the world. As language is a system that produces itself, it both precedes and outlives the individual, meaning that to speak rationally is to participate in a pre-established system of language. One is perceived to be rational if one is able to adequately appropriate the system of words and meaning posed by a given community. For instance, if a scientist is fluent in the language of science, meaning he/she can eloquently articulate the language within the scientific discourse, then he/she is deemed to have scientific rationality. Hierarchies of rationalism are then established based on a society privileging certain language systems over others. Gergen (2001) sees this as being quite problematic as some individuals are considered more rational than others and thus deemed more worthy of leadership, social positions and wealth than people who do not speak the dominant language. He argues these existing hierarchies in various language systems are not a true product of "pure rationality" but rather these explanations and descriptions are rhetorically constitutive, based on what is deemed

appropriate language systems within society. As language is a byproduct of human interchange, there is no independent rational language but rather rationality itself is a result of local, communal participation. Based on this argument Gergen (2001) contends that there is no ultimate means of justifying one form of rationality, description or explanation over another.

Postmodernism also opposes the notion of realism or the belief that reality is real and measurable and that Truth can be uncovered through the utilization of objective, scientific principles. Again, by unearthing the limits of language, the notion of objective knowledge begins to decay. To speak of "the mind" or "the world" as an object of study requires language; therefore to speak of the mind as the mirror of external reality is to disregard the communal construction of language. Descriptions of the material world do not accurately describe what exists in reality; rather, these descriptions are an outgrowth of human tradition, a textual genre of repository statements that constitute a particular tradition. What is considered real and is believed to be transparent is, in fact, embedded in the socio-historical and culture context in which a given statement or a set of propositions emerges.

Postmodernism also challenges the third assumption of modernism, that language is the bearer of truth (Gergen, 2001), with its suggestion that language should be viewed as pragmatic practice. As stated above, language cannot be regarded as an external report of one's internal observations and perceptions. Language gains its meaning from its use in action. In order for one to adequately express oneself in comprehensible terms one must already use existing social codes developed by the local culture to explain and categorize human behaviour. One is only able to express oneself and generate mutual understanding, through the local language systems available in the dominant culture (Skott-Myhre, 2007).

Fourth Interlude

If we were to unpack the PECS training from a postmodern perspective we would begin to be critical of the assumption that language is an accurate representation of one's internal thoughts, feelings and desires and would begin to see language as something that is socially constructed. This would also bring to our awareness the element of power inherent in the PECS training; that is, the training is developed and implemented by those who have typical language for those who do not. Constructing a communication system in this way, we impose our own assumptions on people who are non-verbal of what can and should be considered appropriate language. This thereby perpetuates current beliefs surrounding normal-abnormal communication binaries.

Baggs (2007), speaking from the autistic perspective, further elaborates on this problem when she states "failure to learn your [the dominant] language is seen as a deficit, but failure to learn my language is so natural that people interpret us [people with autism] as mysterious and puzzling rather than admitting to themselves that they are the ones confused."

The majority of the people participating in the PECS training displayed a genuine commitment to their clients, wanting to do whatever they could to "help" the client successfully function in society. Many saw this system of communication as a form of liberation or self-determination, giving a voice to those who are typically incomprehensible to the rest of the world. At a certain level of consciousness this is, in fact, the case.

Yet when we examine the function of techniques such as these, we begin to see how we (as a society) establish certain communication systems as "acceptable" and "unacceptable". This not only limits non-linguistic individuals' capacity to seek their own personal form of communication, but also places constraints on the linguistic population's perceptions of normal speech and communication.

I believe the postmodern argument is extremely valuable, as it forces us to see how we are constrained by current discourses surrounding normality. Yet, in order for communication to be successful, mutual understanding needs to occur. I cannot seem to grasp how people with autism would be able to communicate in a way another can understand if they do not speak a language that is comprehensible to the majority. The majority, could, in fact, attempt to learn the language of subordinate groups (i.e., people with autism), but this would involve others being open and sensitive to this unique exchange of information. Considering we live in a high paced society that thrives on efficiency and productivity, this is not exactly the most proficient alternative.

If we were to view autism languages in the same light as individuals living in North America who have not yet appropriated English as their first language, we would again begin to see autism language in a different light. Individuals with autism would not be seen as non-communicative, but rather incomprehensible to someone who does not speak autism language. This new construction may increase our attempt to understand the person with autism through their own language, by examining alternative means of communication including one's tone and intonation, body language and gestures, etc.

* * *

Yet, I cannot seem to abandon the idea of mutual understanding. If we do not speak the same language, or if we are unable to understand the other's language, then how do we communicate and exchange information? Would the world delve into chaos? Would separatism based on language be even more distinct, leading the divide between languages to further separate humanity into multiple categories?

In a quest for equality and acceptance of difference this does not seem like a plausible alternative.

Chapter 5: Deleuze and Guattari (1987) Escaping Dominant Conceptualizations of Language

This chapter will provide a theoretical summary of Chapter 4 "Postulated Linguistics," in Deleuze and Guattari's (1987) *A Thousand Plateaus: Capitalism and Schizophrenia,* which will be followed by a theoretical summary of Franco Basaglia (edited in 1987 by Scheper-Hughes & Lovell) and the anti-psychiatry movement in Italy. A Foucauldian framework of madness and power will be discussed in Chapter 7.

These theoretical frameworks have been selected to further explore issues surrounding reality, language, progress and notions of the individual subject. These frameworks offer a critical constructionist perspective of what is currently considered "deviant" in our society, relating deviance to the socio-political and economic conditions of society at any specific moment in time. Each framework will be introduced separately so that theoretical concepts can be discussed in detail. This will be followed by a synthesis of the literature in order to pull out commonalities among the readings. Synthesizing theory from the above authors will offer an alternative, critical, postmodern perspective associated with notions of deviancy, otherness and abnormality.

Postulated Linguistics

>*"Language is not life; it gives life order"* (p. 76)

Deleuze and Guattari (1987) challenge modernist interpretations of language. These constructions view language as a form of communication, language as a way to transmit knowledge, and language as a medium for relaying one's internal thoughts, motivations and desires.

The authors argue the primary purpose of language is not to communicate information but rather to impose a pre-established order based on redundancy. Describing language as a series of order words, they contend language is not a specific set of explicit, descriptive statements about a phenomenon, since every act is linked to a statement by social obligation, carrying with it a set of implicit presuppositions which bring about a highly specific outcome.

Referring to the confining nature of language as a "death sentence", the authors argue that within each order word lies a death sentence, limiting the range of possibilities for thinking, interpreting and acting in the world. Put another way, order becomes imbedded in the rules of language, informing us about how language can and should be used, establishing rules to determine when language makes sense and when language does not. As language presupposes how and what we must think and what we must retain as valuable information, the relation between the statement and the act, although immanent and internal, is not part of the person's identity, but rather is one built on the constant redundancy between the statement and the act.

If language is constructed as a pre-established system (based on redundancy) then the authors argue that we cannot assign a non-linguistic point of departure because language does not proceed from what has been seen or felt to something that has been said, but rather goes from saying to saying. Words stand as representations of external events or internal processes, yet they

do not and can not represent the totality of that experience. Considering words are representations of the act, performance, feeling, etc., words are unable to adequately capture the entirety of the experience, leaving something nonlinguistic or unintelligible to remain in excess. Deleuze and Guattari (1987) illustrate the limitations of language when they state: "There are many passions in a passion, all manner of voices in a voice, murmurings, speaking in tongue: that is why all discourse is indirect, and the translative movement proper to language is that of indirect discourse" (p. 77). They argue language is not the transmission of information and it does not "go from a first party to a second party, from one who has seen to one who has not, but necessarily goes from second party to a third party, neither of whom has seen" (p. 77).

Deleuze and Guattari (1987) distinguish between actions and passions affecting the body and acts which are incorporeal attributes or the "expressed" of a statement. Incorporeal transformations occur instantaneously through the expression of a sentence. The statement "your child has a diagnosis of autism" concerns an incorporeal (not actual) transformation of bodies. The expression of the statement immediately and simultaneously is indicative of transformation and the effect the transformation produces. The statement carries with it a variety of assumptions, limiting the range of possible acts. The authors argue language is nothing without the pragmatics that put constraints on certain possibilities.

To elaborate further, in order to distinguish between corporeal and incorporeal transformations, Deleuze and Guattari (1987) discuss two formalizations, one of content and the other of expression. Being heterogeneous in nature, content and expression have their own form, as expression can never be seen as a sole function of representing, describing or understanding content. As language functions as indirect discourse, assemblages of enunciation do not speak of things, but rather speak on the same level as states of things and states of content. A continual
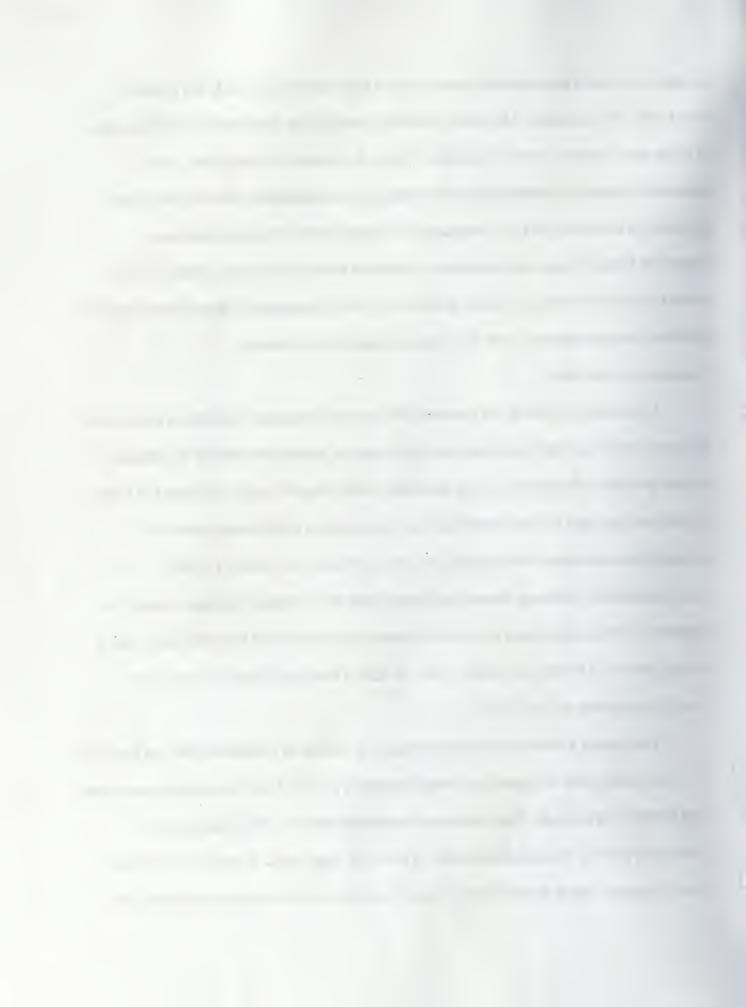
passage from content and expression occurs and it is this reciprocity that leads one to always form a relay with a segment of the other, continually passing from order words to the silent order of things and vice versa. Forms of content and forms of expression are inseparable from deterritorialization (i.e., deconstruction) that carries these concepts away and conversely these forms can be reterritorialized (i.e., reconstruction) through stabilization as contents and expression feed and merge into one another. Expression therefore does not accurately reflect content, but rather forms of expression and forms of content communicate through amalgamation relative to deterritorialization, both intervening and operating in the other.

Language as Possibility?

To summarize, Deleuze and Guattari (1987) construct language as a series of order words that carry with them a death sentence, limiting the range of possibilities between the statement and the act. Forms of expression do not adequately reflect forms of content and these two forms operate independently but continually feed into one another, in a continuous process of territorialization and deterritorialization, thus leading Deleuze and Guattari's (1987) conceptualization of language to seem quite bleak; from this standpoint language is merely the repetition of certain stereotypes and codes of conduct that contribute to the overarching order of things. However, Deleuze and Guattari (1987) do offer a theoretical linguistic escape from merely perpetuating the status quo.

Language is a heterogeneous system that can be viewed as a variable reality, yet in order for the scientific study of linguistics to exist, language is portrayed as a homogenized, centralized and standardized structure. This constructed foundational structure of language, that is insidiously political, becomes the language of power; in other words, it becomes a dominant or major language. Being defined by the power of consistency, the majoritarian language offers

stability. Yet, there is also the power of variation found in what can be called minoritarian

languages, and it is these languages that construct a continuum of diversity, urging all concepts

to be seen from a narrower or broader perspective. It is these minority languages that "make the

dominant language stammer" (p. 104), as they reject common points of reference and are in

favour of difference.

Major language does not stand in opposition to minor languages, but rather these two

languages serve as two functions of language. The problem is not deciding what language

systems should be classified as major or minor languages but rather the problem is one of

becoming. It is a matter of deterritorializing the major language. Minor languages only exist in

relation to the major language from the standardized model. Even though order words carry with

them a death sentence they also carry within them a warning cry or a message to flee. Order

words can mark stoppages. What Deleuze and Guattari (1987) want us to realize is that the

majority language is an "abstract standard," a postulated idealistic reflection of what language

should be and therefore it is reflective of nobody. Whereas the minority language is the

becoming of everyone, becoming to the extent it deviates from organized, homogenous

compositions. It is in the process of "becoming" Deleuze and Guattari (1987) argue, in which

these orders can be extracted into rites of passage.

Fifth Interlude

Throughout this piece I have continually described myself as passive and compliant in nature.
Based on the constant redundancy between the statement and the act (e.g., I am docile, I behave
in docile ways), I have internalized these qualities to be an inherent part of my genetic make-up.
Yet, what contradicts the static idea of "the self" I have come to describe as Sarah, is that one
year ago I decided to abandon everything I have come to know as true, to diverge into illegal
territory. Since this decision, one question continues to linger in my mind; in the midst of my
graduate career why did I decide to alter my academic trajectory, ultimately leading me to
explore alternative epistemological frameworks, and change thesis topics and advisors?

Previously, the scientific method was my majoritarian language. I found comfort in existing dichotomies of right/wrong, normal/abnormal, real/false, objective/subjective, and logical/illogical. Through empiricism and scientific investigation, I operated under the assumption that I could process information in terms of these dichotomies, incrementally adding onto the existing knowledge of the professional community. I found comfort in the idea of empirically, sound and generalizable conclusions about the totality of the human condition.

At the time, social theory seemed utterly useless to me. I failed to see the connection between arguments surrounding the socially constructed nature of human experience and what exists in reality. These theories seemed too vague and abstract to have any sort of practical usefulness. Yet, something during the first year of my graduate work altered my perceptions about the practicality of social theory.

