## THE SOCIAL ORGANIZATION OF HEALTH CARE FOR TRANS YOUTH IN ONTARIO

by

## Rebecca Hammond

Submitted in partial fulfillment of the requirements for the degree of Master of Science

at

Dalhousie University Halifax, Nova Scotia August 2010

© Copyright by Rebecca Hammond, 2010

## DALHOUSIE UNIVERSITY DEPARTMENT OF COMMUNITY HEALTH & EPIDEMIOLOGY

The undersigned hereby certify that they have read and recommend to the Faculty of Graduate Studies for acceptance a thesis entitled "THE SOCIAL ORGANIZATION OF HEALTH CARE FOR TRANS YOUTH IN ONTARIO" by Rebecca Hammond in partial fulfillment of the requirements for the degree of Master of Science.

Dated: August 19, 2010

Supervisor:

Readers:

Departmental Representative: \_\_\_\_\_\_

#### DALHOUSIE UNIVERSITY

DATE: August 19, 2010

AUTHOR: Rebecca Hammond

#### TITLE: THE SOCIAL ORGANIZATION OF HEALTH CARE FOR TRANS YOUTH IN ONTARIO

DEPARTMENT OR SCHOOL: Department of Community Health & Epidemiology DEGREE: MSc CONVOCATION October YEAR: 2010

:

Permission is herewith granted to Dalhousie University to circulate and to have copied for non-commercial purposes, at its discretion, the above title upon the request of individuals or institutions.

Signature of Author

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

The author attests that permission has been obtained for the use of any copyrighted material appearing in the thesis (other than the brief excerpts requiring only proper acknowledgement in scholarly writing), and that all such use is clearly acknowledged.

# TABLE OF CONTENTS

LIST OF TABLES	v
LIST OF FIGURES	vi
ABSTRACT	vii
LIST OF ABBREVIATIONS USED	viii
ACKNOWLEDGEMENTS	ix
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: BACKGROUND & LITERATURE REVIEW	7
2.1: The Production of Knowledge about 'Trans' Individuals	8
2.2 Limitations & Challenges of 'Trans' Research	13
2.3 Portraits of Trans Communities in our Society	17
2.4: Trans Health Care Access: Differing Approaches to the Care & Organization of Trans Identities	26
CHAPTER 3: METHODOLOGICAL FRAMEWORK, DATA COLLECTION & DATA ANALYSIS	31
3.1: Methodological Framework	32
3.2: Data Collection & Analysis	46
CHAPTER 4: THE SOCIAL ORGANIZATION OF TRANS IDENTITY ACTUALIZATION	56
4.1: Identity Actualization: Pathways, Possibilities & Motivations	58
4.2: Hooking up to 'Trans Care': Different Paradigms, Providers, and Pathways	67
4.2.1: Preparing to Access 'Trans Care': Getting a Sense of the Landscape	69
4.2.2: Accessing 'Trans Care': Stories of Difference	77
4.3: Medical and Psychiatric Relations and the Practice of Trans Care in Ontario	
4.4: 'Holding Patterns' & the Legal and Political Coordination of Tra Care in Ontario	
4.4.1: "Holding Patterns": Living in limbo due to clinical and political barriers to care	109
4.4.2 The 'Emerging' Trans Community and the Politico-Legal Organization of Trans Care in Ontario	111
CHAPTER 5: CONCLUSION	124
BIBLIOGRAPHY	132

## LIST OF TABLES

Table 1	Medical Forms of Identity Actualization5	59
Table 2	Provision of Medical Forms of Identity Actualization	51
Table 3	Holding Patterns – Barriers to Identity Actualization 1	.09

# LIST OF FIGURES

Figure 1	DSM-IV-TR: Diagnostic Criteria For Gender
e	Identity Disorder (GID)91

## ABSTRACT

In this study 21 trans-identified youth in Toronto and Ottawa, Ontario, Canada were interviewed about their experiences related to transition. Using the materialist research strategy of Institutional Ethnography, I explore the organization of trans-specific health care services in Ontario. I describe challenges participants had in relation to accessing care and describe key differences in how care is currently delivered in Ontario. The ways in which various politico-legal and medical forms of organization shape the provision of trans care in Ontario are explored in detail. This work provides an empirically grounded addition to the growing literature that seeks to make sense of trans marginalization and exclusion.

# LIST OF ABBREVIATIONS USED

CAMH	Centre For Addiction & Mental Health
CBR	Community Based Research
GID	Gender Identity Disorder
IE	Institutional Ethnography
OHIP	Ontario Health Insurance Plan
OHRC	Ontario Human Rights Code
PHC	Primary Health Care
RLE	Real Life Experience
SHC	Sherbourne Health Centre
WPATH	World Professional Association for Transgender Health
Y-GAP	Youth Gender Action Project

## ACKNOWLEDGEMENTS

This thesis could not have been accomplished without the support of many. I wish to acknowledge my deep thanks to my research colleagues Robb Travers and Nicola Brown, to my friends and family for their patience and support, and to my Department for their ongoing support and their initial faith in bringing me on as a student. I would like to thank the Ontario HIV Treatment Network for their support in funding this research. Most importantly I would like to thank Eric Mykhalovskiy for his support, guidance, and patience. His wisdom and acumen as a supervisor and gifted thinker have been invaluable in shaping this work and my own growth as a researcher.

## CHAPTER 1:

## INTRODUCTION

## "I wouldn't call society 'society', I would call it 'struggle'" - Rachel (Research Participant)

This first chapter introduces the research that I have undertaken, provides an overview of the structure of this thesis, and introduces and defines the community that I am working with. In this work I am looking specifically at the organization of health services for trans youth in Ontario, in particular those related to what I describe as 'identity actualization'. Before delving into the research question and methods, I first start this chapter with a brief overview of who 'trans' people are. I also introduce that while 'trans' people have always been present in our culture, the relative visibility and social and medical understanding about 'trans' people has shifted greatly over time (Feinberg 1997; Drescher 2010).

In this thesis, I forefront the social and medical forces that shape trans identities generally, and organize the work that trans youth need to do to access services related to gender transition (i.e. hormones and surgeries) specifically. In doing so, I open up the analytic window I wish to enter, wherein I explore the organization of trans care and how this hooks into the ways trans identities are understood, classified, and managed in medical settings as well as the everyday world at large.

'Trans' is an umbrella term that I use in this thesis to encompass both transsexual as well as transgender individuals. Transsexual people are those whose gender identity is different from the one they have been assigned at birth. Thus, a transsexual woman is someone whose *gender identity* (ones internal sense of being a 'man' or a 'woman' or something else entirely) is that of a woman but who was assigned a 'boy' at birth. Conversely, a transsexual man is someone whose gender identity is that of a man but who was assigned a 'girl' at birth. Such assignments are routinely and almost universally based on one's sex. In other words male babies are assigned as 'boys' and female babies as 'girls'. For transsexual individuals, making changes to their body, often through the assistance of medical interventions such as taking cross-gender hormones and/or having surgeries to better align their social gender identity and presentation with their internal gender identity are often integral components to their health and well being. Transgender, also known as genderqueer, are those whose gender identity is neither that of a man or a woman. In this work, as I focus on the organization of health care as it relates to the actualization of trans identities, most of my participants were transsexual in their lived experience. That said, for various reasons, as I will expand on in the next chapter, self-identification varies significantly. Thus, I use the term 'trans' not to label participants or to suggest a cohesive or monolithic community, but to provide a discursive name that permits exploration of those sharing a common experience of

moving through the social world and, in particular, of interacting with health care systems.

The development of 'trans' as a term, and 'trans' as an embodied subjectivity is a relatively recent phenomenon (Drescher 2010). While gender-variant individuals have existed across cultures and through time (Feinberg 1997), the past 40 years have seen significant change in how trans identities have been understood by medical professionals as well as in the broader social world. Extending from the often sought after medical interventions integral to actualizing a trans identity, the medical profession – in particularly psychiatry – has been central in both defining trans identities as well as regulating the very existence of trans individuals. To elaborate, since 1973, and continuing to this day, 'trans' identities have been understood as a psychopathological category and presently the diagnosis of "Gender Identity Disorder" (GID) is often required in order to access transition-related health care (Namaste 2000; Lev 2005). Moreover, the application of a diagnosis, and the role that medical professionals play as 'gatekeepers' has been a contentious debate in emergent 'trans' communities and many have commented on the stringent, selective and discriminatory application of these diagnoses (and thus access to hormones and surgery) (e.g. Namaste 2000); the past decade has witnessed increasing critiques of the pathologization of trans identities altogether (e.g. Lev 2005).

Trans people historically and through to this day have been one of the most marginalized populations. This marginalization has, in turn, affected the

health of trans individuals (Lombardi 2001). Bearing witness to this are high rates of HIV (Clements-Nolle et al. 2001; Herbst et al. 2007). Alongside these high prevalence rates, trans people experience disproportionately high levels of violence, incarceration, harassment and discrimination and research has highlighted that trans people experience difficulty finding stable work and safe places to live (Xavier et al. 2007). This can create conditions whereby trans people may find themselves at risk for HIV infection. Trans youth in particular may present their own unique, and potentially even greater, vulnerability to HIV relative to trans adults.

As I detail in the next chapter, recent analytic work has started to shift towards making sense of how trans communities come to experience marginalization. Hooking into both this emergent analytic trajectory as well as the advent of an embodied trans subjectivity and the trans 'community' that has arisen, new language has developed to describe those who are non-trans. In this work I use the term 'cis', the converse of 'trans' to describe those who are 'nontrans' (Serano 2007). This term is useful in several respects. First, it provides the language to define people who would otherwise be known only as 'normal'. This unchecked claim to the privilege that accompanies being understood as 'normal' effectively renders such dominant groups invisible; the ways such groups wield power are also not open to scrutiny by extension of such invisibility (Bauer et al. 2009). Second, and integral for this study, 'cis' permits an exploration of how the world is organized in ways that privilege the experience of those who are nontrans, in particular it better facilitates a discussion of the ways that institutions, medicine specifically, function in ways that assume, are bias towards, and reenforce the central normativity of 'cis' identities and bodies.

The central goal of this work is to explore how the work of identity actualization for trans youth (age 16-25) in Ontario is shaped through the organization of health care services. Starting with the lived experience of my 21 participants, gathered through face-to-face interviews, I explore how forms of medical and politico-legal coordination shape the experience of trans youth. I explore how the regulation of trans identities through ruling texts, such as the DSM-IV(TR) and the diagnosis of GID, produce both the work activities youth must engage in to actualize their gender identity as well as how trans identities are regulated more broadly. In this work I use Institutional Ethnography (IE) to focus on the material forms of organization that regulate the everyday. My analysis is centered on a materialist explication of my participants' experiences rather than attempting to create or confirm a theory to explain what has been documented.

My work accomplishes two key things. First, it provides a description of the everyday experiences of trans youth in Ontario as they go about seeking various medical forms of identity actualization, a term that I introduce to provide a way to describe the activities of trans youth in my research in ways that did not, from the outset, hook into medical ways of organizing and categorizing these actions and struggles. Second, this work details the way trans health care is organized. This explication is one that is empirically grounded in the experiences of research

participants as they engaged with the health care system. I draw on this experience to explore the present disjuncture between an emerging trans subjectivity and the organization of trans identity actualization within a medical context. In particular, I explore how there are presently two distinct forms of organizing trans care and that these different forms of care differ both pragmatically, in how they approach care and in who provides care, as well as ontologically, in how they orient to the autonomy and authority of trans youth and, hence, the role that the trans person has in the organization and delivery of their own care. While a number of studies have provided insights into the challenges that trans youth and adults have with accessing health care, and how barriers to services such as these – akin to other social determinants of health – in turn affect the health of individuals and communities, little has been written, and even less has been empirically derived, about the reasons why this is the case. My work produces an analysis of the organization of trans care in Ontario, using the experiences of trans youth to pry a wedge into, and to produce insights about, the way that trans care is organized. What arises from this exploration is a clear account of the impact that not receiving health care, or experiencing barriers to care or insensitive care, can have for trans youth in Ontario. In the conclusion of this thesis I introduce some practical applications and suggestions for further research that builds on the explication and analysis I develop on the following pages.

## **CHAPTER 2:**

## **BACKGROUND & LITERATURE REVIEW**

From the perspective of a critically engaged researcher, the purpose of a lit review is double-pronged. The first is to understand the research that has been done about a particular topic, assess its validity and summarize its key points and conclusions and contributions to a 'body of knowledge'. The second point seeks to parse apart such information and examine the discourses, methodologies, and standpoints that shape this 'body'. Research literature can be thought of as something that is dynamic and diverse – I liken reading it to entering a boisterous room in which a number of heated exchanges are taking place. It is integral for me, as a qualitative researcher, to understand the particular academic 'conversations' taking place in this room. Understanding this, I can situate my work in relation to these conversation and offer up novel and timely contributions to the research literature.

This chapter will outline the current state of knowledge about 'trans' people. I start by introducing the broad areas of knowledge production in relation to trans identities, in part because different disciplines understand 'trans' people in profoundly different ways. Framing the research body as a fragmented ontological archive, where different disciplines hold radically different perspectives in relationship to 'gender identity' and 'trans' identities, is also important as it provides us with a foundation to understand trans health care barriers and the production of trans marginalization. The second part of this chapter describes in brief some challenges and limitations with respect to undertaking research with trans communities. This is followed by an overview of the current research on 'trans communities', research that has often produced findings that replicate and re-enforce what is generally understood: that trans communities, and the individuals that comprise them, represent one of the most marginalized groups in North America today. The last section of this chapter presents current and past thinking related to understanding trans people in clinical settings. Exploring such distinctions is important as it shapes the experiences of trans people as they articulate with the health system as part of efforts to actualize their identity.

#### 2.1: The Production of Knowledge about 'Trans' Individuals

Research about 'trans' people, very broadly defined, can be divided into three distinct areas. While these different areas of research do often break down along disciplinary lines, it is perhaps more useful to consider how different approaches to undertaking research or developing theory presuppose very different ontological suppositions with respect to what the research questions is/should encompass and precisely who or what is being studied/theorized about. It is important to consider these different areas of research as they both reflect broadly the diverse ways that transsexuality and trans individuals are understood in our society. Moreover, prevailing approaches to researching, theorizing, and generating understanding about 'trans' individuals provides the language and foundation for the way that the world makes sense of trans people beyond the walls of academia. I will provide a cursive overview of these different areas of understanding. In the concluding section to this chapter I revisit how these bodies of knowledge about trans individuals could possibly help understand the way trans identities are made sense of in our social world and assist in explicating the dearth of health services for trans individuals so often pointed out in research studies.

The *first* field of research is psychological literature wherein transsexuality is seen as a psychiatric illness, specifically that of 'Gender Identity Disorder' (GID). This research is undertaken in clinical settings with the aim of measuring the factors associated with those who have 'GID', to assist in accurate diagnosis of 'GID' through the validation of various clinical tools and surveys and to explore various etiological and nosological theories that seek to understand what is perceived as abnormal at best, pathological at worst (e.g. Blanchard 1989; Lawrence 2010; Pfäfflin 2010).

While the psychiatric category of 'GID' does exist, there is not universal consensus, even within psychiatry, as to whether transsexuality is best understood as a mental illness. Some psychologists, most notably Milton Diamond (GIRES 2007) have suggested that gender-variance is better classified as a physical health condition. Others (Roughgarden 2005) have illustrated how gender ambiguity and variance is commonplace in other animal and plant species, suggesting that two gender identities, inexorably linked to two singular sexes is not the norm in human or other forms of life. Fausto-Sterling (2000) also illustrates how the concept of two discreet sexes is largely a social construct supported through medical interventions. Thus, while 'GID' is the predominant way that trans identities have been managed in clinical contexts and associated

research there are emerging ways of understanding transsexuality and gender variance.

In a related vein there are alternative ways of organizing assessment for, and delivery of, hormones and surgery related to physical transition that do not employ the application of psychiatric diagnoses. Such approaches, typically operating within primary care settings, recognize trans individuals as autonomous and competent with respect to knowing their gender identity (Gorton 2007; Feldman & Goldberg 2006). These approaches to understanding trans people renders research that seeks to understand the psychological and social co-factors related to 'GID', or the measurement of clinical instruments to diagnose 'GID' as anachronistic; the role of the clinician shifts to a facilitative and supportive one rather than the 'gatekeeper' role that extends from the psychopathological classification of 'trans' identities (Lev 2005). This encompasses both a shift in clinical location, out of mental health settings and into Primary Health Care settings, as well as a shift in the role of the clinician, away from a role of assessor. As I will expand on at the conclusion of this chapter and throughout this thesis, this has significant implications for the way trans identities are managed in clinical encounters. It shapes the experience of trans people as they get hooked up to care. It also reflects shifting ways of understanding 'trans' people. Stated briefly, this is a shift towards regarding trans people as a population or community rather than a disease category.

A *second* area of research that needs to be considered is that of queer theory. The central imperative of such work is to develop theories and insights into the human condition. Working from post-structuralist ways of understanding gender and sexuality, such work has often considered trans identities as symbols and representations of the fluidity and multiplicity of gender (Butler 1990; Butler 2004; Connell 2010; Kaufmann 2010). While such work does not directly relate to this study, it comprises a significant amount of writing and 'thinking' about 'trans' people. Most significantly, the way this approach to making sense of and, in many respects, using trans identities to serve intellectual ends, provides an insightful homology to how the psychiatric profession has 'used' trans identities to suit their clinical imperatives (Namaste 2000).

Shelley (2008) notes that central to queer theory's endeavour is the critique of binary gender categories. Starting with the seminal work of Butler (1990), queer theory has often used trans people as instruments to highlight the constructed, transient, and intermediary nature of gender. This has been done often without empirical recognition that many trans people feel quite 'normative' and 'binary' in their gender identity and that understanding 'trans' identities as radical or intrinsically 'queer' recapitulates the way that they are regarded as non-normative outside of such academic exercises. Namaste (2000) criticizes queer theory for its lack of attention to the embodied existence of trans people in our social world or in relation to the institutions that organize gender and, by extension, regulate transexuality, that it "overlooks the lives, bodies, and experiences" of trans people (23).

Queer theory thus obviates the very real challenges faced by those living in liminal gender spaces in our society and the pragmatic hurdles that trans people need to go through in order to actually transition from one gender to

another. While transsexuality has been seen as 'sexy' at times for its seeming intrinsic transgressivess, this ignores the 'unsexy' experience of actually being trans in our current social world.

Butler (2004) has since acknowledged the limitations of her earlier work in obviating the embodied experiences of trans individuals; others, such as Kaufmann (2010) attempt to find a middle-ground where trans embodiments are not erased, she describes her work "emancipating gender from heteronormativity" while not contributing to the "analytic erasure" of trans individuals.

The *third*, and final, area of research I will explore is research that seeks to provide us with information about a 'trans' community. Contrasting with the first area of research, such research starts with the supposition that trans people are a community rather than a particular disease. Most commonly such research has been focused on understanding the 'health' of trans communities, and has been carried out using the methods and goals of population health research. Such work includes needs assessments and a range of quantitative and qualitative studies including recent studies with larger samples and / or that employ novel sampling and recruitment methodologies (i.e. Respondent-Driven Sampling used by Trans PULSE). Taken together this body of work provides a portrait of the trans community in North America. This collection of research, as I will elaborate below, details the profound experience of marginalization and barriers to accessing health and social services experienced by trans people across settings and studies. This body of work will be the primary focus of the literature reviewed in this chapter.

#### 2.2 Limitations & Challenges of 'Trans' Research

Before I explore the existing sociological and population health research related to trans communities, it is important to make note of some of the challenges and shortcomings related to research with trans communities. Trans people are often not captured in research, this even includes research that supposedly does include them. Many studies that explicitly try to include trans participants in their sample fall under the generic rubric of "LGBT" research. The Lesbian, Gay, Bisexual, and Transgender/Transsexual (LGBT) community is diverse and the acronym, and the singular community it seemingly denotes, does not often reflect the significant distinctions between its constituent "LGB" and "T" components (e.g. Ussher 2009; Coker, Austin, Schuster 2009) or as Cole & Cate (2008:74) elaborate on:

The assumption behind a GLBT label is that each of these categories is distinct from the other, that only one might be occupied at a time, when the lived reality of many is identification with more than one of them at the same time, or different configurations of one or more of them over the course of an individual's life, or both. Stryker describes trans identity as intersecting with sexual orientation rather than falling somewhere along a hetero-homo continuum, putting the "T" on an entirely different plane from the "G," "L," and "B." Thus a transsexual woman might also be a lesbian...

Thus, many trans people may identify as "straight" and do not have any connection to an "LGB" community and, conversely, many trans people may *also* identify as lesbian, gay, bisexual or queer in some way.

While there are some similarities in the experiences of the two communities, there are many key distinctions between sexual minority (LGB) and gender minority (trans) communities, particularly with respect to legal protections, experiences of discrimination and service access, as well as the interaction many trans people need to have with medical professionals in order to actualize their gender identity.

The practical implications of this conflation have meant that where trans participants have been included in research, this has been done without consideration of how to design the research to surface their experiences as *distinct* from LGB participants. Secondary to this issue is that in quantitative studies, analyses of trans participants can not be done because of insufficient numbers of trans participants.

The same challenges, with respect to specificity of the research design and meaningful inclusion in the analysis, holds true in the very few studies that have included trans participants in larger quantitative population studies. In all cases, when trans participants have been included, they comprised such a small number that meaningful statistical analyses could not be undertaken. Most fundamentally this often involves the absence of any measure or question to ascertain who is trans and who is not in a given sample. In this way, trans participants who do participate in research are erased from the outset of data collection (Bauer et al. 2009).

In addition to the limitations that extend from the erasure of trans individuals, there are also pragmatic challenges with doing research with trans communities. Trans people constitute what can be considered a *hidden population*,

in other words one wherein a sampling frame is not available (Heckathorn 1997). While convenience sampling can provide useful data about difficult-to-reach communities, particularly those who are otherwise inaccessible by traditional research methodologies, the sample can in no way be considered representative of a larger population.

With respect to convenience sampling in trans communities, recruitment strategies further complicate the statistical meaning of the sample as they often rely on venues where only particular sub-groups of trans people may be found (Bauer et al. 2009). Recruitment for 'trans' research projects, especially those with trans youth, have often taken place through established agencies that work with trans communities (e.g. Grossman & D'Augelli 2006). This practice limits potential participants to those who are already users of the particular agency or, who are at least comfortable enough to meet there. In this way the use of convenience samples can skew data towards urban populations and towards trans people who may access services. Trans individuals who may be 'stealth' (i.e. not out as trans, post-transition) or who may otherwise not want to or be interested in associating with other trans people may be left out of the present research. One notable exception is the recently completed Transgender Health Initiative Study (THIS) from Virginia. The methodology used in the THIS project gathered data from other sub-groups of trans community that have previously not been captured by research, groups that many thought did not exist, in particular trans youth and rural and suburban trans communities. The latter two groups comprised 57% of the sample (n=350).

Trans youth, in particular, have also been excluded or occluded from research as well. There are also other particular hurdles with respect to recruiting youth, both ethical as well as pragmatic ones. These are present when doing research with any group of youth. Attaining ethics board approval is frequently a challenge (Sausa 2003). Scrutiny of research proposals is understandably greater when working with those under the age of majority. However, there is considerable evidence highlighting that those under 18, as young as 13 and 14, are *as* capable of understanding the parameters of research consent forms as those over 18 (Mutcherson 2005). Thus, the actual age at which consent can be granted is not reflected by standard legal ages of consent commonly used by Ethics Boards. Another issue that affects all youth research – although it may be particularly problematic in the case of trans youth – is the issue of accessing youth. Very often, the social and institutional spaces where youth congregate are often regulated in such a way whereby researchers are not welcome.

An important note that cannot be understated is that many trans people, including trans youth, may not identify as 'trans', similar in many ways as to how many gay and lesbian youth may not apply such identity categories to their lived experience (Savin-Williams 2001). For trans youth, this occurs for a variety of reasons ranging from stigma around being out as trans to 'trans' being more of a temporary label adopted during one's transition. It is important to be cognizant of this unique relationship to identity categories as it can introduce challenges and bias into the recruitment of 'trans' youth in this study. Assumptions around the size of the trans community<sup>1</sup>, in particular trans youth, raises challenges for attaining funding even where a strong case be made for a particular research project. This makes it easier for funders to dismiss otherwise worthy potential research programs. In a related fashion, the stigma and discrimination experienced by trans people carries over to research contexts, making it difficult to get funding (Boehmer 2002).