The multidisciplinary nature of the Child and Youth Studies program allowed me to investigate a variety of phenomena from different perspectives. I challenged myself to think about the practical usefulness of social and critical theory and how it relates to our everyday experiences. This ultimately led me to examine my own experiences through a critical social constructionist lens, thus leading, in the words of Deleuze and Guattari, "the dominant language to stammer".

<p align="center">*   *   *</p>

In a world surrounded by pathology, I live in constant fear of a diagnosis. Being diagnosed with anorexia when I was 11, I was told by the experts that I would never "recover" from my eating disorder, as eating would continue to be a life-long struggle for me, entering a continuous cycle of starving myself, eating, binging and purging and then returning to "normal" eating patterns.

Under the gaze of the medical model, a variety of reasons were hypothesized for my eating disorder, including biology, genetics, family conflict, sexual abuse, the media, poor peer relations, peer teasing, etc. This ultimately led professionals to conclude that I was born with a genetic predisposition to anorexia; and during a period of elevated stress in my environment, the eating disorder emerged due to my inability to effectively cope with specific life circumstances.

To this day, I do not believe the above psychological bullshit.

Chapter 6: Franco Basaglia and the Anti-psychiatry Movement in Italy

Overarching theoretical framework

In 1961 Franco Basaglia, a young Italian psychiatrist and a scholar of phenomenology left the University of Padua to direct a small provincial psychiatric hospital: the asylum of Gorizia. Horrified by the inhumane conditions of the asylum, and guided by Marx and the Gramscian perspective, Basaglia re-theorized mental illness through a socio-historical and

political lens, taking the side of the patient as a person who suffers and is oppressed. Basaglia's destruction of the Gorizia institution and dialogical struggle with "the other" served as a benchmark for the beginning of the anti-psychiatry, anti-institutional movement in Italy (Scheper Hughes & Lovells, 1987).

Institutional Violence

In Italy, institutional conditions for the insane closely resembled those found in the prison. With an over-emphasis on dangerousness—based on the premise of "what they might do" or "what could happen"—the insane were deprived of their most basic human rights. Basaglia (1987) argued it was the technologies of control (e.g., restraints, straight jackets, wire mesh fencing, grating, bars, gates and keys) found in the asylum that transformed patients into "things". Techniques such as these were designed as a means of mastering madness—as they were done *to* the individual and not *with* the individual. Schizophrenics, manic-depressives, and hysterics were thereby portrayed as objects to be acted upon; being unable to express and experience themselves they remained inactive and submissive: "sitting and waiting for someone to seize upon them, and make them live as they see fit" (p. 78). Basaglia (1987) further states, "the moment I say, this person is schizophrenic I will begin to behave toward her in a unique way, that is, knowing full well that schizophrenia implies an illness for which nothing can be done" (p.8). Here, Basaglia (1987) clearly illustrates how communication between doctor and patient in the asylum becomes objectified as all communication is filtered through the label of madness. Any opposition to the rules of the institution is therefore interpreted as a symptom of the illness, serving to confirm these existing distinctions. By operating under the "doctor knows best" assumption, the patient's experiences of his/her own condition is deemed secondary or illegitimate to medical professionals. This provided justification for the *legalization of violence*.

Sixth Interlude

The Herzog film, based on the life of a man named Kaspar Hauser who was locked in a cellar for the first 17 years of his life, is an excellent illustration of Basaglia's legalization of violence. Following the first 17 years of confinement, Kaspar was "set free" and left in Nuremberg to live a life of liberty, freedom and justice. As Kaspar was without language, communication, gross or fine motor skills, he was placed yet again in a cellar of confinement out of the townspeople's fear of "what Kaspar might do".

Everything Kaspar does and says is explained in terms of his oddities. Failing to consider the world from an alternate view, the townspeople force Kaspar to assimilate the thoughts, beliefs and expectations of the town. Interestingly, however, the more Kaspar appears to progress (according to the townspeople's standards, e.g., learn language, societal expectations and gain knowledge, etc.) the more Kaspar appears to inhabit state of desolation and despair.

"They [the townspeople] are like wolves to me"; "The only place I like is my bed".

Kaspar's desire to be left alone is seen as a symptom as the townspeople continue to act in a benevolent effort to save Kaspar of his idiocy.

*   *   *

Having worked with children with PDD firsthand, I myself have wanted to help these children learn language and communication skills, self help skills, to learn emotion recognition and the ability to take another's perspective, and to decrease aggressive and problem behaviour, with the hope that these children would be able to successfully integrate into society.

These benevolent actions were not driven as a result of the capitalistic desire for these individuals to become productive citizens in order to contribute to the overall economy, nor were these actions based on pure monetary value for myself. Rather these actions were premised on my continual fear that these children would be unable to function independently, would be excluded from the rest of society, and would be unable to form long lasting intimate relationships with others.

Others aren't very accepting of difference. Others gawk and stare when a child excessively hand flaps because they are over stimulated. Since I, myself, would hate to be gawked and stared at, excluded by mainstream society and unable to form long-lasting relationships with others, my actions coincide with what I would want if I was autistic.

But I am not autistic and so I will never fully know if people with autism actually want to adopt the dominant language and communication patterns of dominant society, or maintain adequate social relationships or be included as active participants in mainstream society. Similar to the

townspeople of Nuremberg, I act out of what I can infer from myself and my own personal fears and desires.

Basaglia's Socio-Historical and Political Analysis

Basaglia saw the institution as a microsocial architectural space that was counter-therapeutic and iatrogenic, establishing an illness specific in its procedures and techniques. This was not to say Basaglia believed mental illness did not exist, but rather he wanted to clearly delineate how scientific concepts used to define mental illness were so abstract that they did not accurately reflect what existed in reality. Under the guise of disease, characteristics of madness (e.g., passivity, aloofness, irrationality, delusional speech) were seen as an irreversible cause of illness. This confirmed the need to separate and exclude the insane from the rest of society. Basaglia believed we could not know the reality of mental illness until societal structures and social influences such as poverty, social stigma, segregation and confinement were stripped away (p. 8).

Basaglia's Economic Analysis of Mental Illness

Many professionals working in the asylum throughout the 1970's could not deny the fact that many of the patients placed in these institutions were from marginalized and lower social classes. Basaglia and his colleagues went further in their class analysis, as they recognized psychiatric diagnosis was related to the prevailing economic order. This was guided by a moral economy which defined normality and abnormality in its own rigid class-based terms which, in turn, perpetuated the status quo.

To further elaborate, Basaglia (1987) uses the terms primary and secondary deviance to explain the political tools used to control deviant behaviour. *Primary deviance* refers to deviance as a result of marginalization through the sole exclusion of a group from mainstream social,

political and economic institutions. Basaglia (1987) contends, however, that primary deviance is often masked by *secondary deviance*, which encompasses ideologies that view deviance through a medical model lens. Being framed as a disease rather than a result of marginalization and social exclusion, abnormality is treated the same way as other medical conditions: the professional provides recommendations for how to alleviate symptoms. What Basaglia (1987) points out is that deviance is managed by colliding primary deviance into secondary deviance, so that attention is diverted from the former and the latter becomes the focus of attention. In other words, the social context in which these individuals are marginalized, segregated and excluded from active democratic participation in society is largely ignored. Instead, the focus is placed on mental illness as a disease that resides in the individual that is in need of intervention. What is less obvious are the techniques developed in a humanitarian and benevolent effort to help the insane are also the same procedures used to exclude—placing these individuals even more on the margins than they were initially.

The Political Underpinnings of Ideologies of Deviance

The ideology of deviance is linked to the medical perspective, in which behaviours and emotions deviating from the norm are considered natural and unchanging and are directed towards specific personality typologies. Basaglia (1987) argued the medical ideology of mental illness has little to do with medicine and more to do with production and economic growth. Deviance, in late stage capitalism, occurs when individuals do not actively participate in the productive rhythms of society. He points out that typically people labeled with a mental illness have either lost or never had contractual power with those in charge of production.

What Basaglia (1987) indicates in his analysis of the institution is that placing these unproductive individuals within institutional walls creates a new type of productivity and

efficiency, thereby affording these individuals an entirely new social role. This new social role is directly linked to science, as for every level of economic development there is an appropriate scientific language that arises, concealing existing contradictions and shaping illness according to the direct needs of society. This brings us to Basaglia's analysis of mental illness as a human contradiction.

Illness as a Human Contradiction

Basaglia (1987) argues mental illness itself is a human contradiction that occurs in every society. Definitions used to describe deviancy, psychopathology and abnormality are constructed to resolve these contradictions, as these abstract concepts are reduced to commonalities, labels and value judgments that serve to perpetuate these differences. The gradual manufacturing of a norm is based on the requirements of bourgeois rationality, resulting in a subdivision of different clinical pictures, nuances of differences, and the defining qualities of types of insanities. By engaging in this process society is freed from existing inconsistencies in human development and the concept of "the norm" is confirmed and validated.

Every society shapes illness according to the direct needs and aspects of the functioning society, which will, in turn, determine the future development of that disease. Basaglia (1987) argues psychiatry refuses to see the strong association between, on the one hand, the ideological construction of a norm, governing the techniques and practices used; and on the other hand, the social organization that begins to structure divisions of labour and various disciplines in such a way that the individual must adhere to that norm. Many other authors have articulated a similar concern. Philp (1985) sums up this anxiety with psychiatry quite nicely when he states:

    The normal child, the healthy body, the stable mind . . . such concepts haunt our ideas

        about ourselves, and are reproduced and legitimated through the practices of teachers,

social workers, doctors, judges, policemen and administrators. The human sciences

attempt to define normality; and by establishing this normality as a rule of life for us all,

they simultaneously manufacture it—for investigation, surveillance and treatment—the

vast area of our deviation from this standard. (p. 67)

The Dialogical Nature of Basaglia's work: A Shift toward Liberation Psychology

Basaglia's (1987) collection of readings illustrates controversies surrounding traditional

psychology and the limitations of using existing dichotomies (i.e., sane-insane, normal-

abnormal, and rational-irrational) as real universal concepts about the world. However, he points

out that once we call into question these existing dichotomies, we run the risk of falling into the

same impasse. For example, simply altering our constructions of the asylum from an

authoritarian coercive structure of control to a benevolent humanitarian organization, would

alleviate our guilt towards the patient, but would confuse the issue. Basaglia argues for "a

psychiatry that constantly checks itself against a reality and finds in that reality elements by

which it can challenge itself" (p. 75).

Currently psychiatry aims to resolve the inconsistencies of the human condition through

modernized techniques that are perfectly logical and empirically based. Yet, these existing

conceptualizations perpetuate a relationship between objects where reciprocity is systematically

withheld. The dialogical nature of Basaglia's (1987) work as a process of contradiction allows us

to see the problematic nature of defining reality a priori. The moment we define it, it vanishes

and becomes an abstract concept that is no longer representative of its existence. By attempting

to freeze reality it becomes distorted and irrelevant. Instead of attempting to ignore existing

contradictions, Basaglia (1987) argues for the need to dialogically confront inconsistencies, as it

kicking and screaming into our social environment by displaying "normal" behaviour, is to deprive these individuals of their different-ness. Baggs (2007) clearly articulates this concern: "only when the many shapes of personhood are recognized will human rights be possible."

Many of us fail to see our own invested interest in the modification of "the others" (i.e., our children, significant others, clients, students, etc). Typically we label "the other's" behaviour deviant when it interferes with our (society's) daily functioning. And we cannot forget that when we are successful at modifying the other's behaviours we are also reinforced!

Training a child to wave "hello" gives the child a gesture that can be used to initiate a social interaction: yet we cannot forget the reinforcing social implications it has for others within the child's environment. The child waving hello also enables the adult to feel loved, respected and valued by the child.

It indeed becomes quite difficult to separate the need to "help" children with autism successfully function in society and our own invested interest in modifying certain behaviours the child displays.

Chapter 7: Foucauldian Analysis of Madness and Power

"A history of madness does not exist without a history of reason" (Sheper-Hughes & Lovell, 1987, p. 231)

Brief Synopsis of Madness and Civilization

In the book *Madness and Civilization* Foucault (1965) delineates the path leading reason and madness to be constituted as binary opposites that appear to be "deaf to exchange, and as though dead to one another" (p. ix). Foucault (1965) attempts to give madness back its voice by illustrating how accounts of madness throughout the centuries are not accurate portrayals of madness, but are ultimately the result of a monologue of reason about madness through the gradual evolution of dominant values, rules, beliefs and systems of power.

Morality Justification for Confinement

Prior to the Classical period, madness was seen as an undifferentiated experience; a lower limit of human truth that was not accidental but essential to all aspects of human life. Yet, a shift occurred during the Enlightenment era when madness began to operate as a discrete phenomenon

independent of what was considered rationale. Foucault traces the evolution of madness as a separate entity that occurred as a result of three simultaneous events taking place in European society during the time. First, the feudal economy had given way to early market capitalism, increasing the discrepancies between rich and poor. Coinciding with the change to market capital the notion of protestant work ethic evolved. Hard work was now viewed as a moral duty and the path to salvation was equated with capitalistic gains. Third, the rise of medicine as an objective science allowed psychology to emerge as a practice of moral correction (Danforth, 2000). As a result, institutions such as the Hospital General (1656) were developed, not only as medical establishments, but to maintain the monarchial and bourgeois order being organized in France during the time (Foucault, 1965). These places of confinement provided a new home for madness, fostering a new sensibility to poverty, new reactions to economic problems such as unemployment and idleness, and a new ethics of work where moral obligations were linked to the law by authoritarian forms of constraint. Madness existed only on the other side of the bars, under the gaze of reason that no longer felt any relation to it or dared compromise itself by too close of a resemblance. It was during this period that madness became a "thing" entirely enclosed in pathology.

In the Classical period, the sole function of confinement was to prevent mendicancy and idleness as it was the underlying source of all disorders. For Foucault, the relation between confinement and the insistence on work was not defined by the economic conditions in Paris, but rather was guided by a moral perception that sustained and animated it. Origins of poverty were not a result of a scarcity of commodities or underemployment but rather society attributed these occurrences to the weakening of societal discipline and the relaxation of morals. Therefore, confinement had an ethical tone attached to it, being seen as a moral institution responsible for

punishing and correcting certain moral abeyances. Foucault argues the reduction of madness to "a lack of morality" secretly served as a nucleus for all concepts of madness in the 19th century providing justification for science, positivism and experimental procedures.

Liberation of Madness?

Traditional historical trajectories of the insane identify individuals such as Phillip Pinel and Samuel Tuke as contemporaries involved in the positive paradigmatic shift of perceptions of the insane. As the insane were released from their chains and more humanitarian efforts to "cure" these individuals were developed and implemented. Pinel and Tuke firmly believed madness was a chronic condition only because these individuals were deprived of air and liberty necessary to be cured.

In *Madness and Civilization* Foucault (1965) speaks of a man entering Tuke's Retreat who not only exhibited symptoms of mania but his seizures caused great panic to those around him. Entering the Retreat in shackles and chains, the madman's restraints were removed and he was permitted to dine with the keepers. The madman was told that as long as he did not disobey the rules of the house or the general principles of human morality, he would be free of his previous condition of confinement. At the end of four months the man left the retreat cured. This is one of the many cases in which moral treatment was used to help the madman control and monitor his behaviour. In this context explicit systems of control were no longer needed to manage the madman's behaviour, as he began to restrain himself, taking responsibility for his own actions and the consequences of those actions.

What Foucault (1965) illustrates through this example is that even though explicit instruments of control (i.e., constraints, isolation, torture etc.) were eliminated, the madman was only treated with dignity and care when reasonable and socially desirable behaviours were

exhibited. Any manifestation of irrational, abnormal or disturbing behaviour was linked to punishment or the threat of returning back to the ball and chain. It was this principle of fear (through speech) that became the new instrument of control and power in the management of behaviours of the insane.

Falling entirely in the hands of pedagogy of good sense, of truth and of morality, fear was implanted not in its instruments of curing the sick but in speech (i.e., discourse). From the acknowledgement of himself as object, and from the awareness of this guilt, the madman returned to his awareness of himself as a free, responsible, subject and consequently to reason, thereby objectifying himself to the gaze of the other. Everything became organized so the madman would imagine himself in a world of judgment that enveloped him on all sides, through the sharp awareness that his behaviours are constantly being watched, judged and condemned Foucault, 1965).

What Foucault (1965) points out is that even though efforts to help the insane appear to be progressive, becoming less cruel, torturous, invasive and more humane the function of these new moral and religious technologies remains the same: fear no longer reigned on the other side of the prison gates, but remained under the seals of consciousness. The madman as a human being was no longer guilty of being mad and as a consequence was held morally responsible for everything within him that disturbed his judgment and society. As a result, the madman could not hold anyone but himself responsible for the punishment he received.

Philip Pinel and Samuel Tuke not only opened the asylum to medical knowledge, but Foucault would argue they initiated a personality whose power was borrowed from science in order to justify certain practices and disguise their primary intentions. Power became that of

moral and social order taking advantage of the madman's minority status to inculcate prevailing

norms, values and behaviours of the dominant society.

Eighth Interlude

Nothing about the etiology of my eating disorder made sense, until I encountered an article by Lock et al., (2005) illustrating how the writings of Foucault were incorporated into the practices of narrative therapy. The article described Foucault's analysis of power as being embedded in discourse and the practices and techniques of the social sciences, ultimately leading to panopticism[12].

"As an inmate of the Panopticon, a self-policing subject, self-committed to relentless self-surveillance. This self-surveillance is a form of obedience to patriarchy. It is also the reflection in woman's consciousness of the fact that she is under surveillance in ways that he is not, that whatever else she may become, she is importantly a body designed to please or to excite." (Bartky, 1998 as cited in Bell, 2006, p. 291-292)

This description spoke to me.

I am hyper-sensitive of my obligations as female. I must be beautiful, thin, smart, witty, polite, and docile. I am an excellent self-monitor. I have great self-control, disciplining myself when I do not meet the unattainable expectations I set out for myself.

Average is unsatisfactory. I strive to exceed, moving beyond the grasp of the other. In a way I continue to feel trapped in a cycle of normality; the standards of what is beautiful, intelligent, appropriate, are constantly in flux, leading me to always slightly fall short of victory.

<p align="center">*   *   *</p>

Throughout Catharine Maurice's (1992) book she refers to normality as something corporeal. In a discussion of her daughter's experience with behaviour modification, which she previously describes as intrusive and mechanical, Maurice states that these perceptions of behaviour modification were initially clouded by her emotionality and in reality behaviour therapy was freeing her daughter into normalcy. Specifically she states: "we were not imprisoning her, we were freeing her into normalcy" (p. 131).

The first time I read this statement I didn't give it much critical thought or reflection. As autism is commonly constructed as "the child being imprisoned in a world of his/her own" the statement seemed self-explanatory; as adaptive skills, communication and language increase, the

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[12] Panopticism: An architectural design developed by Jeremy Bentham which illustrates power in its most ideal form; inducing a state of conscious, permanent, visibility to ensure the automatic functioning of power. In this instance control, surveillance and discipline transfer from the public to the private realm, as the subject begins to monitor his/her own behaviour, disciplining him or her self accordingly (refer to p. 67-68 for more details).

child becomes more aware of his/her social world and is better able to function independently within it. Re-examining this statement after reading Foucault, I no longer see this statement as self-explanatory but rather contradictory.

Foucault argues sovereign power (i.e., power over) has been replaced by disciplinary power, which is embedded in our everyday techniques and practices surrounding what is considered acceptable and normative. As these normalizing judgments are internalized, the subject learns, in fact, to monitor and discipline him/herself. Foucault argues this does not "free the subject" to become a master of his/her own fate, but rather creates docile bodies as the person's behaviour resides under the complete control of systems of power, leading the person to become passive, obedient and compliant.

Training someone to "act normal" limits their capacity to behave in innovative and creative ways. Being constrained by discourses surrounding "what is normal" and "what is acceptable", places constraints on our interpretations of another's behaviours. This is not only true in my personal experience of being confined by the representations of what is considered "the ideal female" but is also evident in Herzog's film.

Kaspar's authentic understanding of the world was limited by societal constraints. In an intellectual exercise based on logic, Kaspar was given the following scenario: you are standing at a crossroads, where one path will lead you to the village of truth (where people living in the village can only speak the truth) and the other path will lead you to the village of lies (where people living in the village only speak lies). What is the one question you could ask a person walking along one path if you wished to determine whether he is coming from the village of truth or the village of lies?

Kaspar replies: I would ask him if he's a tree frog!

Although Kaspar's answer was correct, in that the question would determine whether the person was from the village of truth or the village of lies, it was viewed by the intellectual as wrong, illogical and based on description rather than deduction and logic. Placing logic and deduction on a hierarchy above description, innovation and creativity, limits our capacity to behave in novel ways.

Exploring Notions of Power

In many of Foucault's writing (such as *Madness and Civilization*) he refers to notions of power. Yet, it is important to realize that when Foucault speaks of power he is not referring to modernist notions of power as a distinct entity that some people have and others do not. Therefore, it is important to explore Foucault's conceptualization of what he means when he uses the term power. This will not only enhance our understanding of many of Foucault's writings,

but will also illustrate why Foucault urges us to investigate dominant techniques and practices within a given society.

Foucault's Analysis of Power

For Foucault (1980) power cannot not been seen as a commodity that some individuals hold and others do not, as power is neither given, nor exchanged or recovered but rather is exercised, its existence only occurring in action. Power is not a repressive force but rather is productive in that it produces knowledge instigating certain forms of subjugation.

In an attempt to understand the "how" of power, Foucault suggests its mechanisms can be related to two points of reference: 1) Rules of right, providing a formal demarcation of power; and 2) notions of truth that power produces and transmits, that in turn, perpetuate power (p. 93). Hence, Foucault suggests we have a triangle encompassing power, rules of right and truth which are organized in a highly specific fashion. He posits *rules of right* are implicated in relations of power through the production of truth discourses. When Foucault speaks of *rules of right* he is not referring to right in the juridical sense that derived from the rules of sovereignty, but rather in the sense of a natural rule or norm, where disciplinary power is embedded in discourses and techniques, thus carrying the element of domination inherent in its practice.

Foucault contends that within a given society there exist relations of power which permeate and construct the social body. These relations of power cannot exist without the functioning of a discourse. These discourses of Truth, however, only permit certain types of power. Power thus occurs in a circular motion—as we are forced to produce the truth of power our society demands in order to function efficiently. As we are continually on a quest to find or speak the Truth, power never ceases its relation to the truth as it institutionalizes, professionalizes and rewards this pursuit. It is *Truth* that makes the laws in which "we are

judged, condemned, classified, and determined in our undertaking, destined to a certain mode of living or dying" (p. 94). And it is these *Truths* that are bearers of specific outcomes of power.

In summation, Foucault argues rules of right (surrounding societal norms, including the right to treatment, to education, or the right to live in an inclusive environment) are inculcated through the production of *Truth* discourses (grounded in empiricism) which seek to maintain rather than eradicate existing hierarchical power structures.

Importance of Investigating Techniques

Foucault contends the nature of power needs to be investigated, not by focusing one's attention on the conscious domination and material operations of power, but rather by identifying forms of *subjugation* through the investigation of techniques and tactics; that is, cases in which domination is achieved but the intent to dominate is implicit. Referring to this type of power as *disciplinary power*, Foucault argues that such power is exercised through the knowledge, techniques and discourses of the human sciences, all of which create and enforce the norms of human behaviours of modern society.

Chapter 8: Investigation of Autism Practices using the Theoretical Framework of Deleuze and Guattari, Foucault and Basaglia

The modern theory of truth can be viewed as the split between appearance and reality (Danforth, 2000). Modernism assumes that even though we may believe certain truths about the world, they are in fact subject to scrutiny, being loaded with ingredients that make truth finding nearly impossible. These ingredients include immeasurable and subjective characteristics such as emotions, unconscious motivations, ideologies, passions and impulses. According to modernism, True reality can only be uncovered if one takes the scientific steps needed to move beyond "appearances" in order to uncover the True nature of human experience free of human error and

bias. Rationalism, which later translated into positivism, attempts to make sense out of what one does not understand and involves techniques such as defining, classifying and categorizing. Mimicking the models of the natural sciences the above authors would argue that these techniques justify certain practices but disguise their primary intentions.

Basaglia (1987) contends that madness is embedded in the discourse of illness which is guided by the language of the rational. This illness discourse of madness provides justification for the techniques and practices used by the rational professional, since it is thought the patient's reality is clouded by their irrational and incoherent speech, their irregular behavioural patterns and/or their impulsive persona. However, neither Foucault nor Basaglia are persuaded by the scientific model of human behaviour as they are not interested in modernism's quest to find truth. Their work offers a critical socio-cultural and political perspective, attempting to make transparent the political dynamics and consequences of privileging the truths of scientists and professionals over and above those of subordinate statuses (i.e., those labeled mad). The language of science, professionalism and medicine reduces madness to a set of describable and analyzable objects to be trained, corrected, normalized and excluded, as it is the professional's job to move beyond false appearances to get to reality. In this instance, the madman's current history and experiences with the disorder are rendered mute and it is the professional's objective stance and knowledge (grounded in contemporary Truths) that will help or cure the individual of his/her deviance. This rational discourse provides justification for what Basaglia (1987) refers to as the "legalization of violence".

Foucault and Basaglia argue the voice of madness has been silenced by the scientific discourse of rationalism and the gradual manufacturing of professional industries developed in a benevolent effort to serve these individuals. Again, considering Foucault's arguments

surrounding aspects of power which are invested in the dominant techniques and practices of society the following question arises: *Do the techniques and supports used to "help" these individuals reflect there perceived intentions?*

The Political Construction of the Other as Defective

Both Foucault and Basaglia establish a link between those defined as other and the socio-political conditions of the time. Foucault establishes a historical link between the emergence of madness in Europe and the abolishment of leprosy at the end of the middle ages. His genealogy of madness suggested the disappearance of leprosy was not a result of improved medical practices but rather was an outcome of segregation, as the lepers were shipped away on boats to sail the unbounded ocean. What remained longer than leprosy, however, were the lazar houses which maintained the image and values attached to exclusion of the sick and society's fears of contamination. Foucault contends these remaining formulas of exclusion were repeated two and three centuries later, when the poor beggars, criminals and delusional minds would take the place of the leper, being excluded from society based on fear of contamination and violence.

With the birth of the industrial era, attitudes towards madness emerged in terms of economic ideas, attitudes towards labor and the current ideologies of the city, creating a new form of discrimination. The exclusion of groups from society was based on the sole premise of production and it was the individuals interfering with the productive rhythms of society who were constructed as sick, defective, deficient and deviant. Yet, rather than seeing madness as an effect of social factors, it was depicted as a characteristic of the person's inherent personality, thereby perpetuating the defective ontology. Similarly, Basaglia's (1987) analysis also alludes to the idea that patients residing in the asylum in Italy in the 1970's were from lower social class backgrounds. Paralleling Foucault, he argues marginalization is often masked by ideological

reformations that label deviance as a mental health issue. The social conditions in which these labeled individuals are segregated and excluded from active democratic participation are often masked by the medical model perspective which labels these individuals as "abnormal" and in need of treatment.

Both authors argue society shapes illness according to the needs of society, which determines the future of the disease. Basaglia (1987) contends psychiatry refuses to see the strong association between the ideological construction of a norm which governs the techniques and practices used, and the social organization that begins to structure divisions of labour and various disciplines in such a way that the individual must adhere to that norm. Foucault's historical account illustrates how confinement of the unproductive actually established a new economic function. First, institutions began to no longer confine people out of work, but to assign work to the confined, in order for these individuals to contribute to the prosperity of all[13]. Second, the morality discourse in the Classical age led to the use of rigorous forms of constraint (both explicit and implicit) permitting morality to be administered like a trade or economy.

How does this relate to Autism Discourse?

PDD and the window of opportunity hypothesis. Concepts such as autism, deviancy, abnormality, pathology and disorder carry with them a set of pre-established signifiers or what Deleuze and Guattari would call "order words". These order words carry with them a "death sentence" or judgment which influences how we come to understand a given phenomenon. Even though these concepts are open to mutation, definitional change closely parallels the demands of the dominant society—for example, how we have come to think about what it means to have the diagnosis of autism has changed over time. Previously, autism was considered a "lifelong

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[13] Basaglia incorporated this idea as a main element in the destruction of the asylum. Individuals in the asylum were given jobs (i.e., working in the kitchen, gardening, cleaning etc) with fair wages for employed hospital patients that came to resemble the social reality of labor in Italy during that time.

developmental disorder" and carried with it ontological assumptions about the stability of the condition and the bleak future awaiting diagnosed individuals. Currently, dominant autism diagnosis is structured within a late stage capitalist framework as the "window of opportunity hypothesis" carries with it ideas about normalcy, the need for early intervention and ideological constructions surrounding childhood as a period of investment (Jacobson, Mulick & Green, 1998). The belief follows, that if we invest in intensive treatment early, children with autism will likely require less governmental supports and services in the future. Autism services are now portrayed through the profit and yield nexus, being seen as an investment to be made early that will be of extreme monetary savings in the future (Jacobson et al., 1998).