#### 2.3 Portraits of Trans Communities in our Society

I will now provide an overview of the growing body of research that has tried to understand the experiences and health of trans 'communities'. This body of research contrasts in some significant ways with (mental health) clinical research and queer theory writing, as noted above. Incumbent to this body of research is an understanding of trans people as a 'community'. Such work extends from the genesis of an autonomous trans subjectivity that emerged in the 1990's through the work of Bornstein (1998), Califia (1997) and others. Extending from the recognition of a discreet and valid trans subjectivity, trans individuals, have come to be regarded as autonomous and knowledgeable about their gender

<sup>&</sup>lt;sup>1</sup> The often quoted prevalence figure as per the DSM-IV (1994) – 1 in 30,000 for trans women and 1 in 100,000 for trans men – is certainly a gross *underestimate*. The only prevalence figures supported by research, from the Netherlands, provide similarly low prevalence numbers of 1 in 11,900 for trans women and 30,400 for trans men. More recent prevalence estimates, however, provide a different perspective. For example, simply by dividing the number of U.S. trans women who undergo SRS every year divided by the number of male births, Conway (2007) estimates that the prevalence of SRS, as a proxy measurement for the prevalence of trans women, is 1 in 1000. Horton & Goza (2006) come up with a relatively similar number for lifetime SRS prevalence, using similar statistical methods, of 1 in 2500. Conway (2007) notes, however, that a far larger percentage of trans women – conservatively at least three quarters – are not able to undergo SRS for various reasons, meaning that the actual prevalence of transsexuality is thus between 1 in 250 and 1 in 625.

identity. This cleave in research bodies – between psychiatric literature and population health research – recapitulates the different ways that trans health care services are organized and, more broadly, illuminates the contested legitimacy that trans identities have in the present-day social world.

The focus of this emerging body of research is to make sense of the health of a community; issues of diagnosis and etiology are not relevant, nor are they sensible, no more so than any other population or social group could be diagnosed or explained away. Such work thus falls under the rubric of population health research. Through various methodologies and approaches, with different foci and in distinct jurisdictions, these studies comprise a relatively new and growing body of work. Despite their methodological differences and the geographic differences, a relatively homogenous understanding of the health of trans people in North America is emerging.

What we see from this research is a portrait cast in sharp relief. Research to date details a wide range of barriers to accessing care, challenges to one's daily life, and consequent health problems arising from these multiple layers of marginalization.

In the early part of the 2000's, numerous needs assessments alerted researchers, service providers and policymakers to the significant challenges for trans individuals as it relates to experience of violence and harassment, experiencing discrimination with respect to finding stable housing or employment, and in accessing a range of health or social services (Sember et al. 2000; JSI Research & Training Institute 2000; Reback & Lombardi 1999; Reback et al. 2001; Xavier & Simmons 2000). Other studies provided insights into the service access barriers for trans people in health care, homeless shelters, addictions services, and sexual assault services (Namaste 2000). Moran & Sharpe (2004) and Lombardi & van Servellen (2000) highlighted the persistent barriers to mental health, and addictions and police services experienced by trans subjects in their study. Findings from widely different jurisdictions – e.g. Boston (JSI Research & Training Institute 2000) to Ontario (Gapka & Raj 2003); to San Diego (Zians 2006) – echoed one another with stark similarity.

One of the larger studies to date, experiences of discrimination are a profound feature of trans communities in North America. Xavier et al.'s (2007) study of trans people in Virginia found that 1/3 of their sample of 350 had lost or been denied a job because of their trans identity. Almost 10% also experienced barriers to housing. From my own knowledge of the data set extending from my involvement as a co-investigator, data from Trans PULSE (n=432), while not publicly available, has echoed these findings.

With the problems experienced by trans people firmly established, the latter part of the past decade has seen research shift towards larger studies of trans people, particularly studies that encompass samples from more than one city (and that include trans people living in rural areas) as well towards using novel methodologies to produce more statistically robust data. At the same time there has also been a very recent emergence of work that seeks to make sense of the multiple challenges trans communities experience. Much of this research, including the study I have undertaken, draw on smaller qualitative samples to gain rich datasets that provide insights into the processes that shape the numbers larger quantitative studies are producing. The larger studies conducted more recently are Xavier et al. (2007) (n=350) and Trans PULSE (*forthcoming*) (n=432); both used the internet as the primary mode for data collection. Whereas earlier studies recruited from clinics and community spaces where trans people would most likely be found, these studies – though their methods varied significantly – provide a portrait of trans communities as larger, more diverse, and geographically dispersed, than ever previously thought.

While some larger studies have included younger trans individuals as part of their sample, there have only been a small handful of studies exploring the experiences of trans youth specifically and virtually all has taken place in recent years. Prior to the mid-2000s, popular accounts of trans people almost exclusively focused on trans adults – people who transition later in life, typically over age 30. Growing academic attention to 'trans youth' can be seen as a reflection of growing interest and awareness in our broader culture that many trans people come out during adolescence, a number that by all accounts seems to be increasing. Feldman & Bockting (2003: 2) note that "as the transgender population is becoming more visible... younger patients, including children and adolescents, are presenting with transgender concerns". A full 24% of participants in the Transgender Health Initiative Study (THIS) were 18-24 years of age (Xavier et al. 2007). Additionally, this same study asked a retrospective question pertaining to age at transition. A full 22% said they transitioned before they turned 20 and another 33% transitioned between age 20 and 29, meaning the significant majority of trans people in that study started transitioning prior to age 30. In Ontario, a recently released report by Trans PULSE (2010), from our

sample of 433 trans Ontarians found that 34% of trans people are age 24 or under.

Many of the problematic findings found in these large-scale studies of the general trans population were also replicated in studies of trans youth. Many youth encounter problems with finding stable housing. Eighteen percent of the sample in Garafalo (2006) were homeless and 50% of the 24 trans youth in a New York study did not live with their families (note that the average age of participants was only 16) (Grossman & D'Augelli, 2006). Physical harassment and violence are also issues for trans youth (Wyss 2004; Denny 1997). Sausa (2003) found virtually all the trans youth in their study had experienced physical harassment because of their gender identity and expression and three quarters had dropped out of high school.

Because of the spectre of homelessness and a relative lack of financial independence, recent work has illuminated the tension and fears youth have around disclosing they are 'trans' or 'transitioning' to their families and friends as well as doing so in schools or workplaces (Grossman & D'Augelli 2006). Grossman & D'Augelli (2006) also highlight the significant amount of work that youth engage in to come to understand themselves as 'trans' or to transition in a cultural milieu that sees such identities as 'wrong' or 'deviant' making the process of 'coming out' one that can compromise the safety, security, and wellbeing of the young trans person.

In an Ontario-specific context, there have been only three significant studies of trans people undertaken. Prior to Trans PULSE, the only data available was from smaller qualitative studies by Namaste (2000) & Gapka & Raj (2003), both small qualitative studies of trans people using convenience samples. Namaste (2000) provided a radical critique of the organization of services for trans people, and significantly set the stage for research and theory that would build on her study in particular Bauer et al (2009) and Serano (2007); I describe this work below. Gapka & Raj (2003)'s needs assessment echoed the same general findings found in US studies and provided the basis for more in-depth work to follow, including this study and Trans PULSE (2008; *forthcoming*).

I now focus on some of the most recent work that are providing more detailed and statistically significant insights into the health of trans communities. Not surprisingly, research has borne out significant mental and physical health challenges as a result of the profound experience of marginalization trans people experience. Studies have shown high levels of depression and suicide among trans communities (Lombardi, Wilchins, Priesing, & Malouf, 2001), particularly amongst adolescents (Garofalo et al. 2006). 2/3 of the sample in Xavier et al. (2007) study had considered suicide, while 41% had actually made attempts, a number slightly higher than the 31% found in Herbst et al.'s (2007) review of HIV-specific studies of trans people in North America.

One of the most stark pieces of data to come out of the current body of health research with trans communities are the significant rates of HIV found across various sites, particularly for trans women. High levels of HIV have been shown to be present in trans communities with documented prevalence rates from primarily convenience samples ranging from 11% - 86% (Kammerer, Mason, & Connors 1999a; Kammerer, Mason, & Connors 1999b; Clements-Nolle et al. 2001; Cope & Darke 1999; Namaste 1999; Reback et al. 2001; Kenagy 2002; Kenagy, G. P. & Hsieh 2005; Nemoto et al. 2004; Nemoto et al. 2005; Reback et al. 2001; Xavier et al. 2007). A recent meta-analysis concluded that for trans women, lab-confirmed prevalence from studies to-date was 27.7%, a number that increased to 56.3% for black trans women whereas the number was 2% for trans men. Self-reported rates varied greatly, between 6% and 30% depending on the racial composition of the sample.

To explain these very high rates of HIV in trans communities, researchers have called attention to the dearth of trans-sensitive HIV prevention and treatment services; moreover, in broader research studies and epidemiological data collection, trans people are systemically erased from the statistical record (Xavier et al. 2007; Bauer et al. 2009). Other suggested factors that contribute to HIV vulnerability for trans people include the high proportion of sex work involvement, alcohol and drug use, low self-esteem, depression and anxiety, injection silicone use, alcohol and drug use, and a lack of agency and self-efficacy in sexual relationships that further speak to the experience of marginalization witnessed by trans communities and as ways to start to understand the pathways through which social exclusion increases HIV vulnerability. A recent study (Sugano, Nemoto & Operario 2006) concluded that experiences of transphobia not only have an impact on self-esteem, but also are correlated with increased HIV risk among trans women. While HIV prevalence in trans men has been studied to a lesser degree (Kenagy 2005), recent work by Xavier et al (2005) found prevalence in trans men to be 3% in this Washington DC based study, higher than levels found for cis men on average.

With respect to trans *youth* and HIV, Sausa (2003) and Garofalo et al. (2006) remain the two sole studies. The sample of the latter found 22% (n=51) to be HIV positive and both drew connections to the high rates of sex work as a contributing factor. While sex work could be seen as a factor in increasing risk for HIV, it is important to recognize that this is one of the few viable ways for a trans youth to make a living, particularly in the face of having to save money for uninsured surgery and hormones, integral to their identity actualization in many cases. Both studies do not fully address some of the distal factors that can contribute to HIV vulnerability and poor health more generally. Later in this chapter, I will explore how such connections have only begun to be considered. Garofalo et al. (2006) note the particular challenges experience by trans youth of colour.

For trans populations, risk for HIV comes from many different sources. Akin to other marginalized groups, social stigma can lead to lower self-esteem which reduces the value one places on their life and the levels of risk they take (Bockting et al.1998; Namaste 2000). For example, the desire to have one's gender affirmed sexually can set up a dynamic where the trans person is less willing to advocate for their own sexual health in the face of such a selfactualizing experience (Kammerer et al. 1999). A lack of culturally relevant health and social services has also been linked to the spread of HIV and in compounding the marginalization experienced by trans people. Nemoto et al (2004) also discuss additional financial benefits that come with engaging in higher-risk (barrier-free) sexual activity.

While there have been multiple studies that have clearly shown HIV to be a significant problem in North American trans communities, and some have identified the proximal pressures that can lead to higher-risk activity, little has been done to understand how distal forces create the conditions for HIV vulnerability in the first place. Considering HIV vulnerability from a social determinants of health perspective allows us to explore how trans people, akin to other marginalized groups, are at greater risk for HIV.

Connecting these distal measures and proximal actions are a cascading series of events and actions that shape the experiences of individuals as they move about the world. What is important to point out is the lack of research and thought into making visible such inter-connections that could assist us in better understanding the production of poor health in trans communities. However, this is not the fault of academics solely; some of the tools and language to surface the social production of trans marginalization have only recently been come into existence. Therefore, the literature related to making sense of how trans marginalization comes to be – from individual risk to HIV, to barriers in health and social service contexts, to common-place experiences of violence, harassment, and discrimination at home, work and school – are both recent and sparse. Two sections down, I will explore in greater detail this nascent work related to understanding trans marginalization and, pursuant to this study, show how it can help us understand the organization of health care and the management of trans identities in these clinical contexts.

In the next section I will explore in greater detail the current data available as it relates to trans people accessing health care services, particularly transspecific care (hormones and surgery).

# 2.4: Trans Health Care Access: Differing Approaches to the Care & Organization of Trans Identities

Many studies have indicated that trans people can experience significant barriers to accessing health care. Xavier et al. (2007) noted that a third of the sample experienced barriers with respect to accessing hormones or surgery. Not surprisingly, these barriers were most commonly associated with the perceived lack of knowledgeable providers and an inability to pay or to have services covered by insurance. The same problems were identified several years earlier in JSI Research & Training Institute Inc (2000) study of trans health care access in Boston where the lack of knowledgeable and sensitive providers alongside cost barriers were identified as the two main barriers to care.

Accessing health care is often a challenge for trans people of all ages but is particularly challenging for youth. Davis (2002:1) notes that locating relevant health services "is a particular challenge for transgender-identified people, regardless of age. Being young, or a minor, and not having parental support, one's own financial resources, or even the means to get to medical appointments can make medical care nearly impossible for some trans-youth to access". Lombardi (2001) highlights how such barriers can lead to enhanced risk: "current constraints on access to medical care related to gender changes may place people at risk by forcing them to seek unsafe methods of making these changes (e.g., using hormones bought off the street, sharing needles while injecting hormones)". Garofalo et al. (2006) empirically reinforce this link by noting that 29% of youth in their study injected silicone and 71% had used hormones bought off the black market. These rates are quite different from those found by Clements, Katz and Marx (1999) where over 70% of 392 adult MTFs and 97% of FTMs on hormones obtained them from a medical provider.

As this study will explore the social organization of the work that trans youth in Ontario do to actualize their identities, it is important to look at the current state of knowledge related to trans people and health care. This is a sprawling topic with many different stakeholders working from disparate paradigms with divergent research questions. As iterated above, a great deal of 'health research' is undertaken in clinical settings by the same providers who are providing care. In these settings, the mental health provider is simultaneously the 'gatekeeper' to trans care (hormones and surgery) as well as researcher. The power differences and implications for compromised clinical care and for creating questionable validity with respect to such research data has been raised by Lev (2005) and many others since. This body of clinical research is oriented to creating knowledge about the natural history of a psychopathology, assessing instruments used to diagnose 'GID', as well as creating typologies of different types of 'GID'. Most recently, particularly in light of the upcoming revisions of the DSM in 2012, research and writing has been focused on considering how the 'GID' criteria should be revised and if, and where, the diagnosis of GID (or some other modified diagnosis) should be in the DSM-V come 2012 (Drescher 2010; Cohen-Kettenis 2009; Meyer-Bahlberg 2009).

Lev (2005) offers a strong critique of the impact that a gatekeeper can have on sabotaging the physician-client relationship. Bockting et al. (2004:279) notes that "the fact that a mental health provider makes this decision [to determine eligibility for hormones and/or surgery]...reenforc(es) the notion that applicants for sex reassignment suffer from a mental disorder".

Williamson (2010:221) notes that trans people are seeking care in increasing numbers in Primary Care settings but that the demand is often not being met as "many health care providers find it difficult to care for them because of a lack of formal training and few professional resources". Feldman & Bocking (2003), in providing an overview of what trans health encompasses, note that "transgender persons represent an underserved *community* in need of sensitive, comprehensive care"; their work represents one of the first attempts to not frame the provision of trans-related care as contingent on a diagnosis of GID.

As the shift towards addressing the health needs of trans people in Primary Health Care settings has progressed, there have been various attempts to provide Guidelines to organize these practices. Publications by Feldman & Goldberg (2006) for trans men and women as well as Gorton (2007) for trans men have become adopted as North American 'Best Practice' guidelines by many Primary Care providers. Recently, the Sherbourne Health Centre in Toronto – a health clinical prominent in the delivery of trans care in Primary Health Care settings – has also published their medical protocols, further increasing the availability of other peer-driven practice guidelines. Such work has arisen in the absence of significant body of clinical literature. In some ways this absence makes sense given the key empirical research questions related to trans care in

such contexts would be on issues of health care access and equity rather than work relating to prevalence, etiology and nosology. The purpose of clinical research as it relates to trans health care in Primary Health Care settings is thus somewhat obviated, however the guidelines by Feldman & Goldberg (2006) and Sherbourne Health Centre (2009) provide important guidelines for the provision of quality care.

The social determinants of health have increasingly grown in significance as research has highlighted that marginalized groups are at increased risk for disease, ill health, and decreased well-being (Raphael 2004). The social determinants of health encompass a number of distinct but related elements – including housing quality, education, as well as income and poverty measures – that all orient towards how illness and disease is socially produced and unequally distributed. Understanding the pathways through which health and illness are socially produced and mediated provides insight into how particular groups are simultaneously at risk for a number of illnesses. Such an understanding also refocuses the work of policy-makers and health promoters and those working with marginalized groups away from the risk behaviours, the resilience strategies, and other interventions aimed at the level of the individual and instead brings to the fore the important factor that the social world – and its composite institutions and services – play in the production of ill health for such groups.

While the social determinants of health have begun to make their way into ways that we understand the health of marginalized communities, such as trans communities, it is important to note some of the limitations of this work, at least as it has been carried out to date. Research with trans youth and adults, to date, has primarily been documentative and descriptive. Little has been done to connect in greater detail the ways that social determinants of health impact health or to provide a framework for understanding *how* and *why* trans communities, in particular, experience barriers to care, discrimination, and harassment and experience poor health as a result. While recommendations for improvements to services are often noted, few have explored some of the sociolinguistic, institutional, politico-legal, or financial (i.e. insurance billing) challenges that have created, and that sustain, the current way that health care is delivered for trans people. It is this gap in the literature that I hope to shed some light on with the analysis I undertake in this thesis.

### CHAPTER 3:

## METHODOLOGICAL FRAMEWORK, DATA COLLECTION & DATA ANALYSIS

This chapter is divided into two sections. The **first** section explores the methodological framework that shaped the research. It introduces the research tradition of Institutional Ethnography (IE), and how it is ontologically and methodologically distinct from other approaches to undertaking research. This section explores the way that IE has been used in different research contexts, with a particular focus on how it has been used in research related to health and to research undertaken with marginalized or under-represented groups. I also delve into how using IE produces unique insights into how the social world is organized and elucidate why it was that I chose IE as the methodology for guiding this research. An introduction and justification of qualitative methods more broadly forefronts this overview of IE.

I also highlight how I worked to create a community-based research (CBR) project to undertake this research. I detail this Project – the Youth Gender Action Project (Y-GAP) – which represented a partnership with an agency in Toronto that did significant work with trans youth. The empirical data that this thesis draws from were the 21 interviews undertaken by Y-GAP. I also delve into the relative strengths and benefits, drawbacks and strengths, of this research strategy.

The **second** section describes the data collection and analysis process. It explores how I worked in an iterative fashion over the course of data collection,

and in the reading of the research transcripts to refine the central research question and the eventual analytic trajectory of this thesis.

#### **3.1: Methodological Framework**

This section provides an overview of qualitative research in general, and introduces the research tradition of Institutional Ethnography (IE) specifically. I provide an overview of the unique qualities and implications of IE research and discuss my reasons for choosing qualitative methods and IE in particular. I also highlight how using IE research was integral to shaping the data that were produced and the subsequent analytic avenues opened up and explored in the subsequent chapter. I focus in particular on IE's commitment to materialism as well as its ability to empower marginalized groups, particularly through its relevance and responsiveness to the experiences of such groups. The latter part of this section explores how the data for this analysis was drawn from a broader community-based research (CBR) project. I explore the relative benefits and drawbacks of this arrangement and explore how it shaped the data collection and analysis presented in the next section.

I chose to use qualitative research in this particular project as it provided for a rich description of the experiences of trans youth that, as noted above, has not been adequately articulated in previous research. The use of qualitative methods provides an opportunity to develop an understanding of the social world from the standpoint of those whose perspectives and lived experiences are often subjugated to accounts that are more dominant or official, if not missed altogether (Smith 1987).

Qualitative research provides many unique benefits for understanding the health of particular populations. It can offer insight into the actual lived experience of a specific community, it can understand the ways a given group of people experience their own health and illness, how they understand and prioritize such experiences, and how these interface with broader social processes and institutions. Qualitative methods can also be particularly useful in cases where gathering a statistically representative sample is not feasible. Trans populations and trans youth specifically, represent an example of a hidden population (Heckathorn 1997). A hidden population is one where a relevant sampling frame is not available. Under such circumstances, qualitative research provides the richest possible data given the pragmatic limitations of the sampling possibilities.

The data produced through qualitative research yields a particular type of knowledge that is distinct from data extracted using quantitative approaches to research. Whereas quantitative research seeks to measure the distribution of particular features of a given population (descriptive statistics), or to understand the relationships between different features of the population or against external controls (analytic statistics), qualitative research does not try to draw conclusions about a population or attributes thereof. The goal of qualitative research, put simply, is to "describe life-worlds from the inside out, for the perspective of the people who participate... [in order] to contribute to a better understanding of social realities and to draw attention to processes, meaning patterns and structural features" (Flick, vonKardoff & Steinke: 3).

Qualitative methods permit an understanding of the lived experience of communities who are often not understood by researchers. Qualitative research can offer up alternative perspectives on the social world, particularly ones that are typically occluded when working within discourses and frameworks that intend the norms, values, and perspective of those who hold power. Taking account of the way in which power is implicated in the creation of knowledge, and the way it shapes the research agenda itself, is a hallmark of feminist input into sociological and health research (Smith 1987). The use of qualitative methods as a means to offer up alternative perspectives on the social world, in particular ones that that privilege the lived experiences and perspective of marginalized groups, can be traced back as far back to Goffman (1961) who employed qualitative methods to garner the perspective of patients in psychiatric institutions. This work used the perspectives of the patient to disrupt the discourse about 'inpatients' that naturally intended the perspectives of those who held power – the doctors and administrators of the institutions.

I chose to use the specific qualitative research strategy of Institutional Ethnography (IE). IE starts from an exploration of how subjects accomplish their everyday lives, typically as this is expressed in interviews, to explicate how ruling relations reach into and actively shape the work that participants engage in (DeVault & McCoy 2003). Ruling relations are typically systems of organization that coordinate activities across multiple sites (Smith 1990), these can include *physical* forms of organization such as professional bodies, administrations and institutions as well as *intellectual* forms of ruling including dominant discourses, such as the parenting discourse that Smith (1987) wrote

about in her foundational IE text. IE draws particular attention to the ways that the everyday world is coordinated through material interactions with systems, texts, rules, processes, and other devices that regulate the activities of social actors. These devices provide for trans-local coordination of activities across various physical sites and that homogenize the intellectual relations of ruling noted above. While ruling relations often exist outside the purview of people's everyday experience, the interest for IE researchers is to explore how ruling relations manifest and coordinate the everyday lives of research participants. In this fashion, the everyday lives of particular groups are used as a point of entry into examining how dominant institutions and ruling frameworks are actively shaping the social world.

IE research, in its work to understand how ruling relations achieve social coordination, consciously deploys its analysis from a starting point within the lives and standpoints of given groups of people. In this way, materialism is an integral and distinguishing aspect of IE research. Materialism builds on the substantive and observable actions that take place in the lives of actual people. IE looks at how these actions are hooked into broader forms of organization that operate at multiple sites. Moreover, a materialist approach to understanding the social also looks at how actions are coordinated by *other* sequences of action, in other words the focus remains, as one moves through an IE analysis, on how material actions get coordinated *materially*.

To elaborate on how this looks in the context of this specific research, the analytic endeavour stays focused on exploring the material coordination of the everyday lives of trans youth, or at least a specific facet of it. As I will elaborate on below, I chose to focus on the social coordination of trans care to make sense of the way that the process of coming to actualize one's gender identity was organized for the youth I interviewed. Thus, working with a materialist ontology, the social coordination of trans care gets explicated through concrete and observable processes, interactions, and texts that were directly or indirectly interfaced with by the research participants I interviewed. Thus, explanations or rationalizations of participant experiences that orient to conceptual, theoretical or rhetorical device, such as "she was denied health care access because of the cissexist organization of the community health centre" are avoided in favour of materialist explications. These articulate how the embodied actions of participants came to exist as a function of the practices of professionals, and the medical and politico-legal relations that shape care trans-locally across Ontario (and with some applications for other jurisdictions as well).