PDD and productivity. Basaglia's (1987) work led to the destruction of asylum and the reintegration of the mentally ill into society. Yet remnants of asylum are still evident through institutions, such as psychiatric wards in hospitals, out-patient care, and specialized schooling to name a few. Technologies used to remediate autism or help alleviate autism symptoms create a new type of productivity and efficiency. In our current society, psychologists and other licensed professionals have become social technicians deemed capable of classifying, categorizing and providing services to children with disabilities (including children with autism). Pathology is seen as something real that can be quantified, as it is determined by a person meeting a specific number of objective behaviour criteria (APA, 2000). The assumption follows that within the pathological category lies a variety of deviations. These identifiable differences in how individuals deviate from the norm, in turn, affect the services they receive. Entire professional industries then evolve as a means to provide specialized services to groups classified with different diagnoses, yet many individuals operating within the same diagnostic label are treated as one homogenous group.

To make this example even clearer, children identified on the autism spectrum can be labeled with Autistic Disorder, Aspergers, Pervasive Developmental Disorder-NOS, Retts Disorder, or Childhood Disintegrative Disorder. These labels are used to construct professional views, values and interpretations of particular groups of children. Information is then processed based on what deviations among these groups of children are similar. The distinction made between children with Autism and those with Retts Disorder has direct benefits for professionals, as they will base their entire professional practice around these constructions. In this instance, these labels serve as a social reality for the professional, as these constructions are used to guide knowledge, expertise and influence treatment decisions. Yet, for the client, these labels are of limited value and, more insidiously, may position the person as lesser, defective, deficient and lacking the moral and human character of the professionals doing the defining (Foucault, 1975).

This is a clear example of how primary deviance (i.e., deviation as a result of marginalization, social exclusion, segregation) is masked through the ideological development of secondary deviations (i.e., these people have a diagnosis of autism and need to be treated). In addition, individuals deemed unproductive are given a novel social role as capitalism begins to see these individuals as both consumers and commodities—seeking out vulnerable individuals and selling them the path to normality.

Through the political construction of "the other," specialized services particular to the individual enable entire professional industries to be created by targeting one group of individuals. Individuals labeled deviant, and their families, will seek out and invest in services with the long term outcomes in mind. These industries positively contribute to the overall economy by establishing entirely new professional fields. In turn, labeled individuals acquire a

new productive function in their society, being both consumers of the services and a product of the techniques utilized.

Science and Power: Producing Docility

In *Discipline and Punish* Foucault (1975) describes the panopticon (introduced in *Interlude 8, p. 58*): a type of prison building designed by Jeremy Bentham in 1871 to provide maximum surveillance and control within prison walls. The circular shape of the structure, locating security in the center, increased efficacy as it allowed the guards to view various rows of prison cells simultaneously. This "all seeing" space increased guard visibility enabling one guard to view a larger proportion of criminals concurrently. Furthermore, the security hub in the center was surrounded by high walls. This obscured the vantage point of its prisoners, preventing the disciplined individuals from determining at any given moment whether the guards were, in fact, present and monitoring their behaviour. This edifice allowed the power of the guards to be both visible and unverifiable. Visibility of the center tower served as a constant reminder to the prisoner that he was continuously being watched and disciplined accordingly. Yet, the architectural structure remained unverifiable, as the inmates could never be certain whether they were being watched at any given moment in time.

Foucault contends Bentham's panopticon is a diagram of power reduced to its ideal form. Its functional utility increases the number of people to be controlled and monitored and it simultaneously decreases the number of guards needed for the system to operate efficiently. As it induces a conscious state of permanent visibility it assures the automatic functioning of power, the subject being incessantly under the gaze of its dominants, leading him to monitor his behaviour accordingly.

I believe both Foucault and Basaglia would concur that our current western society is enclosed in a state of panopticism. Techniques used in our everyday institutions (i.e., schools, factories, hospitals) perceived to foster intellect, wealth and health, operate under dominant ideologies that guide our beliefs and behaviours. We are continually being told, explicitly and implicitly, what is considered normal, acceptable, and desirable and are disciplined when we do not act accordingly. Dominant practices encountered in our everyday social interactions, either directly (via direct experience) or indirectly (via media) are internalized and as a consequence individuals begin to discipline themselves and others. Explicit systems of control and domination become nested quietly into the woodwork and people begin to behave in ways which reproduce dominant modes of thinking. Through the internalization of society's gaze the individual learns to repress unacceptable behaviour and, in fact, subjugate themselves through vigilant self-monitoring. Thus rendering what Foucault refers to as docile bodies; the person's behaviour residing under the complete control of these systems of domination, leading the person to become passive, obedient and compliant.

How does this relate to Autism Discourse?

PDD as other. In *Madness and Civilization* Foucault contends that from the Classical period onward society became organized in such a way that the madman imagined himself in a world of judgment enveloped on all sides; as his behaviours were continually being watched, judged and condemned. Currently I would argue all of us living in Western society have in some way or another "internalized the gaze of society". Standardizations such as "what is normal" are developed by society and these standards are used to compare all individuals living in society irrespective of their histories, culture and/or personal experiences. These homogenized standardizations allow individual performance to be objectively measured in quantitative terms

and placed on a hierarchy, as certain behaviours are assigned values and not others. These "normalizing judgments" become the greatest instrument of power, and based on the organization of society certain behaviours are seen as acceptable/unacceptable, normal/abnormal and healthy/unhealthy. In this instance power is effective and relatively invisible, since behaviour is not regulated through overt repression but rather through a set of standards and values associated with normality. Entire professional fields are built on notions of the normal curve and those who fall outside the arbitrary numerical cutoff of normal are constructed as "other".

This idea of "otherness" is extremely evident in dominant ideologies within contemporary autism discourse. The cornerstone of empirically supported behavioural interventions used to treat people with PDD rest on the notion of what is considered acceptable and unacceptable behaviour. Guided by dominant societal constructions, the professional decides which autistic behaviours need to be modified by classifying certain behaviours as either productive or unproductive. To put this in even more concrete terms, one common characteristic of PDD is the person engages in restricted, repetitive and ritualistic behaviours, interests and activities, including behaviours such as hand-flapping, rocking, a consistent pre-occupation with parts of objects and/or inflexible adherence to routines and rituals (APA, 2000). These identified "autistic" behaviour patterns are constructed as maladaptive and unproductive by the professional, and techniques used to remediate the behaviour including differential reinforcement, extinction, and habit role reversal are used to decrease "unacceptable" behaviour and increase adaptive and socially acceptable behaviours (Miltenberger, 2005).

Examining behavioural interventions through the lens of power allows power differentials to become transparent. Basaglia might well maintain that once a person is labeled

autistic all information is interpreted through the lens of autism, leading irregular or unusual

behaviour patterns a person labeled with PDD displays to be seen as symptoms of the disorder to

be fixed and cured. These ideological constructions reduce inconsistencies in behavioural

variability and all people with PDD's behaviour become objectified through the label of autism.

This provides support for the argument that people with autism display irregular behaviour

patterns that are in need of remediation by a more "rational" other. Based on the professional's

own ideological constructions of the norm which are embedded in culture and personal

experience, it is the trainer who decides which behaviours are deviant and need to be modified.

This modification process does not allow any democratic participation on the part of the labeled

individual as power lies entirely in the hands of the professional doing the defining[14]. Danforth

(2000) asserts the moment a society begins to develop authoritative knowledge about a group of

people, a knowledge that is considered superior to the way studied individuals know and

describe themselves; truth and power become problematic acts of social power. Basaglia and

Foucault would contend that this form of disciplinary power "makes" individuals, as it produces

docile bodies to be closely monitored and made into productive citizens.

Ninth Interlude

It has been almost 14 years since I have apparently "recovered" from anorexia. Counter to professional expertise I have never experienced a relapse as I continue to maintain a healthy height weight ratio.

Yet, I can't help but wonder what it was about me that labeled me pathological. Was it the age of my first diet? Was it a result of being below the expected weight for my age and height? Was it the sudden change in my eating patterns and exercise routine?

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[14] It is important to clarify that both the person with autism and the professional are guided by dominant constructions surrounding pathology, abnormality and deviance. The professional is not the vis a vis of power but is one of its prime effects. The professional and the autistic are the effect of power and simultaneously to the extent the individual is affected by this power it becomes the element of articulation, thereby perpetuating power in a circular motion (Foucault, 1980).

Did I merely begin to "behave" in more anorexic ways………?

Statements including; "I think I'm fat", "I need to exercise", "Thin is beautiful" continue to haunt my consciousness. Have I merely learnt to monitor my desire for thinness in a more socially acceptable way? I no longer starve myself, I engage in healthy eating; I no longer excessively exercise, I exercise regularly to live a healthier lifestyle and reduce stress.

As anorexic behaviours become less excessive, and statements surrounding these behaviours are reframed in terms of "adopting a healthier lifestyle", instead of striving to fit the societal mold of "what is beautiful," I am no longer seen as having a mental disorder.

Yet societal expectations of what is constructed as beautiful continue to be ingrained in my consciousness.

It is interesting that thoughts are only labeled illogical, pathological and irrational when they transfer into overt behaviours. I no longer behave anorexic, therefore I am considered to have recovered from my eating disorder. It is only when thought processes transfer to overt behaviours that they become under the gaze of society, and hence subject to condemnation and judgment.

<p style="text-align:center">*   *   *</p>

Maurice (1993) acknowledges the ambiguity in distinctions between residual symptoms of autism and normal personality variations: "Negativity, timidness, aggression, forgetfulness, absentmindedness—it's very hard to refrain from over interpreting and jumping to desolate conclusions. Especially when each of these traits or tendencies can be seen as giving its roots in what were once the characteristics (and extreme) behaviours of autism" (p. 296)

Similarly it seems as soon as autistic behaviours become less excessive they are reconceptualized in terms of the child's personality. Extreme aloofness is reframed in terms of timidness, failure to respond to certain social expectations is reframed in terms of forgetfulness/absentmindedness; extreme aggression and inflexibility to changes in routine are reframed in terms of stubbornness.

It seems as soon as the behaviours no longer interferes with the productive rhythms of society, the behaviour is no longer constructed in terms of a mental illness, and is rather seen as a unique characteristic of the child's personality.

Expanding the Gaze: Prevention, Early detection and Remediation for Individuals Labeled "At-Risk"

Through the examination of a series of case studies on madness, Foucault demonstrates how madness has expanded well beyond the realm of overt behaviour, targeting individuals who are perceived to be, according to expert psychiatric opinion, "at-risk" of becoming mad.

Referring to a specific murder case in 1955 of a woman (L) and her lover (A) who murdered the woman's young daughter, Foucault (2003) seeks to show how the rise of psychiatric opinion in the courtroom allowed for the offense to be "doubled" with an entire series of conduct, that is directly unrelated to the act itself, but seen by the psychiatric professional to be the cause, origin, motivation and starting point of the offense. In reference to the 1955 case, Foucault (2003) seeks to show that even though A was not directly involved in the death of L's daughter he was seen by the courts to have influence over L to commit the murder. Therefore it is A, the societal outcast, who is incapable of appropriating the norms and expectations of society and highly capable of resorting to crime according to his history—and who, ultimately, is seen by the courts to have indirectly caused the murder of L's daughter and is thereby condemned by the courts.

Foucault (2003) uses the term "psychologico-ethical double" (p. 16) to describe the final sentence of the case, which targets and condemns A's irregular conduct as the origin and cause of the crime. Thus, through various case studies Foucault (2003) illustrates how from 1850 onward psychiatry no longer needed direct acts of madness (i.e., dementia, delirium, mania, etc.) to evaluate and treat its citizens, as from this point on every behaviour a person exhibited could be under the "gaze" of the psychiatric professional.

The examination and surveillance by the psychiatrist of certain behaviours a person displays has further extended to the realm of biology. Now, in addition to evaluating one's history and previous forms of conduct, the psychiatrist makes attempts to study the biological basis of behaviour and tries to find the psychology there. Or more often psychiatrists attempt to patch together what is known about biology with some data on social influence and envision the psychology to lie somewhere in the middle, thus constituting the bio-psycho-social model (Parker, 2007). With psychiatric opinion now rooted in organic and functional medicine, Foucault (2003) argues that psychiatry is further able to exploit the norm, establishing its natural regularity as a principle of appropriate psychological adjustment.

The medicalization of the abnormal (grounded in biology) Foucault (2003) argues establishes a type of racism different from ethnic racism, a racism against the "abnormal"—against those who are carriers of specific conditions and who may randomly transmit to their ancestors their non-normality. It is this internal racism occurring within groups which permits the screening of all individuals in society.

Interlude 10

Linking back to my personal anxiety surrounding internal-external binaries (refer to p. 70 for details), pathology seems to no longer be defined the moment our thought processes transfer to overt behaviour, but can now be determined well before the occurrence of any overt manifestation of abnormality takes place. More specifically, the normalizing industry is now focused on prevention, as the rise in early detection and intervention is heavily based on neurology. The belief follows that behind each and every disorder lies a distinct neurological pathway, and that by uncovering the underlying neuro and genetic network, one will be better able to predict which individuals are "at-risk" of developing specific disorders.

Emerging technologies such as PGD (Pre-implementation Genetic Diagnosis) which detect chromosomal and genetic mutations in the early stages of embryonic development, allow parents to be informed of whether or not their child will develop conditions such as Downs syndrome, Fragile X, Cystic Fibrosis, etc. These technologies have influenced approximately 90% of families who are told their child will likely have a diagnosis of Down syndrome to terminate

their pregnancy (Harmon, 2007). Parents are bombarded with scientific research, which speculates their child with Down syndrome will likely have a mild to moderate intellectual impairment, be at-risk for congenital heart defects as well as other medical problems and will likely have a life expectancy of around 49.

Counter to scientific research, advocates of families of children with Down syndrome argue the richness of their children's lives are poorly understood by the medical profession, and families need to understand the richness of these children's existence and the joy they bring to their families' everyday lives, prior to deciding to end their pregnancy (Harmon, 2007). Some of these advocates see these emerging preventative technologies (such as PGD) as a form of eugenics that essentially eliminates differences.

Considering PGD has identified the genetic mutation involved in Fragile X and seeing that Fragile X is often co-morbid with autism, it is only a matter of time before medical professionals are able to identify the gene(s) that causes autism.

Yet, what does this mean for individuals and families who do not see autism as a "disorder" but rather view autism to be a different way of being and interacting in the world? Will the elimination of autism, Down syndrome and various other disorders, serve to improve the conditions of society? Or will it merely lead us to be even less accepting of differences?

Klar-Wolfond (2006, ¶5) contends "we always have to ask ourselves what is the end to this means of genetic research. Must we simply accept the good with the bad in the name of progress?" Early detection and prevention with the intention of eliminating differences is highly problematic. Ethical and moral issues surrounding preventative technologies such as PGD need to be dialectically discussed and the ideologies surrounding these technologies need to be further interrogated.

Organizations that seek to fund autism as a difficult and mysterious disorder in order to cure it are at war against the autism population not with them. As Klar-Wolfond (2006) maintains genetic research will go on with or without our support, as there are always people who will find the genes, sell the pills and abort the fetuses; the only thing we can do is keep talking and giving speeches, keep making exhibitions and running media campaigns in order to raise society's consciousness about these fundamental issues.

Chapter 9: The Problem with Dominant Language

"When reason begins to judge madness, the distance between reason and unreason is already fixed: it is the distance created between the subject of judgment and the object that is judged" (Scheper Hughes & Lovell, 1987, p. 235).

The Enlightenment ideal portrays the human as a rational, coherent, unified and stable

system. Humanism posits the subject is able to accurately reflect him/her self through the

transparent medium of language. Yet, as Deleuze and Guattari (1987) point out, dominant language systems are pre-established structures of society, both preceding and exceeding the individual. In other words, in order for one to adequately express oneself in comprehensible terms one must already use existing linguistic codes developed by the local culture. A signifier therefore only becomes meaningful once we, as a collective decide it means something. Prior to collective agreement, the spoken is merely a collection of meaningless, senseless sounds. Mutual understanding is therefore based on this order and premised on our collective recycling of words and phrases in various combinations (Skott-Myhre, 2007). It is through this repetition that certain words and phrases are appropriated by the majority and become meaningful to the rest of society.

Foucault, Basaglia and Deleuze and Guattari speak to the problematic nature of language which privileges certain pre-established language codes over others, immobilizing subordinate languages to never be assimilated into our rational way of understanding and interpreting the world. Basaglia points out that even peculiar and incoherent speech (according to the dominant culture) may be a voice of protest and possibly the only mode of resistance available to those who are continuously silenced, disgraced and excluded. He points out the illogical nature of this rational way of thinking: if delusional speech is madness' subjective expression of its own needs and desires, which can only be expressed through irrationality and unreason, it will never be able to become the voice of rationality and power.

The Question of Individual Voice

To further elaborate on notions surrounding language as a social construction, critical feminist theorists such as Spivak (2006) and Lorde (2001) argue that the capacity of the subaltern to speak—as an act which conveys meaning and generates mutual understanding—is

impossible since one cannot stand outside the dominant regimes of meaning making. Meaning in this sense relies on acts of translation and agreement between the subaltern and the dominant group. Pre-established linguistic codes privilege certain forms of speech over others, leading groups to abandon their subordinate language codes in order to gain access to privilege associated with the dominant group. Privileging certain language systems over others forces all knowledge to be filtered through the dominant framework—if it is to have any legitimate meaning (Skott-Myhre, 2007). In this context individual voice does not exist as one is born into a pre-establish language system that labels which language codes are deemed superior to others. If one is to effectively assimilate into the predominant culture they are forced to appropriate these dominant language codes.

Lorde (1984) further illustrates this in her essay, "The master's tools will never dismantle the master's house," when she argues that using the theories and language of the dominant society may allow for temporary change in a society—yet it will never be able to bring about genuine social change. She argues the subordinate must find his/her own mode of expression outside these dominant realms.

How does this relate to Autism Discourse?

One of the three key characteristics of children with PDD is they commonly display qualitative impairments in communication which may include a delay or lack of spoken language, problems initiating and sustaining information, and/or stereotyped, repetitive and idiosyncratic language patterns (APA, 2000). With this in mind, the social service industry has designed and at times successfully implemented various treatment modalities used to foster language and communication with this group of individuals. These include techniques such as Picture Exchange Communication Systems (PECS), facilitated communication, augmentative

communication systems and sign language. At first glance these interventions appear to be

achieving their pragmatic objectives helping people with autism express themselves in ways "the

normal" can understand. Yet, Foucault, Basaglia, Deleuze and Guattari would likely be skeptical

of these techniques, investigating the underlying function techniques (such as the ones

mentioned above) serve in relation to the larger society.

They would likely conclude that dominant techniques used to produce speech are guided

by the dominant beliefs and ideologies surrounding what is considered appropriate speech. These

techniques not only perpetuate current stereotypes, justifying the exclusion of those who do not

or can not adequately partake in this linguistic exchange of information, but may actually silence

autism's unique voice and mode of expression. Standardized tools used to foster communication

are designed with a set of guidelines in mind including what is considered acceptable and

unacceptable speech and communication patterns. Subjects are disciplined accordingly and

thereby silenced if they do not conform to these dominant speech modes. Thus, people with PDD

lose their ability to determine their own modes of speech and expression as they are forced to

assimilate into the dominant speech regimes in order for their voice to be heard and taken

seriously.

Chapter 10: Insurrection of Subjugated Knowledges

Foucault (1980) suggests over the past several decades an increasing vulnerability to the

criticism of things, institutional practices and dominant discourses has occurred. This increasing

criticism of totalitarian theories which guide our thinking has produced a new kind of reality

which he refers to as a "return to knowledge": where theoretical production is autonomous and

non-centralized and the validity of knowledge is not-reliant on the approval of pre-established

regimes of thought (Foucault, 1980, p. 81). When Foucault speaks of this sensitivity to the

criticism of things, he is referring to alternative discourses (i.e., postmodernism, critical theory, post-colonialism, post-structuralism, etc.) which have emerged over the last several decades that unpack ideas surrounding what can and should be considered acceptable knowledge. Gaining an increasing amount of attention in the academic field, it is these alternative ways of knowing, which were once nested quietly in the woodwork that are being brought forth, establishing legitimacy, and raising fundamental questions about the nature of knowledge.

Foucault (1976) contends it is this increasing criticism towards the production of knowledge that has allowed for the "insurrection of subjugated knowledges" (p. 81). When Foucault speaks of insurrection of knowledge he is referring to two central ideas. First, he is referring to historical contents that have been buried and concealed by functionalist systems of thought and production. For example, anxieties surrounding behaviour interventions are often glossed over with terms such as "effective", "empirically validated" and "scientifically supported". These terms are used to justify these technique and procedures according to what works and what does not, yet these terms unreflectively accept the theoretical foundations behaviour interventions are grounded in. Thus, issues related to power, progress, reality, language, etc. are left seemingly unquestioned. Foucault believes it is these emerging histories (e.g. anxieties surrounding behaviour interventions) that have continually been silenced throughout the past (due to the rise in scientism), that will allow us to re-examine the ruptural effects of conflict and struggle encountered by the current organization of society.

Second, when Foucault speaks of insurrection of knowledge he is referring to an entire set of knowledges that have been deemed irrelevant or largely ignored by society. These naïve knowledges have been located at the bottom of the hierarchy, buried beneath cognition and science. For example, Foucault would argue that it is the knowledges of people of subordinate

statuses (e.g., people with autism) who are commonly constructed as irrational and illogical according to science that we need to focus our attention on. In line with this, Foucault argues it is only by unveiling these disqualified knowledges that are local and particular, that current Truths structuring society can be adequately assessed and evaluated.

From the theoretical perspective of Deleuze and Guattari (1987) the primary role of Foucault's insurrection of subjugated knowledges is to "make the major language stammer" (p. 110). Buried within what is currently constructed as the "Truth" (i.e., order words) remain knowledges that have been largely ignored and discredited. It is these subjugated knoweldges that will allow us to escape the standard models of truth, knowledge, language and individualism, transforming these concepts into rites of passage.

With this in mind, the following chapter will discuss an alternative PDD discourse that is predominately directed by individuals who have been labeled on the autism spectrum. This emerging discourse, which still predominately falls under modernist constructions of the subject and notions surrounding language and objectivity, attempts to make "the major language minor", by opposing many of the dominant autism regimes of thought, specifically related autism as a neurological disorder that is in need of early intensive intervention.

Interlude 11

Recently, I was asked to co-present a paper for the Autism Society of Niagara, reviewing anxiety treatments for people on the Autism Spectrum. Following the presentation a number of parents came up to inquire about their children and seek advice on current treatment recommendations for the dually diagnosed.

Coincidentally, the conversation led to heated discussion about a recent article in the National Post which discussed a group of people labeled with high functioning autism (HFA) who were opposing notions associated with medical model perspectives in which autism is portrayed as a disease in need of a cure. The parent with whom I was having the conversation became visibly upset during the discussion. She explained that without the label, her low

functioning son would be left without the necessary services and supports needed for him to operate and function successfully in school, and in society at large. She went on to argue that autistics who opposed the label and who were critical of the need for empirically validated treatments were, in fact, narrow minded as they were not taking into account people on the lower end of the spectrum. She went on to hypothesize that even though people with HFA and Aspergers may have typical language and communication patterns, they often lack "a theory of mind"; meaning they typically display the inability to describe the mental activities of others, including understanding another's thoughts, feelings, beliefs and desires. The conversation ended with her suggesting these emerging autistic voices should not be taken seriously, as these individuals lack empathy and concern for all people on the spectrum, and are therefore not representative of her son's diagnosis or his life experiences.

Empathizing with the concerns of this parent, I could relate to her intense feelings about services and supports being taken away from her son. I questioned whether HFA could, in fact, speak on behalf of LFA (low functioning autistics), and what the repercussions of a movement such as this would mean to families of children with autism who already lack funding, support and resources. Then it dawned on me. Regardless of whether HFA can represent the extreme variability on the spectrum, these individuals have something important to say about their personal experiences with the autism label. Although this may be inconsistent with our current thinking about autism, disregarding these statements, by seeking to pathologize them—"HFA lack empathy therefore their voice should not be heard or taken seriously"—can be seen to perform the same function as taking away services for children on the lower end of the spectrum, as they both silence autism's voice. Furthermore, if HFA cannot speak on behalf of LFA, then who gives us the right to speak on behalf of children with autism? Although HFA have language and communication, they still experience the stigma of the autism label, something that we, the typical population, cannot personally relate to. Dividing people into binaries categories of normal-abnormal, Low Functioning Autism-High Functioning Autism, Autistic Disorder-Aspergers Syndrome is not productive, and separates our commonalities and our desire to support those who are continually stigmatized, labeled and excluded.

Chapter 11: Autism Voices

"Autism isn't a disease, it's a different way of being human"

At the forefront of this new autism movement (to which I refer to as an emerging autism discourse) are people with HFA and Aspergers (Aspies), including Michelle Dawson (2003a, 2003b, 2004a, 2004b, 2005, 2007) John Sinclair (1993), Dave Spicer (2005, 2006, 2007), Amanda Baggs (2007), Donna Williams (1993) and Temple Grandin (2005), to name a few. Evocative web sites are being created at a high frequency and are run by people with autism and parents of children with autism, who are resisting our current way of understanding autism.

These include: Autism Diva, The Joy of Autism, Autism Hub, The Real Voice of Autism, Abnormal Diversity, Aspies for Freedom, Autism Network International and the Neurodiversity Movement.

One of the most interesting collaborative projects is occurring at the University of Montreal. Dr. Laurent Mottron, a renowned autism researcher and distinguished professor of psychiatry, is working with Michelle Dawson, a person with autism who is a human rights advocate. Using the scientific method to oppose dominant autism theories, Mottron and Dawson seek to alter society's current perceptions of autism. Dawson's main role is to critique the studies' design and form conclusions, contributing to 20% of the final published research papers. Although Dawson does not have a formal post-secondary diploma, Mottron states Dawson continuously challenges his assumptions of autism, and her work has been extremely influential and inspiring, changing the way the world views autism that will have long-lasting impacts on society (Toronto Globe & Mail, 2006).

Truths within Autism Discourse Revisited

1. PDD is considered a mental disorder; a deviation from what is considered normal. Diagnosis is premised on the person meeting a specific number of behavioural criteria found in the DSM-IV.

Parents, professionals and people labeled PDD who are operating within this emerging autism discourse argue the medical model perspective of autism is inadequate, incomplete and based on the faulty premise that autism is a disease. They argue that using the DSM-IV to diagnose people with autism forces all behaviour to be interpreted through a pathogenic lens. "I need to be told that all the work I do will be completely compromised by my diagnosis. My work will only be used to verify my symptoms. Then it will be dismissed" (Dawson, 2004a, ¶13).

As well, they argue using a medical perspective to understand autism provides an incomplete description, one which fails to acknowledge people with autism's own personal experiences with the disorder." I think living with autism for 41 years is a pretty good degree." (Anonymous Person with Autism, Teaching versus Remediation Discussion, 2007, ¶75).

Furthermore, adopting a medical perspective also fails to consider how the current organization of society contributes to definitions of deviance.

> People with autistic spectrum disorders are not victims of autism, they are victims of society. They do not suffer from their developmental differences, they suffer from prejudice, ignorance, lack of understanding, exploitation, verbal abuse, all this and more from that sector of society which considers itself socially able. (Hewson, 2001, ¶1)

These individuals state that operating under the assumption that PDD is a deviation from what is considered normal forces autism to be filtered through the lens of negativity. Rather than focusing on deficits, many people within this emerging discourse suggest the need for empirical research to focus on autism's strengths.

> For some reason once you get a label, you know the strengths, but it's like everything is measured. They focus on your weakness and they become the thing that you have to get stronger and they completely ignore the strengths, and they fail to realize that again if you apply the very same principle you use throughout society, of supporting the weaknesses, enhancing, developing and employing the strengths, you may actually get somewhere (Tisoncik, 2006).

"Whether autism or Asperger's, I'm among some of the best and most fascinating human beings who ever existed. I have a lot to live up to and this I need to be told" (Dawson, 2004a, ¶12). Furthermore, these people articulate the inherent problems with differential diagnosis. Categorizing people into high and low functioning, Autistic Disorder versus Aspergers does not seem to be of any additional value for these individuals.

> Autism versus Asperger's is not a value judgment or a contest. It is not better/worse or us/them. And if my diagnosis is Asperger's or if it isn't, I need to be told that Asperger's is not and has never been a "mild" form of autism (Dawson, 2004a, ¶10).

"It is my profound opinion that those who desire to divide us into high and low functioning autistics deliver a great disservice to our common quest for true equality" (Spicer, 2007, ¶13). Dave Spicer argues a person with high functioning autism or Aspergers should not be considered to have "just a touch of autism." (Spicer, 2006). He points out the illogicality of this statement, arguing it is like saying someone from Russia who speaks English so fluently that there is no trace of an accent, is not Russian. Making a statement such as this would be nonsensical and would deprive the individual of his Russian heritage and thus, cultural identity. Yet, individuals with autism who attain normal functioning are seen as being miraculously cured of autism. For Spicer, just because a person is able to behave in normal and acceptable ways does not mean he/she is no longer autistic, since one cannot separate the autism from the individual, as it is an inherent part of one's identity.

Based on the voices within this emergent autism discourse empirical researchers are beginning to take some of these claims seriously. Specifically, Morton Ann Gernsbacher, who is considered one of the leading experimental psychologists in the United States, and Thomas Zeffiro (MD/PhD), director of the Center for Functional and Molecular Imaging in Georgetown University Medical Center, suggest the need to radically reorient the scientific study of autism, arguing autism should not be viewed as a disease but rather should be seen from the same perspective as those with other neurological and sensory deficits, such as the visual and/or hearing impaired. They propose to look at autism through a multi-disciplinary perspective bringing together leading scholars from a variety of different fields, such as cognitive science, medicine, engineering, and public policy. The ultimate goal of this innovative research project will be to understand autism as a neurological *difference* and to empirically identify the strengths

and competencies this group demonstrates, to determine how people with autism can live successfully (Dawson, 2007).