To provide an understanding of how an IE methodological framework orients in unique ways to the specific social problem being investigated here, let us consider the exclusion of trans individuals from health care services. Many needs assessments, noted in the previous chapter, have repeatedly documented the shortcomings and barriers experienced by trans individuals in health care contexts. Typically, the studies orient to documenting, measuring, and parsing apart the particularities of the barriers, often concluding that the exclusion is a specific example of "transphobia" or, more recently, "cissexism". Whereas these terms offer utility in advocacy and equity contexts, they can achieve an almost reified status so as to obfuscate the material processes that give rise to such instances of "transphobia" or "cissexism". In other words, every instance of a

trans individual experiencing a service barrier can be attributed as "transphobia" or "cissexism". This explanation, however, circumscribes investigation or explication of the material, embodied actions and processes that actively produce the exclusion. Therefore, the materialist focus of IE research makes visible the way that, in this instance, exclusion is actively produced in the work of institutions in individual actors within those setting. In this research then I shift the research problematic away from the documentation of specific instances of cissexism and transphobia and towards the materialist organization of trans care. Providing a foundation for such critiques is the work of G. Smith (1990:634) who illuminated the limitations of understanding bathouse raids as instances of 'homophobia' noting that "instead of events being actively produced by people in concrete situations, they are said to be "caused" by ideas such as "AIDS-phobia".

The unique value of IE research is making visible the organization of the social world in ways that offer up understandings that do not rely on the language or explanations provided to us as researchers as a function of the ruling relations. Making sense of the everyday world presents challenges because the way in which it is coordinated is not often (easily) visible. The workings of institutions are often enshrouded from view, convoluted by an internal logic and discourse that obfuscates their effect in shaping the everyday lives for given groups.

IE has frequently been referred to as a "people's sociology", as a way to privilege and understand the world from the perspectives of actual people. IE's central analytic strategy is to understand how institutional processes of organization and action achieve their coordination and regulation of people's

everyday lives and provide individuals with great knowledge to subvert and challenge domination. In particular, extending from its origins as a research strategy that explores social organization from the everyday lives of women, IE may have particular value to marginalized and non-dominant groups. Thus, while originally devised as a strategy to give voice to the perspective of women, IE can be used to understand how the day-to-day lives of *any* group are coordinated by ruling relations.

The origins of IE as a "sociology for people" (Smith 2005) underscores its intention to ensure research is relevant to, and usable by, groups participating in the research process. IE arose from 1970's feminist activism, methodologically drawing from Marx's concerns with materialist issues of work and production as well as Garfinkel's approach to ethnomethodological description of lived experiences (DeVault & McCoy 2003). The specific catalyst for IE was Dorothy Smith's experience of the women's movement (1987). Smith was drawn to finding ways to work from her standpoint as a woman, rather than having to start from the theories and perspectives of dominant groups. The motivation for IE work, as this methodology would later go on to be termed, rests in an assertion that the mechanisms that coordinate the everyday lives of women (and this has subsequently been broadened to other groups, particularly those that are non-dominant) are rendered wholly or partially invisible to established forms of inquiry. IE thus details how the work individuals engage in is hooked into broader processes of social organization and coordination. In this manner, ethnographic description is only the starting point for inquiry in IE research. Campbell (1998: 56) describes the lived experience as participants as a "ground"

zero of analysis". It is from such a standpoint that the analysis departs, and to where it returns, both conceptually as well as pragmatically. Campbell (1998:56) notes that IE analysis can "open up possibilities for people who live these experiences to have more room to move and act, on the basis of more knowledge about them".

As suggested by Campbell (1998) above, IE researchers have been keenly aware of its potential to empower subjects (Jagosh 2002). Campbell & Gregor 2004: 128) note that, "rather than supporting a ruling perspective and approach, (IE) should... make texts that express the standpoint of people and to help make them available to those who will use the work's subversive capacity in their own struggles". IE's direct relevance to community activists and organizations can, at times, be problematic. The findings from an IE inquiry may, for example, not align with the particular needs or perspectives of community members (Smith, G.W. 1990) and can, as Mykhalovskiy & McCoy (2002: 21) describe, direct "community activists to reflect on their own forms of knowing".

In line with its origins in feminist and Marxist priorities that privilege the subjectivity of excluded and subjugated groups, IE research studies have very often been used to understand the way that ruling relations achieve coordination and control in the embodied existences of such groups as queer/gay (Smith, G. 1988; Khayatt 1994; Smith, G. 1998; O'Neill 1998) as well as trans (Namaste 2000) individuals, among others. These studies have engaged with the work that queer and trans people undertake in their everyday lives. Taken together, they highlight the difficulties encountered by these groups but, more significantly, they also problematize those challenges through an exploration of their genesis

in social and institutional processes involved in the coordination of these groups' everyday experience. Thus, when focused on articulating the standpoints of queer and trans people, IE has employed a materialist ontological approach that traces how the actual everyday for these groups is shaped and produced through forms of social coordination frequently hidden from view. Namaste (2000) notes that while many scholars who apply IE methods typically focus attention on one institution or a specific aspect of the ruling relations, this may not be ideal in some circumstances. Namaste (2000: 256) goes on to note that "such a circumscribed inquiry may also present some methodological dangers by neglecting other important aspects of the everyday world. If institutional ethnography is valuable precisely because it shows how the world works, its greatest weakness for general social theory may be its restriction to one institution". Her interpretation of IE research directs us to consider how ruling relations compound, and interrelate with, one another.

IE studies often attest to starting form the standpoint of particular groups or individuals that are subjugated by ruling relations. This gesture towards operating as a "people's sociology" alludes to IE's supposed ability to create unique ways of understanding aspects of our social world that would not be ordinarily knowable through "traditional" forms of sociological research. Because ruling relations typically frame research priorities and lend the tools and language and analytic focus of such traditional forms of research, IE research attempts to step outside of this dynamic. Consequently, IE praxis seeks to generate knowledge about the ways that ruling relations shape and coordinate the lives of individuals within particular groups or interacting with a given facet

of the social world. Rather than borrowing from conceptual or theoretical concepts to make sense of the coordination, IE research systematically and inductively traces the coordination from the actions of a given group of people into the forms of social organization that make visible the coordinative function of the ruling relations. This is the particular analytic trajectory I use in this study. In this work, the everyday lives of trans youth are used as a point of entry into understanding the social organization of the health care system they are accessing, or attempting to access. I also explore other ways that trans identities, and gender more broadly, are regulated in Ontario.

In addition to using IE, this project also draws from the research tradition of Community-based Research (CBR). These traditions share some common attributes, particularly in relation to the central role that participants play in the research process. CBR privileges participant priorities, knowledge and experience as integral to the production and interpretation of the research data. It seeks to produce data that is relevant and responsive to the research subjects and their respective communities. IE research strategies also privilege participant experiences as central to its materialist endeavour to understand how the everyday lives of particular groups of people are coordinated by broader social forms of coordination. While there have been few instances wherein IE has been used in conjunction with a project that explicitly defines itself as CBR in nature, there is a significant lineage in IE research where participant involvement is both significant and formative (e.g. Mykhalovskiy & McCoy 2005; Campbell, Copeland & Tate 1998; Making Care Visible Research Group 2002) Many IE researchers, including myself, undertake IE research to address aspects of the social world that are often closely relevant to their lives. Often this means developing their research problematic in response to particular disjunctures they may observe between their everyday lives and the world in which they find themselves embedded. Other IE researchers work closely, to varying degrees and in different ways, with particular groups who's everyday worlds form the epistemic ground zero of their research endeavour. In this way, IE and CBR share common goals of creating bodies of knowledge that centre on the relevancies of the everyday lives of groups often under or mis-represented in research.

Frequently, IE work has been initiated by those actually working in a particular setting who wish to explore how their everyday work is organized by ruling relations (e.g. Diamond 1992). In a similar vein, my lived experience as a trans woman is not an incidental component of the methodology but one that – as described above – is central to the motivation for this work and the direction I am taking it.

This issue of having an 'insider perspective' is one that is controversial and much has been written about the insider/outsider dichotomy in CBR. Minkler (2004) provides a strong case as to why being an insider researcher can be advantageous, particularly when researching with a marginalized group. An insider researcher can have a greater attunement to community objectives and stronger insight into the problems that may be experienced by community members. This is particularly key when there is little research to draw from, as is the case in this study. In contrast, critiques of doing research 'from the inside' are typically framed within positivist norms and assumptions about the role of the researcher and their relationship to the objects or phenomena they study. Insider knowledge, in a positivist light, becomes a handicap as it precludes the objective production of knowledge, which is the goal of positivist methodologies.

In carrying out this research, I worked closely with Dr. Nicola Brown at Central Toronto Youth Services (CTYS), a youth services agency that works with trans youth in Toronto. CTYS is undertaking a study of trans youth concurrent to this one. The unlikely circumstance of having two studies of trans youth occurring simultaneously, particularly as very little has previously been done, made this collaboration a necessity to ensure minimal overlap and redundancy of information, minimize participant burnout, and to maximize support for participants and the potential for social change extending from the research projects.

The two projects remained independent research projects with our own internal research questions and objectives and with our own respective publications. While the two projects are distinct, we worked together in the following ways:

- i) in creating a common 'face' for the project, called the Youth Gender Action Project (Y-GAP) – this name was present on all recruitment posters and on the project website;
- ii) in collaborating in the preparation of our empirical work, specifically the separate interview guides, so as to minimize, where possible, overlap and redundancy;
- iii) in recruiting and scheduling of research participants;
- iv) in developing knowledge translation (KT) materials including the project website, a handbook for parents of trans youth, and infosheets that focus in depth on various facets of trans youth lives.

In essence, Y-GAP represented a community-based research (CBR) project in which my thesis, and the work of CTYS were embedded under a single umbrella with a common goal to understand the lives of trans youth with an eye to enhancing services for this group. Y-GAP comprises a pragmatic CBR partnership between an institution and a community member with the aim of enhancing the gathering and dissemination of data.

This project was unique as a CBR project as both the academic research partner (myself) as well as the community partner (Dr. Brown) both had unique and strong connections to, and trust within, the community participating in the research. In addition we hired and mentored a Peer Research Assistant from a small grant that we successfully applied for from the Community One Foundation, a Toronto-based Lesbian, Gay, Bisexual and Transgender granting organization. Additionally, key trans youth community members were consulted with respect to the development of our KT strategy and the various publications that have been created including a guide for parents of trans youth as well as various infosheets on different facets of the trans youth experience. Thus, while this thesis focuses on one aspect of the lives of trans youth who participated in this research, the broader Y-GAP project examines the experience of being young and trans in a more holistic manner. In this way, it attempts to respond to Namaste's critique of IE research, noted above.

For the purposes of this project, CBR can be seen as having four attributes that distinguish it from other approaches to research: the active pursuit of *social justice* through the process of research and knowledge generation; developing a strong community connectedness including building partnerships and engaging community members where possible; a *critical curiosity* towards the production of academic knowledge that seeks to shed light onto injustice, and; an active component of the research process that recognizes the agency of communitymembers and participants to identify the shape and direction of such action (Reitsma-Street & Brown 2004).

CBR does have some shortcomings. In particular, it often does not extend the analytic frame very far beyond the priorities and exigencies of participants. Within IE however, there are attempts to gather information that may extend beyond the local picture. For example IE seeks to develop an understanding of how texts shape the everyday lives of subjects. In the instance of trans youth, it is integral to explore how documents and forms give rise to particular textuallymediated institutional processes related to the organization of health care.

Positivist approaches to research position the researcher as dispassionately removed from the power structures they are embedded in as they make sense of the social world. In such instances, striving to be objective blinds the researcher to the particular biases and assumptions they may be bringing with them into the research process (Becker 2004). Instead, researcher reflexivity can draw attention to their own role in the creation of knowledge. In my thesis research, I worked from an understanding of the social world as nonstatic and dialectic. In this vein, I oriented towards an explication of the social organization of the world that trans youth inhabit.

In contrast, non-positivist approaches call for an altogether novel reconnection with the lived experience and embodied knowledge of research participants. They also call for a critical and self-reflexive lens to be trained on the researcher herself and the role she plays in shaping the research agenda and process and in the production of knowledge itself. This course of research thus yields knowledge about the *experiences* of a given set of subjects but also, and arguably more importantly, goes beyond a simple ethnographic rendering and uses the perspectives garnered through the research as a way to provide an understanding of the systems and structures that comprise the social world. The way in which the social world systemically produces injustice, and in turn, ill health is often obscured through dominant discourses on health that (dis)locate the site of illness etiology and intervention at the level of individual bodies and behaviour. This displacement towards objectifying, static, and individualistic understandings of the social world is similarly reflected in positivist research because it is not critical of its inherent biases and assumptions.

In sum, the methodology I used was committed to privileging the perspectives and everyday lives of trans youth while striving to avoid the negative and objectifying circumstances frequently experienced by trans people with respect to research (Namaste 2000).

#### 3.2: Data Collection & Analysis

The empirical foundation for this research is comprised of 21 face-toface interviews conducted between August 2007 and June 2008 with trans youth in Toronto and Ottawa, the two large urban centres in Ontario, Canada. These interviews consisted of open-ended questions around particular facets of the participants' lives.

Undertaking a research project with trans youth raised several unique difficulties. Challenges presented themselves around reticence to participate in a

'trans' study. Many trans people are either 'closeted' or 'stealth', in other words they may not feel safe with respect to the confidentiality of being involved in a research study. Given the visceral harassment, discrimination experienced by those who are read as trans, many trans youth are reticent to 'come out' and identify as 'trans'; conversely, there are also a great number of trans youth who are 'stealth' and who do not openly disclose their trans identities (or trans histories, as they may be more inclined to term it) for fear of retribution. Thus, the same encounters with social stigma that can affect trans people in their dayto-day lives also serves as a significant challenge to those doing research with trans communities through discouraging potential participants from taking part in a research study that may, potentially, 'out' them.

To counter challenges to involvement of participants, honoraria were offered and interviews were conducted at locations where participants would feel most comfortable. In some cases, interviews were held at LGBT community spaces, such as The 519 Church Street Community Centre however more commonly interviews took place in the respective homes of participants. Moreover the inclusion of myself, as a younger trans woman researcher also helped as it yielded connection to trans youth and enhanced trust amongst participants who were recruited. Lastly was the framing of the research as an important piece of work that will engender benefits to the participant through the knowledge that is produced, particularly with regards to improving service access.

Recruitment for the interviews took place through several pathways to ensure heterogeneity of the sample and a diversity of the accounts provided.

Methods used to recruit participants included using an email recruitment message sent out through trans youth social networks and list-serves dedicated to trans youth or to providers and agencies working with trans youth. These included high school Gay-Straight Alliances, university LGBT organizations, and trans youth groups across the province. Other methods included an ad placed in a local 'gay and lesbian' newspapers, face-to-face recruitment through outreach at trans youth groups and at bars where trans people frequent. Lastly, chain referral was also used wherein participants who already participated would suggest participating to other young trans people.

The inclusion criteria for the research were to self-identify as 'trans' or 'transitioned' and to have taken steps to change one's body or appearance. This latter criterion could be satisfied by any or all of the following: the use of hormones, having had a trans-related surgery, or through significant changes in one's physical presentation so as to live socially – or be working towards that goal – in a gender role different from the one assigned at birth. Participants had to be between age 16 and 25, inclusively at the time of the interview. The upper age-limit cut-off was chosen as age 25 is the standard cut-off in Ontario for many youth-specific programs and services and to have a significantly young sample of individuals to distinguish this study from previous studies of the broader trans population. The lower age-limit cut-off was chosen because of concerns around consent challenges for those under 16. Additionally, given that this research focuses on health care services, the lower age limit was an ideal choice as it coincides with the age limits commonly in practice with respect to the provision of assessments, hormones, and surgery related to changing one's

gender in medical contexts, such as the Standards of Care published by the World Professional Association of Transgender Health (WPATH).

Honoraria were given to participants in return for their involvement in the research. Participants were given \$20 for completion of my section of the interview. For those who also completed CTYS' portion, an additional \$20 was provided by CTYS. Honoraria are often used as a motivational tool to increase participation, particularly for those where the time and expense of attending or completing an interview may represent a barrier to their participation. In a CBR context, honoraria can be seen not only as an incentive in this sense, but as an ethical imperative that signals an attempt to signify the important and integral nature of the participants lived experience and embodied knowledge.

The particular approach to sampling used in this research was standpoint sampling (Smith 2002), a variant of purposive sampling. Purposive sampling strategies seek to gather a broad representation of a given community in lieu of gathering a 'representative' random sample. Purposive sampling also seeks to gather a sample that will provide the richest source of data to address the particular research question being explored. In this project, this meant seeking out a diverse array of accounts around being young and trans in Ontario. As the analytic focus began to distil as the research progressed, particular attention was paid to the experiences that participants had in relation to accessing health care so as to capture a diverse array of accounts that would yield the most diverse insights into the organization of health care for trans youth in Ontario.

Interviews took approximately 90 minutes, although some were significantly shorter or longer. The interview was divided into two sections where I conducted one half and Dr Brown conducted the second half. We alternated who got to interview the participant first. Towards the end of data collection I also undertook three interviews with participants who provided accounts that I felt had not been captured by previous interviews. These were, in particular, trans women of colour and trans women involved in sex work.

IE offers a particular approach to interviewing that directs participants to focus on their day-to-day experiences, particularly around the work practices and activities they engage in. This kind of information provides tangible points of entry into understanding how trans-local institutional processes shape people's local experiences. In the interviews I started with open-ended questions like "what is a typical day like for you" and "what has your transition looked like so far" to provide participants with the opportunity to talk about the work they engage in without pretense or assumptions about what their lives *should* encompass or look like. From this relatively open-ended starting point, I delved into greater specifics about the work that youth engage in with respect to transitioning and surviving (in a broad sense) particularly as it relates to particular services and institutions, and health care, in particular.

The interviews were semi-structured. There was a list of topic areas that I wanted to cover. These topic areas involved lines of questioning related to the everyday activities participants engaged in with respect to living as a young trans person in Ontario. Areas covered included the work that participants had to do: to come to self-identify as trans; to find employment and housing; to access general as well as trans-related health care; to change their identification documents; to avoid and cope with the spectre of violence and discrimination,

and; to come out to, and get support from, parents, partners and peers. Broadly taken together, the line of questioning drew attention to the diverse forms of work that participants engaged in to come to understand themselves as 'trans' and accomplish their physical and social gender transitions. The particular order of the topics varied between each participant; the length of responses and amount of time spent on each area also varied.

In contrast to the sequencing in quantitative research (and many qualitative forms of research as well), the "analysis" in IE research often starts during the process of data collection. In this study, the analysis started while I was conducting each interview. During the interviews, I paid particular attention to accounts of work activities that provided points of entry into forms of social organization that organized the everyday lives of trans youth. I probed further, in these instances, to garner more in-depth information about what participants had to do to accomplish accessing health care or find housing, as two examples. I tried to focus the discussion on the things that participants actually did, such as the places they went, the conversations they had, the preparation they engaged in, and the research they did. In IE research a significant part of the analytic work directs us to examine how textual forms of coordination organize the everyday activities of a given group. Therefore, in the interviews I also tried to draw out accounts of participant interactions with various forms, guidelines, and other texts. Some critiques of IE, for example Walby (2007) point out that this analytic orientation directs participant accounts away from a simple description of the "everyday" and produces accounts that respond to the analytic imperative incumbent to IE research strategies. While I agree with such critiques, I do not

feel they undermine the integrity of the IE research endeavour. While it may not provide unbiased accounts of the "everyday lives" of a given group, as its proponents often claim it does, its analytic orientation to the textual organization of the everyday provides a unique way to understand the social world. In particular, I feel that IE offers an analytic strategy that provides insight into how ruling relations function through various texts to produce social inequity. IE illuminates the way that the organization of the social world, as it is manifest in material texts, can favour and forefront the goals and perspectives of groups that have power and produce consequent negative outcomes for those on the margins.

While the analysis started in the data collection process, as described above, the bulk of the analysis occurred after the interviews were complete and transcribed. My analysis drew on data from the interview transcripts as well as various forms, documents, and other texts. In some cases these were texts that participants referenced explicitly in the interviews. In other cases, I worked inductively, exploring how the particular experience of identity actualization for trans youth was shaped by specific texts. A key part of an IE research endeavour, in this case, involved an elaboration of how these texts organized the work participants did to actualize their identity as 'trans'. Texts such as the DSM-IV, as I elaborate on in the next chapter, shaped the way that health care for trans youth was organized in Ontario and thus was key to making sense of the work participants engaged in related to identity actualization.

The 21 interviews were transcribed verbatim using a word processor. This created over 800 pages of raw data in the form of interview transcripts. In the

process of listening to the transcripts as I transcribed them, and in the process of reading and rereading them, I began to consider how to make sense of the vast amount of data I had before me. Considering I was forefronting the concept of "work" in my line of questioning, I began to consider how the everyday activities that participants described could be seen as instances of 'transition work'. In this way, I oriented to the work that trans youth engaged in, specifically that of existing in this world as trans, from a materialist lens.

Transition work builds on the expansive notion of 'work' that is an ongoing analytic development in IE research, for example Mykhalovskiy & McCoy's (2005) application of 'health work' to describe the activities PHAs engage in around maintaining their health. This provides for a more expansive notion of work that includes activities within the medical system but can encompass other activities and strategies PHAs use to maintain their mental, emotional and physical well-being.

From the interview data, I began to consider how transition work could be broken into constituent parts that, for the purposes of my thesis research, would allow me to explore one aspect of it in greater detail. The facet of transition work that seemed most amenable to further investigation using an IE research strategy was the work participants engaged in as it related to *actualizing* their identity as trans; I introduced the term "identity actualization" to provide a term that encompassed these diverse activities. The utility of such a term was integral. From an IE standpoint, it provided a way to materially explore the social world and make sense of the work that participant engaged in without needing to reference or borrow from pre-conceived notions or frameworks of what trans

youth were doing. The choice of explicating how identity actualization was organized made most sense as it permitted an analysis of the ways that trans identities are organized in the social world. Woven throughout all of the interviews was a shared struggle to come to identify as trans, make physical changes to one's body, and to socially and legally change one's gender. Taken together, this encompassed 'identity actualization' as I will explore in the next chapter. These various activities all draw attention to the ways that trans identities are organized in our social world. As the analysis progressed, it became clear that trans identities are often obviated, regulated, and rendered as non-normative as a function of the textual organization of gender in our social world.

I revisited the interview transcripts with this particular notion in mind. I pored through the pages of data and pulled out references to the various forms of work that participants engaged in to actualize their identity as trans. I encapsulated large passages, distilling the central forms of work that a given participant did in relation to figuring out they were trans, making changes to their body, 'coming out' as trans in their everyday lives, accessing relevant health care services, and legally changing their gender.

After extracting an expansive and diverse range of data from the interviews as it related to identity actualization, the next analytic step was to try to make sense of how these experiences came into being. The role of the researcher in IE is to explore the coordination of the everyday lives of a given group. Often this entails expanding the analytic frame beyond the everyday and into the forms of coordination that can be traced out of participant accounts and into the relations of ruling in the broader social world. With this work, I explicated participants' experience of identity actualization by turning my attention to the texts and practices that regulated the various forms of work I had drawn out of the interviews. In particular, I explored how identity actualization, as an embodied experience, was organized as a function of specific medical, psychiatric, and politico-legal texts and practices.

In sum, this research positions the everyday lives of trans youth at the centre of the analysis. From this starting point, I trace how ruling relations function to organize the particular experiences that participants engaged in with respect to identity actualization; this encompassed delving into texts that served a coordinative function with respect to the organization of trans care and the regulation of trans identities in the Province of Ontario.

The next chapter offers my analysis. It presents a detailed, empiricallygrounded description of the various forms of work participants engaged in as it related to identity actualization. It tells a story about how trans youth come to exist in the social world. It does this through using "transition work" as an analytic resource to make visible the significant struggle that trans youth undertake to actualize a trans identity, in particular accessing trans health care such as hormones and surgery. Most centrally I hope that the following chapter illuminates and then explicates the "struggle" – revisiting the title of this thesis – that trans youth experience in their articulations with health care.

## **CHAPTER 4:**

## THE SOCIAL ORGANIZATION OF TRANS IDENTITY ACTUALIZATION

This chapter explores the work that participants did to *actualize* their gender identity. Most centrally, this encompasses the activities they engaged in to make their bodies more congruent and reflective of the gender to which they were transitioning. Participants were motivated to undertake these activities in order to "embody" their gender and make it socially intelligible. In other words, they wanted their bodily selves to be congruent with their gender. They wanted to be able to fully live in their day-to-day worlds, physically, socially, economically, and sexually with as much gender-body congruence as possible.