2. PDD is most commonly seen as a neurological deficit that has a genetic and biological basis.

> Neurotypical disorder (NT) is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Tragically, as many as 9625 out of every 10,000 individuals may be neurotypical…There is no known cure for neurotypical Syndrome (Institute for the Study of the Neurologically Typical 1998-1999, ¶1).

The above statement is taken from a website developed by people on the autism spectrum. It attempts to provide a humorous account of the belief that autism is a disease by seeking to establish the argument as irrational. Although most professionals, parents and people with PDD alike, would agree that individuals with autism display differences in neurological patterning when compared to their non-PDD counterparts, what many individuals are challenging is how these differences are portrayed. The neurodiversity movement argues establishing hierarchies of neurological patterning is useless, if one considers autism as merely a different way of being human. For example, one does not say a dog is ill or dumb because it is unable to climb a tree, as this would only be the case if you were basing the dog's capacities on that of a cat's, which would be extremely illogical and based on false premises (Woodford, 2006a, ¶15). This characterization is not to say people with autism are not human or less than human when compared to neurotypicals, but rather it is to say that humanity is composed of heterogeneity, and we should be embracing these differences rather than attempting to eradicate them. "Autistics have different brain— the cells are different, the cell organization is different and for certain tasks in the brain is different" (Woodford, 2006a, ¶17).

> Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence.

It is not possible to separate the autism from the person—and if it were possible, the person you'd have left would not be the same person you started with (Sinclair, 1993, ¶5)

Many people with autism can learn to act normal. The issue is that on the inside they do not feel normal. We process information differently and that is not something anyone can see on the outside it is the hidden side of autism (Anonymous Person with Autism, Teaching versus Remediation Discussion, 2007, ¶55)

3. Diagnosis of *PDD is currently on the rise. Prevalence rates are increasing at a greater than expected frequency.*

Media attention directed at autism surrounds arguments questioning whether autism is, in fact, an epidemic. Most professionals and researchers contend that autism is not an epidemic, as there is no strong candidate for any environmental exposure associated with autism (Fombonne, 2003). Although a secular increase in autism cannot be ruled out, elevated diagnosis can be attributed to methodological factors (i.e., broadened diagnostic descriptions, more reliable and valid assessment instruments, etc.). Individuals operating within this critical emergent paradigm argue there is no mysterious, underlying cause for autism; rather where the real mystification lies is why individuals with autism are not seen as human beings and why they are left without individual rights (Dawson, 2003a, ¶18). Dawson (2003b) argues the artificial increase in autism "is artefactual, cultural and sensationalist, and has nothing to do with science, medicine, or the ethical practice of medicine" (sic, ¶29). She speculates the false epidemic has gotten autism a lot of attention, not to mention autism researchers a substantial increase in funding (Fombonne, 2003).

   a) *Sub-truth: 50-70% of people on the PDD also have an intellectual impairment (Yeargin-Allsopp et al., 2003).*

Interestingly, the idea that autism is frequently co-morbid with an intellectual impairment has been put into question by Dawson et al., (2005). They argue that tests used to assess

intellect are normalcentric, as they are based on the norms of typical populations and not the

norms for people with autism. The results of their study revealed people on the PDD

spectrum scored higher on the Raven's Progressive Matrices (RPM), a measure of fluid

intelligence requiring abstract problem solving analysis when compared to the Wechsler

scales (WISC-III, WAIS-III). The opposite was true for people from the typical population;

they scored higher on the Wechsler scales than on the RPM. Furthermore, a detailed case

study of a 15 year old male who was considered non-verbal, having a near floor score (.01

percentile) on the Wechsler FSIQ, was combined with a near ceiling score on the RPM (95th

percentile). The authors speculate autistic intelligence should be considered different from

non-autistic intelligence, and thereby should be measured in terms of autism norms and not

the norms of typical populations.

Interlude 12

As mentioned above, Audrey Lorde (1984) argues the master's tools can never be used to dismantle the master's house, contending that using the theories and language of the dominant society may allow for temporary change within that society but it will never be able to bring about genuine social change. For Lorde and others being critical of this emergent autism discourse would likely acknowledge the flawed nature of this movement, as it maintains dichotomies (i.e., strengths/weaknesses, good/bad, normal/abnormal), adopts the scientific method to" prove" people with autism's competencies (i.e., Gernsbackner and Zeffiro research) and relies heavily on language to illustrate the problematic nature of language (i.e., Amanda Baggs).

Yet to believe we can fully position ourselves outside the many discourses, both presently and historically, that cloud our judgments and interpretations of the world is to believe that we, as individuals, supersede the societal structures we are currently operating within. Throughout this paper I have attempted to interrogate current beliefs and assumptions surrounding myself and how this relates to people with a diagnosis of autism. In doing so, I have tried to challenged y current representations of the world. However, I recognize this process as tenuous and partial, and acknowledge that in many points throughout the process I have failed, perpetuating the current structures, assumptions, beliefs and stereotypes that I wish to abolish.

If there is one objective I wish to achieve by writing this thesis, it is the importance of developing a critical consciousness. This goes well beyond fulfilling certain ethical obligations, as it

involves continuously questioning the epistemological and ontological foundations that colour every belief, value, attitude and experience. What I have come to realize through this process is that rather than pretend inconsistencies do not exist, we need to identify these contradictions in our thought processes and through the continuous process of deterritorlialization and reterritorialization (Deleuze & Guattari, 1987), deconstruction and reconstruction (Derrida as cited in Stocker, 2006), question every taken-for-granted truth encumbering our lived experiences.

4. PDD is in need of remediation. Currently, empirical evidence suggests Early Intensive Behavioural Intervention (EIBI) is the most successful approach to reducing autism symptomatology.

Recent empirical research evaluating IBI is unable to replicate Lovaas' (1987) outstanding IBI treatment outcome, where 47% of the children in the intensive behavioural treatment group attained normal functioning (i.e., normal IQ, integrated into regular school system, indistinguishable from peers) (Anderson et al., 1987; Birnbrauer & Leach, 1993; Boyd & Corley, 2001; Howard et al., 2005; Ozonoff & Cathcart, 1998; Sallows & Graupner, 2005; Sheinkopf and Siegal, 1998; Smith et al., 2000).

A variety of reasons why current empirical research has been unable to replicate the Lovaas (1987) results have been put forth. These include treatment intensity (Anderson et al., 1987; Eikeseth et al., 2002; Smith et al., 1997), the chronological and mental age of the children at the time of treatment entry (Anderson et al., 1987), the length of the intervention (Anderson et al., 1987, Eikeseth et al., 2002) and methodological flaws in design (lack of random assignment, instrumentation, statistical regression) (Gresham & Macmillian, 1997; Smith et al., 1997). Furthermore, Lovaas' (1987) additional control procedure in this study provides another explanation as to why this may be the case. In order to ensure at least one component of the treatment was successful, he systematically withheld contingent aversives (a loud "no" and occasional slap to the thigh), gradually introducing this component experimentally to 4 children

in both the treatment and control group one. Lovaas (1987) found that when contingent aversives were systematically withheld a limited amount of positive behaviour change occurred. Gradual introductions to contingent aversives resulted in rapid and stable changes in positive behaviours, including reductions in inappropriate behaviours and increases in adaptive behaviours. Lovaas (1987) speculates that "it is therefore unlikely that treatment effects could be replicated without this component (contingent aversives)" (p. 8). This speculation has been supported by additional authors (Anderson et al., 1987; Gresham & Macmillian, 1997; Smith et al., 1997)

Due to ethical issues attached to the use of punishment as an appropriate procedure, few if any behaviour treatments targeting children with autism still utilize these procedures. However, concerns still exist about the ethics of using principles of applied behaviour analysis to modify certain behaviours.

In Michelle Dawson's (2004b) paper, entitled *The Misbehaviour of Behaviourists*, she questions the ethical and human rights aspects of the autism-ABA discourse. Relating ABA to power differentials, she argues autistic human rights are being violated every time power is used to substitute odd but necessary behaviours to autistics (e.g., rocking, hand flapping, analytical rather than social or imaginative play) with behaviours that are normal and socially expected (eye contact, appropriate gaze, joint attention) but considered useless to the autistic.

Dawson (2004b) argues that in an area where clients are unable to verbally consent to treatment, ethical considerations surrounding who decides what behaviours to modify are vital to autism-ABA discussion. Rekers and Lovaas' (1974) study, which used principles of reinforcement to modify a 5 year old boy's cross gendered behaviour, was one of the first to raise the fundamental question: "to whom does the therapist owe first allegiance: to the client (or in this case the client's parents), to the therapist's own values, or to the prevailing relevant social

norms?" (Winkler, 1977, p. 549). Undesirable feminine behaviours (i.e., dressing in women's clothing, playing with dolls, feminine gestures) were extinguished and replaced with desirable masculine behaviours (e.g., dressing in a football helmet, playing with a dart gun, toy soldiers, dump truck etc.). Winkler (1977) argues adopting typical sex role behaviours are not necessarily needed for optimal development, alluding to the conflict between a desire to respond to parent concerns and a desire to create normal psychological adjustment. He posits that in the end the therapist has to make a value judgment which ideally is based on full knowledge of applicable and accessible information. Value judgments regarding what should be considered normative and appropriate behaviour and what is deviant and unacceptable behaviour, and according to whose standards, are still pressing issues within autism treatment today. Dawson (2004b) concludes that without addressing ethical issues related to treatment one cannot evaluate what recovery means and how it might manifest itself. Phrases like "scientifically proven" and "medically necessary" encompass assumptions that scientific and medical ethics have been already considered, yet Dawson (2004b) argues these issues have remained relatively untouched, unexamined and unchallenged by professionals. Additionally, people labeled autistic relay similar concerns:

> It's like they thieved this chunk of human life and ripped off all the context of the relationship between the rewarder and rewardee, punisher and punished, and deny the rewarder/punisher could be flat out wrong in what they are choosing to notice, choosing to judge as good or bad, and choosing to reward or punish. There's an assumption that the ABA types are inherently going to do the right thing. (Camille, Teaching versus Remediation Discussion, 2007, ¶2).

Furthermore, many individuals labeled autistic within this emerging discourse argue it is absolutely outlandish to suggest exposure to intensive behavioural interventions can miraculously cure an individual from autism. They argue autism cannot be considered a distinct entity, as it is inextricably linked to the person and his/her identity. Even when treatment is successful and autistics begin to behave in normal and acceptable ways, many state that inside

they feel different. "I will never be non autistic but I am growing and learning more every day...trying to get a disabled person to "act" normal may be the biggest mistake being made within all systems" (Anonymous Person with Autism, Teaching versus Remediation Discussion, 2007, ¶73).

> Even the idea that autism is separate from the child's being and experience, is to suggest that autistics should not be taught the way other children are taught. It doesn't respect the disability and does not ask us to question ourselves or make a better effort to learning about autism and how to best teach out autistic children or accommodate their learning style (Klar-Wolfond, Teaching vs. Remediation Discussion, 2007, ¶12).

Furthermore, attempting to act normally may actually impede the individual from knowing their "true" self. Donna Williams (1993) expresses this notion of "losing oneself" in the book *Nobody Nowhere*. She describes two personalities materializing in the search for acceptance and control: Carol, who strived for the unacceptable, social acceptance— "I learned to talk at people...I had become good at being told what to do, as this was what people liked and people liked Carol (p. 21); and Willie, her second "face" who confronted the world with resentment and self-control, detaching himself from the world around him. These emergent personalities permitted Donna to "hide in the cupboard" (p.20), and in the process of hiding her true self she lost her ability to feel: "I like so many disturbed people, began to hurt myself in order to feel something. It seemed that others people's normality was the road to my insanity. My ability to close them out kept me sane" (p. 56).

Interlude 13

It dawned on me yesterday right before I went on stage to present a paper at the Mapping The New Knowledges conference. As my anxieties were obviously elevated, a friend, in an attempt to give comfort, turned to me and said "Don't worry Sarah, you will do great, look how smart you look today!" Being in a business suit, impersonating the role of a professional, academic and researcher, I wondered if this was, in fact, how people with autism feel when they are trained to modify their behaviour in order to be accepted by the rest of society.

The role of the academic is one of status (hence the business suit), is one of expertise (hence the academic language), and is one of intellect (hence the highly theoretical piece I was presenting). In order to portray these qualities, I had to inhibit my susceptibility to speak without thinking, my awkward and sometimes clumsy mannerisms, my emotions, and my intense fear of being judged and criticized. Any slight sign of any of these devalued qualities will ultimately reveal myself as a fraud in the academy, leading my work to be viewed as insignificant, meaningless or useless knowledge that is not to be taken seriously. Hiding certain personas to fulfill certain obligations and social roles inhibits me from truly feeling comfortable and accepted in the academic profession.

Similarly, people with autism are able to fulfill certain obligations and social roles, leading many to conclude they are no longer autistic. Yet, this may, in fact, prevent this group from ever feeling truly comfortable living in society. As Amanda Baggs points out "we live in a world where how close to normal you appear determines your sense of self-worth". Any slight sign of abnormality is portrayed as a weakness, a devalued quality that is a "residual" symptom of the disorder. Leading us (myself and likely others, possibly including people with autism as well) to live in constant fear that one day their devalued qualities will surface at an inappropriate time and their entire sense of personhood will be thrown into question.

<p style="text-align:center">*   *   *</p>

Autism labels are based on a person meeting a specific number of behavioural criteria. Thought processes cannot be measured until they are verbalized and are thereby left out of the diagnostic equation. Unlike me, someone who is sensitive to the social expectations placed upon me, is it possible that children with autism are merely worse at internalizing the gaze of society? In other words are children with autism less sensitive to the predominant norms and social expectations of how to act?

Quite possibly when children with autism act (i.e., by engaging in inappropriate, odd, irregular behaviour) they are behaving "freely"; acting free of undue external influence.

Could we possibly be making these individuals docile by placing constraints on their ability to act? Dismissing these behaviours as unproductive and inappropriate rather than acts of free will?

Although the above arguments offer a critical framework to examine behavioural interventions, I would argue this emergent discourse is not anti-ABA, as some would argue (Weintraub, n/d), yet much of the discussions surrounding ABA/IBI highlight the need for self-reflectivity. Rather than focusing on the grand meta-narratives of autism treatment (i.e., what treatment is successful for most people with autism), many autism advocates specify the need to be attuned to the heterogeneity of each and every individual with an autism diagnosis. Some urge

us to inquire about our own motives and drives for making certain demands on autistics,

continuously questioning why we feel compelled to help modify certain behaviours (Klar-

Wolfond, Teaching vs. Remediation Discussion, 2007). Others focus on the problematic nature

associated with using a limited and rigid framework when working with autistics. Autistics may

communicate in a multitude of ways and focusing on only one medium of communication may

hinder one's ability to observe and respond to alternative means of communication.

> "I see these children with more severe autism communicating in many different
> ways. I don't think "neurotypicals" can see it. I don't mean to be rude but I really think
> they miss out on seeing what these children are expressing. Maybe it is because of my
> own autism and I see it from a different angle than someone without autism. They would
> never listen to me because they have a degree etc." (Anonymous Person with Autism,
> Teaching versus Remediation Discussion, 2007, ¶74)

> "I am not saying that I know much about parenting but I do know something about
> parenting my son, Adam. I am suggesting that we can all do our part to really observe
> behaviours and ask ourselves whose purpose we are serving when we are making certain
> demands" (Klar-Wolfond, Teaching versus Remediation Discussion, 2007,¶9).

Interlude 14

I have never felt truly comfortable implementing behaviour principles. For myself, reducing the human condition to a set of stimulus and response conditions did not seem to capture the essence of humanity. With a specific set of objectives in mind, procedures used by the behaviour modifier appear to be forced, deliberate, repetitive, and to lack the spontaneity of typical everyday social interaction.

Despite the above anxieties, I cannot disregard the positive impact Skinnerian principles have had on the disability population. Throughout the past 50 years, the scientific validation of behaviour principles has led society to conclude that these techniques are, in fact, effective at "training the untrainable" (Kleinert, 1997); and it is these findings about the malleability of the human brain that have further supported professionals, parents and people with disabilities in their quest to access services.

Yet, this positive ideological shift in the way individuals with disabilities are viewed has also brought about a variety of "side effects". First, it places constraints on what types of services are available to certain groups of individuals. Behaviour interventions offer a large body of empirical support for its effectiveness, leading provinces such as Ontario to only provide EIBI funding for families of children with autism. This deprives parents of the choice of selecting alternatives therapies for their child. Furthermore, the rise in behaviourism for teaching, helping

and in some cases "curing" individuals with disabilities, has led some professionals and service providers to narrow their focus—using solely behaviour principles to treat individuals.

Currently, entire professional industries are dedicated to certifying specific professionals in the field of behaviour analysis (Board Certified Behaviour Analyst, 1998-2007). With only a limited ideological framework to operate within, these individuals are given training on how to effectively implement behaviour principles, but in turn, are left without a critical framework to investigate the function of these techniques, or an alternative framework to explore other possible ways of interacting with this group of people. Even Lovaas et al., (1980), the master himself, recognized the limitations of the behavioural approach: "keep in mind that just as a physicist needs to know more than the laws of gravity to transport a person to the moon, you need to know more than the laws of operant behaviour to move a person to more adequate functioning" (p. 3).

<div align="center">*   *   *</div>

If we were to view therapy from the traditional health perspective of providing remediation to specific health problems following a diagnosis, then in some regard behaviour therapy appears to be achieving its objectives. But, as I have noted in my previous writing, to change the behaviours associated with the illness does not necessarily mean the feelings/internal workings associated with the illness also dissipate (refer to p. 71).

Empirical research has displayed behavioural techniques to be extremely successful at reducing self-injurious behaviours (Iwata et al., 1994), and using operant conditioning to reduce extreme aggression towards self and other prohibits harm: but it should not be considered therapy.

Therapy is a process of healing and should be based on mutual respect and genuine understanding of both parties, ultimately leading to the empowerment and transformation of both the self and other. The eradication of extreme aggressive behaviours such as SIB should not be seen as the endpoint of therapy, but rather the beginning as it is a precondition for exploring other possible types of interaction.

Sometimes I feel we become so hung up on modifying the person's behaviour that we lose sight of the ultimate goal of developing a genuine relationship based on mutual respect and reciprocity, which opens up possibilities for creative interaction.

5. A window of opportunity exists for children with PDD, meaning that exposing children to treatment early can make the difference between a child who is severely disabled and one who has some degree of normal functioning.

Considering EIBI is the only scientifically proven treatment for individuals with autism many professionals and parents argue that people with autism have the right to the most effective therapeutic environment possible (Houten et al., 1988). Equating autism with cancer, Maurice

(1993) argues behavioural intervention is the most effective treatment to-date for children with autism, and therefore should be provided to every individual suffering from this disease. Although IBI, like chemotherapy, cannot guarantee recovery for everyone, she questions whether this is a sufficient reason to deprive people access to these services. Given the high cost of intensive behavioural interventions of approximately $60,000 US a year (Jacobson et al., 1998), parents and professionals within the autism community are banding together to fight for mandatory funding and treatment for each and every individual. Arguments are typically immersed in rights discourses surrounding notions of the individual's right to treatment and hence equality (Houten et al., 1988).

Dawson's paper, *The Misbehaviour of Behaviourists*, provides an alterative framework to examine this argument. She discusses false oppositions, which use an if-then, either-or construction that is based on faulty premises and that is limited to alternative explanations. She argues the belief that autistics need treatment or they are doomed to for failure is, in fact, false. False oppositions and false equations (for example, in Maurice's book, autism=cancer) have become central to the legal, scientific and promotion of the autism-ABA industry. She argues within this medical model discourse, autism becomes incompatible with achievement, intellect, integrity, dignity, autonomy, and learning. Either the person with autism gets IBI, and begins to behave in normative ways, or the person with autism is destined to require life long support.

If we are to take the above arguments within this emergent discourse seriously, namely that autism is socially constructed, that autism should not be considered a disease to be cured or fixed, and that autism needs to be re-theorized in terms of its strengths, then arguments surrounding mandatory treatment and IBI become questionable. Best outcome would not be

defined by our value-laden standards that non-autistics should act, play, move, communicate the

way "neurotypicals" do. Dawson (2003a) states:

> Usually equality is not contingent on the citizen resembling all the other citizens. Jewish people are not required to be less Jewish, nor homosexuals less homosexual. In their own time, both these groups were vilified and considered plagues, and there have been aggressive treatments for homosexuality. Equality rights for autistics, in contrast to all other Canadians, amount to an obligation to be or act less autistic or not autistic at all. Remarkably, everyone agrees to this also... I am autistic and, because I am excluded from the Charter of Rights and Freedoms, *I am not a Canadian.* Now I am not even sure I am human (¶8, ¶15)

Interlude 15

"To those who are frightened enough and desperate enough, it becomes harder and harder to hold on to sense and intelligence, reason and objectivity" (Maurice, 1993, p. 139).

The first time I read Maurice's novel I was persuaded by her words, anxieties and fears. Her personal narrative focused on how she was influenced by the theoretical underpinning of holding therapy and almost abandoned the most effective treatment; behaviour modification, which ultimately led to the "recovery" of both her children. I saw myself in Maurice's story, as she articulated similar anxieties I currently hold towards behaviour modification including its intrusive and mechanical nature. This led me to interrogate my own subjectivities, in particular the "joining" method used in IMTI, as it was guided by a similar philosophy as holding therapy, with a focus on love and acceptance.

Acting out of desperation, concern, anxiety, fear and even intuition may be a "setting event" for parents to be easily persuaded by treatments that are dominated by theoretical and psycho "babble" and are not supported by empirical evidence. This, in turn, could lead parents to divert their attention away from effective treatments and waste a considerable amount of time, money, resources and energy on experimental treatments that promise to cure their child of autism (Metz et al., 2005).

Although IMTI does not guarantee a "cure" for autism, it is inspired by SRP's theoretical philosophy which is based on "love" and "acceptance" and could thereby also be criticized by professionals for providing false hope to parents of children with autism, as it downplays the demising reality of their situation. Furthermore relying heavily on anecdotal and case study reports IMTI currently does not have any scientific evidence to support its effectiveness[15]

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[15] According to Alderson (2007) IMTI supersedes ABA success rates, IMTI having a 100% recovery rate (N=5) (i.e., typical functioning, integrated into regular school system, indistinguishable from peers) in the last 3 years, with so far no failures.

Irrespective of IMTI's "lack of evidence" and "feel good philosophy" the program did not deter Jacob and Josh from excelling and surpassing all of my expectations![16]

<p align="center">*   *   *</p>

This past weekend I attended a celebration in honour of both boys' "recovery" from autism.

During this celebration we watched a video of Jacob's and Josh's progress in the IMTI Program. Beginning when the boys were 3 and had just formally been diagnosed with autism, the footage started with Jacob and Josh displaying odd and irregular behaviour patterns. At the time, both boys were non-verbal and most of their free time was spent engaging in solitary play and displaying repetitive ritualistic behaviours.

I watched Josh's and Jacob's (now 6) reactions to what was being shown on video, as they sat on the sofa and watched with the group, the boys would frequently laugh and converse with each other whenever they caught themselves doing something "funny" (i.e., engaging in odd and irregular behavioural patterns). Being surrounded by family and friends who had always offered unconditional support, acceptance and praise, Jacob and Josh did not seem to be embarrassed by what was being shown on the video. For them, these behaviours were not something to be ashamed of— as they were not considered a symptom of a psychiatric condition known as autism, but rather these odd behaviours were seen as random acts of "silliness".

For the rest of us watching the video (which included family, friends, and IMTI volunteer therapists), we witnessed two boys who previously displayed characteristics of autism transform into normal, adaptive and typically developing children.

<p align="center">Chapter 12: Dialogically Encountering "Otherness"</p>

Reflectivity can only be employed when encountering "otherness". Whether this otherness is through the examination of alternative theoretical frameworks, the unveiling of subjugated knowledges, or analyzing alternative discourses, this dialogical process is meant to challenge our current ways of knowing and force us to re-interpret our own personal experiences with the world (Parker, 2002; Sauko, 2003).

The above theoretical piece of writing attempted to capture the polyvocality (Sauko, 2003) of autism discourse by studying an array of voices (i.e., traditional psychologists and service providers, people with the autism label, and my own voice as a becoming professional) in

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[16] Due to the comprehensive multi-treatment approach that encompasses IMTI, currently it is impossible to determine which components of IMTI effectively contributed to the program's success and which do not.

hopes of giving a fairer account of current discourses related to autism and pathology. By conducting what Saukko (2003) refers to as a "critical ontology of the self", this paper sought to examine the discourses that have constituted the author's subjectivity and was meant to illustrate the limitations of unreflectively accepting the grand meta-narratives that govern our lives. This paper intended to "deconstruct"[17] dominant discourses surrounding the author's constructions of autism, attempting to unveil the "lines of force" that impair the author's interpretation of the phenomenon under investigation. This reflective process allows the author/reader to take a step back from language and to understand the way language has been organized in such a way that it places constraints on possible ways of viewing and interacting in the world. In this way, this polyvocal account of autism discourse shifts dialectically from the author's self, to theory, to the subject under investigation (i.e., people autism) and back again, in order for the author to become aware of the personal and social baggage that impairs both the author and reader's ability to interpret their personal experiences in novel ways. As Sauko (2003) argues, becoming critically aware of the limits of our own understanding will foster a sensitivity or openness towards constructing a radically different world.

General Summation of Thesis

Drawing on the theoretical writings of Foucault (1965, 1972, 1980, 2003), Basaglia (1987) and Deleuze and Guattari (1987) this thesis intended to demonstrate that what we consider to be "True" in society is closely tied to systems of power which produce and sustain it. In relation to autism discourse, this thesis attempted to undermine "regimes of truth" surrounding dominant constructions of autism by unmasking their apparent neutrality. Taking the reader on the author's personal journey through traditional autism discourses and abnormality, to

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[17] Deconstruction is used in a similar way as Parker (2002) defines it when he states one is engaging in discourse when the writer can show how a specific psychological phenomenon is a function of discourse rather than having an independent reality that can be discovered through empirical research (p. 228).

alternative epistemologies which challenge take-for-granted assumptions of the world, this thesis attempted to demonstrate that even what we think is commonsensical is, in fact, up for debate.

In most philosophical texts, arguments are constructed in such a way that guarantee a stable reference point; it is this point of reference that is commonly left unquestioned by the reader, being seen as the Truth to which all other things are compared (Parker, 1995). Paying specific attention to language and dominant techniques used in autism practices this thesis attempted to challenge our habitual tendency to process information according to existing dichotomies (i.e., normal-abnormal, individual-social, internal-external, relativism-realism, common sense-theory, etc.) by unveiling the author's dialogical struggle with alternative epistemologies and how it relates to autism practices.

In fear of perpetuating current stereotypes, prejudices and forms of oppression I so desperately wish to eradicate, this piece of writing explores *the function* of taken-for-granted assumptions that encumber my experiences in the academy. Some key themes emerging throughout this thesis include:

1.   Dominant constructions of language seek to perpetuate ideas of what can and should be considered appropriate language. Techniques such as PECS, sign language, facilitated communication, and augmentative communication systems seek to help the non-communicative transmit information in a way "the normal" can understand, but in turn, place constraints on how we go about interacting and understanding those who do not speak the dominant language.

2.   Psychological techniques developed in a benevolent effort to "help" individuals, which include categorizing, taxonomizing and classifying certain behaviours as abnormal, may in turn serve to maintain constructions surrounding psychiatric diagnosis as real

phenomena that are in need of remediation. Individuals are pathologized when they meet specific descriptions found in the DSM-IV, but are further pathologized when they display "symptoms" of various disorders, but do not neatly fit into one psychopathological domain (Parker, 1995).

3. What is constructed as abnormal is closely tied to the socio-economic and political conditions of the time. Historically, individuals who do not or cannot partake in the productive rhythms of society are labeled deviant and disordered. Capitalism has taken hold of this unproductive ontology, allowing these once unproductive individuals to actively participate in capitalistic endeavors, being both consumers of the normalizing industry and a product of the techniques used.

4. We live in a state of panopticism, under the watchful eye of the other and evaluating the other in return. This hyper-vigilance to the "condemnatory other", without knowing when the other is watching, forces us to monitor our own behaviour for fear of being judged and disciplined accordingly.

Where do we go from here?

In the field of abnormal psychology there is an assumption that the "all knowing" professional has the objective expertise needed to "help" the client, "empowering" him/her to escape his/her own subordinate status. The professional often assumes that in this process of acting upon the other, they are able to separate themselves from their work, imagining his/her own subject position has little or no impact on their perception of the other and the procedures and techniques they choose to use (Skott Myhre & Skott Myhre, forthcoming).

When working with children with autism, we (as professionals) often act as though our own experiences and perceptions do not limit our practices and interpretations of people with

autism's behaviour. Being masked by concepts such as "best practice" and "empirically based treatments", we often act as though we are operating "outside" the agency, uninfluenced by our personal histories, our agency's mandate and their underlying philosophies. We assume the role of the professional is neutral and inherently helpful.