The actions participants engaged in included having trans-related surgeries, acquiring and taking hormones, as well as creating non-medical changes to their dress and bodily presentation. Identity actualization also involved the significant work that participants did to negotiate a medical system wherein medical care to achieve this embodiment was often difficult to locate, complex and time-consuming to access, and frought with other significant barriers and challenges. As such, identity actualization also included the strategies that participants used to navigate health services and negotiate with health care providers who were often charged with a 'gatekeeper' role with respect to participant's identity actualization. Identity actualization also encompassed the work of paying for the costs of hormones and, in particular, any surgeries they desired.

Organized into four sections, Section I describes what identity actualization encompassed as well as the motivations and significance it had for participants. Subsequently, Section II delves into detail about the particular activities participants undertook at actualize their identity. In particular, this section looks at the different sites and 'pathways' to receiving care that were described by participants. This chapter also explores how identity actualization, as an embodied series of activities participants carried out, is socially organized. I explore in particular the institutional organization of medicine and mental health services and how it intimately shapes the work that participants engaged in with respect to identity actualization. I focus specifically on participants' work of accessing hormones and surgery because these activities make visible how medical institutions, and the paradigms and texts informing them, shape how the actualization of 'trans' bodies occurs. In addition to the way that identity actualization is shaped through medical relations (Section III), I also explore the political and legal ways that trans identities are managed (Section IV).

My analysis draws attention to two competing approaches to the organization and delivery of health services for trans youth. These contrasting approaches are found in their fullest expression in the respective work of the Centre for Addiction and Mental Health (CAMH) on the one hand, and the Sherbourne Health Centre (SHC) on the other hand; intermediary and modified forms of health services organization are also described, in particular family physicians in private practice.

I focus, in particular, on the ways that these different health services "constitute" trans youth in significantly different ways and hence have different

ways of organizing the pathways and steps youth must follow in order to actualize their gender identity. I also emphasize how access to bodily transformation, in the case of CAMH in particular, is textually mediated by psychiatric discourse, in particular the diagnostic category of 'Gender Identity Disorder' (GID). In contrast, I also detail how other alternatives to providing care are emerging. These can be found in the Protocols drafted and employed by the Sherbourne Health Centre; these have been adopted to varying extents by other centres and practitioners across the Province.

#### 4.1: Identity Actualization: Pathways, Possibilities & Motivations

My research interviews opened a window onto how the work that trans youth do to acquire hormones and surgeries varied significantly. These pathways varied depending on the health care organization the youth were accessing and their financial resources. Both of these variables were in turn shaped by geographic location, social resources as well as the degree to which youth were able to hook into the collective body of lay knowledge about accessing health services.

The youth I interviewed were at different stages in this process of identity actualization. Some had begun to take hormones and had had surgery whereas others were looking for health providers who would provide access to either or both of these. Table 1, below, provides an overview of the different aspects of identity actualization participants had undertaken at the time of the interviews.

	Trans Man	Trans	Total
	Spectrum	Woman	n=21
	n=10	Spectrum	
		n=11	
Forms of Identity Actualization			
Hormones	5	8	13
Silicone		1	1
Top Surgery	3	1	4
Facial Feminization Surgery(ies)		1	1
Bottom Surgery		2	2
Hysterectomy	1		1
Orchiectomy		1	1
Total Surgery(ies)	4	5	9

Table 1. Medical Forms of Identity Actualization

As Table 1 highlights, some participants had already started taking hormones and/or some had undergone surgery of different kinds. In addition to those who had undertaken these forms of identity actualization, others were in the midst of making decisions about whether they wanted to make these medical changes to their bodies.

What this table does not capture are the significant *non-medical* changes participants made. For example, many on the trans man spectrum bound their chest prior to, or instead of having, top surgery. Those on the trans woman spectrum often engaged in a great deal of work related to modulating their voice in order to achieve a voice that sounded more feminine. All participants, in different ways and in different contexts, changed their hair, style of dress, name and pronoun use as part of actualizing their chosen gender. As a case in point, this participant describes the significant effort she spent on presenting herself in particular ways:

Everything. Everything from walking, to talking, to singing, to acting, to what I say to people, to how I say it to people, what my voice sounds like, if I'm moving my hips enough, if I'm sitting in the right posture properly. I analyze my personality constantly and try to see like, "Is this the kind of personality that I want to be? Am I conveying this kind of personality correctly? Am I..." And it just goes on and on and on and on and on. [Ray-Anne]

The diversity within the sample of people I interviewed highlights how identity actualization varies across time and space and can differ significantly from person to person. In other words, the components regarded as integral to one's identity actualization differed greatly amongst participants.

In addition to variation amongst participants with respect to what they wanted, there was variation in what they were able to actually get. Particularly when it came to being able to acquire surgery, the diversity amongst participants was shaped by the particular financial resources they had, resources that were very much intertwined with the extent to which their parents were willing to support, in such a tangible and material way, their child's actualization of a gender different than the one they had long-believed to be the case<sup>2</sup>. Among the sample of 21, only a single participant – who came from a devout Muslim family – had the full financial support of her parents.

<sup>&</sup>lt;sup>2</sup> At the time data was collected for this research, there was no coverage for trans surgeries in the Ontario Health Insurance Plan (OHIP). Coverage was reinstated in 2008 with significant limitations. I will cover the implications of this reinstatement at the conclusion of this chapter.

Additionally, due to the fact that hormones and surgery are medical interventions, the extent to which participants were able to actualize their gender identity was limited to the extent they were able to access health services. Identity actualization was also contingent upon meeting the requirements of particular providers. In some instances, the physical location of the relevant health services was at issue; often participants had to move, usually to Toronto, in order to receive medical care to assist with identity actualization.

And all clinics are not created equal – so it very much mattered what health service was accessed. There are different approaches to providing care in Ontario. This meant that care varied significantly from place to place. In particular, the approach to care practiced at the two most commonly accessed clinics (CAMH and SHC) varied greatly. Participants also accessed care through their family doctor (including the 410 Sherbourne Health Centre in Toronto or Dr. Bailey [not his real name] in Ottawa), usually in combination with a psychologist. Table 2, below, provides a summary of the central providers participants entered into contact with in their efforts to actualize their gender identity.

	Trans Man Spectrum n=10	Trans Woman Spectrum n=11	Total n=21
Trans Health Care Provider			
CAMH (Current/Previous)		2	2
Referred to CAMH, did not go	1	1	2
SHC (Current/Previous)	5	6	11
410 Sherbourne (Current/Previous)	1		1
Physician in Private Practice		1	1
Dr. Bailey	2	2	4
None	2	1	3

Table 2 Provision of Medical Forms of Identity Actualization

# Note: By 'Current/Previous' I am referring to any contact, regardless of the success or duration, by a participant presently or at any point prior to the interview.

The differing approaches produced concrete differences in how youth came to access a service, who they would see, the relationship between themselves and the provider, and the timelines and requirements needed to acquire hormones and/or surgery.

In this chapter then, the central thrust will be to explore the reasons why care differed across sites, and the way that it was organized through forms of coordination that cut across time and space. Different approaches and requirements meant participants followed different pathways to achieve their identity actualization; both the experience as well the length varied significantly.

It is important to note that the physical changes trans youth seek are not something passing or 'cosmetic'. These medical and non-medical changes to one's body or presentation can best be understood as a response to two motivating factors. The first was a response to rectify a sense of embodied self. Serano (2007) refers to this as an actualization of a 'subconscious sex' in that there is a fundamental sense that one's physical body is not what it should be. According to Serano (2007), everyone has a subconscious sex. The key difference is that for non-transpeople, it is something that is rarely, if ever, considered as their subconscious sex aligns with the sex they had been assigned at birth.

The second motivation is necessitated by the pragmatic reality of wanting to be socially understood and perceived as 'cis' (non-trans). This can also be understood as 'passing', specifically 'passing' as a cis man or a cis woman. 'Passing' yields two benefits. First, by being socially understood as cis, one's

gender identity is not going to be called into question. Participants often

commented on how they would worry about others reaction were they not able

to 'pass'. This anxiety was drawn on experiences wherein their gender identity,

as men or women would be instantly invalidated upon another individual seeing

them as 'trans'. In short, the importance of 'passing' was important to participants

as it represented an external validation of their gender identity. Second 'passing'

was also important as it was often necessary to avoid harassment and

discrimination in a variety of contexts.

in terms of surgery, yes. I mean, personally, I viewed what would be a passing woman based upon what male characteristics in my facial skeletal structure needed to be changed. And really set me aside from being seen as a bio female. And I felt that was my jaw, and that was my nose. So that, to me, that was a for sure decision. [Rachel]

*if you can pass well, then you don't have to out yourself [as trans], and it's easier to access employment that way than being trans and not passing [Carlos]* 

not a lot of trans woman are very passable they try, (I: of course) but they still get gawked at and harassed on the street. you know its easier for the ones who are very passable. [Gia]

'Passing' is often an ongoing concern. Indeed, as the following interchange

elucidates, the *fear* of not passing is significant and onmipresent:

Rebecca Hammond: Um, it seems like that whole piece around looking good is about feeling good and feeling confident and also that particular avoidance of harassment and, um, and just you know people finding out, like being outed in a way.

Rachel: Yeah, like it's happened on the subway before where, you know, before I had longer hair, people could tell. I can see people don't look as much anymore. My image matches more the normative feminine style of a girl. But it's still an issue where I feel like people will look, people will call me out, people will make jokes, people will, you know, call me names. I feel very like, threatened by, you know, particularly young males in groups. As like, you know, a present and physical danger - in terms of abuse. These are things that run through my head, you know, and then the other part is too like, especially in girls' washrooms, I feel this like real uneasy calm because these girls' washrooms experiences are at work and at school. Whereas at school I'm out and embraced and totally cool, but at

work I'm always questioning 'these people aren't the same at school, they don't know about me, but are they talking behind my back, what are they saying'? I just feel like that. Very unsafe space.

RH: Yeah. Um, okay. So in terms of this piece of, of 'safety'. How frequent would there be like, issues, of like, potential harassment or what you feared would be harassment? How often would that happen? Has It changed? Rachel: Um, if you're referencing as to when those thoughts don't go through my head – they're always through my head, every waking second. I walk, I go into the elevator, leave my apartment, go downstairs, walk, get on the bus, um, walk through the halls, go to my class. Actually class isn't a big problem now cause everyone knows. But as soon as I walk back home or if I go to the mall of if I got to the changeroom or go the washroom. There's actually never a moment where it's actually gone. It's sort of always there. And I just have to check myself in. And say to myself: "okay, you are wearing clothes that do feminize your body. You do have make –up. look at yourself in the mirror'. I'm constantly looking. But the threats – they always seem to be there. I can't get rid of them.

This ongoing fear of being socially perceived as trans highlights the key

role 'passing' played in driving and shaping participant's identity actualization:

Up until recently I wasn't, you know, very comfortable leaving the house without make-up. And then, on my part-time job on the weekend, you know I decided you know maybe I look good enough without make-up. And I mean nothing, just absolutely plain. And then what ended up happening was, I was outed by another visibly transitioning woman at work and people who were cisgendered at work were starting to make comments about me and how like, my body shape, my face, they could tell from my face, they said. And that phrase there 'they could tell from my face' of course how I heard that they could tell by face was someone third-party telling me this. So someone said 'well I heard them say they could tell because of your face' and so [I] immediately left there. I felt absolutely shocked. Almost broke down, went home, had a problem, had a crisis. And then from that day on I absolutely could not walk out of the house without make-up, just for fear. [Rachel]

Passing accrues particular benefits to trans youth. These benefits amount

to having the privilege to navigate the world as a 'cis' person or, in other words,

to not have to face the discrimination and invalidation experienced or feared to

be the case as a result of being socially read as 'trans' in one's everyday life.

While for most, identity actualization involved a transition from one expression of gender to another, for some the goal of identity actualization was to achieve a more ambiguous or 'genderqueer' social presentation; in either case, the work around identity actualization was focused on making one's internal gender identity, whether it was that of a man, woman, or something intermediary, more visible and socially known, and intelligible, to others.

Often these motivations – to 'pass' and to respond to a visceral need to make changes to their physical body – were both present. The combination provided equal impetus to undertake this process of identity actualization. The question of motivation is important to consider as it highlights how crucial these forms of identity actualization were for many participants. These desires were neither fleeting nor optional. Many youth had felt the desire to make these changes from a very young age, with some citing initial desires to be a 'different' gender extending back to age 3 or 4. Others expressed despondency and hopelessness upon encountering delays and barriers to accessing hormones and surgery. Not being able to access these forms of identity actualization was also often unsafe due to the visibility of living in a body that was visibly 'trans'. The experiences of youth caught in these 'holding patterns' will be covered in detail in the last section of this chapter.

It is not my analytic goal to make sense of why identity actualization was being undertaken; I touch on this issue here only to provide insights into the disjuncture often present between participants and their providers about the relative necessity of hormones and surgery. These disjunctures around the importance of providing these forms of care will be expanded on below when I discuss the different approaches to providing health care as it relates to identity actualization.

Thus, the rest of this chapter does not explicate the motivating factors behind identity actualization. Rather, as is the case with IE research, the focus is on explicating the social organization of activities that a given set of participants is engaged in. I accept that these processes of identity actualization are important processes and the motivations identified here will hopefully help the reader do the same. In the rest of this chapter I focus on the organization of the activities participants had to engage in with respect to identity actualization.

While some participants were not involved in forms of identity actualization that required them to articulate with the formal health care system, *most* were. In the rest of this chapter I describe the work that they did to access health services that provided access to particular medical aspects of identity actualization, namely hormone therapy and surgery.

My analysis emphasizes the following three features of identity actualization: First, in Section 4.2, I emphasize the work of preparing to take hormones or undergo surgery. This includes the work of deciding what one needs and how one will go about achieving it. Next I explore participants' experiences and interactions with particular health providers. Thus, I approach Section 4.3 with a view to making visible the institutional pathways that participants took to access hormones and surgery. I emphasize the varying organizational standards, timelines, and approaches that participants encountered as well as the strategies they had to use in order to present themselves in ways that fit particular professional expectations about what trans

youth should look like and what narratives they should recount. In this way, I highlight how differing 'models' of care structure the terms of engagement of such interactions and I explore how the models diverge from one another on several key points. Finally, in Section 4.4, I emphasize how for many participants, identity actualization involved prolonged "holding patterns" wherein they were unable to actualize their chosen gender because of forces, financial or institutional, that were not, to continue with this metaphor, permitting them to 'land' but kept them 'circling' until the 'signal' was given so they could finally be 'approved' for hormones or surgery. In this last section I also explore the political and legal ways that trans care is organized in Ontario and the interplay between these forms of organization and the medical relations that manage trans identities that were described in Section III.

In this chapter, then, I explore the various pathways participants took in pursuit of identity actualization and outline some of the frustrations and barriers they encountered. The central thrust of my analysis, which is presented in the concluding sections of the chapter, shows how participants' experiences of acquiring hormones and surgery are organized by translocal, text-mediated medical and psychiatric discourses. This social organization is accomplished through the presence and activation of ruling texts – the DSM-IV, the World Professional Association for Transgender Health (WPATH) Standards of Care, and the Practice Guidelines published by the Sherbourne Health Centre – that guide the practice of health professionals in relation to the provision of these forms of care to either facilitate or negate identity actualization for trans youth.

# 4.2 Hooking up to 'Trans Care': Different Paradigms, Providers, and Pathways

The next few pages describe the various forms of work participants engaged in to prepare themselves to start hormones or to seek out and obtain surgery. It also explores participant's experiences with accessing care at different sites.

I use the term 'trans care' to encompass the variety of approaches to care that assist trans youth with the medical aspects of their identity actualization, specifically hormones and surgery. I use this term as it signifies a neutral heuristic device that permits me to explore the similarities and differences between the approaches to providing these aspects of care. This term is not a part of colloquial or professional parlance, but it does permit me to make a coherent analysis of the different ways of providing these aspects of health care to trans youth in Ontario.

Over the next few pages I explore the experiences that participants related to me about preparing for and accessing health care specific to their identity actualization. In particular, I focus on the particular pathways that participants took to access hormones and surgery, focusing on the interactions with health providers. I will highlight how the experiences of participants' ability to receive care, and the quality of that care, varied significantly depending on the particular institution they were working with.

In this section I produce an ethnographic description of the experiences of participants as they moved through the process of seeking out and acquiring

hormones and surgery. I pay particular attention to the differences between participants as they went about interacting with health care providers.

I also explore the particular activities that participants had to engage in to receive care in particular contexts. This includes the strategies participants used to present themselves in ways that fit the expectations the particular professional had about what they should look like and what sorts of narratives they should have.

# 4.2.1 Preparing to Access 'Trans Care': Getting a Sense of the Landscape

The first steps around identity actualization described by participants involved learning about the range of hormonal and surgical possibilities, deciding what ones made sense for them, and learning how to go about acquiring these changes. The process of learning what was available shaped what participants felt they needed and what they thought was possible. In this way, as participants learned about different options, their priorities and needs shifted as well.

I've wanted some form of top surgery ever since I can remember (laughs), even before I had any concept of anything. I went through puberty when I was 10 and I was an athlete and I was like, 'screw this! Like my body doesn't do what I wanted it to do anymore. [Matt]

Again a bit of issues with body comfort. Like, I wasn't comfortable with a male body. For instance, I was balding. My arms were popping veins. So, that like that, those really set me off... those were really what, what propelled, um, the need to start medical transition. [Jess]

As the above quotes illustrate, some participants were quite certain about the particular things they needed to actualize their gender identity. For most, however, while there was a desire to move towards a particular gender, the particular shape of what identity actualization encompassed was not as clear, at least at the outset. Mapping out what one's identity actualization would look like took up a significant amount of energy and time. It included extensive research as well as in-person and on-line networking with other youth who had already accessed particular services or taken particular steps.

*I did 3 months of research on testosterone and went and did fucking medical testing of my heart to make sure that my body could handle testosterone before I tried it. That's the kind of person I am. [Derek]* 

In addition to similar safety concerns as others, this participant expressed concern that his partner may be averse to some of the physical changes that come with starting hormones and undergoing a second 'puberty':

I'm not really trusting of like, oh no this is totally, like some people don't even give a damn if this is safe, but I'm like. I'd rather be not having to worry about falling over and breaking my bones...but yeah while it does seem a little more natural to be taking testosterone, but yeah there are concerns about that, and then there's also, I guess a lot of it is, um I don't know, i kinda picture anybody who was about to hit puberty at twelve would probably say "no" even though this probably good for them (laughs), and they will probably get used to it, I have a lot of like just like (pause) "Aww man, body hair, i don't know about that!" Just a lot of appearance concerns, and my partner very much does like they're freaked out, that I'll look (pause) yeah that I'll look, like they are attracted to me the way I am, and I'm sure aging is one thing but um having different features and like they like my voice, ya know, this is a problem, cause that'll change. [Nola]

As their life situation changed, whether it meant having access to greater

financial resources or acquiring one component of identity actualization (e.g.

getting 'top surgery'), participant's perceived need for identity actualization also

often changed:

*Um and so I just really wasn't sure. I don't know- honestly, I didn't know hormones were going to be part of my future until the day after I had top surgery. As soon as I had top surgery, I was like, 'I need hormones!' (laughs) this is the way it's gotta go. [Derek]* 

Participants engaged in varying amounts of research into the effects and implications of various interventions in order to decide if it was something they wanted to pursue. This meant balancing some of the intended effects they were expecting with some of the possible negative consequences they could expect based on the knowledge about hormones and surgery they had gathered, including how it could affect their livelihood and skills as a singer as well as uncertainties around long-term health consequences:

The biggest was, um, worrying about voice change because I'm a singer and that's something that's a very important part of my life [pause]. And I don't, there's no guarantee that I'll still be able to sing, or that I'll be able to sing as well, or have as much control over my voice as I do now... that's been a factor [in why I haven't started testosterone] for a long time. [Oliver]

Cordelia: I was in a dilemma situation. I was worried about the cost [yeah] financially and also my health, but also really wanted it [yes] cause I told you that I kept my experience to myself for like 10 years [yeah] that's lots already. I just don't enjoy watching myself turn more and more masculine.

*RH*: *right, and it sounds like money was a worry as was health- like some of the side effects?* 

Cordelia: yes, like breast cancer. Well recently, my mom found out she has a lump on her breast so I'm just worried if she might have cancer-breast cancer [uhun], then for me, my chances are increased.

Other participants also described how their desires in relation to identity actualization shifted in relation to work they were doing to confront their own ideas about what identity actualization *should* encompass. This involved challenging social, medical, and community expectations. Central to this work was coming to find a way of understanding a trans identity as 'valid' and something that they could confidently feel okay about actualizing. I outline three overlapping pressures: cultural beliefs about what a 'real' man or woman should look like or possess; expectations put upon individuals by medical providers, and; pressures from other trans individuals.

I guess I struggle with, I struggled with the thought um growing up it's because, its because like I always grew up in a catholic school and of course its been like I've been brainwashed to um think like a, were brainwashed to, I guess think that its wrong to change yourself than what of course god made you so I guess um I'm struggling with,(pause) I'm just struggling with if I should do it or not cuz I still do believe in god even that I'd be close with him now but I'm just afraid of I guess what would happen to me kind of, I've been, I've been so brainwashed so but I mean definitely I'm looking to starting hormones soon. [Jamal]

Jamal highlights the significant struggles that several participants had about their desires to actualize their gender identity. In this case, Jamal alludes to the shift that had to take place around concepts of what constitutes a 'normal' or 'valid' gender. The Catholic church is one of many institutions – legal, political, religious, and cultural – that reify the arrangement that constitute cis gender identities as the only valid way of being or becoming a man or woman. For Jamal, the way that Catholicism organizes and validates particular genders as normal and others as blasphemy shapes the particular work that he had to engage in to assuage his personal concerns that what he was doing was wrong. For trans youth then, part of identity actualization encompasses a process of becoming aware of these assumptions and they way they have shaped their own understandings of their gender, of rethinking what a 'valid' gender identity can be in the face of a host of forms of organization that delegitimate trans gender identities. Participants like Jamal engaged in these sorts of critiques of forms social organization that made them feel guilty or wrong about the gender they were trying to actualize.

The manner in which identity actualization (IA) encompasses interactions with the institution of medicine is another way that trans identities are constituted as 'invalid'. In other words the manner in which trans identities are constituted as a psychiatric pathology and subsumed within a the diagnostic rubric of 'Gender Identity Disorder' (GID) is a key component that both reflects and reinforces that trans identities are not as valid as cis ones. Whether organized through medical frameworks (as incumbent to the organization of care at SHC) or psychiatric frameworks (that frame CAMHs work), the act of submitting oneself to a medical authority in order actualize one's gender identity is a key way that trans identities can be distinguished form cis ones. Cis men and women do not need to seek out medical assent or approval in order to actualize their gender identity. The medical organization of trans identities further retrenches the broader social standard that holds that being cis is the only valid expression of being a man or a woman. For participants, having to subject themselves to the assessments and authority of medical professionals was both necessary and problematic. It reinforced the already present sense that one's identity, as trans, was at least partially invalid as it required adjudication, or at least some form of assent, by a medical authority in order for it to be fully actualized. Having to interact with medical providers also meant that there were frequent disjunctures between what trans youth actually wanted with respect to their identity actualization and the requisite steps providers thought they should want, or the order that such steps should take:

I think it was my second session... and he said, 'well let's hook you up with a counsellor so you can start working on your chest surgery' and I said, 'excuse me?' and he said, 'well that's something you need to get' and I said, 'why?' 'because you're a trans guy' 'no dude, not all trans guys [I: laughs] want to have

their chests removed. I actually enjoy mine a lot and why would I change something that I like?' and he's like, 'oh no no no no. you need to get it done because if not, you're still in transition' I'm like, 'no, I transitioned. I'm a trans man. I'm not a process of becoming. I am what came from that process' and he couldn't understand that. For him, you're not transitioned until you have sex reassignment surgery so ascribing to the medical model of transness so that's been my (pause) some of my experiences with the medical. [Carlos]

This passage alludes to a particular way that being 'trans' is organized by

medical professionals. In this case, the well-intentioned provider at SHC was

drawing on a medical discourse of what a 'trans' person is, and what they need

to actualize such an identity. Often, this discourse does not resonate in whole or

in part with the perceptions held by trans youth themselves.