This thesis attempted to show the assumption that the professional is in a position to "help" or "empower" the other is extremely precarious. Parker (2002) argues that traditional academic psychology operates as if it is the center, but is ultimately trapped between two absent centers: failure to reflect on society and failure to reflect on the researcher and how this, in turn, impacts our interactions in and against psychology. Parker (2007) argues, "there is no place in psychology or even in discursive psychology for critical work to start" (p. 141), as attempts to emancipate outsiders from the inside often end up only empowering the psychologists (Parker, 2007). Being concerned with what our discipline is doing to the people it studies, Parker (2002) relays the fundamental need to "map" psychology by exploring what we do as psychologists, by drawing on other disciplines such as cultural studies, literary theory, women's studies and social theory. Psychologists and people working in the social service industry need to take the arguments in other disciplines seriously. Instead of ignoring the existence of critical frameworks or shutting down dialogue by providing counter-arguments that merely dispel traditional concepts firmly grounded in the tradition of empiricism, professionals need to engage dialogically in these debates.

It is only when we engage in this material that we can focus on the relationship between what psychology says and what it does; both inside and outside the academic discipline and its clinical practice. Thus, Parker (2007) calls for the need to "educate the educator" (p. 162), rather

than assuming "revolutionaries" have expertise above and beyond what is possible for ordinary people.

Chapter 13: Challenging Dichotomies

Despite current attempts of people with the autism label to resist dominant constructions surrounding traditional autism discourse, many professionals continue to examine autism through a medical model lens, operating under the assumption that autism is a disorder that is in need of remediation. Much like Basaglia's (1987) "deconstruction of the asylum" what is first needed within autism discourse is to undo the logic of dominant autism constructions and practice (refer back to five assumptions surrounding dominant autism discourse, see p. 28-29). Critical disability researchers and collective groups such as the neurodiversity movement and the autism acceptance project are paving the way, setting up opportunities for new, innovative, and more dynamic interactions to occur between and beyond disciplines.

These new constructions attempt to over throw the taken-for-granted stable reference points that are typically left unquestioned by the reader, in order to explore their functions in society. Instead of masking existing human contradictions by covering up inconsistencies with terms such as autism, disorder, abnormal, etc., Basaglia (1987) suggests the need to dialogically confront existing concepts found in the human condition. This does not mean simply privileging the subordinate dichotomy (i.e., the voices of people with autism) over the dominant (i.e., voices of professions) as we would essentially run into the same problem, continuing to fix meaning on one side of the continuum and simply silencing the other. Rather, we need to get at the conceptual policing that keeps these two sides apart. Furthermore, if we only target one existing opposition without deconstructing the other surrounding oppositions, the problem is again reconstructed (Parker, 1995). For example, the above autoethnography attempts to over-throw

the researcher-subject dichotomy, leading the designated role of the researcher to become blurred to its readers. However, if the author does not deconstruct other oppositions surrounding how the researcher-subject role was constructed (e.g., professional-patient, normal-abnormal, reason-unreason, individual-social, pure categories-messy life) then the problem is simply reconstituted.

Furthermore, one must be cautious not to develop an overly idealistic view of the possibility for change at the individual level. In other words, simply talking differently about these issues will not lead to radical social change. What we need to do, as many authors currently (Parker, 1995; 2002; 2007) and historically (Basaglia, 1987; Foucault, 1981) have argued, is to assess different theoretical positions in and against psychology dialogically and recover notions that have been excluded from mainstream society. We need to critically explore power and dominant discourse, taking into account the broader historical and socio-economic conditions of society, offering ways of tackling these contradictions in order to unveil their confining nature. As Parker (1995) states this is where we start not finish!

Throughout this piece of writing I have attempted to give a personal account of my history and experiences with traditional autism discourse and pathology by critically engaging in alternative epistemologies, challenging myself to think "outside" traditional psychopathological frameworks related to autism, and to explore the function of these dominant constructions. However, as was evident throughout the above self-reflections, engaging with discourse may enable the author/reader to become more aware of the "truth effects" of psychopathology, but these constructed "truth effects" are still constrained by certain ideas about the conditions of possibility they produce (Parker, 2002). Many other authors have articulated similar concerns with self-reflective writing including Said (1978, p. 10) who stated;

No one has ever devised a method for detaching the scholar from the circumstances of

life, from the fact of his involvement (conscious or unconscious) with a class, a set of

beliefs, a social position or from the mere activity of being a member in society.

Another inherent problem with reflective writing and postmodern discourse is that there is a

tendency to view this quest as a "better," more "progressive" alternative to the status quo, being

seen as a space for critical reflection that will bring about opportunities for radical change. But

this also means that when we attempt to be "critical" of the postmodern enterprise we are again

faced with "the modern" as our only reference point (Parker, 2002). Parker (2002) argues that,

despite this apparent limitation of postmodernism, the answer is not just to eradicate this way of

thinking altogether, but to understand how specific forms of postmodern rhetoric open up or

close down a dialogical movement of truth and change. Therefore, it is important to note that the

above *analysis of self* was not intended to illustrate the author's liberation from discourse, as

there is no extra-discursive reality (Parker, 2002) lying behind that which is spoken. Rather it

was meant to illustrate how specific discourses set out certain conditions of possibility for

actions and experiences, thereby defining current constructions limits and capacities.

Chapter 14: Future Directions of Autism Research

I do not wish to offer concrete recommendations for "how to be self-reflective" or to

develop a "critical practice for dummies" that will enable people working in the autism industry

to be completely conscious of the underlying functions of the techniques and practices used in

the psychological sciences. As soon as recommendations become manualized, they become in

Deleuze and Guattari's (1987) term, a "major language" limiting our capacity to act in

innovative and creative ways.

What can be said, however, is that what we have to say as professionals about people with autism not neutral and is based on our own limited experiences with the subject in question and our own personal histories interacting with the world. Thus, it is absolutely crucial to evaluate ourselves in relation to the "object" we wish to study or interact with. New and innovative practices are occurring in the social service field and we can turn to these theoretical practices as the beginning for opening up possibilities for actions and interpretations with people with autism, rather than limiting their capacities to act in innovative ways.

Ethics of Care. In the work of Foucault and other critical radical theorists (Skott-Myhre & Skott Myhre, forthcoming), boundaries between the professional and client begin to dissipate as one begins to see the dynamic dialectical relationship between the care of self and the care of the other. Foucault contends that *care of the self* involves critical reflection and the ability to break down lines of discourse where one's "stable" identity has been constructed. Yet this task cannot occur in solitude, as it requires the presence of the other to challenge the boundaries of the self's thinking. The re-conceptualization of the presence of the other as being vital to understanding the self fosters a co-alliance with the self and other, the self informing the other, and the other informing the self in return (Skott-Myhre & Skott Myhre, forthcoming). In our relations with people with autism, again the essential role they play as co-therapist in our interactions should not go unnoticed. Our interactions with this group inform us about ourselves and challenge our thinking about current constructed realities. Emphasizing this creative exchange of information and self-reflection may help to unpack our need/desire to dominate the other.

Hearing Voices Network (HVN). Although many professionals still view hearing voices as a symptom of schizophrenia, the HVN movement initially focused on treating hearing voices

as a discrete symptom on its own, and has currently evolved to show how there is no one correct way to define and solve a problem and that for some individuals, hearing voices is not a problem at all! This group has collectively brought professionals, families and clients together to challenge, accept, and celebrate hearing voices. Some have incorporated mainstream developmental and psychological theories in an attempt to overthrow dominant theories related to pathological behaviours. For example, Vygotsky's analysis of cognitive development, which proceeds from the social to the individual shows that everyone hears voices as a condition of being able to think in the first place (Parker, 2007). A network such as this seeks to challenge and incorporate the multiplicity of voices and disciplines, and is a place for the reader to explore more creative therapeutic relations.

The Son-Rise "Joining" method. What we know about the world limits what we think is possible to do in it. Parker (2007) contends that to treat behaviour as something that can be conditioned through reinforcement and punishment procedures is to lose sight of our capacity to be reflective agents. The joining method developed by Kaufman (1995) is an avenue within the autism industry that is in need of future exploration. In this instance, instead of reducing repetitive behaviours in order for the client to look "more normal", the therapist engages in these repetitive activities as an alternative form of communication and social interaction. These new interactions, which force the therapists to think outside the condition-response box, again offer new possibilities for creative interactions.

Autism Network International. (http://ani.autistics.org). ANI is self-advocacy group organized for and by people with autism. The ANI founded Autreat; an annual conference designed to provide a safe "autistic space" focusing on the positive aspects of living with autism and NOT with the causes, cures or effective techniques used to make autistics look more

"normal." The conference is designed to educate parents and professional about autism acceptance and provides a space for people with autism to relay their concerns and discomforts with diagnosis and the specific autism practices being employed in the autism industry.

The Autism Acceptance Project (www.taaproject.com). This is a project designed to promote alternative constructions of autism, in order to foster understanding and acceptance of diversity. People involved with this project view autism as a part of life both with challenges and abilities that deserved to be supported. The TAA project promotes autism advocacy and the right for people with autism to participate alongside the government being involved in all agencies and committees, thus making decisions that will help to successfully support and empower these individuals.

Concluding Remarks:

It is hoped that his piece of writing offers a possibility for resistance, resistance from the dominant constructions governing our current ways of thinking, that challenges both the reader and author to move beyond these constructions to explore other possible ways of thinking and interacting with people with autism.

Taking into account my own personal struggle with autism discourse and pathology I firmly believe we must not disregard what individuals with autism have to say about their own "condition". We must make it our responsibility to take seriously alternative ways of being in the world. We must, as autism professionals, attend conferences such as the AUTREAT and have people like Amanda Baggs and John Sinclair actively involved in research and policy development. We must not assume that we know something about others' lived experiences or that we know their lived experience better than they know it themselves. We must expand our minds, interrogate our assumptions, and challenge ourselves to think outside our own subject

position. In this way, we are working together, the self informing the other and the other, in turn, informing the self. In this instance power is not used over the other to inform him/her about how to live one's life; rather what occurs is a continuous, infinite, dialogical struggle that constantly challenges all of us to surpass the societal structures that seem to be so firmly in place.

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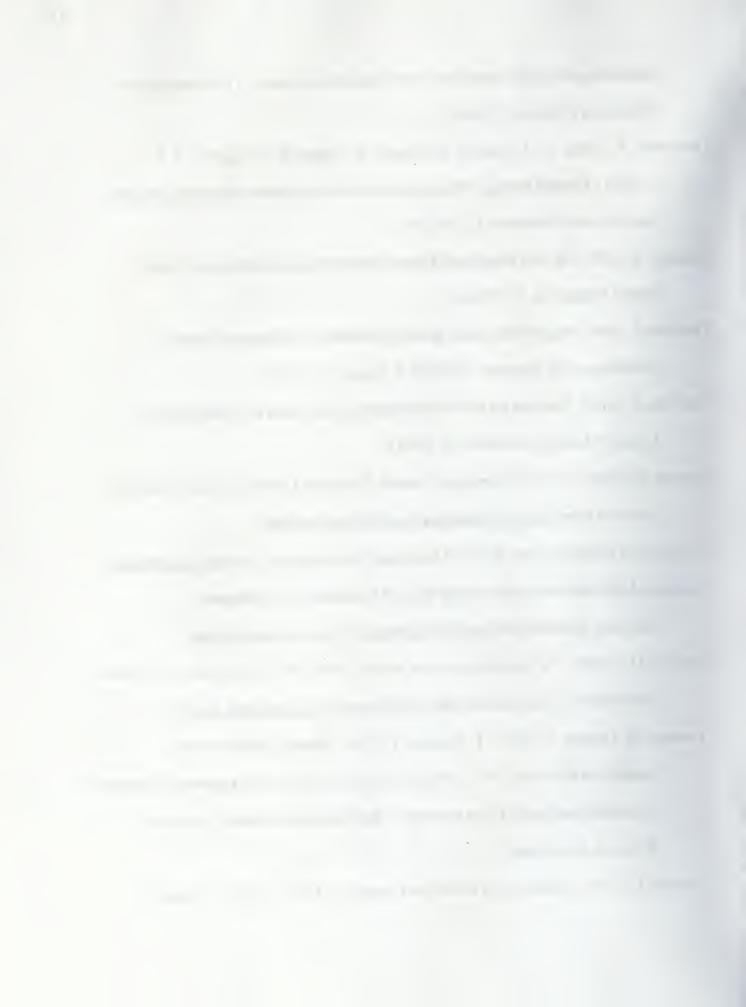
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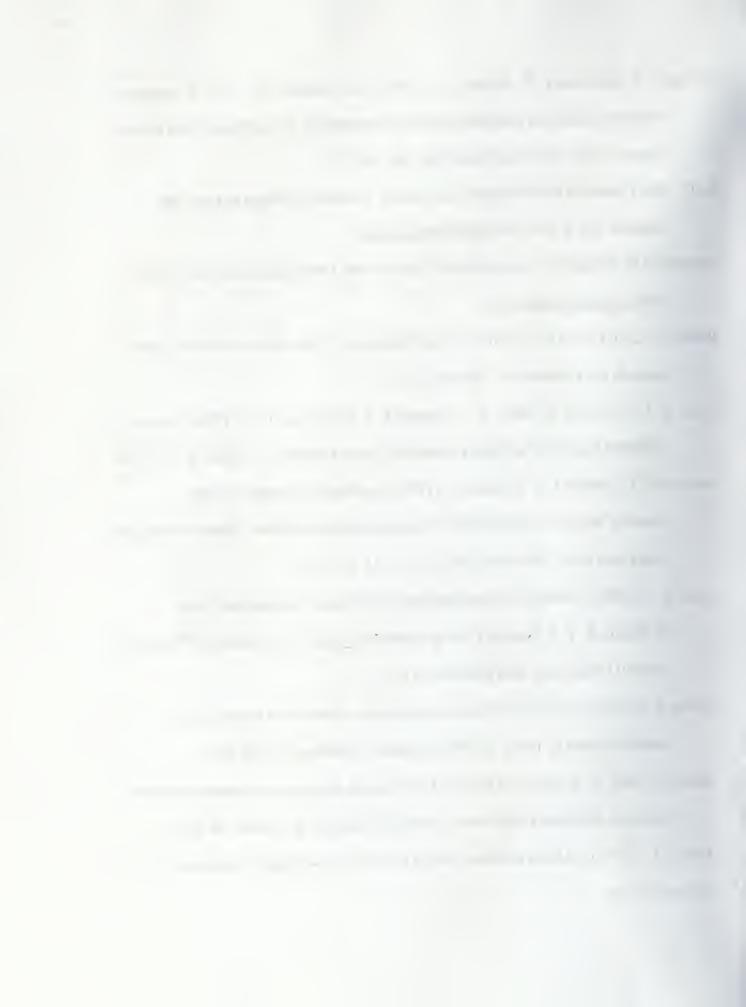
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