Other participants mentioned how they had to challenge and confront

expectations from other trans individuals:

in the beginning it was just an influx of this same story all the time that 'this woman transitioned like this and it ended with vaginoplasty surgery and her life was over' and the same thing and the same thing and the same thing. Um, I never really found many of stories about women who were able to still enjoy their penis, in terms of genitalia, without being stigmatized...When I first set out to transition, because I had to use so much content on the internet about surgeries, I had in my head that in order to validate myself as a woman I'd have to have all these surgeries: facial feminization surgeries, I could list you a whole page. I would definitely incorporate vaginoplasty, definitely breast augmentation and everything else. I even said voice surgery before I knew that voice surgery was not really that successful or desired in the community knowing the results. But I had this idea, this misconstrued perception of what I need to do[to] really transition, to really validate my transition, to really be someone who is, I guess, transgender, *I guess you would say, you would have to go through these surgical steps and* procedures – and that's changed. I've really grown to discover who I am. And I've grown into being comfortable in my body. And in terms of future accomplishments, what I would like to do is continue to assert myself in my comfortable gender, and I think I'm still on that discovering path in terms of who I am as a person – and I think that's a really cool thing... But then I realized that there's this difference and people can choose to identify in so many different ways and that every transition is different [Rachel]

I get pretty aggravated at the fact that the youth have this idea of what a woman is, when its, these ideals aren't even found naturally. I wanna look more natural. Well you're not going to get that by pumping your ass full of silicone. I figure I'm a trans gendered woman I'm a gender unique to its own and I don't know I just don't think I need all these things. I think I'll be appreciated for who I am and not what I look like. [Starr]

Taken together, it is clear that a significant part of identity actualization involves confronting a myriad of expectations about what one should do in order to transition in a 'proper' way. These pressures, often contradictory to one another, meant that participants had to 'find' themselves, and chart their own path. Such a process of identity work, particularly with relation to gender and social presentation is not altogether different than the work that cis adolescents engage in with respect to confronting pressures about what they should do or what they should look like. While it carries some similarities with identity actualization that cis youth undertake, identity actualization differs in significant ways for trans youth and adolescents. These differences include the significant stigma associated with transitioning or being 'trans' as well as the fact that identity actualization for trans youth, as opposed to cis youth, often involves medical interventions. This means that identity actualization is a process that is highly regulated and shaped through youth's interactions with medical systems.

As a consequence of this relationship between identity actualization and medical regulation, participants also engaged in research into what services were available to help them actualize their gender identity. Participants developed a sense of the landscape with respect to trans health care in Ontario. There were many commonalities to the particular understandings participants had about what sources of care were available and their relative benefits and disadvantages. Virtually all participants articulated a clear understanding about the health care landscape they would be entering were they to physically transition. This participant describes how he had to network with friends to learn of options once learning that the Sherbourne Health Centre had stopped accepting patients from outside of Toronto:

um well in [small southern Ontario city], I had my circle of trans guy friends and one of them had somehow gotten into the Sherbourne Health Centre I think- and told me that the Sherbourne was not taking any more people outside of Toronto but that I should call [a nurse] at 410 Sherbourne who might be able to somehow get me in because I was told they were also beginning to restrict their outside of Toronto patients and so I got the number from one of my friends so I guess you could say that was my connection.... I wouldn't want to think about what would have happened if I didn't have connections [Derek]

In particular, participants were also familiar with the practices and

approaches carried out by particular clinics, in particular those at the Centre for

Addiction and Mental Health (CAMH) – formerly known as the 'Clarke Institute

for Psychiatry'). They were also able to draw distinctions between these practices

and those at the SHC and elsewhere:

I had from the very get go, been cautioned away from CAMH. I was told horror stories. I searched the internet, I read them,... [after the assessment, the endocrinologist said], 'um I'll call up the people at CAMH and I'll get you on their list' and I was like, 'actually, CAMH isn't accepting any one any more'. I lied. Um I was like, 'they've closed down'. [Derek]

Thank god I went there and not the Clarke, you know... so there was just Sherbourne and the Clarke, and Sherbourne was the one that I tried. And, uh, after going there, I met people who would talk about their experiences with the Clarke and it's just like, "Yeah, don't ever go there." You know, that's the same thing that I say about St. Catherines. Um, yeah, they would tell me horror stories about how they'd been like screwed around for a year before getting hormones and how like they had to be, you had to like live full time for three months before you'd even be considered, and it's like, I went to the Sherbourne, and I got within like three months, three visits, I was put on both hormones, so. [Ray-Anne] The preceding quote highlights how participants developed a knowledge of the landscape of care that was available to them. They quickly learned that there were significant differences with respect to how care was provided. This meant that certain clinics, particularly CAMH, were to be avoided. It also suggests the forms of research and strategizing participants engaged in prior to even accessing care. These accounts illuminate the bodies of knowledge that participants assembled as they mapped out the health care landscape. As Ray-Anne alludes to in the above passage, there were significant differences with respect to the approaches to providing care at SHC versus CAMH and between these clinics and with other providers. In the next few pages I will draw on participant accounts such as these to explore in greater detail the health care landscape for trans youth in Ontario.

## 4.2.2 Accessing 'Trans Care': Stories of Difference

I went in. I was asked out of the blue how I masturbated. I was told that my partner would leave me. I was, ah, ah, just a whole bunch of bullshit like that... I knew it was going to be a crappy experience. So, I came in knowing that. Most of it I was expecting. Some of them threw me off [long pause], but I pulled through... It's tunnel vision... It's a research facility and they want to prove their research correct, so, and the only way they can do that is by saying... is by at the same time saying, "Well, it's this or this. If you're not this, you're not at all". [Jess]

[at SHC they] aren't afraid to address the issues, aren't afraid to ask the questions like 'how are you feeling, are you okay', instead of just brushing you off, but not only that but assisting you with your choices so that you go to them and say 'I'm considering transitioning'. They're like 'okay, how does this look like to you in the future, what is it that you want to do?'. They don't tell you what to do, they help you do what you want to do... that's the biggest difference between CAMH and the doctors at the Sherbourne. [Rachel] The two passages above highlight how different the experience of accessing care was for participants in this research. The two different locations described here, CAMH and SHC, will be the central focus of my analysis in the rest of this chapter. I will elaborate on the various ways that care, and the approaches informing that care, differed. My reasons for choosing these two clinics is two-fold: first they see the largest number of trans youth clients in both my sample as well as in Ontario as a whole; second (and related to the first) is that the two clinics have a significant role in shaping the practice of trans care across the rest of the Province. Understanding why these clinics occupy a central role with respect to trans care relates to the tripartite relationship between these clinics, ruling texts such as the DSM-IV (expanded on in Section III), and the evolving political organization of trans care in Ontario (detailed in Section IV).

Participant experiences of accessing and receiving care at CAMH were starkly different from the experiences of those who were clients at SHC. In addition, youth accessing care outside either of these two clinics also had their own unique experiences in terms of accessing trans care. Experiences of trans care differed in a number of ways. This included, but was not limited to: the length of time it took for participants to 'qualify' for and receive hormones and/or surgery; the process that youth had to go through in order to achieve readiness for hormones and/or surgery in the eyes of the particular provider they were seeing; the shape and size of the team of providers whom they were seeing, and; relatedly, the relative availability of mental, social support services and other ancillary services.

Before exploring these differences, it is worthwhile noting that CAMH and SHC do share some similarities. Both are located within a few blocks of one another in downtown Toronto. Both have an explicit mandate (specifically the Gender Identity Clinic (GIC) at CAMH and the LGBT Primary Health Care Program at SHC) to provide care to trans individuals (Sherbourne Health Centre, 2010; Centre for Addiction and Mental Health, 2010). Given such prominence, both organizations are well-known by trans youth in Ontario and, as discussed above, both are often the first, if only, sites of care youth come across in the research they engage in prior to accessing care.

This, however, is where the similarities end. These two clinics provide care in significantly different ways, and have radically different approaches that inform their delivery of care.

One central difference distinguishing CAMH with SHC is the different type of health care site each represents. Whereas the former is explicitly a provider of mental health care, the latter has a mandate to provide Primary Health Care (PHC) to local communities, as well as having a specific mandate to provide specialized PHC to 'LGBT' communities in the entire City of Toronto. The SHC says that its work:

...provides responsive, respectful programs and services for the Transgendered and Transsexual (Trans) community. We understand the issues you are facing because we developed our approach to care in consultation with knowledgeable healthcare providers and people like you - members of the Trans community. We believe this approach reduces many of the traditional barriers to care that Trans people and others questioning their gender identity often experience. [Sherbourne Health Centre, 2010] SHC implicitly positions itself as distinct and very much a reaction to the 'barriers' that trans individuals may experience accessing care elsewhere, implicitly at CAMH and through uninformed health care providers elsewhere.

Understanding that the provision of trans care to trans youth in Ontario occurred in these different sorts of institutional settings helps to understand the heterogeneity of experiences participants had when describing their articulations with trans care providers. To elaborate, for participants who went to CAMH, the location of trans care within a mental health care setting meant that participants at CAMH were seen by mental health professionals. They were typically assessed by one or more clinical psychologists. The provision of care was not connected to any PHC that participants were receiving – their PHC provider, if they had one, was not involved in the provision of trans care.

In contrast, at SHC, where trans care was situated in a PHC context, participant's PHC providers were *also* their trans health care providers. At the SHC, PHC (including trans care) was often provided by a team of providers including a counselor, psychiatrist, nurse, and social worker.

Participants reported that in addition to seeing their family physician, they accessed some combination of counselor, social worker, and nurse, in addition to a group for those exploring their gender identity and considering transition; SHC even provided a support group for parents of trans youth (Sherbourne Health Centre, 2010). In the following passage Rachel contrasts the one day of assessments she was to have undergone at CAMH with the comprehensive support network she encountered at SHC:

Basically it came down to that I had an appointment [at CAMH] to see a psychiatrist and psychologist on a particular day and I happened to get down to

Toronto at the Sherbourne Health Centre where I hooked up with a counselor who understood my, my homelessness at the time, my inability to fund my own, like education, my loss of a job, everything and he was like 'we'll get you a doctor'. And thank-god. I got in within two weeks.... And from there accessing health care was amazing. I mean I went through months of counselling and I went through the intake process. I waited the standardized 3 months to start hormones, which was great. And so far my doctor has been good. [Rachel]

The team approach to providing care extends directly from the situating of trans care in a PHC setting. To elaborate, within PHC there is growing attention and focus on social determinants of health and community health principles. There is a recognition that 'health' encompasses more than simply the physical health of an individual but that it includes mental, spiritual, and economic dimensions. For SHC, the provision of care to trans clients includes but is not limited to 'trans care' (the physical work of providing hormone surgery or assessing readiness for surgery). It also encompasses providing, where possible, care and supports to address and ameliorate some of the significant stigma and discrimination that trans youth encounter as they come out and transition. This is reflected in the SHC Protocols in that a significant amount of the text is focused on how to provide support and advocacy for trans clients (Sherbourne Health Centre 2009).

Another significant distinction between care at these two sites is the different role that providers played in determining eligibility for trans care. This most centrally differed around the extent to which the provider gave a diagnosis or 'go-ahead' to proceed with trans care.

Participants experienced the role of the provider at CAMH as that of a 'gatekeeper'. They regarded CAMH providers as having the power and authority to determine whether they would be eligible to receive trans care. I had to go to [to CAMH] for them to write that I am 'truly trans' so I went in and I'm like [to myself], "okay- if I don't prescribe to the medical model of trans, you're not going to fill out this form for me"... so I went in and told him the whole story 'I was born in the wrong body, ever since I was a kid, I've always liked maleness more than femaleness and I used to play with little cars instead of dolls and I hated makeup' which is absolutely lie but I said it in order to get my paper which says I am 'truly trans' and the immigration officer read it and said, "okay, you're truly trans and you can't go back to [your birth country]" [Carlos]

The 'gatekeeper' role, in this context, effectively refers to a text-mediated authority to determine the 'true' gender identity of another individual and, by extension, to permit that individual to receive trans care in order to actualize this gender identity. Given the importance of being able to live in a social gender that fits best with one's gender identity, the spectre of encountering 'gatekeepers' at clinics such as CAMH shaped how participants went about attempting to access trans care.

The presence of 'gatekeepers' when articulating with mental health professionals, particularly CAMH, meant that participants would approach the clinical encounter in ways that would ensure, as much as possible that they would be eligible to receive trans care. In a mental health setting, this effectively meant that they would be presenting themselves in ways that would meet the psychiatric diagnosis of 'GID', or more specifically, how 'GID' was understood, operationalized and measured in a specific clinical context.

*E: actually, I lied quite a bit [R: laughs, it's okay] I'm trying to think [pause: 7] so things I made up just to get the hormones? [yeah] I'd say outright lie, no, but I kind of exaggerate stuff [yeah] the actual criteria they have are impossible to meet. [Eliza]* 

Participants frequently described that they would actively conceal particular aspects of their gender, their history, or their sexuality. They feared having trans care withheld by the 'gatekeeper'. Participants elucidated that they had to 'prove' the veracity of their chosen gender identity at CAMH. This proved difficult, particularly as participants often came up against narrow and restrictive definitions of what was considered clinically legitimate. Participants took particular issue with this process of 'validation' undertaken by CAMH and other mental health professionals working as 'gatekeepers'.

In these settings, the role of the provider was an adjudicative one. Reflecting their role as mental health professionals, working in a mental health care setting, the clinical encounter with trans youth focused on determining the veracity of the trans person's assertion that they were actually 'trans'. In these mental health contexts, the narrow definitions about what constituted a legitimate 'case', as well as their inflexibility meant that participants often had to lie, or not disclose particular things, in order to not take the risk of being denied hormones and/or surgery, as Carlos iterates from his experiences with CAMH:

*if it means you're going to get surgery, if it means you're going to get access to a service, if it means you're going to get employment, we lie very well. [Carlos]* 

Often, participants would present themselves in particular ways that would meet the expectations (or assumed expectations) held by the provider they were seeing; participants also would recount particular narratives that they believed providers would be expecting:

when he was asking these questions, I knew a lot of the answers because I read them on-line. And you know, he was saying, 'how long have you worn men's clothing?' and 'how long have you know you were trans? How long have you known you were a man?', just really stupid, irrelevant questions [R; yeah] um you know and I followed up. I'm like, 'I've always known. When I was 4 years old, I knew I was a boy and I played with boys and I wore boys' clothes I just fed him the DSM-IV entry [R; yeah], which is exactly what he wanted. [Derek] The role of the provider in the delivery of trans care was significantly different at SHC. As iterated above, the location of care at SHC falls under the organization model of a Primary Health Care centre. In this manner, the 'work' that is done at the clinic is to provide 'Primary Health Care' to the communities it serves. At SHC, providing primary care for 'trans' people living within the City of Toronto is explicitly part of their mandate.

The presence of 'trans' people in the SHC mandate has several important implications that distinguish it from the provision of, and approach to, care at CAMH. First, it explicitly situates the delivery of trans care – specifically the determination of eligibility for hormones and surgery – within a Primary Health Care setting. Second, it reframes the process for providing trans care in a key way: the diagnostic criteria for 'GID' do not factor into the clinical encounter, in fact the entire process and power that providers at CAMH have to diagnose and manage trans care is no longer the case. Pragmatically, this means that trans youth are understood, quite explicitly, as a community with particular Primary Health Care needs, needs that include trans care. As participants elaborated, they found the role of the provider at SHC to be not one of a 'gatekeeper' but one of a facilitator:

*Um, my doctor at the Sherbourne clinic is so supportive, like, so incredibly supportive [emphasis]. There were a bunch of times, especially when I was in my androgynous phase back in the summer, when I was afraid that going back to her and getting refills on my hormones would pose a problem. I didn't think that she would still do it because I wasn't being, you know, like the textbook trans person, and she was like, "Oh no, no, no, no. That's no, it's..." She was just incredibly accommodating. [Ray-Anne]* 

As this participant iterates, taking away the diagnosis of 'GID' and any diagnostic criteria also takes away pressure to conform to pre-determined

conceptions of being 'trans'. As a consequence of this arrangement, a great deal

of the preparation that had to occur prior to engaging with health providers was

summarily obviated and trans youth could be more genuine in how they

recounted their narratives or presented themselves. As Steven iterates, he

worked with his PHC at SHC to start at a lower dose of Testosterone than most

trans men do. Contrasted with CAMH, such an action could be read as

ambivalence or hesitation and held against the trans youth, calling into question

the seriousness or 'authenticity' of their gender identity:

RH: So he was very encouraging of you.

Steven: Yeah, very awesome. I think a lot of it was kind of like cause I was his patient from before so we had a pretty cool relationship... and he was kind of excited to [help me] get where I wanted to go.

*RH:* So you felt that the power was in your hands in terms of the choice around starting *T*?

Steven: Definitely. He was really awesome [inaudible] in a little bit slower, because I wanted to know what the right dose would be for me. even though I [inaudible] the standard dose being the right dose I wanted to know for sure that that was the dose that I wanted. So he was pretty awesome about that.

The third implication of situating trans care in a PHC setting, as has

happened with SHC, is that it creates a precedent and model of best practice with respect to providing trans care in PHC settings across the rest of the Province. What this text-mediated positioning of SHC as a site of care for trans people in Toronto does not do however, is imply that it is the *only* site of care for trans people. To elaborate, the explicit inclusion of a particular population within a clinic's mandate is usually done in recognition of, and to counter, systemic discrimination or lack of access in the broader social world. While offering a site of care that is knowledgeable and better able to deal with the needs of a particular community, this explicit delineation of particular groups (i.e. with 'newcomers') is *not* intended to obviate the need or responsibility of other PHC providers or clinics to provide care, or to not provide care in ways that is more knowledgeable and responsive. SHC is not intended to be, nor does it position itself as, a 'gender clinic' akin to CAMH. Rather, quite the opposite is the case. To elaborate, SHC's approach to care reframes the delivery of trans care within a PHC setting (Sherbourne Health Centre 2009), offering up the possibility for multiple sites of trans care. By virtue of the ubiquity of PHC, it is part of the work of SHC, and of the new organization Rainbow Health Ontario, to make such PHC practices more widespread (Rainbow Health Ontario 2010).

In contrast to CAMH, the provider role – as it relates to trans care – was not to determine the individual's eligibility based on the extent to which they met some set of diagnostic criteria for 'GID', rather the role of the provider was to provide trans care to self-identified trans individuals as a component of their provision of PHC (i.e. cardiovascular, respiratory, preventative medicine, etc...) (Sherbourne Health Centre 2009). Instead of engaging in a process of diagnosis, the work of the PHC provider was to rule out any very serious physical health complications that could arise were hormones and/or surgery to be initiated and to assess if there were any mental health concerns that would contraindicate if a patient was not able to provide informed consent. At SHC, mental health professionals enter the picture only under very particular instances, such as when it is necessary to provide an assessment for surgery readiness that some surgeons require before proceeding with a trans-related surgery:

*um yeah SHC has been, has been as good as it could be... my doctors and stuff and, and my mental health care professionals like at SHC and, and my* 

psychiatrist from Mount Sinai (I: ok) who was recommended by my doctor at SHC and they all work together like really well (I: yeah) and they work with me really well (I: right) I feel super supported [Huck]

To recap, the approaches varied greatly between these two clinics. A central difference framing the clinical encounter was the differing role that the provider played. In contrast to the facilitative role of primary health care providers at SHC, mental health providers, particularly those at CAMH, were often taking on the role of 'gatekeeper'. In such a role, their central imperative was to determine whether the participant was a 'valid' trans person, whether their experience of having a different gender than the one they had been assigned was 'authentic' or 'true'. Another key difference underscoring the different practice was the relationship providers had to do with the absence or diagnosis of 'Gender Identity Disorder'.

Starting from these accounts about accessing trans care we can begin to explore how practices such as these are shaped by particular texts and forms of organization, including the diagnostic rubric of 'GID'. In the next section then, I will take up the relative centrality of the 'GID' diagnosis and look at how it shapes the provision of trans care. The next section explores in more detail how medical and psychiatric relations shape the practice of trans care in Ontario. This is followed by an exploration of the political relations that regulate access and availability to trans care.

The next two sections start to make sense of participant experiences with accessing trans care in Ontario. They explore how trans care is organized as a function of ruling relations. I focus in particular on the way that the practice and delivery of trans care is shaped through an iterative interplay between medical and psychiatric relations (Section 4.3) as well as politico-legal forms of organization (Section 4.4). I show how these two relations work together and have a coordinative function with respect to trans care access for trans youth in Ontario.

# 4.3: Medical and Psychiatric Relations and the Practice of Trans Care in Ontario

In this section I will explore the central role that psychiatry retains in making sense of 'trans' identities. In other words, I will examine how psychiatry understands 'trans' identities as deviant, ostensibly seeing them instead as individuals with 'Gender Identity Disorder'. In this way, psychiatric relations were often central in shaping the work the trans youth engage in to access trans care. In particular, this psychiatric organization of 'trans' identities directly organizes trans care in ways that position mental health providers and, in particular, CAMH, as key decision-makers, specifically as 'gatekeepers' with respect to trans youth access to trans care.

I focus on the coordinative function of particular texts such as the DSM-IV and its listing of Gender Identity Disorder (GID). I also explore how other texts – such as the World Professional Association for Transgender Health (WPATH) Standards of Care (SOC), the extensive body of psychological literature related to 'treatment' of GID, as well as the Medical Protocols of the Sherbourne Health Centre – also shape the particulars of the clinical practice of trans care in Ontario as well as at the specific sites of CAMH and SCH.

The way that texts shape clinical practice at these sites can be seen in something as basic as the way that 'patients' are conceptualized in the clinical encounter. While both effectively have the same patient pool, the way they were

understood varied most profoundly. Whereas the Sherbourne Health Centre sees, quite explicitly, its purpose to provide *primary health care* to a *community* of *transgender and transsexual* adults and adolescents, CAMH provides *treatment* to *individuals* with Gender Identity *Disorder*. I have italicized these specific aspects of care between these two sites to draw attention to these particular distinctions.

Thus there are two key distinctions between the approach to care at CAMH and SHC, the first is between *treatment* (specifically treatment within a mental health care setting) and *care* (specifically care within a primary care context). The second relates to the way patients are named and conceptualized (specifically *individuals* with *Gender Identity Disorder* at CAMH in contrast to the transgender and transsexual *community* at SHC). These different approaches to providing trans care directly shaped the work that trans youth had to do to actualize their gender identity and how they approached the clinical encounter; it also shaped the significant differences with respect to timelines and requirements that had to be met in order to actualize one's gender identity.

In the next few pages I explore in greater detail how particular texts such as the DSM and the SHC Practice Guidelines shape practices at CAMH and SHC. In section IV, I also explore how these texts interface (or fail to interface) with the current polico-legal organization of trans care in Ontario.

These texts hook into different ways of organizing trans care. In particular, different approaches to organizing trans care that extend from different approaches to understanding 'trans' identities. The central or peripheral presence of the diagnostic rubric of 'GID' is one key difference. The other is the way that these forms of clinical organization make sense of 'trans' identities. On one hand, mental health care providers, in particular those at CAMH, see themselves working within a particular sub-specialty of psychiatry wherein they engage in a process of differential diagnosis with a relatively rare mental health illness. On the other hand, we have the approach of PHC providers at SHC who see their work, as it relates to trans care, as a component of providing Primary Health Care to a particular community.

In other words, not only were there different texts shaping practice at these different sites, but the way that trans bodies and identities are understood and oriented to also varied profoundly between texts and between clinics. In brief, the organization of care at these two sites hooks into two divergent ways of making sense of trans identities within these medical contexts. In particular, the presence or absence of a psychiatric diagnosis, specifically 'GID', is central to understanding this distinction.

The way that care is organized at SHC forefronts the individual as part of a larger trans community. It provides an understanding that the patient is not a specific case of a particular disease but an individual member of a broader community of trans individuals, as iterated on their website above.

In contrast, the way that care is organized at CAMH sees the trans individual through a psychiatric lens. The organization of trans care in this setting extends from psychiatric ways of organizing and regulating trans bodies. The historical presence of trans care in mental health settings such as CAMH can be understood as a function of the diagnostic category of 'GID' in the DSM. In these settings, it is the trans youth receiving a diagnosis of 'GID' that triggers a series of actions. In this way, the *provider's diagnosis* of 'GID' activates a series of

actions that extend from the trans youth being affirmed as a patient with 'GID'. This then enables the youth to be eligible to receive trans care: hormones and/or surgery.

It is important to look further at how the presence of 'GID' in the DSM-IV shapes the way that trans care is practiced. The 'GID' diagnosis regulates access to trans care through positioning the provider as central to determining eligibility for care. As it is a mental health category, the authority to determine whether an individual meets the inclusion criteria for the 'diagnosis', is assigned to mental health providers. In this set-up, wherein trans care is regarded as 'treatment' for those with 'GID', the mental health provider, in the role of the 'gatekeeper', necessarily holds the proverbial 'keys' to the further actualization of the trans youth's gender identity. Tied into this arrangement is the invalidation of trans identities that occurs as a function of having 'trans' identities be subsumed within a psychiatric diagnosis, specifically that of GID. This also has an iterative interplay with the political regulation of gender in Ontario (and in other jurisdictions) and, recursively, on the regulation and location of trans care in the Province. This is a central issue that I will unpack in the next section.

Drawing attention to the DSM-IV (TR) criteria for 'GID', we can see that there are 4 separate criteria. Each must be present in order for a 'trans' youth to be regarded as having 'GID' and thus be permitted to go ahead with their identity actualization.

# Figure 1: DSM-IV-TR: Diagnostic Criteria For Gender Identity Disorder (GID)

#### Criteria A

A strong and persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex). In children, the disturbance is manifested by four (or more) of the following: 1.repeatedly stated desire to be, or insistence that he or she is, the other sex

2.in boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine clothing

3.strong and persistent preferences for cross-sex roles in make-believe play or persistent fantasies of being the other sex

4. intense desire to participate in the stereotypical games and pastimes of the other sex

5.strong preference for playmates of the other sex **Criteria B** 

Persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex.

Criteria C

The disturbance is not concurrent with a physical intersex condition. **Criteria D** 

The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

These diagnostic criteria shape the diagnostic practices carried out by CAMH as well as by other mental health providers. What is notable about the diagnostic criteria is the way that gender *identity* is used almost interchangeably with gender-normative *behaviour*. In other words, to be legitimately 'trans', in the eyes of mental health providers working from these criteria, one must not only have 'discomfort' with their gender and how their gender is socially perceived (Criteria B) but they must also be 'stereotypical' in their gender expression of their new, chosen gender (Criteria A). The way that a 'strong and persistant' cross-gender identification gets operationalized in the DSM-IV criteria has less to do with a sense of internal gender incongruence, the type that participants described, but rather gets reduced to a measure of the degree to which a trans individual meets socially normative standards of masculinity and femininity of the gender to which they are transitioning. The stereotypical gender roles and behaviours delineated in the DSM-IV Criteria A list, and the need to meet them in order to access trans care, led to much of the strategizing, preparation and lying participants engaged in prior to accessing care at CAMH or from other mental health professionals. The Criteria A components meant that not only was one's gender identity being adjudicated, but that, tied into that, one's gendernormativity was also being assessed. Indeed, few trans youth, without lying or presenting themselves in certain ways, would confidently meet these criteria; even many cis people, as a case in point, do not have a strong preference for the interests and clothes of their birth gender. Having to undergo such restrictive assessments helps understand the work that participants engaged in when accessing trans care in such mental health settings.

The DSM itself does not contain any tools to assess whether someone in fact has 'GID' aside from the broad criteria listed here. Nor does the DSM specify what the treatment for 'GID' actually is. These diagnostic criteria in the DSM-IV get translated into clinical practice through the existing body of academic literature around undertaking 'diagnosis' of those with 'GID'. Thus, while it is the diagnostic category of GID that is central, there are intermediary texts, in particular the extensive psychological literature on how to treat and diagnose 'GID' (e.g. Pfaffin 2010).

In addition to this literature, another commonly referenced document is the World Professional Association for Transgender Health (WPATH) Standards of Care (SOC). The SOC are significant in shaping and reflecting the international consensus around working with 'GID'. Formerly knows as the 'Harry Benjiman International Gender Dysphoria Association' (HBIGDA), WPATH produced Standards of Care that they assert represent a global consensus with respect to care of individuals with 'GID'. A significant aspect of the diagnostic process

according to the WPATH SOC is to undergo a Real Life Experience (RLE) wherein the individual must live in their chosen gender for a period of time before qualifying for hormones and/or surgery. This is not always practicable, as one of my participants clearly iterates:

Chris: so I've been very lucky in not having health care professionals who've followed the Harry Benjamin Standards, which I don't like them because like for instance, for me to have lived as a man for two years without any secondary sex characteristics and with thirty-six double-D, triple-D breasts, it just wasn't going to happen. And it really seems to me, I mean I haven't studied the Harry Benjamin, but I've read them, and it seems to me that it's really designed to really convince people not to do it. It's like, "Well if you're really, really, really, really serious about this, well, live through hell for four years, and then we'll talk." RH: You're speaking specifically around the Real Life Test? Chris: Yeah

The SOC have evolved and the most recent revision changed the language

around the RLE from its former handle: the 'Real Life Test'. As the shift suggests,

the purpose of the 'experience' is more to provide knowledge to the trans

individual about what the reality of living in their chosen gender may be like.

While WPATH may no longer regard it as a 'test' per se, it is still taken up in the

psychological literature as a component of diagnosing 'GID' in clinical settings.

The SOC also now recognize that sometimes the RLE is not always safe or

practical. It also recognizes that it is not necessary to undergo the RLE prior to

receiving hormones or even surgery:

Typically, triadic therapy takes place in the order of hormones  $\rightarrow$  real-life experience  $\rightarrow$  surgery, or sometimes: real-life experience  $\rightarrow$  hormones  $\rightarrow$  surgery. For some biologic females, the preferred sequence may be hormones  $\rightarrow$  breast surgery  $\rightarrow$  real-life experience. (WPATH 2001)

Namaste (2000) has previously raised concerns about the specifics of the WPATH SOC, particularly the presence of the 'Real Life Experience'. Particularly problematic is the way that it gets operationalized, specifically at CAMH, which,

by its own admission, sees it only as a 'minimum' standard in its application of

more restrictive standards wherein the RLE precedes hormone therapy by one

year and surgery by two years [emphasis added]:

The Gender Identity Clinic subscribes to the criteria for Sex Reassignment Surgery outlined in the World Professional Association for Transgender Health (WPATH), Standards of Care, 2001. The International Standards of Care specify that these represent minimum standards. The Gender Identity Clinic at the Centre for Addiction and Mental Health uses these standards as guidelines, however, in terms of the 'real-life experience'; our clinic policy is that a **two year** period of successful cross-living in the felt-gender role is required before a recommendation for sex reassignment surgery can be made. During the real-life experience, individuals seeking such surgery are expected to fulfill various criteria as outlined below and in the WPATH Standards of Care. These criteria include being able to demonstrate successful adaptation in the feltgender role by sustaining either full-time employment, full-time student status or the equivalent of full-time voluntarism, or any combination of these three criteria. Clients become eligible for hormone therapy after one-year of completion of living full-time in the felt-gender role. Source: CAMH (2010)

The RLE has been under a great deal scrutiny from professionals and trans individuals alike. While the SOC recognize that sometimes the RLE is not always an option, it is a non-negotiable standard for CAMH when it comes to providing trans care. Thus, whereas the WPATH SOC, and even other psychiatric ways of orienting to trans care, have shifted away from a mandatory RLE and see it as much as a form of treatment as it is a diagnostic tool, CAMH remains adamant in their insistence on a 1-year RLE prior to even the initiation of hormones. This is both a dangerous practice and out of step with other approaches to trans care, even those provided by other mental health professionals. In this account, one participant describes how the standards at CAMH were both unrealistic and unsafe:

Eliza: Yeah. Yeah, the first time it was, the first time it was like, "Yeah, um, you actually have to be living out like full time and not just every now and then."

RH: And then the second time? E: Hmm, more of the same. RH: And then what changed their minds this last time do you think? E: Well, I'm living in Toronto, so it's a much different environment. It's like [trails off]...

*RH:* So, there's really nothing different in particular, except that you are now living in Toronto and you have more freedom?

E: Yeah, well, yeah, I can actually be the person. Yeah, like full-time Thunder Bay just wasn't possible.... their like "living out" criteria, like it's just, depending on the environment you're in it just isn't, doesn't always work out. E: Yeah. Well, um, kind of the answer I got was, I mean "There may be problems with living out full time, but we want to see that you're, you know, living out regardless of the problems before we start prescribing you stuff."...CAMH said they want to see something, so it's like I have everything on paper, but they don't realize that given the circumstances, you can't really do everything full-time there [yeah] they're just concerned about getting the forms.

*RH:* so you changed your name but you were still working there mainly as a guy, [for the most part] so that was mainly so you could fill the checkbox that CAMH wanted

*E: pretty much. It's like your criteria is pretty ridiculous [yeah] you can't really do that kind of stuff, so you have to fudge the numbers so to speak.* 

For trans youth receiving care from CAMH, the one-year RLE must be supported by documentation that they are working in their chosen gender, that they have 'come out' to significant people in their life, and that they have take other steps, such as legally changing their name. Often, some or all of these are difficult to achieve, particularly without the assistance provided by hormones or surgery. Thus, in a rather ironic fashion, in order to receive trans care as way to actualize their gender identity, trans youth must live in a cross-gender role first, for over a year, prior to being able to actually physically transition and be embodied – via hormones and surgery – in their chosen gender.

CAMH was often regarded as the de facto 'expert' when it came to gender transition. Many participants recounted how they would be referred – by a counselor, social worker, or their family physician – almost autonomically, to CAMH upon coming out as 'trans' or even if they were questioning their gender identity:

*My social worker at the school, she was semi-decent and of course she referred me to the Clarke.* [*Rachel*] (emphasis added)

"um I'll call up the people at CAMH and I'll get you on their list... I'm going to need you to go a psychologist who can", and these are [my local family doctor's] words: "certify that you're not nuts. [Eliza]

In this way, mental health providers, particularly those at CAMH, were often regarded as the default providers of trans care. A related consequence of this reflexive location of trans care in a mental health setting is the dearth of Primary Health Care (PHC) providers, outside of SHC, who would provide trans care. The way that trans youth often get referred to mental health care providers in general, and CAMH specifically, makes sense when we see how trans identities are understood in medical contexts. The textual presence of 'GID' in the DSM-IV means that the organization of medical practice often forefronts the need for a psychiatric diagnosis of 'GID' prior to the initiation of trans care. The approach to care that took place at CAMH was mirrored in private psychiatric practice across the Province, alluding to the way that such care is organized trans-locally through texts and the manner in which they make sense of trans bodies and organize the delivery of trans care:

The initial evaluation that he does includes a 200 dollar test, in which you have to pay for which you have to do or else he won't see you. That's basically a sexual profiling test, to discover or not whether you're a pedophile. The same what he gives to sex offenders. Basically it shows a collection of pictures showing kids ranging I guess from the ages of 3 and up. Probably the oldest one in there might be 15. Basically yes, you have to pay 200 dollars to have this privilege. ... As far as I can tell, the only reason for taking this test is for his own personal research. Basically, he's conducting research on trans people because he can get away with it. And if you don't have money to pay for a private shrink, it's 'go to Branford' or go home. You don't have an option. You have to play his game. [Alana] As the above highlights, the organization of trans care within mental health settings such as the CAMH GIC are shaped by the texts and peerreviewed literature that create a framework for the management of trans identities. In this way, the psychologist or psychiatrist is the 'gatekeeper' and it is that provider's role to adjudicate whether trans care – specifically the medical interventions of hormones and surgery – are to be made available. Thus, we can see how the organization of care extends from the presence of the diagnostic rubric of 'GID'. It forefronts the role of mental health providers and organizes trans care in these contexts in line with the psychological approaches to understanding trans expressions of gender identities. Such expert positioning is enumerated by WPATH in their Standards of Care:

## The Ten Tasks of the Mental Health Professional.

1. To accurately diagnose the individual's gender disorder; 2. To accurately diagnose any co-morbid psychiatric conditions and see to their appropriate treatment; 3. To counsel the individual about the range of treatment options and their *implications*; 4. To engage in psychotherapy; 5. To ascertain eligibility and readiness for hormone and surgical therapy; 6. To make formal recommendations to medical and surgical colleagues; 7. To document their patient's relevant history in a letter of recommendation; 8. To be a colleague on a team of professionals with an interest in the gender identity disorders; 9. To educate family members, employers, and institutions about gender identity disorders; 10. To be available for follow-up of previously seen gender patients. Source: WPATH (2001)

As this list iterates, the role of the mental health provider is very much

one of diagnosis and assessment. While the organization of trans care in this

manner has been the dominant way that trans identities have been managed in

medical contexts, there are other, emerging ways to understand trans identities. This, in turn, offers up different ways of organizing and providing trans care.

As elucidated in the previous section, there are different approaches to providing trans care. The approach taken by SHC is organized by different ways of making sense of trans identities that reflect the texts that frame the practices of Primary Health Care clinics such as CAMH. Most central to this emergent ways of organizing trans care is conceptually understanding trans identities as legitimate and non-pathological and, by extension, understanding individual clients as members of a larger trans *community*. In this way, the organization of trans care in Primary Health Care settings, in particular SHC, is oriented to the provision of trans care as a component of Primary Health Care provision to a community with distinct needs.

There are some key features that characterize the provision of trans care in these contexts. Care at SHC has key features that organize practice at this site. *First,* in understanding 'trans' as a legitimate way of being gendered rather than as a disease category (i.e. 'GID') there such care has at its core the understanding that non-cissexual gender identities are not inherently pathological. By extension, such 'trans' identities are self-determined by the individual rather than a health professional. Thus, the *second* facet is that trans patients are able to determine their own gender identity without undergoing assessments carried out by the primary health care provider.

For participants, the experience of being able to receive trans care in a manner that did not require having to prove their gender identity to the provider of trans care was quite profound, as Derek describes: up until that point, all of my experiences accessing health care in [previous region] had been violent. It was horrible, and so when I called [nurse] I'm sure my message was absolutely pissy and guarded, and she got back to me and was like [cheery tone], 'i'm so glad to hear from you. We're going to try and find you a doctor, and don't you worry. In 2 months, we'll have you on hormones. Everything will work out. It'll be great. It'll be fine. come in and see me and we'll talk about it' and I was just like, 'oh my god' [I: laughs] 'people like this exist?' (laughs) 'this is a possibility for me?' so yeah, I was completely overwhelmed and then when I actually went to the appointment and saw her, I think I actually, after the appointment, went out and sat in the car with my friend and just cried because I can't believe that- because it felt as though, and it's true, she actually wanted to help me through my transition. It wasn't like you're going to have to prove yourself to these doctors and make sure you say all the right things and do all the right things and be the right person in order to gain access to something that you're not even really sure about yet. [Derek]

Participants such as Derek were often 'overwhelmed' by not having to 'prove' themselves as trans or negotiate with 'gatekeepers' or assessors. In contrast to other experiences, this was a particularly profound experience.

The *third* feature around which care is oriented at SHC is the understanding that trans patients are understood as constituents of a larger 'trans community'. Consequently, the relationship between provider and patient is guided by the practice of the patient providing 'informed consent' wherein the trans patient makes the decision to receive particular aspects of trans care based on the knowledge provided to them about the physical and social ramifications and, in some cases, irreversibility of starting hormones or undergoing surgery(ies).

The approach to care taken by SHC, while new relative to the approach to care at CAMH, has become larger and more influential to the point where it now sees more trans clients than the CAMH clinic. Current estimates of active trans clients at SHC exceed 600 (Source: Personal Conversation...). While SHC is also unique in an Ontario context, in that it has explicit recognition of its services for

trans clients, it is certainly not unique when we broaden our scope. There are a number of Primary Health Care clinics in larger urban centres in North America where there is explicit inclusion of trans clients in their mandate and practice.

The multiplicity and similarity of practices at these clinics would lead one to infer that there is a ruling text, akin to the DSM-IV, that coordinates such trans-local homogeneity. However, while there are fundamental similarities, the practices at these clinics are not framed by a single professional text. Rather, it would appear that the organization of medical practices with trans clients is informed and guided by broader shifts in popular discourse towards reenvisioning 'trans' identities as legitimate (e.g. Serano 2007; Califia 1997; Lev 2005).

In addition, there is a nascent body of literature that codifies the approach to care that happens at these clinics. This most directly is encompassed by the various Protocols that guide the practices at specific clinics. Indeed, in devising the original SHC protocols, the existing protocols of other PHC centres who worked with trans clients (e.g. Callen-Lorde in New York or Tom Waddell in San Francisco) were ostensibly used as templates in shaping the SHC protocols and, in turn, the practices that were set up. In addition to these protocols, there are also peer-reviewed articles, as well as medical texts, that delve into the provision of trans care working within Primary Health Care contexts. There is also an emerging body of literature that is establishing professional texts and literature that lays out the provision of trans care within a broader context of PHC (e.g. Gorton 2007).

101

While SHC sees a great number of trans clients, their catchment area is limited officially to those living within the City of Toronto. For trans youth living outside of Toronto, there is no current equivalent to SHC. The frustrating implications of this, in terms of inadequacies or inabilities to access care, were frequently identified by participants, as the following three quotes relate to us:

Sure. I had a family doctor in rural, in the country. And one time I made an appointment, a personal appointment, went by myself, and I said 'you know, what can you tell me about gender identity disorder'? Um, he hushed me up. he said, 'I don't really want to talk about this, I don't really feel that I'm an expert in this'. And then he would just tell me about how like, he did have a client a long time ago who did, and how, you know, he was secretly telling me that her psychologist had informed him that she was doing terrible and that after transitioning into a woman she was doing worse than before just struggling as a male. And then he turned around, 'you know it may not be that way for you, I'll send you some information', I'll get the people who can help you in contact with you'... That's where I left it off at. He tried to get me in contact with CAMH. [Rachel]

I went into the appointment and sat down and the woman kind of saw me, said 'oh you're the one that wants the hormones', went back out, closed the door [R: wow], 2 minutes later, came back in with a bottle of testosterone pills and literally threw them at me. She was like, 'here you go. Have a good week'... 'I really don't understand people like you'

I actually did try to make a serious attempt to explain to her that I'd already been through the whole psychological evaluation, I'm very sure...I'd been to more than one therapist or psychologists at that point. Who wrote letters, and 'yes, this person identifies as male and he needs hormones to live a normal life, he has plans to go through SRS' [R: hmhun] and yet still, she was still not willing to give me hormones, despite the fact that it's her job, as an **endocrinologist** [Jesse]

*I was trying to find out about hormones in the Niagara area and nobody knew what the fuck I was talking about [Derek]* 

As we can see from stories such as these, accessing trans care in a PHC

setting outside of SHC was a struggle. Attempts to do so were often met with

frustration, denial, or referral to mental health care providers. According to

youth I interviewed, family physicians were not just unwilling and unprepared,

they had little interest to develop capacity to deliver trans care. While certainly

some of this reticence to deliver trans care can be reasonably explained as a consequence of the shortage of PHC providers that affects all Ontarians, it is possible that there are other factors shaping the dearth of PHC providers who will provide trans care as part of their practice. Most centrally, we can see such resistance as a consequence of the way that trans identities remain pathologized within the DSM-IV and the subsequent situation of mental health care providers as 'gatekeepers' to the provision of trans care. The centrality of this way of organizing trans care, particularly as it remains entrenched in ruling texts such as the DSM-IV, helps to understand participant's experiences with accessing PHC providers to manage their trans care outside of the SHC

As the last quote above iterates, geography was a significant factor. Given that SHC's catchment area was limited to the City of Toronto, participants often related stories of moving to Toronto, and the dearth of trans care elsewhere was a central factor in that decision to move their life. Once in Toronto however, participants frequently encountered extended wait lists to access care at SHC:

Oliver: I'm on a waiting list to see a general practitioner at the Sherbourne.
RH: And how long have they said the wait is going to be?
O: Um, a few more months, probably [pause]. So, I don't know, when I got on the waiting list, they said that I would probably, um, have a doctor in January, but now it looks like it's going to be a little while longer. Um, they just have [pause], they just have a long waiting list and not enough doctors for everybody.
RH: Has there been any sort of work that you've done in the time while you've been waiting to maybe learn more about hormones, to help sort of to look into alternatives maybe while you're waiting, or is it...?
O: Um, well, I've, the program at SOY, Gender Journeys is, um, mostly about information, just getting information. So I've, I'm currently doing that. But, um, it still seems like that's pretty much the only route to go for me. [Oliver]

The inability of SHC to provide timely care for the number of trans clients

looking to access its services can be seen as a consequence of the creation of a

limited catchment area. The lack of other clinics in Ontario with an explicit mandate to provide PHC to 'trans communties' leaves trans youth from other parts of Ontario with the choice of having to move to Toronto and get on the SHC waitlist, to try to access trans care from PHC providers who lack the knowledge or sensitivity or interest to do so, or to try to access trans care through mental health care providers such as CAMH or local psychiatrists who often work in conjunction with an endocrinologist around the provision of hormones. In Ottawa, the second largest city in Ontario, the lack of a clinic equivalent to SHC has created an alternative structure. All five of the participants that I interviewed received trans care from a local gynecologist. This gynecologist, Dr Bailey, was noted as a pivotal with respect to provision of trans care in Ottawa, as Alana iterates:

Doctor Bailey, the endocrinologist was freaking amazing. [J:He is a saint!] He is the shining beacon of hope in this town when it comes to trans rights. Basically, it's like he looks at ya, 'yeah, you're not insane, what do you want to do?' He's the only person who actually ask you 'what do you want to do?' Not what do I have to do for you, what do you want to do to appease me. 'What do you want to do?' It's like, you don't hear that. [Alana]

Dr. Bailey has been working with trans clients in the absence of there being other clinics or PHC providers willing to do such work. Participants frequently expressed concern about the void that would occur in the not-toodistant future when Dr. Bailey would retire. With a roster of over 150 trans clients, and with no obvious location or provider to provide trans care to the clients upon retirement, such apprehension makes sense. I use Ottawa, the nextto-largest city in Ontario, as a case study to highlight the dearth of PHC options for trans clients outsider of the SHC in Toronto. The story is not all doom-and-gloom. And even in my sample of 21

participants, there were isolated stories about finding PHC providers who would

provide trans care. Within Toronto, the 410 Sherbourne Health Centre (hereafter

referred to as '410'), a PHC clinic affiliated with St. Michael's Hospital, has

increasingly become a PHC option for trans clients. In the following account, one

participant contrasts her experience at 410 with what she went through at

CAMH:

Jess: [410] was relatively hassle-free.... Although they mentioned the risks of transition, of a medical transition, or of HRT in this case. Like you say, the increased risk for osteoporosis, the changes in weight gain, or in body shape weight gain, the likelihood of liver damage, they didn't try to dissuade you. RH: Where, it sounded like at the Clarke, it was very much about dissuading you...

Jess: Yeah, at the Clarke... Yeah...

RH: ... "Your partner is going to leave you," kind of threatening... Jess: Yeah. And there wasn't (sic) a lot of barriers. Like, for instance, the fact that I had or hadn't done my name change wasn't an issue. The way I presented wasn't an issue. My sexuality wasn't an issue. Like, there was (sic) very few barriers, which has since changed, but that's mainly due to another mental health disorder that has pretty much held off any increases in dosage.

410 currently sees approximately 300 trans clients. The practices at 410 are similar to those at SHC, which makes sense given that they directly reference the SHC protocols in providing PHC with their trans clients. In a similar vein, other PHC providers, both inside and outside of Toronto, are increasingly turning to the protocols established by the SHC as a set of guidelines to organize their practice with trans clients. In addition to being available for download on the SHC homepage, the SHC protocols have recently been published on-line on the Rainbow Health Ontario (RHO) and thus are available both to trans clients as well as any PHC provider who may wish to directly reference them. RHO is a recently established Province-wide organization that focuses on 'LGBT' (Lesbian, Gay, Bisexual, and Trans) health. Part of RHO's mandate encompasses training

and education to expand the capacity to provide health care to these

communities across the Province. In addition to the online publication of the

SHC protocols, RHO also engages in training and education to providers across

Ontario, focusing specifically on the provision of trans care within PHC contexts

(RHO 2010). Even with such formal education, many trans youth still need to

draw on the SHC protocols and advocate for themselves in order to receive trans

care from PHC providers, as Cordelia illustrates in this passage:

I was actually scared at my family doctor would be freaked out for trans people, but anyways, I tried it. I talked to her about it and she shocked me that she didn't react like my mom did (laughs)...I'm her first one (laughing). well when I was thinking about should I ask her or not, it was kind of tough, but when I said it, she surprised me that she's cool with it (laughs) [RH: so it sounded like she- not expected it, but she knew what you were talking about? [um well] what was her reaction like?] I would say she's on an open-mind base, although she don't know anything about it, she was open minded to try and deal with it with me. She actually don't know anything about it, but I also told her what the procedure is supposed to be. Like from what I asked from the Sherbourne, they told me I'm supposed to ask my family doctor and get an assessment test- something like thatto see if I'm qualified to go or hormones or not, so that's how she got me to the psychologist. [RH: and so it sounds like you did quite a bit of work before that appt- contacted the Sherbourne?]yeah [and talked to someone there who told you how to go about talking to your doctor?] [Cordelia]

Taken together, these experiences with *attempting* to access trans care can best be made sense of as a function of the way that trans care is organized in relation to psychiatric renderings of 'trans' people. We can see in these accounts how the prevailing way of conceptualizing trans individuals is still through a mental health lens. To elaborate, the presence of GID in the DSM-IV entrenches the central role that mental health care providers, specifically CAMH, have in the provision of trans care. With the exception of SHC and, to a lesser degree, 410 Sherbourne, it is rare for PHC providers to be of the mindset that providing trans care is something that falls within their 'scope of practice'.

As a consequence of the GID diagnosis, when 'trans' clients appear in a clinical practice they are not members of a larger 'trans community' but, rather, they are individual instances of persons with 'Gender Identity Disorder'. In this way, trans care is understood as care that belongs in a mental health setting, to be assessed and regulated by mental health providers. Thus, mental health providers, particularly those at the CAMH, often are regarded as de facto 'experts' with respect to the provision of trans care. Moreover, as a consequence of this organization of trans identities as persons with psychiatric illnesses, mental health providers are empowered with a 'gatekeeper' role with respect to identity actualization for trans youth.

In the next, and final, section of this chapter I will explore in greater detail the various facets of the politico-legal organization of trans care, how it has shaped the current practice of trans care and how it relates to such medical ways of organizing trans care as detailed in this section.

## 4.4: 'Holding Patterns' & the Legal and Political Coordination of Trans Care in Ontario

In this final section I explore another significant set of relations that shape the provision and organization of trans care in Ontario. Whereas in the previous section I focused on how trans care is organized across different sites through different texts, clinical locations, and contrasting ways of understanding 'trans' identities and bodies, in this section I delve into the ways that trans care is organized as a function of political and legal relations that organize the provision of trans care services in Ontario. Clinical practice is shaped most proximally by the particular medical relations that organize the actions of providers and the relationship to patients at these particular sites, as discussed in the previous section. However, to best understand the provision of care on a Provincial scale, it is important to examine the coordinative function that political and legislative decision-making has in shaping what forms of trans care are available. In other words, the provision of trans care, like other aspects of health care, broadly speaking, is going to be shaped as much by the political forces that shape the organization, funding, and delivery of health care across different sites as it is by the practices and paradigms of medical professionals working within specific sites.

In this section I consider how three components of political organization that coordinate how trans care is practiced – by whom, where, when, and so forth – in the Province of Ontario. Specifically, I examine how the following shape trans care and how they inter-relate to one another: government policy decisions to fund or not fund aspects of trans surgeries; the explicit delineation of 'transgender and transsexual' as a *community* for the purposes of providing primary health care and advocating for 'equal rights', and; the regulation of gender on personal identification documents.

In this section I also explore the experience that participants had of being in a 'holding pattern' with respect to trans care. This resulted from both challenges related to accessing or finding trans care in addition to some of the barriers and delays associated with gatekeeping. Thus, I am writing this analysis with an eye to understanding the ways that both the political, as well as the medical (introduced in the previous section) forms of coordination both shape the work that trans youth engage in related to accessing trans care as well as the ways that barriers to care have significant effects for the health of trans youth.

# 4.4.1: "Holding Patterns": Living in limbo due to clinical and political barriers to care

By 'holding pattern', what I am referring to are the experiences participants related to me around not being able to actualize their gender identity due to circumstances beyond their control. Because identity actualization (specifically hormone therapy and surgery) for trans individuals is considered a medical intervention, these 'holding patterns' arise from the organization of medical care (specifically trans care) at specific sites as well as how it is organized across the Province. I have chosen the term 'holding patterns' as it accurately conveys the experience of waiting for the go-ahead, from an outside source, in order to proceed with identity actualization. Table 3, below, provides an overview of the frequency of particular 'holding patterns' in my sample.

	Trans Man Spectrum n=10	Trans Woman Spectrum n=11	Total n=21
Holding Patterns (Current/Previous)			
Cost Barriers/Paying for Care	6	7	13
Difficulty Finding Care	5	5	10
On a wait-list at SHC	3	2	5
Encountered gatekeeper situation	3	4	7
(Forced to see psychologist >3 months,			
RLE, assessment tests)			

Table 3. Holding Patterns – Barriers to Identity Actualization

As the above table illustrates, participants related to me several different challenges to being able to actualize their identity. They identified four primary reasons: an inability to find physicians who were willing to prescribe hormones or provide referrals and/or approvals for surgery; being on a wait list to receive care from a physician who provide hormones and/or approvals for surgery; being unable to afford various aspects of one's identity actualization, in particular surgical costs, and lastly; gatekeeper situations. Each of these 'holding patterns' had significant effects on the health and well-being of participants; as outlined previously, the motivations to actualize one's identity and social and physical dangers related to not 'passing' are not insignificant.

Participants often experienced more than one 'holding pattern', either presently or in the past. The experience of 'holding patterns' varied greatly depending on where, and if, a participant was receiving trans care.

Experiencing 'gatekeeping'-related holding patterns was tied into the process of receiving trans care through mental health providers such as CAMH. The other three 'holding patterns' tie into the provision and organization of trans care across the Province. The other holding patterns result from the organization of trans care across Ontario and thus require extending the analysis beyond the way that medical practices are organized at individual sites to encompass the political ways that trans care is organized. While these two forms of organization are distinct there is an interplay. The political organization of trans care is shaped by the relations that organize medical practice; and, recursively, the current state of medical practice in Ontario is very much shaped by the way trans identities are managed legally and politically.

The first three 'holding patterns' then direct our attention to the political and legislative ways of organizing trans identities and trans care, to the lack of funding for trans surgeries, and to the ways that trans care is shaped through decisions to situate it in PHC or mental health contexts, or alternatively, to not address trans care adequately through either medical pathway. Given the significance they have in creating some of these important 'holding patterns', the rest of this section will delve deeper into the way that trans care is politically organized.

## 4.4.2 The 'Emerging' Trans Community and the Politico-Legal Organization of Trans Care in Ontario

The way trans identities are understood and organized in our social world is something that it always in flux. In this thesis, I focus on the organization of trans care as it is significant in shaping the actualization of trans identities themselves. One significant shift in the social organization of trans identities has been the gradual recognition of the 'trans community'. The 'trans community' situates trans identities as a distinct group that deserving equal rights and protection from discrimination. This gradual political recognition of a 'trans community' has been integral in situating 'trans' issues within a social justice and equity framework. Making a case that 'trans' individuals comprise a community and, by extension, are legitimate in their claim to gender, has set up an arrangement where the struggle for rights and equity has hinged on inclusion of 'gender identity' in various anti-discrimination and human rights legislation.

This recognition of a trans 'community' – a recognition that is mirrored by, and foundational to, the delivery of trans care PHC settings – presupposes that trans identities and, specifically trans *genders*, are intrinsically legitimate and that, as an extension of that legitimacy, are deserving of rights and freedom from discrimination to the same extent that individuals with non-trans *genders* experience. The psychiatric organization of trans identities, wherein trans identities can only be actualized upon receipt of a professional diagnosis of 'GID', stands as an affront to the assertion of legitimacy that has been foundation to the recent struggle for 'trans rights' as an equity-based movement.

On one hand then, we have this movement that forefronts equity for the 'trans community'. This movement stands in contrast to the management of trans identities, as individuals with 'GID', in psychiatric contexts. The recognition of a trans 'community' has been slow but progressive in Ontario politics. With respect to human rights in an Ontario context, these are organized most centrally around the Ontario Human Rights Code (OHRC). The OHRC, established in 1962 to protect particular disadvantaged communities from discrimination, enumerates 15 explicit grounds upon which discrimination in living, working, and other social contexts, is forbidden. The OHRC is managed and monitored by the Ontario Human Rights Commission (The Commission), an arms-length government organization that updates and interprets the OHRC.

With respect to trans individuals, The Commission has interpreted the OHRC in such a way that while 'gender identity' is not an explicitly enumerated grounds for protection, "People who are discriminated against or harassed because of gender identity are legally protected under the ground of 'sex'. This includes transsexual, transgender and intersex persons, cross-dressers, and other people whose gender identity or expression is, or is seen to be, different from their birth-identified sex" (Ontario Human Rights Commission 2010)

Thus, trans identities have been understood as a protected *group* as interpreted by The Commission. Given this orientation to understanding trans individuals as a *community*, the organization of trans care within PHC contexts offers a more accurate reflection of the legislative way trans identities are understood and managed. With this having been said, the next two subsections, will explore the political organization of trans surgery funding – from the 1999 delisting through the relisting in 2008 – as well as the management of trans identities on identity documents. In both cases, I will illustrate how trans identities continue to be managed through psychiatric forms of organization. I conclude that these ways of organizing trans identities act as barriers to identity actualization and, more broadly, continue to delegitimate trans identities. These legal and political ways of managing trans identities reenforce and reflect popular perceptions that trans genders are unnatural or invalid. This political retrenchment – through these documents and legislation – of the psychiatric organization of trans identities also undermines parallel efforts – within The Commission and SHC and other organizations – around working towards equity and human rights for trans communities.

One significant factor that shaped participant's ability to access trans care was the economic reality of being able to afford the uninsured costs of care. For virtually all participants, the costs of paying for trans surgery(ies) were prohibitive.

*Cordelia: I'll be looking for SRS [hmhun] but right now, I think that I'm kind of far away from it.* 

*RH: far away because of money or because?* 

C: I think money and time and steps [yeah] cause right now, I'm hoping to start on HRT.

RH: and do you kind of have a timeline in terms of months or years until SRS or?

*C*: *I* hope *I* can have SRS under 20.

*RH: before you turn 20? [hmhun] and you're 18 now? [18, hmhun] okay.* 

[getting bottom surgery] is a concern but you know it isn't the highest priority on my list right now because I know that there is absolutely no way unless someone who you know, who wins the lottery or is just naturally wish becomes very generous towards me, then maybe I'll be able to afford it you know. Uh like I currently barely make a, barely make my bills you know so I don't even really think about it too much cause I know I can do it [Sorel]

*Ray-Anne: That was a big decision, yeah. That was a huge [emphasis] part of the* decisions. I don't want to spend twenty thousand dollars on that surgery. It, that, that's twenty thousand [emphasis] dollars, you know?! I could do a lot of things with twenty thousand dollars. Um, conversely, in the amount of time it would take to get twenty thousand dollars I could also not do a lot of things, but do a lot of the things that I wanted to do, so.

*RH: It's definitely, there's just bigger priorities.* 

R: Yeah. If it were covered by OHIP, I'd consider it. I wouldn't, like, that's not a "yes," and it's not a "no," but I'd consider it. But, as it is, it's, "Not even going to bother.

At the time of data collection, trans surgeries were not an insured service

under the public health care plan. In order to pay for the uninsured costs related

to their identity actualization, participants often had to make significant

sacrifices:

so we basically gutted our savings [RH: yeah] Like I had 18000 dollars saved up by the time I went for my surgery, and guess what, I don't have savings account anymore (laughs) cause it's all gone [Alanna]

Chris: The hysterectomy will be [covered by OHIP] but the chest wasn't. No, that's where last year's OSAP [Ontario Student Assistance Program] went

[laughs]. Um, but I'm anticipating that OHIP will pay for the hysterectomy, and the fact that I've had a couple, like that I've had an abnormal pap smear, and I've had a couple colposcopies, she should have no problem convincing OHIP that I legitimately [pause] need a hysterectomy. RH: For reasons related to cervical health. Chris: Exactly

Because of the lack of surgery coverage, participants had to pay directly for trans surgeries they wanted. This often involved making sacrifices in order to acquire them. More often it involved having to delay, often indefinitely, getting surgery because of the cost barriers. In addition to the direct costs of surgery, the costs of getting an official approval from a mental health provider was also cited as a significant barrier, adding thousands of dollars to the overall outlay. In this vignette, Jesse describes how he feels 'held hostage' by the costs of having to pay for the letter his surgeon requires:

[My psychologist] won't give me a letter for chest surgery until she's seen me for year at 130 dollars per session. She wanted me to see her every week [RH: yeah, really, when there's nothing discernibly wrong going on] [A: which works out to being about somewhere between 6 to 7000 dollars [RH: yeah] which is more than the surgery cost.] yeah, [RH: that sounds familiar number]. so basically she wants a bribe of about 6000 dollars for a letter [RH: yeah] that's what it ultimately comes down to. [Jesse]

As noted above, the data collection for this research occurred immediately prior to the relisting of 'sex reassignment surgeries' in the Ontario Health Insurance Plan's (OHIP) Schedule of Benefits in 2008. The re-listing provided public coverage only for clients who had 'successfully completed' the program at the CAMH Gender Identity Clinic. This effectively means that one needs to receive a paper diagnosis of 'Gender Identity Disorder' from CAMH in order to qualify for publicly-funded surgeries. This funding arrangement is identical to how public funding for trans surgeries was organized in Ontario prior to the delisting of trans surgeries in 1999. While the landscape of trans care changed greatly over the preceding decade – in particular with the advent of PHC-based trans care at clinics with an explicit inclusion of 'trans' individuals in their mandate, such as SHC – the current funding of trans surgeries through OHIP remains firmly intertwined with the delivery of trans care through a single provincial clinic organized according to psychiatric ways of understanding trans identities. Moreover, critiques of the practices at CAMH have been extensive, pre-dating even the 1999 delisting. Namaste (2000) provided a detailed account of how the clinical practices at CAMH limited 'approvals' for trans surgeries to a small number of individuals who met their restrictive criteria. Assessments at SHC, as I noted in the previous section, serve a different purpose (in that they do not seek to determine if an individual meets the criteria for a 'GID' diagnosis) and are not nearly as restrictive. Thus, in light of changes to the landscape of trans care, particularly with respect to the advent of PHC-based care, it is important to consider why trans surgeries remained delisted for so long and why, after almost a decade, they were relisted in such a limited fashion.

The *first* factor I will explore is the cost of trans surgeries. Through limiting trans surgery coverage to approvals through a single clinic, a bottleneck of sorts is created. Of course, while the costs could add up, particularly after a decade of trans surgeries not being funded, the relative cost burden that such funding would have is insignificant in the context of the Provincial health care budget. The estimated cost of covering trans surgeries was estimated at well under one millions dollars, insignificant in the context of the multi-billion dollar

116

health care budget as a whole (Canadian Press 2008). Nonetheless, while the absolute costs of funding trans surgeries are not significant, they were front-andcentre in the initial messaging from the Ontario Health Minister around the 2008 relisting (Canadian Press 2008). To try to make what would assumably be an unpopular move more palatable, the Minister clearly stated that the relisting would only involve public coverage for a limited number of surgeries per year.

This brings us to a *second* factor around the restrictive relisting: vehement public opposition to the move. The relisting of trans surgeries under OHIP was not a politically popular move. Particularly in a climate of cost rationalization and where other health care services were not receiving coverage (or had recently been cut from the OHIP Schedule of Benefits). Limiting public coverage to patients at a single clinic would lessen the negative effect of the decision to relist through the consequent rationalization of care and restriction of costs. Moreover a return to the previous 'status-quo', meant that the government could assert that this was not *new* coverage but *re-instatement* of coverage that was previously covered.

The *third* and final factor related to the relisting relates to the way that Public health care funding (and arguably all models of funding health care) is intertwined with the disease model. In other words, health care coverage is provided for 'effective' 'treatments' of particular 'diseases'. Briefly, the delineation of 'diseases' and the evaluation of the efficacy of 'treatments' provides supposedly objective criteria that removes politics from the provision of health care funding. Thus, by situating trans surgery approvals within a psychiatric context, the existing and established diagnosis of 'GID' can be used as it provides

the 'disease' to which trans surgeries are the 'treatment'. Organizing public funding for trans surgeries in such a way situates the funding of trans surgeries within medical relations, relying on the 'medical necessity' of such procedures. This provides not just a medical rationale for treatment, as it does for practitioners working from psychiatric approaches to providing trans care, but it also provides an effective political justification for providing coverage for trans surgeries. Coverage for surgeries through an equity and social justice model lacks the same precedent in contrast to providing coverage, as has been done, through a disease model. The provision of publicly-funded surgery coverage for trans individuals, while a certain step forward in expanding options for trans people, also complicates the ongoing efforts to recognize trans individuals as valid and in their claim to gender. The current state of coverage for publiclyfunded trans surgeries rations care through routing all patients (wishing to acquire surgery through the public purse) through CAMH. In addition to the pragmatic reality that subjugating to psychiatric assessment is the only way for some trans individuals to acquire surgery, this arrangement also lends political weight to the medical authority that understands trans identities as inherently problematic or invalid as a function of the way they are organized in these psychiatric ways.

In the preceding pages I have painted a portrait of how the organization of trans care is caught between competing ways of making sense of 'trans' identities. On one hand the increasingly dominant way of understanding 'trans' as a community, as a legitimate way of being gendered, comes up against the

118

way that medical care is organized. The inertia in the public mind, 'trans' identities are not as legitimate as cis ones, factors into this arrangement.

In the final subsection I will explore how gender is regulated on official documents in Ontario. I use this as a way to explore how, despite movements towards seeing 'trans' as a community, that trans gender identities are still subjucated to cis ones, particularly in how medical consent must be obtained in order to change one's gender on various legal documents.

In addition its social function, gender is also regulated textually through its presence on various forms of identification. In Ontario, gender is present on health cards, driver's licenses, and most centrally on birth certificates. The gender on each of these documents is textually inscribed at birth. It reflects the gender that medical professionals, in coordination with parents, have chosen for their child. In virtually all cases, gender is assigned based on what the assumed sex of the child is and 'male' and 'female' are inscribed on birth certificates. The 'gender' (a bit of a misnomer as these are terms to describe one's sex however, in common use they are perennially conflated with one another) assigned on birth certificates becomes one's de-facto 'legal' gender and it is autonomically reinscribed when one receives a health card or drivers license.

The organization of legal and textual gender in this fashion reflects the experiences of cis individuals as it presupposes that all individuals will be cis and that gender is known based on one's birth sex. This process, particularly its automatic character, reinforces many prevailing perceptions that cis gender identities are uniquely (or more) valid in relation to trans identities. The discrepancy between felt gender and legal and textual gender on these documents means that trans individuals must enter into particular processes in order to make changes to ensure their legal documentation matches their social gender. The process through which these changes to 'legal' gender are made in Ontario, particularly in how authorization and authentication must be received prior to any changes being made, further retrenches the arrangement that trans gender identities are peripheral and abnormal in contrast to cis gender identities.

In order to change the gender on one's birth certificate, a particular application form must be completed. This form – Medical Certificate to Substantiate Transsexual Surgery was Performed, The Vital Statistics Amendment Act, 1990 Subsection 36 (2) – must be signed by two physicians, one who performed the 'transsexual surgery' and one who can attest that the surgery has in fact been performed. It is important to note that what constitutes a 'transsexual surgery' is not states on the form and is left open to interpretation. In many cases, individuals, provided their surgeon has been willing to sign the form, have been able to change their gender after having had top surgery (e.g. chest reconstruction/breast removal) or gonadectomies (e.g. orchiectomy or hysterectomy). Changing the legal gender marker on health cards typically requires having first changed one's birth certificate. While this relative flexibility exists, for individuals not able to access or afford trans surgeries (which constituted the majority of my sample), or for those not desiring surgery altogether, the requirement to have surgery in order to legally change one's gender was construed as unfair:

there's no choice for some of the g—for the girls who doesn't wanna have a sex change (RH: yeah like, cause why can't you) cause the government still sees you, they'll still see you as a guy cause you still have your male organs you know.

(*RH*: and then it still says that on the id and all that, yeah). *G*: I don't know why the government cannot understand that. [*Gia*]

Looking more closely at the birth certificate document, it is important to note that one's birth sex can never be changed but, rather, is only ever amended. This also is the case for any changes to one's name, done for gender transition or for other purposes. On Ontario Birth Certificates, any previous names or genders are maintained on the document, with the new names or genders seemingly haphazardly typed next to the original handwritten entries. The originals are parenthesized but not crossed out, thus perennially visible. In this way, legal sex for trans individuals can never be fully changed, or brought into legal concordance in the same way that legal sex for cis individuals as trans people's birth sex will always be visible on these documents.

While trans identities are increasingly seen as valid, these legal ways of regulating 'sex' on official documents is another way that trans identities are delegitimated. Psychiatric and other ways of medically organizing trans identities situates health care providers as the legal authority with respect to changing one's gender.

In a recent discussion paper, the Ontario Human Rights Commission speaks out quite emphatically about the issues that come along with the medical organization and, in particular, regulation, of trans identities. The Comission supports some degree of self-identification as 'trans' as sufficient in itself, particularly in relation to social and legal ways of living in our gendered world. The Commission also highlights the issues associated with inadequate access to trans care: Problems arise when the medical profession is responsible for all aspects of gender identification rather than allowing self-identification by a person who has consistently identified themselves as transgendered. Despite self-identification as transsexual, for example, many institutions require medical certification of what an individual has already stated to be true. The law, in its enforcement and administration, allows for only a minimal capacity to self-declare as transgendered. Thus when dealing with official institutions (i.e. court system, corrections system) even if a person self identifies as transgendered they have no access to medical documentation to support their felt gender identity so that they can be dealt with in the appropriate manner.

Medicalisation means that a transgendered person must receive 'official' recognition from a gender identity clinic, which is not always accessible, in order to receive appropriate service or treatment from the health care system and other organizations that they may come in contact with. General practitioners often do not have the resources or expertise needed to provide appropriate services to transgendered patients. As a result, there are many transgendered individuals who self-medicate and self-treat with hormone therapy, which subsequently puts their health at risk. Many individuals in this situation reported that they felt they have no other option.

#### Source: Ontario Human Rights Commission (2008)

It is my hope that this chapter will add to these discussions and to try to offer some reconciliation between the current provision of trans care and emerging approaches to seeking social justice for trans youth and adults in Ontario.

In conclusion I have illustrated how trans care has been organized through medical and political relations and have begun to explore the interplay between the two. Most central has been the way that trans identities have been organized in these different contexts. Using trans youth's experiences with accessing trans care I have shows how contrasting approaches to making sense of trans identities become visible through the practices at these specific sites. The organization of trans care links closely into the way that trans identities themselves are organized. On one hand we have psychiatric ways of erasing "trans" identities through subsuming the individual within a pathological rubric of GID. On the other hand, PHC approaches to care provision constitute trans identities and the trans individual as both valid and autonomous and, importantly, the embodied expert with respect to their own gender identity. They also see these trans individuals as constituents of a larger trans 'community'.

In conclusion, I have made a case that the implications of medicalizing trans identities actually stands as a barrier to the provision of better health services for trans youth in Ontario. While the medicalization or trans identities and the presence of 'GID' has often provided a basis for health care coverage, looking at the approach to care at SHC and, increasingly at other clinics, can provide other alternatives. While apprehension is reasonable around the outright delisting of GID from the DSM-V when revisions are made in 2012, there are other options that sync up more closely with emerging ways of considering and socially organizing and orienting to trans identities.

The next, and concluding, chapter of this thesis provides a recap of the analysis and hooks it into current academic conversations related to the provision of trans health care. It explores the limitations of this research and provides directions for study. It also highlights some of the potential applications of the work and how the data presented here and the analytic trajectory I have taken can be used by various stakeholders with respect to improving the current provision of trans care in Ontario.

## Chapter 5:

### Conclusion

In this work I have introduced the concept of "identity actualization" to provide a way to explore the activities that trans youth engage in to make changes to their physical and social gender. I focused, in particular, on the interactions that participants had with medical forms of identity actualization. The use of identity actualization allowed for a description of what youth needed to do in order to transition without, from the outset, referencing medical typologies and conceptions. This permitted a documentation of trans youth experiences with respect to accessing care as well as an analytic exploration of how such care was organized.

In my analysis, I drew a distinct demarcation between two different ways of organizing trans care. I explored how these approaches to providing care represent not merely two competing medical frameworks but constitute radically different ontological ways of orienting to trans people and gender identity itself. In the next few pages I touch on how the findings of my research hook into current dialogues in relation to making sense of trans marginalization.

As my analysis suggested, the current way that "gender variance" is managed in clinical settings is in significant flux. The emergence of a unique trans subjectivity and, relatedly, the rise of a "trans community" alongside work to provide legal visibility, validation, and protection for trans individuals has increasingly made pathological forms of understanding "gender variance" anachronistic. And the pace of change in relation to how trans people are understood and how trans care is organized is likely only going to quicken. Next year, the DSM-V will be published. While a full delisting of any psychiatric diagnosis related to "gender variance" is unlikely at this time, there will likely be significant shift in how, and where (i.e. what section) it is textually defined. Similar revisions are also happening to the WPATH Standards of Care. The recent work of Drescher (2010), Meyer-Bahlberg (2009) and Cohen-Kettenis (2009), in reviews they submitted to the DSM committee looking into how to address needed changes to the diagnosis of GID, while they vary significantly from one another, all provide introspection with respect to location of health care delivery, and all point out the limitations and problems of the continued psychiatric organization of trans identities.

Overall, the psychiatric organization of trans identities is increasingly at odds with the subjective experience of trans people that they should be able to access medical care without having to 'prove' the authenticity of their gender, citing the fact that cis people's gender identities do not have to undergo assessment prior to being actualized. Williamson (2010) notes that requirements to undergo a assessment for one's gender identity and to undertake a 'Real Life Experience' (living and working full-time for a set period of time in the gender to which one is transitioning) represents a "patronizing double standard". Pathological ways of organizing trans identities are run counter to the growing ways trans people are regarded as a 'community' rather than a disease category. Such a shift in how both the public as well as academics understands trans people as well as gender variance can be witnessed in the growing body of population research noted above as well as by the rapid shift towards managing trans identities within primary health care settings. The emergence of the provision of trans-related health care in Primary Health Care settings has appeared out of nowhere in less than a decade. It has grown in popularity in spite of the continued presence of 'GID' in the DSM and the lack of a central text, research journal, or diagnostic framework to organize practice. In her work relating to the legal organization of trans health care in BC, barbara findlay [sic] (1999:3) highlights the "movement to challenge the psychiatrization of gender variance". She notes that there is significant contentiousness related to this within trans communities with concerns hinging on the provision of public (and private) funding for trans health care, specifically surgeries, in lieu of a diagnosis. findlay (1999) does suggest that, with pregnancy and abortion as examples, there are other alternative models to providing, and paying for, health care needs that fall outside of a model of treatment and disease.

My work provides new insights into the experience of trans youth as they went about accessing care, or attempting to. The differences in experience between the two ways of providing care were stark. In addition, my work illustrated the overall dearth of services currently available for trans youth in Ontario in addition to the significant problems associated with care delivered by providers working as 'gatekeepers' and applying psychiatric diagnosis as central to the provision of care.

In terms of applications of this work, the unique barriers related to health care services that trans youth experiences draws us to consider how this is further evidence of how the health of trans communities is affected in negative ways due to intersecting challenges placed on them, when one applies a social determinants of health perspective. If we consider how my work signals an exclusion from health care and how this can have possible negative health implications, we can explore how my work contributes to evolving ways that trans exclusion and marginalization has been rationalized and explained.

Most commonly, in academic and everyday contexts, trans marginalization and exclusion been attributed to be a consequence of 'transphobia' (Xavier 2003; Clements-Nolle 2001; Gapka & Raj 2003). While useful, this does have its shortcomings.

In the past few years, attention has increasingly turned to making sense of why, and how, trans people come to experience marginalization. Central to this have been calls to explore the way that binary gender categories and assumptions about gender identity based on birth sex frame the experiences of discrimination and related marginalization that trans people experience (Serano 2007). Herbst et al (2007:17), in the conclusion to their meta-review of HIV studies, note that:

Mainstream society currently embraces binary gender assignment according to birth anatomy rather than viewing gender on a continuum. Consequently, public accommodations (e.g. restrooms) and other services may not be equipped to deal with transgender persons. Additional research is needed to identify structural and organizational policy barriers experience by transgender persons...

While considering marginalization to be a consequence of transphobia may seem logical, and in some cases appropriate, it fails to explore the social and institutional factors that shape the production of transphobia itself and the service barriers, discrimination and ill health experienced by trans people. Certainly, in some cases, direct acts of transphobia do impact the lives of trans individuals however, more often, the marginalization experienced by trans individuals can be traced into assumptions about what constitutes 'normal' gender identities or histories and the attendent privileges associated with such assumptions. As I will elaborate in the last part of this section, there have been recent developments towards making sense of the social and institutional organization of trans marginalization. Les Feinberg (2001:897) foreshadowed this work almost a decade ago, noting that in relation to the lack of trans health care providers:

...even the individuals who were sympathetic lacked the tools to change the systems they worked in . Education is important. But attitudinal change is not the same as institutional change. If education is not tied to transforming systems of health care delivery, then it's as effective as putting out a forest fire with teacups full of water. Sensitivity and diversity training has to be linked to a commitment to institutional change..."

Feinberg draws our attention to the ways institution of health care and the way that it is organized to produce exclusion from health services on an individual level. He frames the problem as extending beyond individual instances of 'transphobia' and as situated in the organization of institutions that (could) provide health care to trans people.

One of the first works that problematized the production of trans marginalization was Namaste (2000). In her work 'Invisible Lives', Namaste (2000) critiques sociology and queer theory for their inattention to both the lived experience of trans individuals as well as their lack of utility in understanding the understanding the social world embodied trans people move in. Namaste (2000) introduces the important concept of 'erasure', offering it up as a both a description of the experience of trans people navigating the social world wherein their identities are often unanticipated or rendered impossible or unintelligible.

Bauer et al. (2009) coin the term 'cisnormativity' to present such a similar process of assumptions built into one's gender identity ascribed based on assumed sex at birth. Bauer et al. (2009) apply a lens facilitated by seeing the world as 'cisnormative' to develop the concept of 'erasure' introduced by Namaste (2000) to make sense of the barriers experienced by trans people across various institutional sites. Building on Namaste's work, Bauer et al. (2009) explore the production of 'erasure'. Parsing it into constituent components of *informational* and *institutional* erasure, Bauer et al. (2009) explore how erasure underscores how trans people are often left out of research studies, how their care needs often go unmet. Erasure draws attention to the organization of health care systems.

To make sense of how the erasure of trans people has come to be such a ubiquitous feature of our social world, Bauer et al (2009) introduce the concept of 'cisnormativity'. Cisnormativity refers to the organization of our social world wherein there are only two binary genders and these genders are assumed to be inextricably linked to one's biological sex. Cisnormative social organization precludes the possibility of trans people or, at best, renders them as anomalous to the experiences and embodied histories of cis people. Institutionally, cisnormativity shapes practices and is 'written into' texts as an implicit organizing feature.

Other thinkers, in various ways, have also begun to attune to making sense of how transphobia and trans marginalization come to be. Shelley (2008)

129

introduces the concept of 'trans repudiation', borrowing from psychoanalytic thought to make sense of the pervasive experiences of marginalization experience by trans people. Others have used the term 'genderism' to describe the systemic oppression that is experienced both by those who are queer or homosexual as well as by those who are trans. And most significantly, Serano (2007) introduces the notion of 'cissexism' to provide an important and novel linguistic framework to make sense of how trans identities have been enduringly constituted as "abnormal". Serano (2007) elucidates the 'cissexual blind spot' wherein most cis people are have an a priori assumption that gender identity and biological/anatomic sex are always congruent and follow intrinsically from one another. Gender identity, for cis people, is thus something that is not often considered and is too tightly wound up in how they hook together sex and gender so they are not able to see it as distinct. While Serano's work spends a great deal of time laying out the importance of such language and of surfacing the incumbent privileges and power afforded to those who are cis, her work, as evidenced by its contribution to Bauer et al. (2009) explication of 'erasure', will likely have significant applications to understanding the production of trans marginalization in health care settings and the social world more broadly.

Thus, my work provides an empirically grounded analysis that shows how concepts of erasure and cisnormativity are organized through material work processes carried out in different settings. I show how medical texts and legal forms, for example, shape the work trans youth must engage in to access care and to actualize their gender identity. In addition, my analysis illuminates how cisnormativity and erasure actually function, how they relate to embodied work processes that get carried out.

Such a material explication provides opportunities to consider how changes can be made in order to counter the cisnormativity, erasure, and, ultimately, exclusion that occurs for trans people in health care settings. The cisnormative approaches to delivering and funding care, for example the current exclusion experienced by legally "male" people who need to get a Pap test with respect to both competent providers as well as the fact that current restrictions on billing prevent the public health care plan from paying for men's Pap tests. Future work that could build on my work could include research around interview providers themselves, to see how they relate to texts and negotiate the complexities of delivering trans care.

## Bibliography

- Bauer, G., Hammond, R., Travers, R., Kaay, M., Hohenadel, K. (2009). "I Don't Think This Is Theoretical; This Is Our Lives": How Erasure Impacts Health Care for Transgender People. *Journal of the Association of Nurses in AIDS Care*, 20 (5), 348-361
- Becker, H. (2004). *Whose Side are We On*?. In Critical Strategies for Social Research, W.K. Carrol (ed.). Toronto: Canadian Scholar's Press. Pp. 23-28.
- Blanchard (1989). The concept of autogynephilia and the typology of male gender dysphoria. *J Nerv Ment Dis.* 177 (10), 616-23.
- Bockting, W., Robinson, B., and Rosser, B. (1998). Transgender HIV Prevention: A qualitative Needs Assessment. *AIDS Care*, 10, 505-25.
- Bockting, W. (2004) Patient Satisfaction with Transgender Health Services. *Journal of Sex & Marital Therapy*, 30 (4), 277 – 294.
- Boehmer, U. (2002). Twenty years of public health research: inclusion of legbian, gay, bisexual, and transgender populations. *American Journal of Public Health*. 92 (7): 1125-30.
- Bornstein, K. (1998). My Gender Workbook. London: Routledge.
- Butler, J. (1990). *Gender Trouble: Feminism and the Subversion of Identity*. New York: Routledge
- Butler, J. (2004). Undoing Gender. New York: Routledge.
- Califia (1997). Sex Changes: The Politics of Transgenderism. New York: Cleis Press
- Clements-Nolle, K., Marx, R., Guzman, R., & Katz, M. (2001). HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. *American Journal of Public Health*, 91, 915-921.
- Cohen-Kettenis, P. (2009). The DSM Diagnostic Criteria for Gender Identity Disorder in Adolescents and Adults. *Archives of Sexual Behaviour*. DOI 10.1007/s10508-009-9562-y
- Coker, T., Austin, S., & Schuster, M. (2009). Health and healthcare for lesbian, gay, bisexual, and transgender youth: Reducing disparities through research, education, and practice. *Journal of Adolescent Health*, 45 (3), 213-215.

- Cole, C. & Cate, S. (2008). Compulsory Gender and Transgender Existence: Adrienne Rich's Queer Possibility. *Women's Studies Quarterly*, Vol. 36, (3/4), 279-287.
- Connell, C. (2010). Doing, undoing, or redoing gender? Learning from the workplace experiences of transpeople. *Gender & Society*, 24 (1), 31-55.
- Conway, L. *How Frequently Does Transsexualism Occur*?. Website [viewed May 28, 2007]. <u>http://ai.eecs.umich.edu/people/conway/TS/TSprevalence.html</u>
- Cope, A. & J. Darke. (1999). *Making Women's Shelters Accessible to Transgendered Women*. Kingston: Violence Intervention and Education Workgroup. Available online: http://www.queensu.ca/humanrights/tap/index.html.
- Davis, C. (2002). *Trans Youth Access to Care: Barriers to Trans-Medical and Mental Health Care; Preliminary Findings*. Presentation to Hunter College of Social Work, May 15, 2002. New York: Author.
- DeVault, Marjorie L. and Liza McCoy. (2001). *Institutional ethnography: Using interviews to investigate ruling relations*. In J.F. Gubrium and J.A. Holstein (Eds.), Handbook of interview research: Context and methods. Thousand Oaks: Sage Publications.
- Denny, D. (1997). *Transgender Youth at Risk for Exploitation, HIV, Hate Crimes*. Youth Resource.
- Denzin, N.K. & Lincoln, Y.S. (2003). *Collecting & Interpreting Qualitative Materials*. London: Sage Publications.
- Diamond, Timothy. (1992). *Making gray gold: Narratives of nursing home care.* The Chicago: The University of Chicago Press.
- Drescher, J. (2010). Queer Diagnoses: Parallels and Contrasts in the History of Homosexuality, Gender Variance, and the Diagnostic and Statistical Manual. *Archives of Sexual Behaviour*. 39, 427–460
- Fausto-Sterling, A. (2000). Sexing the Body: Gender Politics and the Construction of Sexuality. New York: Basic Books.
- Feinberg, L. (1997). Transgender Warriors. Boston: Beacon Press.
- Feinberg, L. (2001). Trans Health Crisis: For us its life or death. American Journal of Public Health. 91, 897

- Feldman, J & Bockting, W.O. (2003) Transgender health. *Minnesota Medicine*. July 2003. Available Online: www.mnmed.org/publications/MNMed2003/July/Feldman.html
- Feldman & Goldberg (2006). Transgender Primary Medical Care. International Journal of Transgenderism. DOI: 10.1300/J485v09n03\_02
- Findlay, Barbara (1999). *Trans People and Health Care: An Equality Analysis*. Prepared out of the Trans Action/Justice Equality Summit. Self-Published.
- Flick, U., Von Kardorff, E. Steinke, I (2004). *A Companion to Qualitative Research*. London: Sage Publications.
- Gapka, S & Raj, R (2003). Trans Health Project: A position paper and resolution adopted by the Ontario Public Health Association. Toronto: OPHA.
- Garofalo, R., Deleon, J., Osmer, E., Doll, M., Harper, G.W. (2006). Overlooked, misunderstood and at-risk: Exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. *Journal of Adolescent Health.* 38, 230–236.
- Goffman, E. (1961). *Encounters : two studies in the sociology of interaction*. Indianapolis: Bobbs-Merrill.
- Gorton, N. (2007). *Medical Therapy and Health Maintenance for Transgender Men: A Guide For Health Care Providers*. Available Online: http://www.nickgorton.org/
- Grossman, A.H. & D'Augelli, A.R. (2006). Transgender youth: Invisible and vulnerable. *Current Issues in Lesbian, Gay, Bisexual, and Transgender Health*, 111-128.
- Grossman, A.H., D'Augelli, A. R., Howell, T.J., Hubbard, S. (2005). Parents' reactions to transgender youths' gender nonconforming expression and identity. *Journal of Gay & Lesbian Social Services*, 18, 3-16.
- Harris, G.E. (2006). Practicing HIV/AIDS community-based research. *AIDS Care*, 18(7), 731-38.
- Heckathorn, D.D. (1997). Respondent-driven sampling: a new approach to the study of hidden populations. *Social Problems*. 44:174-199.
- Herbst. J.H., Jacobs, E.D., Finlayson, T.J., McKleroy, V.S., Neumann, M.S., & Crepaz, N. (2008). Estimating HIV prevalence and risk b ehaviors of transgender persons in the United States: A systematic review. *AIDS and Behavior*, 12, 1, 1-17.

JSI Research & Training Institute, Inc. (2000). *Access to Health Care for Transgendered Persons in Greater Boston*. Report for GLBT Health Access Project. Boston: Author.

Kammerer, N., Mason, T., & Connors, M. (1999a). Transgender health and social service needs in the context of HIV risk. *International Journal of Trangenderism* 3.1+2. http://www.symposion.com/ijt/hiv\_risk/kammerer.htm.
Reprinted in Transender and HIV: risks, prevention and care, ed. by WO Bockting and S. Kirk, Chapter 3, Haworth Press, 2001.

Kammerer CA , Mason T, Conners M. (1999b). Transgenders and HIV risks: needs assessment. *International Journal of Trangenderism*, 3.1+2. http://www.symposion.com/ijt/hiv\_risk/kammerer.htm. Reprinted in Transender and HIV: risks, prevention and care, ed. by WO Bockting and S. Kirk, Chapter 2, Haworth Press, 2001.

- Kaufmann, J. (2010). Trans-representation. *Qualitative Inquiry*, 16(2), 104-115.
- Kenagy, G. P. (2002). HIV among transgendered people. *AIDS Care*, 14, 127-134.
- Kenagy, G. (2005). The risk less known: Female-to-male transgender persons' vulnerability to HIV infection. *AIDS Care*, 17(2): 195-207.
- Khayatt, D. (1994). Surviving School as a Lesbian Student. *Gender and Education*, 6, (1), 47 62.
- Lawrence, A. (2010). Societal individualism predicts prevalence of nonhomosexual orientation in male-to-female transsexualism. *Archives of Sexual Behavior*, 39 (2), 573-583
- Lev, A. (2005). *Transgender Emergence: Therapeutic Guidelines for Working with Gender-Variant People and Their Families.* New York: Routledge.
- Lombardi, E. (2001, June). Enhancing transgender health care. *American Journal of Public Health*, 91(6), 869-972
- Lombardi, E., Wilchins, R. Priesing, D & Malouf, D. (2001). Gender violence: transgender experiences with violence and discrimination. *Journal of Homosexuality*. 42 (1), 89-101.
- Lombardi, E. L. & van Servellen, G. (2000). Building culturally sensitive substance use prevention and treatment programs for transgendered populations. *Journal of Substance Abuse Treatment*, 19, 291-296.

- Making Care Visible Research Group (2002). *Making Care Visible: Antiretroviral Therapy and the Health Work of People Living with HIV/AIDS*. Toronto: AIDS Bureau, Ontario Ministry of Health.
- Meyer-Bahlberg, H. (2009). From Mental Disorder to Iatrogenic Hypogonadism: Dilemmas in Conceptualizing Gender Identity Variants as Psychiatric Conditions. *Archives of Sexual Behaviour*. DOI 10.1007/s10508-009-9532-4
- Minkler, M. (2002). Ethical Challenges for the "Outside" Researcher in Community-Based Participatory Research. *Health Education and Behavior*, 31(6), 684-97.
- Moran, L.J. & Sharpe, A.N. (2004). Violence, identity and policing. *Criminal Justice*, 4(4), 395-417.
- Mutcherson, K. (2005). Whose body is it anyway? An updated model of healthcare decision-making rights for adolescents. *Cornell Journal of Law & Public Policy*, 14 (2), 251-325.
- Mykhalovskiy, E. & L. McCoy. (2002). Troubling ruling discourses of health: using institutional ethnography in community-based research. *Critical Public Health*. 12 (1): 17-37.
- Namaste, V.K. (1999). HIV / AIDS and Female to Male Transsexuals and Transvestites: Results from a Needs Assessment in Quebec. *International Journal of Transgenderism*: 3 (1,2).
- Namaste VK. (2000). *Invisible lives: The Erasure of Transsexual and Transgendered People.* Chicago: Ill: University of Chicago Press, Chicago.
- Nemoto, T., Operario, D., Keatley, J., Han, L, Soma, T. (2004). HIV Risk Behaviors Among Male-to-Female Transgender Persons of Color in San Francisco. *American Journal of Public Health.* 94, 1193-1199
- Nemoto, T., Operario, D., Keatley, J., Nguyen, H., & Sugano, E. (2005). Promoting health for transgender women: Transgender resources and neighborhood space (TRANS) program in San Francisco. *American Journal of Public Health*, 95, 382-384.

Ontario Human Rights Commission (2008). *Discussion Paper: Toward a Commission Policy on Gender Identity*. Queen's Printer for Ontario.

Ontario Human Rights Commission (2010). *Gender Identity: Your Rights and Responsibilities*. Queen's Printer for Ontario.

Pfäfflin, F. (2010). Understanding transgendered phenomena. Handbook of clinical sexuality for mental health professionals (2nd ed) (pp. 425-447). New York, NY US: Routledge/Taylor & Francis Group.

- Raphael, D. (2004). *Social Determinants of Health: Canadian Perspectives.* Toronto: Canadian Scholar's Press.
- Reback, C.J. and Lombardi, E. (1999). HIV Risk Behavior of Male-to-Female Transgenders in a Community-based Harm Reduction Program. *The International Journal of Transgenderism*. http://www.symposion.com/ijt/index.htm.
- Reback, C.J., Simon, P.A., Bemis, C.C., & Gatson, B. (2001). *The Los Angeles Transgender Health Study: Community Report*. Universitywide AIDS Research Program, University of California
- Reitsma-Street, M. & Brown, L. (2004). *Community Action Research*. In Critical Strategies for Social Research, W.K. Carroll (ed.). Toronto: Canadian Scholar's Press.
- Roughgarden, J. (2005). *Evolutions's Rainbow: Diversity, Gender and Sexuality in Nature and People*. Berkeley: University of California Press.
- Sausa, L.A. (2003). *The HIV Prevention and Educational Needs of Trans Youth: A Qualitative Study*. PhD Dissertation: University of Pennsylvania.
- Savin-Williams, R. (2001). A critique of research on sexual-minority youths. *Journal of Adolescence*, 24 (1), 5-13.
- Sember, R., Lawrence, A. A., & Xavier, J. (2000). Transgender health concerns. *Journal of the Gay & Lesbian Medical Assn*, 4, 125-134.
- Serano, J. (2007). Whipping Girl. Berkeley: Seal Press.
- Shelley, C. (2008). *Transpeople: repudiation, trauma, healing*. Toronto: University of Toronto Press.
- Sherbourne Health Centre (2009). Guidelines and Protocols for Comprehensive Primary Health Care for Trans Clients. Available online: http://www.sherbourne.on.ca
- Smith, D.E. (1987). *The everyday world as problematic: A feminist sociology*. Boston: Northeastern University Press.
- Smith, D.E. (1990). The conceptual practices of power: A feminist sociology of knowledge. Toronto: University of Toronto Press

- Smith, D.E. (2005). *Institutional ethnography: A sociology for people*. Toronto: AltaMira Press.
- Smith, G.W. (1990). Political activist as ethnographer, *Social Problems*, 37, 629–648
- Smith, G.W. (1998). The Ideology of "Fag": The School Experience of Gay Students. *The Sociological Quarterly*, 39 (2), 309-335
- Sobralske, M. (2005). Primary care needs of patients who have undergone gender reassignment. *Journal of the American Academy of Nurse Practitioners*. 17 (4). 133-38.
- Stephens, T., Cozza S., Braithwaite R.L. (1999). Transsexual orientation in HIV risk behaviours in an adult male prison. *International Journal of STD & AIDS*, 10(1), 28-31.
- Sugano, E., Nemoto, T. & Operario, D. (2006). The Impact of Exposure to Transphobia on HIV Risk Behavior in a Sample of Transgendered Women of Color in San Francisco. *AIDS and Behavior*, 10(2), 217-25.
- Trans PULSE (2008). *Report on Phase I & Plans for Phases II and III*. Available Online: http://www.transpulse.ca
- Trans PULSE (2010). *Who are Trans People in Ontario: Trans PULSE E-Bulletin #1*. Available Online: http://www.transpulse.ca
- Ussher, J. (2009). Heterocentric practices in health research and health care: Implications for mental health and subjectivity of LGBTQ individuals. *Feminism & Psychology*, 19(4), 561-567.
- Walby, K. (2007). On the Social Relations of Research: A Critical Assessment of Institutional Ethnography. *Qualitative Inquiry*. 13 (7), 1008-1030.
- Williamson, C. (2010) Providing Care to Transgender Persons: A Clinical Approach to Primary Care, Hormones, and HIV Management. Journal of the Association of Nurses in AIDS Care. 21 (3) 221-29
- WPATH (2001). *Standards of Care*. Available online: http://www.wpath.org
- Wyss, S.E. (2004) This was my hell: The violence experienced by gender nonconforming youth in U.S. high schools. *International Journal of Qualitative Studies in Education*, 17, 709-730.
- Xavier, J., & Simmons, R. (2000). *The Washington transgender needs assessment survey*. Washington, DC: The Administration for HIV and AIDS of the District of Columbia Government.

Xavier, J., J.A. Honnold, J. Bradford, Community Health Research Initiative, Center for Public Policy, Virginia Commonwealth University. (2007). The Health, Health-Related Needs, and Lifecourse Experiences of Transgender Virginians. Virginia: Virginia HIV Community Planning Committee & Virginia Department of Health.

Zians J (2006). The San Diego County Transgender Assessment Report. San Diego, California. Available online: http://www.calendow.org/reference/publications/pdf/cultural/ TransAssessmentREPORTFINAL1-18-06.pdf.